Qualitative experiences of disengagement in Assertive Outreach Teams, in particular for 'black' men: Clinicians' perspectives

Wagstaff, Christopher; Graham, Hermine

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Original research

Qualitative experiences of disengagement in Assertive Outreach Teams, in particular for 'black' men: Clinicians' perspectives

Dr Chris WAGSTAFF, BA, RMN (DIP), Msc, Ph.D, Medical School, Nursing, University of Birmingham, Edgbaston, Birmingham, UK, B15 2TT. 0121-415-8589

Dr Hermine GRAHAM, BSc, ClinPsyD, Dip Cognitive Therapy, University of Birmingham

Richard SALKELD, RMN, BA, MA, Birmingham and Solihull Mental Health Foundation Trust

- Chris Wagstaff is the main author and researcher;
- Hermine Graham was a PhD supervisor throughout the study & contributed significantly in writing this paper;
- Richard Salkeld was a participant in the study & contributed significantly in writing this paper.

There were no conflicts of interest and there was no external funding.

4803 words

Age	Majority of staff were in the 46-55 age range
Gender	
Female	8
Male	4
Ethnicity	
White British	11
Black British Caribbean	1
Years working in Mental Health Services (Mean)	19
Years working in AOT (Mean)	5.7 (range 4 weeks to 13 years)

Table 1. Characteristics of Participants

Introduction

Engagement with services is often poor amongst people with severe mental health problems, yet key to improving clinical outcomes.

Aims

This study explores the perception of clinicians on patients with severe mental health problems, in particular the experiences of black men, who disengage from mental health services.

Method

Two focus groups twelve, mainly white, experienced clinicians in the UK were recruited. Transcripts were analysed using Interpretative Phenomenological Analysis.

Results

Clinicians understood that patients' awareness of stigma impacted upon engagement with mental health services. Clinicians were aware that medication negatively impacted on engagement. The passage of time was perceived as impacting upon engagement.

Discussion

The perspectives of the clinicians in this study and the experiences of the patients in a former study converged. The participants had an understanding of the complexities that black men faced when engaging with mental health services.

Implications for practice

This is the first paper to highlight that AOT staff need to be aware of the key role that stigma plays in engagement in treatment, continue to focus on efforts to reduce the stigma surrounding mental health, consider the significance medication and be aware of how patients' attitudes towards mental health services develop over time.

Relevance to practice

This study demonstrates that clinicians are aware of patients' experiences of disengagement from mental health services. However, this study highlights the responsibility of clinicians to develop culturally sensitive care packages and clinical practices that reflect an awareness that patients, black males in particular, feel the impact of stigma of involvement with MHS which in turn compromises their willingness to engage in treatment. Increased clinician awareness of the controversial role of medication for patients, and the use of strategies to engage in collaborative medication management with patients, may positively impact upon patients' willingness to engage with services. Additionally, given that clinicians typically consider the relationship they have with patients in a wider social and political context then there needs to be greater awareness that patients' attitudes towards their mental health problems and mental health services develop and change over time. There is a responsibility for services to remain aware of the clinician and service factors that may contribute to the disengagement of service users and to strategically address this in the design of service delivery

Accessible Summary

- This study is a follow on study to a study into the experiences of disengagement from mental health services for men who described their ethnic identity as 'black'. The aim of this study was to understand the same phenomenon from a clinician's perspective.

What is known on the subject

- Literature highlights that people from ethnic minority backgrounds experience some difficulties engaging with mental health services;
- Disengagement from mental health services is a complex phenomenon that occurs for a variety of different reasons;
- Only one paper previously has investigated clinicians' perspective on disengagement from mental health services;

What the paper adds to existing knowledge

- This paper demonstrates that clinicians are aware that stigma and medication impact upon engagement with mental health services, which were also important components of the patients experience.
- A finding of the former study was that patients' attitudes towards mental health services change over time, with patients engaging more as they get older, a finding was supported by wider literature. However, in this study the participants were not certain that this was the case.

What are the implications for practice

- The implications for practice from this paper are that staff should persist with efforts to reduce the stigma surrounding mental health, carefully consider the significance and impact of medication and have an awareness of how patients' attitudes towards mental illness and mental health services change and develop over time.
- Continued support for an AO approach to practice for people who find it difficult to engage with services, where a multidisciplinary 'team' approach can focus on service user centred recovery goals and a positive space for collaboration.

Qualitative experiences of disengagement in Assertive Outreach Teams, in particular for 'black' men: Clinicians' perspectives

Introduction

This study is a follow on study to an interpretative study (ref) into the experiences of disengagement from mental health services (MHS) for men who described their ethnic identity as 'black'. The aim of this study was to understand the same phenomenon from clinician's perspective. In the former study the participants' accounts of their experience were part of a complex interactive and social context. To further explore the context of these experiences this study sought to explore the clinician's perspective on the experience of disengagement. The participants in this study were from Assertive Outreach team (AOTs) whose role is to stimulate engagement with MHS, the presumption being that the staff in AOTs have an understanding of the patients' experiences of disengagement.

Sainsbury's Centre for Mental Health (SCMH, 1998), Priebe et al. (2005) and Chase et al. (2010) all called for further qualitative research to be done to gain a better understanding of the phenomenon of disengagement from mental health services. As highlighted by Isaacs (2014) one of the roles of qualitative research is to broaden the understanding of how people and communities (clinicians included) understand health related issues.

In the former study participants used a variety of phrases to describe their racial identity and cultural background. However, the common term they all used was 'black'; therefore, throughout the inclusive term 'black' is used (ref & ref2). With regards to ethnicity the Institute for Race Relations define "black" as, *"The way that people of African descent describe themselves in South Africa, USA and parts of Europe."*

Over-representation of people from ethnic minority backgrounds in MHS is an issue of global concern, the reasons being complex and subject to debate within the literature (Starosta, 2015; Rogers & Pilgrim, 2014; Fung et al., 2006). Rogers and Pilgrim (2014) concluded that neither genetic explanations, misdiagnosis nor faults in psychiatric theory and practice can adequately explain the over-representation of people from ethnic minority backgrounds in MHS. They suggested that long-standing external pressure (housing, education and wealth) combined with perceived institutional and personalised racism contribute to the experience of MHS and possibly poorer mental health outcomes. Fung et

al. (2006) stated that reduced participation and isolation within society may be potential reasons for the higher levels of schizophrenia in people of African-Caribbean descent in the UK which reflect multiple risk factors that are evident in the African-Caribbean community. Studies and policies have highlighted the unique challenges faced by ethnic minority communities when engaging with MHS (e.g. DoH, 2014; Robinson, Keating & Robertson, 2011). Priebe et al (2003) and Keating (2007) both highlight that people of African-Caribbean descent are the most over represented ethnic group on the caseloads of AOTs. Additionally, there are a disproportionate number of people from black and minority ethnic groups who are subject to community restrictions in an attempt to 'engage' them in treatment, such as Community Treatment Orders (Care Quality Commission, 2010). People of African-Caribbean descent in the UK were more likely to have a negative experience of MHS (National Mental Health Development Unit, 2011). Additionally people of African-Caribbean descent in the UK also report a poorer experience of MHS relative to other ethnic groups (Fearon et al., 2006; Fung et al., 2006; NICE, 2010).

AOTs were developed and designed to offer a community mental health service response to people with severe mental health problems (SMHP), who through choice, circumstance or by nature of their mental health problems experience difficulty engaging with MHS (Morris & Smith, 2009). Poor engagement is based on a number of influences, severity of illness, lack of insight into their presentation, views on treatment and diagnosis, substance misuse, lifestyle choices, and perspectives on culture and stigma (Kreyenbuhl et al, 2009; Chakraborty et al, 2010). Engagement in treatment and developing effective working relationships between patients and clinicians were perceived as key vehicles within the AOT philosophy to improve treatment outcomes (SCMH, 1998) and a reduction in hospital admissions continues to be evidenced in studies (Hamilton et al 2015, Firn et al 2016) using an assertive community model of treatment. Warne (2013) notes that AOT services remain crucial but that their importance can be overshadowed by services for those who are able to make themselves heard. Commissioning requirements cluster this patient group into those who are difficult to engage within a payment by results framework, but commissioners still expect services to evidence improvements within a limited timeframe. He adds that AOT is a form of treatment that is not easy to align with notions of consumerism and the move

toward marketplace principles, and consequently service design on this basis may only move to exclude this patient group further.

As Priebe et al. (2005) and Chase et al. (2010) stated in order to improve engagement, or interventions which promote engagement, there needs to be further qualitative research to gain a better understanding of the phenomenon of disengagement (or inhibited engagement) from MHS, particularly 'black' men. At present little is known about clinicians' perception of how 'disengagement' is experienced. Thus far the only study that sought the perspective of clinicians on the experience of disengagement from MHS for people with SMHP was an American study by Stanhope et al., (2009). That paper sought the perspective of clinicians to understand why patients with SMHP and a history of homelessness and substance misuse disengage from services; the primary reason given was substance misuse and a desire for alternative living arrangements. Therefore, by studying the perspective of clinicians, in addition to the perspective of patients with SMHP and a history of disengagement, this will generate a broader understanding of the experience of disengagement for patients with SMHP.

Aim

The aim of this study was to examine clinicians' perceptions on the experience of disengagement for patients on their caseloads, with particular reference to the experiences of 'black' men. Following on from the findings of a related study, this study examined clinicians' perspectives on the impact of medication and age on the engagement and what if any, were the unique features of their experiences of working with black men who disengage from MHS.

Methodology

Ethical approval was provided by the local research ethics committee (ERN_13-0093).

Participants & Recruitment

Purposive sampling techniques (Williams & Hewison, 2009) were used to recruit AOT clinicians. The participants were recruited as they had expertise in the phenomenon under

study. The main researcher attended multi-disciplinary team meetings with 3 AOTs and explained the research to potential participants and invited them to become involved. One team declined to participate, due to time constraints. Twelve participants were recruited from 2 AOTs and for reasons related to their availability two focus groups were conducted. One focus group was attended by ten participants (FG1) and the other by two of the participants (FG2). As to the issue of one of the focus groups only having two participants Tomkins and Eatough (2010) argue that a purpose of IPA research is to reflect the individual. So whilst there are different dynamics between a focus group of ten and a focus group of two participants the research methodology allows for the reflection of individual's experiences. Across the two teams there were approximately 36 staff employed, 12 of who agreed to participate in the research. The only inclusion criterion was that the participant had an AOT clinical role.

All participants chose their own research names and given a participant information sheet. They read and signed a consent form prior to the commencement of the study, in order to acknowledge informed consent to participate in the respective focus groups. Both documents explained to the participants that once the recording of the focus group had started they could not withdraw from the study as their comments could not be removed from the subsequent transcript. The resulting material was sufficiently anonymised to ensure that it was not possible to deduce who the participants were.

The focus groups were facilitated by one researcher through group discussion using a series of open-ended questions and structured probes. These involved exploring what if any, were the unique features of their experiences of working with black men who disengage from MHS. Each focus group was audio recorded and subsequently transcribed. Another researcher also attended who noted the subtleties of interaction for example facial expressions and body language. Whilst the opportunity to return to ask clarifying questions had been built into the study design had there been unclear or confusing data, this did not prove to be necessary.

Prompt questions for the focus groups were informed by the interpretative findings from a prior study which focused on the experiences of disengagement for patients. Both focus groups used the same set of prompt questions. Some examples of the open-ended prompt

questions were, *“So why do people prefer oral medication?”*; *“.... do peoples’ attitudes change with age?”*; *“....there is a lot of research showing that black people in general have a very poor working relationship with mental health services, how does this tally with your experiences?”* Each focus group lasted approximately an hour, when all the questions had been asked and the participants felt that they had nothing more to contribute.

A trust employee (also a member of the research team) calculated the figures to comprehend how many patients on two AOT caseloads were male and from Black/Black British – African; Black/Black British – Caribbean; Black/Black British – Other; or Mixed – White and Black Caribbean ethnic backgrounds.

Data Analysis

The two focus groups were recorded; transcribed and thematically analysed using an IPA methodology in an attempt to explore participants’ lived experience (Smith, 2004). The audio recordings were listened through several times to stimulate notes about emergent themes. The transcripts were read multiple times, giving greater clarity to the possible themes in the study and then phenomenologically coded and these codes clustered. This entailed examining the texts more closely for greater depth of meaning and interpretation, identifying and labelling emerging themes and meanings within the text. Interpretative themes were generated from the clusters and subsequently these themes were dialectically related to excerpts of the text in a cyclical process. The process of data analysis was as reflective as possible and included interpretation from the researchers upon the emergent themes.

Guba and Lincoln (1994) suggest four criteria to indicate the trustworthiness of a study: ‘Internal Validity’ (does the study make sense?), does the research data support the reported findings?); ‘External Validity’ (does the study correspond to the reader’s preconceptions of the world?); ‘Reliability’ (did the study have a robust methodology?); and ‘Objectivity’ (was the researcher distanced and neutral enough?). The study met all of these criteria.

Results

Participants

Table 1. Characteristics of Participants

The above table summarises some of the demographic data of the participants. The participants were recruited from two AOTs in a local NHS mental health trust. From data supplied by the Trust regarding the two AOTs, 73% of the patients on their caseloads were men and 27% women. On the caseloads of the two AOTs, 45.8% of the male and female patients combined described their ethnic group as Black/Black British – African; Black/Black British – Caribbean; Black/Black British – Other; or Mixed – White and Black Caribbean. Further break down of the figures highlight that 46.3% of the men (and 41% of women) on the two AOT caseloads were from these specified ethnic groups.

Emergent Themes

After interpretative phenomenological analysis of the transcripts the three overarching emergent themes (for reasons of space minor themes are not reported in this paper) which addressed the clinicians' perspective on patients' experience, in particular the unique features of the experiences of black men, of disengagement were:-

- Cultural aspects to disengagement for black men.
- Significance of medication.
- Age making a difference?

Cultural aspects of the experience of disengagement for black men

The participants expressed several ideas including pride, a desire to be independent, the stigma of involvement with MHS and that MHS were viewed as yet another form of social control.

Repeated references to feelings of pride and a desire for independence were quoted, as indicated below:

"I think there is a level of pride as well with the young black men. They are proud, stubborn, independent, 'I can fend for myself, I'm keeping my own castle. Don't you come ringing at my door.'" {Pat FG1}.

Dave paraphrased what he perceived to be the perspective of the black men on his team's caseload as,

"I don't need you. Don't want you." {FG1}.

In FG1 the participants believed that pride and the stigma of involvement with MHS was a cultural aspect to the experience of disengagement for black men. This perception was illuminated by several of the clinicians:

Pat: *But the cultural thing about pride, a bit of stubbornness, a bit of being king of the castle.*

Victoria: *The shame.*

Dave: *The stigma.*

Victoria: *The shame they hold.*

Interviewer: *From being involved in mental health services?*

General: *Yes.*

Martha: *They want to be accepted and respected in their community.*

Pat: *It affects their street credibility.*

Delores: *Absolutely.*

Pat: *Peer credibility. And their peer groups hold such weight ...*

Delores: *Massive.*

Mr H.: *The stigma of it, really. Being black and being on the mental health services. The stigma. The shame really.*" {FG1}.

Participants believed that the patients they work with were proud men, wanting to be seen as independent and having the respect of their community. Participants also made links between perceived stigma of involvement with, and disengagement from, MHS.

Additionally they felt that the black men on their caseloads viewed MHS as yet another form of social control, Greg describing;

"... because they are already potentially feeling like they are getting the short end of the stick by other services ... that it is just another service that is telling them to do something they don't want to do. ... people who've had a harder time prior to coming to mental health services, who are going to be less willing to want to engage and regard it as just another service that they don't see any benefits in it for them." {FG 2}.

Martha {FG1} summarised by suggesting that, *"We are another social control, aren't we?"*

The significance of medication

Participants expressed an awareness of the perspective of patients viewing medication as control and an attempt to take away their self-determination. As such the participants acknowledged that medication was a very difficult issue, finding that it significantly impacted on their engagement and relationship with patients. In some instances participants felt that patients blamed medication for their mental health problem, for example Delores {FG1} says,

"People blame the fact that they are involved with mental health services and the medication for the fact that they are ill. They say that's the reason they are ill."

Participants knew that the patients they worked with preferred oral medication, but were suspicious of their motives.

"Oh yes, overall they would prefer to take tablets." Ethel {FG2}

Whilst oral medication may return personal choice to patients, the clinicians believed that the reason why patients preferred oral medication is that they could choose not to take the medication, possibly soon after starting. Martha summarised,

“It is, unfortunately, if they were on a tablet, I would say, within a few days they wouldn’t take it.” {FG1}

Participants were aware that medication was an issue which impacted upon engagement, with patients seeing depot medication in particular as taking away their self-determination and also, for some patients, causing their mental illness. Some participants perceived that some patients viewed medication as a source of ‘control’ and the cause of continued ill-health or problems. Clinicians felt that patients saw it as another attempt at control and taking away their ability for self-determination.

Age making a difference?

Some participants argued that patients’ attitudes towards MHS changed as they grew older. The impact of the passage of time was interpreted by some participants as the influence of ‘age and maturation’ and as a key turning point in the process of engagement with treatment, identifying that often relationships had improved as part of a maturation process. However, others perceived this as patients increasingly developing a sense of ‘learned helplessness’ and felt that possibly relationships had changed as patients had succumbed to accepting treatment as they felt ‘beaten into submission’.

In FG2 Greg recognised the point that was being made but was unable to determine whether people changed their attitude as they got older or changed their attitude because they were now experiencing a less restrictive form of service delivery. The participants in both groups were sceptical, additionally expressing disappointment that MHS had in effect;

“beaten the patients into submission” {Martha, FG1}

to which other members of the focus group agreed.

Participants were aware of how patients had previously had a poor experience of MHS and felt disenfranchised from both services and other social structures. Consequently there was a strong desire to deliver holistic care combined with a deep sense of humanity. The

participants wanted the “best” for the patients they worked with and were committed to the AOT model as a means to engage people. Within that there was an understanding that different patients have different needs and that the service delivery needed to reflect this. For example Greg (FG2) said,

“also if you give them a different approach they might feel that there is a bit more in it for them than they thought, and it’s not quite so draconian and they might be more willing to engage if they see there are extra benefits apart from just medication.”

However, other participants disagreed, as Bernard {FG1} pointed out,

“The person that we see most frequently on a long-term scale is in his 80s. ... And if we didn’t see him, he could well be doing heinous things.”

Previous studies have indicated that patients relationships with MHS change and develop over time, the participants in this study recognised this phenomenon and saw different reasons behind it.

Discussion

This study was a follow on study to a study (ref) into the experiences of disengagement from mental health services (MHS) for men who described their ethnic identity as ‘black’; the main themes of that study were that participants felt hounded by MHS; there was antipathy towards medication; that participants valued choice and valued aspects of MHS and that stigmatisation and identity impacted upon engagement. There is a need for qualitative research to be used to generate a more nuanced understanding of disengagement from MHS (SCMH, 1998; Priebe et al., 2005; Chase et al., 2010). A role of qualitative research is to broaden the understanding of how clinicians understand health related issues (Isaacs, 2014). This is the first study into clinicians’ perspectives on disengagement and SMHP patients’ experiences thereof.

The main findings of this follow on study were that there was convergence between the perspectives of the clinicians in this study and the experiences of the patients in the former study (ref). This is the first study to highlight that staff working in AOTs knew about the problems and perspectives with engaging with MHS that service users had. They knew that

the stigma of diagnosis and involvement with MHS had a significant impact upon engagement, particularly for black men. Additionally, they knew that medication was a thorny issue which, again, impacted upon patient's willingness to engage with MHS. However, there was disagreement as to whether patient's attitudes towards MHS altered over time.

The clinicians in this study demonstrated active willingness to attempt to engage all cultural groups in treatment and a desire to facilitate choice. Ljungberg et al (2015) highlighted that the helpful components of the relationship between clinicians and people with SMHP are determined by the clinician's ability to respect the individual preferences, needs and wishes. However it appears that engaging in patients in assertive forms of community treatment can be influenced greatly, not only by personal/therapeutic relationships but also by perceptions of the impact of mental health on the self, capacity for self-determination and the stigma surrounding mental ill-health (which is compounded by experiences of racial discrimination). Biddle et al (2007) and Davies et al (2014) suggest that patients, regardless of ethnic background will reject or avoid MHS because of the stigma and changes to identity that are associated from being involved with MHS.

Clinicians viewed cultural factors as an additional layer that influenced and compounded how patients felt about their mental health problems in relation to the self, self-esteem and cultural acceptability. It is the responsibility of all clinicians to develop culturally sensitive care packages (Calaminus, 2013) and indeed the participants understood that the stigma of mental health diagnosis and involvement with MHS impacted upon engagement, with particular reference to black men. Internationally efforts are still needed to address this stigma (Thorncroft et al., 2008). Globally, examples exist of different types of campaigns to reduce the stigma of mental health (Finkelstein et al., 2008). Media campaigns and targeted interventions with specific groups have been shown to impact positively on mental health stigma (Thorncroft et al., 2008 and Wright et al., 2011).

The 'Butler Inquiry' (2009) reported that for some black and minority ethnic patients coming into contact with MHS was perceived as a 'last straw' and to do so was to be stripped of your dignity. Biddle et al., (2007) support the findings of this study highlighting that the consequences of having contact with services, or indeed having enforced 'help', both

generates stigma and causes changes in identity. Previous literature has suggested that people who experience severe mental health problems are aware of the public stigma that surrounds mental ill-health, and may in time come to agree with that stigma and believe that those public stereotypes apply to them (Knight et al., 2003). This awareness may start to erode the person's identity, self-esteem and their ability to efficiently manage their illness (Fung et al., 2008); which becomes a barrier to the person's on-going recovery and an impediment to engaging with services (Hasson-Ohayon et al., 2013; Smith et al., 2013).

Reflecting the NICE 2009 guidelines and reflecting the acknowledgement that medication is a factor which complicates engagement with mental health services participants were already trying to facilitate choice and trying to discuss desirable alternatives. Again drawing from the NICE (2009) guidelines the participants knew that non-compliance and discontinuation of medication were common place and understandings of why. Priebe et al., (2005) suggested that denial of the need for treatment can be a coping mechanism to cope with the stigma associated with the diagnosis of psychosis.

The participants gave conflicting views about whether patients' attitudes towards mental health services changed over time, as to whether patients became more willing to engage with services as they became older. This research finding sits at odds with previous literature which has highlighted that patients do change their perception of MHS over time (Parkman et al., 1997; SCMH, 1998; Chakraborty et al., 2010; Petterson et al., 2014). Parkman et al., (1997) proposed that older Black Caribbean participants were less dissatisfied than their younger counterparts. However, there is evidence to suggest that it takes between 18-22 months for patients to start to develop an engaging attitude towards AOTs (SCMH, 1998; Petterson et al., 2014).

Contribution to international evidence

This study investigated clinicians' perceptions of the experience of disengagement, in particular any unique features of the experiences of black men. Participants viewed medication as playing a significant role in negatively impacting on engagement and that for some patients medication was perceived as a source of 'control' and the cause of continued ill-health or problems. Whilst this study indicates an active willingness of clinicians to

attempt to engage all cultural groups there was awareness that the stigma of involvement with MHS is a driving force behind continued disengagement.

Limitations of study

There are limitations within this study that need to be taken into consideration including the small sample size and the homogeneity of the mainly white clinicians who participated. Given that the study had a particular focus on the experiences of 'black' men it is disadvantageous that there was only one participant who described his ethnicity as "British Caribbean". Had there been a different mix in the ethnicity of the two focus groups the findings may have been different. Additionally, IPA research celebrates detailed interpretation of unique individual experiences, but using group interviews as the means to gather data means it is harder to develop detailed narratives from single participants (Palmer et al., 2010). Theoretically using IPA to analyse the data generated by focus groups should generate a singular socially constructed narrative, providing detail and depth (Green and Thorogood, 2014). In both focus groups the team leaders participated in the groups and power dynamics of the relationship between the participants may have resulted in some participants being reluctant to express a view that they believed their line manager may have disapproved of (Liamputtong, 2011). So whilst the socially constructed narrative is interesting and useful it may not necessarily reflect dissenting voices.

Conclusions & Implications

This study explored the perspective of mental health clinicians of how they perceive 'disengagement' of patients, in particular their perceptions of the experiences of black men who disengage from MHS. It remains the responsibility of all clinicians to develop culturally sensitive care packages and indeed the participants were aware that patients, black males in particular, felt the impact of stigma of involvement with MHS which compromised their willingness to engage. Majumber et al., (2004) define cultural sensitivity as, 'an ongoing awareness of cultural differences and similarities among populations' (P. 162). As such it implies that staff need to have an awareness of some of the beliefs that different cultural groups have and how these beliefs may impact upon engagement. Participants were aware that some patients viewed AOT and medication as attempts at control and taking away their ability for self-determination. In keeping with current thinking about medication adherence

(see Burgess-Dawson and Hemingway, 2017) through clinicians' vigilance and awareness towards the significance of medication, and a willingness to engage in shared decision making, it may impact upon patients' willingness to engage with services. Additionally, clinicians need to be aware of patient's evolving attitudes towards MHS over time and consider the relationship they have with patients in a wider social and political context.

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