The meaning and experience of work in the context of severe and enduring mental health problems: an interpretative phenomenological analysis.

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### Abstract

Research into mental health and employment has indicated that work holds multiple meanings for people with mental health problems. This paper reports findings from a phenomenological study which aimed to understand the complexity of these meanings by exploration of the perspectives of one individual who was considering returning to work. Data were gathered through a series of three interviews carried out over a period of 18 months. Three themes were identified – Beliefs and Values about Work, Working with a Mental Health Problem, and Planning for the Future. Analysis and interpretation facilitated understandings of what work represented for the participant. What this study has contributed to the evidence base is a deeper understanding of the multiple meanings of work, and the varied roles that work may play in contributing to meaning and quality of life for people with mental health problems.

### Introduction

Several studies have found that work gives meaning to daily life for people with mental health problems by providing structure, a sense of purpose, and social connections (Strong, 1998, Gahnstrom-Strandqvist et al, 2003, Kennedy-Jones et al, 2005, Koletsi et

al, 2009). Work is experienced as a way of managing the symptoms of mental illness (Kennedy-Jones et al 2005, Dunn et al, 2008, Koletsi et al 2009), as well as providing opportunities for building self-efficacy and promoting recovery (Provencher et al, 2004, Gewurtz & Kirsh, 2007, Dunn et al, 2008). Work offers a socially valued role, along with opportunities for meaningful and satisfying occupation (Gahnstrom-Strandqvist et al 2003). It also offers opportunities for developing a sense of agency, providing opportunities for achievement and a feeling of making a contribution (Marwaha & Johnson, 2005).

However, significant barriers to work for people with severe and enduring mental health problems have also been identified in the literature. Stigma, the disclosure of a mental health problem and the symptoms of the mental health problem are frequently described (Secker et al 2001, Marwaha & Johnson, 2005, Boyce et al 2008, Koletsi et al, 2009), as well as feelings of hopelessness, seeing recovery as uncertain, and feeling a lack of encouragement from services (Secker et al 2001, Provencher et al 2004, Marwaha & Johnson, 2005, Gewurtz & Kirsh 2007). Difficulties in accessing occupational health services, having a disjointed work history (Secker et al 200, Boyce et al 2009), lack of work experience, age, lack of motivation and fears about competency (Secker et al, 2001, Koletsi et al 2009), as well as the social benefits system and caring commitments (Secker et al 2001), are also experienced as barriers to accessing employment for people with mental health problems.

Current understandings of the meaning and experience of work for people with mental health problems have been provided by studies which have drawn from the experiences of large numbers of participants, and have tended to use a cross-sectional approach, with participants being interviewed only once. These studies, as reviewed above, have enabled a broad understanding of the experience of work for people with mental health problems, however detailed exploration of personal experiences has been limited by the study design. Smith et al (2008) have suggested that single case studies can be particularly powerful in facilitating understandings of an individual and their responses to particular situations. It also allows the space to explore connections within an account (for previously published examples, see Eatough & Smith 2006a, 2006b). In addition, the individual narrative can provide a detailed example of the process of imagining future possibilities (Dossa, 2006). This account comes from a larger study of the meaning and experience of work for people with severe and enduring mental health problems, and allows the reader an insider view of the experiences of one man over an extended period. By using a single case study and adopting a phenomenological approach a more nuanced understanding may be possible.

### Method

Phenomenological approaches to research have at their core a commitment to exploring the life world of individuals, and the meanings that their experiences hold for them. We wanted to explore the meaning and experience of work for one person in detail, making this a suitable approach. The research methodology was informed by interpretative phenomenological analysis (IPA) (Smith et al, 2009). IPA cannot be said to generate theories which are transferable to other populations; this type of enquiry can provide insights into the experiences of individuals which can then be explored in relation to the extant literature. These may in turn provide starting points in the development of a more

complete account of the experiences of individuals who experience mental distress and who wish to return to work. From this perspective, the findings contribute a sensitivity to understanding the needs of people who use mental health services, and who aspire to return to work which has heretofore been largely absent from research evidence in this field.

# Study design

In-depth semi structured interviews were selected as the most appropriate method for gathering the data as this approach allowed for deep exploration of the topic, as well as the opportunity to facilitate the participant in focussing on related issues. Ethical approval was provided by both the University and the Local Research Ethics Committee. A series of three interviews were conducted over an 18 month period. Multiple interviews were chosen in order to capture changes in the participant's life. The interviews were all conducted by the first author. They lasted between 30 minutes and an hour. Interviews were digitally recorded and fully transcribed. Identifying details were removed during data analysis and the pseudonym assigned to ensure anonymity.

### The participant

John was in his late forties at the time of the first interview. Diagnosed with schizophrenia in his teens, John had been a user of mental health services for most of his adult life. After leaving school he had worked in low paid, low skill jobs. On occasions he had lost his job due his mental ill health, either through being dismissed by his

employer, or choosing to leave. During the course of the study John worked for a short period as a voluntary carer. John described his ethnicity as White British.

# **Data Analysis**

Smith et al (2009) suggest that the steps for data analysis are not prescriptive and encourage researchers to adapt them to their own personal way of working. The approach to data analysis used here was shaped in the way that Larkin et al (2006) proposed. The first strand of analysis is descriptive and concerned with how the participant understands the phenomenon being investigated. It should culminate in an account that the participant would recognise as accurately representing their perspective. The second strand is more analytical and interpretative, and asks what sense the analyst can make of the participants' sense-making in relation to the phenomenon, and in relation to the extant literature.

Analysis was conducted by the first author. Each transcript was analysed in the same way. Initially the recorded interview was listened to a number of times in order to become very familiar with each account. Then the transcript was read and re-read whilst listening to the recorded interview in order to become immersed in the data. Whilst reading the transcript the analyst made initial notes on the transcript, paying particular attention to contradictions, amplifications, use of language and the sense of the person, whilst also summarising key ideas and noting any preliminary interpretations, as recommended by Smith & Osborne (2008). These notes were then grouped together in emerging themes. The themes were then transferred to a table of themes, with identifying quotations assigned, as well as interview, page and line numbers to assist in locating

specific extracts from the transcript. By proceeding with the analysis in this way for each of the three interviews, three theme tables were created which then served as the basis for writing up a narrative account which combined findings from all three interviews in an account which is as close as possible to the participant's view. The analysis was corroborated by discussion with the participant who has reviewed a draft of this paper, and by the second and third authors who were not involved in the data gathering or initial stages of analysis.

### **Findings**

The following themes emerged during data analysis – Beliefs and Values about Work, Working with a Mental Health Problem, and Planning for the Future.

Each theme is illustrated by extracts from the transcripts of the interviews with John. The numbers refer to the interview from which the extract was taken.

# 1. Beliefs & Values about Work – 'I was brought up to believe that you should work'

John's accounts communicated his world view about the human need for work in general, well as his personal view of work, and what it meant to him –

'I was brought up to believe that you should work, and I feel in a childlike sense, I feel ... I'm doing the correct thing, you know? I'm going to work. It's the correct thing to do'. (1)

'I think it's like a herd instinct really for human beings to want to work. Working in our modern day society is the equivalent of us hunter gathering a thousand years ago'.(1)

At one level these extracts could be seen as a representation of himself as someone with a strong work ethic which stemmed from his upbringing. It also seemed he was making a wider claim about the human wish to work, and including himself in this view. His evocation of 'herd instinct' seemed to speak to an evolutionary past, indicating a very deeply rooted human need, as well as something that he had in common with others. However, 'following the herd' and acting in a childlike way could also suggest a lack of choice and autonomy rather than a self-determined requirement, reflecting his acceptance of the social value that is placed on work.

John also suggested that work was a way to contribute to society, whilst at the same time, having an impact on personal development:

I feel these things [volunteer work] help to shape and make you – make you a person that's putting in to society, and enriching, hopefully, your society'.(1)

It seemed that John held a variety of views about work. He saw it as a way to meet many of his stated needs, including a sense of belonging, but also that accessing work could also involve risk. John offered a view that working is socially desirable, and hinted at the uncomfortable feelings that may be aroused by not fitting what he may see as the social norm. To be unable to work in a society that places a high social and economic value on paid employment may be very difficult. For someone who may already feel excluded because of their mental health problems, this may be especially problematic.

# 2. Working with a mental health problem – 'a disobedient dog'

In the first interview John talked extensively about the difficulties of working with a mental health problem, the disruption that the episodes of illness created in his working life and the impact of this disruption on his self confidence. He gave a comment from a tutor in an Adult Education class in which he had enrolled –

'She asked if I'd got my bipolar under control, like it was a disobedient dog or something'. (2)

John's use of the dog metaphor was interesting, perhaps casting some light on how he experienced his mental health problem – both as a source of anxiety and difficulty, but also as something that he was very familiar and quite comfortable with. John went on to describe how his illness had impacted directly on his work and how it made him decide he could not return to work at that time. It is clear to see the disruptive impact of this 'disobedient dog' on John's work history -

I worked at [airport] as an aircraft cleaner...I had a breakdown and they were quite supportive actually but I actually resigned from that job because I felt embarrassed. I could've gone back after I'd been ill but I felt humiliated because I had been ill at work. (1)

John's increasingly powerful use of language to describe how he felt following this episode of illness – *embarrassed*, *humiliated* – suggested that the support offered from his employer was not sufficient to enable him to overcome the painful feelings that had been aroused by having become mentally unwell at work.

In the third interview John spoke in more detail about his experience of illness and of how he lived with it, facilitating a deeper understanding of his experiences. Whilst initially described as 'a disobedient dog' to illustrate the unpredictable element of his illness, it emerged that John also saw the illness as predictable. This apparent paradox is illustrated in the following extract -

'We're dealing with what is, and it is a frustration and something to take into consideration that every three or four years, near as damn it, I'm going to be ill'. 'So perhaps having a little plod-on quietly, as I've suggested I'm going to, with the plans

that I've got and then looking at it [work] after the next time I'm ill, which is a very bad thing to say, but I think it's a realistic thing to say ... gives me another three year run at doing something where I might be able to establish myself wholly in something [before becoming ill again]. (3

This aspect of his illness presented a major challenge for John in his return to work plans.

Conversely, this detailed knowledge of the rhythm of his illness was important to John when planning his future. A detailed understanding of an individual's knowledge of their own mental health problems and the way in which they manage this would seem to be important in making future plans, including returning to work.

# 3. Planning for the Future – 'ready to bat on'

Although he was keen to stress that he thought there was nothing wrong with mopping floors, John indicated that he felt ready to take on bigger challenges and invest in his future -

'I am thinking in the short term about this Better English and this computer course and then I may... be able to think about some sort of training. So that's where I am at the moment. I'm at the blocks really waiting to bat on but I've got hopes for the future and there is nothing, and I mean this sincerely, wrong with mopping floors but I would like to try and raise my sights up a bit beyond that'. (1)

The image suggested is one of a runner, under starter's orders, or a cricketer going in to bat. The runner requires an explosion of energy, the cricketer something more sustained and longer term. Both are positions that John held with regard to his ambitions to get back into work. He seemed full of energy and enthusiasm and he also conveyed a sense of determination in his quest to improve his lot in life. He offered this story as an illustration of his approach to his recovery:

'I once watched an Olympic 30,000 metre race. A man fell over and the commentator said 'oh it's all over for...' He got up and he won that race. I intend to win my race. I intend to arrive, not at the end of my working career but at the other end of my life, having tried.'(2)

John's use of sporting metaphor and analogy provides some understandings about his return to work seen from his perspective. He saw his recovery as a race, a long race which is a sport of loneliness and endurance, but the cricketer is part of a team. Each of these images has something to communicate about John's view of his recovery and the role of work within it, and is important to understand in order to fully comprehend the lived experience of managing a severe and enduring mental health problem and making plans to go back to work.

### **Discussion**

The analysis has highlighted the significance of values and beliefs about work, which may be rooted in early experiences of work and more general cultural understandings. It also shows how factors outside the control of the individual, such as illness and social mores, impact on attitudes to work. By exploring John's personal accounts, a deepened understanding of the lived experience of managing a serious and enduring mental health problem and the impact of this on self concept and attitudes to work is possible.

John held firm beliefs about the importance of work, both for himself as an individual, and for society as a collective. Although he had not worked for a number of years, he presented a strong desire to work and a belief that it was the 'correct thing to do'. Exploration of John's beliefs and personal values about work suggested that work held meaning for him as a way to feel a sense of belonging in society by having a socially valued role, and as someone who was able to a make a contribution to society. Although John's stated goal was to eventually find paid employment, he was emphatic that the

occupation and structure provided by work, be it paid employment or voluntary work, was what he needed. Jahoda (1981, 1982) referred to this function of work, along with the engagement in a collective pursuit, as one of the 'latent functions' of work. The generally assumed main function of work – financial recompense – was not emphasised in John's accounts. This is contrary to much evidence, where payment for work, enabling financial independence, has been seen as very important by people with mental health problems (Boyce et al, 2008, Dunn et al, 2008, Koletsi et al, 2009).

Paid employment of course is not the only route to participating in society. The flexibility provided by voluntary work, and the freedom to engage in other pursuits without being committed to a paid job, has many benefits (Honey, 2004). John indicated that he liked to be autonomous and to have some choice about what he engaged in but also saw return to paid work as a personal achievement. John also valued the opportunity to remain in control of what work he took on and how much, aware of the need to juggle this with the cyclical nature of his mental health problem. It seemed that whether to work or not to work required careful consideration of a number of different factors, the most important of which may be the individual's personal understanding of their mental health problem and how it's course and cycle may impact on working

The difficulties of working whilst experiencing the symptoms of a mental health problem and the associated problems of feeling stigmatised, have been described in the literature (Secker, 2001, Marwaha & Johnson, 2005, Koletsi, 2009). During his working life John had experienced a number of episodes of mental ill health which had resulted in him leaving his job, either because he was too unwell to continue, or sometimes because of

the shame and humiliation he felt as a result. As Dunn et al (2010) suggested, individuals who are still near the beginning of their recovery may be concerned with issues related to their illness. They may view their previous work experiences with a different perspective to those that have progressed further in recovery, or even how they may see themselves as times progresses and their recovery journey unfolds. For these reasons engaging with narratives as they unfold over time is valuable. The three interviews with John over an extended period of 18 months, afforded a unique opportunity to understand his perspective on his mental health problem and the importance of dovetailing his periods of feeling well with his forays into the work place via voluntary work and further education. John had also at times experienced feelings of being excluded whilst at work, and at such times felt deeply aware of difference and a sense of being separate. The dominant social discourse around work and current social policy which aims to get people back to work may lead individuals to feel work is the key to being socially included (Marwaha & Johnson, 2005). It seemed that John held somewhat ambivalent and conflicting views about work. He had talked about it being part of man's nature to want to work - 'a herd like instinct '. This revealed what he saw as a lack of individuality in the choice to work in following the herd or the crowd. John also referred to 'doing the correct thing, in a childlike sense' when he first described his views on work. The repeated use of use of the word correct and the word childlike seemed to suggest a perceived lack of individuality and to convey a sense of doing what was expected of him. This ambivalent view of work is reflected by Marwaha & Johnson (2005) who suggested that behind initial expressed desires to work lie more complex personal and private beliefs and values about work. It is suggested in the current study that these may in part have their roots in previous painful

experiences associated with work, as well as in the cyclical nature of some mental health problems. With the wish to feel a sense of belonging, and seeing work as a way to achieve this, came a powerful emphasis on the painful experience of *not belonging*. In the first two interviews belonging at work was implied. In the third, a wish to belong and feelings of not belonging became more apparent and explicit, and were expressed in a striking metaphor. The 'herd' metaphor, used on more than one occasion, suggested John's feeling of isolation, which was emphasized by being 'left behind when others went off to war' as a way to describe how he felt about not working when other people were.

At the beginning of the study John was charged with hope and optimism, describing himself as being ready to try work. His plans for the future though, were tempered with a need to manage the cyclical nature of his mental health problem in a way that allowed him to formulate future plans. Understanding John's personal interpretations of his illness would seem to be very important in understanding John, and for working with him as a health care professional or vocational worker, as he sees it as a very significant factor affecting his plans. His experiential knowledge of his illness allowed him to plan around it and it is perhaps this intimate and detailed knowledge of his illness cycle that gave John some control and feelings of power over the illness. The paradoxical interpretations of John's illness – the cyclical nature of it that, in John's word 'just is', and the perceived unpredictability of a 'disobedient dog' – are important to highlight, and would perhaps not have been quite so apparent if a different approach to the data gathering had been taken.

This idiographic approach to the topic has added to the literature on work and mental health problems with a more nuanced exploration of some key issues for an individual. Particularly striking is John's paradoxical understanding of his illness which it has been possible to illuminate and discuss. This may be helpful for those people who have been out of the workplace for some time and who wish either to re-enter it, or to derive benefits from occupational engagement other than paid employment.

### **Critical evaluation**

Since this study has presented findings from three interviews with just one participant clearly a judicious approach is required in interpreting the findings. Single case studies present a challenge to the generally accepted norms of transferability. One of the strengths of a single case is that it enables the illumination of the ambivalence, ambiguity and complexity of responses.

The phenomenological approach and the interview style used were sufficiently open to enable the participant to share what was relevant to him around the topic of working and having a mental health problem. In addition, the findings have been shared with John prior to submitting the paper for publication. This gave him an opportunity to add to the credibility of the analysis, and some small changes have been made as a result.

Finally the longitudinal study design has enabled the pathway of recovery to be explored over time, creating an opportunity to explore setbacks and deviations, as well as successes and progress. The importance of timing in accessing work has been illuminated by John's account and provides a reminder that people may not necessarily be ready to work at the time when they are engaged with services.

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