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Psychosis and the Experience of Employment

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Abstract *Introduction* Although unemployment is common among those diagnosed with psychotic illnesses, few studies have looked directly at the experience of those who have gained competitive paid employment subsequent to being diagnosed. This study explored the experiences of people diagnosed with schizophrenia or schizoaffective disorder in relation to paid employment. *Methods* Eight participants with experience of paid employment were interviewed. The data were analysed using Interpretative Phenomenological Analysis (IPA) [Smith et al. (In: Murray, Chamberlain, editors) Qualitative health psychology, 1999]. *Results* Three super-ordinate themes; 'Coping', 'Interpersonal support and reactions', and 'Personal change' were identified. *Conclusions* Interpersonal support seemed to be lacking in workplaces, where discrimination was a reality for people with psychosis. Further study into what facilitates coping with symptoms in the workplace is needed.

Keywords Psychosis · Competitive employment · Qualitative research

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Introduction

Unemployment is common amongst people with mental health problems especially those diagnosed with psychotic illnesses [1]. Meaningful activity is considered an important goal of rehabilitation (e.g. [2]), but few people who have experienced psychosis subsequently enter employment and for those that do little is known about what helps them achieve this.

A literature review using PsycINFO and MEDLINE revealed that vocational outcomes for people with psychosis have mainly been studied in relation to rehabilitative programmes and work schemes. However, few studies were found that had looked directly at the experiences of people with psychosis who had gained competitive employment (e.g. [2, 3]).

The characteristics of psychosis may be especially unhelpful when it comes to the demands of most jobs [4]. Relapses may cause high absence rates, which many employers may be unprepared to tolerate. Symptoms such as paranoia and anxiety affect the interpersonal challenges of the workplace. In addition, working ability may be compromised by side effects of antipsychotic medications [5]. Goldberg et al. [6] found that the effects of long-term psychosis appeared to have a significant damaging effect on vocational rehabilitation, however being in competitive work has been associated with improvements in symptoms and other non-vocational outcomes [3]. Unemployment appears to be associated with poor mental health (for example, [7, 8]) and a review by Murphy and Athanasou [9] concluded that unemployment predicted poorer mental health in most of the 16 longitudinal studies reviewed.

Most literature suggests that between 22% and 30% of people diagnosed with schizophrenia have no further episodes (e.g. [10]). Smith and Twomley [1] suggested that around 10% of people diagnosed with schizophrenia had paid employment. However, 'recovery from schizophrenia' generally focuses on symptom management [11] and pays little attention to social, economic or vocational recovery. A 2002 survey by the Mental Health Foundation [12] indicated that less than half of those with psychosis were employed, although most had some form of voluntary work or unpaid supported employment. This suggests that most people with psychosis may have the motivation or capacity to work, but are unlikely to have self-sustaining paid employment.

There have been several studies evaluating vocational projects (e.g. [13]). A review of 11 randomised controlled trials comparing work rehabilitation interventions by Twamley et al. [14], revealed that approaches such as Individual Placement and Support (IPS) [15] resulted in better vocational outcomes than conventional rehabilitation services.

Bassett et al. [5] found that low expectations about gaining employment, negative symptoms and the sedating effect of medications affected the working opportunities of young people with psychosis. The young people interviewed felt they needed more support around managing their illnesses and finding jobs. The stress of working (and its link with relapse) and the stigma associated with mental illness meant that the participants were ambivalent about disclosing their mental health history to potential employers. Read and Baker [16] surveyed 778 associates of the charity MIND and found that 34% of respondents had been forced to resign or dismissed from work and 69% had avoided applying for jobs through fears of discrimination.

Clearly there are many difficulties associated with competitive employment for those with psychosis. Accordingly, there is a shortage of literature focussing specifically on those with psychosis who have gained competitive employment. This research seeks to explore the experiences of people with psychosis who have succeeded in gaining competitive employment in order to aid our understanding of the experience of this.

Method

Participants

Of twenty-seven individuals approached, thirteen declined to participate in the research, six did not meet the inclusion criteria and eight participated. No information was available for those who did not participate. Participants' demographic details can be found in Table 1. Most participants had a reasonable level of education and qualifications. All participants were local to an area in northern England, which suffered from high unemployment due to the decline of local industry over the past twenty years.

Table 1 Demographic information

Sex	
Male	4
Female	4
Marital status	
Single	5
Married/long-term Partner	2
Divorced	1
Age	
Mean age	42.13
Age range	35–56
Living arrangements	
Supported housing	1
Own home	2
Rented accommodation	4
With parents/relatives	1
Education	
Average age left education	18.75
Range	16–23
Education level	
Up to GCSE/CSE	2
Intermediate (A-Levels, Vocational)	4
University	2
Employment	
Currently employed	3
Currently unemployed	5
Medication	
Old antipsychotic	1
New antipsychotic	8
Mood stabiliser	1
Antidepressant	2
Benzodiazepine	1
Diagnosis (based on participant report)	
Schizophrenia	4
Psychosis	1
Neuroleptic malignancy syndrome	1
Not given	2
Age of onset	
Mean age	26
Range	10–45
Class background (based on parents' occupational level)	
White collar	3
Skilled manual	3
Unskilled labour	2
Ethnic origin	
White UK	8

Procedure

Potential participants were identified by clinicians in the Community Mental Health Team (CMHT) where the research took place and were contacted by letter or approached directly about the study by professionals involved in their care. In order to participate, individuals had to meet the following criteria:

- Diagnosis of schizophrenia, schizoaffective disorder or psychosis[1]
- Receiving mental health services treatment
- Aged between 18 and 65 years
- Experience of competitive employment since their diagnosis and treatment
- Not have a diagnosis of unipolar or bipolar depression, learning disability or personality disorder
- Not currently in crisis or on a section of the Mental Health Act (1983)

Ethical approval and research governance was obtained from the Local NHS Research Ethics and governance committees. Participants were informed of the purpose of the study and that anonymised interview excerpts may appear in published material. The limits of confidentiality were discussed before each interview. A consent form was completed by those who agreed to take part. Participants were reimbursed for expenses with a £10 retail voucher after the interviews.

Design

Methodology

Qualitative methods allow exploration of the impact of situations or experiences on individuals, attach importance to the dynamic processes between investigator and participant and view the data as couched in the social context in which it is collected [17]. The subjective experiences of those taking part can be the main focus of qualitative research, making it ideal for exploratory research.

Interpretative Phenomenological Analysis (IPA), as outlined by Smith [18, 19], is an approach that attempts to explore individuals' personal experience and perception of events. IPA makes no prior hypotheses about the data and the findings are based entirely upon themes extracted from open-ended interview questions designed to guide participants to talk about broadly specified areas. The approach recognises the interactive nature of this process and the potential role of the researcher's bias and background in the design and interpretation. Therefore an open account of the researcher's orientation is necessary. IPA has been widely used in health research (see Brocki and Wearden [20], for a critical evaluation) and has been used with those diagnosed with schizophrenia (e.g. [21]).

Interview

The interview schedule explored three areas related to the research question.

(1) The potentially life-changing experience of treatment and diagnosis [22], as this may be important for understanding the context of psychotic experiences.
(2) The process of re-entering employment after a psychotic episode, focusing on feelings about work and thoughts and feelings about mental health in relation to employment.
(3) Life more generally. This provided an opportunity for participants to add additional thoughts about the impact of psychosis and employment on their everyday lives.

Attempts were made to use neutral words in the interviews. Schizophrenia was termed 'diagnosis (of schizophrenia)' and 'illness' was substituted for 'experience' or 'hospitalisation'. This allowed questions to remain clear without alienating participants who rejected the medical framework for understanding psychosis.

Seven interviews were conducted in CMHT consulting rooms and one in a consulting room at the local hospital. Interviews lasted between 30 and 90 minutes. The interviews were tape recorded and transcribed verbatim by the lead researcher in order to maximise an intimate knowledge of the interviews and the affective responses of the participants.

Analysis

The transcripts were analysed using IPA. Each transcript was read through a number of times, and salient information was noted along with emerging themes. Themes were then examined for interconnections within and between transcripts and clustered into categories, which were grouped into super-ordinate themes containing sub-themes. Quotes identifying the sub-themes were highlighted to ensure that the themes reflected what the participants expressed as accurately as possible [23]. Tables and flow diagrams were used to assess the strength of links and overlaps between themes. As recommended by Smith [23], quality control was maximised by dual analysis of one transcript, full review of the process with the research team, and peer validation. A reflexive log of the research process was also kept.

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[1] Classification was based upon clinicians' opinion. When interviewed two participants did not accept or stated they did not know their diagnosis.

Characteristics and Bias of the Lead Researcher

IPA assumes that interpretations arise from an interactional process between interviewer and interviewee [18], therefore it is good practice to reveal contextual factors that may have influenced the study [24]. The lead researcher was a 32-year-old white, middle-class woman whose interest in psychosis arose from several years of clinical experience with this population. The theoretical orientation of the lead researcher could be described as person-centred and strongly influenced by exponents of the critical psychiatry movement [25] and labelling theory [26]. One particular bias of the researcher was an assumption that being employed would contribute positively to participants' lives. This was based on a preconception that the difficulties faced by people with psychosis were mainly the result of societal rejection rather than arising from the psychotic experience itself.

Results and Discussion

Three super-ordinate themes emerged from the analysis: coping, interpersonal support and reactions, and personal significance. These super-ordinate themes along with the sub-themes contained within them are displayed in Table 2.

Coping

Much of the participants' discourse related to issues of coping with work, mental health issues and all other areas of life. The super-ordinate theme of 'Coping' covered a range of sub-themes, all of which appeared to pertain to practical self-helping aspects of participants' lives.

'Coping with Mental Health Issues at Work' focused upon some of the coping strategies used to deal with symptoms experienced at work. Whilst previous research (e.g. [5, 27, 28]) has linked discrimination among employers, fears of prejudice and stigma, low expectations and aspects of the benefits system to the long term unemployment of those with psychosis, these issues seemed of secondary importance to the challenge of coping with paranoia, hearing voices or anxiety at work.

Table 2 Table of themes

Super-ordinate theme	Sub-theme
1 Coping	1.1 Coping with mental health issues
	1.2 Using resources
	1.3 Meaningful activity
2 Interpersonal support and Reactions	2.1 Social support
	2.2 Disclosure
3 Personal significance	3.1 Personal change
	3.2 The meaning of work
	3.3 Future

Participants dealt with mental health issues in a range of ways that could be classified as approach or avoidance methods. Determination to do one's best despite experiencing symptoms was noted along with a range of other responses such as secret drinking; *"Last job I had I was taking a hip flask with me full of whiskey, you know, just to try and get through." (Pete, 3.5);* overworking (which was considered to cause and maintain mental health problems and therefore was something to be avoided) and changing job which was seen as a (unsuccessful) way to cope, *"Well I left the company and started with a new company. I thought everything would stop, but it didn't. So I had to deal with erm... conversations about 'he's crap at his job' 'he left the other place and now he's here'" (John, 2.4-5).* For some, the severity of their symptoms was too great for them to continue working, *"I couldn't settle down with what I was doing and the amount of panic attacks I were having... And I started having periods... where I didn't go into work [or]... I'd go to work and I'd stop for an hour and... just have to get out." (Ged, 1.2-3).*

Using external resources as a way of coping was important for many of the participants. More than half of the participants mentioned organisations, benefits and schemes that they had found helpful in order to return to work or develop other meaningful activities. Most spoke favourably of their experience of using such resources, *"Last year I started thinking that I was well enough to... look for work. And I discussed it with Dr (name) and sort of made an appointment to see (name) the disability officer who got me a referral to (supported work project) ... and they got me a placement as a receptionist and admin assistant there." (Mary, 4.6)*, However, some found such organisations less positive "*they send them to (organisation) ... take them out of one institution and shove them into another. It's not putting them into community kind of thing, you know" (Pete, 3.1).*

Meaningful Activity (outside the work context) was seen as valuable and an important aspect of coping with the conflicting demands of mental health issues and the need for something worthwhile to do. For most this included making a contribution to others in addition to keeping themselves busy, *"So I'm doing voluntary work, ... So I think I am putting something back in for what I've taken out" (Ged, 1.13); "In summer I help working... working doing the gardening and the lawn... cos she's eighty-three (Grandmother)" (Michael, 8.13).* Many of these activities brought the sense of achievement and self worth that is often associated with paid work [2]. This suggests that the need to do something worthwhile can be as strong as ever among those who have suffered from psychosis, but that it can be especially difficult to meet this need in the competitive working environment. It would appear that the difference lies in the commitment that competitive employment demands, which puts additional stress on an individual and consequently contributes to worsening mental health [29]. In addition, side effects, symptoms, the need to make appointments to see mental health professionals and the sometimes awkward reactions of workmates all add stress to the experience of working with psychosis and demand a measure of tolerance and understanding from employers that might be lacking.

Overall the theme of coping reflects a multifaceted and ongoing set of attitudes and activities used by participants to manage the interface between mental health, identity, working life and societal roles.

Interpersonal Support and Reactions

All of the participants frequently mentioned the support of a range of other people including family, friends and clinicians as helpful to them. The participants who were generally more positive about their lives tended to be those who mentioned having a friend outside of their family who understood their mental health issues. This may have been due to optimistic attitudes among such individuals or alternately having a confidant may have a particularly positive effect on quality of life.

The support and reactions the participants received appeared to be determined by their choices about disclosing their mental health history to others, and as a result disclosure issues have been included within this superordinate theme.

Social Support was seen as helpful by the majority of participants. "*I think there's only me close family really who know and um... me neighbour... I would have thought she would be the sort of person who would have backed off and had nothing to do with me, realise I've got a mental health problem, and yet she didn't. I mean she stood by me and helped me when I really needed friends" (Mary,4.9).*Mental health professionals were also often mentioned as providing invaluable social support. In all cases it seemed that a well-engaged, trusting therapeutic relationship was what had been most helpful. "*Then I met (CPN)... fabulous woman! And... you know I liked her straight away and we sort of... I used to go every week to (place) for me injection and we used to just have a chat about anything... shopping, clothes, you know, anything (Janet, 6.7)*. Professionals were reported to have helped by listening to concerns, being trustworthy, providing good advice about mental health and providing ongoing support through fluctuations in participants' mental health. Such information is potentially useful for clinicians in that it confirms the importance of engagement for people with mental health problems [30]. Clinicians who had a good relationship with the participant were more likely to persuade them to accept help from services.

Within the workplace, an absence of support from participants' managers or support that was seen as unhelpful was common. While some participants attributed loss of employment to their inability to cope with symptoms at work, many felt that their workplaces had been unsupportive. Unsupportive reactions from management included giving the participants menial work, restricting their duties, refusing to allow them time off to see mental health professionals, or persuading them to leave their jobs. Unsupportive reactions tended to be attributed again to ignorance, but from employers this appeared to be experienced as especially hurtful, due to the resultant losses. These findings emphasize the importance of measures such as the Disability Discrimination Act (1996), which may be useful in tackling discrimination and unfair dismissal on account of disability alone.

Disclosure and the decisions about whether to tell others of ones mental health history and how to tell them varied considerably. Through disclosure, many participants gained social support from others. The experience of being accepted despite mental health issues seemed to be extremely validating and reassuring. Some restricted disclosure to friends and family and largely concealed their mental health issues at work. The reactions of workplaces tended to be based mainly on the practicalities of employment, but were also an important source of potential support. Some participants were reluctant to return to former employment due to the potential pressure to disclose reasons for their absence. Others were more confident about disclosure and some viewed it as an opportunity to educate others about mental health, *"I like to think I've changed people's attitudes... I'd just explain to them what it were like. I said 'this is what it were like for me' I said 'everyone's not the same'... I said 'I'm not dangerous or anything or...' the only things they hear about are the ones on the news" (Ged, 1.15).*

The general consensus appeared to be that most friends and colleagues ended up being supportive and accepting in response to disclosure. Most participants seemed to regard those who reacted negatively to their disclosure as being ignorant rather than vindictive. This attribution may have helped the participants maintain their self-esteem and to see unsupportive others as misguided [31]. Several participants reported that when they disclosed, their workmates or friends were initially awkward and avoidant, but then gradually came to accept them, *"I felt that people [at work] were... getting together and saying... 'you mustn't talk to her'... and I don't think that's me being paranoid I think that's the way it was... But... only a couple of months ago we all went out for a meal...and... I think they do kind of* *grasp things better now and what happened, you know... and... we all had... a really nice time... and I thought well 'I'm not bearing grudges, it's no good is it?" (Janet, 6.14).* Others also commented that the reactions of others had become more understanding in recent times and this may reflect an increase in information about mental health issues [32] possibly as a result of anti-stigma campaigns or through direct contact.

The role of support and the reactions of others had powerful and significant effects on the participants in this study. The important relationship between social support and wellbeing was clear although the causal relationship between these factors is not clear. Social support may be linked to an individual's approach to disclosure, but it seems important that individuals see disclosure as the start of adjustment by others to their health, wider abilities and needs. This process was not always easy for the participants, although it appeared to get easier over time.

Personal Significance

All participants experienced life changes through being diagnosed with mental health problems. For some, the changes they had experienced were of a traumatic nature whilst for others there had been many positive changes. Most spoke of the effect of their experiences on the meaning of work and psychosis in the present and future.

There was a great deal of confusion among participants as to the meaning of their psychosis. To some, seeing it purely as an illness that struck randomly facilitated an acceptance which enabled them to continue with their lives as best they could. This strategy was sometimes successful, but occasionally led to the illness being externalised rather than understood and managed. Others appeared to be angrier, focussing on their losses and blaming the mental health system for not helping enough. Sometimes this was an adaptive strategy, as the anger provided energy and motivation, but it could also accompany a destructively helpless and depressed outlook and a sense of powerlessness and entrapment when it came to mental health and or employment. This could have arisen from a genuine sense that their psychosis had led to a 'spoiled identity' [33] that would prevent them from being able to feel in control of their lives again. Often this outlook seemed to go along with poor understanding of mental health issues and application of societal stereotypes to self instead.

Personal Change and loss stemmed for many from their experience of hospitalisation, treatment and ongoing contact with services. For some the negative experience of returning to work after being in hospital led to finding a new and more rewarding life, often outside the workplace. For others work practices such as overworking were altered and personal change in terms of gaining a sense of control, understanding their problems and the importance of taking responsibility for their problems were important, *"I really think that you know, when you get these things ... it's down to you really to... I mean they can give you tablets but... it can't do it on its own... You've got to be there... and trying things that people tell you" (Janet, 6.24-25).* Many mentioned losses that their experiences had brought them, such as loss of time when they were unwell or more tangible losses such as important relationships, *"I lost me girlfriend, lost me flat, I ended up in hospital, come out... stopped me medication... back in again." (Pete, 3.13).* Loss of confidence and hope was also mentioned by some of the participants, *"I've turned out to be very cautious and I don't trust people anymore, which is a shame." (John, 2.9).*

Participants with the most positive viewpoints appeared to be those who were interested in their mental health issues and viewed the experience of them as having a personal message, meaning and purpose. Taking responsibility for problems, finding a positive perspective on difficulties and seeking meaning and purpose in life in general seemed to be the attitude adopted by those who seemed to have come through their experiences with their self-esteem intact and who led fulfilled lives. This lends support to the findings of McGlashan and Carpenter [34] who found that attempts to integrate a psychotic experience led to improved outcomes.

The meaning of work for those that had persisted in working was not only related to the income it provided. Work was also seen to have other important functions such as enabling social contact. *"I live on my own, I've sort of got... I have got family in (local town) but I haven't got any immediate family living with me. I've never had any children and... when I'm not working I do tend to feel a bit isolated." (Mary, 4. 7-8).* Work also was said to bring structure to life and provide something interesting or worthwhile to do, *"I would definitely prefer to work... I get depressed about going... but I did feel... a lot better when my boss gave me some work to do... and it does add structure to your day... and gets you motivated... you know, I've said here, like we all want to be making progress in our lives." (Gillian, 7.20-21).* Work could also create a sense of normality in meeting family responsibilities and financial demands, *"I wanted to do something normal... The normal thing's to work, you see." (Michael, 8.10).*

There seemed to be little relationship between being employed and quality of life for the participants. Some who were still working were constantly struggling with residual symptoms, while others managed well, and of those who were not in paid work, some felt they led productive lives in other ways while others felt the lack of work as a great loss. It would appear that, consistent with the findings of Graetz [35], both unemployment and dissatisfaction with employment could be detrimental to quality of life for the participants.

The future was considered in relation to hopes for the future and considerations about what would be needed in order to work again or change career. For many, the fear of relapse was a prominent consideration and participants varied as to whether or not they felt they could work again. Some feared facing discrimination or losing benefits. *'I would work again if... some policies would change... with benefits and work. You know if... they give you a bit of benefit, a bit of housing benefit and a bit of work... I think... such as me and others would... work, but... while they're getting... benefit they will not have the kind of... initiative, you know, to get into work... If I started work they'd stop me benefit and if I couldn't carry on to work... me benefit would have been stopped and it'd be hard to get back into benefit.' 3.7 Pete*

Limitations

There are some limitations to this study, which require commentary. Participants were recruited on an opt in basis, so it is probable that the individuals who were interviewed were those who were better-engaged with services and who felt more confident to talk openly about the issues under investigation. This was important as this is the first study to seek to explore the experiences of those attempting to engage or remain in competitive employment after a diagnosis of severe mental illness. However, it is possible that those who declined to participate would have had significantly different experiences to those who took part. Future researchers may wish to target those who have a more diverse range of experiences in relation to employment and service provision.

Another issue worth of note is the wider societal context in which this study took place. The decline of heavy industry in the area had affected some participants' opportunities, which would have been the case whether they were suffering from psychosis or not. This may have meant that the employment experiences of the participants in the current study were different to that of a comparable cohort in a different part of the UK, due to the changing socio-political climate and high levels of unemployment in the area. Replicating this study in other parts of the UK may be important in order to understand the relative importance of job type and availability as a contributing factor.

Conclusions

The current study found that the ability to cope well with symptoms at work and resources supporting re-entry into employment were seen by participants as particularly helpful to the goal of working. Many participants also spoke of the importance social support from friends and services, but usually in relation to living with mental health issues rather than work. Symptoms and side effects, unsupportive management and ignorance about mental health problems from employers, peers and individuals with mental health problems themselves were all counterproductive to the goal of work.

These findings suggest that mental health and employment services could provide specific assistance to those with mental health problems in relation to the workplace. Helping individuals develop coping strategies that they can use, and educating employers in relation to how they may assist employees with mental health issues to re-enter vocational roles effectively are just two options. Coupled with this, measures to deal with discrimination from employers on account of mental health problems are also important in order to protect their rights and to persuade employers to rethink discriminatory practice.

The emergence of coping as an important theme in this study suggests that the development of schemes and support organisations such as IPS [13] may be vital in bridging the gap between employers and individuals with psychosis. Many of the participants in the current study mentioned support organisations that had helped them to find work placements, but there was little mention of the follow along support that schemes such as IPS provide. For some of the participants, the stress of coping with symptoms at work and the lack of understanding and tolerance demonstrated by their employers may have been remedied by psycho-educational support to both employers and employees. Vocational outcomes may be improved by further investigation into how psychotic symptoms and fluctuating mental health are most effectively managed in the workplace.

The importance of supportive relationships highlighted by the current study and the lack of allusion to these in the context of the workplace suggests that more could be done by professionals to support people with psychosis who wish to work. It would seem that there is still work to be done in terms of bridging the gap between mental health care and social inclusion within employment.

The current study also suggests that having paid work does not necessarily result in improved quality of life, although it would seem that having meaningful activities does relate to good quality of life. This suggests it is important to not make the assumption that vocational rehabilitation is necessarily an indicator of successful outcome for people with psychosis. Alternately, activities seen as meaningful to the individual (whether paid work or something else), plus a sense of responsibility for problems, personal control and understanding of mental health issues would appear to be important qualities fostered by those reporting a good quality of life.

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