Original citation:

Wagstaff, C. , Graham, H. , Farrell, D. , Larkin, M. and Nettle, M. (2018), Experiences of mental health services for 'black' men with schizophrenia and a history of disengagement: A qualitative study. International Journal of Mental Health Nursing, 27: 158-167. doi: 10.1111/inm.12305

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Experiences of mental health services for 'black' men with schizophrenia and a history of disengagement

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Introduction

For the international mental health nursing community disengagement from treatment and services by people who could benefit from the skills and treatment on offer is an issue of on-going concern. Whilst mental disorders can be disabling they are also treatable, but engagement with services is often poor (Biddle et al., 2007) and disengagement from treatment is a major concern in psychiatry (Stowkowy et al., 2012; Singh Gaurav et al., 2015). Rates of treatment disengagement in psychiatric outpatient services range from 17% to 60% (Turner et al, 2007) and in patients with schizophrenia and related psychotic disorders rates, can be as high as 70–80% (Breen & Thornhill, 1998).

Studies from Denmark (Nordentoft, 2002), Italy (Percudani et al., 2002), UK (O'Brien et al., 2009), USA (Kreyenbuhl et al., 2009), Canada (Conus et al., 2010), India (Singh Gaurav et al., 2015) all highlight that this an international issue and has been for an extended period of time. For example, an American study, Swett & Noones (1989), calculated that 75% of patients prematurely terminated treatment from an adult psychiatric outpatient clinic.

The concept of engagement and disengagement from mental health services is poorly defined. There is no consensus on formal definitions (O'Brien et al., 2009). Hall et al. (2001) defined engagement as adherence to treatment that involved several factors including: remaining in contact with services, collaborative involvement in treatment and openness about difficulties.

The effects of disengagement from mental health services for people with schizophrenia are significant; Kreyenbuhl et al. (2009) highlighted that disengagement from mental health services can have "*devastating consequences*" for people with serious mental health problems. Davies et al. (2014) stated that people with schizophrenia who were disengaged from services had "*more unmet needs, were more unwell and were more socially impaired*" (p. 1360) relative to peers who were engaged with services.

Sainsbury's Centre for Mental Health (SCMH, 1998), Priebe et al. (2005) and Chase et al. (2010) all suggest that further qualitative research needs to be done to gain a better understanding of the phenomenon of disengagement from mental health services. Further research is essential to develop an understanding of the relationship between peoples' beliefs about themselves and why they disengage from services. Any such research would inform the development of interventions to enhance engagement and treatment adherence (Tait et al., 2003). Previous studies have examined models to explain avoidance of mental health services (e.g. Biddle et al., 2007), the fraught relationship between service users and mental health services (Watts and Priebe, 2002 & Keating and Robertson, 2004), the language used when discussing engagement and disengagement (Chase et al., 2010), the perceived support required by this client group (Davies et al., 2014) and the experience of engagement with Assertive Outreach Teams (AOT) (Priebe et al., 2005).

This study examined the experiences of men with a diagnosis of schizophrenia, who described their ethnic identity as 'black' and had a history of disengagement from mental health services. The participants' relationship with mental health services, and the impact that had upon the participants was analysed.

Research question:

What are the experiences of mental health services for men with a diagnosis of schizophrenia who describe their ethnic identity as 'black' and have a history of disengagement from mental health services?

Method

Recruitment and data collection

The study was reviewed and approved by local research ethics committee and the researcher's institution's ethics committee. The study used in-depth, semi-structured interviews to explore and analyse the experiences of the participants.

The inclusion criteria for the study were having a diagnosis of schizophrenia, a history of disengagement from mental health services, being male and an additional inclusion that was later added as outlined below was that participants described their ethnic identity as 'black'. All the participants were interviewed at home. Through purposive sampling participants were recruited from the AOTs in the West Midlands, UK. AOTs are designed to offer a service to people with severe mental health problems who through choice, circumstance or illness find it difficult to engage with mental health services (Morris & Smith, 2009), At the start of the study there were 8 AOTs in the city and an approximate total of 600 people on the caseloads of the AOTs at any one time. Participants were specifically recruited from AOTs because service users on such teams have an established history of disengagement from mental health services. Potential participants needed to have a history of disengagement from services, and were not necessarily disengaged at the time of the interview. At the start of the recruitment process the criteria for inclusion in the study was anyone under the care of an AOT, who by definition would be diagnosed with schizophrenia and have a history of

disengagement from mental health services. However after the first four participants recruited were all men who described their ethnic identity as 'black' an iterative decision was taken to subsequently only recruit participants with a similar ethnic identity, to create a homogenous data set. The participants were compensated for their time with a gift voucher. The agreement was that the participants were given the voucher after the first research interview but most of the participants asked if they could be 'paid' again after the clarifying interview.

Potential participants were initially approached by the researcher, accompanied by a clinician whom they knew and trusted. After the initial introduction the researcher subsequently met with the participants up to three times before the research interview took place.

A total of fourteen people were approached to take part in the research. One person agreed to be interviewed and then withdrew their consent and another man agreed to be interviewed but was felt to be too unwell by the researcher and was not interviewed. One participant declined to be interviewed but then approached the researcher, a few days later, asking to participate. Finally, seven people were interviewed and data from all seven people have been used to inform the research findings. One research interview had to be repeated as the researcher believed, after reading the transcript, that the participant was too acutely mentally unwell in the initial interview for his views to be considered reliable research evidence.

There were two rounds of interviews, with a main interview with the seven service users followed by a second 'clarifying' interview with six of the service users. For further detail see [Insert author ref] (2014). All the interviews with the participants were audio recorded and professionally transcribed verbatim.

Data analysis

The researcher listened to the audio recordings both before and after the transcription and changed the transcripts to highlight participant's emphasis and humour. The researcher used Interpretative Phenomenological Analysis (IPA) (based on the work of Smith et al, 2009) to analyse the interview data. IPA has been specifically developed to allow for rigorous exploration of idiographic subjective experiences and social cognitions, whilst acknowledging the interpretative involvement of the researcher (Smith et al, 2009). After listening to the recordings and double checking the transcripts for accuracy the transcripts were coded. The codes were developed into clusters. Clusters were subsequently reorganised into themes. Through the researcher's interpretation (informed by discussion with service user reviewers, discussion with project supervisors and an on-going reflective diary) an idiosyncratic portrait was developed for each participant. From which superordinate (and subordinate themes) were developed across the participants.

Findings

Below is a table highlighting the characteristics of the participants:

Table 1: Participants' Characteristics

Each participant chose their own research pseudonyms. The participants all lived in the inner city; were long-term unemployed, with limited prospects of employment; limited social networks; frequently moved home and felt limited connection to social structures. The five older participants had left school with no qualifications, one younger participant had a qualification in sound engineering and the other had started university before dropping out.

The four main themes that emerged from the interviews with the participants and were identified in the analysis were:

Theme 1: "*People just keep hounding me*"

Theme 2: Antipathy to Medication

Theme 3: Choice and the value of services

Theme 4: Stigmatisation and identity

and these will be summarised in turn.

1   "*People just keep hounding me*"

As the study investigated the experiences of the participants they were not directly asked why they had disengaged from mental health services nor was it sought in this study. Nevertheless, it is perhaps inevitable that when talking about their experiences of involvement and their relationship with mental health services, the participants would talk about why people disengage from mental health services, consciously or otherwise. Without prompting (and also without directly using the word), the participants described an experience of persecution over many years that clearly had great resonance for them, for example: Josh,

> "*... I done my time and they still trying to control my outlook in life*";
>
> Bubbles, "*I don't know, people just keep hounding me, hounding me*";
>
> or Clue, "*I can't have any peace in my life with those people around*".

Some of the participants (Black Zee and Bubbles, for example) forcibly felt that mental health services could best help them by leaving them alone. For example, Bubbles and Black Zee say respectively,

> "*I just leave them alone, leave people to sort their own minds out*" and
>
> "*... tell people to just leave me alone, leave me alone to live my life*".

However, the older participants appeared to express a sense of no longer seeing a point to actively disagreeing and disengaging with mental health services. These participants were able to appreciate the practical qualities that mental health services brought, housing for example, whilst still resenting the involvement of services. Josh, Rebel and Clue had previously believed that mental health services should leave them alone but over time they had realised both that mental health services were not going to leave them alone and also that they may benefit from the input of services. Clue in the first interview said that he did not want "these people" involved because they did not believe in God, yet in the clarifying interview he put strong emphasis on the fact that services had helped him.

2   Antipathy to medication

Medication is an important component of the treatment that people receive, and for some of the participants it would appear that it is also symbolic of the relationship they perceive they have with mental health services. Indeed, Bubbles characterised the attitude of services as,

> "*Take a tablet and just say nothing*".

Participants had an ambivalent relationship with mental health services, by extension they also had an ambivalent relationship with medication. There are many components of this theme: all that mental health services offer is medication, medication "*messes you up*", the dislike of depot medication, idiosyncratic interpretations of the purpose of medication and the lack of control that the participants felt regarding the prescription and ingestion of medication but also recognising how they benefitted from oral medication. Depot medication is long acting anti-psychotic medication which is given by intramuscular injection (Moncrieff, 2009). Some participants believed that the primary reason why people (including themselves) disengage from mental health services is because of the use of psychotropic medication. For example, Arthur said that,

> *"Well, maybe the pain of taking a needle and those who are on tablets – they are not doing them any good they; refuse to take it".*

One participant expressed surprise that people take psychotropic medication when not legally compelled to do so. *"Poison"*, *"allergic"*, *"mess up my head"* are all expressions used to describe the experience of being on psychotropic medication and so it is no surprise that there is such animosity towards these medications. Black Zee said,

> *"... these drugs – none of it chills out my mind. None of it".*

Arthur further highlighted this lack of perceived benefit when he said that people he knows,

> *"are taking it but are still hearing voices. ... and they are not cured anymore. There isn't one man I know that's schizophrenic and that cured."*

There is particular animosity reserved for depot medication and this animosity is not only from the experience of being under the influence of the medication but also the physical process by which the injections are administered:

> Josh: *"Sticking the needle and dropping my trousers and looking at my arsehole and all that"*

The participants appeared to have developed idiosyncratic understandings of why they were prescribed medication or alternatively they appeared not to understand why they were prescribed psychotropic medication. For example, Josh said that he was prescribed a depot to,

> *"counteract the injection they gave me in prison, so that I can think better and live better in the community, amongst all nation of people and all that. And try to not cause no racist business in the community".*

A further component of both the complex relationship with mental health services and the dislike of psychotropic medication would appear in the sense of lack of control over the medication that they were required to take. There was genuine anger at the lack of control.

Some participants described experiencing coercion, as Josh said when he was asked if he had ever disengaged,

> " ... *well it's not my choice you know. I ain't got a choice because I got, if the mental health people come with me or come to give me medication, I take it, you know what I mean? But deep down I really don't want it*".

The two quotes below further show that the participants felt as if they had very little control over whether to take medication:

> "*But I want to know why they keep giving me injections from in the jail. ... Now I am a free man they are still treating me like a prisoner*"

Rebel felt he was not listened to when he tried to influence the dose of depot medication he was receiving. This subsequently impacted on his experience of taking the medication:

> "*I used to communicate to them to say that I wouldn't like that, in other words, 'Don't give it me'. But they insist ... I just seemed to drift away and just slumber*"

The component parts of this theme are that medication played an important role in the disengagement experience and the participants felt that they had little choice in the process of being treated by mental health services. The participants were genuinely angry at the lack of control over the choice surrounding medication, in particular depot medication. Awareness of this anger is important in understanding both the complex relationship with mental health services and the dislike of psychotropic medication.

3   Choice and the value of services

Whilst through their actions and their words, the participants actively questioned the need for mental health services in their lives. Indeed, Bubbles indicated that he believed that mental health services gave him symptoms of psychosis. However, an emergent theme was that the participants did not perceive themselves as disengaged. The older participants denied that they were disengaged from services; for example, Rebel:

"[Interviewer: So do you feel that there was a time when you have disengaged?] *Not really*"

or Arthur:

"[Interviewer: Would you say that you have ever disengaged from the services?] *No*".

Arthur admitted that he was angry with mental health services but denied that he had ever disengaged from services, despite professionals' descriptions of his behaviour. Bubbles did not believe that he had ever deliberately disengaged from mental health services. He said that he would not take depot medication unless he was forced to and that people who were "ill" should not be given "tablets" {Bubbles}. To explain this perception that he had disengaged, Bubbles attributed it to being "busy" or a misunderstanding. According to Rebel,

"*They left me here and so I was receiving letters in the post saying, we need to assess you and that was, I had no idea what was going on.*"

The younger participants were more forthright, Black Zee said,

"*I really want to disengage from this service, you know that, that's the thing. I really do*"

and T admitted that if he were not on a community treatment order that he would have nothing to do with mental health services.

Disengagement is a term that is generated by professionals to describe the behaviour of some service users. The participants did not think of themselves as disengaged. The participants may have felt persecuted and hounded by services (see quotes above) but they were able to pick and choose those aspects of the service they felt that they needed. Housing is one

example but also oral medication. Clue said that he was happy to listen to guidance from mental health services but he added the proviso that he does not always have to accept it,

>"*I carry on with them rather than listen to them*".

This finding is also illustrated by the participants' willingness to engage in the study; services described these participants as disengaged yet they wanted to speak to a mental health professional about their experiences.

4.   Stigmatisation and identity

The experiences of the participants suggest that mental illness, stigma and disengagement are experienced simultaneously in a social context. One of the reasons why the participants had a complex relationship with mental health services was because they recognised that involvement with mental health services carried social stigma, which negatively impacted upon them. The participants described the stigma of mental illness and the stigma of involvement in mental health services as contributing to their isolation in society. Not only did the participants feel that their association with mental health services had a detrimental effect on their identity but their negative identity appeared to affect the participants' relationship with wider society, their position in the local community, their relationship with their families and the judiciary.

The Bubbles quote,

>"*I'm not the only one, I mean, people they got nowhere else to go, nothing to do, the sad people, funny people, and they go round other people's houses and they just come unstuck*"

is important to the study and the imagery struck by Bubbles' quote is stark. Not only is he describing a group of people who are disengaging from mental health services because the

services do not meet their needs, "*people they got nowhere else to go, nothing to do*" is an expression of unmet needs but he is also describing his peers' experience of mental illness, "*the sad people, funny people*". The phrase becomes an expression for a collection of people experiencing complex social problems accompanied by on-going mental distress, and "*They go round other people's houses and they just come unstuck*" reflects Bubbles' metaphorical understanding of the perceived untreatability of that mental distress. Whilst professionals would never use the language because it is too imprecise and too judgemental, the images that the quote presents highlights the experience of mental distress and the perceived inadequate response by mental health services to constructively help people.

Discussion

The participants were male service users with a primary diagnosis of schizophrenia, who described their ethnic identity as 'black', were substances users and also had a history of disengagement. Intuitively, literature would suggest that service users with these characteristics would be difficult to engage both clinically and in research (SCMH, 1998; Kreyenbuhl et al., 2009; O'Brien et al., 2009; Rooney et al., 2012). However, the participants wanted to engage in the study and they were willing to talk about their experiences, perhaps illustrating the participants' ambivalent relationship with services. The factors that influenced this apparent contrasting style of engagement are of interest.

A factor that may have influenced recruitment and participation was that the participants wanted to talk. One of the emergent subordinate themes was that the participants felt that mental health services had consistently not listened to them. Potentially, the study offered a counterpoint to that, as the researcher wanted to hear their experiences. Most of the participants appeared to enjoy the experience of being allowed to talk about the issues that

were pertinent to them. For example, a participant, who dated his 30-year history of mental illness back to the death of his mother, claimed that he had never talked to a mental health professional about his loss and grief. Another potential reason why the participants were willing to engage in the research was that the participants believed that mental health services were predominately concerned with medication. That there was no agenda of trying to persuade them to take medication may have potentially meant that the participants were more willing to talk. A factor that may have influenced engagement with the participants was that the interviewer could have potentially been seen as someone 'outside' of mental health, subsequently the participants may have felt more able to talk because they knew what they said would be confidential.

That the participants were recruited suggests that if approached and involved in an appropriate way, engagement may cease to be an issue. A point that could be argued, though hard to prove, is that it is not the men who disengage from the system; rather the system had not been able to engage them. The men wanted to discuss their mental health issues but had not found an appropriate person to talk to. None of the men had a partner, they had fractured relationships with their families, most of the participants felt estranged from their community and society, and they felt hounded by mental health services that did not listen to them.

A component of the complex relationship that the participants had with mental health services was that they felt as if they had very little control over the care they received.   That mental health services are sometimes being experienced as coercive, has been documented. The participants, African-Caribbean patients with psychosis in the UK, in Chakraborty et al. (2011) also perceived themselves as powerless, however, over time this powerlessness and resignation had a paradoxical effect; the person no longer sees a purpose in actively rejecting the mental health system and therefore reluctantly agrees to the demands of the mental health services. Consequently, the person develops greater adherence to treatment regimes leading

to better quantitative outcomes. An American study by Stanhope (2009) investigated how the relationship between service users and clinicians and coercion impacted on the quality of service contact for homeless people with severe mental illness with assertive community teams. The study suggested that for the service users, both a strong relationship with clinicians and the feeling of not being coerced were important in having a positive experience of services. Lawlor et al (2010) report that 13.2% of admissions to in-patient units for white British women were compulsory compared to 42.3% for black British women. Burns et al. (2011) investigated the rates of non-statutory pressures, or leverage, exerted on distinct clinical mental health populations in the UK. UK service users were statistically more likely to experience leverage than their US counterparts, according to Burns et al. (2011). Furthermore, that study also reported that housing was the most common form of leverage used, which is significant in relation to this study as participants identified that the organisation of accommodation was an important role that AOTs performed for their service users. Yeeles et al. (2011) reported that in their sample group, 35% of AOT patients had experienced staff using 'leverage' as a means for staff to achieve their objectives (see also Williamson, 2002; Keating & Robertson, 2004; Claassen & Priebe, 2006; Chakraborty et al., 2011 and Morrison et al., 2012). Dutch service user advocate Jolijn Santegoeds has recounted the traumatization of the coercion within mental health services (Santegoeds, 2016).

A finding of the study was that the participants were clear in their dislike of depot medication. Indeed, depot medication was described as symbolic of the "*violence*" (Clue) of mental health services towards them. Variously, the participants reported that all mental health services offer is medication and that medication "freaks you out". However, as with other issues related to their care, the participants either did not understand the purpose of medication or appreciate its role from the professional's perspective. Also, the participants

experienced a lack of control regarding the prescription and ingestion of medication. Yet, simultaneously some participants viewed prescribed medication as a strategy that reinforced their resilience and develop a more positive identity.

For the participations, psychotropic was a significant part of their experience of, and disengagement from, mental health services. The difficult relationship that exists between people with schizophrenia, regardless of ethnicity, and medication is well documented in the literature; and would indicate that that the over emphasis on medication by mental health services is a significant component in disengagement from services for many people. As with this study Davies et al. (2014) found that participants appeared to resent the emphasis mental health services put on medication in their treatment. Similarly (Moncrieff, 2009) suggested that much contemporary psychiatric practice is based around medication. Whittaker (2010) has questioned whether there is a link between the tripling of people who have been disabled by mental illness in America whilst at the same time as there has been a greater use and dependence on psychotropic medication. The issue of race and depot medication has been heighted previously, with Aggarwal and colleagues (2012) highlighting that US service users with schizophrenia from ethnic minority backgrounds were more likely to receive depot medication. Pierre (2000), Bowl (2007) and Chadwick et al. (2009) all report that people of African-Caribbean descent are more likely to be overmedicated relative to other ethnic groups and also not be given enough information about the medications prescribed to them. Indeed, a literature search originating in Belgium concluded that the issue of disparities in pharmalogical treatment for service users from ethnic minorities relative to white peers is a global issue (Lepiece et al, 2014).

As in this study, the participants in Smith et al (2013) disengaged from mental health services because they did not believe that the services met their needs. Whilst the participants in this study found that their diagnosis and involvement with services was stigmatising only a few

participants in Smith et al (2013) gave this as a reason for disengagement. Previous literature has suggested that people with schizophrenia are aware of the public stigma that surrounds mental illness (Knight et al., 2003). The stigma associated with mental illness is a global public health problem for mental health nurses (Griffiths et al., 2014). Griffiths et al (2006) examined stigma in both Japan and Australia, demonstrating that there were stigmatising attitudes in both countries. A study from Brazil by Scazufca et al (2016) found stigma to be lower in the cities as opposed to rural site, highlighting the need for on-going public health education. 32% respondents of a UK mental health survey of ethnic minorities (Rehman & Owen, 2013) reported experiencing discrimination within there own communities as a consequence of their mental illness. There are international examples of different types of campaigns to reduce the stigma of mental health (Finkelstein et al., 2008), the 'Say no to stigma' in Australia for example. Media campaigns and targeted interventions with specific groups have been shown to impact positively on mental health stigma (Wright et al., 2006 and Thornicroft et al., 2008).

The sense of losing personal agency as a result of being involved with mental health services is supported by Priebe et al. (2005). The awareness of public stereotypes and stigma may start to erode the person's identity, self-esteem and their ability to efficiently manage their illness (Fung et al., 2008). The relationship between the erosion of the person's original identity, self-esteem and their ability to efficiently manage their illness then becomes a barrier to the person's on-going recovery (Hasson-Ohayon et al., 2013). As highlighted in the findings, some participants attributed illness, misfortune and negative social dynamics to themselves, perpetuating a pattern of negative self-identity (Fung et al., 2008). Whilst these negative thought patterns could be interpreted as a symptom of schizophrenia, they could also be interpreted as expressions of learned helplessness and social defeat.

Priebe et al. (2005) and Chase et al. (2010) highlighted that understanding a person's need to have both individual agency and identity were crucial in understanding the experience of disengagement and re-engagement. Therefore the participants can be understood as appearing to be determined not to lose their agency and have their identity subsumed into mental health services.

Limitations of Study

This study has limitations. The sample size was small. It is possible that if a larger cohort had been used then the themes generated would have been different, but that consideration needs to be balanced against the benefits of having seven participants, which allowed for greater focus on the individual experience.

Although the service users gave the impression that they were talking in an open, honest and unguarded manner, a persistent question that can be raised against the study is that there was a possibility that if the researcher had been from the same ethnic identity then the responses given by the service users may have been different. However, this could also be true had there been a difference in gender between the researcher and the participants, for example. Ultimately, the trustworthiness and credibility of the research lies in whether at the time of the interview the participants gave the impression that they were discussing the material in an honest and unguarded manner.

Conclusion

This was an IPA study designed to provide a detailed, idiographic understanding of the experiences of a small group of purposively sampled individuals with experience of the mental health care system in England. Although the methods employed did not gather data

that is 'generalisable' (Parahoo, 1997), they provided useful in-depth insights on the phenomenon that are trustworthy and credible (Darbyshire et al., 2005).

The findings of this study indicate that the participants felt "hounded" by services, indeed several just wanted to be left alone by services. However, the older participants reflected that their attitude towards the mental health services had changed over the years, and most of the participants could highlight some positive aspects in their experience of services. Medication proved was a difficult issue and in particular participants expressed a strong dislike for depot medication.

Despite anti stigma campaigns in different countries, the findings of this study suggest that mental illness continues to carry a high degree of stigma which had a detrimental impact upon participants' identity and as such was a significant component in the experience of disengagement. Stigma is an issue that mental health nurses must address to readjust attitudes to minimise the adverse consequences for individuals who are diagnosed with schizophrenia and become involved with mental health services.

By rigorously examining how service users with schizophrenia make sense of their experience of (and disengagement from) mental health services, there is potential to give voice to the experiences of these participants; the complexities of the participants' experiences around disengagement are a reflection of their idiosyncratic social, cultural and psychological lives. Simultaneously, this study should help mental health nurses better understand those experiences and tailor their interventions to be reflective of these.