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**Views and experiences of work among the severely  
mentally ill: a qualitative study**

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## **Back to work**

**Background:** Work is important for mental health but we do not understand why so few people with severe mental illness (SMI) in the UK work.

**Aims:** To identify the opinions of a purposive representative sample of patients with SMI on themes related to employment.

**Method:** A thematic analysis of fifteen semi-structured interviews.

**Results:** Participants identified a range of advantages to working but also expressed substantial doubts. Symptoms, medication and potential damage to health affect the ability to work. Most people would not tell their employers about their illness due to discrimination, but believed it could be helpful if employers knew. Many reported being discouraged from working by professionals and described a lack of helpful employment services.

**Conclusions:** Although most people want to work, given the pressures they face some may choose not to. Barriers that people face are both internal and external and these interact.

**Declaration of interest:** Funding for transcription was provided by Pfizer Inc and Janssen-Cilag

## **Background**

Unemployment is a proxy measure of social exclusion for those with serious mental illness (SMI) and has been identified as a priority area for services (Department of Health 1999). The economic cost of the mentally ill being unemployed is high in the UK (Huxley and Thornicroft 2003) but only 8-20% with a psychotic disorder are currently employed (Kelly et al 1998, UK700 Group 1999) and the number seems to be falling (Perkins and Rinaldi 2002). Although employment probably has positive effects in those with SMI (Carol and Van Dongen 1996) it is currently unclear why so few work. Suggestions include concern that work may be stressful (Vogel et al 1989), loss of disability payments if people start working (Polak and Warner 1996) and discrimination from employers (Manning and White 1995). There is limited evidence of the experiences of service users with SMI in obtaining and keeping employment as well as the perceived barriers to working.

## **Method**

### Aims

This study aimed to identify the opinions of a purposive representative sample of fifteen patients with SMI on the following themes:

- The advantages and disadvantages of working from the service users' perspective

- The ways in which illness affects the ability to work
- The perceived barriers to finding work
- Opinions on current service provision.

### Sampling Frame

Approval was obtained from the local research ethics committee. Four care co-ordinators in the community mental health team (CMHT) were asked to identify patients on their caseload who had a psychotic disorder and were not in hospital. A total of 52 names were provided and consecutively numbered 1 to 52. A random number generator ([www.randomizer.org](http://www.randomizer.org)) was then used to select participants.

A purposive sampling method was used in order to ensure that a full range of service user characteristics and experiences was represented. Thus before recruitment we decided that the sample should include at least 6 males and females, at least 5 unemployed participants and at least 5 who were currently employed (competitive and voluntary). In addition at least 6 people with Schizophrenia and 6 with Bipolar Affective Disorder (BPAD) were to be selected. Those with psychotic depression were excluded as previous research (Bacani-Oropilla et al 1991) suggests that this group have different employment functioning to those with Schizophrenia and BPAD. Given the high level of morbidity required for key-worker allocation in inner city CMHT's

only a very small number were employed in the initial participant list. Therefore a further five participants who were employed were recruited from the out patient list of the CMHT.

Potential participants were initially contacted by phone, told about the study and asked if they would be willing to meet SM to discuss it further. If a telephone number was not available or they were not contactable by phone a letter was sent to them requesting participation.

### The interview

SM developed the qualitative interview with the study aims in mind. To assess face validity and refine the interview it was piloted with three potential participants from the patient list of the CMHT. These people were unemployed, applying for a job and employed (voluntary).

Participants were told that responses were confidential and their identity would be concealed in the final analysis. The interview schedule was used for exploration as a starting point but the respondents determined interview content (design flexibility). This was in order to elicit as wide a range of views as possible. The interviews were recorded on audio-tape and transcribed by secretarial support staff. A sample of the transcripts was proof read and found to be accurate. An outline of the final semi-structured interview used is shown in **Appendix 1**.

Demographic details collected included age, gender, diagnosis, current employment status and previous work record (work pre and post-illness onset). One interview was carried out in the person's home and all the others at a community mental health centre.

### Analysis

Thematic analysis of the transcripts of the interviews was carried out using QSR-NUD-ist Classic (a program which supports qualitative data coding and analysis) to identify beliefs, attitudes and experiences. The main questions informing the analysis were the stated aims of the study. SM initially read and coded all of the transcripts for the demographic details described above. Further reading of the interviews enabled a coding structure to be developed, based on the questions asked during the interview. In this way text within the transcripts was coded into emerging themes. Novel ideas not specifically asked about in the interview were also identified. The text within each code was then re-read to check for the validity of the coding and to see if further themes could be obtained depending on the relative frequency of particular attitudes.

Our study is a descriptive one, with patients' reports accepted at least to some degree as direct reflections of their experiences and views. However, their narratives are also likely to be shaped by their interaction with the interviewer (reflexivity) and thus it is likely that the participants' accounts were actively constructed within the context of the interview.

### Validity and Reliability

SJ independently coded four randomly selected transcripts to check the validity of the coding structure. This had face validity. However the level of text coding agreement between SM and SJ was found to be less than 75%. In response to this the definition of some of the themes were refined and the coding framework was further developed by the addition of new themes. All the transcripts were then re-coded using the new coding framework. SJ independently coded two further transcripts to recheck coding reliability. This was found to be satisfactory at 80%. The main problems were text-coding omissions as opposed to text coding differences.

### The setting of the study

This study was carried out in Islington, North London, an area with considerable deprivation, a population of approximately 176000 and an unemployment rate of 9.1% (OPCS 2001). Local specialist employment services for those with mental illness are limited and are mainly provided by the voluntary sector. Available services include the MIND Employment Project, which assesses work skills and provides training on how to get work and a day centre, which provides some vocational rehabilitation. Sheltered employment is limited and there is no substantial scheme providing supported placements in competitive employment. There is a high quality benefits advice service (Islington Peoples Rights).

## **Results**

Table one here

The socio-demographic details of the final sample are shown in **table one**. Everyone in the sample had done some form of work in his or her life. Nine people selected did not participate. Two of these were uncontactable and seven refused.

### **Desirability of working**

Nearly all of the interviewees (13 out of 15) said that they wanted to work. Two of the participants, both of whom had schizophrenia, felt they could not work because they were not well enough. One of these said: *“I would like to work if I didn’t have mental health problems. I have a lot of insurmountable mental health problems that get in the way”*.

Although people almost always said they wished to work, 6 wished to work only part-time as they felt they could not cope with starting full-time work directly from unemployment. An unemployed man with schizophrenia said *“I would prefer to do part time jobs for a few years to see if I can handle that. It’s a lot easier to do.”* When asked why, he said *“ basically to see the stress levels aren’t too high.”* However some respondents said that they would not consider part-time work because the pay wouldn’t be enough given the loss of benefit entitlement.

Table two here

The participants gave a number of reasons of why working would be advantageous to them and **table two** shows the frequencies of these themes. The most frequently cited reason was financial gain. This was not solely related to the desire to be wealthier but also to increasing a sense of autonomy and independence by ceasing to rely on benefits. Participants believed it would give them control over their lives. For example an employed woman with BPAD said *“the advantage for me in work is the sense of self esteem...the fact that I would be earning my own money, making decisions about my life”*.

Participants talked about work giving them a clear role and empowering them to become part of mainstream society once again. For example a man with schizophrenia said, *“ it would certainly help to give me more of a purpose to life. On the mental health scene if all you do is visit day centres, it means you’re just drifting. It’s not like having a career or a job”*.

Four participants, 3 of whom were employed said that working was good for their mental health. An older employed man said *“... I mean I’d hazard that yes, It’s extremely stabilising. It’s a form of creative Lithium if you like”*. There were no other obvious differences by employment status.

After the initial strong assurances of wanting to work and its advantages many participants went on to express substantial doubts. These ranged from a fear of letting people down to concern over physical ability to work. Concern over benefit entitlements if they were working was common in the sample (7), but

less so among the employed (2/7). A woman with bipolar disorder said “...*I think the benefit system does work against people with mental health problems actually getting back to work*”. There seemed to be a good deal of uncertainty about how much money you could earn and its relationship to loss of benefits. When asked what would happen to his benefits if he earned ten pounds a week an unemployed older man with Schizophrenia said, “ I would lose my benefits”.

Also there was a range of opinions on whether people in reality would be financially better off. An unemployed man with schizophrenia said, “*I don't think it would make a lot of difference...I'd have to pay council tax...I'd have to pay fares. I don't think I would be better off financially. I mean people just say I should work but they don't think of the consequences*”. Four of the participants said that they would only be willing to work for between £50- £200 extra a week compared to their current benefit entitlement.

A number of participants, often those whose level of social functioning appeared generally high, expressed reservations about having to work in an unskilled or unsatisfying job. For example a woman with BPAD said “*something that was interesting, of value, that I felt appreciated in...I mean basically I' m pretty sure I could get a job stacking shelves in Safeways or whatever but I don't want to do that*”

Some respondents suggested they had found alternative activities from which they gained some of the satisfaction they might get from work. For example a

woman with BPAD said, “ *I consider I’m already working. I’m a mother, I’ve been engaged in promoting good practices in mental health....I’m a regular member of the day centre.....so I’m constantly engaged in doing things*”.

### ***Mental health problems and effects on work***

When asked how their mental health problems might affect the ability to work most participants (12) said that symptoms of their mental illness, primarily affective or psychotic ones, would interfere with functioning at work. A woman with schizophrenia said, “*the voices... lack of concentration*”. She went on to say “*I need help with the voices. It would help if I didn’t hear them anymore*”. Two participants also thought concentration or memory problems would affect their ability to function at work.

Approximately half said that taking medication would affect their ability to work, because of side effects (6) or the practicalities of taking it (2). An unemployed man with schizophrenia said “*now I have to have an injection every two weeks... do you tell your prospective employer that you suffer from mental illness and that you want time off to go have your injection or do you make some excuse every time...it’s a bit of a quandary really*”. A minority of participant’s (4) talked about problems getting up in the morning making it difficult to work.

Nine (5 unemployed and 4 employed) participants were concerned that employment might lead to a relapse of their mental illness. A few had experienced this while others saw it as a risk. A typical comment was

*“...could be stressful job and I won't be able to cope with it and I'd end up having another breakdown.”*

Many talked about their experiences whilst at work and how their mental health problems had affected these. An unemployed woman with schizophrenia said *“my face is always red, I look very anxious. I used to work in a shop and realised I looked very anxious, so I stopped working in the shop”*. A man with Bipolar Disorder said *“...other times I've probably gone over the top in (work). I remember writing down dozens and dozens of comments, overflowing”*. When asked if his employers were supportive he said *“ I just left and gave up my job...and that damaged my career irreparably”*.

When people stopped work due to their illness they nearly always left of their own accord and were not asked to leave by their employers. This had often happened at a time when their illness was becoming worse but they did not feel able to talk openly to their employers about it. They either resigned or simply did not turn up for work because of behavioural disturbance or being admitted to hospital. In a typical comment an unemployed woman with schizophrenia said *“Well that is why I left telecoms, because I walked.... Well I thought people were talking about me and then things started going fast in my head”*.

However pressure from employers and colleagues may have contributed to these decisions to leave work. A number of people described feeling

discriminated against at work when they became ill, and also on their return to work. It appeared that this was often disguised; for example being asked to move to an area which was not so easy to commute to or being asked to take a demotion. A man with BPAD who took medical retirement when he returned to work after a manic episode said *"well what happened was, I went back and I felt a bit ostracised. People weren't as friendly as they were before. I don't know why"*.

Only three participants had been sacked. This was because their employers believed they could not do the job any longer due to their mental health problems. An unemployed woman with schizophrenia said *"after I went into hospital, I started again and then they said I must not work in this place...I get tired very quickly and nobody helped me....I started making simple mistakes. Before I never done these things"*

Despite these problems several people described instances of obtaining work or keeping a job despite illness. Participants commonly talked about having support in their employment as being the key in enabling them to continue. Also employers knowing about their mental health problems was seen as important. For example a 24-year-old employed man with schizophrenia said *"and they said that if it didn't increase (work-rate) they wouldn't be extending my application for a full-time position. But I told her about my Schizophrenia and afterwards she said, well I'll scrub off the statement about not keeping you on, but if you can make those improvements"*.

***Attitudes to employers and the perceived beliefs of employers.***

Stigma was frequently mentioned when people talked about their prospects of finding work. Approximately two thirds of the participants said they wouldn't tell potential employers about their mental health problems because of the resultant discrimination. A 35-year-old man with schizophrenia said, *"I don't think you'd get a foot in through the door that way. You wouldn't get taken on in the first place if you told them you had a big mental history."*

Even though most people would not tell a potential employer about their mental health problem, approximately a third thought their situation would be better if the employer was aware of and accepted it. This belief was not mutually exclusive with wanting to hide mental health problems from the employer. For example a man with schizophrenia said *"Not if I wanted the job but then that would increase my likelihood of going nuts, because I wouldn't let anyone get too close or meet my friends who did know I have a mental health problem"*. The most commonly cited reason for telling an employer was so that they would be forewarned that the person might become ill and that this might effect their performance at the job.

The belief that employers would prefer not to employ people with mental health problems was almost universal. Most people (11) believed that employers would worry about their functional ability to do the job as well as risks. A 35-year-old man with schizophrenia said *"it's a risk to the employer and they might go mad one day with a big knife and attack someone. Or they might just not be as efficient as someone who hasn't got mental health"*

*problems*". Participants reported that as well as the risk of violence, employers would be concerned about the number of sick days taken and disruption to the work force. The three people who were competitively employed had not told their employers about their illness at interview.

Interestingly a significant minority of participants' (6) thought that employers were justified in their concerns and reluctance to employ people with SMI. A young man with schizophrenia who was employed commented "*just say there's two different people. One with mental problems and one's fine. The one who's fine can be told I need you to stack four shelves today...whereas this one he can do it but he still needs support...I think he'd be a bit of a burden on the employers*". Some participants had self-stigmatising views of those with SMI with regards to work. A woman with BPAD said "*in all seriousness I'm not sure unless you had a vacancy you couldn't fill you'd take on someone with mental health problems anyway*".

### **Getting a job**

Only a minority of participants was currently actively seeking employment. Seven participants talked about advice regarding work received from professionals or the lack of it. Older participants (over 40 years) seemed more likely to have been advised against working or against more demanding employment. In talking about her struggles to lead a normal life an older woman with BPAD reported "*one psychiatrist told me I'd only ever do menial work, that I'd never be fit to do anything that required responsibility. I named*

*her Dr Murderoch*". Two participants under 40 years said that no one had mentioned work to them or explained what services were available.

When asked how they might go about finding a job people mentioned three strategies: attending the local *MIND* employment project, trying to find work themselves by looking through adverts or going to the job centre. The latter was perceived as the least effective option. For example an unemployed woman with BPAD said "*...I think they'd push me into a job that I didn't think I'd be able to do... I find going to the job centre the most soul-destroying experience. Then again everyone would.*" The people who used *MIND* found the service friendly although not always successful in aiding them in obtaining competitive employment.

The majority of participants had done some form of voluntary work in their lives. Many of them discussed this aspect of work positively as increasing their self-esteem and providing an environment where they felt supported and could work despite their mental health problems. However three people also said that they would never do voluntary work because of the lack of financial remuneration. Eight participants reported that they believed voluntary work did not prepare you for competitive employment with half as many reporting the reverse. A man with BPAD described the positives and problems with voluntary work. He said "*I just saw it as voluntary work, I didn't really see it as preparation for a full-time job. The discipline of getting up in the morning is a good idea...but all other aspects doesn't.... because you can do what you like, you can either work or you don't.*"

There was a general view that not enough specialist employment services were currently available. People identified a range of functions that a dedicated service might provide. This included help with filling out application forms and curriculum vitae's, support and advice on interview skills as well as the provision of references. Three participants said that such a service should provide a list of jobs that were available or might be suitable for them. Furthermore they wanted these jobs to be ones in which their mental health problems were known. An employed man with Schizophrenia said *"I think they should have a lot more links with employers. It would be nice to have a list of employers who have been to a weeks training on mental health issues and understand the ins and outs. .... and that you don't have to start a blank slate with."*

## **Discussion**

### ***Working***

As in previous studies (Hatfield et al 1992, Secker et al 2001) when asked for a yes or no response nearly everyone said they wanted to work. However this was frequently followed by the expression of substantial doubts and these initial firm assurances may to some extent reflect the social desirability of work. These initial statements about wanting to work could be described as public accounts (Pope and Mays 1995), behind which a set of rather more complex and contradictory private accounts emerged on a more detailed exploration.

Working was seen to have many advantages, especially related to perceived financial gain (although this was later questioned), social contact, self-esteem and being able to lead the kind of life that people without SMI have. It may be that in practice some people with SMI do not do paid work as they are able to obtain these advantages through other social roles such as being a carer, advocate or in voluntary work. Based on exploration of the views and experiences of the long-term unemployed in the general population, Jahoda (1981, 1982) has identified a range of latent functions of work. Loss of these as well as work's manifest function as a source of financial reward are important in understanding the psychological and social effects on individuals of unemployment. Latent functions of work include the imposition of a time structure, participation in a collective purpose and the enlargement of the scope of activities into areas less emotionally charged than family life. These themes, especially the first two, also emerged from our data, and it is likely that most people with SMI want to work under the right conditions. But, some may believe that looking for work may not be the best option given their level of morbidity, discrimination, the barriers they face and the possibility of having to do very menial work. They may find that other social roles and activities are more rewarding sources of the latent functions of work.

Participants' accounts of previous experience of working suggest that they leave of their own accord into unemployment or acute psychiatric care. This is somewhat different from some US evidence (Becker et al 1998) in which more than 50% of job terminations were due to the person being sacked, although this sample was made up of assertive community treatment clients. In our

group, discrimination seemed to be felt most potently when people tried to return to work.

### ***Barriers to working***

There are external and internal barriers that patient's face and these interact.

#### *a) External (Societal)*

Most participants talked about enacted stigma (a mark of disgrace or discredit that marks a person out from others) at some point during the interviews and there is substantial evidence for this from previous studies (Crisp et al 2000, Manning and White 1995). In particular participants believed that employers were worried about a number of risks including violence, extensive sick leave and the potential for them to be a disruptive influence in the work environment including to their colleagues. Respondents talked about support as being the key to enabling them to work and the need therefore for their employers to be forewarned about their potential problems. However most would not tell employers when trying to get a job because of potential discrimination. This dilemma may be a key barrier as people feel they must conceal their illness to get a job, but that doing so seriously jeopardises their chances of keeping it. A solution may lie in persuading employers to accept the risks, educating them about their extent and in making support available to employers in trying to deal with problems that may arise.

In line with previous work (Rinaldi and Hill 2000) loss of benefit was seen as a major reason not to return to work. The extent of the monetary disincentive to

work is large. For example a 25 year old man with Paranoid Schizophrenia who worked for 3 years before he became ill, has now been unemployed for 2 years and lives in a 1 bedroom council flat in Islington is entitled to a little under £15000 in DHSS benefits. Around £9000 of this is as disposable income (personal communication from Islington Peoples Rights). Assuming a patient works a 40-hour week on the minimum wage of £4.20 they would receive about £9000 a year. Therefore the reservation wage (Berndt 1991) (the wage at which working becomes economically viable) for those with SMI is high. The fear of having difficulty in getting benefits reinstated if an attempt to start work is unsuccessful may be a further deterrent to giving them up. This may be particularly so when considering part-time work.

Understandably people reported they would only work if their wage was more than their benefits entitlement. The reported lack of easily accessible information about losing benefits and employment may be partly responsible for the level of concern expressed about this.

*b) Internal (individual)*

The internal barriers consist of people's attitudes and beliefs. It is likely that they are reflections of low self-esteem, worries and past experience. For example if you are unlikely to get a reasonable job, it may be in some ways a healthy and adaptive response to give up trying and try to obtain the advantages work might offer from other sources. A minority of participants said they were not well enough to work although a greater number felt they were well enough to work on a part-time basis only. In addition many people

said that working might lead them to become unwell. These fears primarily expressed by those who were unemployed corroborate previous work (Carol and Van Dongen 1996) suggesting that those who are unemployed are more fearful of working than those who are actually employed. An impediment to work, which may be modifiable by clinicians, is the side effects and practicalities of taking medication.

Although participants complained about discrimination from employers some believed that the employers were justified in their concerns. Many people's comments suggested that they accepted these attitudes with a degree of fatalism and felt that there were not good enough reasons for employers to change them. A number of people also talked in a way that was very self-stigmatising with regards to work. The belief that one is not as able or employable, as someone without mental health problems from the outset is likely to act as a severe disadvantage when selling oneself to the labour market.

### **Current service provision**

Advice regarding work may reflect mental health professionals' views about the importance and feasibility of employment for those with SMI. Received work advice seemed more stigmatising for the older age (40 plus) group than for younger people. Although work advice was not directly asked about some participants complained about the lack of it and indeed there is evidence that vocational services do not tend to be included in care plans for people with schizophrenia (Lehman and Steinwachs 1998a). As well as hindering people's

progress back to employment, this may reinforce low self-esteem and hopelessness with regards to work.

When attempting to find employment the respondents had used a variety of different strategies, although attending a specialist employment service for those with mental illness was seen as most helpful. The main criticism of this service was that it often directed people into unpaid rather than competitive employment. Voluntary work was seen as therapeutic by nearly everyone who had done it but the majority reported that it did not prepare them for competitive employment.

Given the level of service provision available, it was unsurprising participants reported that there was not enough help offered in relation to employment. As well as wanting practical help in the process of finding work they also wanted services to have links with sympathetic employers and in some ways be advocates for them with those employers. It appeared therefore that they wanted something very much like the supported employment programmes for which there is good evidence of effectiveness in the US (Crowther et al 2001).

### **Limitations of the study**

Seven people refused to participate in the study. Although a reason for refusal was not required several mentioned that they did not want to be recorded on audiotape, despite assurances regarding the security and confidentiality of these. It may be that those who agreed to be interviewed had particularly

strong opinions on the subject. However, from interviewer observation there was a wide range of illness severity and strength of opinion in the participants.

The respondents were aware that the interviewer was a psychiatrist. This may have led to socially desirable answers, although the doubts that people expressed about working would temper this view.

Although the participants were selected to represent a full range of characteristics and experiences among people with SMI and therefore to some extent the results will be generaliseable, the sample size is small and all drawn from a single inner city area. Opinions and attitudes may well be different in areas that provide differing levels of employment services and have other levels of deprivation, and there is a need for further research to fill the striking gap which has thus far existed in the evidence on this issue.

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## **Appendix 1: Interview Guide**

- **What work would mean for the person?**

Do you want to work?

What kind of work would you like to do?

Do you think there are advantages/disadvantages to working?

- **How does illness affect ability to work?**

What potential problems would there be with you working?

How might your mental health problems affect your ability to work?

Would you find it difficult to work?

- **What are the perceived barriers to finding work?**

What stops you working?

Have you tried to look for work- any problems?

Would you have particular worries about getting paid work?

What worries do you think employers would have in hiring you?

Would you tell them you had a mental health problem?

- **Current service provision**

Have you had contact with services that to get you back to work?

Have you had experience of sheltered or voluntary work-what was it like?

Did it prepare you for competitive employment?

How did it affect your views on getting paid work (if appropriate)?

Have you had experience of competitive work?

What was it like working?

What happened when you stopped working?

Where would you go to get help with finding a job?

Are there particular kinds of help you need in getting work because of your health problems?

Is the help available at the moment that you believe is needed?

What help is not provided that could be?

**Table one: Socio-demographic details of participants**

<b>Characteristic</b>	<b>Number of participants (N = 15)</b>
<b>Gender</b>	
Men	8
Women	7
<b>Diagnosis</b>	
Schizophrenia	8
Bipolar Affective Disorder	7
<b>Age</b>	
18-40 years	9
Over 40	6
<b>Employment status</b>	
Unemployed	8
Competitive employment	3
Voluntary or sheltered employment	4
Worked pre-illness and post illness onset	14

**Table two: Advantages of working: frequency of themes.**

Theme	Frequency
Financial gain	11
Independence, autonomy	9
Chance to meet others	9
Daytime structure	7
Effects on mental health	4

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