Voluntary and Involuntary Mental Health Service Users' Views on How Their Human Rights Were Considered.

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ABSTRACT

Background: The legal framework for governing involuntary treatment in England and Wales is set out in the Mental Health Act (1983) which gives health professionals power, in certain circumstances, to detain, assess and treat people considered to have a 'mental disorder', in the interest of their own health and safety or for public safety. It is accompanied by a Code of Practice and other statutory safeguards that aim to preserve service users' human rights. While some people find psychiatric inpatient treatment helpful and necessary, there are growing concerns that services are failing to protect service users' human rights.

Aims: To deepen an understanding of how service users' human rights are respected on psychiatric inpatient wards. Key research questions were: what are voluntary and involuntary inpatient service users' experiences of staff respecting their human rights; what are voluntary and involuntary inpatient service users' experiences of being informed about their rights; and what impact do these experiences have on voluntary and involuntary service users?

Method: A mixed methods approach used. Semi-structured interviews with twelve service users with experience of psychiatric inpatient treatment in England were carried out. In addition, a brief 10-item questionnaire was completed at the end of each interview. Interviews were transcribed and analysed using thematic analysis. Data from questionnaires were analysed using descriptive statistics.

Findings: Five themes were generated to describe participants' experiences: Deprived of Rights; Rights Upheld, Emotional Impact; Battle for Rights; and Information about Rights. Participants' raised a number of concerns with regards to how their human rights were respected. Their accounts were characterised by restrictions on liberty and autonomy, a lack of privacy dignity and respect, and issues relating to equality and discrimination. Concerns were also raised regarding the provision of information about their legal rights.

Implication: Interventions across multiple levels are required to promote a human rights-based approach. Organisational policies and practices must be scrutinised; staff must be made aware of how human rights apply to their work and offered regular support to cope with the emotional demands of the role; and a review of government policy is needed to examine structural factors that both inhibit and promote change.

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1. INTRODUCTION

1.1 Overview of Chapter

This section provides an outline of the subject area of this study: voluntary and involuntary service users' views on how their human rights were respected. The first section provides an overview of the historical context for the study and current mental health and human rights legislation in England and Wales, with a particular focus on how they intersect. Secondly, the chapter will present a literature review which aims to synthesise current understandings of the experiences of people admitted onto psychiatric inpatient wards in England and Wales. Lastly, the rationale and justification for the study will be given in the context of current gaps in the literature, and the chapter will conclude by presenting the research questions for the current study.

1.2 A Brief History of Mental Health Legislation in England and Wales

The management of madness has a long and complex history and a full exploration is far beyond the remit of this thesis. What follows is a brief outline to provide a historical context to current mental health legislation.

1.2.1 Institutionalisation

Institutional segregation for those considered to be of 'unsound mind' has existed in the UK in various forms since the fourteenth century. For example the religious house of St Mary of Bethlehem which provided shelter for the sick and infirm in 1247 began to accept the mad by the late fourteenth century (Porter et al., 1997). These were neither regulated nor standardised and operated with no involvement from the state (Porter et al., 1997).

The growing perception of a problem with pauper lunacy during the seventeenth and eighteenth centuries brought about a degree of state intervention and social engineering. Foucault (1971) refers to the regime of confining madmen in institutions alongside criminals, vagrants and the unemployed, as the 'Great

Confinement'. He argues this process "had nothing to do with any medical concept" but "served the function of isolating those who challenged the moral values of the bourgeois" (p. 40). This served both the economic function of forcing people to work for very little pay, and the political function of suppressing the increasing unrest amongst the unemployed (Foucault, 1971). He argued that across Europe, the mad and anyone else considered an inconvenience or threatening to those in power, were being locked away.

The 1714 Vagrancy Act is the first piece of legislation to specifically provide detention of lunatics (Porter, 2002). This reflected the old law policy of punishing those who could work but refused to do so, the "undeserving poor" (Bartlett, 1999, p.35). In 1774, the Madhouse Act was introduced to regulate private madhouses. It set limits on the number of people who could be admitted into a madhouse, created licenses and regular inspections, and made it necessary to obtain medical certification for the confinement of lunatics. During this period, the treatment of lunacy remained largely unregulated, and a synonymous relationship between insanity and detention developed (Szmukler, 2014). Conditions in asylums were often deplorable; they were cold and damp, often infested with fleas and rats, and detainees were sometimes grossly abused by staff; beating and whippings were frequent and many female detainees were sexually abused (Scull, 2015). The number of people detained in asylums grew rapidly due to social changes related to industrialisation, and management of inmates became increasingly custodial.

Legislations relating to the management of lunacy continued in the nineteenth century. The Wynn's Act of 1808 advocated for the better care of lunatics and enabled but did not require counties across England and Wales to construct county asylums. The 1845 County Asylum Act required the compulsory building of asylums in England and Wales, and the Lunacy Commission was established to regulate them. The 1890 Lunacy Act was passed in response to growing concerns that people were being wrongfully detained and provided a legal system in which two medical certificates were required for admission into an asylum. By the middle of the twentieth century, various social, technological and economic changes affected how people with mental health problems were cared for.

1.2.2 Deinstitutionalisation

Mental health services have undergone fundamental changes in the past 70 years with the shift in care and support of people with mental health difficulties from psychiatric institutions into the community. The development of anti-psychotic drugs built hope that people with mental health difficulties could be treated in the community. The increasing financial costs of Victorian asylums, along with a number of scandals in 1960s such as Ely Hospital in the UK, highlighted the traumatic experiences that many people endured whilst in psychiatric institutions (Charlesworth et al., 2015). During this period there was an increasing awareness that to keep people in hospital when they had recovered from their acute stage of ‘illness’ was an infringement of their human rights (Turner et al., 2015). In addition, Goffman's (1968) study of psychiatric institutions showed the poor standards of care and quality of life for people living in them. He referred to asylums as “total institutions” where individuals were cut off from wider society for a period of time and received impersonal treatment which stripped away their dignity and individuality.

Numerous legislations presaged the closure of asylums and the integration of psychiatric care into wider hospital systems (Turner et al., 2015). The Royal Commission on the Law Relating to Mental Illness and Mental Deficiency (1957) recommended that service users should be retained in hospital no longer than needed. The Mental Health Act (1959) was the first mental health legislation that clarified the need for someone to be admitted to hospital against their will. Individuals presenting with a ‘mental disorder’ could be detained against their will for a period of 28 days. It required a recommendation from two medical practitioners. The Hospital Plan (1962) predicted the closure of mental health beds. In the years that followed there was a dramatic change in the provision of psychiatric services as there was a shift towards the provision of community-based services for people considered to be suffering from mental illness, including supported housing, day services, and community mental health nurses and social workers (Turner, 2004).

1.3 The Current Context

The present legal framework for governing involuntary treatment in England and Wales is set out in the Mental Health Act (MHA; 1983). It is unique to mental health service users and gives health professionals power, in certain circumstances, to detain, assess and treat people considered to have a 'mental disorder', in the interest of their own health and safety or for public safety. The MHA was amended in 2007 following concerns that the law was not providing adequate provision to ensure the safety of both the public and those considered to have a mental disorder. There were also concerns that the MHA was not consistent with the European Convention on Human Rights (Lawton-Smith, 2008). The amendments introduced several significant changes which aimed to increase autonomy and to address incompatibility between the MHA and the European Convention for Human Rights (ECHR; 1948), such as the right for service users to apply to change their nearest relative.

The MHA has a number of sections outlining the rules for the use of compulsory treatment. For example, Section 2 is concerned with assessment and treatment, which can be for up to 28 days, and Section 3 governs admission for treatment, which can be for up to six months although it can be extended. For the MHA to be used, an agreement must be reached between two doctors (e.g. psychiatrist and GP) and an approved mental health professional (e.g. social worker) regarding whether the use of the Act is necessary and appropriate.

Voluntary admission was first introduced by the Mental Treatment Act in 1930, but were not common place until outlined in the MHA in 1959, after which the numbers of voluntary admissions rose (Rogers, 1993). It enabled service users an option to choose to accept the terms of inpatient treatment, rather than be detained against their will. However, the concept of voluntary consent among voluntary service users has been criticised. Richardson (2008) suggests that many voluntary service users may feel that their decisions are influenced either by the knowledge that legal powers to detain them exists or by the power differentials existing between service users and professionals which creates pressure for voluntary service users to comply with treatment proposed by mental health services. In practice, not all voluntary service users are free to leave and their status as an informal patient is often changed to formal (Kelly, 2016).

1.3.1 The Use of the Mental Health Act

National data show that detentions under the MHA have been steadily rising over the past 25 years (NHS Digital, 2019). NHS statistics showed that in 2018-2019, more men than women were detained under the Act and the highest proportion of people admitted were aged between 18-35 years-old. Moreover, higher proportions of people from Black and minority ethnic (BAME) backgrounds were detained (NHS Digital, 2019). These figures are consistent with well-established findings showing that people from BAME background are disproportionately detained under the MHA (Bhui et al., 2003; Care Quality Commission, 2018a). Explanations for this have included that it reflects institutional racism (Fernando, 2017), and higher rate of distress amongst Afro-Caribbean populations and late presentation to services (Dein et al., 2007). Research also indicates that compulsory detention is highest in the most deprived areas of the UK (Keown et al., 2016).

1.3.2 Balancing Autonomy with Paternalism

There are constant tensions between balancing individual rights of service users and the protection of the public. Throughout history, reason and rationality have been the foundation on which autonomy should be respected and restricted (Bloch, Green, & Holmes, 2014; Scull, 1979). Paternalism refers to restricting someone's liberty or autonomy, with the aim of doing good or avoiding harm, while autonomy is the freedom to make decisions for oneself. Mental health legislation in England and Wales generally adopts a paternalistic view moderating peoples' rights to autonomy with the protection of a person's health and safety, the protection of others, and the right of people considered to have 'mental disorders' to access treatment and healthcare (Rosen et al., 2012).

However, criticisms have been directed towards the MHA for detaining people on the grounds of risk of harm to others (Petch, 2001; Szmukler & Holloway, 2000). The majority of violence is committed by people without mental health difficulties (Swanson et al., 1990). The risk of violence is only modestly increased in certain groups of services users, such as those who misuse substances (Steadman et al., 1998). UK statistics show that the proportion of homicides committed by those who have had contact with mental health services in the previous 12 months is approximately 10% (Appleby et al., 2016). Research suggest that being diagnosed with a psychiatric diagnosis is far less predictive of violence than being young, male, unemployed, from a lower class, and substance dependent (Elbogen & Johnson, 2009; Hiday, 1995). People with psychiatric diagnoses are six times more likely to die by homicide than the general population (Hiroeh et al., 2001). The MHA is intended to reduce risk of harm to self but a report published in 2012 showed that only 27% of people who took their own lives had been in contact with mental health services in the 12 months prior to their death (Appleby et al., 2012) A report also showed that involuntary treatment does not remove the risk of suicide; in 2012/13 48 detained service users died of ‘unnatural causes’ including deaths by hanging and self-strangulation (CQC, 2014).

1.3.3 Role of Clinical Psychology

Psychological interventions in acute settings are delivered on multiple levels; directly to service users, indirectly through staff members and through consultation to teams to encourage a reflexive environment (British Psychological Association, 2012). Evidence suggests that psychological input on wards can be effective in helping service users make sense of crises, improve relationships and satisfaction with ward experience, and promote recovery (Donaghay-Spire et al., 2016; Paterson et al., 2018; Wykes et al., 2018). The revisions of the MHA (2007) made it possible for psychologists and other mental health professionals to act as “responsible clinicians” in the use of the MHA. This has been the subject of much debate (e.g. Cooke et al., 2002; Gillmer & Taylor, 2011; Harper, 2005; Holmes, 2002). Supporters argue that it may be appropriate if the intervention is predominately psychological and it provide a means of delivering care around psychological formulation (Parsloe, 2012). Critics, however, propose that psychologists would be drawn into a social control function which would adversely affect the relationships with the clients (Holmes, 2002).

1.3.4 Efficacy of Compulsory Treatment

The aim of psychiatric inpatient treatment is supposedly to provide treatment and care to the most acutely distressed and vulnerable service users in a safe and therapeutic setting (DoH, 2002). Accordingly, success of admission and readiness for discharge is considered based on reducing risk to self or others, and improvement in psychiatric 'symptoms' and general functioning (Katsakou & Priebe, 2006). However, research indicates that psychiatric inpatient treatment does not always significantly reduce risk of harm to self (Goldacre et al., 1993; Huber et al., 2016; Valenstein et al., 2009) and treatment efficacy is widely debated (Burns et al., 2013; Cooke, 2017; Hopko et al., 2002).

1.3.4.1 Medication

Medication is the most common intervention given to service users in psychiatric inpatient units (Baker et al., 2006; Bowers, 2005; Gilburt et al., 2010; Healthcare Commission et al., 2007; Rogers & Pilgrim, 1993). National guidelines recommend using antipsychotics for individuals presenting with severe mental distress (National Institute of Clinical Excellence (NICE), 2009; 2011; 2014). Recent evidence suggests that the efficacy and effectiveness of antipsychotics to produce clinically meaningful benefits have been overestimated. A meta-analysis showed that while there may be a statistically significant effect of antipsychotics in comparison with placebo, changes in 'symptoms' did not meet an empirically derived threshold for minimal clinical improvement and only 17-22% experienced a significant improvement (Leucht et al., 2009). A subsequent systematic review found that antipsychotics are associated with less than minimal improvement (Lepping et al., 2011). Antipsychotics also cause adverse side effects, such as uncomfortable restlessness (akathisia) and involuntary movements of the jaw, lips and tongue (tardive dyskinesia). A recent survey of 832 service users in 30 countries found between 27-54% reported, on three measures, that antipsychotics made them worse, and the majority experienced a range of adverse effects, including emotional numbing, drowsiness and suicidality (Read & Williams, 2019).

1.3.4.2 Electroconvulsive Therapy

UK government guidelines recommend using electroconvulsive therapy (ECT) as last resort, when other treatments have failed (NICE, 2003). Research has previously indicated that it is an effective treatment for depression (Gábor & László, 2005). However, a recent systemic review, was unable to identify any studies that showed ECT to be superior to placebo beyond the end of treatment (Read & Arnold, 2017). There is also no evidence that ECT prevents suicide (Read & Bentall, 2010). There are also concerns about its usage. Recent data from the ECT minimum data set shows that in the UK during 2016-2017, 1821 courses of ECT were given to 1682 people, most commonly for severe depression that was life threatening and was unresponsive to other treatments (Buley et al., 2017). Of these individuals, 51.8% were informal at the start of treatment, suggesting many people are given ECT against their will. In addition, an audit of ECT in England between 2011-2015 showed of 2987 people, 38.7% were given ECT without their consent (Read et al., 2018). It also showed that service users were given ETC without having first received psychological therapy, constituting a breach of NICE guidelines, and not all mental health trusts followed the correct procedures regarding second opinion doctors, a breach of section 58A of the MHA (Read et al., 2018).

1.3.4.3 Community Treatment Orders

Community treatment orders (CTOs), introduced in the 2007 amendments, are an order made by a responsible clinician to give service users supervised treatment in the community following discharge from their admission. This may include orders to live in a certain place and to take prescribed medication. Research, however, has found “no support in terms of any reduction in overall hospital admission to justify the significant curtailment of service users' personal liberty” (Burns et al., 2013, p. 1627).

1.4 Human Rights and Mental Health

1.4.1 The Relationship Between Human Rights and Mental Health

There are three fundamental relationships between human rights and mental health. Firstly, mental health policies and practices can ultimately lead to the violation of peoples’ human rights (Cady, 2010; Gostin & Gable, 2004). For instance, the MHA gives mental health professionals the power to restrain and administer treatment without consent. Although such powers are intended to be beneficial for the welfare of the individual, their family and society, they affect a variety of basic rights, including autonomy, bodily integrity, privacy, property and liberty (Richardson, 2008). Secondly, human rights violations have a causal effect on distress (e.g. (Johnson et al., 2010; Neufeldt, 1995; Steel et al., 2009). For example, discrimination and invasion of privacy can have a negative impact on a person's mental wellbeing by undermining dignity and self-worth (Hendriks, 1995). Lastly, mental health and human rights are intimately linked. They both collaboratively contribute towards improving the quality of life of people and allow them to contribute and engage in political and social life: fostering good mental health enables people to make the most of the rights that may be available to them, and promoting human rights is necessary to provide security, protect people from harm and promote mental wellbeing (Gostin & Gable, 2004).

1.4.2 Human Rights Act and the Mental Health Act

The HRA sets out 16 legally enforceable human rights which applies to all actions of public authorities and their employees, including services providing care for SU under the MHA (Hewson, 2000). Rights under the HRA can be broadly described as 'absolute' or 'qualified' (Dickens and Sugarman, 2015). Absolute rights, such as the right the life and the right to remain free from torture or inhuman treatment, can never be limited or infringed upon by in any circumstances. Qualified rights, such as the right to respect for private and family life, may be restricted proportionately by a public authority to promote expressly, legitimate aims, such as public safety. Limitations on rights must be in accordance with law which requires the provisions limiting the right be set out in legislation, such as the MHA, or the common law (Liberty, 2010). This is of relevance to mental healthcare since it allows 'persons of unsound mind' to be detained against their will if the procedures used are legal. Central to the HRA is the principle of proportionality which balances the demands of the general interest of the community and the requirements of the protection of the individual's fundamental rights (De Burca, 1993; Reid, 2007). It requires that interference with a Convention right must balance the severity of the interference with the intensity of the social need for action, which aims to protect individuals from arbitrary decisions (Curtice et al., 2011). As an example, an individuals' right to have their privacy respected is protected by Article 8 of the HRA which means disclosure of confidential information may breach Article 8 unless considered necessary and proportionate response to a specific situation (Curtice et al. 2011). A criticism of proportionality is the assumption that pubic interests, as a matter of principle, can always be weighed against human rights. (Tsakyrakis, 2009). Additionally, it is assumed that measures aimed at promoting a public interest may succeed unless they force an excessive restriction compared to the benefit they secure (Tsakyrakis, 2009). Despite the introduction of the HRA, a report in 2009 concluded *"*a culture of respect for human rights has largely failed to take root among public authorities in England" (Donald et al., 2009). Other critics have pointed towards the governments ineffectiveness in using the HRA as a tool to improve to delivery of public services (Joint Committee on Human Rights, 2008). Nonetheless, a human rights framework can assist staff to reach objective, balanced and proportionate decision and be more confident in their decision making (Equality and Human Rights, 2009).

The HRA is of particular significance for people detained under the MHA as admission into a psychiatric inpatient unit restricts a number of freedoms, such as the right to refuse treatment, the ability to leave with ease, manage one's time, and to choose activities (Cady, 2010). Furthermore, under capacity legislation, a person may lose the ability to manage importance decisions such as managing their own finances and legal affairs. If mismanaged, mental healthcare procedures, such as confidentiality and the right to have the least restrictive care can also raise concern. Critics of the MHA argue that current laws inherently discriminate against people with mental health problems (Bindman et al, 2003). The UN Convention on the rights for persons with disability (2006; CRPD), ratified by the UK, but not part of domestic law, states that "the existence of a disability shall in no case justify a deprivation of liberty" (The Office of the United Nations High Commissioner for Human Rights, 2009; p1.). Therefore, under the convention, disability, including 'mental disorder', cannot be used as a factor in determining whether involuntary treatment may be imposed (Bartlett, 2009). Szmukler, Daw and Callard (2014) argue that the MHA violates a number of CRPD rights, such as the right to be free from discrimination of any kind on the basis of disability, the right to enjoy legal capacity on an equal basis with others in all aspects of life, and Article 14 which states that the existence of a disability shall in no case justify a deprivation of liberty. They propose a ‘fusion’ of mental health and mental capacity law that involuntary treatment is based solely on an individual’s capacity, to make their own decision.

From a human rights perspective, relevant rights for those who are detained under the MHA include: the right to life; the right to liberty and security; the right not to be tortured or treated in an inhumane or degrading way; the right to a fair trial; the right to respect for private and family life; and the right not to be discriminated against (Equality and Human Rights Commission, 2019). These are discussed further below which have been referenced from two sources: Barber, Brown and Martin (2016) and Department of Health (2008)”.

1.4.4.1 The right to life

Article 2 ensures the state has a duty to protect every person’s life, to refrain from unlawful killing, to investigate suspicious death, and to protect life. The most relevant aspect of this Article to the MHA relates to the issue of suicide. The Article requires hospitals to take measures to ensure procedures are in place to secure an individual’s right to life. The use of force, such as restraint, in psychiatric inpatient units, also potentially violates this Article. For example, a report published in 2011 showed that between 2003-2009, there were four deaths where restraint was identified as a cause of death of service users detained under the MHA (Independent Advisory Panel on Deaths in Custody, 2010). A subsequent report showed that between 2000-2014, 46 service users detained under the MHA died as result of restraint-related deaths (where restraint was used in the previous seven days) (Independent Advisory Panel on Deaths in Custody, 2015).

1.4.4.2. *The right to liberty and security*

Article 5 states that every person has the right to personal freedom, which cannot be taken away without good reason. It is the only Article which lists the conditions in which governments may justifiably deprive a person of their liberty. This includes a provision referring to “persons of unsound mind” which is taken to mean ‘mental disorder’. It is, therefore, under this Article that compulsory treatment on account of mental health difficulties is allowed. It is the obligation of the state to inform people detained under the MHA of the reasons for their detention and provide a prompt review of the detention by an independent court of tribunal. In practice, this is carried out under Section 132 of the MHA which requires hospital managers to ensure that people who are detained receive information about the legal basis for detention and their right to challenge it.

1.4.4.3 *The right to be free from torture and cruel, inhumane or degrading treatment*

Article 3 is an absolute right, allowing no derogations. Public bodies must refrain from subjecting anyone to torture, treatment or punishment that is cruel, inhumane or degrading. Although it is an absolute right, it can be interpreted in different ways. In psychiatric practice, Article 3 may be relevant to complaints arising from the conditions of detention and the use of seclusions and restraint. Yet, the Article states that whether an act constitutes inhuman or degrading depends on various factors as well as the individual circumstances of each case. Whilst the European court recognises that service users are protected under this Article, it maintains that a measure which is therapeutically necessary cannot be regarded as inhumane or degrading (see Herczegfalyy Vs Austria, 1993). Therefore, in terms of the law, it remains contentious whether or not compulsory detention, restraint, and enforced treatment are inhuman and degrading.

1.4.4.4 The right to a fair trial

Article 6 requires every person who has been charged with a criminal offence, or whose civil liberties have been limited by the decision of a public body, to the right to a fair and public hearing. This is relevant for service users detained under Section 2 and Section 3 of the MHA who can appeal their detention through a mental health review tribunal or to hospital managers hearing.

1.4.4.5 The right to privacy and a family life

Article 8 protects service users' right to privacy and a family life. The primary aim is to protect people against arbitrary interference by public authorities. Public bodies are required to protect the right to personal autonomy, dignity, physical and psychological integrity, and ensure that any restrictions are limited to occasions when they can be legally justified. This means people should be able to maintain and enjoy family relationships and that staff respect patient's privacy and life choices, so long as they do not interfere with the rights of others.

1.4.5 Protecting Service Users' Rights

The MHA contains a significant number of safeguards to prevent the misuse of the act, to protect people's rights, and to enable people to challenge the use of the Act (Barber et al., 2016).

1.4.5.1 Information and understanding

Section 132 requires hospital managers to ensure that people who are detained under the MHA receive information about the legal basis for detention and their right to challenge it, as soon as practicably possible. Staff must also remind service users of their rights and check that service users understand the effects of the MHA. This enables service users to understand how the MHA will affect them, encourage them to be involved in their care and discuss any concerns with staff (Department of health, (DOH), 2015). Although not subjected to the MHA, voluntary service users must also have their rights explained to them.

1.4.5.2 The nearest relative

Section 11 of the MHA requires approved mental health practitioners to inform or consult a person's nearest relative where "practicable" or "reasonably practicable" when considering the use of section 2 (application for assessment), section 3 (application for treatment) or section 7 (application for guardianship). Under Sections 2 and 3, the nearest relative is able to request for their relative to be discharged, however this can be stopped by the responsible clinician.

1.4.5.3 Mental health review tribunal (MHRT)

The MHRT is the principal mechanism in England and Wales for appeal against the use of the MHA's powers of detention, guardianship or supervised community treatment orders. The MHA requires hospital managers to ensure that service users understand their rights to apply for a tribunal which can protect service users against inappropriately long hospital admissions (Wood, 1993). Tribunals provide particular detained service users with legal rights to challenge their detention, which is enshrined in the ECHR (Article 5). They have the power to uphold detention and discharge service users from detention, and the power to make a number of recommendations for service users on treatment orders.

1. 4.5.4 Hospital managers

Section 23 of the MHA gives hospital managers the powers to discharge detained service users and service users on community treatment orders. Service users are permitted to apply for a manager's hearing in addition to a tribunal. An application to a manager's hearing provides particular detained service users with legal rights to challenge their detention, which is enshrined in the ECHR (Article 5).

1.5.5.5 Second opinion appointed doctors (SOADs)

SOADs safeguard the rights of service users detained under the MHA who either refuse treatment or are considered incapable of consenting by providing independent medical views and assessments of service users' capacity to consent to treatment to review the continuation of treatment. In 2017-18 SOADs carried out 14,503 visits to review service users' treatment plans (CQC, 2018c). The MHA requires that SOADs consult with two persons who are professionally concerned with the service user's treatment; a nurse and a non-registered medical practitioner. An audit of ECT in England between 2011-2015, however, found that six trusts were not using the correct selection of professionals to provide second opinions, a breach of section 58A of the MHA (Read et al., 2018).

1.4.5.6 Independent mental health advocates (IMHA)

IMHA services were introduced in England and Wales in 2007 to safeguard rights of eligible service users and promote self-determination. IMHAs ensure that service users understand their rights, the rights of others (for example nearest relative), any conditions placed upon them and what treatments can be given to them. Advocates are independent of the care team and are concerned with the care and treatment of the service users.

1.4.5.7 The Code of Practice

The Code of Practice (DoH, 2015) provides statutory guidance to mental health professionals to inform their practice, safeguard service users' rights and ensure compliance with law. Its core objective is to help people who are detained or subject to the MHA by outlining how mental health professionals should carry out functions under the Act. Enshrined in the Code of Practice are five overarching principles which should be considered when making decisions with regards to treatment, care and support provided under the Act. These principles promote independence and recovery, maintain that service users should be fully involved in decisions about their care and emphasise the need for service users to be treated with respect and dignity.

1.5 Literature Review: Voluntary and Involuntary Service Users' Experiences of Psychiatric Inpatient Wards

This section aims to synthesise existing research on peoples' experiences of inpatient wards. To understand experiences of psychiatric inpatient wards related to current legislation and practice, the search concentrated on studies that were conducted in England and Wales.

1.5.1 Search Strategy

A systematic database search was conducted to identity studies that explored services users' experiences of voluntary and involuntary psychiatric inpatient admission and treatment. The search was conducted using PsychINFO, PsychArticles, Academic Search Complete, and CINAHL Plus via EBSCO. The search concentrated on academic journals published between 1990-2019 as papers identified were likely to reflect experiences of psychiatric inpatient wards related to current legislation and practice. Two different search criteria were used. The following search terms were used with Boolean operators AND and OR to detect studies exploring service users' experiences of psychiatric admission: mental health act, detention, legal detention, coercion, compulsory detention, forced treatment, involuntary treatment, inpatient, psychiatric hospital, patient, service user, survivor, experience, views, satisfaction. To maximise identification of studies relating to service users' human rights, the following search terms were also used with Boolean operators AND and OR: human rights, civil rights, mental health act, detention, legal detention, coercion, compulsory detention, forced treatment, involuntary treatment, inpatient, psychiatric hospital. Further papers were identified using Google Scholar as well as the reference lists of the relevant papers identified in the initial search. Appendix A outlines the limiters, inclusion and exclusion criteria that were used, together with the number of studies identified. In addition to peer reviewed studies, it was felt grey literature, such as reports conducted by the government and mental health charities, would be a useful source of information, facilitating a more comprehensive understanding of the topic area. Relevant grey literature was found by searching relevant charity (e.g. Mind) and organisations websites (e.g. CQC).

1.5.2 Search Results

A total of 36 studies were identified as relevant for the study; relevance was defined as studies that explored aspects of voluntary and involuntary admission and treatment, such as service users' experiences of therapeutic relationships, coercion, safety and involvement in decision making. Twenty-nine studies used qualitative methods, six studies adopted quantitative methods, and one study used mixed methods. Within the grey literature, a total of four surveys and four reports were identified as relevant.

1.5.3 Quality of Relationships

Fifteen papers generated themes about service users' relationships with staff; ten identified both positive and negative experiences with staff, while five only found negative experiences. Treating service users with dignity and respect are enshrined in human rights framework (Universal Declaration of Human Rights, 1948; CRPD, 2006) and are fundamental principles that underpin the Code of Practice (DoH, 2015). It is, therefore, important to understand service users' experiences of therapeutic relationships on inpatient units.

The majority of studies reported staff to be punitive, coercive, uncaring, dismissive, disrespectful, infantilising (Goodwin, 1999; Hughes et al., 2009; Rose et al., 2015; Seed et al., 2016; Stewart et al., 2015) or unable to understand their experiences (Cheetham et al., 2018; Secker & Harding, 2002), which led some participants to feel devalued (Chambers et al., 2014). In two studies, participants detained under the MHA expressed concerns that communication with staff centred around rule enforcement rather than therapeutic engagement, and felt staff prioritised procedures rather than the individual needs of service users (Hughes et al., 2009; Stewart et al., 2015). In addition, participants described an "us and them" attitude whereby staff used their power and position to humiliate, embarrass and discriminate against service users, leaving them feeling disempowered (Barnes et al., 2000) distressed, persecuted and betrayed (Loft & Lavender, 2016). In another study, participants described feeling intimidated, felt they were not listened to or understood, and felt staff were unavailable and unwilling to help them when they felt threatened by other service users, resulting in feelings of helplessness (Wood & Pristring, 2004). These accounts are consistent with evidence that shows service users in psychiatric inpatient units are often not treated with dignity or respect (CQC, 2019; Mental Health Alliance, 2017; Hearing Voices Network (HVN), 2018).

In three studies, relationships with staff were central to participants' experiences. Participants who described staff as threatening, untrustworthy and unavailable, rated their experiences more negatively, whereas participants who felt genuinely cared for had an overall positive experience of their admission (Chevalier et al., 2018). Moreover, relationships characterised by good communication, respect, sensitivity to culture, and non-coercive practices, were key to a satisfactory experience of admission (Gilburt et al., 2008; Katsakou et al., 2011). A lack of trust, poor communication and the use of coercion, on the other hand, were barriers to positive relationships with staff (Gilburt et al., 2008; Katsakou et al., 2011).

Instances of kind and compassionate care were evident in five studies, suggesting a small minority of service users experience respectful and dignified therapeutic relationships with staff. In these studies, some participants reported feeling cared for and believed they received a high standard of care (Hughes et al., 2009). Participants described having positive relationships with staff when staff listened, were empathic and treated service users equally and non-judgementally (Seed et al., 2016). Furthermore, service users reported being treated as an individual person, not just in terms of their clinical characteristics, which they felt facilitated their recovery (Goodwin, 1999; Stewart et al., 2015). Secker and Harding (2002) explored the inpatient experiences of twenty-four African and African Caribbean service and found that whilst the majority of service users described having poor relationships with staff, some felt staff took the time to help them understand the difficulties they were experiencing.

Important components of a therapeutic relationship were identified as staff's ability to listen and understand service users (Wood & Pistrang, 2004), a caring attitude, being positive about the future, being reliable and delivering on promises, which were fundamental in building trust (Laugharne et al., 2012). Factors that undermined trust included coercive treatments and over reliance on the medical model (Laugharne et al., 2012). In another study involving 59 involuntary service users, respect was consistently linked to the quality of relationships between service users and staff Valenti et al., (2014).

1.5.4 Involvement in Decision Making

Themes relating to participants' involvement in their treatment were identified in six studies. The involvement of service users in decision making is considered a fundamental aspect of healthcare (CQC, 2018b) and is emphasised in the Code of Practice (DoH, 2015). From a human rights perspective it relates to, but is not limited to, the principle of autonomy.

The majority of participants described poor experiences of shared decision making. Participants commonly described feeling ignored (Chambers et al. 2014) and felt their views about treatment were disregarded (Seed et al., 2016), which contributed to them feeling a lack of control (Secker & Harding, 2002). In one study, participants viewed shared decision making practices as preserving autonomy, increasing a sense of safety and conveying respect, however, 92% felt they were not involved in decisions regarding their treatment (Valenti et al., 2014).

In two studies, participants highlighted the importance of being giving sufficient information to be able to make decision regarding treatment. Laugharne et al. (2012) found that information about treatment as well as previous experiences of involuntary treatment facilitated shared decision making. Whereas some participants wanted to actively engage with treatment, and viewed the sharing of power in shared decisions as a dynamic process, some believed they had no choice in their care, which was influenced by feelings of coercion. Participants' emphasised that their ability to make choices in their care increased with experience of being distressed and the effectiveness of past treatments. They felt that having knowledge and information gave them power to make decisions but that experience of their mental health difficulties made them more able to exert that power. Though the authors did not discuss this finding, perhaps participants felt more confident in their own decisions after a period of allowing the 'experts' to make decisions for them. Pollock et al. (2004) conducted focus groups with a sample of 90 service users, carers and mental health staff regarding service users concerns about the provision of medication on an acute on a psychiatric inpatient ward. The need for information reflected a desire to be able to understand and address their difficulties through informed choice and enhanced their ability to negotiate aspects of their care with staff. However, professionals, carers and service users agreed that service users were given little information or opportunity to discuss their medication. Service users felt they had little input into treatment decisions and reported not knowing what medication they were taking.

The evidence reviewed here is consistent with a recent report by the CQC which raised concerns regarding the lack of service user involvement in decision making and found that advance decision making was not used routinely or considered binding (CQC, 2019). It is also consistent with findings from a recent survey which found that 65% of respondents felt staff did not ask for their opinion (HVN, 2018). These issues were raised in a CQC report ten years ago which found that only half of service users felt that they were always listened to by their psychiatrist and were given the opportunity to discuss their care (CQC, 2009).

1.5.5 Experiences of Coercion

In nine studies, the relationships between coercion and service users' experience of voluntary and involuntary treatment were highlighted. Coercive practices include physical restraint and forced medication to more subtle forms of coercion, such as perceived threat of punishment or force (Gilburt et al., 2010; Lloyd-Evans et al., 2010 Lützén, 1998).

Perceived coercion was present in both voluntary and involuntarily admissions. Sheehan and Burns (2011) interviewed 164 service users and found that 47% of voluntary and 89% of involuntary service users reported high levels of coercion. Katsakou et al. (2012) explored service users' views on their experiences of involuntary admission in a sample of 59 service users and found that 68% were exposed to coercive measures, such as restraint, seclusion or forced medication. In another study, Katsakou et al. (2011) measured rates of perceived coercion in 270 voluntary service users and found that 34% felt coerced into admission and continued to do so a month later. These figures are similar to those reported by Bindman et al. (2005) who found that 33% of voluntary service users felt coerced into their hospital admission. Many voluntary service users felt coerced into hospital and to accepting unwanted treatment out of fear of having their autonomy restricted by being detained under the MHA (Gilburt et al., 2008; Katsakou et al., 2011), which contributed to negative attitudes towards psychiatric services (Rogers, 1993).

Whilst some participants viewed coercive practices as necessary in some situations, they also acknowledged the adverse physical and psychological consequences for those subjected to them (Chambers et al., 2014). Many participants experienced coercive interventions as distressing and frightening, which contributed to feeling out of control (Katsakou et al., 2012). Seclusion, restraint and forced medication, evoked high levels of fear amongst service users and were a particular source of distress (Seed et al., 2016), causing some service users to feel dehumanised (Hughes et al., 2009). Some compared these measures to being assaulted or violated and felt they had been used as an unnecessary response to feelings of anger caused by being locked up and unable to access fresh air (Rose et al., 2015).

Katsakou et al. (2010) found that treatment satisfaction among involuntary service users was associated with perceptions of coercion during admission and treatment. Service users who perceived less coercion were more satisfied with their treatment. In a subsequent study by Katsakou et al. (2011), participants acknowledged that they had mental health difficulties and needed support regardless of whether they felt coerced during their admission into hospital.

However, whereas participants who did not feel coerced believed that they were a risk of harming themselves before their admission and valued being able to recover in a safe place, the majority of service users, who felt coerced, viewed their hospital treatment as ineffective or believed alternative treatment would have been more beneficial.

1.5.6 Quality of Environment

Twelve studies constructed themes relating to the quality of the environment. From a human rights perspective, these relate to the safety, security and the physical and mental integrity of service users, the right to the highest attainable standards of physical and mental health, and the right to non-discrimination.

In some studies, participants viewed their admission as a place of refuge, describing it as non-judgemental, accepting and safe, which facilitated recovery (Barnes et al., 2000; Fenton et al., 2014; Seed et al., 2016). In others studies, participants described their experiences as chaotic and unsafe (CQC, 2009; HVN, 2018; Fenton et al., 2014), reporting incidents of verbal and physical abuse, and sexual harassment (Valenti et al., 2014; Mind, 2004; Wood & Pistrang, 2004). This is consistent with a report published in 2018 which found that over a third of NHS Trusts were rated as needing to improve in relation to providing a safe environment for service users (CQC, 2018b).

In seven studies, participants compared their experiences to that of imprisonment (Barnes et al., 2000; Chambers et al., 2014; Chevalier et al., 2018; Fenton et al., 2014; Gilburt et al., 2008; Goodwin, 1999; Rose et al., 2015). Unjust restrictions on freedom, feeling powerless and having little autonomy were commonly described by service users in these studies. In two studies, a lack of privacy, autonomy, constant supervision and having to negotiate all wants and needs had an adverse effect on service users' sense of dignity (Valenti et al., 2014; Wood & Pistrang, 2004) and increased service users' feelings of anger and paranoia towards staff, resulting in increased levels of aggression (Barnicot et al., 2017). Three studies reported the experiences of racism which was experienced directly and indirectly, in the form of racial insults, and more subtly such as staff lacking cultural competency and being stereotyped as being violent (Gilburt et al., 2008; Jones et al., 2010; Secker & Harding, 2002).

1.5.7 Service Users’ Views of Human Rights Issues

In four studies, participants talked about their experiences in terms of being deprived of their human rights. Three constructed themes relating to participants’ lack of freedom (Gilburt et al., 2008; Loft & Lavender, 2016; Valenti et al., 2014) and one constructed a theme relating to invasion of privacy (Barnicot et al., 2017). Concerns included not being able to leave the ward (Gilburt et al., 2008) being forced to comply with treatment decisions (Loft & Lavender, 2016), not being involved in treatment decision (Valenti et al., 2014) and a lack of privacy due to constant observations (Barnicot et al., 2017).

These findings are consistent with recent surveys. Analyses conducted by the CQC found that human rights-based principles are not always being applied to the care and treatment of detained service users (CQC, 2019). A small service user survey of 23 participants showed that 39% believed staff did not respect their human rights and 70% believed their human rights were not respected by staff who placed them under section (HVN, 2018). In a survey of 8000 service users, carers and professionals, 40% disagreed that people are treated with dignity under the MHA and 72% disagreed that the rights of service users are protected and enforced as effectively as those of people living with a physical illness (Mental Health Alliance, 2017). Though results from these surveys are of value, they are limited in their depth of understanding of service users’ experiences and views of human rights issues on inpatient wards.

1.5.8 Information and Understanding of Legal Rights

Six studies were identified that explored service users’ awareness and understanding of their legal rights. Themes relating to information about service user rights were constructed in five studies that explored service users’ experiences of psychiatric inpatient units.

The literature review indicates that many service users do not have their rights explained to them at the point of detention, or in the right format and at appropriate intervals. In one study, the majority of participants could not recall receiving any information regarding their legal rights, such as their right to appeal and right to IMHAs (Banks et al., 2016). In four studies, participants believed the information they received for their hospitalisation and about their rights was inadequate (Barnicot et al., 2017; Fenton et al., 2014; Katsakou et al., 2012; Marriott et al., 2001). A lack of information about the reasons for being detained and being excluded from decision making contributed to feeling powerless and increased distress (Chevalier et al., 2018; Fenton et al., 2014).

Four studies highlighted gaps in service users' awareness and understanding of their legal rights. In a sample of 117 voluntary service users, only 57% believed they were legally allowed to leave hospital and 47% believed they had the right to refuse treatment (Sugarman and Moss, 1994) More recently, Lomax et al. (2012) found, in a sample 105 participants, that 90% of voluntary service users were aware of their legal status, while only 60% of involuntary service users knew their legal status. Of the voluntary service users, 39% felt that they had their rights explained to them, 33% had been given a leaflet about their rights and 67% knew they could refuse treatment. Of the involuntary service users, 61% felt they had been informed of their rights and 50% said they were given a leaflet explaining their rights. Ashmore and Carver (2017) reviewed information given to voluntary service users in 61 NHS Trusts and found that only 44% of services provided written information regarding voluntary service users' rights. They also reported inconsistencies in information regarding discharge, freedom of movement and the right to refuse treatment.

Galappathie and colleagues (2013) interviewed 65 service users detained under the MHA and found that only 21% were aware they could request a tribunal via clinical staff, 55% were aware they could request a tribunal via solicitor, and 2% were aware they could request a tribunal via the MHA office, indicating a lack of knowledge about the tribunal process. Nonetheless, 78% of participants were aware of the powers of tribunal to discharge and 69% were aware of at least one method of initiating a request for a tribunal, suggesting that efforts to ensure that service users understanding their right to appeal vary. Similarly, Dolan, Gibb and Coorey (1999) report a significant lack of knowledge and understanding of the tribunal process in service users in a high-secure hospital. More recently, a report found that a lack of explanation of the tribunal process, limited access to reports, which are used as part of the evidence upon which the tribunal base its decision, delays in the hearing, and a lack of lack of private spaces to talk with lawyers contributed to negative experiences (CQC, 2011).

One study raised concerns about the provision of information regarding IMHAs; participants were not always aware that IMHAs services existed and when they were aware, chose not to use them because of a lack of understanding of the services they provided (Newbigging et al., 2015). There were also concerns about gaps in service provision for BAME groups (Newbigging et al., 2015). In addition, a recent report highlighted that advocacy services are not as fully available and responsive as service users had hoped for and have concerns over the quality of advocacy (CQC, 2019).

Contrary to the evidence presented thus far, a recent report found improvements in the information given to service users regarding their legal rights (CQC, 2019). It found that 94% of case notes reviewed showed evidence of service users being provided with information about their rights in an appropriate format. In addition, 85% of case notes reviewed showed further attempts to explain rights and 93% showed evidence of discussions about rights and assessments of the service users' level of understanding of them. These findings, however, are based on audits of case records written by staff and fail to capture service users' actual awareness and understanding of their rights.

1.5.8 Literature Summary

The studies reviewed here highlight positive and negative aspects of psychiatric inpatient treatment both within and between studies. In the majority of studies, participants describe a lack of autonomy and participation in decision making, experiences of coercion, feeling devalued, unsupported, terrified, traumatised and disempowered, and view treatment as inadequate and inappropriate. Positive aspects of psychiatric inpatient treatment included feeling respected and cared for and viewing hospital as a safe space for restoration. In addition, independent reviews of the MHA have highlighted consistent concerns about the provision of information, safety, dignity and service users' involvement in care planning. There are also consistent concerns regarding service users understanding of their legal rights, including the role of mental health review tribunals, which acts as an important safeguard to protect service users' rights to challenge their detention. The review also highlights the paucity of studies exploring service users' views on how their human rights are respected during inpatient admissions. Whilst the studies presented in the review can be interpreted through a human rights lens, for example in their relationship to the right to liberty and security and the right to be free from inhuman and degrading punishments, they do not explore service users' experiences of human rights issues in depth, and therefore provide a limited understanding of how service users' human rights are respected from a service user perspective.

1.6 Rationale and Aims

The current study seeks to extend our understanding of how service users experience psychiatric inpatient wards with a particular focus on their experiences of how their human rights are respected. It is important to note that the study does not focus on what actually happened - were participants' rights respected or not, but explores participants' experiences of what happened. This is pertinent since human rights are of paramount importance to mental healthcare. Having greater knowledge of this topic area might contribute to improving existing policy and practice, and reduce or ameliorate the potential negative effect of their use, which will ultimately improve the experience of people admitted onto inpatient wards.

1.7 Research Questions

The study focuses on participants' views of how staff respected their rights under the MHA, which includes some human rights. Three research questions were addressed:

1) What are voluntary and involuntary inpatient service users’ experiences of staff respecting their rights under the Mental Health Act?

2) What are voluntary and involuntary inpatient service users’ experiences of being informed about their rights under the Mental Health Act?

3) What impact do these experiences have on voluntary and involuntary service users?

2. METHOD

2.1 Overview of Chapter

This chapter discusses the epistemology, methodology, and method used in this study to address the research questions.

2.2 Epistemological Considerations

Epistemology considers how we can know what we know and the degree to which our knowledge is reliable (Harper & Thompson, 2011). Willig (2012) identifies three epistemological frameworks: realist, phenomenological, and social constructionist. These frameworks are differentiated by the extent to which data is seen as mirroring and reflecting reality, which lies along a continuum from relativism to realism (Harper, 2011). A critical realist position assumes the existence of an objective reality that exists independently of our knowledge or perception of it which can be known more accurately through scientific research (Archer et al., 2013; Bhaskar, 2013) . However, critical realism acknowledges that knowledge is subjective, discursively bound, and constantly changing (Vincent & O'Mahoney, 2018). Therefore, despite its ontological realism, critical realism allows for a degree of epistemological relativism (Smith, 2006). From a critical realist position, research participants do not need to be consciously aware of what processes are influencing their experiences and therefore data needs to be interpreted 'in order to further our understanding of the underlying structures which generate the phenomena we are trying to gain knowledge about' (Willig, 2008; p.70).

This study adopted a critical realist epistemological position. There was an assumption that there is a 'real' world in which physical structures, social structures and psychological processes exist, and that these exist independent of the researcher's own perceptions, theories and constructions (Willig, 2016). It was also assumed that these structures and processes could be identified and described by the researcher. This position was adopted as it was felt necessary to acknowledge that a 'reality' existed in which research participants have lived experience of distress and of voluntary and involuntary treatment on psychiatric inpatient wards, whilst also recognising these experiences were influenced by psychological processes, social factors and cultural interpretations. Pilgrim and Bental (1999) argue that critical realism is a useful framework for advancing our understanding of mental health difficulties because it “respects empirical findings about the reality of misery and its multiple determinants but does not collapse into the naive realism of medical naturalism” (Pilgrim & Bental, 1999; p. 271).

2.3 Methodology

2.3.1 Design

This study employed a convergent mixed method design. This involved gathering different but complementary data on the same topic to address the research questions (Morse, 1991). In contrast to using a single approach, mixed methods can maximise the strengths of different approaches (Johnson & Onwuegbuzie, 2004) revealing the varied dimensions of a topic (Jick, 1979). This enables researchers to gain a richer and more complete description of a phenomenon being studied (Fielding & Fielding, 1986; Murphy, 1989; Patton, 1990; Yardley & Bishop, 2008). Integration of qualitative and quantitative methods occurred at the data collection phase. This involved embedding a brief 10-item questionnaire within a semi-structured interview in order to enrich the views of the sample participants (Morse, 1991). This is known as a concurrent nested model, where data is collected in one phase of the study, during which quantitative and qualitative data are collected simultaneously (Creswell, 2003). In contrast to the traditional triangulation model, a nested model approach has a principal method that guides a study. The researcher then synthesises the data collected from these methods during the analysis phase to capture a more complete and holistic understanding of the research question (Creswell, 2003). In the current study, a qualitative approach (i.e. semi-structured interviews) was considered the principal methodology, while quantitative methods (questionnaire) was considered an adjunct.

2.3.2 Rationale for Mixed Methods

Qualitative methodologies are considered an appropriate method to explore, understand and portray the experiences and actions of people (Willig, 2008). It aims to create a rich understanding of the phenomenon of interest by giving voice to the perspective of the people being studied. Quantitative methods are commonly used to examine service users' experiences in healthcare systems (Coulter et al., 2009). They offer an objective means of collecting information about service users' belief, attitudes and behaviour (Bartlett, 2005; Oppenheim, 2000). Quantitative methods can also compare experiences of different service user groups in different services and monitor changes over time (Cleary, 1999). Using both approaches was considered advantageous for the proposed study as it enabled the topic of the MHA and human rights to be examined through different but complimenting lenses: one that explored participants' views of how their human rights were considered and the impact this had on them, and one that obtained quantifiable information about participants' knowledge and understanding of their human rights, as well as their beliefs and attitudes towards their experiences, and to compulsory detention more broadly.

2.3.3 Rational for Thematic Analysis

Thematic analysis (TA) and interpretative phenomenological analysis (IPA) methods were considered for data analysis. Phenomenology is concerned with the subjective meaning of personal experience (Smith et al., 1999), and IPA aims to understand participants' experiences of reality, in detail, in order to gain an understanding of the phenomenon in question (McLeod, 2001). Interpretative phenomenological analysis would have been useful if I had wanted to examine the personal lived experience of service users' voluntary and involuntary treatment, and interpret the sense they made of their experiences (Pietkiewicz & Smith, 2014). However, the primary aim of interviewing service users was not to make interpretations of what they said; it was to capture what participants had to say about their experiences of how their rights under the MHA, including some human rights, were respected. Thematic analysis, on the other hand, aims to explore "the specific nature of a given groups conceptualisation of the phenomenon under study" (Joffe, 2012, p. 212), which is in keeping with the study's main aims. Therefore, this method was deemed the most appropriated to use in this study.

Thematic analysis is “a method for identifying, analysing and reporting patterns within data. It minimally organizes and describes your data set in (rich) detail” (Braun & Clarke, 2006, p. 79), and is compatible with a critical realist epistemological position (Willig, 2013). The process of TA involves searching across the data set to distinguish repeated patterns of meaning, or themes (Braun & Clarke, 2006). Thematic analysis can focus on different types of meaning; manifest or interpretative. The manifest level reflects the information that is directly observable, for example the explicit content of what a participant has said. The interpretative level, on the other hand, reflects the interpretations the researcher has made, for example about what a participant has said. Given the study’s critical realist epistemological position, both observable patterns of meaning and those influenced by underlying phenomenon were considered. This enabled the generation of themes which concerned both explicit and implicit content (Joffe, 2012). In keeping with a critical realist epistemology, the aim of analysis was to focus on participants’ experiences rather than their views of an objective reality.

Within TA, themes can be generated from either a data-driven (inductive) approach, or a theory-led (deductive approach). An inductive TA aims to arrange and describe data “without trying to fit it into a pre-existing coding frame” (Braun & Clarke, 2006, p. 83). Therefore, themes that emerge from inductive analysis are grounded in the data and do not reflect the researcher’s theoretical commitments. Deductive TA, on the other hand, comprises mapping data onto preconceived themes based on theory or existing knowledge.

Joffe (2012) proposes a dual deductive-inductive approach which enables the researcher to approach the data set with an awareness of existing literature but also being open to new ideas and concepts, and thus avoids the repetition of previous research and facilitates the production of new knowledge in relation to the phenomenon being studied. Therefore, the current study utilised a combined inductive-deductive approach, with a particular emphasis upon a data-driven approach.

2.4 Researcher Reflexivity

In qualitative research, it is important for the researcher to engage in a continuous process of personal reflexivity which involves “reflecting on the ways in which our own values, experiences, interests, beliefs, political commitments, wider aims in life and social identities have shaped the research” (Willig, 2013, p. 9). Reflexivity in research is important as it improves transparency in the researcher’s subjective role in conducting research and analysing data, and increases the rigour and quality of the research (Jootun et al., 2009; McCabe & Holmes, 2009; Smith, 2006) as well as the creditability of the research findings (Gilgun, 2006).

It is, therefore, important to reflect on my position as a Trainee Clinical Psychologist and how my experiences, beliefs and interest in this topic may have shaped this research. I am a 32-year-old male who identifies as Indian British. My experience of clinical psychology training has been underpinned by a critical approach to distress. Rather than focus on individual pathology, the role of context has been discussed extensively throughout my training. More recently, experiences of training have been underpinned by a human-rights based approach, which has resonated with me.

I have worked in the field of mental health since 2011, and through these experiences have formed ideas about what is helpful and less helpful practice when people are in distress. Whilst recognising the importance of having a law that enables vulnerable people to access and receive support that they might not otherwise receive, I am of the view that the use of force and coercion is unhelpful and harmful unless in extreme circumstances. My experiences have also led me to value peoples’ understanding of their own distress more than reductionist, medical conceptualisations.

Working as a Trainee Clinical Psychologist in the NHS, I recognise that I participate in a system that uses coercive practices to ensure people adhere to treatment that they may not otherwise choose. During my first-year placement, I worked on an acute inpatient ward and witnessed a number of coercive practices and saw first-hand the impact these practices had on service users. Upon completing my undergraduate degree, I worked as a graduate mental health worker on an acute inpatient ward. In this role, I was both witness to and involved in coercive practices, including: restraint, seclusion and depot medication. These experiences haunt me and I am often filled with guilt, anger and regret when reminded of them.

All these contexts may have influenced how I participated in conversations with individuals I interviewed, how I subsequently made sense of the conversations and transcripts, and played an important role in the design of the study. This is discussed further in section 4.3.2.

2.5 Ethical Considerations

2.5.1 Approval

Ethical approval was granted by the University of East London Ethics Committee (see Appendix B). The main ethical issues were consent, confidentiality and potential distress to participants as a result of discussing their experiences. All participants were informed that they could stop the interview or take a break at any time if they would like to. The interview schedule (see Appendix C) was created so that participants only shared what they wanted to, and therefore the risk of emotional distress was considered to be low. I was also able to offer participants contact details for appropriate organisations where they could access support to should they have wished to. None of the participants became upset during the interviews or needed any after-care.

2.5.2 Informed Consent

All potential participants were given an information sheet and a consent form (see Appendix G) prior to verbally agreeing to take part in the study. In addition, the researcher explained the nature, purpose, and aims of the current study to potential participants. Potential participants were given opportunities to ask the researcher further questions with regards to participating prior to agreeing to take part in the study. Participants were provided with an information sheet to review again and the opportunity to ask further questions at the interview site. Participants were then provided with a consent form (see Appendix D) to sign. All participants were informed they could withdraw from the study before April 2020, at which point data analysis would have begun. A thorough explanation of the present study was provided once the interview was complete.

2.5.3 Confidentiality

The limits of confidentiality, with regards to risk and safeguarding concerns, were made clear before each interview. Participants were aware that interviews would be audio recorded and that I would be transcribing them verbatim. All data was anonymised. Participants were aware that transcripts might be read by my research supervisor and examiners, and that anonymised extracts would be included within the final write-up of the research and future publications. Identifying data such as consent forms were kept securely and separately from all other material related to this study in accordance with the Data Protection Act (1998). All electronic data was held on a password-protected computer within password-protected files. Participants were informed that following examination and award of the doctorate, the audio-recordings would be destroyed and that anonymised transcripts would be held securely for five years' post submission.

2.6 Recruitment Procedure

Participants were identified using volunteer sampling. Two recruitment strategies were used. Mental health service user led organisations were identified as being a suitable place for recruitment. Three organisations were contacted (see Appendix E) and agreed to advertise the study online. In addition, to reach a larger audience, the study was advertised on social media. The advert (see Appendix F) described the study and interested persons were asked to contact the author via his university email address. Forty people enquired about the study and were all emailed an information sheet (see Appendix G). Two people decided not to participate. Three people did not meet criteria for the study. Twenty-two people did not respond to further correspondence. Thirteen people wished to arrange a mutually convenient time and location to conduct the interview.

2.6.1 Inclusion Criteria

All participants had to have been a voluntary or involuntary mental health service-user aged between 18 and 65 years after the implementation of the MHA (1983).

2.6.2 Exclusion Criteria

Due to restrictions of time and resources mental health service users who were not fluent in English were unable to participate in the study as it was not possible to have an interpreter present during the interviews.

2.7 Participants

A total of 13 people who had experienced admission to a psychiatric inpatient unit in England were recruited. Eleven had experience of being detained under the MHA. Seven were men and six were women; six identified as White British, one as White Canadian, one as White European, two as Black British, one as Asian, one as British Pakistani, and one as White Mixed. Their age ranged from 20-65 years. Collectively, participants had had inpatient stays in over 10 different hospitals in England and comprised both service users who had had multiple admissions over several years and those who had few inpatient admissions.

2.8 Data Collection Procedure

2.8.1 Interviews

Interviews have been described as conversations that capture the interviewee's perspective on a given topic (Kvale, 1996) and are a commonly used method of data collection with social sciences (Edwards et al., 2014). This study employed a semi-structured interview method (Bartholomew et al., 2000). During the process of semi-structured interviews, questions act as triggers that encourage participants to generate their own responses (Willig, 2013). Semi-structured interviews allow the researcher to stay close to their main areas of interest, while also being inquisitive and asking follow up questions in order to magnify the interviewee's responses (Rubin & Rubin, 2005). Therefore, semi-structured interviews enable a deeper understanding of the interviewees' perspectives (Rubin & Rubin, 2005) which is in keeping with the current study's overarching aim.

2.8.2 Developing the Interview Schedule

The interview schedule (see Appendix C) consisted of a few broad, open-ended questions, followed up by questions that encouraged a more detailed discussion about the topic of interest (Bartholomew et al., 2000). The aim of the interview schedule was to facilitate an exploration of participants' views of how their rights under the MHA, including some human rights, were respected; how participants were given information about their rights under the MHA; what information they were given about their rights under the MHA, participants understanding of their rights under the MHA; what they considered to be the effects of these experiences; what they felt had been helpful in managing these experiences; and what they felt could be done different. As data generation and initial analysis progressed, minor amendments were made to the interview schedule to ensure all pertinent issues were explored.

2.8.3 Questionnaire

Morse (1991) highlights the usefulness of primarily qualitative designs embedding some quantitative data in order to enrich the description of the sample participants. Questionnaires can be used by researchers as a strategy in which participants self-report to express their attitudes, beliefs, and feelings towards a given topic (Tashakkori & Teddlie, 2010). Questionnaires may be closed ended, open ended or both. Closed ended questionnaires are employed more frequently than open ended questionnaires because items with closes ended responses are more efficient to administer and analyse (Tashakkori & Teddlie, 2010). Qualitative interviews and closed ended questionnaires are commonly used for mixed method approaches (Creswell et al., 2003), and was deemed an appropriate approach to permit a more complete description of the participants.

2.8.4 Developing the Questionnaire

A brief 10 item questionnaire (see Appendix H) was co-developed with the author's research supervisor to capture the following: participants' attitudes toward their admission; participants' attitude towards compulsory detention; participants' understanding of their rights; and the information participants were given about their rights. Likert scales (Likert, 1932) were considered an appropriate method of measuring participants' level of agreement or disagreement with multiple items related to the topic area. In addition, dichotomous questions asking for either a yes/no answer were used.

2.8.5 Interview Process

Interviews were conducted in person (n = 6) and on Skype (n = 7). Interviews in person took place at an interview room in the University of East London. Before beginning each interview, all participants confirmed their understanding of what participating in the study entailed and were given an opportunity to ask questions or seek clarification. All participants were reminded that interviews would be audio recorded. All participants signed a consent form and were reminded about confidentiality and its limits. Interviews lasted between 45 and 109 minutes. The questionnaire was administered at the end of the interview process. Participants who attended an interview in person were reimbursed for their travel expenses with £10 Amazon vouchers after the completion of the interview. To develop rapport and increase the quality of the data, I used participants' language and repeated words or comments in their questions (Willig, 2013).

2.9 Data Analysis

In keeping with a critical realist epistemology, the focus of the analysis was on participants' experiences of what happened. One participant was omitted from analysis as they were unable to provide answers to the questions posed in the interview schedule. The remaining twelve participants' audio recordings were transcribed verbatim using a qualitative data analysis computer software package. The data was then analysed using Braun and Clarke's (2006) guidelines for Thematic Analysis. Both inductive (bottom up) and deductive (top-down) strategies were employed during analysis.

2.9.1. Phase 1: Familiarisation with the Data

Braun and Clarke (2006) propose that the researcher should immerse themselves in the data in order to become familiar with the depth and breadth of its content. I read and re-listened to the interviews at least five times and made notes on potential codes and patterns before formally beginning the coding process.

2.9.2. Phase 2: Generating initial Codes.

Codes identify a feature of the data that appears interesting to the researcher (Braun and Clarke (2006). NVIvo was used to systematically analyse and code the data. I kept some surrounding text around the codes to avoid losing context (Bryman & Bell, 2001). Individual extracts of data were coded for as many potential themes as possible.

2.9.3 Phase 3: Searching for Themes.

After all the data was coded and collated, the analysis progressed to the broader level of themes. This involved sorting different codes into potential themes and sub-themes, and then organising the relevant coded data extracts within the identified themes. I mapped out this process on paper to support my thinking (see Appendix K).

2.9.4 Phase 4: Reviewing Themes.

The internal homogeneity and external heterogeneity was assessed by reading and re-reading all the coded extracts within the themes and sub-themes multiple times to see whether they formed a coherent pattern (Patton, 1990). Where appropriate, amendments were made to the definitions of the themes, and the coded data included within them. The entire data set was re-read to code for any data that may not have been included during earlier stages, and the thematic map was refined accordingly. Examples of each theme, sub-theme and code were reviewed by my research supervisor until agreement as to what determined sufficient demonstration of an accurate representation of a theme became evident.

2.9.5 Phase 5: Defining and Naming Themes.

Themes were defined and further refined by analysing and organising the data within the themes, to create accounts of the data that were coherent and internally consistent. The validity of the themes was addressed by sharing examples of data extracts and their themes with my research supervisor. These were reviewed in terms of how relevant the extracts were, as well as how clear and meaningful the definitions of the themes were.

2.9.6 Phase 6: Writing the Report.

The final stage of the analysis consisted of writing up the report (see Results Chapter). Sufficient evidence of the themes within the data is provided by choosing extracts that were vivid and/ or captured the essence of the theme.

2.9.7 Independent Rating of Coding

To assess the reliability of themes and subthemes, and coding, thirty excerpts were blindly coded into the ten initial subthemes by an independent rater (the researcher's research supervisor). These 30 quotes comprised two from each of the ten subthemes (randomly selected) and an additional ten excerpts selected randomly from all the remaining quotes. This was to ensure that all themes were assessed, without the independent rater knowing how many quotes were from each subtheme. The independent rater had had no part, at this point, in the process of identifying and defining the themes and subthemes. He was given the name and definition of the themes and subthemes simultaneously with the 30 quotes. There were nine disagreements out of the 30 ratings representing an agreement rate of 70%. This translates to a kappa score (which allows for agreement by chance) of .67, which is in the "fair to good" range (.40-.75; Fleiss, 1981). The inconsistencies were resolved by discussion. The majority had resulted from one or other of the raters missing (or misunderstanding) some text; for example, missing information about participants' rights. During this process, instances of the researcher being over inclusive and missing secondary thematic categories were identified, which resulted in the further refining of subthemes These changes are discussed further in Appendices J-L.

3. RESULTS

3.1 Overview of Chapter

This chapter has two parts. The first section is related to the primary research questions: What are participants' experiences of staff respecting their human rights? What are participants' experiences of being informed about their rights? What impact do these experiences have on participants? It reports the thematic analysis of interviews conducted with 12 service users. The final section presents findings from the questionnaire participants completed during the interview process, concerning their knowledge and understanding of their rights, and their beliefs and attitudes towards their experiences and to compulsory detention more broadly.

Table 1: Overview of Participant Demographics

Pseudonyms	**Age Range**	**Gender**	**Ethnicity**	**No. of admissions**	**Experiences of involuntary detention**
Paul	55-65	M	White British	4	Yes
Sarah	35-45	F	Black British	10	Yes
Hilder	25-35	F	White Canadian	1	Yes
Lee	20-30	M	White British	1	Yes
Ekon	25-35	M	Black British	2	Yes
Lyra	45-55	F	White European	1	No

Julie	20-30	M	White British	9	Yes
Abhin	40-50	M	Asian	4	Yes
Claire	35-45	F	White British	20	Yes
Kabir	50-60	M	British Pakistani	4	Yes
Becky	30-40	F	White British	10	No
Simone	30-40	F	White Mixed	1	Yes

3.2 Section One: Thematic Analysis of Interviews

In this section, service users' perspectives of how their human rights were considered were analysed using Braun and Clarke's (2006) guidelines for thematic analysis. Using thematic maps (see Appendix K), five main themes, within four themes between two and five subthemes were identified. The themes are listed in Table 2 along with the number of participants whose responses were coded into those themes and subthemes. Some quotes were coded into more than one theme or subtheme.

Table 2: Themes and Subthemes

Themes (no. of participants)	**Subthemes** (no. of participants)
Deprived of Rights (11)	Restricted Freedoms (7) Stripped of Autonomy (9) Invasion of Privacy (8) Dignity and Respect (11) Equality and Discrimination (3)
Rights Upheld (8)	Respected and Valued (6) Maintaining Connections (5) Reasonable Adjustments (1) Privacy Respected (2)
Emotional Impact (8)	No Subthemes.
The Battle for Rights (12)	Staff have the Upper Hand (7) Fighting for Rights (10)
Information about Rights (12)	Left in the Dark (12) Sources of Information (11) Rights are not a priority (5)

3.2.2 Theme One: Deprived of Rights

This theme is concerned with participants' views on how staff respected their rights. The examples provided by participants covered a range of different experiences, including restrictions on liberty and autonomy, invasions of privacy, distress from untherapeutic relationships, degrading experiences in seclusion and during observations, and dietary restrictions. Eleven participants shared examples which have been divided into the following sub-themes: Restricted Freedoms; Stripped of Autonomy, Invasion of Privacy, Lack of Dignity, Equality and Discrimination. These are outlined below, accompanied with illustrative excerpts.

3.2.2.1 Subtheme one: restricted freedoms

This subtheme relates to the different ways participants believed their liberty was restricted, and was mentioned by seven participants. Participants, who had been detained under the MHA, spoke about their experiences as being an infringement of their human rights. Being forcibly removed from the community and placed into a locked environment adversely affected participants.

> *"I always referred to it as being deprived of my human rights, because that is what it felt like, you are locked in, physically, you are behind the locked doors, whether it is the door to your room or the door to the ward, you are locked in and you are not allowed to leave, and that was always the most, the biggest negative impact on me, because knowing I am not allowed, I am stuck here, I am deprived of my human rights, that's how I felt about it".*
>
> Hilder.

Participants spoke about their physical freedoms, such as being able to go outside or leave the ward, and their ability to attend to basic needs as being unreasonably restricted. Participants were often not able to utilise their leave due to inadequate resources, poor weather conditions or because staff were not motivated to escort them, which prevented them from accessing fresh air. Accessing fresh air was deemed important and, when restricted, contributed to participants' distress:

> *"…requesting to go out for fresh air and it being denied for something stupid, like the fact that it was raining, or the staff didn't have the right shoes on…. there were times where I was in hospital for weeks and weeks and weeks and weeks and weeks and weeks and weeks and weeks and weeks without ANY fresh air at all".*
>
> Becky.

> *"Like, for example, I should have had a right to fresh air, I should have had a right to do activities, I should have had a right to certain activities, but because over time I requested, it was like 'well we are short staffed', 'we are short staffed'… 'short staffed'".*
>
> Abhin.

Becky and Lyra compared their experiences to being in prison, which conjures up images of being confined and having few freedoms. Becky felt so distressed about being locked in that she escaped and walked around the car park:

> *"I was like a prisoner, I actually experienced the sectioning as being in prison…That is a common experience, this sort of, because your liberties are taken away, so you feel like being in prison and you actually have less rights than a prisoner".*
>
> Lyra

> *"We walked around like that a couple of times, I then sat on the grass outside the front door and he came and sat down near me and we sat in silence for a bit, then he said 'are you ready to go up?' And I was, and it was just like, he had such sort of sensitivity and for me as well it's like, that's all I needed, I just needed to not feel like a prisoner for about ten minutes and then I was ready to be a prisoner again".*
>
> Becky.

Claire illustrates how her freedom to attend to basic needs were restricted:

> *"You can't go for a shit without permission, you can't go to bed without permission, if you don't eat breakfast they want to know why, if you eat extra food at dinner they want to know why, if you haven't been to the toilet they want to know why, if you're going to the toilet too much they want to know why".*

Claire.

Participants also described how their liberties had been restricted, despite having informal legal status:

> *"I was like 'can I just go down to the shops and get a break and come back?' And they were like 'no you can't'. So, I was like 'fine can I go supervised?' And they were like 'no we don't have anyone to send off site because you are being supervised here' and that kind of really annoyed me because I was like you can't tell me that I can't leave if I am here on a voluntary admission, I should be allowed to just be able to go and if I come back I come back and if I don't it's fine".*

Ekon.

3.2.2.2 Subtheme two: stripped of autonomy

This subtheme relates to participants' experiences of being involved in decisions about their treatment, mentioned by nine participants. Overall, participants felt they were not included in decisions about their care and described being deprived of autonomy:

> *"But there were lots of things I found about being an inpatient very very frustrating; you are deprived of a lot of power and autonomy"*

Lee.

A lack of choice and involvement led some participants to feel as though they were being controlled:

> *"Yeah, not having choice, not feeling in control, things being done to me rather than I having choice about what should be done to me, assumptions*

> *being made about me just by my behaviour rather than someone really understanding my emotions".*
>
> *"It was very difficult to be independent or autonomous in a system where you are actually control by things, that are not in your control, like medication, like the entertainment system, not being able to do things, not having a place to express yourself, it was very difficult".*
>
> Abhin.

Participants felt that staff were overly paternalistic which impacted their ability to express and exercise choice. For instance, Ekon explains how he was not allowed to take his medication at his preferred time:

> "*I was like 'I take this medication and this one at the same time' and they are like 'no, you will take this one at 8 and then this one at midnight' and I was like 'yeah but then you have to get someone to wake me up at midnight just to take this medication, why can't you give it to me at 8, so I can go to bed, I am tired, I have had a horrible day' and they are like 'no, this is how it is".*
>
> Ekon

3.2.2.3 Subtheme three: privacy

This subtheme relates to participants' experiences of privacy, mentioned by eight participants. Participants commonly spoke of not having an area that safely provided privacy. There were often not enough private spaces for participants to meet friends and relatives on the ward, and whilst participants were able to use the ward phone to contact friends and relatives, they had to use it in the view of a staff member, which they felt did not offer enough privacy.

> *"I don't think there was ever much privacy or any sort of private life, even when I was in with visitors there wouldn't be someone in the room with me but there would be somebody sort of sitting in the corridor outside"*
>
> Lee.

Julie describes how staff contacted her mother without her permission, which could be interpreted as a breach of confidentiality:

> *"I wouldn't say my privacy was hugely respected - only once can I think of a staff member not entering my room when I asked them too, and they contacted my mother more than once when I had asked them not to".*
>
> Julie.

Hilder explained that her room was searched without good reason. This highlights the power differentials between staff and service users, and also suggests that staff do not always adhere to protocols.

> *"They once searched my room without any obvious reason or whatever, and I had actually just a few days before, or whatever, I read this section on their right to search, I don't know what it is called, and then after it occurred to me that, wait actually, they are not allowed to do that, you are not allowed to go through my stuff, you know".*
>
> Hilder.

Staff observations were experienced as a particular invasion of privacy and were deemed as unnecessarily restrictive by four participants:

> *"Well it is unnecessary and I think that staff watching you go to the toilet, shower, being in arms-length away from you while you are sleeping is a massive invasion of privacy".*
>
> Claire.

3.2.2.4. Subtheme four: dignity and respect.

This subtheme relates to participants' interactions and relationships with staff, losing basic freedoms, such as a lack of privacy and autonomy, and coercive and intrusive practices, which illustrates how human rights are interconnected. Excerpts from eleven participants were included in this section.

Participants described their relationships and interactions with staff as authoritarian, uncaring and neglectful, and two felt that staff misused their power and position to punish them:

> *"I mean I do really think there was a lot of staff who I came into contact with who I feel like they got off on their power and would really, they would sort of yeah pull rank and kind of just be constantly on the defensive about their decision making and their authority even if it is something as simple as you know me asking if they would open the toilet for me, which is again a kind of humiliating thing in a way to have to do all day every day, or telling them your feelings about a particular situation and instead of being met with compassion and warmth being met with a really stern".*

Becky.

Eight described staff as disrespectful:

> *"On the ward, it felt beyond disrespectful, when nurses would just flat out ignore you, I mean, I have no idea how many countless times I would have stood in front of the nurses' station knocking on the window and there were 4-5 people in there, and they flat out ignore you".*

Hilder.

Participants described wanting caring relationships with staff but were met with hostility and rudeness:

> *"I guess the response was not a compassionate response it was like 'oh this person is a nuisance' or 'go back to your room', I was sent to my room, I mean, you know, the thing is, and I needed to be pacing up and down because of the antipsychotics, I couldn't stay still, and to be sent to my room, like a five-year-old, you know, that is not dignity is it, or respect?"*

Lyra.

Three participants described the process of being admitted onto the ward as frightening and degrading:

> *"It was quite terrifying, it was quite uncomfortable and it didn't feel like a therapeutic environment, it felt more like being detained without any choice and it was also sometimes being devalued and not respected as a human".*
>
> Abhin.

Four participants felt like they were treated like animals:

> *"To be locked up, sometimes it's like, not necessarily just in inpatient contexts but some of these places of safety can feel like a zoo, you are behind the glass window and people stare at you from outside the nursing station, they refuse to talk to you and you are just there like knocking, you know, you are treated like a second-class citizen or something".*
>
> Hilder.

Participants described their experiences of seclusion and observations as degrading and dehumanising. These were particularly dehumanising when participants had to attend to personal needs in front of staff members:

> *"Even, like if you are in seclusion, not being allowed to go the toilet, having to, when, you know there is a perfectly good toilet just outside of the room, you know, having to defecate on the floor with staff watching you, is massively degrading".*
>
> *Claire.*

Claire believed that staff had become desensitised to service users being treated inhumanely:

> *"It is a massive power imbalance but I just think that is inherent in the system, again I don't think that is because you know most staff are set out to you know be judge, jury and executioner, but it just very matter of fact, they are there to do a job, there are time pressures, they are short staffed, they*

> *are governed by these policies and procedures and I am afraid they get so desensitised to this that caring and you know that genuine human connection, I don't think it is shocking for them to see a fellow human being locked in a room with only a mattress having to go to the toilet on the floor, that is not shocking for them".*

Claire.

3.2.2.5. Subtheme five: equality and discrimination

This subtheme speaks to participants' experiences of how their specific needs, relating to physical health and diagnosed disability, were considered. Three participants had specific dietary needs which were not always met:

> *"Sometimes you can't get soya milk and you have to get someone to bring it in or you have to wait a week for it to come. Because I am lactose intolerance so if I have milk I will go to the toilet a lot through the back end or I will get a cold because my body can't break down the lactose".*

Sarah.

> *"And with the diet, the dietary needs, for some people this is linked to religion, but in my case, it's linked to the fact that I have Crohn's disease, and I was supposed to have some kind of special effort, you know, to provide appropriate food, that never happened… eventually I had a flair up but I don't think it was just because of the food, I think it was the whole stress, but I mean they should have made an effort for that and they didn't".*

Lyra.

Claire has an autism diagnosis and describes how the ward did not make any reasonable adjustment to meet her autism needs:

> *"I think my sensory needs were not considered and that is part of the condition. I have a need to get proprioceptive feedback, so I have a need to run and pace, and that is not provided, like when I need to do that to modulate my sensory system to remain calm, they wouldn't let me go in the*

> *garden or they wouldn't let me go outside to use the court yard, and I think that again, is deliberately exacerbating my dysregulation and it's very uncomfortable for me, and that is one of the main things that was completely disregarded and complete misunderstood and just completely breaches my rights of any kind of reasonable adjustment with somebody with a registered disability".*
>
> Claire.

3.3.3 Theme Two: Rights Upheld

This theme is concerned with participants' experiences of their human rights being respected. Participants talked about their rights being upheld in relation to their privacy and family life and relationships and interactions with staff. In addition, one participants talked about reasonable adjustments being made. Examples were given of having private spaces to meet with people and felt supported to maintain connections with friends and family, feeling valued and cared for, and adjustments made to support one participant with an autism diagnosis. For clarity, these have been divided into the following subtheme: Respected and Valued; Maintaining Connections; Respecting Privacy; and Reasonable Adjustments. Excerpts from eight participants were included in this section.

3.3.3.1 Subtheme one: respected and valued

This subtheme relates to the positive interactions and relationships participants had with staff, mentioned by six participants. Participants described incidents of kind and compassionate care which made them feel respected and valued.

Becky's account below illustrates the importance of therapeutic relationships in reducing the negative impact of coercive and intrusive practices. She describes how staff acknowledged that what they were doing was harmful and felt valued when a staff member took the time to get to know her during a one-to-one observation. Paradoxically, these experiences left her feeling cared for:

> *"There were a lot of positive experiences during that admission and I really had a lot of love and respect for staff and they also had to do things to me that were traumatising, they often did it acknowledging that it was*

> *traumatising which was I think it was a helpful thing to do, they would talk to me about it after or their general interaction with me would be that I felt genuinely cared about by them".*
>
> *"I have been one 1:1 with staff members who were so much more sensitive, you know, or people who knew how to, you know, make me feel valued as a person, and interested in what I was doing, so if I did start doing some art work, they would be curious and they would want to know and would be supporting me with it, or engaging with me, or who would have the sensitivity to know when to back off and give me time to myself or who would come up with creative ways where they would still be watching me".*
>
> Becky.

Julie described occasions where she felt respected when staff listened and gave her space to express herself, while Lee valued staff who displayed empathy and treated him like an equal:

> *"I would say those who spoke to me when they saw me, asked me how I was that day and tried to help if I appeared to be struggling tried to do this. Staff who gave me time to express myself and didn't talk over me, and let me communicate in writing if I was struggling verbally, exhibited respect".*
>
> Julie.

> *"The best members of staff were very good at, I was going to say talking to me as a person, and I am not entirely sure what that actually means, but treating me as an equal, sympathising with the situation".*
>
> Lee.

3.3.3.2 Subtheme three: respecting privacy

This subtheme is related to experiences of privacy being respected, mentioned by two participants. Privacy was spoken about in different ways. Simone talked about privacy in the context of having a private space on the ward to be alone and to meet with an advocate:

> *"So, my privacy, when I went to see the advocate they left me on my own with that and there was another member, another lady would come along, so they gave me that choice I suppose, little bit of a window of choice to see someone and then someone would come and talk to me, and a lady from a charity".*
>
> Simone.

Ekon valued having a room to himself which he could retreat to at times when he wanted to be alone:

> *"We had a private environment, where you could say 'I am not coming out of my room today because I don't want to deal with all these other patients and I don't want to see them, I am just going to stay in my room, can someone bring food through to my room, I can't deal with those people', they would accommodate for that".*
>
> Ekon.

3.3.3.3 Subtheme four: reasonable adjustments

This subtheme related to one participant's account of staff making reasonable adjustments to accommodate her needs related to her diagnosis of autism:

> *"They have appeared to try harder doing things like changing my room when someone loud was put next door, passing me on my ear defenders from my mum, letting go of me when I told them to, letting me answer questions by writing instead of speaking in MDT meetings, sending a single staff member to deal with me when distressed as opposed to a whole load of them, informing me of meetings well in advance of them, sometimes weeks in advance, rewording questions when I haven't understood them or have found them too open to respond to, not asking me to rate my feelings on a numerical scale, which makes no sense to me."*

Julie.

3.3.3.4 *Subtheme five: maintaining connections*

This subtheme is related to experiences of being able to maintain connections with friends and family, mentioned by five participants. Participants felt supported to have visitors and were able to use the ward phone to contact friends and relatives.

> *"I suppose there was an underlying thing they were very good at allowing me visitors, allowing visitors to bring me things which really helped, I was very fortunate in that respect, and I think that is really what saw me through".*

Lee.

However, Julie highlights the inconsistencies in the ways she was supported to stay in touch with her family.

> *"I was allowed visitors and often leave out with family members too. Sometimes they gave me the ward phone in order to contact my mum, but sometimes they did not".*

Julie.

3.3.4 Theme Three: Emotional Impact

The third theme describes the negative impact of participant's experiences, mentioned by eight participants. Four participants talked about the impact of being subject to coercive and intrusive practices. Observations were carried out from a distance with little engagement with participants, causing participants to feel dehumanised. In addition, one participant said it made him feel more paranoid:

> *"What I found really frustrating and very dehumanising were the more regular observation, someone coming to see you every now and again".*

Lee.

> *"It just, made, it made everything really tiring. At first, I was really*

> *paranoid, because I was like I can't, I can't have any privacy, I can't do anything on my own, this is just, it's starting to bother me. Like [girlfriend] came to visit and we would just sit and chill and watch a film or something, and like they would be like peeping in and I would be like go away [laughs] just leave, can you not let me feel a little bit normal for once?".*
>
> Ekon.

A common experience for participants detained under the MHA was not being able to utilise their leave and being stripped of their autonomy which caused three participants to feel dehumanised, traumatised and hopeless:

> *"It made me crazy, it makes you crazy, it makes you unwell, it makes you sick even more, you feel like an animal locked in a cage".*
>
> Abhin.

> *"I really would say that the cumulative effect of being in a place like that is quite traumatising actually, and the daily grind, it was exhausting, the daily grind of asking for loos to be opened, of requesting to go out for fresh air and it being denied for something stupid, like the fact that it was raining, or the staff didn't have the right shoes on, the daily grind of being stuck in this tiny enclosed bubble or you know the frustration of not being able to totally be yourself and, you know, I think all of that is also accumulatively...wears you down".*
>
> Becky.

Participants also talked about the impact of being compulsorily detained. Being aware that they were unable to leave contributed to a feeling of having no control and as though they were being punished:

> *"I think you feel very isolated, you, you feel even more unfit to exist in this world, you feel very lonely, you know, even more lonely then the fact that you have been taking away from society. Eh and I think that that being locked away like that so far has a huge psychological impact, you know you can't leave those doors".*
>
> Claire.

> *"Once again it was very frightening to have this lack of control and it was frightening because it felt like I was in a prison, rather than a place of help, you know, I was being punished for something".*
>
> Simone.

Two participants described the impact that these experiences had on their sense of identity:

> *"I think it is disorientating, it adds to your sense of hopelessness, and you feel very unimportant and you feel a bit like a drain in society, it just reinforces those negative thoughts you have of yourself at a time where you are most vulnerable".*
>
> Claire.

3.3.5 Theme Four: The Battle for Rights.

This theme describes the challenges participants experienced in enforcing their rights. Participants described their rights as something that had to be negotiated and bargained for, and felt that the inequality in the relationship between service users and staff meant that it was a battle to ensure their rights were respected. All twelve participants spoke about this in different ways; the main sub-themes are outlined below with illustrative excerpts.

3.3.5.1 Subtheme one: staff have the upper hand

This subtheme describes the inherent power imbalances that participants experienced which made it difficult for them to enforce their rights and resulted in some participants being resigned to the experiences of having their rights infringed upon. In such cases, it was believed to be safer to comply with the ward team to avoid further coercive measures. This was commonly talked about by participants during voluntary admissions when they were told they could not leave the ward, but were also spoken about by participants detained under the MHA. Excerpts from seven participants were included in this subtheme.

Two participants described the powers that staff hold as outweighing their ability to enforce their rights:

> *"I suppose I have come to feel that staff always hold the upper hand, that as a patient you have rights in theory, but in practice they are incredibly hard to enforce, that staff can mistreat you however they want and get away with it, because they write your medical records, control who you can contact and when, can argue the issues are part of your mental health condition rather than due to their behaviour, they can take away your rights by sectioning you etc".*
>
> Julie.

> *"My understanding today is, even if you have got all them rights, you know, people that have power over you, can covertly do what they do, and, you know, make it difficult for you, make it challenging for you, because they have the power dynamic, and they are the hierarchy when it comes to power".*
>
> Kabir.

Complying with treatment decisions due to the threat of their rights being restricted further was a common experience for participants:

> *"I complied because I don't want to cause a problem, I complied, it helped to relieve the little bit of anxiety and stress levels"*

> *"…Well if you are in an institution and you want to be, you know contradictory to what they want to do then you are going to end up with a lot of, you know, I suppose heavy handiness and they will bring in people that will, even though I wasn't sectioned, they can bring in people that can reinforce that".*

Kabir.

> *"I am here voluntarily, I have a bit of freedom, if just comply, things will be okay, but if I kick up a fuss and they section me, there is nothing I can do, that's how it feels, I am, you can appeal it but the section comes in first, the appeal comes in later, so you might lose 14 days of your life, no control".*

Ekon.

3.3.5.2 Subtheme two: fighting for rights.

This subtheme describes the ways participants upheld their rights. Participant felt as though upholding their rights was not a priority for staff which created an environment whereby participants had to "push" and "fight" for their rights to be upheld. This involved challenging the ward team when they felt they were being unlawfully deprived of their rights.

Five participants described having to fight for their rights by being assertive with staff and repeatedly reminding staff of their rights:

> *"You just fight for them, I get my solicitor to ring or I just say to them I have been here this long and I have not been out. And you know, they will say okay, or staff will approach you and say well I think it is time for you to think about leave."*

Sarah.

Hilder recounts how she had to convince staff to allow her leave to be able to look for a place to live:

> *"Well, I had to fight for every bit of it, I basically...I searched for other rooms I could look up and then my very first unescorted leave for like 2 hours or so I went out and looked at... In the end, I found the one room, I then ended up moving into but I had to do that, I mean out of hospital on escorted leave I went to the old place to take out all my stuff and sort of in a cab to the other one, drop of my belongings and then back to hospital, but I had to fight for it all".*
>
> Hilder.

Here, Becky describes feeling uncomfortable spending time with her boyfriend in the presence of staff and talks about persuading staff to allow her to see her boyfriend in private:

> *"They were supportive of connection with family and friends, there were visiting times, you were allowed to have privacy if you needed it, even if I was in 1:1, I used to have to really try and persuade them but I would ask to just be to have private time with my boyfriend rather than having someone there, sometimes they would insist on someone being there, which was always just super awkward, I couldn't really relax at all, they were very strict about everything had to happen at certain times so that was always quite awkward".*
>
> Becky.

In addition to participants contesting their rights, four described their support network advocating for their rights:

> *"I think after that, kind of my boyfriend said to them 'you have to give Lyra leave', you know, 'If you don't want to break her you need to give her some leave', but they gave me leave, you know, they, after that I had leave".*
>
> Lyra.

> *"I had a close relationship with my parents and professors who were willing to advocate for me and ring up the nurse in charge an*

> *talk about this that and the other and that meant that things got done, I think if I did not have close relationships with people on the outside or if they weren't as or if they didn't have English as first language, or they didn't have this that or the other, I think that a lot of that would have worked very differently"*.

Lee.

3.3.6 Theme Four: Information About Rights

The fourth theme relates to participants' views about the information given to them about their rights, how their rights were explained to them, and their understanding of their rights. All twelve participants shared examples which have been divided into three subthemes: Left in the Dark, Kept Informed, and Rights are not a Priority. These are outlined below with illustrative excerpts.

3.3.6.1 Subtheme one: kept in the dark

This subtheme relates to the lack of information and explanation participants were given about their rights. All twelve participants described incidents of not being given information about their rights and not having their rights explained to them:

> *"I can't remember them actually sitting down and saying 'this is what your rights are, what you can do', they hid that from me to be honest… I was kept in the dark about everything".*

Simone.

> *"Nobody did explain to me what it means to be sectioned, I mean I knew, I knew it meant I would go to hospital against my will but that was it you know, nobody explained to me, what would happen. There was no explanation about my rights beforehand or when they were you know saying well 'we are going to section you'".*

Lyra.

Four participants explained that the information and explanations they were given about their rights were insufficient:

> *"So, I have been thinking this actually because, you know, in the context of human rights, I think, you know, in my experience the kind of information that is given to patients is really, I think it is poorly handled, I think it is patchy. Sometimes I would have been given a pack of information that was often really out of date and you might be kind of like tossed it when you first arrive".*

Becky.

Four participants spoke about finding it difficult to understand information when they first arrived on the ward:

> *"When you first arrive you are a rabbit in head lights, you don't want to be there, you might have been dropped off my your parents, you feel like you are about 3 years old, you are totally vulnerable, or you are furious, you are not in the head space to sit down and read some information, and then actually a lot of the time the information you were given didn't tell people the answers to questions they really could have done with knowing like what is a ward round? What is a CPA?"*

Becky.

Four described having little or no understanding of their rights:

> *"I would say that during early admissions I didn't know much about my rights at all, other than if I was informal I was allowed to leave the ward when I wanted to, though that was confusing because it's not what happened in practice".*

Julie.

Three felt that informing service users of their rights was an inconvenience for staff:

> *“They need to signpost a lot better, in that regard, but I think it is also inconvenient for them because whenever the advocate gets involved then they are being, well they actually have to follow the rules, or they are being held accountable to what they are not doing right, so yeah, it is probably easier for them if nobody explains the service users their rights because then they don't need to”*

Julie.

3.3.6.2. Subtheme two: sources of information

This subtheme describes the different ways participants were kept informed about their rights, and was mentioned by eleven participants. Whilst some gave examples of staff informing them of some or all of their rights, participants commonly described learning about their rights by doing their own research, through speaking to other service users on the ward, by reading posters on the ward, and by talking to advocacy services and solicitors.

Five participants gave examples of staff informing them of their rights. This included being given information in written format and being told during discussions with the ward team:

> *“I was given a lot of literature, various booklets and it was, for the most part, it seemed to be quite practical, it was like 'this is how the ward runs', again there were stuff about calls to the solicitors and appeals to tribunals”.*

Lee.

> *“Well the psychiatrist said I could appeal against it, but I did not want to so I didn't.*

Paul.

Five participants explained that the most reliable way of becoming informed of their rights was by doing their own research:

> *“By the time I was first sectioned, I had read most of the Mental Health Act, and as such, I knew I wasn’t allowed to leave the ward unless I was granted Section 17 leave, I knew they could hold me up to 28 days for assessment, I knew they could forcibly medicate me should they choose to, I knew I could appeal my Section and I knew I should be read my legal rights. None of that information came from the ward however, it’s just what I had found out myself”.*
>
> Julie.

Three participants explained that they found out about their rights by talking to other service users on the ward. For example, Simone explained that she found out about the chaplaincy service by talking to a friend of a service user, and Becky explains that other service users helped her understand how to make requests for leave and helped her understand her section status:

> *“Through a patient, through someone who came to see a patient, a friend of a patient who would come to see them, and then he said 'I know this lady which... would you like to me to ask her to come see you’ and I said ‘yes’”.*
>
> Simone.

> *“I learnt from other patients, 'what's this? We are expected to fill out ward requested, what are ward requests?’ You know we are expected to...’what is a status sheet?' You know?”*
>
> Becky.

Four participants found out about their rights through reading information posters on the ward, patient advice and liaison services, and by talking to solicitors:

> *“I mean they did have that poster, little like A4 poster on the nursing station saying the advocates name, so, and you can contact her on this number, and it did work because that is how I got in touch with her, but I don't think, any nurse ever actually verbally told me about it.”*

Hilder.

> *"Because the solicitor told me there were loads of different options, well not loads but you can appeal your section, go to tribunal...or I know now it can get lifted without going to tribunal, or you can do the nearest relative rights thing, I think it's called".*

Sarah.

3.3.6.3 Subtheme three: rights are not a priority

This subtheme refers to participants' experiences of how they were given information about their rights and their perception of how staff viewed their rights, and was mentioned by five participants.

Four participants described the process of having their rights read to them as satisfying administrative requirements rather than helping them to be informed of their rights.

> *"All of this is down to how something is delivered and how something is communicated to you, and I think the reading of the rights, or telling you your rights, always just felt like a very scripted, routine, mundane things, where it is like the staff had in their mind a checklist of what needed to be done…you know, rather than it being like 'this right reading moment is a really crucial point where we get Becky to understand what she can and can't...do' you know".*

Becky.

> *"I don't feel as though staff took the matter seriously at all - the one time they read my rights and gave me info leaflets on them, they just randomly walked into my room about 5 days after I'd been admitted and announced 'we've come to read you your rights', then proceeded to very briefly explain my section (i.e. how long I could be held for, the purpose of that section and my right to appeal it) before requesting I sign to say I'd been read them".*

Julie.

Three felt as though informing and upholding their rights were not a priority for staff. For example, Hilder describes how upon arriving to the ward she was given a leaflet about her rights but not given an opportunity to ask any questions about it because the staff member went on a break, while Lee described the main priority as being the daily running of the ward which he felt was more important than his right to leave or stay connected with his friends and family.

> *"Well none, because it was the middle of the night and she is like 'I'm going off on break now, you can ask me later' and I am sitting there at 3am in this strange place and I have this leaflet, I read it back for forward but obviously, I have a million questions and it's not like anything would have been interested in talking to me [laughs]"*

Hilder.

> *""The priority is the running of the ward, me being able to go out for 5 minutes in the afternoon or make phone call or buy a newspaper isn't particularly high".*

Lee.

Three participants mentioned systemic issues that prevented staff from being able to appropriately address participants' rights.

> *"As I say don't get me wrong, I don't think any of these people go to work, to like do a bad job, I don't think that, and I don't think, like, they are against me, I think that there is an inherent power imbalance, and at the end of the day they're there to do a job and they have to read me my rights and they have to attend these tribunals and they have to write reports and they haven't, they just don't have time to actually, the whole rights element, they just don't have time for it".*

Claire.

3.3 Section Two: Analysis of Questionnaire.

In this section, data obtained from the questionnaires was analysed using descriptive statistics (see Table 3).

3.3.1 Participants' Knowledge and Understanding of their Human Rights.
Participants were asked about their knowledge and understanding of their rights. Forty-nine percent of participants agreed with the statement 'I knew my rights under the MHA' compared to 33% of participants who disagreed. Eight percent stated that they were unsure what their rights were. Thirty-three percent of participants agreed with the statement 'I was informed of the role of an independent mental health advocate', 33% of participants said they were not informed, and 33% were unsure. Twenty-five percent of participants stated that they understood the role of an IMHA, compared to 50% who stated that they did not understand the role of an IMHA. Twenty-five percent of participants said they were unsure. Fifty-eight percent of participants stated they were informed, 17% said they were not informed, and 25% said they were unsure. Forty-two percent of participants stated that they understood the role of the MHT, compared to 34% who said they did not understand, and 25% of participants that said they were unsure. These results are displayed in Table 3.

Table 3. Participants' knowledge and understanding of their human rights.

Question	Response	No. of participants	Rate %
1. I knew my rights under the Mental Health Act	Strongly agree	1	8%
	Agree	5	41%
	Unsure	1	8%
	Disagree	4	25%
	Strongly Disagree	1	8%

2. Staff informed me of my rights to an independent mental health advocate.	Yes	4	33.3%
	Unsure	4	33.3%
	No	4	33.3%
3. I understood the role of an independent mental health advocate.	Strongly Agree	0	0%
	Agree	3	25%
	Unsure	3	25%
	Disagree	3	25%
	Strongly Disagree	3	25%
4. Staff informed me of my right to a tribunal.	Yes	7	58%
	Unsure	3	25%
	No	2	17%
5. I understood the role of a mental health tribunal.	Strongly agree	2	17%
	Agree	3	25%
	Unsure	3	25%
	Disagree	2	17%
	Strongly Disagree	2	17%

3.3.2 Participants' Beliefs and Attitudes Towards Their Experiences, and to Compulsory Detention.

Participants were also asked about whether they were treated with dignity and respect, about the helpfulness of their compulsory treatment, and about their beliefs about service users' human rights (see Table 4). Fifty eight percent of participants did not believe they were treated with dignity and respect, 17% believed they were treated with dignity and respect, and 25% of participants were unsure. Over half the participants stated that being detained under the MHA was unhelpful compared to 36% who said it was helpful. Nine percent said they were unsure. Twenty percent believed that being treated against their will was helpful, 20% said it was unhelpful and 30% said they were unsure. Sixty-six percent agreed that human rights should be ignored in the interests of safety, 8% disagreed and 25% were unsure. Eighty-three percent of participants agreed that service users should have the same rights as everyone else, 8% said they should not, and 8% percent were unsure.

Table 4. Participants' beliefs and attitudes towards their experiences, and to compulsory detention.

Question	Response	No. of participants	Rate (%)
1. Staff treated me with dignity and respect.	Strongly Agree	0	0%
	Agree	2	17%
	Unsure	3	25%
	Disagree	5	41%
	Strongly disagree	2	17%
2. How helpful was being detained under the mental health act?*	Very helpful	0	0%
	Helpful	4	36%
	Unsure	3	9%
	Unhelpful	3	27%
	Very unhelpful	1	27%
3. How helpful was the treatment you received against your will under mental health act?**	Very Helpful	0	0%
	Helpful	2	20%
	Unsure	2	30%
	Unhelpful	3	20%
	Very Unhelpful	0	0%
4. In some circumstances, human rights should be	Strongly agree	1	8.33%
	Agree	7	58%
	Unsure	3	25%

ignored in the interests of	Disagree	0	0%
safety.	Strongly Disagree	1	8.33%
5. People in inpatient units should have the same rights as everyone else.	Strongly Agree	7	58%
	Agree	3	25%
	Unsure	1	8.33%
	Disagree	1	8.33%
	Strongly Disagree	0	0%

*Based on 11 participants.

** Based on 10 participants.

4. DISCUSSION

4.1 Overview of Chapter

This chapter discusses the thematic analysis and results from the questionnaire in the context of the research questions, the literature outlined in the introduction and other relevant literature. It then evaluates the quality of the study and discusses the study's limitations. Finally, research and clinical implications will be considered.

4.2 Discussion of Key Findings

Research Question 1: Service users' experiences of staff respecting their human rights.

4.2.1 Human Rights Issues

This study explored service users' experiences of how their human rights were respected. The majority of participants raised concerns about how staff respected their rights. They may raise issues concerned with Articles 5, 8, 14 of the HRA; that is: the right to liberty and security, the right to respect private and family life and prohibition of discrimination. There are also implications for Article 3, the right to freedom from torture and cruel, inhuman or degrading treatment, Article 17 of CRPD, protecting the integrity of the person and Article 3 of CRPD, which includes respect for inherent dignity and individual autonomy. Whilst they are inter-connected, they are discussed separately here for clarity.

4.2.1.1 Liberty and Autonomy

Participants' experiences speak to the debate on autonomy versus protection (DoH, 2018). Most participants recognised that they needed support prior to their admission, however having their liberty and autonomy restricted by being compulsorily detained exacerbated participants' distress. Once admitted, participants experienced restrictions as excessive: observations were experienced as overly intrusive and frequent, participants felt unable to make choices regarding treatment, unable to utilise their leave, and felt that they did not have sufficient access to fresh air, which were all deemed as detrimental to their wellbeing. Using the least restrictive option and maximising independence are guiding principles of the MHA. The Code of Practice states that “any restrictions should be the minimum necessary to safely provide the care or treatment required having regard to whether the purpose for the restriction can be achieved in a way that is less restrictive of the person’s rights and freedom of action” (DoH, 2015, p.23). Participants’ experiences suggest that restrictions far outweigh service users’ right to freedom, exemplified by several participants feeling imprisoned.

Another related aspect of participants’ experiences were the concerns raised regarding their autonomy. Autonomy is considered a fundamental ethical principle of healthcare (Beauchamp & Childress, 2001) and includes the freedom to act and the freedom to decide and participate in decision-making (Curtice & Exworthy, 2010). Literature shows that satisfaction is higher when service users feel that their autonomy is respected (Boydell et al., 2010; Hughes et al., 2009; Ruggeri, 1994). Making decisions about what treatments would be helpful, raising concerns, and having these opinions acknowledged and acted upon was seen as a vital aspect of being human. However, participants experienced psychiatric inpatient treatment as restricting and they felt controlled by staff. Consequently, participants felt disempowered and infantilised which increased their distress. Although similar experiences have been reported elsewhere (Akther et al., 2019; Barnes et al., 2000; Rose et al., 2015; Seed et al., 2016), participants in this study spoke about their experiences in terms of infringements of their human rights. This is important since services have a legal duty to protect service users’ rights, including their right to autonomy, which participants in this study believe they are failing to do, emphasising a need for change in how psychiatric inpatient treatment is currently delivered.

4.2.1.2 Privacy and family life

Participants' accounts of privacy and maintaining connection speaks to the right to respect privacy and family life. Respecting privacy comes in many forms, including the right to enjoy one's property, the right to protect one's medical and personal information as confidential, the right to control one's personal space, and the right to carry on one's life privately, without intervention from the state. Privacy is an important constituent of a therapeutic environment (DoH, 2015). It enables individuals to uphold their autonomy and identity, allows people to seek freedom from identification and surveillance from others (Westin, 1967), and relax and unwind in the privacy of their surroundings (Woogara, 2001).

There is a paucity of research exploring service users' experiences of privacy on psychiatric inpatient units. This study deepens current understanding by highlighting the different ways participants felt their privacy was both respected and intruded upon. Privacy was spoken about in terms of having a space that safely provided privacy which was interrelated to dignity and autonomy. Two participants valued having a space where they could retreat to away from the demands of the ward. Participants also felt supported to have visitors, although some found visiting friends and relatives in the presence of staff members difficult. Being able to have visitors on the ward was important for participants to be able to maintain relationships with friends and family. In addition, one participant was discharged after being admitted to hospital a hundred miles away from her home, which she felt deprived her of her right to a family life. The majority of participants, however, felt their privacy was intruded upon. Participants' raised concerns regarding confidentiality, arbitrary searches, and intrusions into their personal lives. Concerns about privacy were previously reported in an ethnographic study of acute medical wards (Woogara, 2005). The author found that staff had little awareness of the importance of the HRA and government policy about service users' privacy and often compromised service users' privacy and dignity. Participants' experiences in this study extends these findings, suggesting a low awareness and compliance of HRA principles amongst psychiatric inpatient staff with regards to respecting service users right to privacy.

Significant concerns were also raised in the context of observations. Observations are a recognised part of psychiatric inpatient treatment and are commonly used to monitor risk, such as self-harm, suicide and absconding (Len Bowers et al., 2000). In line with previous research (Barnicot et al., 2017; Bowles et al., 2002), this study found observations were experienced as intrusive and a significant invasion of privacy. Participants found the lack of privacy particular difficult when showering, using the toilet and trying to sleep, which caused participants to feel degraded, punished and powerless. Observations failed to meet service users' needs and promoted a negative environment. Participants' accounts suggest that processes in psychiatric inpatient units no longer encourage staff to talk to service users, instead staff perform tasks that involve an intrusive disengaged gaze on their suffering.

4.2.1.3 Dignity and respect

Fifty-eight percent of participants felt they were not treated with dignity and respect. Dignity and respect are enshrined into the Code of Practice (DoH, 2015). Dignity in care is defined as any setting which supports and promotes, and does not undermine, a person's self-respect (Curtice & Exworthy, 2010). Dignity is interconnected with the principles of autonomy and respect, and includes the right to bodily integrity and to control one's body and health (Patel, 2019). Adherence to the principles of dignity requires staff to treat service users as human beings (Curtice & Exworthy, 2010).

The majority of participants spoke about dignity in the context of interactions and relationships with staff. Participants' accounts of undignified treatment included feeling ignored, infantilised and invalidated. Some felt staff discounted their knowledge, skills, concerns and feelings. In addition, several participants talked about their experience of being treated like an animal, which led to feeling dehumanised. Dignity was preserved by being treated as an equal, which was achieved when staff showed genuine interest in participants and by respecting their views and privacy. The findings are reminiscent of those presented by Chambers et al. (2014) whereby participants detained under the MHA felt their dignity was compromised by poor relationships with staff.

Dignity was also spoken about in relation to restrictions participants felt were placed upon them. Observations were experienced as degrading: participants described a lack of engagement and communication which contributed to the process becoming depersonalised, mechanistic, and carried out from a distance. Participants also felt deprived of privacy. Observations were experienced as particularly dehumanising when participants had to attend to personal needs in front of staff members. Participants frequently reported feeling traumatised and dehumanised during seclusion and restraint. These practices are widely recognised as being untherapeutic (WHO, 2017), and known to cause significant psychological and emotional harm through the subjugation of oneself to a person in power, the loss of control and dignity, re-traumatisation, and degradation, demoralisation, humiliation, helplessness, disempowerment and dismissal (Borckardt et al., 2011). If is of note, however, that one participant believed the harmful effects of coercive and intrusive practices were minimised by staff who were compassionate. Similar accounts have been reported elsewhere. In a thematic review of 56 studies in 11 countries, Akther et al. (2019) found that the impact of coercive interventions could be mitigated by kind and caring staff. Research has shown that positive perceptions of coercion are associated with service users believing staff are acting in their best interests (Bennett et al., 1993; Lorem et al., 2014), when coercive practices are administered transparently and fairly (Hotzy & Jaeger, 2016), and through collaborative and trusting relationships with staff (Thøgersen et al., 2010). This emphasises the importance of staff building relationships with service users in a way that values them as human beings and supports their self-respect.

Participants' experiences indicate that psychiatric inpatient treatment is can be delivered in ways that infringes service users' right to be free from inhuman or degrading treatment or punishment (Article 3, HRA). They are also consistent with recent reports (e.g. CQC, 2019) and service user surveys (e.g. HVN, 2018; Rethink, 2017). Together, it suggests that current standards of psychiatric inpatient treatment do not protect service users' right to be treated with dignity and respect.

4.2.1.4 Equality and Discrimination

Human rights legislation repeatedly emphasises their application to *all*, and stresses that human rights should be enjoyed without discrimination (e.g. United Nations, 1948). Another related legislation is the Equality Act (2010) which places a duty on service providers to make ‘reasonable adjustments’ for people living with disability. The findings indicate that services inconsistently meet the needs of service users living with disability who are admitted onto psychiatric inpatient units.

For one participant, perceived discrimination on the basis of an autism diagnosis had a significant impact on their level of distress. The need to improve mental health services for people with an autism diagnosis was highlighted in a recent report (CQC, 2018b). It found that in many inpatient units staff lacked the training they needed to support people who have received an autism diagnosis, particularly those with behaviour that is seen as ‘challenging’. For one participant, these experiences led to her being misunderstood and resulted in her experiencing more restrictions. An important aspect of her experience was the physical environment of the ward which affected her sensory system. A recent qualitative analysis of 20 service users with a diagnosis of autism highlighted problematic aspects of psychiatric inpatient units’ environment which were a source of anxiety (Maloret & Scott, 2018). This included excessively bright lighting, overpowering smell of cleaning products, the loud air conditioning system and the taste, smell and texture of hospital food (Maloret & Scott, 2018). Similarly, one participant in this study often experienced the ward as overstimulating, and was unable to regulate her sensory system as she was unable to leave the ward, which she viewed as an infringement of her right for services to make reasonable adjustments. However, this contrasted with another participants’ experience who also had an autism diagnosis. She felt that in her most recent admission staff took time to understand her needs and adapted their practice in order to meet them.

Three participants spoke about their dietary needs, which has not been previously mentioned in studies that have explored service users’ experiences of psychiatric inpatient treatment Nutritional care has beneficial effects on the recovery of service users and their quality of life (NICE, 2011). The Royal College of Psychiatrist standard on food states that “Patients are provided with meals which offer choice, address nutritional/balanced diet and specific dietary requirements and which are also sufficient in quantity” (Perry et al., 2015; p.18). Participants in this study did not feel that staff supported them to meet these needs. Consequently, one participant became ill after eating food that was known to aggravate her stomach and another one lost a significant amount of weight since she was unable to eat some of the food that was provided to her.

4.2.1.5 Adherence to human rights principles

The HRA and government policies (e.g. DoH, 2007) intend to place human rights at the heart service delivery. Human rights considerations are also embedded into the Code of Practice. Participants viewed their liberty, autonomy, information about their rights, privacy, dignity, and equal treatment, as being fundamental rights. However, fulfilment of these rights was experienced as secondary to the running of the ward, where the priority was completing procedural tasks, such as administering medication and undertaking ward-rounds, and maintaining control of service users through use of observations and coercive measures. This elaborates upon why many service users experience psychiatric inpatient wards as abusive and traumatic. Participants’ experiences of having to “push” and “fight” for their rights to upheld, and complying with treatment to avoid further repercussion illustrate how human rights principles are not at the core of psychiatric inpatient treatment. Similar accounts were reported by Gilburt et al. (2008) who interviewed 19 service users about their experiences of psychiatric inpatient treatment in six London boroughs and found that participants reacted to coercive practices by “following the rules”. Within the literature, this has been referred to as ‘pseudo-compliance’ whereby service users’ motivations are to avoid additional coercive treatments and accelerate discharge to regain their independence, despite significant change in how they are feeling (Hughes et al., 2009; Olsen, 2003; Wallsten & Kjellin, 2007). The MHA requires consent from voluntary service users before treatment can lawfully be given. Consent under coercion which is sufficient to render consent involuntary in law is unlawful, even if it was given with full decision making capacity (Richardson, 2008). Yet participants admitted voluntarily commonly described consenting to treatment under undue influences, which could be considered unlawful in a court of law.

Participants’ experiences echo Goffman's (1968) accounts of psychiatric hospitals’ management of “human needs” (p.7) which he described as being bureaucratic and impersonal, and is consistent with previous research showing how nursing roles are dominated by administrative tasks which restricts the amount of therapeutic time they spend with service users (Bee et al., 2006; Handy, 1991). This is perhaps linked with how staff manage the emotional demands associated with their roles. Research shows how institutional defences are used by nursing staff to protect themselves from the anxiety they feel in their work (Menzies-Lyth, 1988; Stokes, 2003). Decreased emotional involvement is considered a protective coping strategy for staff to protect against emotional exhaustion and stress brought on by the everyday contact with distressed service users (Menzies-Lyth, 1988; Stokes, 2003). Participants in this study could be describing the use of similar coping mechanisms by psychiatric staff. Privileging procedural tasks and distancing themselves from service-users might have enabled them to fulfil their job description.

4.2.1.6 Section Summary

Participants experienced many aspects of psychiatric inpatient treatment as infringing upon their human rights. Key human rights and principles for service users include the right to privacy and individual autonomy, freedom from inhuman and degrading treatment, the principle of the least restrictive environment, and respect and dignity. These are enshrined in international, (e.g. CRPD), regional (e.g. ECHR), and domestic (e.g. HRA) human rights legislation, and are fundamental principles underpinning the Code of Practice (DoH, 2015). Whilst it is a matter of court of law to decide whether unlawful deprivations of participants’ rights have occurred, participants’ accounts call into question whether psychiatric inpatient wards always ensure compliance with human rights legislation. It also raises concerns regarding compliance to the Code of Practice.

Research question 2: What are service users' experiences of being informed of their legal rights under the MHA?

4.2.2 Provision of Information about Legal Rights

A number of studies have highlighted the inadequacy of information provision regarding service users' rights on psychiatric inpatient wards (Akther et al., 2019; Galappathie et al., 2013; Katsakou et al., 2012; Shaw et al., 2018). For example, a central theme in Akther et al's (2019) review related to service users' wanting more information about their legal status and legal rights.

This study attempted to expand these findings by exploring participants' experiences of the processes that services use to inform service users of their rights (e.g. Section 132). Participants felt that information about the MHA and service users' rights was supplied in a non-systematic manner: all twelve participants said they were given very little information about their legal rights and felt staff spent little time explaining them. Some felt that staff made them aware of their rights under the MHA in responses to particular situations, for example one participant became aware of her right to an IMHA after a particular conflict arose. Others felt they were made aware too late, for example being informed about the right to tribunal a few days before discharged. The Code of Practice gives clear guidance regarding informing service users of their rights: information should be communicated in a way that the service user understands and staff should repeatedly check that service users have understood their legal rights. In this study, the provision of information was described as a 'one-off' bureaucratic task that was rushed and lacked meaning, which contributed to the feeling that participants' rights were not a priority. Two participants spoke about the timing of providing information. They described their admission onto the ward as traumatic which made it difficult for them to listen to and process the information they were given. Whilst it is important to provide service users with information about their rights during the admission process, these accounts highlight the importance of checking to see whether service users have understood them.

4.2.3 Awareness and Understanding

The study highlighted gaps in awareness and understanding of participants' rights. At the time of their admission, participants described being more familiar with their right to a tribunal and IMHA but less familiar with the role of hospital managers, nearest relative and advance statements. For example, six participants had never heard of advance statements, compared to over half who were aware of their right to a tribunal. Comparable accounts were reported in a thematic review of studies exploring the experiences of the nearest relative provision (Shaw et al., 2018). A central theme that emerged was the need for service users and carers to be informed of the role of the nearest relative, and for more information to be given regarding this role. This study also showed that whilst some participants were aware of their rights under the MHA they did not necessarily understand them: a third of participants said they were informed of their rights to an IMHA but 50% did not understand their role, and 58% of participants said they were informed about their right to a tribunal but 34% did not understand its role. This is similar to findings reported by Newbigging et al. (2015) who found a lack of awareness of IMHA provision amongst service users detained under the MHA (see section 1.5.7). Participants also described becoming informed of their rights over a period of time through a variety of sources. The most common way was through doing their own research. Other sources included speaking to service users and reading information displayed on the wards. Similar to previous research (e.g Newbigging et al., 2015), participants also valued the support they received from IMHAs in helping them to understand their legal rights. However, these sources may not alone be sufficient for service users who are acutely distressed, where impairments in processing and retaining information may prevent them from being able to exercise their rights. This highlights the importance, as stated in Section 132 of the MHA and the Code of Practice, of staff ensuring that service users understand their rights under the MHA when they are given information about them.

4.2.4 Information and Paternalism

Participants spoke about staff not informing them of their rights due to the possible "inconveniences" it may have caused. Goffman (1968) argues that limiting service users' access to information and knowledge regarding their treatment serves to give "staff a special basis of distance from and control over inmates" (p.9). Similar findings were reported by Pollock et al. (2004) with regards to medication whereby staff were concerned about compliance if they were to inform service users of the side effects of their medication (Pollock et al., 2004). Previous research indicates that reluctance to involve service users in discussions about their treatment is associated with professionals' doubts about service users' competence and capacity (Crawford & Kessel, 1999; Rogers, 1993; Stallard, 1996).

Concepts underpinning the MHA, such as 'capacity' and 'insight' may contribute to a paternalistic attitude amongst staff who believe that informing service users of their rights will lead to service users challenging aspects of their care they disagree with, creating barriers to treatment which staff think are helpful. This form of paternalism conflicts with the Code of Practice values of respect and dignity and may be detrimental to developing trust within therapeutic relationships (Laugharne & Priebe, 2006; Palmieri & Stern, 2009). However, three participants felt a lack of adequate staffing as a barrier that prevented staff from having discussions with them about their rights, and shortage of time was also mentioned as a constraint in providing information to service users in the study reported by Pollock et al. (2004). Systemic issues allow abuse to develop and go unchecked (Commission for Health Improvement, 2003), and it is, therefore, important to also considered how structural factors (e.g. budget cuts, staff shortages) inhibit staff from being able to fulfil their duties effectively.

4.2.5 Importance of Information

The importance of having accessible information about service users' rights was highlighted by Akther et al. (2019). Providing service users with information reduced fear and the impact of coercion and improved relationships with staff. In this study, several participants believed that an awareness and understanding of their rights would have led to an increased sense of control and enabled them to hold staff accountable when they believed their rights were being unlawfully deprived. However, little awareness of their rights during their initial hospital admissions contributed to feeling scared and powerless, and contributed to participants complying with treatment decisions they may have otherwise contested, which could be conceived as a form of deception (Szmukler & Appelbaum, 2008). Newnes and Holmes (1999) suggest that increased access to information could facilitate the separation of the social control and helping functions of mental health services. Participants accounts support this, emphasising the importance of providing service users with relevant information about the MHA to minimise unnecessary infringements of their human rights (Fiorillo et al., 2011).

4.2.6 Section Summary

The findings presented here add further understanding to how information is provided on psychiatric inpatient units. They indicate that current processes of informing service users of their rights need improving: some participants described being unaware of their rights and their understanding of their rights varied, which contributed to feelings of powerlessness. The most common ways participants became aware of their rights was by doing their own research and by talking to service users on the ward.

Research Question 3: What is the impact of these experiences?

4.2.7 Iatrogenic effects of psychiatric inpatient treatment

The MHA authorises significant restrictions on individuals' rights on the basis of 'mental disorder' (see section 1.4.4). The removal of a person's right to liberty is presented as serving the best interests of the service user because 'treatment' will restore them to normal functioning by alleviating 'symptoms' of their 'illness'. Moncrieff (2003) argues that this both conceals the coercive aspects of psychiatric inpatient treatment and maintains hope and morale amongst staff, by encouraging the belief that the treatments they are specially trained to apply make a significant difference to the outcome of the psychiatric problem.

This study highlights the iatrogenic effects of psychiatric inpatient treatment. Several participants described their experiences as being akin to imprisonment. They described restrictions on liberty and autonomy which led to feeling frightened, trapped and punished. Being in a locked environment and not having access to fresh air was particularly difficult and exacerbated participants' distress. Moreover, participants described having to negotiating all wants and needs which felt infantilising and exhausting. In addition, participants felt that a lack of information and understanding about legal rights increased feelings of powerlessness and compliance with practices that participants may have otherwise challenged. These accounts conflict with policies that intend to preserve service users' human rights (e.g. DoH, 2007; 2015) and are consistent with research conducted 20 years ago (e.g. Barnes et al., 2000; Goodwin, 1999; Quirk & Lelliott, 2001) suggesting little change in how psychiatric inpatient treatment is delivered.

The study also highlights the impact of feeling undignified during psychiatric inpatient treatment. Some participants described a lack of privacy, overly authoritarian staff, and being unable to express oneself and be heard, which caused participants to feel dismissed, ignored and invalidated. Previous research found that coercive and punitive staff relationships led to a loss of self-esteem, self-efficacy and hopelessness (Hughes et al., 2009). In this study, diminished self-worth was spoken about in the context of not being treated with dignity and respect, exemplified by two participants who described feeling like a "drain" on society. The use of seclusion and observations, in particular, were described as degrading and traumatising. Seclusion and restraint uses physical force against a person to prevent, minimise or subdue a person's behaviour (DoH, 2014) in order to prevent harm or give treatment (Bowers et al., 2012). Research indicates these practices have harmful physical and psychological consequences (Chieze et al., 2019) and are associated with feelings of punishment (Tooke & Brown, 1992). Despite this, the European Court sets a high threshold of severity before it regards such treatment as unlawful and gives a substantial reliance on medical opinion through the notion of "medical necessity" (Richardson, 2008).

Analysis of questionnaires showed that 54% of participants who had been detained under the MHA believed that compulsory detention was unhelpful and only 20% of participants who received treatment under the MHA believed that the treatment helpful. However, it is important to note that 36% believed being detained under the MHA was helpful and 58% believed that safety should be prioritised over individuals' human rights. Differences in views with regards to compulsory treatment were also highlighted by Katsakou and colleagues. They interviewed 59 service users who had been detained under the MHA (Katsakou et al., 2012) and identified three groups with distinct views on their involuntary hospitalisation. Some believed that being detained against their will was right and ensured they received treatment, averted further harm and offered them the opportunity to recover in a safe place. They believed restricting their autonomy was necessary as they had been unable to recognise they needed help and experienced treatment has restorative. Those who believed that involuntary treatment was wrong believed that their problems could have been managed differently, using less coercive interventions, and experienced involuntary treatment as an unjust infringement on their autonomy and threat to independence. Those who were ambivalent believed they needed hospitalisation to prevent further harm and offer them an opportunity to recover, however believed some of their problems could have been managed through less coercive interventions and shorter admissions. These findings illustrate the complexity of balancing autonomy and protection.

4.2.8 Section Summary

The HRA intends to protect fundament freedoms such as liberty, bodily integrity, peaceful enjoyment of a private and family life and human dignity. Article 5 of the HRA lists the conditions in which public authorities may justifiably deprive a person of their liberty, such as the provision referring to "persons of unsound mind", and the MHA gives professionals power, in certain circumstances, to detain and treat individuals considered to have a 'mental disorder' against their will. Participants raised numerous concerns in relation to how they felt their human rights were respected which led to participants feeling traumatised, devalued, dehumanised and punished. These findings add to concerns about the powers afforded to MHA. While some service users find involuntary detention helpful (Akther et al., 2019;

Chevalier et al., 2018; Valenti et al., 2014), the findings from this study stand alongside previous research in which involuntary treatment has been described as counter-productive and harmful (HVN, 2018; Hopko et al., 2002). The answer to the fundamental tensions of autonomy versus protection, or restriction versus safety, is complex, however, participants' accounts indicate the need to question privileging values of medical paternalism in favour of respect for personal autonomy, and the blanket use of unnecessarily restrictive interventions.

4.3 Critical Review

4.3.1 Quality of research

There are extensive debates about whether, to what extent, and how qualitative research can be evaluated. Traditionally, the evaluation of research has centred on assessment of validity, reliability and generalisability. However, while these criteria relate well to quantitative methodologies, such criteria cannot be meaningfully applied to qualitative research which is concerned with meaning in context (Willig, 2013). There are also discussions about whether criteria should be specific to the research method or whether it is feasible to have broad criteria for assessing qualitative research more generally, resulting in a number of different sets of criteria being constructed. Spencer and Ritchie (2012) have identified widely recognised principles that qualitative research should consider: contribution, credibility and rigour.

4.3.1.1 Contribution

Contribution refers to the value and relevance of research evidence produced by a project, whether this is in terms of developments to existing theory, policy, practice, methods or to the lives and circumstances of individuals. Research should aim to improve existing understanding of the subject matter, either by generating new hypotheses, identifying processes or developing analytic concepts (Spencer & Ritchie, 2012). This study explored service users' views concerning how their human rights were respected during voluntary or involuntary inpatient treatment, which may offer new insights into how service users' feel their human rights are protected and, to some extent, generalisability to other mental health service users, thereby holding wider clinical significance.

4.3.1.2 Credibility

Credibility refers to whether the claims made by the research are plausible and defensible. It is concerned with methodological validity - the rigour of the research process, and interpretive validity - how convincingly a claim is made and supported by evidence. Spencer and Ritchie (2012) suggest that researchers may demonstrate credibility by including extracts of raw data and providing descriptive accounts of how data has been categorised. Chapter two provided a detailed description of the process involved in carrying out this research, and examples of raw data and research decisions can be found in Appendices J-L

4.3.1.3 Rigour

Rigour is often viewed as being synonymous with the validity of the method, and is concerned with the appropriateness of research decisions and the dependability of evidence, as well as whether research has been conducted safety (Spencer & Ritchie, 2012). Research that is rigorous is considered transparent. Transparency is achieved through careful documenting and reporting of research decisions, orientations, roles and impacts (Merrick, 1999). It also includes researcher reflexivity; the process through which the researcher describes the research process and assesses the impact of their own role, assumptions and theoretical orientation on the research process (Spencer & Ritchie, 2012).

Chapter two described the decisions behind the methodology, data collection and data analysis, how ethical issues have been addressed, and considered researcher reflexivity. This illustrated the thinking that took place to ensure the study was able to meet its aims (Mason et al., 2016; Patton, 2002; Strauss & Corbin, 1998) and highlights a number of conceptual problems that exist throughout the study. Firstly, the inception of the study fused together two qualitatively different phenomena, human rights *and* rights under the MHA. This is evident in the research questions in which there is a blurring of service users' human rights *and* rights under the MHA. Whilst there is some overlap, a focus on human rights is fundamentally different from focusing on rights under the MHA.

The philosophy of human rights has a rich and complex history. Reflections on the existence, content, nature, universality, justification and legal status of human rights exists as a sub-filed of political and legal philosophy with an extensive literature (Nickel, 2019). Theorists have sought to explore the idea that human rights can exist in a deeper, more independent form; innately in human beings as justified moral outlooks or as basic moral norms (Morsink, 2009; Nickel, 2019). Rights under the MHA, on the other hand, refer to legal norms set out in the MHA as required by the HRA, which include some human rights. Secondly, it is unclear whether the study focused on exploring service users' subjective views or experiences of their human rights/rights under the MHA, or views on what actually happened. Therefore, it is unclear from the outset whether the aims of the study were to explore participants' subjective experiences of how they felt their human rights/rights under the MHA were respected (critical realism) or whether it focused on determining objective truths about whether their human rights/rights under the MHA were respected or not (naïve realism).

The conceptual problems discussed above had a significant impact on the method that was adopted. Interviews were used to explore participants' experiences of how their human rights/rights under the MHA were respected and a questionnaire was used to obtain information that focused on participants' attitudes and views of what happened. The aim of using a questionnaire in conjunction with interviews was to evaluate the implementation of the MHA by obtaining participants' views relating to their knowledge and understanding of their rights under the MHA and their views of compulsory treatment. The interviews, on the other hand, were intended to understand participants experiences of their human rights and rights under the MHA. This illustrates the epistemological inconsistencies in the conception of the study. By using a questionnaire, the study focused on what happened to participants rather than exploring their subjective experiences which is inconsistent with a critical realist epistemology. While a critical realist epistemology endorses ontological realism, it proposes that reality is subjective, dynamic and contextual. Reality, therefore, is based on how people experience things and changes depending on experiences. A realist epistemology, on the other hand, proposes that external reality is objective, static and measureable. From this perspective, truth can be discovered by using objective measurement, such as questionnaires.

The conceptual problems also had a significant impact on the analysis. Analysis focused on both human rights and rights under the MHA. For example, themes ‘Deprived of Rights’ and ‘Rights ‘Upheld’ addressed how participants felt their human rights *and* rights under the MHA were respected. Moreover, theme four, ‘Information about Rights’, addressed participants’ awareness, knowledge and information they were given about their rights under the MHA, but not all of these rights are human rights. In addition, analysis of data from the questionnaire focuses on rights under the MHA, not specifically human rights. These examples highlight how, throughout the study, the author interchanged between focusing on two different phenomena; human rights and rights under the MHA.

4.3.2 Other Limitations

4.3.2.1Sample

The sample size was small and self-selected. Participants were recruited from survivor networks which traditionally differentially attract service users who have had negative experiences with the mental health system. Therefore, the study may have been biased towards capturing views of service users dissatisfied with their psychiatric admission and treatment, and/or opposed to compulsory detention, and may not represent the views and experiences of service users who had more positive experiences. To address this, an interview schedule was constructed which encouraged participants to think about both positive and negative experiences they may have had, and the order of questioning was counterbalanced throughout the interview. The study showed, however, that 54% believed that being detained was unhelpful and 50% believed the treatment they received was unhelpful, suggesting the sample was not strongly biased towards negative views, if at all.

4.3.2.2 Methodology

Thematic analysis was employed to focus on an understanding of patterns across interviews rather than individual insights. Valuable aspects of individuals' experiences may have been missed. While other forms of methodological approaches may have been used, for example IPA, it was felt that TA was most appropriate in answering the research questions (see section 2.4). Themes in TA are constructed by the researcher(s) and are not 'revealed' (Braun & Clarke, 2006). These reflect what the researcher considers to be significant, not necessarily the interviewee (Willig, 2013). Flexibility in TA can lead to inconsistencies and a lack of coherence when developing themes (Norvoll & Pedersen, 2016). To overcome inconsistencies during data analysis, an independent rater was used to assess the reliability of codes, themes and subthemes (see section 2.10.4). An alternative, or additional, approach would have been to use Participatory Action Research (PAR) which would have allowed for greater co-construction of the questions and methods, consistent with the human rights principle of participation. However, given the constraints of the thesis, where I must be the individual author, it would not have been possible to include others in all aspects of this thesis.

4.3.2 Researcher Reflections

As previously mentioned, the research topic, methodology, interpretations and conclusions were all influenced by the author's contexts. It is, therefore, important to consider the impact of the author's context on interpretation of data. Below I outline how my experience influenced the research and how the process of doing the research has influenced me.

4.3.2.1*Conceptual Limitations*

While the thesis intended to explore service users' experiences of a particular phenomenon, for example their experiences of how their rights were respected, it also felt important to evaluate how the MHA was implemented. While many safeguards are embedded into the MHA, it felt most feasible to examine how services implement Section 132 of the MHA. This was done by using a questionnaire to explore service users' views of their knowledge and understanding of their rights under the MHA. This was considered necessary and important if this study was going to have its desired outcome in improving the way psychiatric inpatient units deliver care. On reflection, my previous experiences of working in the NHS and my commitment to improving service users' experiences of inpatient unit may have inhibited my ability to engage with the subject matter authentically which resulted in uncritically fusing two epistemologically positions during the early stages of the study's inception. This may explain the epistemological inconsistencies apparent from the outset where the focus of the study fused participants' subjective experiences (critical realism) with what did or did not happen (naïve realism). Rather than focusing on participants' subjective experiences of, say human rights issues, the focus of the study interchanged between their subjective experiences of human rights and rights under the MHA, and on whether participants' human rights and rights under the MHA were respected or not.

4.3.2.2 Gender

My gender may have affected the questions I asked and what I responded to during the interview process. UK statistics show that women are more likely to subject to violence than men (Office for National Statistics, 2018). Being a man, I may have been less primed to ask prompts about the experiences of safety on the ward, and may have missed opportunities where more subtle forms of violence against women were alluded to, which I could have asked more about. For example, when reviewing Simone's transcript, I noticed during the interview she talked about feeling uncomfortable on mixed sex wards, which could be interpreted as feeling unsafe, but this was not followed up.

4.3.2.3 Professional Privilege

Throughout the interview process I was aware that I was afforded a certain degree of power or respect through my affiliation with the university and role as trainee clinical psychologist. In addition, I was aware that as a trainee clinical psychologist, I work for a system that is viewed by many people as unhelpful and harmful. This may have affected participant's ability to trust me, or identify with me, and subsequently affected the information they felt able to share with me. Having said this, I felt able to build rapport with all the participants.

4.3.2.4 *Experiences and Beliefs*

My experiences of working in mental health services, including psychiatric inpatient wards, have led me to being critical of mainstream discourses about mental health difficulties (see section 2.4). In particular, I hold the view that one of the functions of psychiatric inpatient treatment is to suppress thoughts, feelings and behaviours that are considered to be disturbing to those with the power to determine and enforce social norms, and that 'treatments' are often unhelpful and harmful. At times, these views made it difficult to consider positive aspects of participants' experiences. For example, Claire's account of being locked in a cage and having to defecate on the floor in seclusion evoked a lot of anger about the way she was treated, and it felt invalidating to ask her later in the interview about ways she thought staff *did* respect her human rights. However, as documented in the literature review, peoples' experiences of psychiatric inpatient wards vary, and my aim was to capture the multitude of experiences participants may have had, good and bad. With this in mind, I used the interview schedule as a guide, to ensure that I offered an opportunity to capture different elements of participants' experiences.

4.3.2.5 Reflections on the limitations

While the limitations discussed in section 4.3.1.3 are disappointing, they provide an opportunity to learn and grow. I was aware from the outset that this research was likely to have a powerful impact on me. The intersection between human rights and the MHA is complex. Debates about how best to safeguard distressed individuals while also preserving their autonomy are ongoing and there is no simple solution to these complex issues. Our training has focused extensively on issues of power, social inequality and alternative ways of conceptualising and 'treating' mental health difficulties. I was aware of the feelings of guilt resulting from my role in past events that I believed were wrong and harmful, such as my involvement in the practice of restraint as a graduate mental health worker, and the things I had seen and heard but not acted upon to change. I was also aware of my feelings of wanting to change and improve psychiatric inpatient care and that I had a strong and impassioned position against, what I see as, the unjust and harmful treatment of many service users admitted onto inpatient wards experience. However, I was blinded by the extent to which this position would intensify my feelings of guilt and helplessness. The interview process and analysis also had a profound impact on me. During the interviews, I was very aware of the power I possessed and recognised the trust participants had put in me to tell their stories. I was struck by their passion and courage to change the status quo. Having their faith and trust was a great a privilege but were also, at times, a great burden as I felt acutely responsible for ensuring their experience was reflected accurately and discussed in detail. Listening to participants accounts again during the analysis may have also affected how I engaged with the study. Participants gave powerful accounts of their experiences and I was reminded of the privilege I felt for them giving up their time to speak to me and with the responsibility of accurately representing their experiences.

On reflection, these experiences may have made it difficult for me to remain 'objective' throughout the research process and inhibited my ability to understand the complexities of experiences on inpatient units. My commitment to remain faithful to participants by representing their experiences accurately may explain the inconsistencies in the epistemological position throughout the study as it may have felt a disservice and invalidating to understand their powerful accounts as subjective experiences rather than objective truths about what actually happened to them.

4.4 Implications

This study adds to the concerns that service users in psychiatric inpatient units are not receiving the care and treatment they require in a way that respects their human rights (e.g. HVN, 2018; CQC, 2019). Change is required across multiple levels of context to build an environment in which services are able to fulfil their obligations to respect, protect and fulfil service users' human rights. Bronfenbrenner's Social Ecological Model (1979) is one way for health-care professionals to frame how a human-rights-based approach can be supported at different levels of context. It is of note that ideas presented here, or variations of them, have been suggested by different groups in the past, including the authors of the MHA review (DoH, 2018). It is important, then, to also consider why such changes have not occurred, which will be discussed in the following sections.

4.4.1 Directions for Future Research

While the study adopted a broad focus in terms of human rights, it could also be considered narrow since it only considered service users' views of their human rights. Though important, it missed exploring the perspectives of staff. If the MHA is to be used appropriately, greater awareness and understanding of professionals' views regarding service users' human rights is needed. Whilst research indicates that staff have inadequate knowledge and understanding of the MHA (Marriott et al., 2001), little is known about psychiatric staffs' views of service users' human rights. Considering systemic issues and staff attitudes were felt to be barriers for staff to be able to fulfil their duties effectively, it would be useful to explore professionals' views of service users' human rights and of informing them of their rights under the MHA. Both staff and service users participated in Pollock and colleagues's (2004) study which provided a useful insight into the lack of information regarding medication that was reported by participants; staff underestimated the importance of giving service users information regarding medication and felt that informing service users of the side effects would decrease compliance.

4.4.2 Practice Considerations

4.4.2.1 Provision of information

The findings from this study advocate for better provision of information regarding service users' legal rights. Clinicians need to spend more time explaining how the MHA affects service users' rights and continually review service users' awareness and understanding of them, rather than see it as a one-off exercise. The MHA contains a number of procedural safeguards designed to ensure that service users are informed of their rights (e.g. Section 132) which have traditionally been delegated to nurses to perform. Independent mental health advocates are another important source of information and support for service users, but research indicates that less than half of service users have sufficient access (Newbigging et al., 2015). Action is needed to ensure service users are aware of, and able to benefit from, their rights. The right to an advocate should also extend to voluntary service users who experience high levels of coercion to diminish the risk of 'de facto' detention.

4.4.2.2 Role of Clinical Psychologists

Understanding human rights is an important role of clinical psychologists working in the NHS, both from a legal and ethical standpoint (Patel, 2019). A human-rights based approach to psychological practice implies a respect for human rights principles, together with ethical obligations, in all areas of psychological practice. Psychologists working in psychiatric inpatient units are in a unique position where they are not necessarily tied down with the everyday running of the ward which participants in this study viewed as a barrier to effective communication about their legal rights. Clinical psychologists should use their positions to advocate for service users' more regularly, supporting them to understand their legal rights and promote a shared understanding of how human rights principles and legal standards may be at risk within the wider team.

Clinical psychologists could also promote a human-rights based culture on psychiatric inpatient wards. Although not explicitly a human-rights based approach, 'Star Wards' was an intervention on improving service users' experience of psychiatric inpatient units which encompassed many human-rights based principles. Its focus was on the provision of high quality information for service-users, establishing good therapeutic relationships between service-users and staff, avoidance of conflict, a holistic approach to treatment, and the importance of the physical ward environment. In a report that examined the impact of Star Wards, Simpson and Janner (2010) found improvements in staff morale, service users' satisfaction and quality of care. Moreover, there was a 71% reduction in aggression on the ward and a reduction in the need to use special observational methods.

4.4.2.3 Reducing paternalism and increasing reciprocity

The study emphasises the need to move away from the institutional function of control to care and concern. Research indicates that increased transparent and coherent dialogue is important for reducing both the need and fear of coercive practice (Gilburt et al., 2008; Rose et al., 2017). Clinicians could reduce the feelings of paternalism through entering into meaningful dialogue with service users about their experiences, offering more choices and collaborating more regularly (CQC, 2018c). If restrictive and intrusive practices are to be used, they should be used as a last resort and services need to acknowledge the harm they cause. As with previous research (Sheehan & Burns, 2011), the study showed that perceptions of coercive practices can be mediated by compassionate staff who acknowledge the traumatic nature of the experience.

4.4.3 Service Considerations

4.4.3.1 Reducing Restrictions

Alternatives to inpatient environments may also be effective ways to increase service users' liberty and autonomy, which have been advocated for previously (Cooke, 2017). Research suggest that crisis houses and safe houses are more satisfying to service users, provide environments that feel safer and staff that are more trusted (Nijman et al., 2011; Rose et al., 2017). Furthermore, they may be just as effective, in terms of outcome and cost, as hospital admission (Mosher, 1999). However, this research is often criticised for using a population that was "less distressed" than inpatient populations, and that for many service users, the "risk" of a non-restrictive environment would be too great (Lloyd-Evans et al., 2010).

Further consideration should be given to increasing freedoms in psychiatric inpatient units. Examples of this include providing unlocked gardens that are accessible to service users. Research in physical health settings indicates that service users who use gardens report reduced stress and improved emotional-wellbeing (Marcus & Barnes, 1995; Sherman et al., 2005). This is imperative as it offers opportunities for fresh air and connects service users with the environment which was viewed as an important way to feel human again. Increased freedoms may reduce tension and frustration on the wards which can further reduce violence and "extreme behaviour" (Nijman et al., 2011; Diana Rose et al., 2017).

This could be achieved by having unlocked wards for voluntary service users, or giving them access cards.

4.4.2 Structural / Policy change

Whilst the issues discussed so far are important and need to be brought to the forefront of practice, they can only happen in the event of systemic change. Despite calls for improvements in the care and treatment of service users in psychiatric inpatient units by various groups in the past decade, the findings presented in this study continue to raise concerns. It is important to consider the wider socio-political culture to understand why change has been so difficult and slow.

4.4.2.1 Alternative Conceptualisation

The concept of 'mental illness' sets up an assumption that people with mental health difficulties are separate and different from people who are not labelled as 'mentally ill' (Harper, 2001). Indeed, research indicates that staff who hold biomedical causal beliefs perceive service users as more disturbed (Langer & Abelson, 1974) and have less empathy for service users (Lebowitz & Ahn, 2014). Research has also shown that individuals who are given psychiatric diagnoses are perceived as aggressive and dangerous (Pescosolido et al., 2010). Related to these ideas is the concept of dehumanisation (Haslam, 2006). Martinez et al. (2011) propose that in the absence of other information about a person, people who are given mental health diagnoses trigger dehumanising responses from others who ascribe them with a lowered human status, which in turn is associated with perceiving them as threatening and dangerous. Thus, it is possible that prevailing biomedical explanations lead to dehumanising perceptions and responses to people given mental health diagnoses, including those who are admitted onto psychiatric inpatient units. Considerations in mental health training programmes should be given to alternative conceptualisations that considers the links between wider social factors, such as poverty, discrimination, inequality along with traumas such as abuse and violence, such as the Power Threat Meaning Framework (Johnstone et al., 2018).

4.4.2.2 Systemic Issues

It is important to consider health and social policy that inhibits services from delivering psychiatric inpatient care in a way that respects service users' human rights. A reduction in the number of psychiatric inpatient beds in the past 50 years (Ewbank et al., 2017) has increased the threshold of severity for admission. Subsequently, service users in psychiatric inpatient units are more likely to be acutely distressed, and a high proportion of those are detained under the MHA (Samarasekera, 2007). This has occurred in the context of a significant decrease in the nursing workforce (House of Commons Health Committee, 2018). During this time, wards have become more reliant on bank and agency staff as more experienced nurse have moved to work in the community (Thornicroft et al., 2013). These changes have put psychiatric inpatient wards under pressure and impacted their ability to deliver quality care. Research suggests that in the context of reductions in funding of the NHS there has been an increase in staff sickness, stress and work place bullying in the NHS (Campbell, 2017; Carter et al., 2013; Greenwood, 2017; Johnson, 2015). These factors may result in reduced staff and compassion and helping towards others (Darley & Batson, 1973). This is compounded by the nature of the psychiatric inpatient work: shift systems and rotating staff placements makes it even harder for staff to be with those they're working with, which reduces compassion and relationship building (Menzies-Lyth, 1988) It is within these contexts that abuse develops and goes unchecked (Commission for Health Improvement, 2003).

4.4.2.3 A New Mental Health Act?

The recent review of the MHA has stated its commitment to "shift towards a more rights-based approach, improving respect and dignity, and ensuring greater attention is paid to a person's freely expressed wishes and preferences" (p. 17). Whilst this is a positive step towards respecting service users' human right, critics of the review (e.g. HVN, 2018) advocate for more radical change, informed by people with lived experience, carers, academics and practitioners. They have urged the government to re-evaluate the fundamental concepts that underpin the MHA, such as mental disorder, capacity, insight and risk, which are widely contested (Cooke, 2017; Pūras, 2008). Amongst their recommendations include an end to long-term detention and the introduction of short-term detentions only as a last resort, representing a shift from accepting the inevitability of involuntary detention.

4.4.3 Dissemination

The study will be written up for publication in academic journals and will also be shared with services, professionals and interested organisations. Consideration will be given to the roles and responsibilities of wider social and political structures that can both inhibit and promote change to avoid an overly staff-blaming narrative. Moreover, it will be important to avoid critiquing the current system without offering suggestions of an alternative.

4.5 Conclusion

The motivation for this research grew from concerns regarding peoples' experiences of psychiatric inpatient units and the need to better understand how services can improve in order to provide care that promotes service users' need for respect, dignity, autonomy and equality. Exploring service users' views on human rights within psychiatric inpatient units has added further depth to existing understanding of psychiatric inpatient treatment. The study adds to growing concerns about the implementation of the MHA, revealing the multitude of practices can be experienced as disrespectful, harmful, discriminatory, and diminishing of service users' dignity and opportunities to exercise autonomy. Whilst the study has highlighted the complexities of transforming services amidst a back drop of austerity and cuts to services, it demonstrates the urgent need to develop services which put users' human rights at the heart of policy.

In order for change to occur, it is important to consider the wider socio-political context in which services are operating in and acknowledge the systemic pressures on staff that shut down avenues for change. Therefore, change must occur on multiple levels: organisational policies and practices must be scrutinised; staff must be made aware of how human rights apply to their work and offered regular support to cope with emotional demands of the role; and de-stigmatisation programmes must not solely focus on biomedical causes. It is hoped that this study will contribute to improved understanding of how psychiatric inpatient wards are experienced and improve services as a result.

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Legislations and Legal Documents

County Asylum Act (1845)

European Convention on Human Rights (1953)

Equalities Act (2010)

Human Right Act (1998)

Madhouse Act (1774)

Mental Capacity Act (2005)

Mental Treatment Act (1930)

Mental Health Act (1959)

Mental Health Act (1983)

Hospital Plan (1962)

Lunacy Act 1890

United Nations Convention on the Rights of Persons with Disabilities (2006)

Universal Declaration of Human Rights (1948)

Vagrancy Act (1714)

Wynn's Act (1808)

Jurisprudence

Herczegfalvy v. Austria, 244 Eur. Ct. H.R. (ser. A) at 50-51 (1992)

6. APPENDICES

6.1 Appendix A: Literature Search

The search was conducted using PsychINFO, PsychArticles and CINAHL Plus via EBSCO. The search concentrated on academic journals published between 1990-2019. The following search terms were used: (mental health act OR detention OR legal detention OR coercion OR compulsory detention OR forced treatment OR involuntary treatment OR inpatient OR psychiatric hospital) AND (patient OR service user OR survivor) AND (experience OR Views OR satisfaction).

(Human rights OR civil rights) AND (mental health act OR detention OR legal detention OR coercion OR compulsory detention OR forced treatment OR involuntary treatment OR inpatient OR psychiatric hospital).

Further papers were identified using Google Scholar and Research Gate, as well as the references lists of the relevant papers identified in the initial search.

The following limiters were applied:

- Dates: 1990-2019
- Language: English
- Source Type: academic journals

A total of 1351 papers were identified via EBSCO (PsychINFO, PsychArticles and CINAHL Plus). All titles and abstracts were reviewed for relevance. The following criteria were applied:

- Specific focus on voluntary and involuntary inpatient experience in England and Wales.
- Participants were between the ages of 18-65.

The search identified a total of 32 relevant papers, 16 were identified in the EBSCO search and 17 were identified via reference lists and Google Scholar.

6.2 Appendix B: Ethical Approval

For research involving human participants

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

REVIEWER: Lucia Berdondini

SUPERVISOR: **John Read**

STUDENT: Tarun Limbachya

Course: Professional Doctorate in Clinical Psychology

Title of proposed study: TBC

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY
(Please indicate the decision according to one of the 3 options above)

APPROVED

Minor amendments required *(for reviewer)*:

Major amendments required *(for reviewer):*

Confirmation of making the above minor amendments *(for students)*:

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name *(Typed name to act as signature):*
Student number:

Date:

(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

YES

Please request resubmission with an adequate risk assessment

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐ HIGH

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.

☐ MEDIUM (Please approve but with appropriate recommendations)

☒ LOW

Reviewer comments in relation to researcher risk (if any).

Reviewer *(Typed name to act as signature)*: Dr Lucia Berdondini

Date: 27th February 2019

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

RESEARCHER PLEASE NOTE:

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

University of East London

Psychology

REQUEST FOR TITLE CHANGE TO AN ETHICS APPLICATION

FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS

Please complete this form if you are requesting approval for proposed title change to an ethics application that has been approved by the School of Psychology.

By applying for a change of title request you confirm that in doing so the process by which you have collected your data/conducted your research has not changed or deviated from your original ethics approval. If either of these have changed then you are required to complete an Ethics Amendments Form.

HOW TO COMPLETE & SUBMIT THE REQUEST

Complete the request form electronically and accurately.

Type your name in the ‘student’s signature’ section (page 2).

Using your UEL email address, email the completed request form along with associated documents to: Psychology.Ethics@uel.ac.uk

Your request form will be returned to you via your UEL email address with reviewer’s response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.

REQUIRED DOCUMENTS

A copy of the approval of your initial ethics application.

Name of applicant: Tarun Limbachya

Programme of study: Doctorate in Clinical Psychology

Name of supervisor: Professor John Read

Briefly outline the nature of your proposed title change in the boxes below

Proposed amendment	**Rationale**
Old Title: How are human rights experienced on inpatient wards?	The new title more accurately captures the aims of the study and the methodology used.
New Title: Voluntary and involuntary mental health service users' views on how their human rights were considered.	

Please tick	**YES**	**NO**
Is your supervisor aware of your proposed amendment(s) and agree to them?	√	
Does your change of title impact the process of how you collected your data/conducted your research?		√

Student’s signature (please type your name): Tarun Limbachya

Date: 24th March 2020

TO BE COMPLETED BY REVIEWER		
Title changes approved	APPROVED	

Comments		

Reviewer: Glen Rooney

Date: 01/04/2020

6.3 Appendix C: Interview Schedule

Introduction

- Participant information sheet – check read
- Consent form

Demographics

- Age, gender, ethnic origin, marital status, how many admissions and status, diagnosis given,

---

General experience

- How would you describe your inpatient experience?

Human rights

- What was your understanding of your rights as a patient while on the ward?

Prompts: What gave you that impression? How did you find out about these? In what ways did staff help explain these?

- How would you describe the way in which staff respected your rights?

Prompts: In what way were you/weren't you treated with treat you with dignity and respect? How did staff respect your privacy and help you stay in contact with friends and family? How were you supported to be independent and autonomous? How was the need for admission explained to you? How were your religious and spiritual needs considered? How engaged were you with the treated you received?

- What information were you given about your rights?

Prompts: What was it like when your rights were read out to you? Did you understand? What effect did that have on you? Did anyone ever check that you had understood them? Who could you ask if you did not understand?

- *What was your understanding of your rights?*

Prompts: consent to treatment? (ALL) Advance Statements/Decisions? (ALL) your detention being reviewed? (S3: NR, Tribunal 3 months, HMD S2: appeal after 14 days, HMD) advocacy services? (ALL) role of the CQC? And complaints? (ALL)

Ending questions

- Can you suggest anything that would improve yours or other people's experience of inpatient treatment?
- What would help people be more aware of their rights when being detained under the MHA / admitted as a voluntary patient. What could services do to protect these?
- Is there anything else you think I should know/understand better?
- Is there anything you would like to ask me?

6.4 Appendix D: Consent Form

UNIVERSITY OF EAST LONDON

Consent to participate in a research study

How are human rights experienced on inpatient wards?

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data after analysis of the data has begun.

Participant's Name (BLOCK CAPITALS)

……………………………………………………………………………………….

Participant's Signature

………………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS)

……………………………………………………………………………………..

Researcher’s Signature

………………………………………………………………………………………

Date: ………………………..…….

6.5 Appendix E: Anonymised Email Contact with Charity

Dear X

Sorry for the delay in getting back to you, I have been in the process of finalising my research proposal which I have now submitted to the university.

I am just following up on John's email about recruiting participants from the [name of organisation] email list and/or newsletter.

I am conducting research into people’s experience of how their human rights were considered and/or denied during admission to a psychiatric inpatient ward. For example, topics of discussion might be: What are peoples' understanding of their rights when they were admitted into hospital? How did they find out about their rights? What did staff do to explain these?

I am still waiting for ethical approval before we can start recruiting but I think it was suggested that the project could be put on a newsletter as way of recruiting potential participants? If so, I am wondering how that would work? For example, how much information about the study could I include? I’ve attached a draft information sheet that outlines the study but I’m aware that might be too much for a newsletter. I’m also wondering about the when the newsletter gets sent out and to how many people?

Realistically, I’ll start recruiting from April 2019.

Best wishes
Tarun

6.6 Appendix F: Example Blurb on Online Advert

You are being invited to participate in a research study exploring peoples' experience of how their human rights were respected during admission to a psychiatric inpatient ward. The research is being conducted by Tarun Limbachya, Trainee Clinical Psychologist, under the supervision of John Read, Professor of Clinical Psychology at the University of East London.

While there is some research that examines peoples' experience of psychiatric inpatient wards, there is very little research which specifically focuses on peoples' experiences of how their human rights were respected. This study aims to find out more about these experiences and their impact on people. This is important because having greater knowledge of this topic will hopefully help to improve the experience of people admitted onto inpatient wards.

Participation will involve an interview of about 40-60 minutes at the University of East London or via Skype. To make it as convenient as possible, I can reimburse you for part of your travel from anywhere in England, Scotland and Wales in vouchers (£10 Amazon) or I am willing to travel within 50 miles of London to meet you at a location that suits you.

If you are interested in taking part or would like to find out more about the study, please contact me, Tarun Limbachya, via email at u1725786@uel.ac.uk Interviews will be taking place from June 2019.

6.7 Appendix G: Participant Information Sheet

UNIVERSITY OF EAST LONDON
School of Psychology
Stratford Campus
Water Lane
London
E15 4LZ

The Principal Investigator
Tarun Limbachya
Trainee Clinical Psychologist
E-mail: u1725786@uel.ac.uk

PARTICIPANT INVITATION LETTER

You are being invited to participate in a research study. Before you agree it is important that you understand what your participation would involve. Please take time to read the following information carefully.

Who am I?
I am studying for a Doctorate in Clinical Psychology at the University of East London and. As part of my studies I am conducting the research you are being invited to participate in.

What is the research?
I am conducting research into people's experience of how their human rights were considered and/or denied during admission to a psychiatric inpatient ward. For example, topics of discussion might be: What was your understanding of your rights when you were admitted into hospital? How did you find out about your rights? What did staff do to explain these to you?

Why is this project being carried out?
There is very little research which specifically focuses on people's experiences of how their human rights were considered and/or denied. This study aims to find out more about these experiences and their impact on people. Having greater knowledge of this topic will hopefully help to improve the experience of people admitted onto inpatient wards.

My research has been approved by the School of Psychology Research Ethics Committee. This means that my research follows the standard of research ethics set by the British Psychological Society.

Why have you been asked to participate?
You have been invited to participate in my research as someone who may fit the kind of people I am looking for to help me explore my research topic. I am looking to involve people over the age of 18 who have previously been admitted into a psychiatric hospital, either as a voluntary or involuntary patient.

I am not looking for 'experts' on the topic. You will not be judged or personally analysed in any way and you will be treated with respect. You are quite free to decide whether or not to participate and should not feel coerced.

What will your participation involve?
If you agree to take part, you will be invited to an interview at the University of East London. The interview will be like having an informal discussion and will last approximately 45-90 minutes. It will be audio-recorded on a secure device to help me remember what we talked about. Only I will listen to the recording when I am writing up the study.

Before starting the interview, you will be asked whether you have read this information sheet and will be given an opportunity to ask any questions about the project. If you are happy to proceed, you will be asked to sign a consent form.

The interview will involve me asking you about your experiences of being in hospital. The questions will depend partly on what you want to talk about.

I will not be able to pay you for participating in my research but your participation would be very valuable in helping to develop knowledge and understanding of my research topic. Your travel expenses to the interview will be reimburses for you if you bring your receipts or tickets with you.

Your taking part will be safe and confidential

Your privacy and safety will be respected at all times. I will not have access to your medical files. You will be asked to provide some basic information about yourself at the interview, such as your age, gender, ethnicity, mental health diagnoses (if known) and approximate dates of previous psychiatric hospital admissions and whether these were under a section or not.

Anonymity will be assured by assigning you a code. The code and consent forms will be kept in a secure filing cabinet. These will be kept separate from the recordings of the interview, transcriptions of the interview and basic information about participation (names, age).

Confidentiality will be protected by anonymising all identifiable information contained in the interviews. This means excluding any names that are mentioned including yours, and anything you say that would mean someone could identify you, A small number of quotes from the interviews may be used in the final write up of the study. These will be anonymous and so will not be identifiable.

It is important to tell you that I would only need to tell someone else what we talked about if you told me something that made me think you or someone else was at risk of harm. If this happened, if it was possible, I would try my best to let you know that I need to tell someone else before doing so.

Taking part in the study should not put you at any risk of injury or accident injury, and is not intended to cause any harm or distress. However, because of the sensitive nature of the topics that will be discussed, some participants may become upset during the course of the study. There will be an opportunity to talk about the study and the potential affect it has had on you at the end of the interview. I will also have details for appropriate and accessible organisations that can offer further support. You do not have to answer all the questions and can stop the interview at any point.

What will happen to the information that you provide?

The interviews will be audio recorded so I can accurately remember everything that we talked about. This is important because I do not want to misrepresent what was discussed. The recording will be typed up on a document so it can be analysed.

The audio file and typed document will be saved on a computer that is password protected to prevent anyone else from accessing them. Only my supervisor at the University of East London, the examiners who will be marking the research, and I, will have access to the transcript. Only I will have access to the audio files. Audio files will be deleted after examination. Transcripts will be kept for three years and might be used to write the research up into an article to be published in a psychology journal.

What if you want to withdraw?

You are free to withdraw from the research study at any time up to two months after the interview, without explanation, disadvantage or consequence.

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Name: xxxx

Email: xxxxx

If you have any questions or concerns about how the research has been conducted please contact the research supervisor xxxxx School of Psychology, University of East London, Water Lane, London E15 4LZ,

Email: xxxx

or

Chair of the School of Psychology Research Ethics Sub-committee: xxxxx School of Psychology, University of East London, Water Lane, London E15 4LZ.

(Email: xxxx

6.8 Appendix H: Questionnaire

1. **Staff treated me with dignity and respect**

Strongly agree Agree Unsure Disagree Strongly Disagree

2. **How much did you know about your rights under the Mental Health Act?**

Strongly agree Agree Unsure Disagree Strongly Disagree

3. **Staff informed me of my right to an independent mental health advocate?**

a) Yes
b) No
c) Unsure

4. **If yes, how much do you agree with the following statement: I understood the role of independent mental health advocates.**

Strongly agree Agree Unsure Disagree Strongly Disagree

5. **Staff informed me of my right to attend a mental health tribunal**

a) Yes
b) No
c) Unsure

6. **If yes, how much do you agreed with the following statement: I understood what the role of a mental health tribunal was.**

Strongly agree Agree Unsure Disagree Strongly Disagree

7. **Please answer if applicable: How helpful was being detained against your will under the Mental Health Act?**

Very helpful Helpful Unsure Unhelpful Very unhelpful

8. **Please answer if applicable: How helpful was the treatment you received against your will under the MHA?**

Very helpful Helpful Unsure Unhelpful Very unhelpful

9. **In some circumstances human rights should be ignored in the interest of safety?**

Strongly agree Agree Unsure Disagree Strongly Disagree

10. **People in inpatient units should have the same human rights as everyone else?**

Strongly agree Agree Unsure Disagree Strongly Disagree

6.9 Appendix I: Coded Extract Example

Interview Transcript	Code
I: Overall how well you feel your rights were respected?	
P6: My sense, well basically, nobody did explain to me what it means to be sectioned, I mean I knew, I knew it meant I would go to hospital against my will but that was it you know, nobody explained to me, what would happen erm... There was no explanation about my rights beforehand or when they were you know saying well 'we are going to section you'.	No explanation of sectioning No explanation of rights
Erm...I remember, spending the night in the unit because, well I don't remember, I was told by my mum afterwards, that I spent the night, I actually fought a lot with staff because I wanted to leave so I remember that, I remember people you know sort of holding me because I wanted to leave, I didn't want to be there, probably well they sedate me, I don't know, I don't remember, I don't know, but according to my mum I slept there and then the following day they took me to the [name of hospital] Erm...and I don't, again I don't remember anybody explaining anything to me erm...in my records, my care records, there is something about somebody, a nurse, reading my rights to me, I don't have any recollection, and if they did it once they should have done it again, I was very unwell.	Restrictive environment No recollection of rights being read. Admission a distressing time
I: Can you remember anyone coming up to you again during that first week, or couple of weeks to have that conversation with you?	
P6: No, no, no. There was no information, for example of advocacy, I mean I know at the time, the independent mental health advocates, erm thing, was not a statutory right yet, but still they should have told me about advocacy, they should have told me about what a section is, you know I opened the door and I went out, well I don't remember that, but I read it in my notes, because, nobody said 'hang on a minute, you	No information about advocacy Unclear about ward policy

can't do that', so I just opened the door and went out for a walk you know around the grounds of the hospital. I mean nobody said to me you can't do that, do you know what I mean? It was like, no explanation of the fact that you can have section 17 leave, er that you need to.... that you can appeal, apparently they mentioned after my section 2 was about to expire I think they mentioned to my boyfriend that we could appeal the section, er....but I mean, I don't know to what extent he was explained things were, but nobody explained to me, in a way that I can remember er...so well....no I think there was no, nothing. And also, my nearest relative, my mum was my nearest relative, er, and not my boyfriend, they had put down a boyfriend, of course it was convenient because my mum doesn't speak, well didn't speak good English, so they would have, they would need an interpreter, nobody explained anything to my mum. My mum came to hospital for every single day for three months, nobody explained to her what this is, they only found an interpreter towards the end, erm...a really good guy, a Greek guy, and he came to a couple of ward rounds, it was the only time, but that was towards the end, of the three-month period, that erm... you know my mum was able to speak to somebody and ask questions about what was going on, I think that was part of my rights too wasn't it? But....her rights, there was no, nothing about that.... It was always, we can't find an interpreter.	Informed boyfriend Told too late No explanation Lack of information Lack of explanation to relatives Lack of involvement of relatives
I: What was your understanding of the right to have your detention being reviewed? P6: Oh, nobody told me about that? Nobody told me about that no. Afterwards I, I was, I started doing is, er research myself, I found out about advocacy er...you know, the procedure... I: Did you do the research yourself? P6: No, no, no, when I got back to research, because I was a researcher myself, so, after, you know a year later, I was in involved in a study	Not informed of right to have detention reviewed/ Wards not a source of information

about advocacy and it was then that I found out about you know all these things about tribunals, about the right to appeal, there was no...nothing when I was inpatient, no. I: What information were you given about advance statements?	Unaware of legal rights.
P6: [Laughs] You must be joking! There was no information about advance statements, during my admission?! No! I have got an advance statement now but it was, it was you know after I got out of hospital, you know a lot later.	Not informed of advance statements.

END OF EXCEPT

Interview Transcript	Code
I: What was it about the ward that had such a negative impact on you? P3: Well, the yeah, the restrictions, not being able to do what I wanted, when I wanted, erm, yeah I don't know erm, always having to ask nurses for every little thing and then often them not being available, it's almost what always caused my panic attacks. Erm, yeah I don't know how else to put it. I needed something to do otherwise I would just go crazy I always do better if I have something productive to occupy my time and I can't sit around and do nothing.	Restrictive environment Lack of autonomy Increased distressed
I: What about, I want to ask you, in what way were you treated with dignity and respect? P3: I mean, that was, the fact that she gave me unescorted leave that was, she was clearly respecting my needs in some way as much as possible given the circumstances. Erm, but I often... on the ward, it felt beyond disrespectful...erm... when nurses would just flat out ignore you, I mean I have no idea how many countless times I would have stood in front of the nurses station knocking on the window and there 4-5 people in there and they flat out ignore you, for I don't know how long, sometimes the entire station was empty for long periods of time because two were on 2-to-1 one person was on break, the other person was doing medication, and that was it, you know, or someone was on leave with someone, and they were always very short staffed, so not being able to access anyone when I needed and then often erm...I mean this was just when I was, I would only go there if I actually needed something or I was distressed if for any reason I worried about something and I needed to talk to someone and then to be refused that opportunity is the most disrespectful, you known their job is to try and help, that is what they are getting paid for you know, and then just flat out ignore you, or even if they saw how distressed I was just tell me to go to my room, that is when I always ended up self-harming, I would bang my head, for the next... I am sorry it is still growing back, erm..but for the like the next year my head was egg shaped like this, I have never self-harmed more than those 7 weeks because they could not have cared less, that is the thing, they knew what I was doing, it was loud, you know, on a, I don't know what solid wall it was, erm... they must have all heard it and they could not have cared less.	Feeling respected Staff as disrespectful Being ignored Staff unavailable Being dismissed Disrespectful encounters with staff Staff interactions increases distress Strategies to cope with experiences

I: How did they respond when they heard that? P3: They just ignore, they never, the only time they did someone I accidentally, and that is how I got myself sectioned, erm... the day I was supposed to be discharged, I ran, I sort of ran into the door, I was trying to bang my head, I normally did but that door, it was not my normal wall so that door had a little window on that you know on sort of eye level and I did not tilt my head enough so i ended up hitting the edge and I, I spilt open my forehead, erm... so it was bleeding profusely and then they were not happy they were mad at me, erm... but otherwise they could not have cared less [laughs].	Being ignored Staff are uncaring
I: How did staff talk to you? Were you treated as an equal? P3: I was terrified of this one guy, he scared me to death... I: What scared you? P3: He was the guy who was there when I was admitted, it was also like late like maybe 10pm on an evening and they weren't any people around, it seemed like it was just him, he turned up to the charge nurse there, I think, or whatever they called him, and then one bank staff who obviously had no clue what she was doing, and I remember that, that's why I was so scared of this guy, because he treated me with such disrespect and then there, because I got there, the night I got there, I didn't know, it was a new ward, I didn't even know what was going on, nobody explained anything to me it seemed like, and he was so condescending and I kept asking him questions, and he was like 'no I am busy, I will get to you later' and it was midnight and I am on my own and he is refusing to talk to me, I ask them for, erm water, but I have OCD and they didn't, I didn't want to touch any of the erm, ones that were standing around that anyone could have touched, and they flat out just refused to give me a clean cup they were like 'no you have to wait until tomorrow morning' I did not have any water for the next 12 hours or so because they refused to give me a clean cup, you know erm... so it is like he, since then I was terrified of him, I actually sort of locked myself in my room and whenever he was around I would not walk past him, I would not...he just seemed to beyond disrespectful to me.	Agency staff lack knowledge Feeling confused No introduction to the ward Being dismissed Staff unwilling to meet needs Neglected Fearful of staff Treated differently Stigma of diagnosis

Hmm... And others...well...obviously they accused me of 'splitting' there is nothing more, anyone else without my diagnosis they would not think twice about it if they get along with some nurses and not with others, however if you have my label - borderline - obviously, but then you are being accused of being splitting and manipulative and erm...and it is never their fault, they cannot do anything wrong it is always us.	

END OF EXCERPT

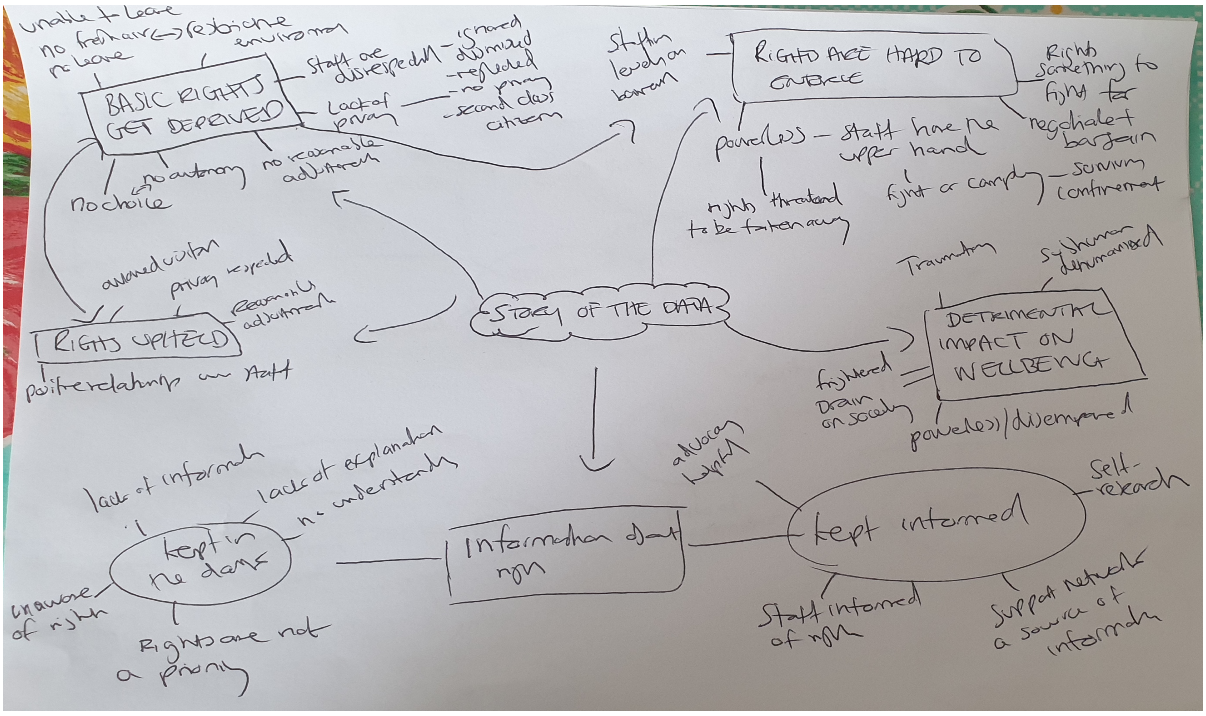
6.10 Appendix J: Example of Coding Table from Theme: Deprived of Rights

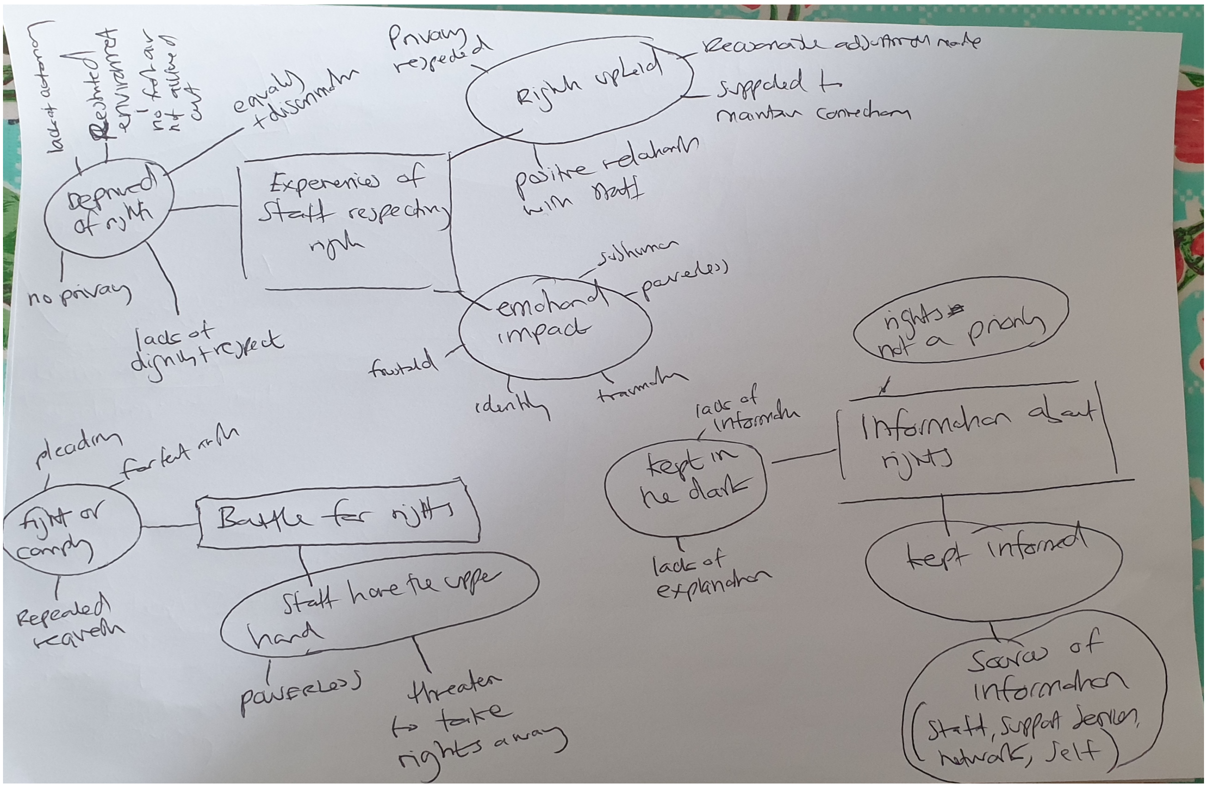
Theme	Subtheme	Code	Excerpt
Deprived of Rights	Restricted Freedoms	Leave denied Staff not supportive of leave	P12: Oh yeah, we were frequently denied a walk if it was...fair enough if it is pouring, but we were frequently denied it if it was bit too cold or a bit wet or there weren't enough staff erm... or they would give those reasons but you would just suspect that they just weren't up for it, like...I just.
		Restrictive environment Unable to leave	P5: I just want to go to the shops' I didn't have that and they would make points when visitors came, and say 'you can't take [participant's name] out of the hospital because you are not qualified to be his carer in his current condition'.
		Rights taken away	P:10 I think that, I think that we all kind of have a right to exist with our own uniqueness and I think in terms of my rights, like in terms of my human right of, my right to liberty, my right to family life, I think that that was taken away from me.
		Deprived of rights Locked in	P3: I always referred to it as being deprived of my human rights because that is what it felt like, you are locked in, physically, you are behind the locked doors whether it is the door to your room or the door to the ward, you are locked in and you are not allowed to leave.

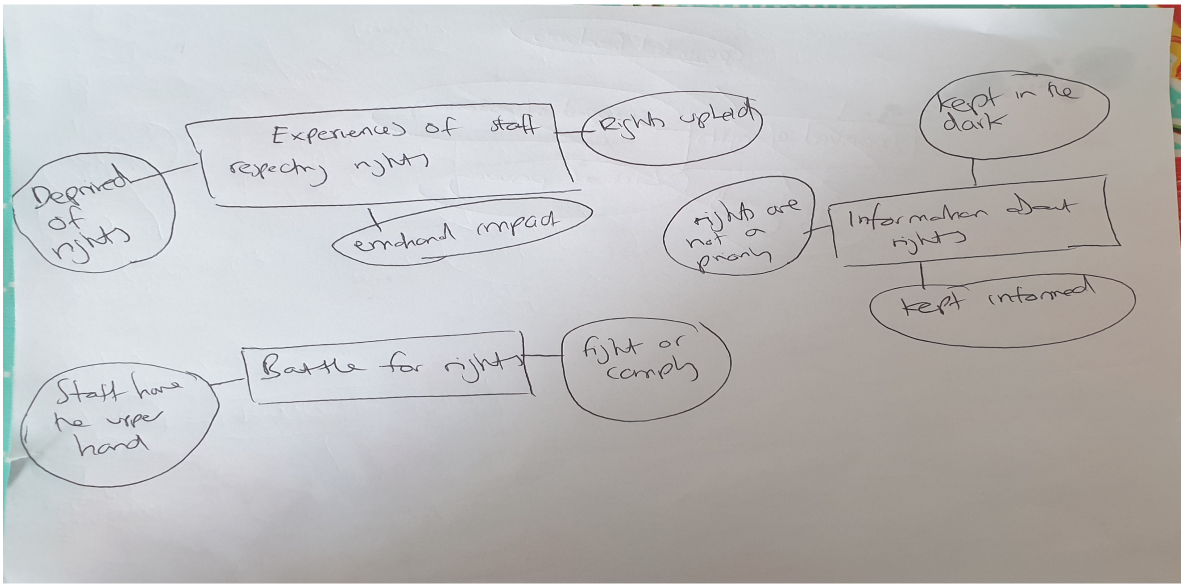
		No access to fresh air Denied leave Staff levels a barrier to leave	P9: Like, for example, I should have had a right to fresh air, I should have had a right to do activities, I should have had a right to certain activities, but because overtime I requested, it was like 'well we are short staffed' 'we are short staffed, short staffed'.
	Dignity and respect	Staff are infantilising Lack of respect	P2: I was treated, because of my age I don't think I am respected because people don't know how old I am, so they presume I am like 28 or 34, and they think they can treat me like I am a little child
		Neglected	P13: Also, just leaving me to my own devices, when I needed food, because I was too depressed to eat I was just left in my room and nobody cared, erm...yeah.
		Treated like an animal Lack of dignity	P10: Well, I think that you know hand cuffing somebody and putting them in cage for a few hours is not good for people, I don't think that any human being should, unless they are some kind of prolific rapist or murderer or something, should have to sit in a cage you know small one, looks like like you get impounded by a dog...
		Treated like an animal Lack of dignity Staff are refuse to talk Lack of respect Treated as an inferior	P3: To be locked up, sometimes it's like, not necessarily just in inpatient contexts, but some of these places of safety can feel like a zoo, you are behind the glass window and people stare at you from outside

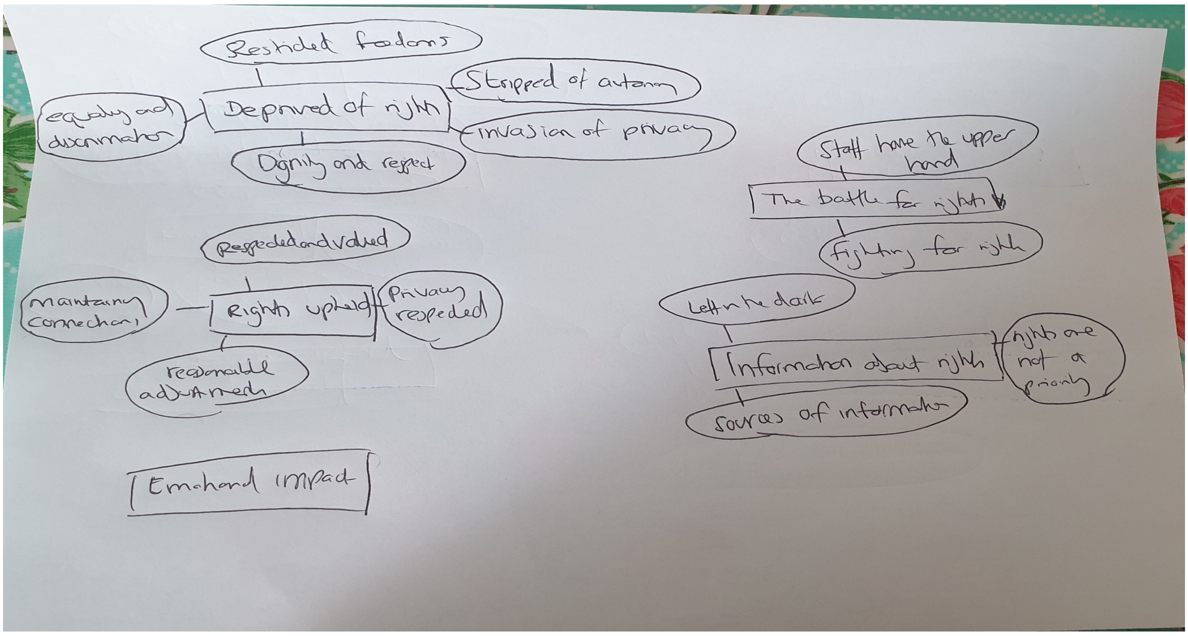
			the nursing station, they refuse to talk to you and you are just there like knocking you know? You are treated like a second-class citizen or something.
		Staff are disrespectful. Paternalistic attitudes. Threatened use of MHA	P5: I didn't think they showed me a lot of respect of my own intellect, erm or respect of my own knowledge when it was clear what I knew about my own condition, how the hospital works, the legal recourse I had, they didn't treat me with respect with that, it was very patronising, it was very 'you are the patient, we will deal with this, don't do anything wrong or else we will section you as a punishment'.
		Being ignored. Neglected.	P7: Initially they ignored me (and I mean for a few hours), then one nurse told me they'd called the doctor. They then left me for more hours and only mentioned they'd called the doctor again when other patients started begging them to help me.

6.11 Appendix K: Candidate Thematic Maps



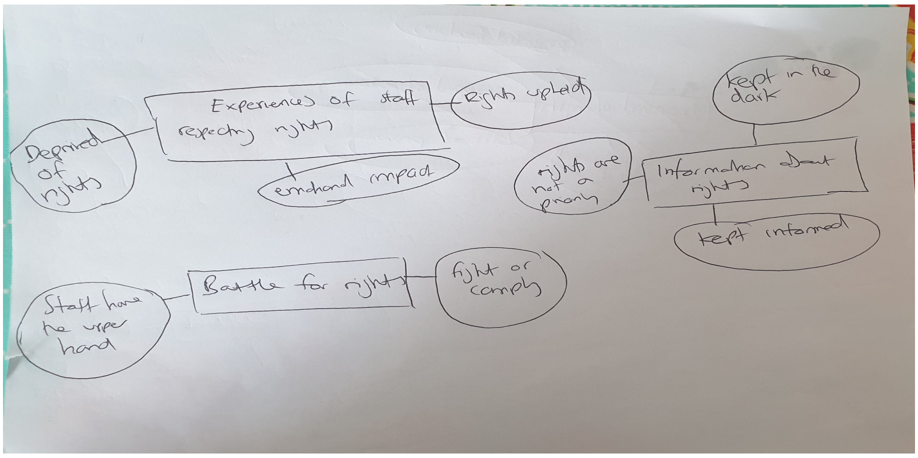



Experiences of staff respecting rights
Rights upheld
Deprived of rights
emotional impact
Kept in the dark
rights are not a priority
Information about rights
kept informed
Battle for rights
fight or comply
Staff have the upper hand


Restricted freedoms
Stripped of autonomy
equality and discrimination
Deprived of rights
invasion of privacy
Dignity and respect
Staff have the upper hand
The battle for rights
fighting for rights
Respected and valued
maintaining connections
Rights upheld
Privacy respected
reasonable adjustments
Left in the dark
Information about rights
rights are not a priority
sources of information
Emotional impact

6.12 Appendix L: Development of themes and subtheme

There were initially three main themes and eight subthemes. The themes were: Experiences of Staff Respecting Rights; Battle for Rights; and Information about Rights. Sub-themes were: Deprived of Rights; Rights Upheld; Emotional Impact; Fight or Comply; Staff have the Upper Hand; Left in the Dark; Kept Informed; Rights are undervalued. These are illustrated by the following thematic map:



Changes were made to the themes “Deprived of Rights” and “Rights Upheld”. These were initially subthemes to the theme “Experiences of Human Rights being Respected”. It was thought, however, that there were too many distinct categories within each subtheme. There were at least five subthemes within “Deprived of Rights”, many of the codes related to different human rights, and it felt necessary to represent these different categories within the data. Similarly, “Rights Upheld” was formed into four subthemes, as it was thought that there were four sub-categories of codes within this theme relating to ways in which participants’ rights were respected. The subtheme “kept informed” was changed to “Sources of information”. Initially these were two separate categories, but following independent coding review, it was thought that these categories were not distinct enough as they both described how participants found out about their rights. The subtheme “fight or comply” was changed to “fighting for rights” as it was felt that this was a distinct category that described the ways in which participants negotiated and bargained for their rights to be upheld. In addition, by including the word “comply”, there was too much overlap with the subtheme “staff have the upper hand”, which essentially described the same aspects of data.