

The subjective experience of adults with intellectual disabilities who have mental health problems within community settings

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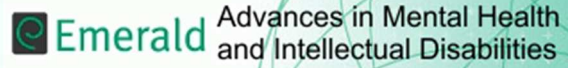
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The subjective experience of adults with intellectual disabilities who have mental health problems within community settings.

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Review

The subjective experiences of adults with intellectual disabilities who have mental health problems within community settings.

Abstract

Purpose:

Research into the views of people with dual intellectual and mental health difficulties is sparse. This study aims to gain a greater understanding of how individuals with mild intellectual disabilities living in the community understand their psychotic symptoms and experiences.

Methodology:

Five participants with intellectual disabilities and psychotic symptoms living in the community were interviewed. The interview schedule explored key areas: understanding and experiences of having an intellectual disability and a psychotic disorder, and of services provided. The data were analysed using Interpretative Phenomenological Analysis.

Findings:

The analysis elicited three main themes: Self Concept: “How I understand and see myself”, incorporates what participants understood about their labels, their experiences, and how these labels fitted in with their self concept; Impact: “How having mental health problems and learning difficulties affect my life”, encompasses communication barriers, lack of control, and stigma and vulnerability. The third main theme was Coping: “How I cope with my mental health and learning difficulties”.

Implications/limitations:

The findings suggest that the participants, rather than identifying with specific psychiatric labels perceive themselves as having individual and specific needs. The analysis highlights areas that can be developed to help with coping; ensuring people are respected and heard, empowerment through the development of positive social roles, and psycho-education. These results are a step towards developing understanding of this group of service users.

Originality/Value:

There has been no previous research into the perspective of this service user group in the community. The authors make recommendations for future person-centered interventions.

Key Words:

Intellectual disabilities, psychotic symptoms, community settings, subjective experience, adults, mental health.

Classification: Research Paper.

Introduction

Individuals with intellectual disabilities are at a higher risk of developing additional mental health problems than the general population (Whitaker & Read, 2006). There has been a growing body of research evidencing diagnostic issues (Moss, 1998), prevalence rates of comorbidity (Cooper et al., 2007), factors that influence the onset of symptoms (Hastings, Hatton, Taylor, & Maddison, 2004), and effectiveness of therapeutic interventions from a service perspective (Whitehouse, Tudway, Look, & Stenfert Kroese, 2006). However, despite UK government policy emphasising the importance of inclusion (Department of Health, 2001; 2009), there has been a lack of research on the service user perspective. This suggests a gap between policy and practice, with this group still being marginalised (Young & Chesson, 2006). Over the last decade this gap has been recognised to some degree, and there has been a growing momentum of researchers seeking the views of people with intellectual disabilities. The intellectual and functional difficulties that people with intellectual disabilities and mental health problems encounter are likely to compound their mental health difficulties (Stenfert Kroese, Rose, Heer and O'Brien, 2013), suggesting an additional level of need compared to people with mental health needs without intellectual disabilities, for example around issues of consent, understanding of symptoms and related experiences, communication, and practical daily living skills. 'Valuing People' (Department of Health, 2001) states that people with learning disabilities should be treated within mainstream mental health services rather than specialist services where possible. Parkes, Samuels, Hassiotis, Lynggaard and Hall (2007) explored the experiences of people with intellectual disabilities who were admitted voluntarily for mainstream inpatient psychiatric treatment. The findings showed experiences were mixed. This service user group found it frightening and received limited explanations about what was happening on the ward. However, they appreciated the social contact with other patients, and having an identified member of staff when needed. McNally, Beail and Kellett (2007) explored the experiences of individuals with intellectual disabilities who were detained under the Mental Health Act (1983). They found that these individuals experienced vulnerability, victimisation, and a sense of powerlessness. These experiences compounded negative views of self. In addition, they found that participants with a more positive perception of their inpatient experiences had created positive 'roles' within the system, and appeared to be coping better.

O'Brien and Rose (2010) explored the views of people with intellectual disabilities about their experiences of the support they received for their mental health needs and found that participants valued how services were delivered more than by whom (mainstream or specialist services). Service users valued a person-centred service in which professionals listened, treated them with respect, and attempted to help. Life experiences of bullying and injustice came out as important issues that these individuals had had to face and continued to experience. Jahoda, Dagnan, Jarvie and Kerr (2006) have suggested that greater awareness of difference and negative treatment by others increases risk of depression. It is, therefore, not surprising that establishing a good relationship was found to be important in the O'Brien and Rose study, as was giving the service user choice and control over their life. Stenfert Kroese, Rose, Heer, and O'Brien (2013) examined the experiences of services of people with intellectual disabilities and mental health problems. They found that mainstream mental health services for people with intellectual disabilities lacked quality and ease of access. They explored service user and staff views on desirable personal qualities for staff working in this area. Their findings supported those of O'Brien and Rose (2010) and indicate that a genuine interest in people, approachability, empathy and communication skills are important staff characteristics. Participants valued competence-promoting support and being given the opportunity to be involved in decisions. Service users equated quality with responsiveness, good communication between staff in mental health and intellectual disability services, and training and supervision for staff.

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3 Much of the research that has been conducted into the views of service users has focused on their experiences of
4 services, treatment pathways and specific interventions. There has, however, been limited exploration into this group's
5 understanding and experiences of their mental health and diagnosis per se, and how their intellectual disability may
6 affect this. One exception was Cookson and Dickson (2010). They explored the views of people with intellectual
7 disabilities who were detained in a medium secure unit, specifically their perceptions of their diagnosis and experience
8 of psychosis. They identified three main themes; 'reality of symptoms', 'making sense / a search for meaning', and
9 'perceptions of being labeled'. Their first main theme 'reality of symptoms' was made up of two sub themes; 'voices as
10 controlling / malevolent' which captured how threatened, submissive and inferior the participants felt in relation to their
11 voices, and 'symptoms as a real lived experience' which involved participants attributing their experiences to external
12 sources rather than as a symptom of mental illness. The second main theme, 'making sense / a search for meaning',
13 encompassed three sub themes to highlight different frameworks used by the participants to aid their understanding of
14 their experiences. Firstly, 'normalisation' which involved participants using their past life experiences to understand
15 their current experiences. Secondly, 'religious / spiritual explanations' of what they were experiencing, and thirdly
16 'psychotic symptoms as a sign of illness'. This last sub theme had a focus on the medical model and tended to run
17 alongside the other themes. The authors hypothesised that this may be because participants had more recent exposure to
18 a medically oriented environment than the other themes. The third main theme, 'perceptions of being labeled', was
19 made up of two sub themes, 'acceptance versus rejection' which took into account power relations and compliance with
20 treatment plans, and 'impact of diagnosis' which captured stigma, changes in relationships, and practical and emotional
21 effects. The authors concluded that together these themes highlight the impact that schizophrenia has on identity,
22 understanding of these experiences, and the lack of power experienced in relation to both the illness and professionals.
23 These themes reflect those found in previous literature on psychosis and people without intellectual disabilities.
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33 The views of service users with intellectual disabilities and psychosis have not been explored within community
34 settings. Residential and supported accommodation in the community allows greater freedom, autonomy, and
35 opportunities for service users, but is also potentially a less supportive, shielded and protective environment compared
36 to inpatient units. This study therefore aims to gain a greater understanding of how individuals with intellectual
37 disabilities within the community understand their psychotic symptoms and experiences. This will help provide greater
38 understanding into the needs of these individuals, allowing for more effective person-centred interventions.
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43 **Methodology**

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46 This study has adopted a qualitative design and used Interpretative Phenomenological Analysis (IPA) as the analytical
47 method.
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49 **Participants:**

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53 Seven adults with intellectual disabilities completed the pre-interview screening assessments. The participants were six
54 men and one woman aged between 22 and 55. IQ scores ranged between 55 and 69, confirming all participants
55 functioned within the mild to moderate intellectual disability range. Two male participants dropped out prior to
56 interview, leaving five participants who completed the study (Table 1). While this is a relatively small number it is
57 consistent with practice in IPA research (Smith, Flowers and Larkin, 2009). Of these five participants, four had a
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diagnosis of schizophrenia, one had a diagnosis of bipolar disorder (this individual frequently experienced psychotic symptoms) and they all were prescribed a variety of anti-psychotic medications. All of the participants lived in residential accommodation within the community. All interviews were conducted in English, however English was the second language for one participant and the interview was mainly conducted in English. Both this participant and the interviewer were native Punjabi speakers, enabling the interviewer to ensure the participant’s comprehension.

Table 1: Participant Demographics

	Trina:	James:	Tom:	Phil:	Simon:
Age:	35	43	52	55	32
Sex:	F	M	M	M	M
Ethnicity:	Indian	White British	White British	White British	Afro-Caribbean
Languages:	English & Punjabi	English	English	English	English
FSIQ 2: WASI II	58	60	62	66	62
Diagnosis:	Intellectual Disability Schizophrenia	Intellectual Disability Bipolar Disorder	Intellectual Disability Schizophrenia	Intellectual Disability Schizophrenia	Intellectual Disability Schizophrenia
Psychoactive Medication:	Quetiapine Lithium Carbonate Lorazepam	Citalopram Valproic Acid Lithium Carbonate Olanzapine Fluphenazine decanoate Procyclidine	Aripiprazole Clozapine Fluoxetine	Amisulpride Depakote Procyclidine	Aripiprazole Fluoxetine Haloperidol Diazepam Procyclidine
Accommodation :	Residential Home with 24 hr staff support	Residential Home with 24 hr staff support	Residential Home with 24 hr staff support	Supported Living with visiting staff support	Residential Home with 24 hr staff support

Procedure**Recruitment**

Following National Health Service (NHS) ethical approval (12/WM/0353), potential participants were identified by clinicians working within Intellectual Disability and Early Intervention Services from the West Midlands region. The inclusion criteria included participants with a mild to moderate intellectual disability, psychotic symptoms, and accommodation within the community. Clinicians gave information sheets, consent forms, and opt-in letters to potential participants and their carers and asked them to consider participation in the research.

If participants opted in, formal consent was obtained by explaining the research to individuals using an easy read information sheet and using four standardised questions related to the study, to check understanding (Arscott, Dagnan and Stenfert Kroese, 1998). Only participants who answered these questions correctly, and were assessed as having an intellectual disability which was supported by having an IQ of less than 70 as measured by the two sub scales of the Wechsler Abbreviated Scale of Intelligence (WASI-II), were eligible to participate in the study. Participants were made aware of their anonymity, their right to withdraw, and how participation would not impact on their care in any way.

Semi structured interview

An interview schedule was designed for the purpose of this study. It was based on themes that emerged from Cookson and Dickson's (2010) study, the broader literature, and was revised through discussion with two experienced clinical psychologists. The interview was based on open ended questions that focused on experiences and understanding of the diagnosis of intellectual disabilities, the diagnosis schizophrenia or bipolar disorder and of services provided.

The researcher met each participant at a location convenient to the service user to conduct the interview. The researcher gained consent for the interview to be audio recorded. Interviews lasted between 20 minutes and an hour. The recordings were transcribed verbatim, and each participant was given an alias to maintain anonymity.

Data Analysis

IPA was used to explore the perceptions of people with intellectual disabilities in relation to their psychotic symptoms and experiences. This approach allows in-depth exploration into how individuals make sense of their subjective experiences within specific situations (Smith, Jarman & Osborne, 1999).

The analytical procedure followed the IPA guidelines set out by Smith, Flowers and Larkin, (2009). This involves developing an awareness of personal preconceptions, and how these may influence the analytical process. Preconceptions were reduced by the primary analyst being naive to both the patient group under exploration and the relevant literature base until after the analysis was complete.

The analysis entails line-by-line coding of each transcript in turn and documenting exploratory comments in the margin of the text. Initial themes that emerge from this analysis were collated into a table. These themes are used as a 'base' when analysing the following transcripts. Additional emergent themes are subsequently included into the table. When

complete, these themes are organised into a structure, demonstrating the relationship between them. In order to achieve validity and credibility, each stage of the analytical process was discussed with an academic supervisor.

Results

At times during the interviews, Trina and Tom gave brief answers, requiring a number of prompts from the interviewer. Nevertheless, all of the five interviews produced data sufficient in depth and quality to conduct IPA and to elicit a number of themes.

The three main themes elicited were: ‘Self Concept’: “How I understand and see myself”; ‘Impact’: “How having mental health problems and learning difficulties affect my life”; and ‘Coping’: “How I cope with my mental health and learning difficulties”¹. Table 2 presents these three themes and the sub themes they encompass.

Table 2: Table of themes:

Superordinate themes:	Sub themes:
<u>Self Concept</u> “How I understand and see myself”:	What I understand about my labels.
	How I understand my experiences.
	How these labels fit me
<u>Impact</u> “How having mental health & learning difficulties affect my life”:	Ability to express myself & feel heard.
	The level of control I have over my experiences and my life.
<u>Coping (buffer)</u> “How I cope with my mental health and learning difficulties”	Stigma, victimisation and vulnerability.

Theme 1 - Self Concept: “How I understand and see myself”.

This theme encompassed what these individuals understood about their diagnoses, how they made sense of their experiences, and whether they accepted or rejected their labels. These views tended to impact on their self-reported self concept and sense of identity, and how they perceived they fitted in with the world around them.

Sub theme 1 - “What I understand about my labels”:

¹ The term ‘learning difficulties’ equates to ‘intellectual disabilities’. The terms ‘learning difficulties/disabilities’ were found to be more familiar and accessible when talking to the service users, therefore these terms were used to label and describe the themes rather than the term “intellectual disabilities”.

1 When asked to talk about their experiences of having a learning disability and mental health problems, participants
2 appeared to have little awareness and knowledge of the meaning of these labels. Trina had not heard of the term
3 'learning disabilities' before, "Not really, I haven't", but suggested, "What you are or you look like?". Simon appeared
4 unsure, "Is it like you need a wheelchair?", and asked, "Does it mean you know nothing? (...) the word has something
5 to do with learning (...) I have heard of the word but not the meaning". Phil specified the difficulties he experienced,
6 "It means you can't read and write". When asked about whether they had heard of the word schizophrenia, Trina had
7 not, "No I haven't". Simon was unsure, "I have heard it once or twice (...) is it an illness?" James demonstrated a
8 similar limited level of understanding of bipolar disorder, "I've got that", but could not explain it, "I don't, not off by
9 heart (...) It's a disorder". Tom appeared to have better understanding of this diagnosis than he did of learning
10 disabilities, "When you hearing voices and when you talking to yourself, that kind of thing".

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17 Sub theme 2: "How I understand my experiences":

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19 The participants described their psychotic experiences in a variety of ways Tom did not appear interested, "Hmmm I
20 don't know (...) I just take my tablets" whereas Phil stated that he avoided thinking about his symptoms. He worried
21 this might cause them to reoccur, "I don't want to talk about it really because I might end up that way again, coz I
22 might end up worse and I might not come out of it". Trina switched between different explanations that other people
23 had suggested to her. She questioned whether the experiences were real, "I was frightened thinking who the hell is
24 that"; supernatural, "I was frightened of the ghosts and devils"; dreams, "There could be someone in my dreams
25 scaring me"; or her being unwell, "my tablets are good for me, these strange noises I was hearing are completely
26 gone." She did not commit to any one explanation, and appeared unsure what to believe.

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32 Sub theme 3: "How these labels fit me":

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34 Overall, there appeared to be a lack of identification with the diagnostic labels, instead the participants identified with
35 specific areas of difficulty. Phil divided people with learning disabilities into different categories according to severity.
36 He identified with people who functioned highly, "What about everyone else who has learning disabilities who can't
37 get a job there, it's not fair on us is it?", whereas he distanced himself from people who had more severe difficulties,
38 "Most can't read and write here at the centre, some are like kids (...) they can't understand what I'm talking about".
39 Similarly, Simon only identified with symptoms that affected him, "Nothing wrong with me, I only hear voices
40 sometimes". James identified with the label bipolar disorder to a greater degree than the label learning disability,
41 possibly because it had a greater impact on his life, "I've got bipolar disorder. I've got that for the rest of my life (...)
42 One minute I could be laughing and joking, and then I'm like smashing things up". However, he also recognised that
43 together they had a greater impact than individually, "If I didn't have learning disabilities or mental health, I wouldn't
44 be in this situation now".

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51 Theme 2 - Impact: "How having mental health and learning difficulties affect my life".

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54 This theme reflects the impact that having both mental health and learning disabilities have on participants' lives,
55 whether it be emotional, practical, or both. The sub themes relate to communication and feeling heard, levels of control
56 the participants felt they had over their mental health experiences or decisions in general, and vulnerability and
57 expectations of discrimination.

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3 Sub theme 1 - "Ability to express myself and feel heard":
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6 Some participants talked about finding it difficult to communicate with others. Tom explained that people did not
7 always take the time needed to understand him. This impacted on his mood, causing feelings of isolation and loneliness,
8 "I get very anxious when they can't understand what I'm trying to say", and "Don't have anyone to talk to and
9 sometimes I get ignored". James also lacked confidence when communicating his needs, "I'm not much good with
10 words and stuff", and "I get very frustrated (...) I can't express myself". He described how this sometimes resulted in
11 aggressive outbursts "I can go downstairs and go off on one (...) That's the challenging behaviour". Phil spoke about
12 not feeling listened to. He either avoided professionals or behaved aggressively in order to feel heard, "I explained to
13 them what was going on, and afterwards I got fed up with them coming so I went to my brothers (...) I didn't want to
14 talk about it and he wanted to carry on and on, and I didn't like it (...) when they were asking me questions about my
15 voices it was making it worse (...) it was making me aggressive".
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21 Sub theme 2 - "The level of control I have over my experiences and life":
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24 Many of the participants spoke about the unpredictability and lack of control they felt they had over their psychotic
25 experiences, mood fluctuations, and their consequences. Phil noticed this in a number of areas of his life; in relation to
26 his voices, "you don't know it's going to happen until it happens."; his level of engagement, "I had to deal with them
27 because they can just take me"; and his life in general, "When I was in hospital they checked me out and found I had an
28 ulcer (...) So they operated on me without me knowing". James described feeling at the mercy of his mood fluctuations,
29 finding them overwhelming at times, "One minute I have shot up, and the next I have shot down (...) I don't understand
30 that (...) That's my life (...) You can't control yourself." Simon found his voices intrusive, interfering with his ability to
31 function, "it stops me from having a shower (...) when I am in the shower I can hear it saying things to me". He also
32 described how his difficulties prevented him from achieving life goals, causing disappointment and upset, "like driving,
33 having a girlfriend, having a job (...) I wish I could have a girlfriend". Phil on the other hand rejected the disability
34 role, giving him a sense of control over parts of his life, "I worked in a factory and I have never had a problem there".
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41 Sub theme 3 - Stigma, victimisation, and vulnerability:
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44 Some participants appeared to demonstrate a lack of awareness and/or indifference to other people's opinions. Simon
45 stated, "I don't see nothing wrong with it (...) Probably don't take any notice", as did Trina, "Don't know really (...) I
46 don't care about other people". Most of the participants did not see their difficulties as being obvious to other people,
47 therefore they only expected stigma and discrimination if they specifically disclosed this information. James stated,
48 "I'm just a normal person like everyone else", but acknowledged a reluctance to tell others, "I don't tell nobody (...)
49 They might turn against me". Phil voiced similar views, "I don't think they knew (...) It's none of their business anyway
50 (...)". Phil had experienced humiliation in the past, "I put words down, and when they took the papers into the office,
51 all you could hear, they were laughing at it (...) I didn't like it one little bit, felt like I wanted to give my job up and walk
52 out of there".
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57 Theme 3 - Coping: "How I cope with my mental health and learning difficulties":
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1 Many of the participants did not view themselves as disabled or victims, they focused on their specific needs rather than
2 overall diagnoses. A variety of coping methods were mentioned to manage their difficulties.
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5 James felt that his constant emotional turmoil restricted his ability to cope, *"You can just never tell which day it is going
6 to come on"*. He felt unable to take up opportunities in the community, *"I don't feel up to it (...) I wouldn't do it"*. A
7 number of the other participants, however, did feel able to take up meaningful activities and roles within the
8 community. They felt that this distanced them from their labels, and instead of focusing on problems, kept their minds
9 occupied and stimulated, promoting self-esteem, purpose, and mental wellbeing. Tom kept active within the
10 community, *"I do working four days a week"*. Simon achieved self worth through his sporting activities, *"I'm good
11 with the ball, and good with goal and good at scoring (...) I go [sic] that park up there sometimes to play with my
12 friends"*. Trina valued going to college, *"I have mostly been doing my work (...) doing some writing"*.
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18 Willingness to work with professionals also impacted on coping, as these participants received moderate to high levels
19 of support to complete weekly activities. Most participants viewed the support staff as helpful facilitators, enabling
20 them to maintain their position within the community. Tom found emotional and practical support helpful, *"I go out
21 with staff to do shopping and that"*. Trina also described a positive attitude towards support and psychiatric staff, *"Yeah
22 he's helpful to me (...) because he's the one that helped me get the tablets"*. However, she also highlighted conflict,
23 *"Staff shouting. It makes you angry. They start shouting: "Dddd... Then it makes you angry then"*. Phil tried to avoid
24 psychiatric support, he viewed it as threatening, *"They (psychiatrists) just keep coming and keep bringing it back, and
25 that's making it worse (...) and it might start up again"*.
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30 A lack of awareness to labels and public perceptions may have provided some of these participants with a protective
31 resilience. This enabled them to reject the disability role and continue with life shielded from some of the associated
32 negativity, disappointment, or discrimination. Phil did not spend much time thinking about his learning disabilities, *"I
33 don't really think about it half the time (...)"*. Similarly, Simon did not view his disabilities as a problem, and did not
34 care what others thought of him, *"I don't see nothing wrong with it (...) Probably don't take any notice"*.
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39 The participants used varying coping strategies to help them manage their difficulties. Phil described pro-active
40 strategies to help him manage his learning disabilities, *"I used to copy off the tins (...) of what I want, it's a lot easier
41 that way"*. When managing his mental health and psychotic experiences, he used avoidance, *"didn't say a word about
42 it. I just ignored it. There was nothing else I could do"*. Simon used distraction techniques to keep himself occupied, *"I
43 like to play R&B and reggae, and play on my play station"*, as did Tom, *"I watch TV, play my play station or listen to
44 music (...) I don't listen to them or don't notice them (voices)"*. He also found talking supportive, *"It's been helpful (...)
45 talking about things"*. James also used self-soothing strategies, *"I just go for a walk... cool off, then come back"*.
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51 Discussion

52 The findings of this qualitative study suggest that people with intellectual and mental health difficulties are confused
53 about the meaning of their diagnoses, and do not identify with the labels given to them. The participants in this study
54 described themselves as individuals with specific difficulties and needs. They were able to provide rich accounts of
55 their experience and there were no obvious difficulties with acquiescence or a willingness to please the interviewer,
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1 suggesting that the quality of the interviews were good. Rather than identifying with the psychiatric labels given to
2 them, they reported on the practical and emotional difficulties as a result of their intellectual and mental health
3 difficulties, which significantly impacted on their lives. These accounts are in line with Bentall's (2003) symptom /
4 complaint focused approach, which places emphasis on psychotic symptoms, social environment, and life experiences,
5 rather than on the diagnosis.
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10 Care needs to be taken when considering the data from these interviews as there were only a small number of
11 participants however; some suggestions for further exploration are raised from the data. Key themes included feeling a
12 lack of control over their psychotic experiences and their lives, vulnerability and discrimination, and expectations of
13 stigmatisation. These themes are largely similar to those found in Cookson and Dickson's (2010) study reported in the
14 introduction. However, the findings of the two studies also vary possibly due to the different environments in which the
15 participants were living. Cookson and Dickson's (2010) study elicited more details on how the participants made sense
16 of their psychotic experiences. This could be due to a more recent experience of acute psychotic symptoms. The
17 accounts described in the current study focus on how participants felt their difficulties impacted on their lives and how
18 this affected the way they viewed themselves. Coping emerged as a major theme, possibly because service users living
19 in the community require a range of skills in order to manage effectively. Inpatients on the other hand tend to have more
20 acute problems, receive greater levels of support, and are likely to be in earlier stages of developing their coping skills.
21 Medication was referred to by some participants in this study as helpful, however a greater emphasis was placed on
22 practical and social strategies.
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29 The analysis identified three areas where clinical practice could be improved in or to better support people with
30 intellectual disabilities and mental health problems. They are: enabling service users to feel listened to and understood;
31 facilitating meaningful roles within the community; and psycho-education.
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35 Most of the participants experienced difficulties expressing themselves, and did not feel they were listened to or that
36 their opinions were taken into account. This led to feelings of frustration and isolation, sometimes resulting in unhelpful
37 behaviours such as avoidance or aggression. This highlights the importance of tailoring care in order to give service
38 users time and support to communicate their thoughts, feelings and needs effectively. Gifford et al. (2012) stressed that
39 this was particularly important for individuals with intellectual difficulties as they often have reduced social networks
40 and thus less people to speak up for them, and fewer opportunities to have their voices heard.
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45 Secondly, individuals with meaningful roles within the community appeared to experience a greater sense of wellbeing
46 and control over their lives, compared to those in the community that did not. McNally et al (2007) hypothesised that
47 gaining status through meaningful roles improved self esteem, confidence, and subsequently coping ability. It must be
48 noted, however, that although being present and participating in the community appears to be beneficial, this needs to
49 be facilitated in a supportive manner, as greater access to the community might also increase risk of discrimination and
50 stigmatisation. Participants recognised this risk and voiced their reluctance to disclose their diagnoses as they expected
51 this to result in victimisation and discrimination. These issues were of importance to the people interviewed here and
52 the importance of being listened to in a constructive manner was emphasised as was providing support constructively
53 and not in a way that could be perceived as blaming or being shouted at.
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1 Thirdly, the participants had limited understanding of their diagnoses and symptoms. Most had tried to make sense of
2 these, although some voiced disinterest or concern about deepening their understanding. This led to some participants
3 avoiding psychiatric support for fear of negative consequences, such as provoking the onset of psychotic symptoms.
4 Crowley et al (2008) ran a psycho-educational group for people with a dual diagnosis of psychosis and mild intellectual
5 disabilities. Psycho-education helped these individuals increase their understanding of their illness and recognise early
6 signs of relapse, empowering them to manage their mental health by developing their coping. However Jahoda (2006),
7 advised caution as for some individuals, lack of awareness appeared to be protective of their self esteem and identity.
8 Clinicians need therefore to consider for each service user whether psycho-education may be beneficial or not to that
9 individual.
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11 Although the current findings have provided rich and clinically relevant material, they must be interpreted with caution
12 as the study sample size was smaller than preferred. This was due to difficulties recruiting individuals with intellectual
13 disabilities and psychotic symptoms in the community, and two participants dropped out of the study. Smith, Flowers
14 and Larkin (2009) stress that the primary concern of IPA is with detailed individual accounts and that the quality rather
15 than the quantity is of importance. Nevertheless with a larger sample more areas of clinical and research interest may
16 have been identified. Moreover, the sample was not as homogeneous as was planned in terms of ethnicity and mental
17 health diagnosis. IPA is most effective when the participant sample is homogeneous, allowing for the exploration of a
18 group of people with shared characteristics (Smith, Flowers and Larkin, 2009). These results must therefore only be
19 regarded as an initial step towards understanding the views of people with mild intellectual disabilities and psychotic
20 symptoms. Future qualitative research may throw further light on this group's understanding of their psychotic
21 experiences in comparison to service users without intellectual disabilities. This will help tailor therapeutic intervention
22 to this group, aiming to increase meaningfulness and service user satisfaction. Future research may also distinguish
23 between different types of intervention appropriate for different therapeutic environments and stages of the recovery
24 process, for example inpatient versus community settings.
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