

MARY SEACOLE AWARDEE REPORT 2016/2017

The Lived Experiences of Black and Minority Ethnic Patients within a High Security Hospital

Dr Ada Hui

Assistant Professor, University of Nottingham Mary Seacole Leadership Awardee 2016/2017



ACKNOWLEDGEMENTS

This peer reviewed report has been completed as part of the Mary Seacole Leadership Award 2016-2017. The project was funded by Health Education England in association with the Royal College of Midwives, the Royal College of Nursing, Unison and Unite. The logistics of the project were supported by the School of Health Sciences, the University of Nottingham and the Nottinghamshire Healthcare NHS Foundation Trust. Without the support of these organisations, this project would not have been possible.

Thank you to all members of the Mary Seacole Steering Group Committee – with particular thanks to my mentors, Janet Fyle and Dr Calvin Moorley – for sharing your knowledge, wisdom and networks. To my colleagues – most notably, Dr Alison Edgley, Stacy Johnson and Professor Gina Higginbottom – thank you for your continued encouragement, and for keeping me focused and grounded amidst my ideas, readings and challenges throughout this project. Thank you to Susan Bookbinder and Ed, and fellow Mary Seacole Awardees - Deborah Isaac and Philomene Uwamaliya - for sharing this special year-long journey.

Finally, greatest thanks to all those individuals who took part in this study – whose voices form the foundations of this report – through which work can begin towards addressing social suffering, structural violence and systemic inequalities. It has been a real honour and privilege to be associated with Mary Seacole's legacy, and to have had the opportunities to work with such a marginalised and underrepresented community – thank you all for the recognition and belief in this project.

Dr Ada Hui October 2017

ABSTRACT

Black and minority ethnic (BME) communities are disproportionately overrepresented in mental health and legal systems within the UK. People from BME communities are detained more frequently, receive poorer mental health care, and are restrained and secluded more often than individuals from non-BME backgrounds. High security hospitals represent the physical spaces in which mental health and legal disciplines merge, thereby offering unique contexts for study.

Ten narrative interviews were conducted with individuals who identified themselves as being of BME backgrounds within a high security hospital. These aimed to i) explore the experiences of BME individuals accommodated within a high security hospital; ii) investigate BME individuals' experiences of coercion and restrictive practices, including security, restraint, seclusion and segregation; and iii) identify themes that promote health outcomes for BME individuals in this context. Data was analysed using an iterative-inductive approach, allowing for the emergence of themes from the data, and for links to be made between findings, theories, policies and practice.

Three themes emerged from the findings: i) turbulent journeys; ii) discovering stability; and iii) freedom, hope and aspirations. Turbulent journeys related to the challenges of seeking help and support, and of experiencing oppression, hopelessness, fear and mistrust. Discovery of stability had subthemes rooted in breaking the vicious cycles of detention and discharge, of working with rather than against the system, and of developing individual roles, identities and forms of self-expression. Freedom, hope and aspirations captured the importance of relationships, occupation, health and wellbeing.

Based on these findings, this report recommends that: i) BME individuals must have equal access to mental health care, and fair treatment within mental health and legal services, to improve their experiences of health, care and wellbeing; ii) guidance mist be revised, developed and implemented to ensure that restrictions within secure hospitals do not impinge upon individuals' expressions of self, identity and culture; and iii) it is imperative that restrictive practices, for example, restraint, seclusion and segregation, do not inadvertently become forms of structural violence by perpetuating the fear and violence they set out to contain. These are each paramount to improve the health and wellbeing of BME individuals.

CONTENTS

Acknowledgementsi
Abstractiii
Chapter 1: Introduction1
1.1 Black and Minority Ethnic Communities1
1.2 Context
1.3 Restrictive Practices and Coercion2
1.3.1 Objective Restrictions2
1.3.2 Subjective Restrictions
1.3.4 Normative Restrictions
Chapter 2: Review of the Literature4
2.1 Restrictive Practices
2.2 Preferences
2.3 Seclusion as Punishment
2.4 Physical Restraint and the Therapeutic Relationship7
2.5 Mechanical Restraint and Choice7
2.6 Involvement and Decision-Making8
2.7 Limitations9
2.8 Discussion10
2.9 Conclusions
Chapter 3: Methodology and Methods12
3.1 Aims and Objectives12
3.2 Methodology12
3.3 Ethics
3.4 Recruitment and Sample14
3.5 Data Collection
3.6 Data Analysis15
Chapter 4: Findings
4.1 Turbulent Journeys17
4.1.1 Seeking Help and Support17
4.1.2 Oppression
4.1.2 Hopelessness, Fear and Mistrust18

4.2 Discovering Stability	19
4.2.1 'Breaking that Cycle'	20
4.2.2 Working with, not against	20
4.2.3 Role, Identity and Cultural Expression	21
4.3 Freedom, Hope and Asiprations	23
4.3.1 Rejuvenation: From nothing, to something	23
4.3.2 The Enigma of Time	24
4.3.3 Daring to Dream: Freedom, Hope and Aspirations	24
4.4 Challenges and Limitations	25
Chapter 5: Discussion	26
5.1 Social Suffering	26
5.2 Structural Violence	27
5.3 Identity and Self Expression	28
Chapter 6: Conclusions	
Chapter 7: Recommendations	31
References	33
Appendices	
Appendix 1: Summary of Literature Reviewed	40
Appendix 2: Interview Schedule and Topic Guide	43
Appendix 3: Letter of HRA Approval	44
Appendix 4: Participant Information Sheet	47
Appendix 5: Participant Consent Form	49

Figure 1: Search Terms	4
Figure 2: Literature Search and Review Process	5
Figure 3: Themes from the Findings	16

CHAPTER 1: INTRODUCTION

This peer reviewed report documents a year-long study, exploring *The Lived Experiences of Black and Minority Ethnic Patients within a High Security Hospital.* This study comes at a time when global political landscapes are uncertain. Despite a general tendency towards the language of 'internationalisation', in 2016, the UK referendum voted to leave the European Union, whilst the US election saw Donald Trump voted in. The 'Black Lives Matter' movement remains a prominent international campaign against violence and systemic racism towards black people. Individual human rights remain a concern, especially in terms of how people with mental health problems are treated and where they are detained. With increasing financial pressures on the National Health Service, much media attention has been drawn towards individuals with mental health problems being placed in police custody through a lack of appropriate accommodation and hospital beds. This study considers each of these topical issues by drawing on the challenges facing legal and psychiatric systems, specifically: i) black and minority ethnic communities; ii) context; and iii) restrictive practices.

1.1 BLACK AND MINORITY ETHNIC COMMUNITIES

African-Caribbean men are particularly overrepresented in mental health services, and those from black and minority ethnic (BME) groups are more likely to be detained under the Mental Health Act 1983 (Cabinet Office, 2017; Chandler-Oatts & Nelstrop, 2008). Evidence suggests that BME communities are disproportionately overrepresented in mental health and legal systems (Department of Health, 2005; Morgan et al., 2005; NIMHE, 2003; Warnock-Parkes et al., 2010). People from BME communities are detained more frequently, receive poorer mental health care, and are restrained and secluded more often (Benford Price et al., 2004; Bowers et al., 2005; Cabinet Office, 2017; Gudjonsson et al., 2004; Mind, 2013; Pannu & Milne, 2008; Singh et al., 2007; Singh et al., 2014). Despite this overrepresentation in legal and psychiatric systems, people from BME communities have historically been underrepresented in health research (Rugkåsa & Canvin, 2011). In addition, the voices and experiences of those incarcerated in forensic psychiatric systems are rarely studied (Hui et al., 2013). Current guidelines seek to address health inequalities and to reduce the uses of restrictive measures nationally and internationally (Cabinet Office, 2017; Health Education England, 2017; National Mental Health Working Group, 2005; NICE, 2015; Queensland Government, 2008). It is therefore timely to consider in greater detail the experiences of BME patients within secure hospitals, as well as the organisation and practices of forensic psychiatry.

1.2 CONTEXT

High security hospitals represent the most restrictive of hospital environments. They are the physical spaces where legal and psychiatric disciplines merge (Gunn & Taylor, 1993). The institution is referred to as a hospital, those incarcerated are deemed patients, and those working inside are healthcare professionals. Yet, the security arrangements are equivalent to Category A and B prisons (Department of Health, 2000; 2008a; 2010). The competing ethoses of the forensic and psychiatric disciplines create tensions in balancing care and containment. These are reflected in the everyday language and practices of these institutions. On the one hand, the patients contained within high secure hospitals are considered the most vulnerable as a result of their severe mental health problems. On the other, they are considered amongst the most dangerous within society as a result of their criminal propensities. Those incarcerated are stigmatised for experiencing mental health problems and for having committed a criminal offence (Pilgrim & Rogers, 2003; Thornicroft, 2006; Vassilev & Pilgrim, 2007). They are therefore considered 'deviant' for being 'mad, bad and dangerous', whilst neither conforming to legal nor psychiatric systems alone (Lemert, 1951). High security hospitals thus offer a unique context in which to study such tensions and individual experiences.

1.3 RESTRICTIVE PRACTICES AND COERCION

The terms 'restrictive practices', 'restrictive interventions' and 'coercion' are often used interchangeably within the literature, albeit to different ends. The considerations for which term is used, and when, seem to centre on i) whether the action taken might be considered 'objectively' restrictive; ii) whether actions might be considered 'subjectively' restrictive; and/or iii) whether the actions might be considered 'normatively' restrictive.

1.3.1 OBJECTIVE RESTRICTIONS

Objective restrictions are perhaps most commonly cited as 'restrictive interventions'. These are interventions used to intentionally or forcibly reduce movement, such as through restraint, seclusion or segregation (Davison, 2005; Department of Health, 2008b; Jarrett, Bowers & Simpson, 2008; NICE, 2015). Although these actions are sanctioned via policies within high security hospitals, these interventions impose upon another with intent, and are thus considered overtly, and therefore objectively, restrictive actions (Currier, 2003; Davison, 2005; Jarrett, Bowers & Simpson, 2008).

1.3.2 SUBJECTIVE RESTRICTIONS

Subjective restrictions, in contrast, relate to the attitudes, values and perceptions associated with the uses of restriction, notably, the relationship between what is done and what is felt. Although relevant to all forms of restrictive interventions and practices, subjective restrictions might generally be considered through the language of 'coercion'. Coercion may be overt or covert. These acts of persuasion may be considered along a continuum, with either intended or unintended effects (Currier, 2003; Davison, 2005; Jarrett, Bowers & Simpson, 2008). As such, subjective restrictions are the feelings and emotions of those individuals involved, whether of those taking action, or those experiencing actions against them.

1.3.4 NORMATIVE RESTRICTIONS

Finally, normative restrictions take into consideration the context in which these actions and feelings occur. Such considerations include whether these actions are considered legitimate or illegitimate within the given context, what sanctions are in place to allow or prevent such actions from occurring, and with what consequences (Currier, 2003; Davison, 2005; Jarrett, Bowers & Simpson, 2008). Within a high security hospital, daily restrictions include high fences, locked doors, specific rules and routines (Department of Health, 2008a; 2010). Whilst these are normative to the high security hospital environment, they would be alien to the everyday lives of the general public. Normative considerations therefore take into account the broader contexts and influences by which restrictions occur, such as the environment, atmosphere and cultural practices. For the purposes of this study, objective, subjective and normative restrictions will be explored in relation to the lived experiences of BME patients, specifically within the high security hospital.

CHAPTER 2: REVIEW OF THE LITERATURE

A systematic literature review was conducted to examine publications relating to patient experiences of inpatient forensic mental health services, and, specifically, patient experiences of restrictive practices within these contexts. The electronic databases ASSIA, CINAHL, EMBASE, MEDLINE and PsycINFO were used. All papers published between 1980 and 2016 were considered for review. The key terms used in the search process related to forensic mental health, secure hospitals, coercion, restrictive interventions, restrictive practices and qualitative experiences (see Figure 1).

A total of 586 papers were found using this method. Following a process of careful review and selection based on the criteria outlined in Figure 2, it became apparent that only five papers examined patient experiences of restrictive practices specifically within secure forensic psychiatric hospitals. Of these papers, two were reports of studies conducted within the UK, with one in Croatia, one in Finland and one in New Zealand. Three of these were comparative studies, examining forensic and general patient perspectives (Keski-Valkama et al., 2010; McKenna et al., 2003), or patient preferences of restrictive interventions (Haw et al., 2011). The other two papers examined the uses of physical and mechanical restraints (Knowles et al., 2015; Margetić, 2014). These are summarised in Appendix 1.

1.	coerc* or restrict*
2.	restraint or physical restraint or mechanical restraint or chemical restraint
3.	seclusion or segregation
4.	forensic psychiatry
5.	mental health or psychiatric hospitals or secur* hospitals
6.	mental health patients or mentally ill offenders or psychiatric patients
7.	qualitative research or experience or interviews
8.	1 or 2 or 3
9.	4 or 5 or 6
10.	8 and 9 and 10

FIGURE 1: SEARCH TERMS

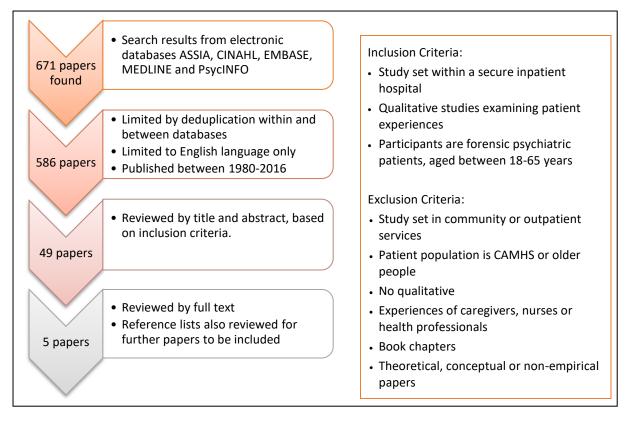


FIGURE 2: LITERATURE SEARCH AND REVIEW PROCESS

2.1 RESTRICTIVE PRACTICES

In each of the five papers reviewed, restrictive practices were defined differently. Restrictive practices were considered as seclusion (Keski-Valkama et al., 2010), physical restraint (Knowles et al., 2015), mechanical restraint (Margetić et al., 2014), a combination of seclusion, restraint and intramuscular medication (Haw et al., 2011), and procedural justice, that is, how patients experience choice and involvement in their care and treatment (McKenna et al., 2003). These variances highlight the broad scope of examining restrictive practices, where different emphases and priorities might lie, and how these may influence the findings to follow.

2.2 PREFERENCES

A study conducted in a medium secure unit in the UK explored patient experiences and preferences of restraint, seclusion and intramuscular medication (Haw et al., 2011). All three restrictive interventions were perceived negatively, with participants reporting having felt humiliated and shameful following their experiences (Haw et al., 2011). Comparable negative thoughts and feelings were reported by participants, including fear, shame, embarrassment, humiliation, trauma and loss of control (Haw et al., 2011). These thoughts and feelings tended to relate to losses, particularly

surrounding communication with staff, a lack of knowledge regarding the processes, whether the types of medication administered or the length of time one would be secluded. Losses were also related to a lack of individual control over their situation, including leave and discharge (Haw et al., 2011).

Of the three restrictive interventions, intramuscular medication tended to be preferred to seclusion (Haw et al., 2011). Seclusion differed from restraint and intramuscular medication in that participants compared this to being imprisoned for an indefinite period of time. The austere environment was perceived as being a particularly negative aspect of seclusion, although seclusion was perceived positively in terms of providing sanctuary and quiet time for reflection (Haw et al., 2011). By contrast, intramuscular medication was perceived as having positive effects on mood, with participants reporting finding the calming and sleep-inducing properties helpful (Haw et al., 2011). Similarly, physical restraint was perceived as beneficial in preventing injury to self and others (Haw et al., 2011). Despite some positive aspects of these interventions being reported, the overarching findings from this study were the differences between individuals' preferences towards restrictive interventions, and a lack of documentation of these preferences within personal records and care plans (Haw et al., 2011).

2.3 SECLUSION AS PUNISHMENT

Keski-Valkama et al. (2010) compared forensic and general psychiatric patients' views of seclusion using structured interviews. Participants were interviewed shortly after they had experienced seclusion, and re-interviewed at follow-up around six months later. Forensic patients differed from general patients in that they were secluded more frequently and for longer periods. Two thirds of the participants perceived seclusion as a form of punishment; however, forensic patients perceived seclusion as being a form of punishment more frequently than general patients. Possible reasons for this were attributed to the more frequent and longer-term use of seclusion amongst forensic patients, as well as perceptions of punishment amongst forensic patients being influenced by the underlying cultures and environments associated with secure hospitals (Keski-Valkama et al., 2010).

Where seclusion was perceived as a form of punishment, patients believed that seclusion was used because of 'bad behaviour' although they were not always sure of the specific reasons or behaviours associated with this. Others believed seclusion was used because they had been detained in an 'inhumane environment'. Patients reported that interactions with staff during this time were limited and opportunities to interact with staff would have been beneficial during this time. Patients also suggested alternatives to seclusion that would have been more helpful to them, including time in their own room, verbal de-escalation, medication, activities and music.

Of those participants involved in follow-up interviews, two-thirds still remembered the reason for their seclusion, whilst the remaining third either remained confused about the reasons for their seclusion or had no recall. The negative and punitive perceptions of seclusion remained at follow-up, and it is suggested that opportunities to talk with staff about these experiences may have helped with better understanding and processing of these experiences. Considerations of how seclusion is conducted and opportunities for patients and staff to talk about these experiences through debriefing were recommended for improving patient experiences.

2.4 PHYSICAL RESTRAINT AND THE THERAPEUTIC RELATIONSHIP

A study by Knowles et al. (2015) examined the impact of physical restraint on the staff-patient relationship. Eight interviews were conducted with patients in a medium secure unit in the UK and analysed thematically. Five themes emerged, as follows: i) that restraint reinforces the inequality of power in the staff-patient relationship; ii) that physical restraint is abusive, degrading and traumatic; iii) that whether restraint is viewed as justified impacts on whether it is accepted; iv) the negative attributes and motives of (some) staff; and v) learning to cope with powerlessness during and following restraint.

Physical restraint was seen as a means for staff to control difficult situations in what can be a volatile environment, but was also sometimes seen as taking advantage of the considerable power imbalance between staff and patients (Knowles et al., 2015). Where restraint was attributed to misuse of power and negative attitudes of staff, this served to emphasise barriers in the staff-patient relationship. Where restraint caused physical pain, emotional distress and post-traumatic reactions, patients coped with this by further distancing themselves from staff. Findings from this study therefore questioned how restraint might be reconciled with recovery-orientated practices, whilst challenging the therapeutic milieu of secure mental health services.

2.5 MECHANICAL RESTRAINT AND CHOICE

The study by Margetić et al. (2014) reports on patient views on the uses of mechanical restraint in Croatia. The authors reported that, in Croatia, seclusion practice is a rare phenomenon, but

regulations stipulate that family members, guardians and/or personal representatives must be informed immediately when a patient has been restrained (Margetić et al., 2014). This differs from the UK where family members and personal representatives are not required to be informed.

Reasons for informing family members, guardians and personal representatives are thought to be helpful in protecting patients from punitive treatment and the unjustified use of restrictive interventions. However, informing relatives and representatives as standard practice denies patients the choice of whether or not they wish others to be informed, and may have consequences for reintegration of patients into their families (Margetić et al., 2014).

Findings from this study revealed that patients were ambivalent as to whether or not their families should be informed (Margetić et al., 2014). Patients reported that the use of restraints may be required for safety where there were no alternatives; however, the use of restraints was often associated with punishment and humiliation (Margetić et al., 2014). Furthermore, a majority of patients believed that a patient who has requested to be placed in restraints should be allowed this option, although this should be documented and acknowledged as voluntary rather than 'coercive' (Margetić et al., 2014).

2.6 INVOLVEMENT AND DECISION-MAKING

Two studies explicitly examined patient choice within forensic mental health care: Margetić et al. (2014) and McKenna et al. (2003). Whilst the study by Margetić et al. (2014) focused on choice specifically relating to the uses of mechanical restraint, McKenna et al. (2003) explored choice and the notions of procedural justice more broadly amongst patients admitted to forensic mental health services.

Procedural justice within this paper was defined as the 'strategies that enhance patients' experiences of involvement in fair decision-making processes' (McKenna et al., 2003, p. 355). This encompassed consideration of 'fairness', 'voice', 'validation', 'respect', 'motivation' and 'information' (McKenna et al., 2003). The study aimed to describe the experience of coercion for those admitted to a forensic psychiatric hospital, and to determine which aspects of procedural justice might reduce patients' perceptions of coercion (McKenna et al., 2003). The study was conducted using surveys and structured interviews, comparing the perceptions of patients admitted to a forensic psychiatric hospital with those of involuntary patients admitted to a general psychiatric hospital (McKenna et al., 2003). Findings revealed that perceptions of coercion were high amongst both patients admitted to a forensic psychiatric hospital and those admitted involuntarily to a general psychiatric hospital (McKenna et al., 2003). Although forensic patients experienced objective coercion (restrictive interventions) more frequently than general psychiatric patients, there were no significant differences in perceived coercion between the two groups. Possible reasons for this were attributed to coercion becoming a normative experience for forensic patients over time; the authors suggest that 'for marginalised groups in society such as prisoners who do not experience a sense of autonomy in their daily lives, hospital admission may be just another coercive interchange, which is no different from others that are experienced' (McKenna et al., 2003, p. 367). Other possible reasons include the application of procedural justice principles prior to and during admission, such that the process of admission might alter and override any experiences of objectively coercive events (McKenna et al., 2003). Finally, it is hypothesised that the expectations of being admitted to a forensic hospital and a more caring ethos might alter patient perceptions of coercive treatment (McKenna et al., 2003). These suggestions were probably based on the researchers' perspectives and so follow-up is required as to whether or not these ideas might be substantiated from a patient perceptive.

2.7 LIMITATIONS

This literature review is limited given the paucity of literature published in this area. Research in forensic mental health services has a tradition of being limited due to the challenges of establishing and conducting research within secure environments, whether this is a result of security, gatekeeping or a combination of the two (Martin, 1984; Weaver Moore & Miller, 1999). This patient population might also be neglected in research due to the stigma surrounding offender patients and the uncertainties of where they belong, given the dualities of organisations they inhabit (Lemert, 1951; Weaver Moore & Miller, 1999; Pilgrim & Rogers, 2003; Vassilev & Pilgrim, 2007).

Whilst the search terms used in this literature review were formulated through discussions with specialist librarians, it is worth acknowledging that the search terms used will ultimately have influenced the literature found. It is also of note that, although the terms 'physical restraint', 'mechanical restraint', 'seclusion' and 'intramuscular medication' were used in the five papers reviewed, these were not clearly defined within each paper. It is recognised that differences in training and practices occur across different countries, and so these may influence cultures, practices, perceived acceptability and therefore the findings of each of the papers reviewed.

2.8 DISCUSSION

The review of literature on patient experiences of inpatient forensic mental health services has highlighted the multifaceted nature and spectrum of what might be broadly considered 'restrictive practices'. These include seclusion, physical and mechanical restraint, and a combination of seclusion, restraint and intramuscular medication, as well as choice and involvement (Haw et al., 2011; Keski-Valkama et al., 2010; Knowles et al., 2015; Margetić et al., 2014; McKenna et al., 2003). With policies outlining the need to reduce restrictive practices and to use the 'least restrictive measures', it is imperative to explore what restrictive practices mean to patients and stakeholders and what methods are experienced as 'least restrictive', particularly within secure environments (NICE, 2015).

The study conducted by Haw et al. (2011) found that patient preferences differed too much for it to be possible to generalise what 'least restrictive' means at an individual level. In order to be truly person-centred, individual preferences must therefore be taken into consideration and documented as part of advance statements and care plans (Haw et al., 2011). This would depend on whether those individuals have experience of restrictive practices and interventions, and considerations must be taken into account of how discussing these practices might be perceived. For example, it should be considered whether conversations about the uses of restrictive interventions might induce fear and anxiety or be perceived as threats or consequences for patients, and, similarly, whether this might influence or be affected by staff values, attitudes and confidence (Ching et al., 2010; Maguire et al., 2012).

There were subtle differences between the findings of the two studies comparing forensic and general patient perspectives (Keski-Valkama et al., 2010; McKenna et al., 2003). Whilst both studies were consistent in finding that forensic patients were subject to restrictive interventions more frequently than general patients, the forensic patients within Keski-Valakama et al.'s (2010) study perceived restrictive interventions as more punitive than general patients did. Findings from the study conducted by McKenna et al. (2003), however, did not reveal any significant differences between forensic or general patient perceptions, although this study had a broader focus on perceptions of coercion, rather than on restrictive interventions per se.

2.9 CONCLUSIONS

In considering these studies collectively, perceptions of punishment may be related to the physical environments in which restrictive practices occur, as well as the associated emotions they reveal

(McKenna et al., 2003; Keski-Valkama et al., 2010). As such, it is not only the acts of coercion and restrictive interventions that need to be considered, but also the contexts in which these occur and the subjective feelings that they evoke. The literature alludes to environment, atmosphere and culture as having an influence on patient experiences, yet few studies have considered what these mean from a patient perspective, including those from different ethnic and cultural backgrounds (Haw et al., 2011; McKenna et al., 2003). Interestingly, despite much published literature on the wider issues of BME patients being disproportionately incarcerated within mental health and legal systems, none of the papers from the literature reviewed considered BME patient experiences specifically. The constant tensions between care and containment, security and treatment, control and respect create a conflict between top-down and bottom-up approaches (McKenna et al., 2003). The review of this literature therefore points to questions of how patient voices might be heard within secure environments, how procedural justice can be fostered amidst procedural security, and ultimately how patients experience these environments, and the restrictive practices within them, to improve relationships, foster recovery and enhance care.

CHAPTER 3: METHODOLOGY AND METHODS

Given the limited exploration of patient experiences within secure psychiatric hospitals, and the evidence to suggest marginalisation within society and mental health services, this study aimed to provide a voice for those BME individuals incarcerated within a forensic psychiatric high security hospital.

3.1 AIMS AND OBJECTIVES

This study aimed to provide a voice for BME individuals incarcerated within a high security hospital. The ethos of advocacy and empowerment underpinned this project, with specific aims and objectives as follows:

- To explore the experiences of BME individuals incarcerated within a high security hospital.
- To investigate BME individuals' experiences of coercion and restrictive practices.
- To identify themes that promote health outcomes for BME individuals within high security hospitals.

3.2 METHODOLOGY

The interviews were conducted using a narrative interview approach (Jovchelovitch & Bauer, 2000; Mason, 2016; Muylaert et al., 2014) and were analysed interactively and inductively, using a broadly constructivist thematic approach (Mason, 2016; Blumer, 1954; Charmaz, 2011; Glaser & Strauss, 1967). A narrative interview method seeks to allow opportunities for BME individuals to talk openly about their experiences, using their own words, rather than having set questions imposed upon them (Mason, 2016). Narrative interviews emphasise the importance of individual storytelling located within temporal and social contexts (Mason, 2016). As such, this approach was deemed most appropriate given the emphasis on exploring the voices of marginalised BME communities and the unique context of the high security hospital in which this study was located.

A constructivist narrative approach is conducive to the researcher being guided and informed by the participants' narratives, rather than imposing their assumptions upon the data being collected (Blumer, 1954; Charmaz, 2011; Glaser & Strauss, 1967). An iterative-inductive methodology further guides the questions asked of participants, based on the individual and collective experiences of living within a high security hospital. Although an interview topic guide was designed by way of framing this

study and presenting initial questions (see Appendix 2), subsequent questions were based on participant responses and emerging themes. The employment of an iterative-inductive approach offers an openness for ideas and emerging themes, thus placing individual participant voices at the centre of this study. Together, these will allow individual experiences to be explored and reflected upon, themes to emerge, and theory, policy and practice to be guided and informed by these individual narratives (Blumer, 1954; Charmaz, 2011; Glaser & Strauss, 1967).

3.3 ETHICS

Ethical approval for this study was granted by the National Health Research Authority (REC Reference: 16/EM/0492) and the Nottinghamshire Healthcare NHS Foundation Trust (IRAS ID: 213876). This included approval of all forms used throughout the study process, including the participant information sheet, consent form and interview schedule (see Appendices 3-5). Ethical considerations have been taken into account throughout the study process, from recruitment and data collection through to writing and dissemination. Following NHS Research Ethics procedures, patients were first informed of the study through being given a participant information sheet by a member of their usual care team (for example, the modern matron, ward manager/team leader, consultant psychiatrist or named nurse). When participants expressed an interest in taking part in the study, their care team would inform the researcher, and a mutually convenient time would be arranged for the researcher and potential participant to meet and discuss any questions they might have with regards taking part. Where required, arrangements with the hospital interpreter were made to assist with the discussion of the study, participant information sheets and consent forms. Participants were made aware that they were able to withdraw from the study at any time, without giving reason, and that this would not affect their care or treatment. When individuals declined to take part, they were not contacted again. For those happy to take part after being given the opportunity to ask questions and after receiving full information about the study, signed consent was sought and the interviews would commence.

In any qualitative research, there is always the potential for participants to disclose personal and emotive experiences. Given the topic of this study, the researcher was particularly careful about this, and, as a qualified mental health nurse, was aware of the need to inform a member of the participant's usual care team should any of the participants became distressed. Given the nature of the environment in which the study took place, the participants' care teams were also aware of the nature of the study as well as the participants' involvement, although the researcher is not aware of any participants becoming distressed either during or after the interviews.

Considerations for anonymity and confidentiality were taken into account throughout the study process so as to protect the identity of research participants and safeguard against the invasion of privacy (Goodwin, 2006). Consent forms were stored in a locked cupboard for secure storage within pass-protected University premises. These were kept separately from the interview recordings. Hospital security procedures were followed regarding the use of a digital voice recorder that was encrypted and approved by the hospital's security department. The voice recorder was kept in secure hospital premises when not in use, and any names or other identifiable information mentioned during interviews were removed from the transcripts. Transcriptions of interviews were password-protected and paper copies were stored in locked cupboards when not in use. Given the relatively small number of participants interviewed, the decision was made not to disclose the types of wards or directorates the patients were accommodated in, or which cultural backgrounds these patients belonged to, when using direct quotes from the interviews.

3.4 RECRUITMENT AND SAMPLE

Due to security measures at the hospital, potential participants were informed of the study via gatekeepers (for example, modern matrons, ward managers and nursing teams). When potential participants expressed an interest in taking part in the study, arrangements were made to meet to discuss any questions, to gain informed consent and for the interviews to be conducted. Eligible participants included all those accommodated within the hospital who identified themselves as being of black or minority ethnic background. All participants within the hospital were aged eighteen years and over. There was no upper age limit for participants taking part in this study. Participants of any gender were eligible to take part; however, all ten participants who expressed interest in taking part in this study were male.

3.5 DATA COLLECTION

The interviews took place in a side room on each of the patient's wards. Of the ten participants, there were six participants for whom English was not their first language. Two of these interviews took place with an interpreter. Aside from the two interviews where an interpreter was present, all other interviews took place with the researcher and participant alone. However, due to the security arrangements at the hospital, the interviews were often observed by hospital staff, either intermittently, outside the interview room, or via security cameras. All interviews were digitally recorded and professionally transcribed by hospital administrators.

3.6 DATA ANALYSIS

Throughout the process of data collection and analysis, three key questions were examined and reexamined to formulate further questions during the interviews, and to interpret the data during analysis:

- What are the lived experiences of BME individuals incarcerated within a high security hospital?
- What are their experiences of coercion and restrictive practices?
- What areas might be developed to improve BME individuals' experiences of living within a high security environment?

The researcher kept a reflective research diary throughout the data collection and analytic processes. Notes were made of new and emerging findings from each of the participant narratives, and these were used to formulate further questions and areas for exploration, allowing closer, in-depth, examination of ideas and themes. Notes of these emerging themes formulated the initial stages of the data-coding process, and re-coding occurred as further interviews were conducted and new findings emerged. The data was analysed by both listening and re-listening to the recordings, and reading and re-reading the transcripts to ensure accuracy and transparency across audio and visual data. It is through the close examination of the data and the revisiting of these questions that links were made between the findings from the study and the wider literature relating to policy, social theories and practice.

CHAPTER 4: FINDINGS

Ten narrative interviews were conducted with individuals who had identified themselves as being of black or minority ethnic backgrounds within the high security hospital. Individual ethnic backgrounds included British-Afro-Caribbean, British-Asian, African, Asian and European. All participants were males. Participants included those who had been admitted to the high security hospital either from prison or secure psychiatric services, with lengths of stay at the high security hospital ranging from seven months to twenty-five years. Of the ten participants interviewed, five mentioned having had previous contact with mental health services.

Whilst it should be recognised that each narrative revealed a personal story, common to each of these accounts were the expressions of i) turbulent journeys; ii) the discovery of stability; and iii) freedom, hope and aspirations (see **Error! Reference source not found.**). In relation to experiences of turbulent j ourneys, individuals narrated challenges in seeking help and support, and in experiencing oppression, hopelessness, fear and mistrust towards those who were supposed to offer care. Discovery of stability had subthemes rooted in breaking vicious cycles, of working with rather than against the system, and of developing personal roles, identities and forms of self-expression. In terms of freedom, hope and aspirations, individuals spoke of the importance of relationships, occupation, health and wellbeing. Challenges associated with each of these themes were identified at social, organisational and individual levels. Each of these will be presented in turn, followed by discussions of these findings in relation to the wider literature.

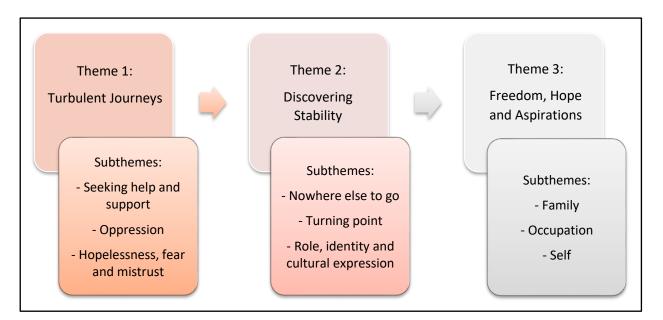


FIGURE 3: THEMES FROM THE FINDINGS

4.1 TURBULENT JOURNEYS

Participants frequently spoke of their personal challenges in seeking support for their mental health and wellbeing, experiencing cycles of admissions and discharges to and from hospital, as well as the negative experiences of being treated against their will – each of which led to increased feelings of anxiety, fear and oppression.

4.1.1 SEEKING HELP AND SUPPORT

For some participants, seeking support in the community was a challenge. Once detained in services however, participants often experienced challenges either in being discharged, or in receiving appropriate support following discharge into the community.

There's people in the community who need help and they can't get help, and then they go committing crimes and things like that... they're not coming to hospital when they need to be in a hospital, and then people are not being moved on when they need to be moved on and things like that, and it's not good to be fair... (Participant 5)

The first time I become unwell was in 2001. I got to the hospital. I spent two months. I get discharged. I suffer six months after discharge. It was a shock for me. I started becoming unwell. Far away from my family. I felt very different. Then after six months I get well again and I start to go out, and I start, I found work. Then, yeah, after, I relapse again, and I went to hospital again. I get discharged in two months... And I start work again. Similar each year I did that. (Participant 7)

4.1.2 OPPRESSION

Being detained within mental health services was perceived to be oppressive by those who were interviewed. Experiences of mental health services were often felt to be punitive, even when not intended as such. Participants expressed concerns at losing their individual rights and freedom and at being expected to conform to institutional rules and regulations. The consequences of this were detrimental to individuals' health and wellbeing.

I've lost my rights since I've been incarcerated. I'm giving up, I'm moving on... They put my hopes up and then they drop it down. Put my hopes up, they play with my emotions you know. (Participant 6)

If you are patient, you never win. As long as you are patient you never win because you can't beat the system, you know. You can't beat the system. (Participant 6)

There's lots of problems that come with being a minority, you know what I mean... Especially in an environment like this, which can be quite oppressive. (Participant 4)

I think what it was, it was more or less like, you know, saying we'll do this as punishment because you've done certain things, but we're not going to call it punishment, we are just going to call it something else, you know what I mean, don't call it punishment, we're not punishing you, we're not oppressing you, we are just doing this... (Participant 4)

It's not a good place to be, to be fair, it's not a good place to be at, that's all I can say really. Not a good place to be... you're locked away from your family, you can't be with your family and things like that. (Participant 5)

4.1.2 HOPELESSNESS, FEAR AND MISTRUST

Negative experiences of mental health services frequently resulted in increased feelings of hopelessness, fear, anger and mistrust. Participants spoke of feeling let down by others, as well as feeling as though they had let down their loved ones, describing their actions and responses to detention as being 'out of character'.

I was put into a secure room because they couldn't find anything else to do with me, because I wasn't cooperating at all... I felt people were working against me and I couldn't trust them, I couldn't trust them... (Participant 3)

I wanted out of the hospital, so I kept kicking off. Every time I kicked off they put me in seclusion, so that would get my back up a bit so I, I'd kick off again because I wanted

to be let out and not get injected... The main reason that I carried on the way that I did was because I was suffering from side-effects. The side-effects that I was having were that bad that I just couldn't cope like that, so the doctor said to me when I got to this place after three years, he said it's atrocious, it's absolutely atrocious what happened to you. Being secluded the amount of times that you have been secluded. Do you realise how many times, he said you've been secluded over 100 times in the last three years. Basically, it's every week for three years. (Participant 3)

I feel I've let my family down, you know what I mean. Part of the reason why I am so angry all the time is because I've let my family down, I've let my family down, but I don't know how to get myself my freedom now. (Participant 10)

I'm not that kind of person [violence/fighting back], I had so much anxiety. (Participant 3)

Unfortunately, I had a bad ride at the beginning, which put a lot of distrust. Now things are fine, you know, but it's twenty-two years later, but, you know, a lot of things have happened, you know. I think I needed help really, you know, with the problems that I had. (Participant 3)

I mean, maybe when I was coming here I was frightened of the system. And I was against the system. I think the system gave me a lot of problems you know, and I give a lot of problems to the system. (Participant 2)

To an individual, you know, you know, you might have all the reasons in the world to be acting the way you are acting... the flight comes in, and you get really nervous about the whole situation... You are put under an immense amount of pressure because of that. (Participant 3)

4.2 DISCOVERING STABILITY

Following cycles of admission and discharge, or of having committed an index offence through lack of mental health support, participants spoke of gaining a sense of stability through being accommodated

within a high security hospital, and of having nowhere else to go since they had entered the most secure of spaces. This physical sense of security therefore represented a 'turning point' for many, of recognising the need to work with, rather than against, an imperfect system, since this was their only chance of freedom. This physical sense of stability, however, was frequently juxtaposed with the emotional challenges of experiencing the highest levels of security and of attempting to reconcile their individual roles, identities and expressions of self.

4.2.1 'BREAKING THAT CYCLE'

Participants spoke of being accommodated within a high security hospital as breaking a downward spiral of anxiety, anger and frustrations. This vicious cycle was broken, in part, because the high security environment represents the greatest level of incarceration and restriction, and also because there is nowhere else for these individuals to go.

You are given a choice: either you can swallow it, or you can sort it out and get yourself in trouble. (Participant 3)

My changing point it was coming here... really that has, that's turned it all round for me, breaking that cycle and coming away from that kind of vicious circle, coming here and, and just learning new skills and, you know, having no changes, you know. (Participant 1)

4.2.2 WORKING WITH, NOT AGAINST

In recognising the high security hospital as the 'end point', individuals spoke of changing direction from a path of hopelessness and self-destruction to learning to work with, and within, an imperfect system.

We are all slaves to the system, you have to cut your clothes to fit with the system... so you have to work with the staff, talk to the staff, your named nurse, your associate nurse, your doctor, you have to communicate with everyone. (Participant 2)

I mean the problem is that when you have your liberty taken away from you, you're locked up in a hospital and you've been given drugs which are bad for your health physically, I suppose, and mentally, making you tired or whatever, and, you know, you want your freedom back, and you want, you know, you're young and you want to get out, it's very easy to think that people are against you, whereas if you step back for a bit and sort of make a bit of commitment, and I suppose commit yourself to the place, you can find that a lot of people are trying to help you really. (Participant 3)

4.2.3 ROLE, IDENTITY AND CULTURAL EXPRESSION

Individuals spoke of the challenges of reconciling their roles, identities and cultural expression as being threefold: working on themselves, their relationship with others and their environment.

4.2.3.1 SELF

Participants spoke of their personal identity changing when admitted to a high security hospital. For some, this was managing the shock of being perceived as both dangerous and vulnerable, of being associated with forensic services as well as psychiatry, and of working with the uncertainties connected with this. For others, this also meant that their recovery and healing was as much about the acceptance of their actions and mental distress as it was about learning to manage their mental health and wellbeing.

I've never break the law, this my first contact with the police and this was shock for me what, how everything happened to me. Shocking events for me this was. So all my life I was good person. I was a worker, I worked very hard for my family, to provide for my family for the future, but something unexpected happened in my life. And now I am stuck here and I must spend time, I don't know how long time, I must spend here. (Participant 9)

The thing that's with my culture, you don't associate my culture with being in this environment. (Participant 4)

4.2.3.2 OTHERS

A lack of diversity amongst hospital staff and patients was perceived to be an obstacle to understanding different cultures and self-expression.

I think they haven't got a lot of black staff here. They've not got many, like hardly any at all to be fair... I think it might, it might better inform people, about people with different needs and about backgrounds and stuff like that. Different perspectives. (Participant 4)

There is not many people who share same... there is not many people who come from same background from where I come from. For example, I have been here ten years and I've met one other... I missed my own culture, I missed that. (Participant 7)

4.2.3.3 THE ENVIRONMENT

Whilst the high security hospital was generally experienced as offering a sense of physical stability, participants spoke of the emotional challenges of being contained within the high secure environment, of having to learn new rules, of working through their new roles and identities, and of discovering new forms of self-expression as dictated by the security measures enforced within the institution.

In prison it is different. In prison you keep yourself to yourself, you don't trouble anybody. You just get on with your business, staff will like you. Yeah, they like you. You become enhanced prisoner, you get privileges. Yeah, more money to spend. But in psychiatric hospitals, negative, that means you not well. So if you isolate yourself a lot, it's not well. (Participant 6)

If I, if I want to speak to anyone on the phone they have to listen to my conversation and then they interpret. So every phone call I make they listen. I use one phone and there's another phone, they are standing next to me, listening whilst I am talking. If I write a letter in my language, it stays in the hospital system for two weeks. Before they file it. Because they translate. You see, so they know what has been written and then they file it. So if I send any letter to [home], to people who speak my language, if I write in my language, it takes maybe two weeks to get out of hospital, but if I write in English, two days. (Participant 6)

I missed my own culture, I missed that. (Participant 7)

My English is not that bad, to be honest, to need an interpreter. When my friend come to visit I don't need interpreter. They [the interpreters] just sit and listen what we say. (Participant 7)

I feel more, more confident to speak your own language, with your countryman or your friend who speaks the same language as you. Sometimes the interpreter wouldn't come and they say, do you want to cancel the visit, or let the visits go on? So I ask my friends to come, but we speak English. That's sometimes bad for me. When we speak about particular things, yeah, you have to think twice. You understand... To speak [in personal dialect], it's a comfort. (Participant 7)

4.3 FREEDOM, HOPE AND ASIPRATIONS

Individuals spoke of their journeys, from being accommodated within the highest levels of security and having nothing to lose, towards daring to dream, to hope and to have aspirations.

4.3.1 REJUVENATION: FROM NOTHING, TO SOMETHING

The narratives were indicative of journeys towards rejuvenation. Individual perceptions changed from believing they had nothing, and therefore nothing to lose, to becoming self-assured in working towards freedom.

There are so many things I have to lose, so I can't afford to throw it all away or flush it all down the toilet, I mean I have to maintain my current pathway. (Participant 1)

You know, I've had my ups and I've had my downs... I've got through a lot of problems and those problems have been sorted out eventually... One point when I was in hospital, you know, it was very difficult to maintain. Because you didn't really see much of a life, but I am now at a point where I'm looking at leaving, moving on and having every chance of having a decent life, so you know it's been quite a positive experience ultimately. (Participant 3)

4.3.2 THE ENIGMA OF TIME

Having and maintaining aspirations were often met with the uncertainties of time, as well as a perceived lack of ownership and control of personal futures, detention and release from hospital.

I'm more worried about what my life will be like in the long term. (Participant 8)

I don't know how long I will spend here. (Participant 9)

4.3.3 DARING TO DREAM: FREEDOM, HOPE AND ASPIRATIONS

In spite of the often turbulent beginnings, individuals spoke of their aspirations towards freedom, moving on from incarceration towards having a family and an occupation, each of which appeared to motivate and ground individuals towards recovery.

I like to get my freedom, my freedom more than anything... I mean freedom means more than anything to me. (Participant 2)

I hope to be, to maintain and keep well. And to see my family and to find a job I hope. And to wish well for everybody who is suffering like me or have this experience of mental health. (Participant 7)

I would like to start everything from the beginning really. That's my aim. Yeah, can probably start a family. Maybe start some business. That is what I would like. Fresh start, yeah. With a lot of experience to be honest because of that time in my life. (Participant 8)

That's my only hope, to be honest to be out there to go to my family and be out there... that's it really. (Participant 10)

I've got big dreams, I've taken those steps to get there. I want to have a business online or a business in, like, a shop form or something. I don't know what it's going to be yet, I mean, I know I want to work for myself. Yeah, I've worked a lot on my situation since I've been here and I like to do things. I'm always active, I'm doing stuff every day. (Participant 4)

I will come back to my home to live with my son, with my family. I will open my own business. (Participant 9)

4.4 CHALLENGES AND LIMITATIONS

Challenges were faced in accessing this marginalised community, not only as a result of the security measures in place at the hospital, but also in gaining ethical approval for working with a population that is considered both vulnerable and dangerous for a lone researcher. Security measures placed restrictions upon the type of digital recording equipment permitted, security protocols dictated that approvals had to be sought in taking a digital recorder onto the wards, and security training had to be undertaken by the researcher in order to enter the hospital.

Due to the nature of the hospital and patient population, the researcher was reliant on gatekeepers to inform individuals about this study, and to organise the logistics of meeting with participants and conducting the individual interviews, as well as being reliant on administrative staff within the hospital to transcribe the subsequent interview data. These all culminated in some significant delays with the set-up of the study and receipt of the transcripts.

During this study, it is recognised that this hospital is unusual, in terms of being one of only three high security hospitals in England and Wales, but also in terms of having unusually small numbers of BME individuals accommodated within it. All of the participants interviewed were males. As such, it is not known what female patient experiences might be. As a result of the small numbers of BME patients within the hospital, and the relatively small number of patients interviewed, demographic details of individual participants have not been included, and specific details of participants have been omitted from the individual quotes. The intention of this has been to maintain anonymity, although it is hoped that this will not detract from the voices and crucial messages contained within.

CHAPTER 5: DISCUSSION

This study set out to explore the lived experiences of BME individuals incarcerated within a high security hospital, and to learn of the experiences of coercion and restrictive practices, with a view to examining what areas might be developed to improve individual experiences of the high security hospital environment. Whilst it is recognised that the high security hospital offers a unique context for study, what has transpired from listening and re-listening, reading and re-reading the narrative interviews, is the challenges and complexities of individual experiences relating to i) social suffering, ii) structural violence, and iii) identity and self-expression. What has also become apparent is that these personalised, individual experiences would not have been made accessible had the interviews not been conducted via an iterative-inductive approach towards narrative inquiry.

5.1 SOCIAL SUFFERING

At the societal level, individuals spoke of the challenges of seeking help with their mental health problems. This was either due to lack of knowledge of whom to speak to and where to go, or due to the fear, stigma and increasing marginalisation associated with seeking support. Individuals spoke of the cultural differences in which mental health problems are considered, and the potential to be ostracised from their communities. Individuals also spoke of the challenges of being from diverse backgrounds, and of often feeling marginalised, oppressed and excluded within society, as well as within forensic and mental health services. These findings are in support of the existing literature, notably that individuals of BME backgrounds are likely to experience marginalisation, oppression and poorer health outcomes (Benford Price et al., 2004; Bowers et al., 2005; Cabinet Office, 2017; Department of Health, 2005; Gudjonsson et al., 2004; Morgan et al., 2005; NIMHE, 2003; Pannu & Milne, 2008; Singh et al., 2007; Singh et al., 2014; Warnock-Parkes et al., 2010). The social influences and experiences revealed in these individual narratives can be located within the social science literature relating to the social suffering of marginalised populations (Bourdieu et al., 1999; Kleinman, 1997; Kleinman, Das & Lock, 1997; Wilkinson & Kleinman, 2016). These specifically relate to loneliness, isolation and lack of belonging.

The literature on social suffering considers the intersectional relationships of different social injustices (Bourdieu et al., 1999; Kleinman, 1997; Kleinman, Das & Lock, 1997; Wilkinson & Kleinman, 2016; World Health Organisation and Calouste Gulbenkian Foundation, 2014). In this instance, being of a BME background, experiencing mental health problems, and having a violent or criminal history each place the individual as further removed from the norms of society, and as such as different and

increasingly disenfranchised. The individual narratives of fear, anxiety, trauma, oppression and inequalities tell of the systemic social injustices that occur within modern society, and of the needs to work towards inclusion amongst increasingly diverse communities and to overcome exclusion and social barriers to seeking support, care and treatment (Bourdieu et al., 1999; Kleinman, 1997; Kleinman, Das & Lock, 1997; Wilkinson & Kleinman, 2016; Singh et al., 2007; Singh et al., 2014).

5.2 STRUCTURAL VIOLENCE

The individual narratives speak of the challenges surrounding marginalisation and 'non-belonging'. These continue even once mental health services have been accessed, and particularly within forensic psychiatry, since individuals incarcerated within forensic psychiatric institutions do not belong completely within either legal or mental health systems. These pluralistic disciplines and institutions create constant frictions between what is valued, what is done and what is felt (Hochschild, 1983; Hui, 2016; Hui, 2017; Kraatz & Block, 2008; Lawrence, Suddaby & Leca, 2009; Martin, 1984). At an organisational level, individuals speak of the systemic challenges associated with the organisational culture and practices of forensic psychiatry. Within a high security hospital, those individuals incarcerated are patients, and staff are healthcare professionals rather than prison or security officers. Care should therefore be at the forefront of patient experiences, yet the patient narratives frequently speak of security dictating their daily experiences of treatment and self-expression.

Individuals speak of their experiences of restrictive practices as being fearful, whilst actions of violence were frequently fear-driven, for example, fighting against staff through fear of being involuntarily medicated. Individuals spoke of fear breeding fear, and thus breeding mistrust, leading to violence, further fear and anxiety, and perpetuating trauma. These feelings of fear, anxiety, mistrust and trauma result in what the organisation might refer to as 'negative actions' – those of violence, fighting back at the establishment and being labelled 'violent and dangerous', thereby leading to increased incarceration and restrictions. These cycles of aggression on the part of the individual, and coercion from the organisation, are documented in the literature as the 'aggression-coercion cycle' (Goren, Singh & Best, 1993). What this study adds, however, are the journeys and lived experiences of these through increasingly restrictive practices and increasingly secure accommodation. Furthermore, this study suggests that these practices might be studied through the social theories of structural violence (Orelus, 2017; Wilkinson & Kleinman, 2016; Žižek, 2008).

The notion of 'normative' practice has previously been conceptualised in the introduction – that is, the idea that certain practices are context-specific, and thus legitimatised and sanctioned through organisational policies and protocols. Restrictive interventions are an example of this, in that there are policies in place to allow the use of these under certain circumstances. The ideas about structural violence question normative practices when these supposedly 'beneficial' actions do harm rather than good. Such is the case presented here, when the labels of violence, dangerousness and risk, and the subsequent practices of restrictive interventions and actions, become apparently detrimental to individual experiences of care, treatment, health and wellbeing.

Individuals spoke of these continued cycles of fear, mistrust and increasing incarceration, to the point of being accommodated within a high security hospital. Individuals spoke of the secure hospital space as one of relative stability – the certainty being that they had reached the end point, that there was nowhere else to go, with this being the maximum level of incarceration possible. It is harrowing to learn that individuals experience the high security environment as a place of relative safety and stability, and questions must be asked as to what other experiences these individuals must have lived through to come to these conclusions. Furthermore, questions are asked as to what could be done to stop individuals from requiring such levels of secure accommodation by preventing fear, mistrust and trauma within organisations that are purported to provide care, and how these turning points might be reached without necessitating such levels of incarceration and restriction. It is proposed, therefore, that there is scope to develop an area of work where social theories of structural violence might be used to inform organisational change.

5.3 IDENTITY AND SELF EXPRESSION

Individuals spoke of working through processes of rejuvenating themselves, and of working with their identities and finding new forms of self-expression. These were in relation to their environments, attitudes and perceptions of others, as well as their perceptions of themselves. Their journeys to recovery and freedom were therefore multifaceted and several-fold, shaped by the complexities of being accommodated and restricted by the pluralistic institutions of law and psychiatry (Kraatz & Block, 2008; Lawrence, Suddaby & Leca, 2009). For those who had been transferred from prison to the high security hospital, a change in mindset was required, especially with regards to time – a prison sentence means that time is definite, whilst, in contrast, detention in hospital has no fixed term. For those transferred from other mental health services, the rules, regulations and heightened security of the hospital posed similar quandaries and processes of resettlement.

Individual narratives told of the stories of differences in expectations between prisoner and patient roles: being a 'good prisoner' was to go unnoticed, to 'do time' and be released, whereas being a 'good patient' required much introspection, attending courses and personal disclosure, all whilst time remained an uncertain entity, beyond one's control. The enigma of time was found to be challenging in setting personal goals, in maintaining hope and motivation. The environments which individuals inhabit, whether these were prisons or secure hospitals, also shaped how individuals might perceive themselves. For those who had committed index offences whilst experiencing mental distress, overcoming these traumas was often a challenge. Similarly, being associated with both legal and psychiatric services presented challenges in perceptions by self and other, with questions as to whether individual experiences were intentionally or unintentionally punitive, and as to individuals' role and identities within a high security hospital.

Individuals spoke of a lack of ethnic diversity within the hospital, amongst the staff and patient population. Although current guidelines recognise a need for staff diversity, the reasons for a lack of diversity within this hospital are unclear for staff as well as patients. Contact with other patients of a similar cultural background was often restricted by the security measures in place at the hospital. Likewise, patients were often prevented from expressing themselves in languages other than English, despite this being perceived as a crucial form of a cultural expression and self-expression. Where least restrictive practices are to be considered, it is therefore paramount to consider these not only in terms of restrictive interventions but also in terms of wider security measures, the roles these have and their effects on the individuals within.

CHAPTER 6: CONCLUSIONS

This study has explored the lived experiences of black and minority ethnic patients within a high security hospital. Ten narrative interviews were conducted. From these, key themes emerged surrounding i) turbulent journeys, ii) discovering stability, and iii) freedom, hope and aspirations. Individuals of ethnic minority backgrounds recounted their turbulent journeys in terms of their challenges in seeking help and support during their time in the community, and of experiencing oppression in society, as well as within forensic and mental health services. Individuals spoke of self-perpetuating cycles of fear breeding fear, further breeding mistrust and fear-driven violence. Each of these led to further labels and constructions of risk, dangerousness and escalating levels of security, restriction and incarceration. Individuals spoke of reaching a 'turning point' once accommodated within the high security hospital, through recognising that there was nowhere else to go. This peak of incarceration, security and restriction thus represented a period of relative physical stability, in which individuals recognised that they would need to work with an imperfect system in gaining freedom. Individual hopes and aspirations centred on freedom, relationships and occupation.

These findings are in support of the conclusions in the wider literature that individuals of BME backgrounds frequently experience oppression, marginalisation and challenges in seeking support (Cabinet Office, 2017; Department of Health, 2005; Morgan et al., 2005; NIMHE, 2003; Warnock-Parkes et al., 2010). In addition, the findings of this study point towards the social suffering resulting from systemic injustices, structural violence occurring through legitimatised institutional sanctions, and individual actions resulting from fear, anxiety and trauma. All of these serve to perpetuate the cycles of increased security, incarceration and restrictive practices. Furthermore, the findings from this study indicate that with emphasis placed on risk and security, restrictions are imposed on expressions of culture and individual self-identity. In order to break these vicious cycles of fear, mistrust, risk and security, steps must be taken towards ensuring that individuals feel safe within least restrictive environments, such that high security detention can be avoided. Policy and practice require closer integration so as to recognise diversity and inclusion and to achieve least restrictive practices. It is only through practising in the least restrictive ways possible that steps may be taken to overcome fear, anger and mistrust, whilst working towards addressing social and organisational inequalities and imbalances of power.

CHAPTER 7: RECOMMENDATIONS

Individuals of BME background have the right to feel safe throughout their contact with forensic and mental health services. In order to achieve this, the following recommendations must be urgently addressed:

- BME individuals must have equal access to mental health care, and fair treatment within mental health and legal services, to improve their experiences of health, care, and wellbeing.
- Develop and implement revised guidance to ensure that restrictions within secure hospitals do not impinge upon individuals' expressions of self, identity and culture.
- Review and update policies and practices relating to the uses of, and access to, translators, to ensure that BME patients are involved in the decisions made about their care, and to ensure regular contact with family and friends, including hospital visits, telephone calls and letters.
- It is imperative that the uses of restrictive practices, for example, restraint, seclusion and segregation, do not inadvertently become forms of structural violence by perpetuating the fear and violence they set out to contain.
- A transparent system for monitoring, reporting and reviewing restrictive practices among BME patients must be implemented.
- Where restrictive practices are deemed necessary, opportunities should be made for BME individuals to discuss this with their care teams, so that therapeutic relationships can be developed and maintained, and care plans, including preventative strategies, can be formulated in moving forwards.
- In challenging the current cultures of secure hospitals, guidance for standards of practice must be developed, implemented and monitored, specifically relating to the training needs of healthcare professionals, to work towards a reduction in the uses of restrictive practices amongst BME patients.
- Develop a charter that places care, rather than containment, at the forefront of secure hospitals. This is to be developed with key stakeholders, including healthcare professionals, policymakers, carers and user groups, to demonstrate the commitment of forensic mental health care to improving the health and wellbeing of BME individuals, whilst working towards organisational change.

REFERENCES

Benford Price, T., David, B. & Otis, D. (2004) The Use of Restraint and Seclusion in Different Racial Groups in an Inpatient Forensic Setting. *Journal of the American Academy of Psychiatry and the Law*, 32(2): 163-168.

Blumer, H. (1954) What is Wrong with Social Theory? American Sociological Review, 18: 3-10.

Bourdieu, P. (1999) *The Weight of the World: Social Suffering in Contemporary Society*. Cambridge, Polity Press.

Bowers, L., Douzenis, A., Galeazzi, G.M., Forghieri, M., Tsopelas, C., Simpson, A. & Allan, T. (2005) Disruptive and Dangerous Behaviour by Patients on Acute Psychiatric wards in Three European Centres. *Social Psychiatry and Psychiatric Epidemiology*, 40: 822-828.

Cabinet Office (2017) Race Disparity Audit: Summary Findings from the Ethnicity Facts and Figures Website. [online]:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/650723/RDAweb. pdf [accessed 17th October 2017].

Chandler-Oatts, J. & Nelstrop, L. (2008) Listening to the Voices of African Caribbean Mental Health Service Users to Develop Guidance Recommendations on Managing Violent Behaviour. *Diversity in Health and Social Care*, 5(1): 31-41.

Charmaz, K. (2011) Grounded Theory Methods in Social Justice Research. In: Denzin, N.K. & Lincoln, Y.S. [Eds.] *The Sage Handbook of Qualitative Research,* California, Sage, pp. 359-380.

Ching, H., Daffern, M., Martin, T. & Thomas, S. (2010) Reducing the Use of Seclusion in a Forensic Psychiatric Hospital: Assessing the Impact on Aggression, Therapeutic Climate and Staff Confidence. *Journal of Forensic Psychiatry & Psychology*, 21(5): 737-760.

Department of Health (2000) *Report of the Review of Security at the High Security Hospitals*. London, Department of Health.

Department of Health (2005) Delivering Race Equality in Mental Health Care: An Action Plan for Reform Inside and Outside services; and the Government's Response to the Independent Inquiry into the Death of David Bennett. London, Department of Health.

Department of Health (2008a) *A Framework for the Performance Management of High Security Hospitals*. London, Department of Health.

Department of Health (2008b) Mental Health Act 1983: Code of Practice. London, Stationary Office.

Department of Health (2010) *High Secure Building Design Guide: Overarching Principles for Ashworth, Broadmoor and Rampton Hospitals*. London, Department of Health.

Glaser, B.G. & Strauss, A.L. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New York, Aldine.

Goodwin, D. (2006) Ethical Issues. In: Pope, C. & Mays, N. [Eds.] *Qualitative Research in Healthcare*. Third Edition, London, Blackwells, pp. 53-62.

Goren, S., Singh, N.N. & Best, A.M. (1993) The Aggression-Coercion Cycle: Use of Seclusion and Restraint in a Child Psychiatric Hospital. *Journal of Child and Family Studies*, 2(1): 61-73.

Gudjonsson, G.H., Rabe-Hesketh, S. & Szmukler, G. (2004) Management of Psychiatric In-Patient Violence: Patient Ethnicity and Use of Medication, Restraint and Seclusion. *British Journal of Psychiatry*, 184: 258-262.

Gunn, J. & Taylor, P.J. (1993) *Forensic Psychiatry: Clinical, Legal and Ethical Issues*. Oxford, Butterworth-Heinemann.

Haw, C., Stubbs, J., Bickle, A. & Stewart, I. (2011) Coercive Treatments in Forensic Psychiatry: A Study of Patients' Experiences and Preferences. *The Journal of Forensic Psychiatry and Psychology*, 22(4): 564-585.

Health Education England (2017) *Health Education England Strategic Framework 2014-2029*. London, HEE.

Hochschild, A.R. (1983) The Managed Heart. Berkeley, CA, University of California Press.

Hui, A. (2017) Institutional and Emotion Work in Forensic Psychiatry: Detachment and Desensitisation. In: Middleton, H. & Jordan, M. [Eds.] *Mental Health Uncertainty and Inevitability: Rejuvenating the Relationship between Social Science and Psychiatry*. Palgrave MacMillan, pp. 137-165.

Hui, A. (2016) Mental Health Workers' Experiences of Using Coercive Measures: 'You Can't Tell People Who Don't Understand'. In: Völlm, B. & Nedopil, N. [Eds.] *The Use of Coercive Measures in Forensic Psychiatric Care: Legal, Ethical and Practical Challenges,* Springer, pp. 241-254.

Hui, A.M.L. (2015) *The Use of Coercive Measures in a High Secure Hospital: Expression of Institutional and Emotional Work*. [online]: <u>http://eprints.nottingham.ac.uk/29557/</u> [accessed 20th October 2017).

Hui, A., Middleton, H. & Völlm, B.A. (2013) Coercive Measures in Forensic Settings: Findings from the Literature. *International Journal of Forensic Mental Health*, 12(1): 53-87.

Jovchelovitch, S. & Bauer, M.W. (2000) Narrative Interviewing. In: Bauer, M.W. & Gaskell, G. [Eds.] *Qualitative Researching with Text, Image and Sound: A Practical Handbook*. London, Sage, pp. 57-74.

Keski-Valkama, A., Koivisto, A.M., Eronen, M. & Kaltiala-Heino, R. (2010) Forensic and General Psychiatric Patients' View of Seclusion: A Comparison Study. *Journal of Forensic Psychiatry and Psychology*, 21(3): 446-461.

Kleinman, A. (1997) Everything That Really Matters: Social Suffering, Subjectivity and the Remaking of Human Experience in a Disordering World. *Harvard Theological Review*, 90(3): 315-336.

Kleinman, A., Das, V. & Lock, M. [Eds.] (1997) Social Suffering. Berkeley, University of California Press.

Knowles, S.F., Hearne, J. & Smith, I. (2015) Physical Restraint and the Therapeutic Relationship. *The Journal of Forensic Psychiatry & Psychology*, 26(4): 461-475.

Kraatz, M.S. & Block, E.S. (2008) Organizational Implications of Institutional Pluralism. In: Greenwood, R., Oliver, C., Suddaby, R. & Sahlin-Anderson, K. [Eds.] *Handbook of Organizational Institutionalism*. London, Sage, pp. 243-276.

Lawrence, T.B., Suddaby, R. & Leca, B. [Eds.] (2009) *Institutional Work: Actors and Agency in Institutional Studies of Organizations*. Cambridge, Cambridge University Press.

Lemert, E.M. (1951) *Social Pathology: A Systematic Approach to the Theory of Sociopathic Behaviour*. New York, NY, McGraw-Hill.

Maguire, T., Young, R. & Martin, T. (2012) Seclusion Reduction in a Forensic Mental Health Setting. *Journal of Psychiatric and Mental Health Nursing*, 19: 97-106.

Margetić, B., Margetić, B.A., Ivanec, D. (2014) Opinions of Forensic Schizophrenia Patients on the Use of Restraints: Controversial Legislative Issues. *Psychiatric Quarterly*, 85: 405-416.

Martin, J.P. (1984) Hospitals in Trouble. London, Blackwell.

McKenna, B.G., Simpson, A.I.F. & Coverdale, J.H. (2003) Patients' Perceptions of Coercion on Admission to Forensic Psychiatric Hospital: A Comparison Study. *International Journal of Law and Psychiatry*, 26: 355-372.

Mind (2013) *Mental Health Crisis Care: Physical Restraint in Crisis – A Report on Physical Restraint in Hospital Settings in England*. London, Mind.

Morgan, C., Mallett, R., Hutchinson, G., Bagalkote, H., Morgan, K., Fearon, P., Dazzan, P., Boydell, J., McKenzie, K., Harrison, G., Murray, R., Jones, P., Craig, T. & Leff, J. (2005) Pathways to Care and Ethnicity: Sample and Characteristics and Compulsory Admission. *British Journal of Psychiatry*, 186(4): 281-289.

Muylaert, C.J., Sarubbi, V., Gallo, P.R., Neto, M.L.R. & Reis, A.O.A. (2014) Narrative Interviews: An Important Resource in Qualitative Research. *Revista Da Escola de Enfermage Da University of San Paolo*, 48(2): 184-189.

National Mental Health Working Group (2005) *National Safety Priorities in Mental Health: A National Plan for Reducing Harm, Health Priorities and Suicide Prevention Branch*. Department of Health and Ageing, Canberra, Commonwealth of Australia.

NICE (2015) *Violence: The Short-Term Management of Disturbed/Violent Behaviour in In-Patient Psychiatric Settings and Emergency Departments*. London, National Institute of Clinical Excellence.

NIMHE (2003) *Inside Outside: Improving Mental Health Services for Black and Minority Ethnic Communities in England*. London, Department of Health.

Orelus, P.W. (2017) Social Justice for the Oppressed. London, Rowman & Littlefield.

Pannu, H. & Milne, S. (2008) Use of Seclusion in an English High Security Hospital. *Medicine, Science & the Law,* 48(4): 288-294.

Pilgrim, D. & Rogers, A. (2003) Mental Disorder and Violence: An Empirical Picture in Context. *Journal of Mental Health*, 12(1): 7-18.

Queensland Government (2008) *Policy Statement on Reducing and Where Possible Eliminating Restraint and Seclusion in Queensland Mental Health Services.* [online]: <u>http://www.health.gld.gov.uk/mentalhealth/docs/sandrpolicy_081030.pdf</u> [accessed 22nd August 2017].

Rugkåsa, J. & Canvin, K. (2011) Researching Mental Health in Minority Ethnic Communities: Reflections on Recruitment. *Qualitative Health Research*, 21(1): 132-143.

Singh, S.P., Burns, T., Tyrer, P., Islam, Z., Parsons, H. & Crawford, M.J. (2014) Ethnicity as a Predictor of Detention under the Mental Health Act. *Psychological Medicine*, 44(5): 997-1004.

Singh, S.P., Greenwood, N., White, S. & Churchill, R. (2007) Ethnicity and the Mental Health Act 1983: Systematic Review. *British Journal of Psychiatry*, 191: 99-105.

Thornicroft, G. (2006) *Shunned: Discrimination Against People with Mental Illness*. Oxford, Oxford University Press.

Vassilev, I. & Pilgrim, D. (2007) Risk, Trust and the Myth of Mental Health Services. *Journal of Mental Health*, 16(3): 347-357.

Warnock-Parkes, E., Young, S. & Gudjonsson, G. (2010) Cultural Sensitivity in Forensic Services: Findings from an Audit of South London Forensic Inpatient Services. *The Journal of Forensic Psychiatry and Psychology*, 21(1):156-166.

Weaver Moore, L. & Miller, M. (1999) Initiating Research with Doubly Vulnerable Populations. *Journal of Advanced Nursing*, 30(5): 1034-1040.

Wilkinson, I. & Kleinman, A. (2016) *A Passion for Society: How We Think About Human Suffering*. Oakland, University of California Press.

World Health Organisation and Calouste Gulbenkian Foundation (2014) *Social Determinants of Mental Health*. Geneva, World Health Organisation.

Žižek, S. (2008) Violence. London, Picador.

APPENDICES

APPENDIX 1: SUMMARY OF LITERATURE REVIEWED

AUTHORS, YEAR AND TITLE	COUNTRY	STUDY AIMS	METHODS	FINDINGS AND RECOMMENDATIONS
Haw et al. (2011) Coercive treatments in forensic psychiatry: A study of patients' experiences and preferences.	UK	Inpatients' experiences and preferences about physical restraint, seclusion and emergency intra-muscular medication.	Mixed methods: semi- structured interviews and review of case notes (<i>n</i> = 57 patients).	Patients generally perceived seclusion, restraint and intramuscular medication as negative experiences. Seclusion differed from restraint and IM medication in terms of the physical environment, humiliation and time for reflection. Negative perceptions of restraint and IM medication surrounded staff approaches. Patients' views should be incorporated into care plans and advance statements.
Keski-Valkama et al. (2010) Forensic and general psychiatric patients' view of seclusion: A comparison study.	Finland	To compare the views of secluded patients in a forensic setting with the views of those in a general psychiatric setting.	Interviews: one interview shortly after seclusion and one follow-up interview six months afterwards (<i>n</i> = 106).	Forensic patients viewed the use of seclusion as a form of punishment more frequently than general patients did. Seclusion was viewed negatively, and participants were generally

				dissatisfied with the lack of opportunities for interaction. Although seclusion cannot always be avoided, it could be conducted in a more therapeutic manner with opportunities for discussion and debriefing.
Knowles et al. (2015) Physical restraint and the therapeutic relationship.	UK	To explore medium secure patients' perceptions of the impact of restraint on their relationships with staff.	Semi-structured interviews (<i>n</i> = 8).	Five themes were identified: power imbalance, trauma, the importance of justifying restrictive practice, negative attributes and motives of staff, and the impact of coping with powerlessness.
Margetić et al. (2014) Opinions of forensic schizophrenia patients on the use of restraints: Controversial legislative issues.	Croatia	To determine the views of psychotic offender patients on the use of mechanical restraint as a kind of punishment, and on the voluntary use and sharing of the information about the use of restraints with the family.	Mixed methods: Likert scales, questionnaires and interviews (<i>n</i> = 54).	Patients with a history of being restrained believe more strongly that a patient should be restrained upon request. Patients were equivocal as to whether families should be informed when restraints are used or whether restraints can be used as punishment for intentionally aggressive behaviour.

McKenna et al. (2003)	New	To describe the experience of	Surveys and structured	The perception of coercion was
Patients' perceptions of coercion on admission to forensic psychiatric hospital: A comparison study.	Zealand	coercion among those	interviews (<i>n</i> = 138).	high for patients admitted to
		admitted to a forensic		forensic hospitals as well as for
		psychiatric hospital, and to		patients admitted involuntarily to
		determine which aspects of		general psychiatric hospitals.
		procedural justice might		Despite patients in the forensic
		reduce patients' perceptions		psychiatric group being exposed
		of coercion.		to greater frequencies of
				objective coercion, there were no
				significant differences in
				perceived coercion between the
				two groups. Possible reasons for
				this were that coercion occurs
				with such regularity that it
				becomes a normative experience,
				the application of procedural
				justice principles might override
				concerns about specific objective
				coercive events, or the
				expectation of admission to a
				forensic psychiatric hospital may
				have modified the impact of
				coercive events and the
				experience of perceived coercion.

APPENDIX 2: INTERVIEW SCHEDULE AND TOPIC GUIDE

- Which ethnic group would you consider yourself belonging to?
- Do you have any specific cultural needs?
 - Have your cultural needs been met during your time in the hospital?
 - In what ways?
- How long have you been in this hospital for?
- What type of environment were you transferred from?
- What have your experiences been in this hospital? Specifically relating to the following areas:
 - Restrictive practices.
 - Restrictive interventions, e.g. seclusion, restraint, segregation, blanket restrictions.
 - Therapy/activities.
- What might be done differently?
- What are your aspirations for the future? How are you being supported with these?



Email: hra.approval@nhs.net

Dr Ada Hui Teaching and Research Associate in Mental Health University of Nottingham Institute of Mental Health Jubilee Campus Nottingham NG7 2TU

18 January 2017

Dear Dr Hui

Letter of HRA Approval

Study title:

IRAS project ID: Protocol number: REC reference: Sponsor An exploration of the lived experiences of BME patients within a high secure hospital. 213876 16083 16/EM/0492 Research and Graduate Services, University of Nottingham

I am pleased to confirm that <u>HRA Approval</u> has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read Appendix B carefully, in particular the following sections:

- Participating NHS organisations in England this clarifies the types of participating
 organisations in the study and whether or not all organisations will be undertaking the same
 activities
- Confirmation of capacity and capability this confirms whether or not each type of participating
 NHS organisation in England is expected to give formal confirmation of capacity and capability.
 Where formal confirmation is not expected, the section also provides details on the time limit
 given to participating organisations to opt out of the study, or request additional time, before
 their participation is assumed.
- Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

IRAS project ID 213876

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A List of documents reviewed during HRA assessment
- B Summary of HRA assessment

After HRA Approval

The document "After Ethical Review – guidance for sponsors and investigators", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as
 detailed in the After Ethical Review document. Non-substantial amendments should be
 submitted for review by the HRA using the form provided on the <u>HRA website</u>, and emailed to
 <u>hra.amendments@nhs.net</u>.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation
 of continued HRA Approval. Further details can be found on the <u>HRA website</u>.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application

IRAS project ID 213876

procedure. If you wish to make your views known please email the HRA at <u>hra.approval@nhs.net</u>. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is 213876. Please quote this on all correspondence.

Yours sincerely

Rekha Keshvara Assessor

Email: hra.approval@nhs.net

Copy to: Mr Ryan Keyworth Ms Shirley Mitchell, Nottinghamshire Healthcare NHS Foundation Trust

APPENDIX 4: PARTICIPANT INFORMATION SHEET



Nottinghamshire Healthcare



UNITED KINGDOM - CHINA - MALAYSIA

Participant Information Sheet (Final version1.1: 2nd January 2017)

Title of Study: An Exploration of the Lived Experiences of Black and Minority Ethnic (BME) Patients within a High Secure Hospital

IRAS Project ID: 213876

Name of Researcher: Ada Hui

We would like to invite you to take part in our research study. Before you decide whether or not you would like to take part, we would like you to understand why the research is being conducted and what this would involve. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish, and ask us if there is anything that is not clear.

What is the purpose of the study?

Research suggests that individuals from Black and Minority Ethnic (BME) backgrounds are frequently detained within legal and mental health services. However, there is often little opportunity for the voices and experiences to be heard. This study aims to provide the opportunity for individuals of BME backgrounds to narrate their experiences of being within a high secure hospital, and specifically their experiences of restrictive practices. This is with the view to improving patient experiences, care and practice within mental health services.

Why have I been invited?

You are being invited to take part because you are currently residing in this hospital and are considered to be of Black and Minority (BME) background. We are inviting all participants of BME, or 'non-white British' background across the hospital to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your care and legal rights.

What will happen to me if I take part?

If you choose to take part, you will be involved in a one off informal interview. This is not like a 'job interview' but rather, an opportunity for you to talk about your experiences of being within a high secure hospital, what experiences of restrictive practices you might have had, what you might change and what could be improved. The interview will be digitally recorded with your permission, and will last between thirty minutes and one hour. You can choose to end the interview at any time you wish, without giving a reason.

What are the possible disadvantages and risks of taking part?

The researcher will aim to work around your schedule, and meet with you at a convenient time. If you become distressed at any point during the study, either yourself or the researcher may choose to terminate the interview, and your ward team will be informed to offer you support. This does not affect the care you would normally receive.

What are the possible benefits of taking part?

We cannot promise the study will help you, but the information we get from this study may help to improve services in the future.

Page 1 of 2

HSH BME Patient Experiences Participant Information Sheet Final Version 1.1 2rd January 2017

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. A member of your ward team may be present for the interview if you usually have someone with you, or if you wish to have support from a member of your ward team. The researchers contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this via your ward team who can escalate on your behalf, or you can contact the Patient Advice and Liaison Service (PALS) on: 01777 247396.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, some parts of the data collected for the study maybe looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept strictly confidential, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the hospital will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Your personal data (name and ward) will be kept for 12 months after the end of the study so that we are able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). All research data will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

Although what you say in the interview is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons. This will be done in accordance with hospital's disclosure policy.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your care and legal rights being affected. If you choose to withdraw at any time, the information collected so far cannot be erased, and this information may still be used in the project analysis.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by the Mary Seacole Foundation, in collaboration with Higher Education England and the Royal College of Nursing.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Nottingham Research Ethics Committee (REC reference 16/EM/0492).

Further information and contact details

Dr Ada Hui Honorary Researcher/Chief Investigator University of Nottingham Institute of Mental Health Nottingham NG7 2TU

Page 2 of 2

HSH BME Patient Experiences Participant Information Sheet Final Version 1.1 2rd January 2017

APPENDIX 5: PARTICIPANT CONSENT FORM



Nottinghamshire Healthcare NHS Foundation Trust



Please initial box

CONSENT FORM

(Final version 1.1 2nd January 2017)

Title of Study: An exploration of the lived experiences of Black and Minority Ethnic (BME) patients within a high secure hospital

IRAS Project ID: 213876

Name of Researcher: Ada Hui

Name of Participant:

 I confirm that I have read and understand the information sheet final version dated 2nd January 2017 for the above study and have had the opportunity to ask questions. 						
 I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my care or legal rights being affected. I understand that should I choose to withdraw, the information collected so far cannot be erased, and that this information may still be used in the project analysis. 						
3. I understand that data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential.						
4. I understand that although what I say in the interview is confidential, should I disclose anything that may be deemed to put myself or anyone else at any risk, it may be necessary to report this to the appropriate persons in accordance with hospital's disclosure policy.						
I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports.						
I agree to take part in the above study.						
Name of Participant	Date	Signature				
Name of Person taking consent	Date	Signature				
2 copies: 1 for the project notes and 1 for the participant's r	ecords					

HSH BME Patient Experiences Consent Form Final Version 1.1 2nd January 2017

A copy of this report is free to download from: eprints.nottingham.ac.uk

Hui, A. (2017) *The Lived Experiences of Black and Minority Ethnic Patients within a High Security Hospital,* London, Health Education England.

For further information please contact:

Dr Ada Hui MNursSci (Hons) PhD PGCHE RNMH FHEA

Mary Seacole Leadership Awardee 2016-2017 Assistant Professor, University of Nottingham Honorary Researcher, Nottinghamshire Healthcare NHS Foundation Trust ada.hui@nottingham.ac.uk