

A Qualitative Study Exploring the Lives of Disabled Muslim Women in the UK

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ABSTRACT

This thesis explores the experiences and perceptions of Muslim women living with disability in the UK. Disabled Muslim women in the UK often face multiple discriminations based on disability, gender, religious, and racial grounds. Qualitative research exploring the disabled Muslim women's experiences and how they perceive themselves and cope in their everyday life is limited. Addressing this gap, my study extends literature on the intersections of disability with gender, race and religion, and draws upon narrative interviews with five Muslim women living with disability in different parts of the UK. Data were analysed by a 'narrative intersectionality' approach which explores how each participant experiences her multiple identities within different social contexts.

The findings illustrate the complex ways in which disabled Muslim women experience various modes of everyday disablism. Much of the oppression and barriers that they experienced were socially determined, both through direct discrimination, stares and prejudicial attitudes, and indirectly through numerous instances of stigma and fear of others' reactions whilst in public spaces. However, the women in this study did not present themselves as victims in the face of a challenging present and uncertain future. Instead, each one of them portrayed herself as a source of "help" (Samia), "fighter" (Nadia), "activist" (Kinza), "successful" (Farah), and "friendly" (Zara) woman who resists and overcomes daily social challenges to recreate a better world for herself, other disabled Muslim women, and the next generation of disabled people. Some of the women found creative ways to redefine, reconstruct, or celebrate their unique identity as disabled Muslim women in the UK, that otherwise would be invisible or perceived negatively in their social world.

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CHAPTER ONE: Introduction

1.1 Background

This thesis provides an account of the experiences and perceptions of Muslim women living with disability in the UK. Disabled Muslim women, irrespective of impairment, are often disadvantaged on multiple fronts and face discrimination in everyday life situations (Dossa 2009; Jawad and Benn 2003; Hanna and Rogovsky 1991; Schur 2003; Turmusani 2001). Discrimination against these women is not merely a function of the women's subordinate position in society (Dossa 2009), it is a result of the intersections of gender, race, religion and disability identity.

Discrimination against women is defined as *“any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, ... on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field”* (United Nations [no date], p. 2). According to the Equality and Human Rights Commission's (2015) review, men in the UK are almost twice as likely as women to be a senior official. In addition, the employment rate for women in the UK was 69.7% lower than that for men, and women were more likely to be the victim of rape or domestic violence (Equality and Human Rights Commission 2015). Women also tend to be judged by their physical appearance more than men, this is because they are more likely to engage in social comparisons of perceiving a same-sex person as having better physical qualities than themselves (Brennan et al. 2010; Neagu 2015; Quick 2013; Parker 2009; Taub et al. 2003).

Disabled women, even more intensely than women in general, have been cast in the collective cultural imagination as inferior, unfit, useless, undesirable, asexual and incapable of independence (Garland-Thomson 2005; Hanna and Rogovsky 1991). They face double discrimination on the basis of gender and disability disparities, these combine to produce poor outcomes such as lack of access to healthcare, low employment, education, lower income levels, and fewer opportunities for vocational training (Ekblom and Thomsson 2018; Kim et al. 2020; Schur 2003). Moreover, disabled women are vulnerable to sexual violence because of the stigma and prejudice associated with their disability. As such, they are among the most vulnerable and marginalised social groups of society (Ekblom and Thomsson 2018). Yet, Asian or Black disabled women face the triple oppression of sexism,

racism and disablism and, as a consequence of these social categories, they are socially excluded and placed in an extremely marginalised position (Begum 1992).

On the other hand Jawad and Benn (2003) suggested that most Muslim women experienced double oppression, from the culture of their community and the culture of their religion. In the community, Muslim women are up to 71% less likely to be employed than White Christian women of the same age and qualifications because employers may perceive them as a threat in the post 9/11 world (Dugan 2015; Selod and Embrick 2013). Moreover, Muslim women were amongst the targeted victims of anti-Muslim hate crime encountered by Muslims living in the UK because they wear one of the most recognisable symbols of Islam - the hijab (Dodd 2019; Jawad and Benn 2003). This symbol has become riddled with racial meanings such as 'foreign', 'violent', 'oppressive', and 'misogynistic' (Al Wazni 2015; Siraj 2011; Selod and Embrick 2013). Taken together, these stereotypes result in the belief that a Muslim woman's body is incapable of Western ideals and values (Selod and Embrick 2013), which justifies why they also experience racial discrimination since only 1.2% of Muslims in the UK describe themselves as being of White British origin (Ali 2015). Regarding the culture of their religion, Muslim women have traditionally been assigned for motherhood and homemaking roles. This is the case despite the fact that Islam states that such roles are neither exclusive nor inflexible (Islam House 2013).

Literature addressing inequality, which is related to gender, race, religion and disability identity, has largely overlooked the concerns of disabled Muslim women in the UK. Furthermore, debates about identity, gender, race, religion and disability often take place in isolation from each other (Hussain 2005). Yet, these markers of difference need to be considered in relation to each other to bring to the fore the paradigm of intersectionality and to show that disability does not function in isolation from other social categories. Rather, they accentuate each other contextually and as a process.

While few studies have examined the experiences of disabled Muslim women (Dossa 2009; Hussain 2005; Turmusani 2001), it is believed that there have not been any studies exploring the everyday life and experiences of disabled Muslim women in the UK. Thus, the goal of this study is to address this gap in the literature. The study explores the lives of disabled Muslim women in the UK, they share their stories of what it is like to be subject to discrimination as a result of multiple identities. It aims to answer the following research question:

What stories do participants share and construct based on the experience of being a woman, Muslim and disabled in the UK?

Taking into account the participants' racial background, this study also addresses the limited information regarding daily life experiences of disabled Muslim women, and specifically how they make sense of and cope with their multiple identities in the UK. Yet, since there is neither a single method for narrative analysis nor the analysis of the intersectional identities (Nasheeda et al. 2019; Turan et al. 2019), it was necessary to develop the 'narrative intersectionality' approach with the aim of crafting an analytical tool that was sensitive to the intersectional identities of the participants throughout their narratives.

Chadwick (2017), and Blackie et al. (2019) highlighted the concept of narrative intersectionality. As narrative research emphasises the individuality of a person's story, they argued that individuals' lives could not be understood as categories in isolation because an individual's identity is a product of summing up their different identities. This individuality is key to the link between narrative and intersectionality. For this link, the individual person may embody many categories of identity in his/her narrative, reflecting the concept of intersectionality. Thus, the narrative intersectionality approach allows the researcher to explore how particular identifications are always co-constructed and intersected with other categories of identities throughout a person's life.

I, therefore, decided to develop a narrative intersectionality approach as the analytical approach, this draws from Chadwick (2017), and Blackie et al.'s (2019) concept of narrative intersectionality. I found this approach to be the best method for capturing the experience of living with multiple minority identities. It conceptualises each participant's narrative as multidimensional and comprised of multiple analytical layers concerning multiple identities, the story is co-constructed between the participants and other actors throughout their lifetime within different social contexts.

In this thesis, the terms impairment and disability are used. Impairment refers to a medical concept which implies a change in one's health status (Walker 1993). It is an illness, injury or congenital condition that causes or is likely to cause a loss or abnormality of psychological, physiological or anatomical body structure or function. On the other hand, disability, as used in this thesis, refers to a non-medical phenomenon (Walker 1993). It is the limitation or loss of opportunities to take part in society on an equal level with others due to social and environmental barriers.

Within this thesis, I also reflect on my role as a researcher investigating the lived experience of a group which is hard to gain access to (Boulanouar et al. 2017). In doing so, I pause to consider not only the emotional impact on my participants of taking part in my research, but also how I was affected by listening to their narratives. I considered how my position as a

registered Occupational therapist helped to reassure the participants that they were dealing with a trusted health care professional in the UK. In addition, I reflect on how my identity as a disabled Muslim woman assisted in increasing participants' level of comfort and drew their attention to the researcher as part of their world. Being reflexive constantly reminds me that the individuals involved in this research are subjects, not objects and allows me to focus on the differences and unfamiliar situations, as well as writing up my failures (Lumsden et al. 2019). The detailed discussion on reflexivity within this study can be found in the discussion and conclusion chapter (section 10.6).

1.2 Aim and objectives

The overall aim of this study is to add to existing research by exploring Muslim women's experiences of living with disability in the UK, using an intersectional lens. The specific objectives were:

1. To explore the experiences of daily life from the viewpoint of disabled Muslim women, how they perceive themselves when they are living with multiple identities of being a woman, Muslim and disabled in the UK.
2. To explore how the social and cultural contexts influenced participants' identity, choices, decisions and actions.
3. To foreground what strategies those women have developed to make sense, cope and adapt as disabled Muslim women in everyday life.

1.3 Significance of the study

This study aimed to explore Muslim women's experiences of daily life whilst living with disability in the UK. Living as a disabled Muslim woman is unique to each woman, this uniqueness varies from one socio-cultural context to another. Understanding each participant's experience from their viewpoint gives the woman a voice within the location of oppression, inequality, discrimination and negligence. It also enables a greater appreciation of these women's complex lived experiences beyond the story told. In addition, the knowledge acquired, through this research, will give a greater understanding of the way in which the participants' multiple identities were influenced when the burden of discrimination was combined with the disability, of how they felt about themselves and faced people, and whether they obtained any privileges from these multiple identities.

The United Nations (2017a, art. 6) concluding observations, on the initial report of the United Kingdom of Great Britain and Northern Ireland, raised concerns about the *“the lack of measures and available data concerning the impact of multiple and intersectional discrimination against women and girls with disabilities”* in the UK. Yet, this group of disabled Muslim women remain underrepresented in research and there are also few such studies in other countries. The goal of this study is to address this gap in the literature by exploring how disabled Muslim women live and cope with disability in the UK in addition to their gender, race and religious identities. Findings from this study could offer a valuable addition to critical disability studies and provide empirical evidence to develop policies that better address multiple discrimination against disabled women.

1.4 Conceptual framework

I aimed to explore daily life with a disability from a broader perspective, focusing on how participants experience and make sense of their life in their own local context, in the presence of a disability and their gendered, racial and religious identity. Therefore, in this thesis I relied on the theory of intersectionality to conceptualise how social categories, such as gender, race, religion and disability, combine to shape the participants' experiences. This framework allowed for an empirical analysis of how participants' multiple identities were socially constructed, in the convergence of their local context, in order to engage with the research question described above.

Intersectionality was developed as an area of research and theory by Kimberle Crenshaw (1989). Crenshaw critiqued mainstream feminism and race/ethnic studies because women's studies often gave primacy to White women, whereby race/ethnic studies often focused on racial inequality from the perspective of a man of colour. Thus, both areas of studies did not account for the experiences of women of colour (Crenshaw 1989; Windsong 2016). Similarly, this study aims to use intersectionality theory as a conceptual framework to explore the experiences of disabled Muslim women in the UK, this is seemingly overlooked across women's studies, race studies, religion/Islamic studies and disability studies.

Intersectionality is both an explanatory conceptual framework and an effort to address social inequality based on intersecting social identities, as demonstrated at both the individual and group level (Caiola et al. 2014). According to Hankivsky (2012), a core epistemological assumption of intersectionality is that knowledge should develop from the perspective of the oppressed social group, not the dominant group. Intersectionality is a way of understanding how multiple social identities overlap, with no one social identity taking primacy. It exposes

the different types of discrimination and disadvantage that occur as a result of the combination of those identities (Caiola et al. 2014; Symington 2004).

Intersectionality aims to address the manner in which sexism, racism, class and other systems of discrimination create inequality. It takes into account the social, historical and political contexts and recognises the unique individual experiences resulting from the coming together of different types of individual identity (Symington 2004). Moreover, it demonstrates the impact of these converging identities on opportunities and access to rights, and shows how services, programmes, policies and laws that impact on aspects of individual's lives are inextricably linked to others (Symington 2004). In this study, intersectionality is used to conceptualise how participants' social identities such as gender, race, religion, and disability accentuated each other, focusing on their interactional effect rather than viewing disability as a master category under which other categories are subordinated.

McCall (2005), highlighted the fact that because intersectionality takes account of multiple social identities, complexity is a core concern. Hence, McCall (2005) identified three approaches researchers could use to manage that complexity: anticategorical, intracategorical and intercategorical complexity. The anticategorical complexity aims to deconstruct analytical categories. The intracategorical complexity focuses on a specific single social group that highlights particular intersections, such as a group of disabled Muslim women in the UK. The intercategorical complexity focuses on the complexity of relationships among multiple groups (McCall 2005).

In the light of McCall's (2005) approaches, I followed Choo and Ferree's (2010, p. 147), statement that *"it might be part of a methodological strategy to consider how a design will denaturalize hegemonic relations, particularly by drawing attention to the unmarked categories where power and privilege cluster"*. In this regard, the intracategorical complexity approach was considered in this study, taking into account the importance of studying oppression alongside privileges as suggested by Choo and Ferree (2010). This is because participants' experiences are not only impacted by their gender, race, disability or religion but also by other factors such as built environment, cultural differences and social support. Thus, by exploring how these determinant factors interact and impact positively or negatively, it could be assessed whether any of those factors might be subject to amendment.

According to Evans (2016) and Samuels and Ross-Sheriff (2008), intersectional studies should recognize the ways in which social context can affect social inequalities, particularly the way in which historic, economic and political conditions can shape participants' experiences, and can cause resistance to marginalization and exploitation across various

contexts. In this regard, Groenmeyer (2011) highlighted the fact that concepts of women and men are often presented as binary opposites or dichotomous, rather than contextually or socially constructed within a particular environment. This approach misses the opportunity to examine the social relationships between women and men within a particular context (Groenmeyer 2011), and the linkage between oppressive and supportive environments. Therefore, this study aims to explore how women's multiple identities are influenced, shaped and co-constructed in specific social contexts by different actors throughout their lifetime, taking into account their unique individual experiences within their social context.

In short, intersectionality calls to consider women as whole beings; to recognize that not all women experience their womanhood in the same way. Many women face multiple forms of oppression but not all of them are rendered powerless (Samuels and Ross-Sheriff 2008). I found it important, however, to push this concept further and suggest that individually disabled Muslim women in the UK experience their multiple identities and various interlocking oppressions differently in different contexts.

1.5 Organisation of this thesis

This thesis is comprised of ten chapters. Chapter 1 introduces the background to this study, presents the research question, aim, objectives and the significance of this study. The first chapter also outlines the conceptual framework that supports this thesis and the organisation of its structure. Chapter 2 presents a review of the related literature. Given the paucity of literature exploring the everyday life experiences of disabled Muslim women, I drew upon the wider literature related to the categories of their multiple identities, in order to give a comprehensive overview of relevant knowledge. As such, the literature review is focused on four types of literature: critical disability studies, disability and gender, disability and race, as well as disability and religion. The literature review also provides an overview of the research studies which explored Muslim women in general, and those living in the UK in particular. The chapter closes with a discussion of the research studies which examine the experiences of disabled Muslim women (Hussain 2005; Dossa 2009; Turmusani 2001).

Chapter 3 outlines the methodological approach which was adopted, addressing the research questions in five sections. In section one, the rationale for choosing the qualitative research and narrative inquiry is discussed, also the connection of narrative inquiry to studies of identity. Section two provides a detailed account of the data collection methods which were followed in this study. The sampling and recruitment process aimed to identify and engage with eligible participants who reflected the main characteristics of the inclusion criteria from different parts of the UK. Since minority ethnic populations, such as disabled

Muslim women, can be difficult to engage in research (Gerrish and Lathlean 2015), this section includes the steps which were followed to build a relationship of trust between myself as a researcher and the prospective participants. The settings, in which participants felt they would be comfortable and safe to tell their stories during the interview, were also discussed. Data collection tools included multiple narrative interviews combined with semi-structured interviews, observing nonverbal communications and note-taking data. Constructing the researcher and participant relationship was also discussed as a significant tool for the collection of data.

Section three describes the data analysis methods, these included the transcription, data storage and management, and the analysis process. Data in this study were analysed using the narrative intersectionality approach, this was developed based on Chadwick (2017), and Blackie et al.'s (2019) concept of narrative intersectionality. The aim of this approach was to craft an analytical tool that would be sensitive to the multiple identities of the participants. Section four describes the measures which were taken to ensure the quality and trustworthiness of this research. Section five discusses the principles of the ethical considerations which underpinned this study.

Chapter 4 marks the beginning of the empirical chapters and introduces the five narrative chapters. Chapters 5-9 present the unique individual narratives of the five participants in this study. Chapter 5 discusses the factors that affected an older disabled Muslim woman's social life and led her to describe herself as an "*isolated*" person. It explores the challenges of living with a disability, particularly in the context of her home, focusing on the impact of physical impairment and its significance socially such as loss of independence and reduced social interaction. Chapter 6 considers the role of power dynamic and racial discrimination in health and social care. Chapter 7 highlights a disabled Muslim woman's attempt to engage with the world around her in an attempt to change wider perceptions of disability, rather than to present herself as a victim or as a tragic person. Chapter 8 considers the practices that a disabled Muslim woman enacted to live her life without letting her visual impairment define her. It also describes the challenges she faced in everyday life, trying to challenge the dominant social perception of visual impairment and celebrate her different identity as a disabled Muslim woman. Chapter 9 relates the story of a black, disabled Muslim woman who wore a niqab, she described how she felt she was stared at, socially excluded and vulnerable due to hostility towards body differences in her ordinary everyday life context.

Chapter 10 discusses the findings in relation to the objectives of this study. It also considers the implications of the study for the development of research methodologies which are sensitive to capturing the experience of living with multiple minority identities. Finally, it

highlights the limitations of this study, challenges encountered during its process, recommendations for future research, reflexivity used within this study, and finally draws the main conclusions. Throughout the thesis, some terms have been used in the literature review and other terms appear more frequently in the narratives as they relate to the lived experiences of the participants as Muslims. These terms are defined and explained where they occur in the text.

CHAPTER TWO: Literature review

2.1 Introduction

Chapter 1 described the overall aim of this study, to add to existing research by exploring Muslim women's experiences of living with disability in the UK from an intersectional lens. This chapter examines research related to the multiple identities of disabled Muslim women in the UK to provide a context for this study. Recently, there has been a significant increase in scientific literature which reviews and explores the unique experiences of people living with intersecting identities (Cho et al. 2013). This renewed interest is, in part, attributable to the promise of promoting equality and addressing discrimination against disabled people from different minority groups. Very few studies have explored Muslim women's experiences of disability, but it would appear that no research has been undertaken looking into these women's experiences from a disability perspective (including the medical, social and person-centred perspective). I begin this chapter by outlining how I identified relevant literature. From here, I draw on the wider literature located within critical disability studies, feminist studies, critical race studies, and religious studies, which results in identifying any gaps within which the experiences of the disabled Muslim women fall in various bodies of literature.

This chapter is presented in eight sections prefaced by this introduction section. The second section includes a summary of how I searched the literature in the literature review chapter. The third section focuses upon the critical disability studies literature. The limitations of disability studies are considered and, in particular, the social model of disability which led to the emergence and significance of critical disability studies. Critical disability studies are characterised by their intersectional perspectives of considering how gender, race, class, disability and other markers of difference constitute or contradict one another (Goodley 2013). This type of perspective fits well with the aim of this study. Thus, the approach to study disability in this thesis builds upon Goodley's (2013; 2014; 2017), and Goodley et al.'s (2019) argument that the purpose of critical disability studies theory is to start with disability but never end with it. My rationale in adopting this approach is to explore what it means to be a disabled Muslim woman in the UK because, despite their multiple minority status, the concerns of these women are overlooked in various bodies of literature.

Given the paucity of the current literature on disabled Muslim women, this literature review includes research related to the categories of their identities in relation to gender, race and religion. The fourth section considers literature which examines the relationship between

disability and gender. The experiences of disabled women are described and how these women have been subject to double oppression due to their gender and disability identity (Schur 2003). I also review the emergence of feminist disability studies and highlight how this field of studies foregrounds “*whiteness as its constitutive underpinning*” (Bell 2006, p. 275). Thus, feminist disability studies scholars were often not able to engage with race as an analytical category despite the acknowledgment of its significance (Schalk and Kim 2020).

In the fifth section, I consider literature which discusses the relationship between disability and race, examples of the conflation of race and disability are provided. I also highlight how Black disabled women experience a complex nexus of inequalities due to their gender, race and disability (Moodley and Graham 2015). Then, I point to recent proposed frameworks, such as a Black feminist disability (Bailey and Mobley 2018), and feminist-of-colour disability studies (Schalk and Kim 2020), which call to integrate critical race work in feminist disability studies. Considering the intersectionality of gender, race and disability in such frameworks, I argue in this literature review that critical disability studies have yet to consider the issue of religion as an additional layer of social identity, which segregates people and sets them apart (Elliot et al. 2013; Oni-Eseleh 2021).

In the sixth section, I consider literature which discusses the relationship between disability and religion. I show how the studies of religion and disability focus on the representation of bodies in texts such as the New Testament in Christianity, the Torah or the Talmud in Judaism, the Quran in Islam, or stories about the Buddha and Hinduism (Petro 2016; Schumm and Stoltzfus 2016). In other words, the central theme of this field of studies focuses on how people perceive the disability from a religious lens. I argue that experiences of disabled Muslim women fall through a gap in various bodies of literature which do not consider the intersectionality of their religion identity with their gender, race and disability identity. As a consequence, in the seventh section, an overview is provided which explores who are the Muslim women in the UK. This overview explains that Muslim women have been subject to many challenges, such as the increased acts of violence related to Islamophobia and discrimination related to their practice of hijab. Finally, in the eighth section, I consider the key findings from three available research studies exploring the experiences of disabled Muslim women in Britain (Hussain 2005), Canada (Dossa 2009), and the Middle East (Turmusani 2001).

2.2 Literature search strategy

A three-step approach was used to identify extant literature on the experience of disabled Muslim women. The three steps were: broad-based terms scoping; full electronic and non-

electronic scoping; and a screening stage (Hamdy et al. 2006; Shaw et al. 2004). In order to minimise potential researcher bias, this search was conducted once the analysis of the narrative interviews was completed (Holly et al. 2012).

The broad-based terms search began, through the support of a professional reference librarian, with the generation of preliminary key words, “disabled/with disability”, “Muslim”, and “woman/women”. The search undertaken identified a few relevant studies (Dossa 2009; Hussain 2005; Turmusani 2001). Discovering a paucity of literature on the experience of disabled Muslim women, related documents were subsequently located using the electronic citation chaining and author tracking functions that are available in the electronic databases such as CINAHL, ScienceDirect, Scopus, and Google Scholar. In order to target the literature search on electronic database, Bettany-Saltikov (2012) recommended to clarify an inclusion and exclusion criteria.

The inclusion criteria comprised of literature dated 2002-2022. However, I became aware that this period excluded some key theories, seminal texts and other relevant literature. Therefore, the criterion was extended to allow for their inclusion. The relevance of studies identified by the searches was defined by whether the studies were relevant to the topic of disabled women, Muslim women, ethnic minority women, studies on women and intersectionality, and whether they used a recognised methodology. The literature search was also widened to include international studies in addition to those from the UK. Only studies in the English language were considered, whereas studies that included men in their samples were excluded.

An additional strategy used included non-electronic scoping of relevant core journals, as there is an abundance of editorials, commentaries and opinion papers within the literature regarding disabled women and Muslim women. However, my focus remained on primary research studies. The focus of the non-electronic search was on known experts within the disability (for example, Shakespeare 2014, and Goodley 2013, 2014, 2017) and feminist (for example, Garland-Thompson 1994, 2002, 2005, 2017) literature, along with hand-searching relevant journals as some databases restrict access to the more recent publications and recognised articles’ reference lists. The hand-searching involved searching the grey literature which are not indexed in the major electronic databases such as policy literature, government documents, white papers, annual reports, and conference presentations.

The on-going screening stage, with its emphasis on relevant studies and their abstracts, allowed for elimination and appropriate procurement. Reading the obtained studies fully

allowed for additional scrutiny in regards to the inclusion and exclusion criteria. For example, several selected studies about Muslim women focused on their experience of wearing a hijab. As this was not the focus of this research question, this led to an additional exclusion criterion being added. This was followed by undertaking a methodological analysis of each chosen article to ensure the papers used were robust and trustworthy. In the end, literature searching continued until references were redundantly identified and no related ones were apparent.

2.3 Critical disability studies

The rise of the critical disability studies field has built upon the early work of disability studies (Goodley et al. 2019). Disability studies emerged as a distinct field of academic research and professional education across much of the Western countries in the 1970s and has continued to expand over the last two decades in several countries worldwide (DePoy and Gilson 2008; Söder 2009; Meekosha and Shuttleworth 2009). In the 1980s, the growing presence of disabled people in society raised disability as a human rights issue in the global public discourse which, in turn, lent weight to the legitimacy of the new discipline of disability studies (Meekosha and Shuttleworth 2009).

Countering research and teaching about disability as a medical deficit, disability studies scholars and disability rights movement activists in the late 1980s and early 1990s aimed to explain disability as an outcome of certain principles that make sense to society and frame it as a social phenomenon (DePoy and Gilson 2008; Goodley 2017). They argued that disability is not inherent in the individual but rather a result of the complex relationship between an individual's body structures and functions, daily activities and social participation, while recognising the role of the environmental factors in which the individual lives (Bianquin and Bulgareli 2016).

This paradigmatic shift generated a new discourse which exposed the ways in which disability has been made exceptional. It viewed those whose embodied appearance or experience did not fit within the normative, and were subject to cultural discrimination and exclusion, as full citizens with a right to participate fully in the social life of their communities (DePoy and Gilson 2008; Dossa 2009; Goodley 2017; Linton 2005). In other words, disability studies relocated disability to various barriers related to social, cultural, economic and political factors. As such, having an impaired body did not equate to a disability. Instead, disability was a problem belonging to society (Goodley 2013). People are disabled by society which denies them equitable access to resources, not by their impairment or having a different body.

This field of disability studies has theorised the ways in which culture defines and understands disability with the goal of not only exploring what it means to be disabled, but also recognising the ways in which disability is represented, what it means, and what the stakes of such representations and meanings are in articulating and fighting for disability rights (Chess 2016). Central to disability studies is the social model of disability that emerged in reaction to the medical model; the latter depicts disability as a biological problem belonging to an individual's body and which must be medically addressed (Chess 2016; Dossa 2009; Thomas and Sakellariou 2018). According to the medical model, when impairment occurs something has gone wrong and a medical cure is required to restore and repair the individual through corrective surgeries, prostheses and other forms of intervention (Bailey and Mobley 2018). Although medical intervention can be vital for many disabled people, the medical model for understanding disability has been criticised for '*othering*' disabled people. It frames their impairments as pathologies or defects that set them apart from '*normal*' (i.e. non-disabled) individuals (Chess 2016).

In contrast, the introduction of the social model of disability was an important impetus in conceptually moving disability away from a discourse of abnormal and medical deviance, into the discourse of human construction, diversity and discrimination (DePoy and Gilson 2008; Dossa 2009). This model does not seek to change disabled people so that they can be accommodated in society. Instead, rather than focusing on a cure for atypical bodies and minds, this model seeks to change society through advocating for social and political change, legislation, and accessibility adaptations. Thus, the world would be more open to accommodating bodies and minds of all kinds (Chess 2016). This theoretical shift pushes the impact of disability studies onto the research agendas of many other disciplines.

Starting with the social sciences and the humanities, disability studies has synthesized interdisciplinary thinking from multiple academic and professional fields, such as architecture, design, engineering, medicine and natural sciences, in order to inform definition, analysis and response to disability (DePoy and Gilson 2008; Meekosha and Shuttleworth 2009; Söder 2009). An example of the difference between the medical model and the social model is highlighted in people's everyday life when talking about or studying disability. Whilst many people in the UK use the term 'people with disabilities' to express their respect and support by choosing people first, this term implies that disability is individual. Therefore, the social model proposes to use the term 'disabled people', this is the term that is used in this thesis because people are disabled by barriers in their society, not by their bodies (Shakespeare 2014).

There are, however, limitations to disability studies, and, in particular, the social model of disability. First, the manner in which an ableist society defines disability creates disability as an absolute category and denies impairments.abled people tend to think of disabled people as the blind, the deaf, and the orthopaedically impaired (Davis 1995). However, impairment of the human body is relatively common (Davis 1995), and disability includes, according to the International Classification of Functioning, Disability and Health (ICF) by the World Health Organization (WHO), impairments, activity limitations or interference with participation in daily life activities (World Health Organization 2002). These limitations include hearing, speaking, seeing, walking, thinking and moving. Under this definition, one has to include those with invisible impairments including diabetes, arthritis, multiple sclerosis, AIDS, and so on to the category of disability (Davis 1995).

According to the medical approach, disability seems to be an absolute rather than a gradient one, people's bodies are split into two immutable categories: *abled* and *disabled*, *normal* and *abnormal*, *functional* and *dysfunctional*. Second, disability studies often fail to take account of difference and present disabled people as a unitary group. To take an example, Hall et al. (2019) refers to deafness as an inability to master at least one language – spoken or signed – properly. Davis (1995) argues that if deaf individuals could understand and speak English, there would be no problem for them or the wider community. In this respect, the question one needs to ask is what if deaf individuals do not speak English? The sign language, according to Davis (1995), is the locus between the body, language and the world. Deaf individuals have their own history, community, diverse backgrounds, experiences and culture (Golos et al. 2021) and moreover, they tend to intermarry (Braun et al. 2020), thus perpetuating that culture.

Another limitation is that disability studies has struggled to engage with other transformative fields such as feminism, critical race and queer theory (Goodley 2013). The absence of disability issues (e.g. gender, race, sexuality and age) within these fields led Olkin (2002, p. 136) to ask "*whether the door will be held open*" for disabled people if they "*board the diversity train*"? This has led to the development of critical disability studies, in which disability scholars adopted a number of intersectional engagements whereby disability is directly wrapped up with other categories of difference, experiences of marginality and forms political activism (Goodley 2013; Meekosha and Shuttleworth 2009).

Critical disability studies moved away from the preoccupation with binary understandings between impairment and disability, the social model and medical model, and the British versus American disability studies (Meekosha and Shuttleworth 2009). With its intersectional perspectives, critical disability studies asks how gender, race, sexuality, class and disability

constitute or contradict one another (Goodley 2013). This type of discussion offers a rich understanding of diversity and stresses the importance of appreciating intersectionality with further dimensions of multiplicity to produce a body of knowledge that boasts sophistication and nuance. This is, however, not to say that disability studies before this critical turn was simplistic or basic. But what critical disability studies has done, is to welcome divergent viewpoints and clashing perspectives from inside and outside of the disability experience (Goodley et al. 2019).

What unites critical disability studies scholars, according to Meekosha and Shuttleworth (2009), is an agreement that disabled people are unrecognized, undervalued and discriminated against – and this situation cannot be changed simply through liberal or neo-liberal legislations and policies. This thinking fits well with the term '*critical*'. For Goodley et al. (2019), the word '*critical*' denotes a qualitative shift in studies of disability from the traditional to the new, from the orthodox to the evolving and from the specific to the expansive. The latter point recognises the significance of intersectional thinking which works through the convergent processes of exclusion and discrimination on the grounds of multiple identities (Crenshaw 1991; Goodley et al. 2019).

Matereke (2020) shared the notion that the term '*critical*' serves to highlight two points. First, it is critical in its perspectives, these are embedded in epistemological and ontological frameworks that highlight disability studies as not only an analytical field which develops its own theoretical frameworks and conceptual categories. Instead, similar to other critical theories¹ it draws from the Frankfurt School and Postmodernism, critical disability studies emphasises how experiences of discrimination, oppression and exclusion for disabled people are socially constructed. Second, disability studies requires a critical approach in order to emerge from the limitation of disciplinary biases and better understand the experiences of disabled people from multiple perspectives (Matereke 2020).

In accordance with Matereke's (2020) points, Goodley (2013; 2014; 2017), and Goodley et al. (2019) argue that the purpose of critical disability studies theory is to start with disability but never end with it, as it is the space from which to think through a host of theoretical, practical and political issues that are relevant to all. In other words, the politics of disability are intertwined with many other politics such as those associated with sexism, racism, classism, transphobia, heterosexism, colonialism and developmentalism (Goodley et al.

¹ Critical theory marked one of the first concerted efforts at challenging and problematizing the way power operates in structural and discursive constructs of society in a modern disciplinary context (Garlitz and Zompetti 2021).

2019). In this way, critical disability studies should seek to be in tune with these complexities through direct engagement with the actual lived experiences of disabled people. The aim is to consider how their experience of discrimination, oppression and exclusion is socially constructed, as a result of the relationship between disability and the socio-cultural, economic and political environments that are unresponsive and maladaptive to the needs and aspirations of disabled people. This is what Matereke (2020, p. 88), has called “*disablement*” — a term that has nothing to do with the mind, body, and impairment of the person but rather a pointer to how disability is socially constructed.

In this thesis, my approach to studying the experiences of disabled Muslim women in the UK starts with disability but does not end with it. In this sense, while placing disability in the foreground of the debate, I seek to engage with literature that is intersectional, recognising how disability intersects with gender, race, religion and sexuality to illuminate the world-making, power relations, and affects at stake for these women in their mundane everyday life. My aim in adopting this approach, which builds upon Goodley’s (2013; 2014; 2017), and Goodley et al.’s (2019) argument, is to explore what it means to be a disabled Muslim woman. Because despite their multiple minority status (gender, race and religion) the concerns and needs of these women, as disabled citizens of the UK, have been overlooked in the literature.

For example, in several prominent UK-based surveys (GOV.UK 2021; Pillai et al. 2007; Equality and Human Rights Commission 2017; Department for International Development 2018), there is no mention of disabled Muslim women as a category or subject of discussion. In addition, the UK is a signatory of the United Nations (2007) Convention on the Rights of Persons with Disabilities (UNCRPD), and as such has a commitment to enforce and promote equality and improve the lives of disabled people (Williams et al. 2018). Yet, the report of the UNCRPD during 2016 ruled that the UK approach to austerity measures unfairly discriminated against disabled people with a detrimental impact upon the provision of social care, inclusion in society, financial income, housing, work, mobility and mental health (United Nations 2017b).

The British government’s failure to adhere to the UNCRPD, as a consequence of several factors, including cuts to services, acts as an indicator that many disabled people find themselves disadvantaged in precarious situations (Goodley et al. 2019). When gender, race and religion are added to these situations, the impact of compounded social exclusion and oppression is considerable. At the same time, communication between institutions, from international to national to regional bodies, has also led to the development of a top-down approach that does not address the lived realities and concerns of this group of women. In

the following sections, three interrelated issues in disability studies are discussed: gender, race and religion and the gaps in the literature in relation to the experiences of disabled Muslim women.

2.4 Disability and gender

Disability plays a significant role in the construction of gender categories and the ways in which people's gender is understood in the world (Chess 2016; Shifrer and Frederick 2019). Stereotypes about gender compound disability oppression, and they demonstrate how compulsory gender norms and heteronormativity support compulsory able-bodiedness and the myth of normalcy (Chess 2016). Women have often been excluded from enjoying their full citizenship because of gender stereotypes which characterise men as more agentic than women, and women as more attuned to others and being emotionally, mentally, and physically disabled (Baynton 2001; Hentschel et al. 2019).

Being both a woman and disabled has been called the "*double handicap*" (Schur 2003, p. 31). This is due to the combination of social burden and the oppression of disablism and sexism, which non-disabled women and disabled men do not face. As such, disabled women find themselves doubly disadvantaged because it is impossible to confront one type of oppression without confronting the other. Thus, the point that disablism cannot be confronted in isolation from sexism is crucial to understanding disability and gender oppression (Sheldon 2014). Disabled women often feel that their concerns are overlooked and their experiences of oppression are neglected (Sheldon 2014). It is because disabled women are said to fall between two identity based movements: as women in the women's movement, and as disabled in the disabled people's movement (Lloyd 2001).

As women, they are not seen as fit to fill a woman's traditional role of being a mother, wife, lover, nurturer, and house maker (Singh 2015). Disabled women are often discouraged from becoming mothers in more indirect ways. They are persuaded that their own health might be affected as a result of motherhood, and that their own impairments will hinder their mothering capabilities, or that their babies might inherit their impairment (Thomas 1997). Disabled women were also found to have a lower chance of marriage (World Health Organization 2011), and employment when compared with non-disabled women, these roles are often seen as inappropriate for them (Singh 2015). Powell (2019), reported that the employment rate for disabled women in 2019, was 25% lower than that for non-disabled women in the UK.

Disabled women, even more intensely than women in general, have been cast in the collective cultural imagination as passive, inferior, useless, needy, dependent, undesirable,

unattractive, incapable, asexual and of lower intelligence (Sheldon 2014; Taub et al. 2003; Garland-Thomson 2005; Taleporos and McCabe 2002; Begum 1992). Viewing women based on their impairments disregards their personalities, skills and abilities (Taub et al. 2003), which in turn might lead these women to have a negative perception of themselves. This negative perception, combined with stigma and discrimination, can lead to internalised oppression (Rohwerder 2018). According to Marks (1999), the experience of internalised oppression is so painful that it cannot be consciously experienced, but it continues to affect self-esteem, and shape thoughts, feeling and actions even when the disabled person is unaware it is there.

Disabled women have for a long time been a neglected group within feminist, gender studies and disability studies (Dossa 2009; Olsvik 2006). Dossa (2009) stated that internalising the socially constructed equation that disability equals dependency, led nondisabled feminists to exclude disabled women in their activist work and scholarship. In addition, a broad feminist critique of disability studies emerged in the 1980s when many disabled feminist activists had been active in the women's movement. They were attentive both to the construction of a male agenda in disability studies and to male control of the disability movement (Meekosha and Shuttleworth 2009). Disabled women wanted to find their voice in the emerging discipline of disability studies as well as in the feminist movement (Meekosha and Shuttleworth 2009). One participant in Duffy's (1881) study, cited in Begum (1992, p. 73) described the contributions to be made:

“Able-bodied women can learn from the disabled, who have had to learn this before they can truly cope, that the physical body is not as important as the person that lives inside; that one is first a person, and second a female; that sex is less important than these two; and that every woman who is honestly involved in her own personal growth is making a contribution to the women's movement whether she is aware of it or not”.

At that time, when disabled women were being marginalised on account of their gender and disability, disability studies began to engage with the feminist theory in the late 1980s with the bulk of work focused on the lives of disabled women (Schalk and Kim 2020). Then, in 1994, Garland-Thomson introduced the term *feminist disability studies* which emphasised the need for feminist disability studies which include, but is not limited to, disabled women (Schalk and Kim 2020). In this article, Garland-Thomson names and redraws the boundaries of the feminist disability studies by reviewing from a disability perspective the work that “*participates in the discourse of feminist disability studies without ever announcing itself as such*” (Garland-Thomson 1994, p. 592). The emergence of the feminist disability theory was significant for disabled women and brought to the fore issues such as abuse and care, and

the right to reproduce and parent. As a result, it became clear, for disabled women, that issues about control of the agenda by disabled men comprised only one part of the picture (Meekosha and Shuttleworth 2009).

Similarly, Hall (2015, p. 2) asks “[w]hat is the place of disability in this feminism?”. Disability studies is simultaneously interested in theorising the body and in advocating for antidiscrimination legislation to support disabled people (Chess 2016). Likewise, feminist studies is simultaneously interested in advocating for gender equality and analysing the ways that the environment shapes the body, while emphasising the diversity of women’s voices and experiences, including disabled women (Garland-Thomson 2002; Garland-Thomson 2005).

Therefore, it is no coincidence that disability studies has flourished alongside feminist studies, since both fields have shared concerns, values, and methodologies in areas such as social justice, political engagement and human diversity (Garland-Thomson 2002; Chess 2016). In addition to their interconnected histories and missions, these fields attend to intersectionality that speak of gender, sexuality, disability, class and other social identities which justify discriminatory practices that shape the lives of both disabled and nondisabled women (Chess 2016; Garland-Thomson 2005). So, although feminist studies has often overlooked disability as a part of its discourse (Moodely and Graham 2015), and disability studies has often overlooked women as part of its discourse, feminist disability studies brought into conversation the benefit of both disciplines.

Feminist disability studies understands disability along with gender, sexuality and class as a system of exclusions that stigmatise bodies we consider to be disabled and reveals discriminatory attitudes and practices directed at those bodies (Garland-Thomson 2005). Understanding how disability functions with other exclusionary attitudes and discriminatory practices clarifies how all these social practices intersect and mutually constitute one another (Garland-Thomson 2002). Although feminist disability studies has taken the issues of gender and disability and claims to examine the complexities of intersectional identity and the challenges of disabled people, its engagement with the issue of race remains limited (Chess 2016; Dossa 2009; Schalk and Kim 2020).

Feminist disability studies scholars, according to Schalk and Kim (2020), are mostly, though not exclusively, White women. Therefore, the field has often assumed a default subject position of whiteness with the focus of the arguments and citational practices that foreground “whiteness as its constitutive underpinning” (Bell 2006, p. 275; Chess 2016; Schalk and Kim 2020). However, the whiteness of feminist disability studies is perhaps predictable given the

whiteness of disability studies (Schalk and Kim 2020). In this regard, Bell (2006, p. 278), points out that “[d]isability studies claims to examine the experiences of a vast number of disabled people, yet the form that representation takes is, far too often, a white one”.

Yet, feminist disability studies recognised the need for engagement with race before Bell’s (2006) critique of the whiteness of disability studies. For example, Begum (1992, p. 70) states that “disabled women cannot be treated as a unitary group”, emphasising that “factors such as types of disability, race, sexuality and class will influence... [their]... individual experiences and these may differ from the experiences of other disabled women”. Similarly, Smith and Hutchison (2004, p. 5) argue:

“disabled and women have particular concerns about the realisation of their rights as citizens and consumers—roles that carry enormous weight in the contemporary world. When gender is taken into account, disability activism itself seems to participate in the discriminatory world in which race and masculinity are privileged”.

Despite early acknowledgments of the importance of race and the inclusion of racial analysis, feminist disability studies scholars, according to Schalk and Kim (2020), were often not able to engage with it. This is the focus of the next section.

2.5 Disability and race

Notions of disability are also central in constructing race as an axis of social categorisation (Shifrer and Frederick 2019). In a racist determination of disorder on the basis of phenotype, for example, Down’s syndrome was originally conceptualised using “colonial, scientific and medical discourses on race and idiocy” as the regressive Mongoloid racial category (Tong 2021, p. 1). This conceptualisation was because Down syndrome’s purported similarities resembled the Mongolian ethnic group (Ashwal 2021; Tong 2021). In another example of the conflation of race and disability, Hayman (1997, p. 220) observed that “[w]hite men without disabilities, it seems, are almost always in charge of everything. They must be really smart. Smarter, on average, than black folks or other racial minorities. Smarter, on average, than women. Smarter, on average, than people with disabilities”.

Hayman’s (1997) assumption fits well with Moodley and Graham’s (2015) findings that Black disabled women have the lowest levels of education, are the most likely to be economically inactive and earn the lowest income. Moodley and Graham (2015) contend that Black disabled women are more affected than Black men without disability and White disabled women, because they face a triple burden of the legacy of inequalities due to their gender, race and disability. Similarly, Bailey and Mobley (2018, p. 27) claim that the tropes used to distinguish between supposedly superior White bodies and purportedly inferior bodies of

colour have relied on corporeal assessment which “*take the able white male body as the centre and norm*”. In other words, cultural practices of shaping, marking and evaluating human bodies are intertwined and partitioned by descriptors of disability and race (Campbell 2008). As a consequence, notions of disability informed how theories of race were formed, and theories of racial embodiment and inferiority (racism) produced the ways in which disability is conceptualised (Bailey and Mobley 2018).

Bell (2006) concedes that the failure of disability studies to engage issues of race and ethnicity in a substantive capacity, positioned whiteness as its centre. In his article, Bell (2006) discusses various examples, from published works to conferences and documentary films, to illuminate the fragile relationship between disability and race in disability studies. For example, Bell (2006) argues that Davis (1995) takes whiteness as a norm in his well-known and highly-influential book “*Enforcing normalcy: disability, deafness and the body*”. On the other hand, traditional race studies have often focused on the experiences of people of colour with structures of racism within whiteness, or more accurately, “*White racism*” (Leonardo and Broderick 2011, p. 2208). Campbell (2008) believed that critical race theory problematized the notion of race as a permanent and abiding category, thereby considering racism as a natural part of Western life rather than an aberrant one.

Gillborn (2015) argues that critical race theory is itself accused of racism by focusing on racist inequity as a result of a permanent race category. Key among Gillborn’s (2015) argument is an understanding that race is socially constructed and that racial differences are invented and reinforced by society. In this approach, racism is understood to be complex and flexible, it manifests itself differently in different contexts, where minority groups are subject to a range of different stereotypes (Gillborn 2015). Thoruis and Waitoller (2017) point to the historical relationship between racism, ableism and oppression that have often intersected and relied on one another. In spite of this, it is important to appreciate how race intersects with other axes of oppression at different times and in different contexts in order to understand how racism works.

Bailey and Mobley (2018), Gillborn (2015), and Smith and Hutchison (2004) all shared the view that the terms disability and race are usually assumed to be relatively obvious and fixed, but are actually socially constructed categories. Historically, according to Gillborn (2015), both terms have operated to define, oppress and segregate. In other words, as with disability, race is a relational system. In terms of disability, constructs such as abled and normal cannot function without those deemed to be disabled, incompetent, incapable and abnormal. In terms of race, Whiteness, which creates the dichotomized racial class system, cannot exist without its antithesis of Blackness or people of colour in general (Bailey and

Mobley 2018; Leonardo and Broderick 2011). In both cases, the privileged group received honour and investment, whereas the marginalised group is dishonoured and oppressed (Leonardo and Broderick 2011). Thoruis and Waitoller (2017) suggest that we cannot address race/racism without addressing the issues of disability, because the ideas of racism and dis/ablism are so intertwined.

Bailey and Mobley (2018) proposed a Black feminist disability framework in order to think in generative ways about the intersectional nature of oppression between gender, race and disability. In their argument of the construction of this framework, Bailey and Mobley (2018) referred to two myths. The first myth suggests that Black women are uniquely strong and able to endure pain and difficulty due to their innate tenacity, therefore, they are not allowed to be defined/seen as disabled. The second myth is that “*Black people are not as smart as White people*” (Bailey and Mobley 2018, p. 25). Therefore, they argue that the Black feminist disability framework helps shift this paradigm by dislodging the White male body as the norm in disability studies, and examining how bodies are raced and the ways in which they intersect with disability and bodily sovereignty.

Yet, in contrast to Bailey and Mobley (2018), Gillborn (2015), Smith and Hutchison (2004), and Leonardo and Broderick (2011) argue that disability is like race. Thoruis and Waitoller (2017, p. 254) argue that “*dis/ability is not the same as race*”, nor is dis/ableism the same as racism. This argument is because disability and race as identity markers have distinct histories, cultural practices and oppression. For example, the history of enslavement of African Americans is not the same as Pakistani and Indian genocide or the institutionalisation of disabled people (Selod and Embrick 2013; Thoruis and Waitoller 2017). Along this argument, in their open letter to White disability studies, Miles et al. (2017) advocate for a *critical intersectional disability studies* that centres the perspectives, interests and needs of marginalised disabled people of different backgrounds and acknowledge the racial, gender, class and other injustice-based disparities which exist within the disabled population.

Similarly, Schalk and Kim (2020, p.32) proposed a framework that they call “*feminist-of-color disability studies*”. Schalk and Kim (2020, p. 34) note the limited engagement of “*(white) feminist disability studies*” with feminist-of-colour scholarship. Thus, they build their work on extant scholarship, such as Bailey and Mobley (2018) and other feminist-of-colour work in disability studies, in order to articulate a framework which integrates existing critical race work in feminist disability studies. According to Schalk and Kim (2020), the feminist-of-colour disability studies framework is not an addition for feminist disability studies or a replacement. Rather it is an element of the field which must be integrated fully to strengthen our

understanding of intersecting and mutually constitutive oppressions of multiple systems of gender, race and disability in ways too often excluded by the field to date.

Overall, having reviewed the work which addresses the relationship of disability to gender and race, it was felt that all prejudices and issues related to these social identities might apply to the majority of disabled Muslim women from minority backgrounds. Yet, the way in which they experience and interpret these issues is likely to differ, as their religious identity interacts with these markers to shape their everyday life experience. To put it another way, while critical disability studies values diversity and recognises the significance of intersectional thinking on multiple identities including gender, race and disability (Goodley et al. 2019), this field has yet to deal with the issue of religion as an additional layer of social identity which also segregates people and sets them apart (Elliot et al. 2013; Oni-Eseleh 2021). Likewise, it is argued that feminist disability studies and critical race theory have yet to accommodate the convergence of religion and disability. The next section examines the literature on the subject of the relationship between disability and religion.

2.6 Disability and religion

Religion plays a central role in the way many people make sense of their world (Imhoff 2017). Religion has also played a significant role in the history of disability, the way in which disabled people are treated and the way their bodies and disabilities have been imagined and constructed (Petro 2016; Schumm and Stoltzfus 2016). For instance, the theme of the nascent studies of religion and disability, which emerged in 1995 from the Society of Biblical literature, was concerned with the ways in which religion or the Bible have been positive and/or negative in helping disabled people to define themselves (Avalos 2007).

Scholars of religion often study the representation of bodies in texts such as the New Testament in Christianity, the Torah or the Talmud in Judaism, the Quran in Islam, or stories about the Buddha and Hinduism (Petro 2016; Schumm and Stoltzfus 2016). The Buddhist texts, for example, are negative towards disabled people (Schumm and Stoltzfus 2016). To take another example, Imhoff (2017, p. 186) reports *“that Judaism paints all disability as deserved or inherited through sin”*, but she argues that Jewish texts approach disabilities in a different way. There is no unified category of disabled people in the Jewish texts. In fact, some mental and physical differences, such as inability to memorise or to walk, have no marginal status in Jewish tradition (Imhoff 2017). Avalos (2007) and Blanks and Smith (2009) also make the point that there is plenty of evidence to show that the Hebrew and Christian Bibles link disability with punishment for sins and God’s wrath, which means any action that violates God’s commandments or moral order.

On the other hand, Al-Aoufi et al. (2012) provide an analytical perspective of Islamic philosophy on disability by examining some texts from the Qur'an and Sunnah. They used the term 'disadvantaged people' throughout their paper, as stated in the Qur'an when referring to disabled people. According to Al-Aoufi et al. (2012), the Qur'an declares the existence of disability as a natural part of human nature and provides principles and practical suggestions for caring for disabled people. The Qur'anic view of disadvantaged people is that of protection of honour, it emphasises the notion of social responsibility and duty to provide such individuals with basic needs such as food, safety, care, shelter, educational, marital and other human rights (Al-Aoufi et al. 2012).

Al-Aoufi et al. (2012) and Imhoff (2017) found that religious values were mixed with cultural perspectives, this often shaped cultural images of disability which could be falsely attributed to religious faith. For example, Petro (2016, p. 373), reported that Catholic culture in the mid-twentieth century represented disability as a punishment inflicted upon an individual by God as a result of sin, but also "*as an occasion for deep holiness so long as the disabled person remained cheerful*". In some Islamic cultures, Al-Aoufi et al. (2012) described how the presence of a disabled child was seen to be a test from God, disabled children were buried alive in some Middle Eastern cultures in the distant past. As such, Boehm (2021) recently contended that different religions had their own sacred texts and cultures which provide different ideas about the meaning of disability and reshapes the way one understands and responds to disability.

Imhoff (2017) argued that disability studies would benefit from integrating religious studies into its discourses and calls for disability scholars to pay attention to the complexities of religious texts, beliefs, practices and cultures. Likewise, Boehm (2021) and Petro (2016) suggested that disability studies can help scholars of religion to think holistically about bodies, cultural norms and lived religious experience. Each of the various stakeholders, such as theologians, researchers and especially disabled people, can bring something unique and important to the conversation about religion and disability. Attention to the intersection of disability and religion can also lead scholars to look outside the usual boundaries of religious texts and practices (Petro 2016).

However, according to Imhoff (2017), critical disability studies rarely engages with the topic of religion. This is in part, Imhoff (2017) suggests, because of the ways crip theory² has

² Crip theory is a merging of queer theory and critical disability studies, which explores how the social pressure and norms around able-bodiedness intersect with the social pressure and norms around heterosexuality, and, as a consequence, offers a piece of thought on how to theorize disability (McRuer 2008).

modelled itself on queer theory, a field that has largely neglected religion and at its worst been overtly hostile to it. To take an example of the hostility between homosexuality and religion, Hodge (2005) finds that some gay men, lesbians, and other progressives perceive orthodox religious believers to be perpetrators of oppression. Whereas many orthodox believers and people of faith believe that gay men, lesbians, and other progressives wish to marginalize people of faith (Hodge 2005). It is also in part because of the ways intersectionality studies tend to neglect religion (Imhoff 2017). In other words,

“[w]hen a woman is not given a promotion because of her gender this act is labelled sexism and the discriminator is labelled sexist. If an Indigenous person is not given a promotion because of their race this act is labelled racism and the discriminator is labelled racist. If a person in a wheelchair is not given a promotion because they cannot walk”

this act is labelled ableism (Harpur 2009, p. 167), and the discriminator is labelled ableist. Likewise, if a religious person is not given a promotion because of their religion this act is labelled Christophobia, anti-Semitism, Islamophobia, or other forms of religious bias (Scheitle and Ecklund 2020), and the discriminator is labelled anti-Christian, anti-Semitic, Islamophobic or anti-religious.

Scheitle and Ecklund (2020, p. 1) shared that “*while a sizable minority of Christian adults report such experiences, a much greater share of Muslim and Jewish adults report experiences with interpersonal hostility, organizational discrimination, and violent victimization due to their religion*”. While issues related to the intersection between gender, race and disabled identity have been widely considered in the feminist, race and disability literature (see for example: Garland-Thomson 2002; Garland-Thomson 2005; Bailey and Mobley 2018; Moodley and Graham 2015; Schalk and Kim 2020), the concern of the religious identity has not been given the same attention at such intersection. There, therefore, seems to be a gap in various bodies of literature through which disabled (racialised/other than White) Muslim women fall. This gap is also related to the fact that an increasing body of literature, within Christianity and Judaism, deals with issues of disability but little has been written from the perspective of other religions as reported by Black (2013). To the researcher’s knowledge there have been very few studies which discuss the experience of Muslim women with disability. Below, I provide an overview about Muslim women’s experiences in general, and in the UK in particular before I evaluate the results of these studies and identify the gaps to be addressed in this study.

2.7 Muslim women in the UK

Islam is the fastest growing religion in the world (Tackett et al. 2018), and the Muslim population is larger than all other non-Christian religion groups in the UK (Ali 2015). The majority of Muslims in the UK come from many different parts of the world. As such, Muslim communities are highly diverse in terms of their ethnicity, nationality, language and cultural backgrounds (Iqbal 2016). Some Muslims find a sense of community within their own ethnic group, while others may find solidarity with the broader Muslim immigrant community or prefer to integrate with the wider society (Kabir 2016).

Muslims in the West, in general, continue to face many challenges including an increase in Islamophobia since the terrorist attack which was carried out by radical Muslims in America on 11/9/2001, and the London Bridge attack in June 2017 (BBC 2018a; Fergus 2005; Ryan 2011). Muslim women have been victims of hate crimes and acts of violence more often than men, this is due to their religious visibility because of the hijab (Al Wazni 2015; Jawad and Benn 2003). In the UK, there have been many reported incidences of Muslim women being subject to verbal or physical assault from strangers in places such as shopping centres, parks, and more commonly on public transport (BBC 2018b; Zempi 2020).

While most Muslims in Britain share the same religious identity, the expression of their religion is often practiced and shaped by their various cultural traditions. For example, there are many interpretations of how to conform to Islamic expectations in terms of presenting the body and dressing modestly. For example, Al Wazni (2015) found that many Muslim women wanted people to know that their image as an oppressed non-Western women is the result of their Islamic culture and patriarchal traditions and not a part of Islam. Al Wazni (2015) also referenced media images post 9/11 as a major contributor to the proliferation of the assumption that Muslim women who wear the hijab are oppressed or controlled by men. As a result, Jawad and Benn (2003), suggested that most Muslim women experience double oppression resulting from the culture of their religion and the culture of their society. Thus, similarly to disabled women, Muslim women fall between two identity-based movements: as a woman in the women's movement, and as a Muslim in the Muslim people's movement.

Muslim women are often perceived as invisible people, they are portrayed as passive, inactive, highly dependent on others, "*or as cultural outsiders stubbornly refusing to engage with British society*" (Ryan 2011, p. 1046; Kabir 2016; Zempi 2016; Sakai and Yasmeen 2016). The Western perception of the hijab as a symbol of Muslim women's suppression has partially supported this problematic view of Muslim women (Jawad and Benn 2003). As a consequence, the popular perception that associates the hijab with oppression, often creates

pressure in a Muslim woman's daily life, it restricts her ability to navigate her expectations in a multiple social environment (Sehlikoglu 2018). Portraying Muslim women using this view can make living in non-Muslim societies very challenging.

Muslim women were also found to face worse discrimination in employment when compared with other non-Muslim women. Although Muslim women who do not wear the hijab may face less discrimination, according to Tariq and Syed (2016) their names may reveal their Islamic identity. Dugan (2015) reports that British Muslim women are up to 71% less likely to be employed than White Christian women of the same age and qualifications, they also have the lowest chance of being considered for managerial roles due to their religious background. As a result, Harris and Karimshah (2019), and Tariq and Syed (2016), shared the view that some Muslim women have tended to adopt a Western appearance as a survival strategy in the labour market, while others work from home to avoid such discrimination, stigma and to negotiate their constitution as abnormal.

The relationship between Muslim women and men is framed through the Islamic construction of sisterhood, wifehood and motherhood (Brown 2006). Islam states that these roles are neither exclusive nor inflexible. Women can work in society, and men can take the responsibility of their household or children (Islam House 2013). Traditionally, however, educated Muslim women can be viewed as a threat in their community, men may expect them to be subservient and obedient (Jawad and Benn 2003). Therefore, all these oppressive circumstances are cultural-based and not related to Islam (Jawad and Benn 2003), thus, they may lead Muslim women to lose their self-esteem and perceive themselves negatively.

With regard to their dressing style, Baker et al. (2013), reported that the Islamic dress, which includes cultural variations of wearing hijab (headscarf to cover the hair), niqab (veil to cover the face except the eyes), or burqa (veil to cover the full face), is the most frequent topic associated with Muslim women in the British press and discourses. On the other hand, the Muslim women's perspectives and their reasons for wearing the hijab are usually absent from media, political and public debates (Zempi 2016). Rahmath et al. (2016) state that Muslim women who wear hijab are viewed paradoxically as either threatening or oppressed. One argument is that the hijab and specially the veil is seen a threat to the British way of life. The Daily Express newspaper writes in 2007: *"anyone sincerely wishing to integrate into the British way of life would never wear such an alien and threatening outfit"* (In: Baker et al. 2013, p. 211). In other words, hijab is viewed as a foreign cultural threat and nonconformity to Western culture and lifestyle (Zempi 2016). Thus, Muslim women are not merely stigmatised at an individual level, but also by a wider socio-structural level such as media

and government policies (Yang et al. 2007, cited in Ryan 2011, p. 1050). Another argument claims that the hijab prevents women from performing their jobs properly, to swim in the sea, smile at their babies or feel the sun on their skin (Baker et al. 2013). This argument indicates that hijab oppresses women's way of life.

Muslim women who wear hijab respond to this view of oppression by stating that wearing hijab is both a religious duty as well as a matter of their personal choice (Jacobsen 2011). Jawad and Benn (2003), Siraj (2011), and Hopkins and Greenwood (2013), argue that although hijab can be seen as a restriction to women's freedom in society, it can also be viewed as an embodiment of modesty, privacy and protection which allows women to reflect the performance of their religious identity. For most Muslim women, hijab *"not only expresses the value of modesty, but it is also the means through this value is acquired"* (Baldi 2016, p. 173). Thus, the body emerges here as a *"medium for"* acquiring value, and *"not a sign of"* an oppression (Baldi 2016, p. 173). Therefore, wearing a hijab should not be confused with lack of agency (Abu-Lughod 2002). Abu-Lughod (2002) argues in her ethnography of a Bedouin community in Egypt that putting the black head cloth to cover the face in front of men is considered a voluntary act by women who are deeply committed to being moral. These women have a sense of honour tied to family and decide for whom they feel it is appropriate to veil (Abu-Lughod 2002). As such, hijab is a form through which women can assert their right to be free by dressing as they wish and the outcome of their professed desire to establish a personal relationship with God (Mahmood 2005).

As Muslim women may at times fear stigmatisation in their own communities if they are wearing hijab, some may adopt personal strategies. According to Ryan (2011), some women show themselves in a positive light by doing good deeds for others. This includes letting others go in front of them in a supermarket queue, or always giving way in the car. Whereas others preferred to keep their hijab within the norms of Western dress style as far as possible, so they did not attract attention or distance themselves from non-Muslim women in their society (Tariq and Syed 2016; Jawad and Benn 2003). Bakhshi (2011) found that increasing integration into the Western culture could increase vulnerability towards a negative perception of oneself, as a woman is likely to adopt cultural attitudes that may conflict with her own culture. Thus, being a Muslim woman, and wearing a hijab in particular, may be regarded as both a source of positive body image and also a source of stigmatisation and oppression. In the following section, I evaluate the studies which discuss the experience of Muslim women who are living with disability.

2.8 Previous research on disabled Muslim women

There is limited research exploring Muslim women's experience of disability. In this section, three available studies are referred to, these explore the experience of Muslim women who are affected by a disability or who are carer-givers of a disabled person. In the first study, Hussain (2005) undertook a qualitative study to evaluate how disability, gender and ethnicity are negotiated simultaneously for South Asian young disabled Muslim and Sikh women. The way they negotiate these identities is analysed in the realm of family relationships, religion and marriage within the UK. Semi-structured interviews were conducted with 29 young disabled people of whom 16 were men and 13 were women, 19 Muslim and 10 Sikh. In addition to this sample, 14 parents were interviewed (8 Muslim and 6 Sikh), and 14 brothers and sisters were also interviewed where a match was possible with the gender of their disabled sibling. Although the paper focuses on the experiences and identities of young disabled women, it argues that inclusion of disabled men, parents and siblings in the sample allows for some important comparisons and considerations to be made, particularly on gender.

The findings indicate that disabled young women conform to the religious practices of their parents as a further expression of their ethnic identity. However, there were different experiences of religious practices between ethnic groups. Most of the Muslim participants practised their faith more than their Sikh counterparts; for the former, faith was an integral part of their lives. For both Muslim and Sikh women marriages were difficult to arrange or negotiate, the likelihood for many young South Asian disabled women in this study was that they would not get married. The findings conclude that young South Asian disabled women are constructing new forms of identity in Britain, it also suggests that these findings may apply to South Asian groups more generally. However, while the study focuses on the identity of young disabled women, the number of young women was smaller than the number of men and parents without clear justification.

In the second study, Dossa (2009) examines the ways in which the Canadian immigration system oppresses and discriminates against racialised disabled Muslim women and how these women produce strategies to rework such forces. The data are derived from narrative interviews with four South Asian and Iranian immigrant Muslim women who live with a disability, either since birth or due to accident or who happen to be carers to a disabled family member in metropolitan Vancouver. Through their individual stories, Dossa (2009) indirectly comments on how the Canadian immigration system erroneously casts these women as a drain on the social system in a context where disability as a condition is already subject to stigma.

Although Dossa (2009) produced an intersectional scrutiny of gender, race and disability throughout the narratives, religion was not considered in the same way. Muslim women from different backgrounds dress, behave and present themselves differently in their local context. Thus, it is useful to know whether they wear hijab or not and how it affects their daily life experiences, particularly at the intersection with their gender, race and disability. However, Dossa (2009) and Hussain (2005) did not focus on participants who were disabled Muslim women. In the first study, Hussain included Sikh women, and in the second study Dossa included Muslim women who were mothering disabled children. Although the experience of disability, such as barriers in terms of inclusion in Muslim community, lack of access to resources and social stigma, is part of the Muslim mothers' daily lives when they care for their disabled children (Othman et al. 2022), those women do not experience the convergence of the illness or physical pain with the social barriers of disability that disabled Muslim women face in their everyday life.

The third study (Turmusani 2001) presents an account of disabled women in Islam and Muslim culture based on textual analysis. The study provides a close exploration of three bodies of literature: disability in the Middle East, Islamic texts and disabled women, and feminist perspectives on disability in the Middle East. Evidence related to practices against disabled women in Middle East is drawn from studies conducted in Jordan, Palestine and Lebanon (Turmusani 2001). The study argues that disabled people living in the Middle East have substantially restricted access to services such as education, healthcare, welfare and employment. It also argues that the care disabled people received is either provided within the context of their home or through charitable institution when out of the home.

On the other hand, the study analyses texts from the Qur'an (the Islamic sacred book), and Hadith (the collected traditions of the Prophet Muhammad, based on his sayings and actions) in relation to disabled women. Drawing from the analysis of these two major sources of the religion of Islam, the study states that Islamic society is strictly patriarchal. Women tend to be kept out of the public eye and disabled women in particular are invisible. It also argues that socio-political movements, such as feminism in the Middle East, are bound to be rejected by the Muslim society. The study concludes that disabled Muslim women have a lowly position in society due to historical perceptions, these relate to both the inferior position of women in Islam and the inferior position of disabled people in society.

Despite the insight offered into a disabled woman's position within the Muslim culture, Turmusani's (2001) study has a number of limitations. Firstly, there is a potential source of bias in text interpretation, the study presents highly selected Islamic texts that lean towards a certain outcome without explaining the rationale behind them. For example, Turmusani

(2001, p. 76) mentions the word “*Qawwamum*” (Qur’an 4:34) from the Qur’an to report that men are superior to women for two reasons: their mental and physical capabilities and their responsibility to maintain women financially. However, in Islam, men and women are equal in God's sight according to the Qur’an’s verse *“The believers, men and women, are protectors one of another: they enjoin what is just, and forbid what is evil: they observe regular prayers, practise regular charity, and obey Allah and His Messenger”* (Qur’an 9:71).

This verse begins with a general command that calls men and women to remain mutually supportive through a spiritual, emotional and companionate alliance based on a common belief in God and His Prophet. It is a benevolent association that is portrayed in terms of allying with one another, where one is part of the other in communion and harmony (Lamrabet 2012). According to Lamrabet (2012), this verse was interpreted by most scholars as spiritual equality, especially in worship. Therefore, Lamrabet (2012) argues that the verse constitutes the core of injunction to enjoin common good and to discourage bad actions, this is an independent provision which precedes acts of worship. In other words, the verse first describes men and women as people who help each other on equal terms, then as people who perform their religious duties in mutual unity.

Another example is manifested in the author’s argument that women are “*constantly*” mentioned in Hadith as residents of hell (Turmusani 2001, p. 77). According to a series of Hadith, Prophet Muhammad claims the majority of the inhabitants of hell will be women, but this is due to an inclination for gossip, conjecture, lack of gratitude for kind treatment from their spouses and idle chatter (Sahih al-Bukhari 29 [no date]), not merely because they are women. Secondly, while Turmusani (2001, p. 77), reports that *“Islamic texts have generally portrayed people with impairments as less and as different”*, and that *“in Qur’an and Hadith, there are various statements referring to other types of impairments [other than blind people] in a negative and stigmatic way”*, Bazna and Hatab (2005) report contrasting findings.

Bazna and Hatab (2005), seek to explore the Islamic position and attitudes towards disability by examining texts in the Qur’an and Hadith. They attempt to understand the intent of the terms, such as blind, deaf and weak, in the Qur’an by examining the roots of these Arabic words and confirming their meaning with the Hadith. The study concludes that the concept of disability, in the conventional sense, is not found in the Qur’an. Instead, *“the Qur’an concentrates on the notion of disadvantage that is created by society and imposed on those individuals who might not possess the social, economic, or physical attributes that people happen to value at a certain time and place”* (Bazna and Hatab 2005, p. 6). Lastly, Turmusani’s (2001) study does not include direct evidence text about the disabled Muslim women. Instead, a conclusion is drawn from the assumption that disabled Muslim women’s

position in Islamic society is the sum of the experience of women and disabled people in such society. Although their intersected experience cannot be wholly captured by looking at the dimensions of gender, religion and disability in isolation (Crenshaw 1991).

2.9 Chapter summary

This chapter offers an overview of the literature which provides the foundation for the empirical chapters that follow. Due to limited literature about disabled Muslim women's experience, I highlighted in the first four sections of this chapter the wider literature related to the categories of their multiple identities. Firstly, I consider the critical disability studies with its intersectional perspectives of considering how gender, race, class, disability and other markers of difference constitute or contradict one another (Goodley 2013). In this sense, my approach to the study of disability in this thesis followed Goodley's (2013; 2014; 2017), and Goodley et al.'s (2019) argument that the purpose of critical disability studies theory is to start with disability but never end with it. I believe that adopting this approach will allow me to explore what it means to be a disabled Muslim woman because despite the multiple minority status of these women, their concerns are overlooked in various bodies of literature.

Secondly, I have taken the decision to include literature which discusses the relationship between disability and gender. Whilst feminist studies' acknowledgement of the importance of considering disability as an analytical category resulted in the emergence of feminist disability studies (Garland-Thomson 2002), feminist disability studies was not always able to engage with race despite the recognition of its need in the experience of disabled women by some feminist (Begum 1992), and gender (Smith and Hutchison 2004) scholars. Therefore, I also included literature which discusses the relationship between disability and race. I provide examples showing the conflation of race and disability and the recent proposed frameworks which call for integrating existing critical race work in feminist disability studies, such as, Black feminist disability studies (Bailey and Mobley 2018), and feminist-of-colour disability studies (Schalk and Kim 2020).

Considering the intersectionality of gender, race and disability identity in such frameworks, I argue that critical disability studies has yet to consider the issue of religion as an additional layer of social identity. I review, therefore, literature which discusses the relationship between disability and religion. The studies of religion and disability focus on the representation of bodies in the religious texts and how people define and perceive disability through a religious lens. This, in turn, highlights a gap into which disabled Muslim women fall since various bodies of literature, such as critical disability studies, feminist disability studies,

race studies and studies of religion and disability, have overlooked the intersection of their gender, race, religion and disability identities. Yet, as this study explores the experience of disabled Muslim women, the fifth section provides an overview which helps to explain who the Muslim women are in general and in particular, those living in the UK.

Finally, I discuss the studies which explore the experience of Muslim women with disability. Hussain (2005) found that young South Asian disabled women were constructing new forms of identity in Britain. Dossa (2009) found that disabled Muslim women in Canada were reclaiming their multiple identities in a disablist world. However, neither study focused on the participants who were disabled, Muslim, and women. Hussain (2005) included Muslim and Sikh women, and Dossa (2009) included Muslim women who were not disabled but caring for a disabled person. Turmusani (2001), presented an account of the disabled Muslim women in the Middle East, arguing that they had a lowly position in society due to historical perceptions which related both to their inferior position as women in Islam and the inferior position of disabled people in society.

I have not been able to identify a substantive understanding of the experiences of Muslim women living with a disability in the UK, how they perceive themselves, and how they cope with their multiple identities in everyday life. What marks the experience of disabled Muslim women as different from other disabled women in minority groups, is that they face the challenges of Islamophobia together with the discriminatory acts related to their gender, race and disability. This is where, I believe, my thesis makes its contribution. The next chapter describes the methods used to achieve the objectives outlined in this thesis and to answer the research questions. This will be followed by an introductory chapter which explains the five empirical chapters that contain the key findings of this study.

CHAPTER THREE: Methodology

3.1 Introduction

The focus of this study was to explore the experiences of the Muslim women living with disability in the UK, how they perceive themselves and cope with everyday life. The research methodology detailed in this chapter aimed at establishing a communication relationship that constitutes the participants as “*real-life storytellers*” (Mattingly 2010, p. 89), and myself as an audience in “*a position of telling and listening*” (Dossa 2009, p.27), which Bamberg (1997, p. 335) called “*a window to people’s experiences*”. Thus, this study sought to present and construct multiple narratives, unique to each participant, rather than breaking stories into common themes across the participants’ experiences.

This chapter outlines the methodology adopted in undertaking this research, it is divided into five sections. In section one, the methodological approach underpinning the research is described. This research utilises a narrative inquiry as a form of qualitative research, this focuses not only on “*individuals’ experiences*” but also on exploring “*the social, cultural, and institutional narratives within which individuals’ experiences are constituted, shaped, expressed, and enacted*” (Clandinin and Rosiek 2007, p. 43). Section two details the data collection methods. Sampling and recruitment were carried out with the aim of engaging with participants who were from different parts of the UK, reflected the characteristics of the inclusion criteria and could share rich stories. Data were collected through multiple narrative interviews combined with semi-structured interviews, observing nonverbal communication and note-taking data. Section three describes the data analysis methods, these include transcription, data storage and management, the analysis approach, and the analysis process. Data in this study were analysed using the ‘narrative intersectionality’ approach, which was developed based on Chadwick (2017), and Blackie et al.’s (2019) concept of narrative intersectionality. The aim was to craft an analytical tool that would be sensitive to the intersectional identities of the participants throughout their narratives. Section four outlines the measures undertaken during the study, these ensured the quality and trustworthiness of the research. Finally, the principles of the ethical considerations are discussed in section five.

3.2 Methodological approach

3.2.1 Qualitative research

The aim of this thesis is to explore the lived experiences of disabled Muslim women through an intersectional lens. Adopting a qualitative research approach enables the collection of rich and informative data by interacting directly with participants through listening, interpreting, and retelling their accounts in a manner that is meaningful within their natural setting (Creswell and Creswell 2018). Qualitative research often involves a close relationship between the researcher and the participants and considers the role of context in framing the understanding of reality. Thus, qualitative research makes it possible to “*stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry*” (Denzin and Lincoln 2005, p. 14). As a result, it can be assumed that reality within qualitative research is not something which is separate from the participants' experiences, but it is considered to be constructed through recurring social discourses. Since qualitative research is not grounded in a positivist framework (Merriam 2009), the aim of this study is not to seek an ultimate truth, but to explore the meaning of the experience as described from the perspective of the participants.

3.2.2 Narrative inquiry

The technique of the narrative derives its concept from the Latin word *narrare*, this means to report or tell a story (Jovchelovitch and Bauer 2000). Narrative inquiry was selected for this study because of the role that it plays in giving a voice to silenced and marginalised people (Bruner 1991; De Fina 2015). It is a way to share and create meaningful content, from which people's experiences can be transmitted (Muylaert et al. 2014). The term narrative carries many meanings and it is often used synonymously with story (Riessman 2008), such as in this study.

Parker and Shotter (1990) described narrative as the verbal recounting of life events as a story. Gilbert (2008) explained that narrative is used to describe a form of speech that aims to tell a story and may be structured according to the chronological order of plots. Thus, narrative is a life-based story which is told by one person to another. According to Lauritzen and Jaeger (1997), a life-based story is usually an embroiled version of facts, this emphasizes that any fact reflects the narrator's point of view, but cannot be considered as a factual account of reality. Harden (2000) also suggested that a life-based story in research offers a representation of the research participant. Subsequently, it is represented by the researcher's interpretation to the extent that it is meaningful for the narrators and readers, but not to prove facts or reality.

For Elliott (2005) narratives are chronological, meaningful and social. The story is usually structured chronologically with a beginning, middle and end (Riessman 2008), as the events occur, progress and afterwards. Narrative then is responding to questions like: then what happened? why?, why is this worth telling?, and what is interesting about it?, as one event leads to another (Brockmeier and Carbaugh 2001; Riessman 2008). Constructing a narrative entails imposing a meaningful pattern on what would otherwise be disconnected and random (Riessman 2008). According to Mattingly and Garro (1994), narratives allow people not only to tell what happened in the past, but also to enhance people's understanding of the present and possibly their future as well.

Through narratives people try to make sense of how things have come to pass and how their actions and the actions of others have helped to shape their life story (Mattingly and Garro 1994). Thus, people use narrative to understand and make sense of who they are and who they may become, by reference to where they have been and what they have been throughout their life. Selecting narrative inquiry in this study allowed me to focus on personal narratives, to start with each individual woman's situation from the onset of her disability up until the time she tells her story. This, in turn, allowed me to see the whole web of these women's experiential reality of living with their multiple identities.

3.2.3 Narrative and identity

Although narratives can encourage a narrator to speak, remember, justify, and persuade the listeners, they also have a robust impact beyond the self (Riessman and Quinney 2005). Narratives have been used in the field of social sciences for many years as evidence to support the changes promoted by several organisations and social movements especially for women's rights (Gubrium and Holstein 2001; Riessman and Quinney 2005; Riessman 2008), such as disability and feminist movements. Thus, narrative can motivate others to take action for social change, which is an ultimate goal of this study, to inform the field of critical disability studies about the underrepresentation of the disabled Muslim women. Riessman and Quinney (2005) argued that a push toward narrative in social movements and organisations initially comes from contemporary preoccupations with constructing identity.

Narrative permits the study of identity, therefore narrative and identity are often regarded as closely connected (De Fina 2015). People use narrative to construct and maintain a sense of their own identities, to tell themselves and others about who they are, who they are not, and how they want to be known, and to negotiate their identities with others (Elliott 2005; Andrews et al. 2008). Bilgrami (2006) describes identity as what a person conceives himself to be and how he might be viewed in light of certain biological or social facts about himself.

Understanding people's identities, according to Polkinghorne (1996), requires listening to their narrative.

Research on narrative and identity is relatively new (De Fina 2015). The most significant contribution to this field was the narrative turn which started to gain strength as a movement in social sciences back in the 1990s (Bruner 1990). Bruner (1990, 1991) highlighted the power of narrative to construct the self and shape identity, he also argued that construct meaning in individuals' narrative is tightly linked to their culture. The research of narrative and identity has since grown in diverse disciplines such as social psychology, history and anthropology. As a result of this, narrative-based studies belong to different traditions and use widely different methodologies (De Fina 2015). Paul Ricoeur is also one of the foremost contributors to the notion of narrative and identity. Ricoeur highlighted that the term identity can be understood in two ways. First, the notion of identity as identical or exactly the same identity. Secondly, identity as something continuous or to be traced through time (Ricoeur 1991).

According to Elliot (2005) narrative fits with Ricoeur's conceptualisations of identity which provides the practical means by which people can understand themselves and make sense of their identity as a performance through time, without sameness through time (Elliot 2005). Thus, while people try to maintain their identical identity, they also aspire to incorporate an element of change, progress and improvement to develop the construction of their continuous identity as per Ricoeur's second notion of identity. For example, the identity of a woman might develop from being a daughter to a wife, mother and then grandmother. Through the stages of achieving all these identities she retains her identical identity as a family member, but with different aspects of her continuous identity.

Riessman (2008, p. 8), argued that identity is fluid, *"always producing itself through the combined processes of being and becoming, belonging and longing to belong"*. That is to say the narrative of identity must be considered within context. Elliot (2005) highlighted the importance of focusing on the context as people's narrative must be supported, or at least influenced, by others around them. Parents, siblings, college friends, neighbours and strangers might all have shared in the narrated stories to some extent. Elliot (2005) also emphasised that other formal settings such as medical clinics and research interviews may provide even more control of the way in which a personal narrative can be told. Therefore, during my conversations with participants I tried to bear in mind the impact of the social and physical context to ensure that the appropriate participants' narratives are elicited.

3.3 Data collection methods

3.3.1 Sampling

There are no definite rules on sample size in qualitative research with regard to the number of participants for a study (Patton 2002). This is because qualitative research tends to be more focused on detail and the depth of information, thus a small number of participants is considered appropriate in certain circumstances (Boddy 2016; Miles and Huberman 1994). According to Hennink and Kaiser (2022, p. 9), “[s]ample sizes in qualitative research are guided by data adequacy, so an effective sample size is less about numbers (n’s) and more about the ability of data to provide a rich and nuanced account”.

In addition, Hennink and Kaiser (2022) recommend that a sample size should be refined, taking into account the aim of the study. Therefore, this study set a sample size of between 5-10 participants with the aim of collecting rich data on the experience of living as a disabled Muslim woman. This richness was thought of as being inherent in the different stories shared by the participants and their different perceptions and experiences, rather than the number of participants (Hennink et al. 2017). In other words, because this study is not concerned with generalizing the result and is dedicated instead to developing an in-depth understanding, fewer participants will allow more in-depth information to be collected about the phenomena under exploration. The eligibility criteria involved Muslim women who were:

- ✓ Residing in the UK
- ✓ At least 18 years of age
- ✓ Spoke English or Arabic
- ✓ Self-identified as disabled

A purposeful sampling was used to recruit participants with different experiences, ages, backgrounds and educational levels in order to reflect the diversity of this population (Patton, 1990). Although all potential participants were women, Muslim and disabled, they differed in terms of their age, marital status, education, occupation, ethnicity, social community, culture, class and impairment. These differences may have great importance in shaping their identities, and thus influencing their personal experience, as has been suggested by Allmark (2004).

3.3.2 Recruitment

Once ethical approval had been granted by Cardiff University, School of Healthcare Sciences Research Ethics Committee, I contacted the women using the following sources:

- ✓ Disabled women's organisations and networks
- ✓ Feminist organisations and groups
- ✓ Women's groups
- ✓ Muslim women's networks

An invitation letter was sent/emailed/handed to the centre /organisation /network /group's leader for them to forward to their members. The leaders were asked to identify potential participants and distribute the invitation letter without giving me access to the potential participants. At some leaders' requests, the invitation was sent as a short post for their followers on Facebook or Twitter account. The invitation letter was also sent as a recorded voice message to be forwarded via WhatsApp to people with limited literacy through the leaders. Then, interested prospective participants were able to contact me on a study specific phone number or using the Cardiff University email address.

Various mosques and Islamic centres in large urban areas of Southern England were visited, due to their large Islamic communities. Once the mosque's Imam approval had been gained, a copy of the invitation letter was placed on the mosque's noticeboard. In addition, using a study specific Instagram account, the invitation letter was sent to a number of personal Instagram accounts which belonged to women who presented as Muslim and were disabled. Snowball sampling was used to gain further access and reach participants in the Muslim community, participants were asked if they could refer their relatives, friends or colleagues. The entire recruitment process, including the recruitment sources contacted and a number of interested and actual participants in the study, is detailed at Appendix 1.

Attempts were made to contact participants through 23 recruitment sources including: 6 disabled people's organisations and networks, 5 feminist organisations and groups, 3 Islamic mosques, 2 Muslim women's networks, 4 women's groups, and 3 sources involving personal Instagram accounts and snowball sampling. The number of participants who expressed their interest in the study were 14. Six participants consented to take part in the study, one of whom withdrew later. As such, the total number of participants is five.

3.3.3 Building trust

Sometimes, according to Gerrish and Lathlean (2015), minority ethnic populations are difficult to engage in research, especially if there are cultural and language differences. Horn et al. (2011, p.839) argued that “*privacy concerns influence trust*”, which required researchers to build and sustain a chain of trust through a number of mechanisms, these include developing relationships. Thus, for those who expressed their interest but were reluctant either to meet face-to-face or to reveal their number/home address for personal or privacy reasons, additional steps were implemented. For example, they were sent a personal photo of myself in which I was dressed smartly in a black suit and wore a badge which identified myself as a member of Cardiff University. This assisted with establishing a relationship, participants want to know who is conducting the research (Horn et al. 2011).

For additional reassurance, the participants were also sent a link to check my Occupational Therapy registration at the Health and Care Professions Council (HCPC). This reassured them that they were dealing with a trusted and registered health care professional in the UK. A copy of my Cardiff University student ID card was also sent to some potential participants upon request. Following this, the participants were sent the information sheet which gave them full information about the study. After a minimum of ten days, an email or telephone call was made to introduce myself as a researcher, to establish a rapport, answer any questions and give participants the opportunity to select the interview date, time and location. An initial agreement (verbal consent via phone/written consent via email/text message or Instagram messenger) was given at this stage. For those who gave their initial consent via WhatsApp message, the information sheet was explained over the phone and this was repeated prior to the interview. A consent form was then sent to each participant via email or post with a pre-addressed stamped envelope.

3.3.4 Setting

Elliot (2005) described the research interview setting as one of many formal settings which can provide more explicit control of the way in which personal narratives are told. Therefore, the interview was conducted at participants' place of preference, this included their homes, public libraries or other mutually agreed locations. The arranged setting was quiet as much as possible and convenient for the participants, somewhere where they felt comfortable and safe to express emotions that otherwise might remain hidden.

Multiple interviews were conducted with each participant, this gave them the opportunity to disclose new details which had not been reported in the initial interview (Szojka et al. 2022). The initial interview was conducted in-person, this was true for all participants, but the

following interviews were conducted via virtual platforms due to COVID-19 restrictions. I used Zoom video meeting service, this gave participants the chance to tell their story from the comfort and convenience of their homes. As the participants had already been met in-person during the first interview and a rapport had been built with them, no issues were reported during Zoom interviews with regard to participant distress or discomfort.

3.3.5 Data collection tools

This study used narrative inquiry to collect stories from disabled Muslim women who told of their life experiences in the UK. According to Muylaert et al. (2014, p. 186) "*Narrative can be gathered from different forms of data collection*". Narrative interviews were combined with semi-structured interviews, observing nonverbal communications and using note-taking to collect data for this study. However, constructing the researcher and participant relationship was also an important tool in collecting the data for this study.

3.3.5.1 Researcher and participant relationship

In narrative research, the story emerges from the collaborative dialogue, exchange and interaction between the researcher (interviewer) and participant (interviewee). Thus, it is important to note that narrative interview is always co-constructed, and marked by variations in mood and style. For example, from sadness and seriousness to humour and light-heartedness (Thomas et al. 2009; Muylaert et al. 2014). Muylaert et al. (2014) and De Fina (2015) both emphasise the importance of the researcher's behaviour, and their role in the co-construction of meaning in general and identities in particular, should not be overlooked.

Finlay (2002, p. 531) stated that "*our behaviour will always affect participants' responses, thereby influencing the direction of findings*". In addition, Anderson and Kirkpatrick (2016) reported that in order to be a good narrative interviewer, the researcher must establish rapport and trust early in the interview. A personal photo and an HCPC registration link were sent to some hesitant prospective participants to help in building rapport and trust. When visiting participants' homes, I followed the common Muslim practice of taking off shoes when entering homes based on the Islamic ritual of cleanliness. This also helped to build trust, as my behaviour was being evaluated by them.

I presented myself and gave my participants some personal information before they started to narrate, this was done to build a rapport based on mutual feelings. This entailed telling them of our similarities, I am a woman, Muslim and living with an invisible disability (diabetes). This would enable some of my participants, I believed, to connect me to their life world to some extent. I tried to keep my influence at a minimum to elicit a less imposed, and

more vivid rendering of my participants' perspectives, but not all the time. This is because as Jovchelovitch and Bauer (2000) stated, participants generally assume that the researcher knows something about their story, it is not discussed because they take it for granted. Thus, I included myself as a figure in the construction of their narrative by occasionally asking some sort of confirmation/elaboration questions, and as an active audience for their narrative by continually showing interest.

3.3.5.2 Narrative interviews

Narrative interviews were chosen because they *"place the people being interviewed at the heart of a research study"*, and privilege *"the meanings that they assign to their stories"* (Anderson and Kirkpatrick 2016, p. 631). When people construct their narratives they do not merely tell of their experiences, they may also use it as an opportunity to reflect on something that they had not even thought about previously (Muylaert et al. 2014). That is why in the narrative interviews, the researchers do not set out a fixed agenda, rather they tend to let the interviewees control the direction, content and pace of the interview (Anderson and Kirkpatrick 2016). Thus, the narrative interviews can provide participants with an opportunity to prioritise their perspectives and freely choose what to say or not to say, rather than it being imposed on them by the researcher's agenda.

The narrative interviews are considered as a form of in-depth interview, which emerges from the life stories of the participants and their context (Jovchelovitch and Bauer 2000). According to Muylaert et al. (2014, p. 184) *"they allow the deepening of research, the combination of life stories with socio-historical contexts, making the understanding of the senses that produce changes ... motivates and justify the actions of possible informants"*. Hence, using narrative interviews can lead to a better understanding of the participants' perceptions and their social world. This understanding can then be applied to explain why participants have made a particular decision or followed/unfollowed a particular social group.

Jovchelovitch and Bauer (2000) stated that a participant's perspective is best revealed when the participant is using their own spontaneous language in the narration of the story. Thus, narrative interview necessitates using everyday communication language in order to reach a participant's vivid perspective. Yet, according to Anderson and Kirkpatrick (2016) narrative interviews can be conducted together with semi-structured interviews and observation. Semi-structured interviews seek to uncover the person's lived experience (Walker 2011). It permits the researcher to use open-ended questions that allow the participants to respond in their own words, and describe the richness of their personal experiences in relation to their context (Bryman 2012; Polit and Beck 2014).

From the participant's perspective, semi-structured interviews can situate them at the centre of the process by giving them the prospect of telling their stories from the expert perspective. It provides them with a space to think and to build a mutual and meaningful rapport with the researcher. From the researcher's perspective, it gives an opportunity for purposeful dialogue with a topic-expert narrator (King and Horrocks 2010). The interview process in this study was developed in a way that ensured the focus was on participants' perceptions of their multiple identities and its association to their experiences of everyday life.

3.3.5.3 The interview process

The function of the interview process is to offer the researcher guidance, and to orient the participants in order to elicit rich narration on the topic of the study. Fraser and MacDougall (2017) asserted that deviations from pre-planned questions in narrative research can produce rich data. Thus, during the interview, questions were added or replaced based on the flow of the interview and the participant's response, without losing sense of the aim of the study. Jovchelovitch and Bauer (2000) explained that following these roles is likely to lead to a non-threatening situation, and maintains the participants' willingness to tell the significant events of their stories.

Three in-depth interviews were conducted with each participant. Each interview lasted between 45-90 minutes, depending on the interest, willingness and availability of the participants. The participants in the study participated in 15 interviews, these resulted in 7,000-10,000 words of data in total (transcribed interview and note taking from observing non-verbal elements). The aim of the first interview was to get in depth information about the participant's story and to cover the interview process, while the subsequent interviews allowed further clarification and follow-up questions.

Each interview built upon the preceding ones, going into more depth until a storyline emerged and a narrative was constructed with a full understanding of all the issues raised, this continued until there were no new issues. Following Hennink et al. (2017), recommendation that a small number of interviews can be sufficient to capture a comprehensive range of issues in data, the participants in this study were interviewed three times to reveal their experiences as they are informed by their socio-cultural contexts. Interviewing each participant three times also enabled me to build rapport with the participants and allowed them enough time to open up about their experiences and the related problems.

The interview process was based on the elicitation technique as proposed by Jovchelovitch and Bauer (2000). Appreciating differences in perspectives, which could be between the

interviewer and participant or between different participants, is central to this technique. The interview process is comprised of three basic phases: initiation, main narration and concluding talk. The basic concepts and questions of each phase comprising the interview process is summarised at Appendix 2.

1. Phase one: Initiation

The first phase was comprised of the opening part, the following points were explained to the participants:

- ✓ The aim and context of the study in broad terms
- ✓ The interview process, and that it would be audio-recorded
- ✓ Maintaining confidentiality

The participants were asked to give their permission for the interview to be audio-recorded and asked to sign the consent form. Once the consent form had been signed, the tape recorder was started and participants' demographic information, such as their age, ethnicity, type of disability, marital status and occupation, was obtained. This basic information is important in providing "*thick description*" about the scene for the reader (Tracy 2010, p. 843; Polit and Beck 2014).

2. Phase two: Main narration

To encourage the participants to start telling their story, a broad general question was asked, 'Can you tell me how do you see yourself as a disabled Muslim woman, when did this start, and what has happened since then?' Whilst the participants told their story I listened attentively, until there was a clear sign that the participants had paused and signalled the end of the story. According to MacLean et al. (2004) interviews conducted with participants speaking in a second language might require more encouraging feedback from the researcher. This is particularly significant when they are struggling to search for words to convey their thinking. Thus, during the narration I used some verbal and non-verbal signals, for example, head nodding, smiles, saying hmm, yes, true, I see and so on. These signals were used to convey interest and encourage the participants to continue the narration freely (Jovchelovitch and Bauer 2000; Anderson and Kirkpatrick 2016).

Riessman (1993) reported the difficulty for the researcher when deciding whether to intervene whilst a participant is talking, particularly if the contents of the story are personally sensitive, emotional or traumatic. Sometimes I had to ask a short "*pulse of questioning*", this pushed the stream of narrative performance forward, and provided an "*interactively*

accomplished co-narration" (Slembrouck 2015, p.242). These probing questions were in a form of confirmation such as 'Do you think/mean this happened because of this?', or for additional elaboration like 'Do you mean...?' Probing questions were used to search for deeper meanings beyond a participant's words and taken for granted feelings (Fraser and MacDougall 2017). When the participants marked the end of their story, usually by asking me 'Did I answer your question?' I asked them 'Is this all you want to tell me?' This acted as a probe for the end of the main narrative before moving on to the semi-structured interview.

The semi-structured interview is meant to elicit new and additional information beyond what has been told in the story. Jovchelovitch and Bauer (2000) explained this as a moment in which the attentive listening by the researcher bears its fruits. Here, the researcher's questions used the participant's own language to fill the gaps in the study (Jovchelovitch and Bauer 2000; Anderson and Kirkpatrick 2016). The researcher's questions refer to "*research questions or the researcher's interest that arises from her/his approach to the topic being researched*". The structure of these questions then, relied on the "*themes and topics brought by the informant*" (Muylaert et al. 2014, p. 186). Thus, the researcher's questions may concur totally, partially or not at all with the participants' own language, based on each participant's narrative.

To elaborate on the participant's narrative, I asked questions such as 'Can you say a bit more about...?', or 'What happened then/before/after?'. Further questions were asked, which had been identified earlier from the related literature, if they had not been covered by the participant's narrative. These questions highlighted some of the issues related to their society, culture, local community, and the impact of their family, also the type of strategies being used by the participants to cope and live with these issues in everyday life.

3. Phase three: Concluding talk

At the end of phase two the tape recorder was switched off. Jovchelovitch and Bauer (2000) declared that asking opinions and why questions may be an entry point for the analysis, when the participants reveal what they hold about themselves. The reason for this is that when the interview is being recorded, the participants are aware that their experiences and opinions are being listened to and that they might be evaluated or judged by another person. Hence, unlike the first two phases, in this last phase when the tape recorder was turned off, the participants could relax their defence. Al-Yateem (2012) noticed that communication which was not being recorded tended to be less formal and more relaxed, spontaneous and sociable. Thus, in order not to miss important information, a notebook was used to summarise the concluding talk and this was done immediately after the interview.

This phase was mainly planned to develop a discussion in the form of a small-talk that lasted between 2-5 minutes. According to Jovchelovitch and Bauer (2000) talking in a relaxed mood after the more formal account during the narration proves to be crucial for a contextual interpretation of each participant's account. Thus, I asked the participants 'In your opinion what matters the most for you as a disabled Muslim woman in the UK, and why did you participate in this study?'.

3.3.5.4 Observing nonverbal communication

Narrative is not simply description of personal story, but construction of self. De Fina (2015, p. 352) reported that "*the self is not the essential expression of an individual but a historical and interactional construction subject to constant work and revision*". Thus, narratives relate to the meaning of one's life experiences, which means that they are "*firmly bound up with identities*" (Elliot 2005, p. 140). Riessman (2008, p. 106) conveyed that "*identities are situated and accomplished with audience in mind*", and that "*one can't be a self by oneself, rather identities are constructed in shows that persuade*". Shows are expressed by people's performances during the interview.

Observing nonverbal communication was particularly important in this study because all the participants were constructing their self out of multiple and intersected identities. Thus, observing the unfolding nonverbal interaction and the effect of the context was used during the interviews to enrich the data with all the meanings that are taken for granted. For example, facial expressions, silence, gaze, gesture, posture, tone of voice, shaking legs and other nonverbal interactional communication and body languages that could not be captured by the audio recorded interview. I was conscious about observing the interaction that occurred during the interview and I reported it in detailed notes immediately after each interview.

3.3.5.5 Note-taking

Note-taking is an important component of data collection and analysis which serves in constructing rich descriptions of the study context (Phillippi and Lauderdale 2018). In this study, notes were taken immediately after completion of the interview when I had left the venue, as recommended by Phillippi and Lauderdale (2018), this often took the form of jotting. Jotting was used to help me recall as much information as possible whilst it was fresh in my memory, this assisted with writing detailed notes later. The notes were written down after, rather than during, the interview for several reasons. Narrative requires attentive listening, it was felt that writing notes might distract the participants and lose eye contact. In

addition, note taking could result in participants feeling that their actions may be reported, this could hinder spontaneous reactions. Writing notes after interview, as Watt (2007) reported, also allowed me to assess and reflect on my thoughts, bias and feelings and how these might influence the study.

The detailed notes consisted of two parts: descriptive information and reflective information (Schwandt 2015). The descriptive information was completed on the train when I was returning home, immediately after interview, or by the end of the day at the latest. The descriptive information constituted detailed and accurate descriptions of what participants said in the concluding talk after the recorder had been switched off, what I saw/observed during the interview, non-verbal communications and any impact I may have had on the situation. The reflective information included my impressions, thoughts and insights about what had been observed, and why it happened in a particular way.

3.4 Data analysis methods

The data analysis methods were comprised of transcribing the recorded interviews, data storage and management and developing the 'narrative intersectionality' approach to analysis and interpretation of the collected data.

3.4.1 Transcription

Transcription has been described as a central part of the interpretation and analysis process (Fraser 2004; MacLean et al. 2004). Each interview transcript included both the speech of the participant and myself, this demonstrated that my position as an active audience contributed to the construction of the narrative. Yet, what is being said in the interview, is only one of many different things the participants aim to achieve in their act of narrating (Bamberg 1997). A decision was taken for the interviews to be manually transcribed by myself rather than assigning the task to a transcriptionist or using an analysis software programme, this was felt to be important. Transcribing the interview enabled me to listen very carefully to the recording at a slow speed and to write the data numerically line-by-line. Each line was numbered as it made it easier to navigate between lines for data analysis, also for the reader when different scenes of the interviews are referred to (Fraser 2004). This also enabled me to capture the meaning conveyed by the words each participant used, and in the meantime to contextualise the interview notes with what had been said in order to bring their story to the fore.

MacLean et al. (2004) and Riessman (2008) recommended the use of transcription symbols and non-verbal elements. This included capturing fillers (i.e. umm, aha, oh), stutters,

repetitions and speech pauses at all times. Non-verbal elements were also captured, these included facial expression, laughter and tone of voice. These elements were chosen not only to help tell the story, but also to show how the story was told interactionally and why it was told in this way. According to Yardley (2008), the performative characters of narrative can take us beyond the reported and recorded data. This in turn helps to reveal the inner life of the narrative which is usually obscured within the text. A list of the transcription convention used in this study is included at Appendix 3. After the first draft of each interview had been completed, I re-listened to the tape while reading the transcript to make sure everything was transcribed correctly as Riessman (1993) suggested. Reviewing the transcript enabled me to become familiar with the story, and to better understand the way it had been told, this provided me with clues about the meaning of what had originally been said.

3.4.2 Data storage and management

In keeping with best practice following the Cardiff University guidance on data management and storage, I utilised the following practice to record, store and manage data. All interviews were recorded using two digital voice recorders: an Olympus WS-833 digital voice recorder, loaned out from Cardiff University plus a personally owned voice-recorder. After each interview, the digital recording was downloaded immediately onto my laptop computer. The consent form was also scanned and saved on my laptop computer. The laptop is protected with an up-to-date security software and a password known only to myself. Recorded data was then deleted immediately from the digital voice recorder, but remained on my laptop until completion of this thesis.

For each participant I developed a document including the interview recording, transcript and analysis. Every participant's document was saved under pseudonym and protected with password and 'no access' permission. The file that includes all participants' personal data and consent form was kept away from research data, and was encrypted before the personal data were stored. The personal data file is to be kept during the study in case I need to get in touch with any participant, but it will be safely destroyed when this study is completed (Hutchinson 2018).

All hard-copy data such as consent forms, notes, paper copies of the transcripts and any other written information were kept in a safe, locked filing cabinet inside my office at Cardiff University. The office is situated in a building with access code as the only means of gaining access and is covered by security patrols and electronic alarms. All electronic data were regularly transferred from my laptop computer through a USB cable onto my office's computer using my password-protected university student account. As a backup strategy,

such as during the period of COVID-19 lockdown, I converted all hard-copy data to electronic data which were also stored on my laptop computer.

3.4.3 Narrative intersectionality approach

The purpose of the analysis was to develop narratives which were sensitive to the multiple and intersectional identities of participants. Since there is neither a single method for narrative analysis, nor the analysis of the intersectional identities (Nasheeda et al. 2019; Turan et al. 2019), I reviewed the previous research that had used narrative approaches/analysis and intersectionality theory in their studies, such as Buitelaar (2006), Ludvig (2006), Prins, (2006), Cole (2009), Mirza (2013), and Fraser and MacDougall (2017). For example, Mirza's (2013) study explored the experience of three immigrant Muslim women from different backgrounds who lived in the UK. Mirza (2013) used intersectionality as a conceptual framework, a narrative interview as a data collection tool and analysed her narrative data via thematic cross-coding.

Mirza's study was critiqued by Chadwick (2017). Chadwick argues the lack of narrative account in this study asking the question of "*what exactly gets to count as narrative research?*" in Mirza's study (Chadwick, 2017, p. 10). Chadwick's argument is based on the fact that narrative research co-constructs a series of events in a temporal order, with a beginning, middle and end, it is characterised by plots rather than representing segmented events or isolated categories of a person's identity (Chadwick, 2017; Fraser and MacDougall, 2017). Mirza (2013) considered women's race, Islamic religion and transnational experience as isolated categories within her themes. She did not, however, consider them in relation to one another, this counteracts the concept of intersectionality which insists that one identity cannot stand isolated from other identities. Segmenting these identities from each other can obscure the understanding of different types of discrimination and disadvantage resulting from the intersection of multiple identities (Groenmeyer, 2011; Prins, 2006). Ludvig (2006), also analysed a narrative life-interview of a migrant woman in Vienna, her gender, class and ethnicity were presented as isolated categories. Ludvig (2006, p. 246) argued that

"the weaknesses of intersectionality become more obvious when trying to apply it to empirical analysis: its implications for empirical analysis are, on the one hand, a seemingly insurmountable complexity and, on the other, a fixed notion of differences. This is because the list of differences is endless or even seemingly indefinite. It is impossible to take into account all the [person's] differences that are significant at any given moment".

On the other hand, Chadwick (2017), and Blackie et al. (2019) highlighted the concept of narrative intersectionality. As narrative research emphasised the individuality of a person's story, they argued that individuals' lives could not be understood as categories in isolation because individuals' identity is a product of summing up their different identifications. This individuality is key to the link between narrative and intersectionality. For this link, the individual person may embody many categories of identity in his/her narrative, reflecting the concept of intersectionality. Thus, the narrative intersectionality approach allows the researcher to explore how particular identifications are always co-constructed and intersect with other categories of identity throughout a person's life.

Goethals et al. (2015) described the way that disabled people are frequently assumed to share the same experiences, regardless of their gender, age, religion, cultural background and other differences. As a result, primacy is given to disability over other key categories, meaning that the interaction of other determinants are often neglected. In response to this issue, a number of disability studies began to engage in an intersectional approach which explored multiple axes of difference (Goethals et al., 2015; Naples et al. 2018; Shaw et al. 2012). Garden (2010) argued that narrative, particularly first-person accounts, provided a critical resource by representing the world from the disabled people point of view, and by offering a means of examining the social determinants of disability.

The decision was, therefore, taken to develop a narrative intersectionality approach as the analytical approach, drawing from Chadwick (2017), and Blackie et al.'s (2019) concept of narrative intersectionality. This approach was felt to be the best option for data analysis in this study, it conceptualises each participant's narrative as multidimensional and comprised of multiple analytical layers concerning multiple identities in which the story told is an interaction between the participants and their social contexts at any given time (Chadwick 2017). Personal narrative was used, this located the related theory within the participants' narrative and let the conceptual framework inform the analysis. The data analysis process below contains a description of the practical steps taken in developing the narrative intersectionality approach and how it was used in practice to analyse the data for this study.

The analytical process included 7 steps, these were organised into 4 stages. The first stage involved 3 steps, focusing on understanding and developing the participants' stories. These first 3 steps were descriptive, seeking to develop initial plots. The second stage was interpretive, aiming to produce meaning by engaging the emerging storylines with the related theory. The third stage involved 2 steps, these were interactive and aimed to interweave between the data collection and analysis process. This process was reiterated until meaningful narratives were constructed. The fourth stage involved writing-up, aiming to refer

to the conceptual framework to illuminate the complexity of the participants' experiences and engage the co-constructed narratives in a critical discussion with the relevant theories.

3.4.4 Data analysis process

Stage 1

1. Initial reading

In this step, a file was made for each participant. The entire interview was focused on and the complete transcript read several times to actively engage with the data. A4 paper was used, this enabled me to summarise each participant's story in a bullet point, drawing from my notes. Using bullet points facilitated the coding process. The data were then coded, these codes were relatively broad and referred to common issues discussed by each participant in their story. My aim in doing this coding was to identify significant storylines or emerging plots so they could be organised in temporal order. The set of storylines were put in chronological order and also put in an order which conveyed a particular meaning or offered an explanation of who the participants were and how they wanted others to see them (Riessman 2008). In this step, I also highlighted participants' utterances which could be cited in the result as a quote, by asking myself which extract each participant might want me to use to communicate their overall viewpoint effectively (Watts 2014).

2. Re-reading and making initial notes on a story

During this step, whilst making initial story notes, notes were made of anything which was felt to be of interest. My main goal was to develop a detailed set of notes for the three specific categories which created each storyline, these included participant, significant other people and the general context (Polkinghorne 1995). Names were given to the participant's various identities. Recognising the participant's identities helped me explore and compare the struggles, emotional state, advantages, and disadvantages related to each identity. The transcripts were returned to several times to consider at what point these identities became apparent and when and how they intersected (Blackie et al. 2019). Then, I named significant other people who played a particular role in shaping the story. Recognising the relationship between the participant and other people, such as parents, siblings, partners, children, friends, healthcare professionals and strangers, was required in the development of the plot (Polkinghorne 1995). I was also aware of my role in the participant's story, as the story is shaped by the responses the interviewer gives (Wong and Breheny 2018).

Information on the social, cultural and political context in which the story took place was also included (Polkinghorne 1995), such as country's name, medical clinic, school, university,

local shop and public transport. According to Wong and Breheny (2018, p. 12), *“both the location of telling and the location of the story itself shape the story and the unfolding events”*, but these locations may not match. For example, part of one participant’s story took place in her home country (Nigeria) but was told from her home setting in the residence country (the UK). Considering the various contexts offered a greater appreciation for how the story was retrieved and re-introduced in a new context (Dossa 2009). It also allowed me to explore participants’ former identities and understand how and where their new identities were developed and co-constructed.

The second reading objectives were to make notes of the participant, significant others and context, and to guide my attention towards recognition of categories other than gender, religion, and disability, such as race, literacy, social roles, and class. In this study, I argued that participants’ multiple identities were the product of their social context. Thus, I treated all these categories as fluid and subject to change rather than stable because social institutions and environments can change gradually, suddenly or radically during one’s life. According to Walby et al. (2012), the only analysis that treats categories as fluid truly merits intersectionality. Thus, organising the storylines using events that happened in a particular context, rather than by events related to identity, can illuminate the intersection of participant’s fluid identities and the complex ways in which they are connected to the world through these identities in different contexts. This helped focus on exploring a new category produced at the point of multiple identities intersection, not on the prior components of identity. That is, to understand disabled Muslim women as a distinctive category.

3. Listening and reconstructing a story

During step 3, I reconstructed the individual story shared by each participant. The codes from step 1, as informed by notes from step 2, led to the development of emerging plots, or storylines, outlining the main elements of the participant’s story. Reconstructing each storytelling was influenced by the following concepts: temporal order (Ricoeur 1980; Polkinghorne 1988), distanciation process (Ricoeur 1984), listening guide (Chadwick 2009), and first-person perspective (Dossa 2009; Mattingly 2013).

Polkinghorne (1988) emphasised the importance of temporal order to narrative. The value of a temporal order is especially significant in organising the storylines to convey a particular meaning for the participant’s story (Wong and Breheny 2018). The temporal order concept is useful to understand the way life events unfold across the life course and how participants made meaning of their lives at a particular time and place (Dossa 2009). At this stage in the analysis process, I reconstructed each participant’s story in chronological order. Re-ordering

participants' storylines into brief stories, told in their own words, enhanced my understanding of how their context and relationships with others influenced their identities over time.

During this stage, I also engaged in the process of distanciation (Ricoeur 1984). Distanciation was achieved in this study by making narrations linked to each participant's interview, where I merely was a narrative finder away from any impact on the data (Dreyer and Pedersen 2009). I was distanced from the narrated events themselves but not my preconceptions, which I wanted to include in the analysis. Given this orientation, I focused on the following questions in each storytelling: what and where events happened (offering example and quoting interview excerpts), why those events were important, what participants did, what effect did that have, what happened next, and what they might mean for the participants. According to Wong and Breheny (2018), distancing oneself from participants' stories can be difficult as participants adapt to constructing a story that draws the interviewer in to make their experience seem sensible. Thus, I became cognisant of my impact on the data and I kept a piece of paper next to me to make notes on the influence of my presence during the interview in constructing the story.

The attention to a participant's multiple voices in her narrative has significant potential when undertaking narrative intersectionality analysis (Chadwick 2017). Thus, following the distanciation, I used the listening guide in which listening to the participant's multiple voices became central to the analysis. This method is based on the assumption that there will always be simultaneously co-occurring voices present within each individual self and story (Chadwick 2009). To take the idea of listening seriously, the audiotape recording was used as my prime source of data during this stage, but not the transcripts. The task involved listening to what participants said and being attuned to the cracks, absences and discontinuities in stories and what they might mean. Careful listening to the tapes allowed me to trace between the participants' various 'I' voices of the self, where each voice or collective of voices is embedded in a specific context and carried by a first-person voice (Gilligan et al. 2003, p. 163). Thus, the listening guide offered a concrete tool for analysing the intersected, heterogeneous and contradictory voices of each participant.

Listening to participant's voices enabled me to recognise the significance of re-introducing each story in a participant's own words, using the first-person perspective. Mattingly (2013) argued that a first-person perspective is not only an individual person's life experience but also this very split between the person and their social relationship with others and the physical environment. Thus, the challenge, in reconstructing narrative using a first-person perspective, was to listen to these women's voices in a manner which allowed me to

understand their lived reality whilst simultaneously understanding how the dominant system and presence of other people shaped their identities.

This analysis step enabled me to focus on what was important for the participants rather than on what I thought was important. The goal here was to construct events that were still contingent and might even be disrupting the story, but with an internal coherence that gave them a meaningful place. Meaning-making was continuous by constructing separate events into a meaningful whole (Hartog et al. 2020). Thus, stories at this stage were more descriptive than analytical and were informed by the practices performed during the first three steps of the analysis process.

Stage 2

4. Interpreting the story

This step of the analysis was interpretive. I started to interpret the stories using the conceptual framework underlying this study. I discussed the data in relation to theory, and the theory was then used to fill the meaning-gaps in the emerging storylines and explain the story. The selection of the theory was based on the objectives of this study and the question I wanted to explore. The various theories that were used to interpret the stories are presented in the findings chapter. My choice of particular theories did not eliminate the value of alternative theories to the stories of my participants. The stories could be interpreted through the lens of several theories, such as psychological theories or theories of oppression. Using these theories would have resulted in different findings, and therefore, another study.

Stage 3

5. Further data collection

This step entailed going back to the field to collect further data from the participants, this was done in order to develop a fuller understanding of the complexities of the emerging storylines. During the analysis, I often realised that a particular aspect of the participant's life in the story required more clarification or explanation and I would arrange to meet her again for further data collection. Rather than a weakness of the design, this was one of its strengths because it did not only allow for a full grasp of the aspects of story in specific context, but also contributed to advance the theoretical depth of the narrative intersectionality analysis. During this step, I fed back to the participants to see that I understood their story from their perspective, or to gain alternative interpretations to the ones I reached during the preceding steps of the analysis process.

6. Repeat process

The data analysis and collection processes from steps 1-5 were repeated several times for each participant until a meaningful narrative was reconstructed. These narratives were meaningful in relation to the events narrated in particular contexts and the theories used to interpret them.

Stage 4

7. Reconstruct narrative

The reconstructed narratives at this step were the final result of this study, and their outcomes were derived from each participant's unique story. While participants' stories in this study are unique, they are by no means exhaustive. Congruent with my conceptual knowledge of the narrative analysis and intersectionality analysis, narrative of intersectionality is always provisional and incomplete (Alsaker and Josephsson 2011; Ilmonen 2020). Thus, the narratives I analysed below were provisional and heuristic as well. These stories represent one of the ways in which the world of the participants could be represented from their viewpoints, suggesting other stories could be told.

3.5 Quality measures

Many researchers have discussed the different sets of quality criteria used in qualitative research (Tracy 2010; Ryan et al. 2007; Shenton 2004; Patton 2002). Tracy (2010) suggested that every criteria of qualitative quality may be achieved through a variety of flexible skills depending on the aim of the study and skills/preference of the researcher. The narratives in this study were developed through an interaction between myself as a researcher, the participants and their context. Use of a different researcher or participants in a different context would result in different narratives. Therefore, quality in this study neither refers to finding generalizable themes to a wider population, nor does it refer to the reproducibility of the finding or representing the truth. Instead, quality focuses on the notion of trustworthiness, which refers to the depth, richness, plausibility, transparency and integrity of the research findings. Two criteria explain some of the decisions I have taken to ensure trustworthiness, these are rigour and credibility (Ryan et al. 2007; Shenton 2004).

The rigour of the study is established when the reader is able to audit the actions and development of the researcher (Ryan et al. 2007). The research processes undertaken for this study are discussed in depth within this thesis. There is congruence between the research methodological approach, data collection methods and data analysis methods, which are all rationalised. This adds weight to the decisions reached by the researcher,

allowing the reader to judge the rigour of this study through a thick and rich description (Creswell and Miller 2000). The way in which confidentiality issues and the rights of participants have been dealt with during the research process are also described in the ethical considerations section below, this indicates the ethical rigour (Tracy 2010; Ryan et al. 2007). Credibility refers to the faithfulness, plausibility and persuasiveness of the research findings (Tracy 2010; Ryan et al. 2007). Lincoln and Guba (1985) contended that credibility is one of the most important criteria in establishing trustworthiness, and ensuring that participants' experiences are described thoroughly. The following methods were used to enhance the credibility of this study:

- a) Combined narrative interviews, semi-structured interviews, observing nonverbal communication and note-taking (Creswell and Miller 2000). This approach helped with sorting through the data to locate minor and major issues/concerns relying on multiple forms of evidence rather than a single source of data.
- b) Prolonged engagement with participants supports rigorous data collection, and gives a better understanding of the research context from the participants' point of view (Ryan et al. 2007; Shenton 2004; Creswell and Miller 2000). Data collection occurred through meeting and interviewing each participant on three occasions over a period of several months. There was at least a 4-8 month period between each interview and it was essential to maintain contact with the participants during this time to reduce attrition. Maintaining engagement with participants facilitates a building of trust in the relationship. Participants had time to reflect, expand and speak openly about their stories, particularly about issues at the second and third meeting, and sometimes during the regular contact through email, text message, WhatsApp or Instagram messenger.
- c) Member checking occurred during each interview. Shenton (2004, p. 68) termed the provision of the accuracy of the data during the interview course as "*on the spot*" check. I re-framed questions or expanded on them using probing questions to explore issues the participants were describing in more detail.
- d) Accurate recording, detailed transcription and handling of the data were significant parts for the establishment of credibility. Each interview was recorded on two digital audio-recorders, one was loaned from Cardiff University and the other was personally owned. Thus, I was able to verify any inaudible passages by comparing the two recordings to ensure the accuracy of my transcription. Non-verbal

communication, such as sighs, yawning, laughter and tears were reported in the transcribed text, an example of a transcript is presented at Appendix 4.

e) Participants' direct-quotes were used in the findings. Direct quotes according to Krieken (2019) increase both the liveliness and the faithfulness of the stories, allowing for more expressivity of the participants' original words. In addition the direct quotes, which involved the voice of disabled Muslim women describing their experiences of disability, became not just data but allowed these women to be "*active theory builders*" as Garland-Thomson (2005, p. 1578) suggested.

f) A detailed audit trail was maintained to provide evidence of the research journey. The aim of the audit trail was to monitor my own developing construction and activities throughout the study. Audit trail is considered critical in establishing credibility and transparency of the research process as it develops (Tracy 2010; Shenton 2004). This was achieved through maintaining both a physical and intellectual audit trail for this study (Carcary 2009). The physical audit trail documents give a detailed description of all key stages and developments of the research process, recording data collection and data analysis decisions and procedures (Creswell and Miller 2000). The physical audit trail was used during monthly supervision sessions as an aide memoire, to document the supervision discussion, recommendations and agreed actions plan. An example of the physical audit trail is presented at Appendix 5. The intellectual audit trail outlines my thinking, perception, experience and initial impressions at each stage of the study. This information was documented in a notebook, which informed the writing of the methodology and findings chapters of this study.

g) There was a monthly supervision meeting with the research supervisors. The frequent supervision meetings allowed for critical discussion with my research supervisors who have consistently questioned, commented and challenged my research decisions. These meetings helped in widening my vision, drawing my attention to possible shortcomings/challenges in my actions, and recognising my own biases and preferences. The supervision meetings were recorded and summarised as a supervision date log, which is submitted for research monitoring and annual review. There were also quick catch-up meetings with my supervisors once every two weeks, or whenever necessary, by telephone/Zoom to check how the research was progressing.

3.6 Ethical considerations

3.6.1 Ethical approval

Ethics is a key principle which underpins this study. It is a continuous, dialogic and reflective process, which is embedded throughout the duration of the study (Johnson and Long 2015). Ethical considerations in qualitative research involve obtaining participants' consent to take part in the study, securing confidentiality and taking into account the possible consequences of the study for the participants. The first step in this process is applying for the ethics review. The ethical approval for this study was granted by the Research Ethics Committee of the School of Healthcare Sciences at Cardiff University (Appendix 6).

3.6.2 Informed consent

Johnson and Long (2015) emphasised that participants should be given enough information to consider what their participation will involve, and to be able to decide whether to participate in the study or not. Thus, potential participants were fully informed of the study via the participant information sheet, this was available in two languages: English and Arabic (Appendix 7 English version, and Appendix 8 Arabic version). In order to achieve informed consent, Johnson and Long (2015) highlighted the importance of making any given information easy to read and understand. To ensure the clarity of information provided, the participant information sheet and consent form were based on a guidance adapted from template examples provided by the School of Healthcare Sciences at Cardiff University. The informed consent which was gained from the participant in this study is not a single event, but a continuous process. Thus, to ensure that participation in this study was free from any sort of coercion, the informed consent was achieved through four stages with each participant: expressing interest, initial agreement, signing off the informed consent form and continuous checking.

1. **Expressing interest:** an invitation letter (Appendix 9 English version, and Appendix 10 Arabic version) was introduced to the potential participants through various centres, organisations, networks and groups. Those who were interested in participating expressed their interest by contacting me by email, phone, WhatsApp or Instagram messenger.
2. **Initial agreement:** the participants' information sheet was sent to interested participants, this gave them sufficient information concerning the study and provided an opportunity to consider their participation and to respond to any questions. Participants were given at least ten days to think about their participation before they

were contacted to find out if they were still interested, they could then voluntarily agree to take part in the study. An initial agreement (verbal consent via phone/written consent via email or text message) was accepted at this stage. A consent form was then sent to each participant.

3. **Signing off the informed consent form:** the informed consent was ensured through the receipt of the signed consent form from each participant before commencing the interview (Appendix 11 English version, and Appendix 12 Arabic version).

4. **Continuous checking:** during the data collection of the study, I checked continuously with the participants to find out whether they were still willing to participate and take part in further interviews. This was ensured by letting the participants know, for example, that their first interviews had been transcribed or were undergoing analysis. However, there were some questions which needed further clarification. I also used an opt-in approach to inform the participants about the study. Participants who expressed their interest and consented to receiving the results of the study were added to an email list, they would then receive the results at the end of the study.

3.6.3 Withdrawal

The consent form was sent to the participants after their initial agreement had been received. This allowed participants time to freely reconsider their participation in the study. At this stage, all participants were advised that they were free to withdraw from the study at any time should they so wish. This meant that participants were free to withdraw before, during or after data collection without any explanation, prejudice or consequences.

3.6.4 Confidentiality

Each participant who expressed an interest in taking part in the study received the participant information sheet which detailed the study and dealt with issues such as confidentiality. In addition to this written information, I spent time with some participants describing in detail how confidentiality would be ensured, this took place prior to their agreement to be interviewed. Finally, prior to each interview, the participants were assured that strict confidentiality would be maintained throughout the study and drew their attention to the section on confidentiality in the participant information sheet.

With respect to issues of anonymity, pseudonyms were allocated and some of the minor details about the participants were changed. The use of a pseudonym according to Gerrish

and Lathlean (2015) protects the anonymity of the participants, thus making them unrecognizable in any report from the study. Each participant received a pseudonym which was used throughout this study. None of the participants' names were disclosed in this thesis and they will not be used in any reports, presentations or papers produced as a result of this study. Some personal and demographic information was concealed such as using an approximate rather than exact age of the participants. Walford (2018) argued that in a less-interconnected world a limited anonymity could be maintained, but this is no longer possible in this time of social media. Thus, anonymity was further maintained by omitting some of the data in the interview transcript or by judging what should be left out in the analysis based on the interview.

3.6.5 Participant and researcher safety

Every research project is different, but the risk depends on the nature of the research (Johnson and Long 2015). As the nature of this research question involved high levels of disclosure about participants' personal stories it was important to be as sensitive as possible to avoid any emotional harm. Yet, Johnson and Long (2015) asserted that whilst complete avoidance of harm may be impossible, this should be kept to a minimum. Thus, from the beginning of the interview, the participants were reassured that they could decline to answer any question that they may feel uncomfortable responding to. Participants were also offered the opportunity to discontinue the interview or have a break if they felt distressed, unwell or even disinterested (Oliver 2010). I acknowledged that sensitive and painful experiences might be discussed and the participants may become upset and distressed during the interview. In this case, I would stop the interview and calm the participant. In addition, I had the Muslim Community Helpline line available in case participants required any additional support.

Physical harm to participants was also avoided at all times. The environment of data collection during the first interview with each participant was assessed for possible risks prior to commencing the interview, such as checking the fire or nearest exit using the Cardiff University Generic Risk Assessment Form (Cardiff University 2014). Examples of potential risks to the participants as well as the researcher and ways to address them are discussed in Appendix 13. I adhered to Cardiff University Research Integrity and Governance Code of Practice to ensure that the research was conducted in accordance with the required standards (Cardiff University 2018). In the interest of researcher safety, and in line with Cardiff University's lone working policy, I informed the study supervisors or a close friend before and after each participant visit.

3.7 Chapter summary

In this chapter, I outlined the methodological processes used in the study. I explained the rationale for adopting qualitative research methods to explore the individual experience of Muslim women who are living with disability in the UK. I also described the narrative inquiry design which was used to facilitate in depth storytelling by the participants. I explained the tools which I used to collect the data for this study including narrative interviews, semi-structured interviews, observing nonverbal communication and note-taking. Then, I described the data analysis methods including transcription, data storage and management and the data analysis approach and process.

To analyse the data, I sought to create the 'narrative intersectionality' approach as an analytical tool which would illuminate the complexity of a participant's experience of their multiple identities within different social contexts. Then, I described the measures which were undertaken to ensure the quality and trustworthiness of this research. Finally, I acknowledged the ethical issues which arose when discussing a personal experience and how I adopted strategies to minimise harm to participants. The findings of this study are presented in Chapters 5-9. These narratives are prefaced by Chapter 4 in which I represent an introduction to the findings chapters.

CHAPTER FOUR: Findings

The recruitment process for this study commenced in September 2019 and continued until February 2021. The period of recruitment was extended due to the low response from prospective participants after the first few months of inviting eligible women to participate. In addition, I aimed to meet the participants at different intervals of their life. For example, the first interview with all participants was conducted before the COVID-19 pandemic, whilst the second and third interviews were conducted through the COVID-19 lockdown.

During the recruitment process, fourteen disabled Muslim women expressed interest in participating in the study. Six women participated, one of whom withdrew later due to privacy concerns related to fear of being identified from the told story. Reasons for not taking part in the study after expressing interest varied between lack of interest, health issues or issues around trust. The list of the five women who participated is presented, using pseudonyms, in Table 4.1 below. All interviews were conducted in English.

In chapters 5-9, I focus on experiences of everyday life and the enactment of coping strategies, paying particular attention to the choices, desires, actions and reactions of five Muslim women who live with disability in the UK. The narratives of these women *“are tailored to context”* (Mattingly 2010, p. 49). Situating their narratives within a socio-cultural and theoretical context enabled me to understand how these participants’ identities were co-constructed and influenced by their contexts because stories *“take their meaning not only from their content but also from the situation in which they are performed”* (Mattingly 2010, p. 49).

However, this study does not provide categories on the way in which Muslim women make sense of living with disability or general themes. The five narratives presented in the following five chapters are by no means exhaustive of how Muslim women live and cope with a disability in the UK. Several stories of other disabled Muslim women in the UK remain unknown, untold and unheard. Thus, the narratives in this study illustrate the unique ways in which some Muslim women experience life with a disability and the strategies they enacted in their everyday lives through various decisions, interactions with other people or everyday activities.

Although the narratives presented in the findings are essentially unique, each woman’s story resonates with those of her peers. Their stories speak to the larger social issues of stigma, discrimination, stereotyping, bullying, staring, reduced social interaction, violence, and the formation of coping strategies in the face of these issues. Although telling individual stories,

these women speak in a collective voice, evident in the way they change from 'I' to 'you' and 'we'. This speaking reflects their desire to work towards a social change. They are aware that their stories form part of a chain of experiences shared by other disabled Muslim women in the UK. This realisation is what led me to focus on the stories of five women. Although I did not rule out the options of including general themes across the stories of these women, I decided, after careful consideration, that there was greater merit in focusing on individual stories.

I wanted to recognise these women as authors of their texts. I felt that their struggles and their attempts to recreate their worlds would be accentuated through individual stories which *"can have powerful consequences upon how the present is experienced and what future actions seem most reasonable"* (Mattingly 2010, p. 49). The individual stories also allowed the participants *"to reason about what to do on the basis of what has occurred (as events are rendered through the story), who is to blame, who is responsible, who the characters are, what can be hoped for, and the like"* (Mattingly 2010, p. 49).

This, however, does not mean that the narratives provide an exhaustive account of the participants' experiences of living with disability. More specifically they foreground some parts of these women's experiences with disability, in their local context and in a specific time frame, where other parts of their experience are not given the same attention. Meanwhile, their narratives also bring to the fore the paradigm of intersectionality to show how differences of gender, race, religion, and disability accentuate each other, which is to be understood contextually and as a lifetime process. Consequently, the narratives that follow in the next five chapters do not make any claims for the generalisability of Muslim women's experiences of living with disability, rather they highlight the everyday life experience of specific disabled Muslim women in the UK.

In the chapters that follow (Chapters 5-9) I aim to highlight how specific Muslim women experienced life with disability, how they perceived themselves in their local contexts and how they coped in their everyday lives. These narratives could, of course, have been presented in many different ways, highlighting different issues. In Chapter 6, for example, I chose to focus on power and racial discrimination in health and social care. Another potential narrative could have been one on healthcare rights for minority groups. Similarly, in Chapter 7, I focus on Kinza's attempt to change wider perceptions of disability rather than to present herself as a victim. However, she also spoke about the fear of losing disability benefits; this could have been a different narrative. My main guiding principle for choosing which storyline to bring to the fore was dependent on the data which had been collected; I chose the

storyline which had the richest data so that I could construct the most coherent and plausible narrative of the participants.

Chapters 5-9 are woven in a way which presents the unique individual narratives of Samia, Nadia, Kinza, Farah, and Zara. In each participant's narrative, the quotes are presented verbatim and any grammar error/mistake is because of their own dialect. Chapter 5 discusses Samia's story and the factors that affected her social life. Her story provides a script of what it is like for an older disabled Muslim woman to live with a disability, focusing on both the impact of physical impairment (e.g. pain), and what it signifies socially, such as loss of independence and reduced social interaction. Chapter 6 documents Nadia's story of fighting with the health and social care professionals for herself and her two disabled sons. Her story shows the role of power dynamic and racial discrimination in health and social care. Chapter 7 includes the story of Kinza, a wheelchair user, who left Nigeria due to negative experiences related to the societal perception of disability. Her story highlights the way she engaged with the world around her, through activism work in the UK, in an attempt to change wider perceptions of disability rather than to present herself as a victim.

Chapter 8 focuses on Farah's story of being a "*partially sighted and legally blind*" young woman who is a solicitor and uses a white cane. Farah's story shows her desire to live her life without allowing her visual impairment to define her, the practices she enacted to challenge the dominant social perception of visual impairment and celebrate her different identity as a disabled Muslim woman. Chapter 9 tells Zara's story, a retired nurse who uses crutches and wears a niqab. Her story highlights how she tried to be independent, cope with people staring and to present a positive image of her identity as a "*Black*" woman and "*lady with a niqab*". She described feeling socially excluded and "*vulnerable*" due to the general hostility towards body differences in her everyday life contexts. In Chapter 10, I discuss how the narratives presented in Chapters 5-9 provided a response to the objectives of this study and I illustrate how participants in this study resisted and overcame daily social challenges to recreate a better world for themselves, other disabled Muslim women, and the next generation of disabled people.

Table 4.1: List of participants

NO	Name	Age range	Ethnicity	Marital status	Underlying health condition or impairment		Occupation	Assistive equipment
					Physical health	Mental health		
1	Samia	Mid-60s	Black British	Widow	Osteoarthritis, spinal disc problem, and stomach ache	Depression and previous suicidal thoughts	Retired	Walking frame
2	Nadia	Mid-30s	British South Asian	Married with three children	Rheumatoid arthritis (advanced/inflammatory), hand swelling, ulnar deviation, severe pain in all joints, especially hands, legs and feet, sciatica and Reynolds's disease	Stress and anxiety	Housewife	N/A
3	Kinza	Early 40	Black	Married No children	Poliomyelitis	Bipolar disorder, severe anxiety, panic attack, insomnia self-harm and previous suicidal thoughts	Postgraduate student, disability right activist, feminist and LGBT representative	Powered wheelchair
5	Farah	Mid 20s	British South Asian	Single and lives with family (parents and seven siblings)	Legally Blind	N/A	Solicitor, barrister trainee, Instagram influencer and disability advocate	White cane and black shade glasses
5	Zara	Early 50s	Black British	Married with two grown children who live away	Fibromyalgia, osteoarthritis, HIV, chronic IBS, stomach ulcers and limitation with walking movement	Bipolar, borderline personality disorder and post-traumatic stress disorder	Retired nurse	Crutches indoor and outdoors

CHAPTER FIVE:

“I decided I’m not going anywhere; I’m gonna stay indoors”

Samia is a woman in her mid-sixties. She lives in a big metropolitan city and takes pride in her house, which she keeps immaculate. She has lived in the same neighbourhood for 18 years, ever since she came with her husband and children from a West African country to live in the UK, with a determination to build a new life. At that time, Samia started in full-time employment. She had been an independent and friendly woman who enjoyed participating in the community by regularly attending Friday prayers, communicating with neighbours, joining a group of women for dinner, and spending some time out with them. Samia described feeling depressed when her husband died in 2010 and she started experiencing body pains. She was later diagnosed with osteoarthritis, spinal disc problems, and stomach ache. During our meeting, she reported that her hands and arms were becoming increasingly weaker and that she was finding a variety of everyday activities challenging. From washing her body to dressing, cleaning the house and walking to the local shop, her repertoire of activities was become more and more restricted.

At our interview in late 2019, Samia was using a walking frame indoors. She was waiting for a manual wheelchair to be delivered for her to use outdoors. She also received three daily visits from carers who helped with washing and dressing in the morning and some housework and meal preparation in the afternoon and evening. Her daughter lived nearby, and she was the only visitor besides the carers. Her physical impairments had, however, resulted in an alteration to her independent living at home and in the community; she had changed from an “*active*” woman to a woman who is “*not doing anything*”. During the year prior to her participation in this study, Samia had seldom left the house, preferring to remain in her bedroom most of the time. “*I decided I’m not going anywhere*”, she said; “*I’m gonna stay indoors*”. This chapter discusses the factors that affected Samia’s social life and made her feel and describe herself as an “*isolated*” person. It provides a script of what it is like for an older disabled Muslim woman to live with a disability, focusing on both the impact of physical impairment (e.g. pain), and what it signifies socially such as loss of independence and reduced social interaction.

5.1 The beginning of illnesses and life at home afterwards; “Everything is difficult”

“The ill started in, started a little, a little bit in 2010 when I lost my husband. Then I started like physical problems, like mentally, depressed, I go much depressed like a mental problem, they started to take me to the hospital and give me some depression medications. Suddenly I start the leg swelling, and it goes like this, in one year, there is a lot of stuff coming out”.

When Samia lost her husband, she described finding it a challenge to cope and said that her grief led to severe depression. During our discussion, Samia described how she tried to commit suicide and “*started to kill [herself] three times*”. As a consequence, she was hospitalised for six months for depression treatment. Fiske et al. (2009) found that suicide attempts in older people were more closely associated with depression. Yet, Samia was also diagnosed with osteoarthritis during her time in hospital, this began suddenly with leg swelling. After returning home from the hospital, Samia stated she did not go out much because she struggled with osteoarthritis, which mainly affected her knees, shoulders and hand joints. The joints that she needed in order to walk and perform basic daily activities. Soon after returning home, Samia found herself no longer able to perform the tasks that she once could do with little difficulty, such as cleaning and cooking. She said:

“I can hover, now I can’t hover anymore, I can cook, now I can’t cook anymore, when I hold the knife, the knife was fell down, I can’t cut onion, the hand is paining me too much, that is suddenly a lot of stuff, a lot of stuff, and then we check it, they are ‘oh you have a problem for disc’”.

When Samia found she had a problem with her “*spinal cord, that makes pain 24/7*”, the doctor recommended a surgical intervention to help relieve the pressure caused by the damaged disc on her spinal cord. She was admitted to the hospital again to have the operation, despite acknowledging that the surgery could not cure the problem, it could only reduce her lower back pain and its associated limb numbness. Spending time in hospital, rehabilitation and then at home recovering resulted in Samia feeling isolated, however, she did not report this until later when she returned home to resume her daily life after recovering from surgery:

Samia: “I’m not doing anything, I’m isolated, I was active, and I was working before, now I stop work, I can’t do anything, I can’t go out without anyone because it makes me feel like I’m not stronger to walk any more outside”.

Amani: Is this because of the pain?

Samia: “Yeah, the combination of the pain and I feel like dizzy, I fell down a lot in my, inside my house and outside as well, that means when I go outside, I suppose to have someone”.

Smith et al. (2019) and Poscia et al. (2018) described social isolation as the consequence of a lack of meaningful and sustained communication with a reduction in the social network size and interactions. Samia experienced social isolation in two ways: through not working and not going outside the house. She described her pain following the surgery, saying, “*day after day it goes worse, now this leg [pointing to right leg] is not working properly, it’s like a muscle cramp*”. Due to the chronic pain she was experiencing she stopped working, this had been taking her outside the house every day. Samia also described how her physical impairments affected her strength and balance, making her more likely to fall. As a result, she needed someone to ensure she was safe while walking outdoors, in case she felt dizzy or her legs felt cramped or weak. The fear of falling affects between 3 and 85% of older people who have fallen, but also older people who have never experienced a fall (Scheffer et al. 2008). Fear of falling, according to Faes et al. (2011), can play a significant role in an older person losing their autonomy, this results in activity restriction and a loss of confidence in their ability to walk safely and independently.

However, while the help Samia needed outdoors seems minimal, it was necessary. If, for example, she felt dizzy, someone had to be there to take her hand and guide her to sit in a safe place. In other words, it is not so much that Samia needed help when walking outdoors, but that the help she needed could not be planned in advance. Worrying that she might need this help outside the house, in combination with pain, led to her decision to stay at home. It was not only walking outdoors, though, as Samia explained, she also required assistance in many activities around the house as well. She said:

“I’m very clean woman, I’m independent, now my house I can’t clean until I beg people to clean it for me, or maybe my daughter saying ‘no, not today mum I’m sorry, I’m going to clean it for you next day’, I fell ahh [sigh], why these things I’m not going to do it myself, I can’t stand up in the kitchen to wash dishes, when I stand up I feel pain, I can’t stand up to cook I feel pain, I can’t go to shower myself I need help to whether is I’m going to fall down, everything is difficult. You think you are going to be happy like that, no, no, you can never be happy”.

Samia’s issue was not in relation to getting the dishes washed, the meal cooked, or the house cleaned; it was about not using her body to carry out a familiar task that was common in the repertoire of her everyday life. Therefore, what mattered for Samia was not the housework task itself, as she stated someone else could do it for her, but the degree to which this seemed to be altered or became unsafe for her to perform. In other words, it was the perception of losing independence. For Samia, independence meant being able to continue with her daily tasks without the help of another person. But the difficulties posed by her physical impairments challenged this concept, especially when it became clear that

assistance (i.e. a form of inter-dependence) was needed to perform daily tasks. She described feeling upset at having to ask for help, even when seeking assistance from her daughter. Idaiani and Indrawati (2021) found that older people with decreased functional status and a high level of dependency were at the greatest risk of becoming depressed, compared with those without functional impairment, or with independence in performing their activities of daily living.

In her account, Samia revealed the aspects of everyday life that are taken for granted until they become subject to disruption: washing dishes, cooking dinner and having a shower. This disruption has been termed by Bury (1982, p. 167) as a “*biographical disruption*”, it highlights the cognitive and material resources available to individuals, modes of explanation for pain and suffering, and sources of alteration in one’s experience. For example, when Samia stated that she could not perform these activities by herself, she tended to evaluate her performance compared to her level of competence before the onset of her illnesses. Cleaning the house, for instance, may have been a routine task prior to her illnesses. However, since the beginning of her physical impairments, this task may have become almost impossible. She used to keep her house clean and tidy. Thus, being a “*very clean woman*”, as she explained, became part of her gender identity, this was threatened by the difficulties brought about by her illnesses.

Samia recognised that her physical impairments had affected her life, this was the result of the difficulties she experienced and their effect on the way she performed in the world around her. Being unable to complete routine tasks affected her ability to be “*independent*”. This realisation increased her feeling of being dependent on others, it was at these times she felt she had such chronic conditions she could never be happy again. It was at these times she also described feeling unable to muster up the energy to do anything because she believed “*everything is difficult*”. Samia received three daily visits from carers who helped with washing and dressing in the morning and some housework and meal preparation in the afternoon and the evening. Nevertheless, she reported other challenges associated with this care:

“The carer comes here does something different the way you do in Muslim, we don’t wear shoes in the house, you know, and this one now is okay, but before they were sending anyhow maybe morning sending another carer, afternoon send another carer, that’s mean all the carers they are going to see you, you’re naked because they supposed to wash you, they supposed to wear you ... I need one carer for every day, I don’t want change, that’s the way I am, me I don’t want change”.

Having qualified for funded home care, Samia found she was expected to fit in with the service provided, rather than the service being provided according to her needs. In other words, Samia sought the assistance of the carers because of her physical weakness and needs. Thus, the core element of caring was to aid Samia, who was in a vulnerable situation as a patient but still had the right to personal privacy. Help with activities such as washing and dressing is often referred to as body work or intimate personal care, this demands direct or indirect contact with the bodies of others or exposure to their body's private parts (Cohen and Wolkowitz 2018; Cambridge and Carnaby 2006). The nature of this care, therefore, means that dignity and privacy are significant considerations in delivering this type of work. Because body work, as suggested by Cohen and Wolkowitz (2018), involves varying amounts of embodied touch in which the social meaning of touch is altered by both the body of the person who performs this work and the body of the person being touched.

Samia reported receiving care from female carers, but she explained feeling uncomfortable because she was receiving care from different carers during the same day. Toileting, showering, dressing and undressing involve nudity and, therefore, vulnerability which involves an aspect of power as well as a literal stripping (Wedgwood et al. 2018). This power imbalance is heightened by the unfamiliarity of the caring staff (Wedgwood et al. 2018), even if they are all female. In Samia's words: "*all carers they are going to see you, you're naked*". Cohen and Wolkowitz (2018) and Twigg et al. (2011) argued that the care provided by female carers can be interpreted as sexually neutral or safe, which in turn deflects anxiety about intimate touch. Twigg et al. (2011) also argued that carers and the bodies they work upon must be in the same place and in the same time. Yet, Samia highlighted a crucial dimension of this care, in line with Cohen and Wolkowitz (2018) and Twigg et al.'s (2011) argument, which would require her to have the same female "*carer for every day*". According to Thomas and Sakellariou (2018, p. 24-25), "*assistance with dress that required intimate hands-on care and exposure to the unclothed body was experienced as a distortion of the ordinary*" body privacy. Samia tried to "*reassert boundaries of bodily privacy*" as suggested by Thomas and Sakellariou (2018, p. 25), through reconstructing personal boundaries, as she said above: "*I don't want change, that's the way I am, me I don't want change*".

Another issue resulted from the care which Samia received, this related to her Islamic identity. Samia described her disappointment with some carers, they would come into her house, through the open door, and into her bedroom without taking off their shoes. Samia explained that, according to Islamic tradition, Muslims must remove their shoes when entering the house as the soles are seen as dirty and unsanitary. In addition, her carpet was symbolic, it was important for her to keep it clean. For Samia, this behaviour was an indirect

intrusion of her living space, mainly because she found it hard to explain the implications of this behaviour to each carer she received. Recognising this as a problem she wanted to have the same carer every day, she could then explain how she felt and express her needs. During our conversation, Samia told me how she worked around this dilemma by getting the Carers' Allowance and paying for the care herself without involving social services. According to Twigg et al (2011), attempts to empower patients through more patient choice may reduce a patient's feeling of vulnerability because these discourses do not address the physical vulnerability of patients when they are often naked, weak and subject to the control of clothed staff. Thus, the Carers' Allowance gave Samia independence, control and choice about how to enhance her care and how to spend her money. In other words, hiring her own carer enabled Samia to ensure her personal carer was respectful of her (Wedgwood et al. 2018), and her religious and cultural traditions. It also affirmed her agency and helped avoid her being perceived as passive in more significant decisions, such as the care options she required. She commented that

“with this one [Carers' Allowance] now it is okay, now you can take your money and call the care yourself and pay the carer yourself, now by ourselves”.

During our conversation, I also asked Samia how she was coping with her everyday life struggles after the illnesses and what she usually did. This was her response:

Samia: “To cope with, like the way I say is very, is very, I'm not coping with anything because the active person, I'm not sleeping all the night, I sleep only two hours every day ... I can't get to sleep because I'm thinking too much ... I think a lot about myself, my body, you know the way I was before and now just why, why just ask myself why, why me, why all the time”.

Amani: I see. So what do you usually do these days?

Samia: “I'm not doing anything, just stay home, waiting for prayers, then pray and come back and sitting down and read Quran and listen, or maybe I watch TV for a little bit and sometimes all week I can stay in the bedroom day and night, that's the way my life is [tearful eyes], you know, sometimes I feel like a, life is not fair and umm, when you think you see another person maybe when you go to hospitals, and you come back and say 'ah I saw that person, he has a lot of problems more than me, look at this one who don't have all two legs', I have a leg Alhamdulillah [thank God]”.

In the early days after her illnesses, Samia told me that she “*was crying every single day*”. Nine years after losing her husband and being ill, she also described finding it challenging to cope and how her sleep had been impacted. In asking “*why me?*”, Samia was not seemingly seeking an answer, but arguably this was a rhetorical question directed to an unseen interlocutor, the body, challenging a perception of her physical impairments as a loss of “*the*

active person” she used to be. Samia painted a more nuanced picture, where her body was supposed to present an “*active person*” image. However, this picture was disrupted by the impact of the physical impairments on her body. Thus, she reflected on how she tended to re-evaluate her life and appreciate things she had taken for granted before.

Samia explained that she started to take advantage of what was there in her body. For example, she mentioned that her leg was “*not working properly*”, but she explained that being grateful had changed how she perceived herself, particularly when she realised that another person had no legs. It was her coping strategy, it acted as a reminder that others have a worse situation than herself. In other words, she acknowledged that her leg was not working properly, but she appreciated that she still had it and it allowed her to walk. Yet, she also brought to the fore how Islam embodied in her everyday life through waiting for prayers, praying, reading Quran or listening to its recitation. She stated that Islam helped her cope with every day struggles. These religious practices had inspired her to counteract her negative and suicidal thoughts, especially when being ill was clouding her mind. She commented:

“When I think like that [why me] I become just a.., maybe I put some Quran to make me don’t think bad, but before I would think I will do a lot, I start to kill myself three times”.

Samia also described how she used to attend the Friday prayers at the mosque every week, but factors discussed in the following section affected her social activities in the community.

5.2 Social life and community: “I don’t want to see people”

Having a ‘social life’ played a significant role in Samia’s narrative. There have been times in her life where she described having almost no time to think, she used to meet a group of women from all walks of life with shared interests. She also often described enjoying craft activities, such as sewing and drawing and going out with the women:

“We go by bus, and we go to maybe lake siding, we do exercises, we eat lunch and around three or four you come back home, you don’t have a time to think because we meet people, but who stays indoor makes more stress ... but I’m not turning there [now] because of the pain, and I don’t want to see people anyway”.

While Samia commented on what a positive influence being able to go out had on her life and that staying at home was linked to an increased feeling of stress, she stopped joining this group. After being ill, Samia experienced some issues that made her withdrawn, she did not want to go out and see people:

Samia: "I can sit down with you now and suddenly it can, the pain, the pain until I'm crying in front of people that's why I decided I'm not going any far"

Amani: When did you stop going out?

Samia: "I stopped to go almost now, umm one year" [silence 00:09]

Amani: Have you had any incidence with people?

Samia: "Yeah, some people stare, and they come straightway they say 'hey what happened? What is wrong with you?' [imitating a sharp voice], ... and I decided I'm not going anywhere, yeah. I was every Friday I go to the mosque, now I stopped I'm not going anymore so I pray indoor".

Samia enjoyed going out, but she described deciding not to go out anymore. There were three reasons for her decision: (1) she needed someone to be with her, (2) pain, and (3) people's reactions. Since 2019, Samia recounted that she could walk "*slowly, slowly*", with the aid of her stick, to the nearby shop. One year before our meeting, Samia's legs became weak, she found walking alone difficult, and she reported falling inside and outside her house. She told me that her social worker made a referral to the local wheelchair service, she was waiting for the delivery of a manual wheelchair which would make it easier for her to go outdoors.

Firstly, going out with a wheelchair requires planning and several considerations. Before lifting the wheelchair into the car, the leg rests and arm rests must be removed to minimise the weight of the wheelchair. The wheelchair frame has to be folded and pushed open again. Then, the wheelchair has to be loaded and unloaded onto the back seat or the trunk of a car. It also has to be propelled by users themselves. Samia could not self-propel, and she needed someone to do all the accompanying tasks for her as well. She described receiving support from her daughter through giving her lifts to appointments and sometimes spending time out, but she could not be with her every time she wanted to go out. Thus, without the support of her daughter, Samia became isolated. She was isolated by an interaction between a body affected by physical impairments and a lack of support which would meet her needs. A change in any of these elements could eliminate the isolation that Samia experienced; whilst changing her body was not an option; getting a personal assistant, either through a publicly funded service or privately, would enable her to go out again. Yet, because she could walk, with difficulty, and had support from her daughter this meant she was less likely to qualify for a funded personal assistant for outdoor support. Thus, she coped by not going anywhere and staying at home.

Secondly, the pain was another challenge that Samia mentioned in terms of her ability to go out. She had to always carry a "*higher dose of morphine*" (strong painkiller to treat severe

pain) since she could have pain at any time. Samia also made it clear that predicting pain prior to a particular task was impossible. For example, she explained she could have cried in pain suddenly while sitting on the sofa during our interview. Thus, she could not predict when the pain would strike or how much it would affect her, it was completely unpredictable, and she described having no control over her emotions once a severe pain hit her without warning. In other words, her physical impairment controlled her. In an instant, her physical impairment might cause severe pain and she would cry out in front of people. As a consequence, she decided to stop going out. Smith et al. (2014) and Nyvang et al. (2016) reported that people with chronic musculoskeletal pain might actively limit their social relationships when they had difficulty in managing social events or meeting people, leading to greater social isolation.

Thirdly, Samia said that she was subjected to people staring at her. She also described feeling that people, in general, did not know how to approach her. Their entry and exit points of interaction were often confined to “*what happened?*” or “*what is wrong with you?*” exchanges. Samia felt they were not asking about her diagnosis, instead, she believed they were looking for a why and what made her body look different. With repeated emphasis on “*disabled status*”, Deegan (2010, p. 34) argued that even the person with a physical impairment who is usually “*feeling normal*” may be altered into “*feeling disabled*”. (Goodley 2014). Being forced to verify, “*what is wrong with you*” repeatedly to people demonstrates one’s lack of achieving normality and provides a means of defending against one’s own sense of lacking and insecurities (Deegan 2010; Goodley 2014). As such, Samia became caught in the violent maintenance of the normative order

Here, staring implies both recognition (staring at Samia’s body), and negation (staring through people’s social perception of disability) (Goodley 2014). As Curran et al. (2018, p. 46) put it: “*they repeat the mistake of asking what is wrong with you? rather than what is wrong with society? and what needs to change?*”. People’s reactions are painful, focusing on the functional aspects of Samia’s body rather than her personhood. This changes Samia’s social interaction as a result of being stigmatised by a disability status (Deegan 2010). For example, Samia had affirmed her membership in the Muslim community through attending Friday prayers. But people’s reactions were the major reason which led to her withdrawing from participating in her religious community, ritual practices and worship in the mosque. She coped by praying at home.

As our conversation developed, it became evident that there were three painful areas which impinged heavily on Samia’s identity and were difficult to resolve. Those areas related to independence, isolation, and body appearance. It is Mills’s (2000, p. 226) recognition that

what has been painted as “*personal troubles cannot be solved as troubles*”, but must be understood in terms of social issues, which Galvin (2005) argued is the key to the development of an effective strategy of liberation. If Samia found both (1) an adequate social support (i.e. personal assistant), and (2) if people accepted her differences, she might not be isolated at home. Samia integrated this recognition into her attempt to contribute to social change not only to her own process of emancipation but to the raising of the status of other disabled Muslim women. When the invitation for this study was sent via WhatsApp messages, Samia was the first person to contact me. During the concluding talk of our first interview I asked Samia why she participated in this study, she said:

“To help those disabled Muslim women who are isolated at their homes”.

5.3 Chapter Summary

Samia’s story highlighted the factors which led an older disabled Muslim woman to make the decision to stay at home and thus to describe feeling socially “*isolated*”. Following physical impairment, Samia found herself dependent on others for self-care and support. She was left to her own devices to negotiate the reality of her life with the illnesses from which she was suffering and the resulting pain. Samia told her story of what it was like to struggle for independence and to try and accept the consequences of its loss. Her sole contact, apart from her daughter, was a personal carer. The carer’s indifference to Samia’s situation is a function of societal insensitivity to her multiple identities: Samia belongs to a non-Western culture, she is Muslim, and she is disabled. In her narrative, Samia also revealed a nostalgic image of herself prior to her illnesses as an “*active*” and “*very clean woman*” who liked to “*meet people*”. She presented her embodied understanding to highlight the paradox of independence and sociability versus dependency and social isolation.

The impact of Samia’s physical impairment affected her life at home and changed her social interaction in the community. Due to the lack of a personal assistant, Samia had to cope by going out with her daughter from time to time, she also tried to control the sudden pain by making sure to carry a “*morphine*” when she went out. Yet, she described not being able to cope with people’s reactions and their intrusive questions and stares, which ultimately isolated her further. But Samia reconstituted her world using scant resources. She emphasised the importance of addressing her religious traditions when carers entered her home, chose her personal carer, and paid the carer herself, this is how Samia affirmed her agency and tried to avoid being perceived as a helpless victim. She also tried to make something positive out of her negative experience when she portrayed herself as a source of “*help*”, focusing not only on her situation but also on isolated disabled Muslim women as a

whole. She attempted to effect social change so that the onus would not be placed on the disabled Muslim women to integrate into the community. Overall, Samia's narrative provides a script of what it is like to live with a disability, particularly in the context of her home, focusing on the impact of physical impairment and what it signifies socially such as loss of independence and reduced social interactions. The following chapters extend this focus – with reference to other participants' stories – they explore the combination of both 'impairment' and 'disablism'.

CHAPTER SIX:

“If I was different, I probably wouldn’t be treated like that”

Nadia is a woman in her mid-30s who was born in the UK to parents born in Pakistan. She described herself as a person who used to have time to wear makeup and holiday with friends. When I met Nadia, she expressed her wish to get a little of that time back, but she said, “*I can’t, and I guess because I love my family too much, and that is like my committed time to my family*”. In her narrative, Nadia prioritised her family before herself and her needs. Nadia has three children: the eldest is an autistic child³, and the youngest had a referral for autism and experiences anaphylactic attacks and severe asthma. Nadia’s husband is autistic as well.

Three years before her participation in this study, Nadia was diagnosed with rheumatoid arthritis. Being relatively recently diagnosed with rheumatoid arthritis, Nadia tried to find her way around the health and social care systems. She believed that the health and social care system should sort things out, but she described feeling that this system, not herself, held the power to decide and that various professionals controlled and discriminated against her. Nadia’s experience with a few health and social care professionals, such as a rheumatology doctor and a social worker, informed her perception and understanding of the entire system. She said, “*Everything comes with struggles, push, push, fight, fight*”. She described pushing herself, “*trying to push [her] luck*”, “*fight with medical professionals*” and “*fighting for [her] children*”. Nadia struggled physically with rheumatoid arthritis which she described as progressing faster than she was able to adapt. In this chapter, the role of power and racial discrimination in health and social care is described. Also, discussed is the way that Nadia felt she was discriminated against whilst trying to seek support from health and social care services and how this experience affected her health, family and everyday life.

6.1 Nadia’s diagnosis

Nadia recounted that rheumatoid arthritis started with flu-like symptoms when her mother “*was on a life support machine and in a hospital during her final life*”. Nadia stated she was not allowed to be around her mother due to her symptoms. She visited her GP and explained that she could not have a cold or the flu for an extended period, which stopped her from seeing her mother. “*I used to stay outside her bedroom and wave*”, Nadia commented.

³ Although many autism organisations, particularly those focused on children, use the terms ‘with autism’ or ‘on the autism spectrum’, I used the term autistic child in order to follow what my participant used to describe her child. Likewise, I used the term autistic that the participant used to describe her husband as there is no single term which is accepted by everyone in the UK (NHS [no date]).

She explained that after trying different medications and when her face and hands swelled and she was in a lot of pain, the GP referred her to a rheumatologist. After a series of tests, Nadia received a diagnosis of rheumatoid arthritis. The first few months after the diagnosis was difficult, with Nadia trying to get over the shock of the diagnosis and figure out what her family life would be like. She told me how rheumatoid arthritis affected her limbs and explained having painful swelling in all her joints, especially hands, fingers, knees, ankles, and hips:

“Arthritis was noted in my fingers and hands, so when the doctor does observations, they call it MCP [metacarpophalangeal joints]”.

Nadia’s condition progressed quickly over a three year period. On our first meeting, I noted the deformity in her hands. Hand deformity in which the MCP’s swelling (the big knuckles at the fingers’ base) caused her fingers to become displaced, tending towards the little fingers. When Nadia needed to drink water she held the glass using one hand to bring it to her mouth and the other to support it at the base of the glass. She described experiencing a heavy leg sensation due to numbness and tingling in her lower limbs, causing loss of balance and falling. On one occasion, Nadia reported falling down the stairs when she could not control her balance while holding her son.

“I remember when I was holding him [youngest son] in my arm, and then I fell, so I quickly tried to get my hand underneath him to protect him; so the first I tried to do is trying to protect my child, so I think in my life the one thing that made me feel upset about disability has been this area”.

Rheumatoid arthritis threatened to encroach upon Nadia’s control over her life. She described feeling upset and worried about rheumatoid arthritis colliding with her children’s needs and her ability to care for them. During our conversation, Nadia also expressed her frustration about not getting any support from healthcare, social care services and her extended family. She said, “*I’m not supported medically*” and “*I never get the support from them*”, namely, the social care services. Moreover, she described her family as “*not being very supportive*” or being there for her when she needed them most.

Regarding health and social care services, Nadia believed that the main barrier to receiving support was the discriminatory attitude due to her identity of being “*different*”. In her words, “*being a Muslim woman who is disabled in my own way I thought that I never been supported or helped and the communication is going to be a lot harder*”. The following sections discuss Nadia’s experience of racial discrimination in two contexts: in healthcare as a patient and then in social care services as a mother of disabled children.

6.2 The rheumatology clinic: “Those people have power”

“When I have my [rheumatology] consultations with the doctors, it seems like she is an English White lady, and I always thought like it’s their way or no other way, when I go to talk about what difficulties that I’m having and I have got continuous difficulty like the pain, the managing, they [doctors] don’t want to hear it, they just want to increase your medications and like send me back ... and I think to myself, is it because maybe I’m a Muslim? Is it because I’m an Asian person? If I am an English White lady, I will be heard. I will be honest with you right now while I’m sitting with you; I take the medications that the doctors have given me; I feel like why am I still in pain? I’m hurting, it’s like, is there something more that can be done to support me or listen to my views because it’s been going on for a very long time”.

This account highlighted an issue faced by Nadia: the tension between being a patient and being an Asian Muslim patient. As a patient with a rheumatic condition, Nadia recounted attending her appointment with an expectation of discussing her health issues, pain complaints and managing her concerns. In other words, Nadia believed that her role as a patient would entail engagement with the doctor to co-create an optimal treatment plan, this would enhance her life opportunities whilst living with rheumatoid arthritis. However, Nadia described that this was not likely to be the case if her appointment was with “*an English White*” doctor.

Nadia described her appointment with the “*English*” rheumatology doctor as a shift from the patient role to that of an Asian Muslim woman. Nadia believed her doctor treated her as other, not as a patient, because she was not an “*English White lady*”. When she tried to talk about her difficulties, Nadia felt the doctor did not listen carefully and was more likely to dismiss her concerns and suggest increasing medications instead. Nadia’s statement “*it’s their way or no other way*”, may be read as they are always right and there was no way to argue or approach discussion. This points to power disparities which distinguish between individuals on the basis of their power status in a healthcare context (O’Shea et al. 2019). In relation to issues of ethnicity, Walby et al. (2012) emphasised the importance of recognising the role of racism in silencing ethnic minority women. In other words, noting the power of the actions of the dominant group, in each of the intersections of gender and race, might shift some of the focus from the inactions of White feminists to the actions of White racists (Walby et al. 2012). Subsequently, as Nadia mentioned, she took her prescribed medications, but she noted that it did not help to relieve her pain; she was “*hurting*” for a long time.

Pain, according to Kempner (2014), interrupts mind/body dualism in ways that can make it difficult for others to understand. This difficulty is complicated by a person’s identity, such as gender and race. According to Hoffmann and Tarzian (2001), women are more likely than

men to be inappropriately diagnosed and undertreated for their pain. This is because the gender norm considers that the woman's combination of female biology and the reproductive role, serves to equip her with a 'natural' capacity to endure a higher level of pain than men. As a result, their pain is not taken seriously (Bendelow 1993; Smith 2002). Such a perspective, some may argue, is reflected in healthcare contexts (Samulowitz et al. 2018; Smith 2002).

Hoffmann and Tarzian (2001) reported that women have a greater repertoire of coping skills to help them deal with their pain, this includes a greater ability to describe their pain, to seek healthcare intervention, and to gain emotional support. These coping skills, in turn, may lead physicians and healthcare providers to discredit the severity of their pain (Smith 2002). On the other hand, Hoffman et al. (2016) contend that racial bias in pain perception is associated with racial bias in pain treatment recommendations. For example, MacLellan et al. (2022), found that Black, Asian and ethnic minority women in the UK are at a higher risk of dying during pregnancy, childbirth and postnatally compared to their White counterparts. Discrimination against ethnic minority women is known to negatively impact upon their ability to speak up, be heard and their experiences of care (MacLellan et al. 2022). As such, Nadia described realising that she had a patient's right to speak with her doctor, to review the medications or to re-evaluate her pain. However, she felt that her religious identity, in combination with her gender and racial identity, compelled her to stay silent because

“as a Muslim, you feel very afraid to speak or tell anybody because you think they aren't going to care”.

Nadia believed that her identity as a Muslim brought to the fore the experience of Islamophobia, rendering her to “*feel very afraid to speak*” with the doctor about her persistent pain. Sheridan (2006) argued that religion might supersede race or ethnicity as a predictor of discrimination. Muslim patients experience increasing discrimination in UK healthcare settings (Laird et al. 2007; Samari et al. 2018; Younis and Jadhav 2020). Some Muslim women, in particular, often fear discrimination and lack of understanding from healthcare providers because their mode of dressing readily identifies their religion (Modibbo et al. 2016; Padela and del Pozo 2011).

Nadia's attempt to share her experience of being a Muslim patient showed how difficult it was for her to speak about her pain. By describing how she was treated in the clinic, Nadia revealed the absence of individual care which she had expected from healthcare providers. In addition, she wanted to be recognised as a woman, a patient and a valued person, though this was not always the case. Nadia aimed to seek medical support for her health problems, which resulted from rheumatoid arthritis, but she described facing problems resulting from

how she looked and the identity which her body represented. These problems appear to relate to instances of racial discrimination and stereotyping, as Nadia pointed out in perceiving her Asian identity.

“The medical system finds that you know, I think that this is how they’re [Asian people] generally perceived, very needy and looking for all the help that they can get, but I think that’s not true. I think that every individual should be looked at case by case”.

When healthcare providers assign a patient to a particular group, Rodriguez and Green (2013) argue that they may unconsciously assign preconceived stereotypes to individual patients. Likewise, Nadia believed the stereotype that Asian people are “*needy*” seemed to reduce the importance of her healthcare needs. Being constructed as needy and demanding, Nadia thought she was given a group identity which had nothing to do with her healthcare needs or how she perceived herself. She described being socially constructed as dependent on the healthcare services for unnecessary help, which constituted grounds for exclusion. Similar findings were reported by Jomeen and Redshaw (2013, p. 281) who found that midwives in the UK stereotypically view Asian women as having a tendency “*to make a fuss about pain*”, and of being too demanding. What was essential for Nadia was that she maintained her identity which included her Asian heritage but was not dominated by it. She wanted to be involved, respected, listened to and to receive individual care, rather than being discriminated against on the grounds of her racial identity. But she believed that everyone who is Asian Muslim would be treated in the same way.

“Like the way I saw many years ago with my parents when they got really ill, it seems like this doesn’t stop. Because of that, I need to be in the emergency department moving with a broken leg, or you know something severe, then I might just be imagined to be treated but currently in the waiting line”.

Nadia’s statement aligns with Smedley et al. (2003) who claim that ethnic minority groups are less likely to receive appropriate medical care services and experience a lower quality of healthcare than nonminority. Nadia felt that this discrimination was experienced by both herself and her parents. Thus, she believed it was a form of experience which would also be experienced by her children. Sullivan (2013) reported that healthcare disparities due to racism are not limited to the specific person who is the target of racism but extends to that person’s offspring, passing from one generation to the next. As such, Nadia described how she and her family were, over time, treated categorically based on their race and religion rather than individually, and in the process of doing so they were devalued.

Based on her experiences of discrimination in the healthcare system, Nadia highlighted the fact that racial bias could translate into medical bias, where some human bodies were worth

more than others, unless they had severe injuries or life-threatening illnesses. Here, Nadia emphasised how her identity as an Asian Muslim was a barrier to receiving the support she deserved in order to care for herself as a disabled person. As a result, she had to choose whether to accept her condition and the negative consequences of her identity or to fight for equal access to healthcare. In the following section, Nadia reflected on how she fought for her children's social care and how the continued impact of her racial identity affected her family and her identity as a disabled mother.

6.3 The social worker's visit: "I think she is racist"

When Nadia was initially diagnosed with rheumatoid arthritis, she thought that "*under government there is a general guide of how [disabled] parents should be supported*". At the same time, she explained that it was hard for her to receive this support unless she was "*wheelchair-bound*", she described her rheumatoid arthritis as "*a very hidden disability*". In other words, Nadia believed that her impairment did not make her look physically disabled and that only parents who used wheelchairs qualified for government support. Nadia thought that this rule equally applied to her husband, who was also living with an invisible disability (autism).

Nadia believed that her husband's autism brought further challenges to their family relationship and parenting role, in addition to her own condition of rheumatoid arthritis. On one occasion, Nadia discussed the difficulties they experienced as disabled parents due to lack of support and how they might improve their family's life situation. He said to her, "*we should be prepared to leave this country*". But Nadia told me that:

"This is the thought of an autistic person being fed up with this system; you know, he doesn't have the capacity to really think like the logistic of it. He just likes to say something because of how the feeling is".

Other than support from her husband, Nadia had no social support. But given her husband's sensory and emotional needs, Nadia's views on autism had an impact on her parenting and gender role (Jack 2012). This situation created additional difficulty for Nadia, she described how she took responsibility for most of their children's care, responsibilities and activities. As she stated:

"I'm one person fighting for my children to look after them and to have that [social] support, so I'm a fighter you know, but there is no way I want to wreck my brain to show you how ill I'm, in a way I can say I feel like I'm neglecting myself, but it's not purposely".

Considering her belief about her husband's autism, Nadia described fighting alone to get the support she needed to look after her children. She framed her story as an example of

'agency and resistance' to the powerful social services and stereotype belief that contributed in constituting her as "needy" for so many years. In view of that, placing herself against the social system, refusing to be submissive by deliberately creating illness for attention, and lacking to attend to her self-care needs were the strategies Nadia adopted to demonstrate her agency in challenging such a system.

In his research with mothers of children diagnosed with Down's syndrome, Thomas (2021) explained how mothers spoke of their painful and prolonged communication with local authorities, healthcare institutions, educational settings, and welfare/social services with a discourse of 'fighting' and 'battling' for access to such services. Thomas (2021, 2022) argued that the central source of those mothers' everyday troubles, and of their general frustration, upset and angst, was not the effect of their child's impairment but their 'fights' (e.g., for healthcare services) in a society that does not adequately support them. Mirroring Thomas's (2021, 2022) findings, Nadia also expressed feelings of upset and frustration. She explained that she did not receive the support which disabled parents are entitled to because she had an invisible disability. Consequently, Nadia claimed that she was putting her children needs before her own needs and sometimes this was at the risk of her own health.

Nadia: "I don't really talk to my doctor about my role as a carer because there is a stigma and risk involved on you as a disabled parent. Are you able to cope and manage? I will show you when I have pain in my fingers and hands, and I couldn't manage you can see this is a band's mark, I often injured myself as well, but I can't talk to anyone, I will never tell any medical professional the in-depth of how I am affected because I'm afraid to, because of the consequences".

Amani: What are you afraid of?

Nadia: "Child protection, and I think this is the reason that made me want to talk to you".

Being a disabled mother added extra layers of complexity to Nadia's life. She had to carry out her motherhood duties whilst experiencing pain and the other physical limitations imposed by rheumatoid arthritis, such as joint swelling and fatigue (Caiola et al. 2014; Wasserman 2011). As Shakespeare and Watson (2001, p.18) argued, some impairments "*because invisible, may not generate any disability whatsoever, but may have functional impacts, and implications for personal identity and psychological well-being*". Nadia explained how she often injured herself due to the difficulty of performing daily activities, such as cooking and cleaning, because of the deformity of her hand or, as she mentioned, carrying her son around. She told me that these activities could become a challenge, especially when she had a "bad day" in which rheumatoid arthritis caused increased joint

pain, stiffness and swelling. Despite Nadia's everyday challenges as a carer and disabled mother, she did not talk about them. She felt that if she talked to her rheumatologist or GP about her struggles as a carer for her children they would look at her as an incapable parent.

“You have children and as a result, what could be an adverse negative impact, are you going to be supported or are they going to look at your incapability and perceive it as a judgement on you as a disabled parent”.

Likewise, if she talked to health professionals who were involved in her children's care (e.g. social worker) about her struggles as a disabled mother, she believed they might also judge her ability as a disabled carer to look after the children. This concern has also been reported by Disability Rights UK (2018), they commented that children's social care professionals often see a parent's impairment as a potential risk to their children. This could result in them prioritising monitoring visits over meaningful parenting support that would keep families together. Nadia described being silent and unable to talk to any medical professionals about her difficulties. Here, her silence was out of fear that child protection services might get involved due to possible concerns about her children's well-being being raised. It was a form of silence that could indicate a form of oppression, physical and emotional pain (Ellingson 2017), Nadia reported how she often injured herself but did not want to tell anyone.

Nadia's eldest son was diagnosed with autism, this created additional challenges for Nadia to meet her child's needs while simultaneously managing her own health needs and looking after other family members. Therefore, she asked for respite care from the local authority.

“I can't sit the demand on me to physically keep him [eldest son] active, seriously not because I have physical health but because I have another child to look after who is got a referral for autism as well, and the complexity comes in because of such medical conditions they have such as anaphylaxis for my youngest child, so he experienced anaphylactic attacks, and that was very severe, and he is asthmatic, so it's so much stress on me and my body the fact that when we talk about social care or additional support, there is no support to help me to assist my child apart from the medications given, so I requested that my elderly child, he had a respite package but the local authority want to take it away during the COVID-19 [pandemic]”.

Nadia requested respite care for her eldest child, not to look after her own health needs or take a break from caring and everyday tasks at home, but rather to care effectively for the youngest child who suffers from anaphylactic attacks and severe asthma. Caring for three children, two of whom were disabled, added to the stress levels for Nadia as a disabled mother with her own health needs. Studies have shown that mothers face a physical burden caused by the physical effort in taking care of their child, as a result of which stress,

muscular pain, and fatigue are common problems (Chang and McConkey 2008; Kimura and Yamazaki 2013). Nadia's eldest son had a respite package, he was taken away for short periods away from the family home. Yet, as Nadia stated, the local authority decided to end this care during the COVID-19 pandemic.

The COVID-19 pandemic placed everyone at risk, but certain types of risk are differentially severe for groups already made vulnerable by pre-existing forms of discrimination (Scully 2020). For Nadia, the COVID-19 pandemic threatened to leave her with no support to help her children, apart from their medication. Nadia showed me the number of medications that she had to administer, in specific order and time, to control the reaction of anaphylaxis allergy in the youngest child. Administering these medications on a daily basis was time consuming, it meant equal support for the eldest child was out of the question. This situation made Nadia stand up for her eldest child's right to continue respite care as she acknowledged the significance of social interaction for nurturing her autistic child. Thus, she had launched an appeal because the local authority's decision to end the respite care did not address her child's social needs. As a result, a social worker was involved to assess the child's needs and gain a clear picture of his condition.

“When she [social worker] attended to my house, and I was putting the bandage for my son, I said, please note this, it's not an easy job, and it's a two-person job ... she said, 'why don't you get your husband to you know to do his parenting', and I shouldn't be asking the local authority for this level of support [silence- eyebrow raised] ... and the social worker thinks that there is a concern about my capability to look after my children and because of her concern they put my three children under the child in need [while the social worker's visit concerns the assessment of the eldest child's to continue the respite care, the social worker referred all Nadia's children to the child in need plan for their protection from any possible harm or risk]. So that's why I never ask for their help or support”.

The second meeting with Nadia was conducted at the beginning of the COVID-19 pandemic in 2020 via Zoom. At that time, the United Kingdom's Coronavirus Act (2020) suspended the Care Act (2014) in England (In: Shakespeare et al. 2021), and the government guidance allowed local authorities to cut most of their care responsibilities toward disabled people, leading to pressure on informal and unpaid carers (Independent Living 2021). As a result, Nadia faced the loss of valuable support when she needed it most.

When the social worker made a visit to the family Nadia tried to demonstrate that she was a capable parent by concealing her rheumatoid arthritis. Grue and Lærum (2002, p. 271) reported that disabled mothers felt they had to present themselves as managing “*normally in order to be accepted as ordinary mothers*”. In an effort to avoid the stigma associated with

her physical impairment, Nadia utilised what Goffman (1963, p. 92) referred to as “*passing*”. According to Goffman (1963), if the stigma is invisible, known only to the person and not apparent to strangers unless verbally disclosed, one may conceal information about themselves by intent in a well-organised effort to avoid the problems associated with stigmatised identity.

Viewing her case as an ordinary mother of a disabled child, Nadia tried to demonstrate to the social worker how meeting her children’s needs was not easy and equated to “*a two-person job*”. For that reason, Nadia expected the social worker to appreciate her efforts in the hope of continuing the respite care for the eldest child. Instead, there was a concern about Nadia’s capability, and all three children were put under a child in need plan. This situation means that the local services have a responsibility to provide services which will maintain a reasonable standard of health or prevent significant harm to the children in their home. However, Nadia, the person who has been caring for those children, could not continue to provide suitable care due to incapability concerns. The social worker’s decision could lead the local authority to arrange for the children to live somewhere other than their home, under child protection services, which Nadia feared due to concerns of her capability. As a consequence, Nadia described feeling devastated by the social worker’s decision rather than feeling supported. She said:

“This [decision] makes me feel intimidated by their approach, and she [social worker] had an unethical view as a professional, perceiving me and judgmental on me, discriminating me, and I do think it is because I’m an Asian, I think it’s because I’m a Muslim, I think it’s because I wear a headscarf ... and I think she is racist because I think if I was different, I probably wouldn’t be treated like that”.

Nadia was quite clear about what she wanted to achieve from the social worker’s visit: to get a professional view of her eldest child’s situation to support her appeal to continue respite care. She did not reveal the details of other visits except to say she was stressed out whilst administering the bandages for the youngest son and looking after the other children simultaneously. These efforts, Nadia believed, were not acknowledged and valued and Nadia felt she was perceived neither as a mother who strived to meet her disabled children needs nor as a case for considering respite care service. Nadia believed her case was judged and evaluated based on her racial identity, which led to a feeling of vulnerability and intimidation.

Nadia believed she was being discriminated against mainly because of her physical appearance. For example, Nadia’s choices about shaping her appearance through the Islamic custom and other characteristics that she did not choose, involving her gender and

race, combined to present a body that did not comply with the social norm. Ellingson (2017, p. 72) referred to the bodies that do not conform to the social norms of a White, male, affluent, and able-bodied person as “*vulnerable bodies*”. The vulnerable bodies are those bodies that are stigmatised and viewed as problematic by the social norms. They are, as with Nadia’s body, subjected to embodied intersections of sexism, racism, Islamophobia, and other forms of discrimination based upon perception of bodily characteristics (e.g. skin colour), practices (e.g. wearing a headscarf) or performing things differently (Crenshaw 1991; Ellingson 2017; Inckle 2014). In this sense, Nadia believed that her identity as an Asian Muslim woman who wore a headscarf determined the parameters of the social worker’s behaviour towards her. She described the social worker as “*racist*”, and she believed that if she was White, she would have been respected and not been discriminated against. This perception resulted in Nadia deciding not to ask for help and support as a disabled mother, she realised that her disabled identity would add another marker of difference to her gendered, religious and racial identity.

In her narrative, Nadia made some efforts to keep the support that her autistic child needed despite the difficult circumstances. She could not tell anybody about her rheumatoid arthritis, her disease progressed quickly, and the health and social care services were not meeting her needs. The feeling of lack of control and the anxiety Nadia described about the future were particularly pronounced in the following excerpt. Nadia’s voice grew softer and slower when she said:

“I don’t know if tomorrow is going to be a better day or not, but I know today I’m suffering, and I think to myself, ‘can I get any better, or shall I prepare for the worst’. When I say I’m suffering, I talk about my own health physically; with pain in my back and in my body, I see my head start to really hurt with the stress and pressure, sometimes I wonder how worse it can get and the implications when I have a family to look after, and it’s not a nice place to be”.

The pressure that rheumatoid arthritis, the associated family caring responsibilities and lack of support had on Nadia’s life was distressing. Nadia expressed concern about the future and whether she would be able to cope and manage, not only in the face of chronic pain and progressing illness but also without support for her children. She did not say anything about the future and said she was not preparing for it because she was suffering. Yet, her suffering was multidimensional. Part of Nadia’s suffering was social, she believed this resulted from the pressure of the stressful and discriminatory experience with the social worker. Siebers (2017) reported that minority identity is often based on painful feelings of injustice. Nadia also described some of her sufferings as physical. Living with progressive rheumatoid arthritis means living with pain, fatigue and unpredictable physical ability due to the uncertain

prognosis of the condition. The challenge of living with an unpredictable disability created different forms of suffering because it drew attention to uncertain situations that might jeopardise Nadia and her family's future (Siebers 2017; Wendell 2017). Ellingson (2017) found that the time spent worrying about uncertain prognosis might pass with excruciating slowness. Thus, Nadia suffered the fusion of the struggle from the physical pain, social discrimination and the uncertainty of unpredictable physical abilities in the future.

Throughout her narrative, Nadia repeatedly used the word *"fighting"*. She spoke *about "fighting with medical professionals"*, fighting the system and *"fighting generally for [her] children"*. Nadia emphasised that her fight for disability support concerned her family and other Muslim women with disabled children.

"I know some Muslim women who don't have a disability, but they are a parent of disabled children, sometimes you know I like to be umm, just the listening ear at the moment, you know there is not a lot that I can do, or if I come across any advice of information, I will share with them".

Nadia endeavoured to change the world in small ways in the spaces within her reach. She fought because she believed that whilst disability is not curable, the system is. Nadia's goal was to share information or be the listening ear for other Muslim women with disabled children, even if they were not disabled themselves, conveying her double struggle as a disabled Muslim woman who is a mother of disabled children.

6.4 Chapter summary

The core issue addressed in this chapter was the relationship between Nadia's identity as an Asian Muslim woman and her experience of discrimination from health and social care professionals. Nadia shared her narrative to show how her racial identity was a barrier to getting her deserved support as a disabled person. Her experiences of the health and social care system were not merely about caring and support. Instead, Nadia pointed out that health and social care experience is about understanding, listening, and considering everybody involved in the care relationship. Part of her experience was her relationship with the rheumatology doctor. Nadia believed that her health problems could be understood if the health professionals listened to her views and details of the pain she was experiencing as part of her condition. She wanted to be involved, respected and treated with dignity when receiving care, but she realised that her identity as an Asian Muslim woman meant she was excluded and ignored.

Another part of Nadia's experience was her relationship with the social worker. Nadia concealed her impairment from the social worker so that the social worker would focus on

her children's case and she would get essential support. Nadia was concerned that her impairment would have a negative impact on the situation. Instead, she described being discriminated against for her race, religion and perceived abilities as a mother. As a result, Nadia said that the social worker involved in assessing her children left a lasting negative feeling of the profession as a whole. In her narrative the health and social care professionals, who Nadia believed discriminated against her, were not connected. She felt that the stereotypical belief about Asian Muslims as a needy group informed the professionals' discriminatory attitude against her. From this perspective, Nadia told a story of how things are and how they ought to be in the health and social care context could sometimes be different. She highlighted the fact that as a result of her identity, as an Asian Muslim woman, she was a recipient of care services but was being intimidated due to the deployment of societal norms.

Lastly, the narrative strategy Nadia used to share her experiential knowledge of the system is of particular interest. She presented herself as a fighter rather than submissive to the local authority or health and social care professionals' decisions. She spoke about her experience with health and social care professionals, she appealed against the local authority decision, and shared knowledge about information regarding disability support. She endeavoured to create a small social change, even if it was in spaces which were within her reach. In the following chapter, Kinza's attempt to change the wider perception of disability and her desire to '*make a change*' is illustrated'.

CHAPTER SEVEN: “I want to make a change”

Kinza is a woman in her early 40s. She was born with poliomyelitis in Nigeria and lived there up until the age of 30 when she moved to the UK. During her time in Nigeria, Kinza used crutches as a walking aid. Her post-polio muscle weakness progressed slowly, resulting from the gradual deterioration of nerve cells in the spinal cord that were damaged by the initial poliovirus attack. When I met Kinza, she was using a powered wheelchair for moving in indoor and outdoor spaces. In her narrative, Kinza described feeling affected not solely by the post-polio condition but also by cultural and social factors. When I asked her how she perceived her identity, she said:

“What’s identity? Identity is what truly identifies us, like I’m a Black, I’m a woman, I’m queer, I’m disabled, you know, because of the culture I was born in Africa, what’s the word? The culture of where we were born or our society governs us, and because it governs us, it affects our identity”.

Kinza emphasised the significance of cultural and social contexts in the construction of her identity. In Nigeria, Kinza did not perceive herself as disabled as everyone told her, “*you’re not disabled*”, as Black as she was living in a Black African community, or as queer as “*you can’t be a Nigerian Muslim and say I’m a queer*”. But in the UK, Kinza foregrounded herself as a Black disabled woman and embraced her queer identity “*because there is a freedom of speech in this country*”. Kinza also identified herself as a “*survivor*” when she got through the difficulties she faced in the refugee centre during the asylum-seeking process. During her life in the UK, Kinza described herself as an “*LGBT representative*”, “*queer activist*”, “*disabled activist*” and “*feminist*” who took part in a lifelong mission of rendering herself and other minority and disabled people socially visible. Around the time that Kinza was interviewed she had been invited to share her story at a symposium on disability and intersectionality.

This chapter aims to illustrate how Kinza engaged with the world around her in an attempt to change wider perceptions of disability, rather than to present herself as a victim or as tragic. The structure used by Kinza has been retained to frame the account of her life in Nigeria, then in the UK. In addition to maintaining a temporal order, this structure highlights how Kinza’s identities were constructed within both hostile and welcoming social contexts. It also makes it possible for Kinza to take the position of:

“A subject who actively participates in the making or unmaking of his or her world, and a subject who suffers and is subjected to actions by others, as well as forces of circumstances that lie largely outside his or her control” (Jackson 2002, p. 12).

This aspect of actor/acted upon helps to locate Kinza in-between the space of agency and structure necessary to construct the life she wanted to live. It is also an essential strategy for reconstituting events, as illustrated in the way Kinza situated her story temporally and in context.

7.1 Remembering life back in Nigeria

To make sense of her experience, Kinza started by telling her story of living with polio in Nigeria. She said:

“I remember my mum telling me the story and saying that when she had me, she left me in the hospital because I was disabled, so that’s just one thing about being disabled because I was like a curse for my mum, so I was a curse. So disability is like a curse or a taboo, and I’m still fighting to let it go”.

In this passage Kinza provided a context for the beginning of her journey with poliomyelitis. She recounted her mother telling her the story of when she was born. Kinza’s mother left her in the hospital and did not carry her home because Kinza’s legs “*were not straight and bent*”. In Kinza’s narrative, what made her mother leave her in the hospital was the social perception that perceived her bent legs as “*a curse or taboo*”, or as Kinza put it, “*because I was disabled*”. Thus, Kinza was cast in a negative light, as somebody who was unwanted, from the moment she was born. Since that time, Kinza explained, she had lived with poliomyelitis in a culture that perceived physical impairment as a curse, but also where different ways of being are dismissed. During her life in Nigeria, Kinza recalled everybody telling her she was not disabled.

Kinza: “When I was in Nigeria, I will be crying when I had pain in my legs, but people were telling me ‘you aren’t disabled, you aren’t disabled’, you know when I look in the mirror, I see my legs are not okay but when I came out, and people tell me ‘oh you aren’t disabled’ it confused me”.

Amani: Who did say to you, ‘you aren’t disabled’?

Kinza: “Everybody, you know my family will be saying that. My mum and dad were saying ‘you aren’t disabled’. If you go to the mosque, you know, they will say ‘you aren’t disabled’”.

Amani: Why do you think they used to say ‘you aren’t disabled’?

Kinza: “Because if they say you are disabled, you get labelled, but if they say you aren’t disabled, you won’t be disabled ... you know I was telling my friend I don’t like to look in the mirror because I see my legs are different from yours”.

What does it mean to say “*you aren’t disabled*” in a community where disability refers to bodies that look different? According to Kinza, “*if they say you are disabled, you get*

labelled". That is, saying "*disabled*" is an all-encompassing term that could define Kinza's whole being and influence how people react to her. As Yunker (1987) and Zola (1982) reported, the term disabled could also be interchanged with words suggesting a 'deformed', 'defective', and 'invalid' person. On the other hand, saying "*you aren't disabled*" could be seen as a form of protection against Kinza being recognised as a disabled person. Through this utterance, Kinza was interpellated into a position of non-disability, which contradicted her lived experience. She described feeling pressurised to perform in a social world designed only for people who could walk, which brought her a new set of difficulties. She said that she felt the contradictions which became an integral part of her life. She had to act as able-bodied people, to fit and blend in a community that rejected different bodies and to accommodate her difference in a positive way. At the same time, Kinza was crying over leg pain, she disliked seeing her image in the mirror with legs that looked different from other people's legs.

While rendering Kinza "*not disabled*" might have been a means of minimising the difference of disability; this strategy did not allow Kinza to do things differently, to understand her condition or understand why people treated her differently from non-disabled others. She had to carry out day-to-day activities within an environment that did not accommodate her difference, allow her to do things according to her needs/pace, or ask for support. When her legs ached, she described crying but without being able to voice her pain or to complain. According to McLaughlin and Coleman-Fountain (2018), if disabled people can do things the same way that other people do, the consequence is to be accepted by others. McLaughlin and Coleman-Fountain (2018) also added that for those disabled people who appear unable to do everyday things, like walking, exclusion through social rejection is the dominant social response. Kinza described feeling rejected in the mosque, despite people there telling her "*you're not disabled*". In Kinza's words:

"You think that the mosque should protect you because if you look in the Quran, you know, the Quran teaches us to love. Okay, let me run away from the society and go to the mosque and see someone who will love me, who will say 'okay don't worry, I'm here with you, I'm riding this journey with you', but you come to the mosque and people who are going to meet you outside the mosque are going to meet you inside the mosque ... so I face the perception of disability, and I'm scared to go".

Kinza was seeking '*love*' from the Muslims in the mosque. This love, as Kinza explained, is untainted by any worldly interests or ulterior motives, and its purity is derived from the light of the Quran. It is a bond that links Muslims regardless of their ethnicity, skin colour or disability. Kinza believed that this kind of love was the only way to escape from "*the*

perception of disability” and find support. But while trying to seek support in the mosque, Kinza described seeing herself facing the same wider societal perception of disability as a curse or a taboo. She pointed out that “*the society’s rules govern*” people’s perception, which was associated with how people were treating her.

“People who are there in the mosque don’t come from heaven; they are coming from society, so they drag it from the society, so when they drag it into the mosque, their perception of disability in the mosque is the same as their perception of disability outside the mosque”.

Kinza believed that the perception of disability was constant because people hold the same perception regardless of their context, making it difficult for Kinza to feel included in the Muslim community. This situation, in turn, made Kinza feel scared of going to the mosque to practise her religious beliefs. She described feeling excluded, and her sense of Muslim identity was diminished by the construction of bodily difference as a deviation from the norm. However, Kinza did not let her impairment limit her life. She attended school and earned good grades, and then she went to university. She used both arms to move, pushing her weight on underarm crutches. Yet, the university experience brought her to a new realisation, in often hard and sometimes uncomfortable ways. She said:

“It was hard for me in uni [university] because it wasn’t an accessible environment for me and for my disability in Nigeria, and that affected me, so when I got a job, it was [also] hard ... it was difficult for me to use the toilet and stairs, you know”.

The pervasive perception of disability was just one factor affecting Kinza’s life; infrastructure design was another obstacle to her participation in social life. Kinza described having difficulties gaining access to facilities such as the toilet and stairs in the university. The difficulties included an inadequate toilet design and size that made it difficult for Kinza to use with her crutches. In addition, steps at doorways or within the building level could only be entered by ascending or descending a staircase. Hopping up and down stairs on crutches with weak and bent legs was not easy or painless. These strategies were just to get Kinza through her day at university. She described getting along with her impairment challenges, thus not acknowledging the unequal opportunities she faced every day.

As Kinza pointed out, she tried to perform routine daily activities (e.g. toileting and navigating stairs) in the same way as her able-bodied counterparts in university, without asking for support, although this was hard and exhausting. In their article on people living with paralytic poliomyelitis, Hammarlund et al. (2021) found that participants were not considered to need any specific help when they were at school because people, in general, looked at their impairments as nothing special. Considering Kinza’s experience at the university, seeking

support was sometimes essential to do particular daily activities, but if, for example, she asked for support, would she be perceived as disabled? This was a question which Kinza was continually asking herself.

“You know there is something wrong with you [when doing daily activities], but because of that [utterance: you aren’t disabled], it confuses you; you will be like, am I disabled, am I not disabled”?

Kinza described holding the perception that she was not disabled, reinforced by the utterance “*you aren’t disabled*” until she got a job. She worked as a consultant at an international organisation, and she proudly described her job as “*a very good job*”. Part of this organisation programme aimed to keep African children safe from poliomyelitis by increasing mothers’ awareness about the significance of the polio vaccine for their children. As a member of the organisation with poliomyelitis, Kinza took part in this work.

“My polio is visible polio, it is a visible disability, so everyone who is going to look at me will know that I’m disabled ... so they [the organisation] use me as a front person because I have polio, so people believe that this disability is true and real. Yeah, they use me as an example that if you don’t give your children vaccination, your children will be like this lady, like me yeah, but there are some mothers who are like ‘no I don’t want my children to be like that, and now I agree for my children to be vaccinated”.

Using Kinza’s body as “*an example*” of the visible impact of polio gave rise to a situation where she was compelled to represent a disability identity that she did not see in herself. Representation of such an identity undermined Kinza’s personhood. Due to polio, she was looked upon as a disabled person, connoting a negative image of passivity, burden, and dependency. Kinza’s body was also used as the quintessential physical disability to signify a potential future that had to be avoided. This experience made Kinza realise what it was like to be different due to a visible disability. She used the phrase “*like me*” to refer to her body as a site of disability, that mothers should protect their children by agreeing to take the vaccine, or their “*children will be like this lady*”, like Kinza. With her disabled body as the focus of attention, Kinza’s experience as a woman living with polio and identity as a consultant at her workplace were relegated to the background.

Although the crucial role of women at all levels in polio eradication was highlighted in a recent global report (see, for example, OCHA 2020), Kinza’s contribution spoke of the way power is exercised in constructing disabled people as objects. As Kinza said, “*they use me as an example*”, instead of letting her speak about polio. When the organisation used Kinza’s body to demonstrate what it was like to be disabled in Nigeria, her body spoke; her words remained unspoken. In such a situation, Coleman-Brown (2017) and Dossa (2009) argued

that disability becomes the master status that colours the identity of the entire person, where all other aspects of the person are subsumed under the category of disability. Yet, even during this experience where her body was used to demonstrate the reality of a visible disability, Kinza did not see herself as disabled.

“When I go, and I’m fighting polio, my brain still tells me, ‘you aren’t disabled, you aren’t disabled’, which is confusing me. I had a very good job in Nigeria, but I wasn’t happy because of my disability, I wasn’t happy with my family ... I never had a voice in Nigeria, Amani, I couldn’t talk about what happened to me, and the cultural myth was holding me tight you know, you can’t just be anything. I was trying to cheer myself because I was tired, I was tired of the life you know, and I just wanted to go because nobody was there with me, because of that I tried to find a way, so I got admission in the UK, and I came to the UK”.

The cultural myth that perceives different bodies due to physical impairment as a curse, impacted Kinza’s self-perception. She described perceiving herself through the lens used by those who wanted to protect her against the cultural myth, through the utterance “*you aren’t disabled*”, not her perception or intuition. In addition to feeling confused about the status of her body condition, Kinza described how she fitted her impairment into her life, by creating her own way of living with weak and bent legs, until she completed her undergraduate degree and got a good job. She believed that problematic cultural myths, which circulated with respect to narratives of disability, affected her identity in every context and thus she felt she had “*never had a voice in Nigeria*”. Having a voice meant having power, agency, and a way to express her feelings, needs and the difficulties that had impacted upon her life opportunities (Shah et al. 2016). But what happens when that voice is silenced in some way?

Kinza pointed out two contexts where she did not feel happy or have a voice: family and work. Kinza “*couldn’t talk about what happened to*” her or voice her pain with her family since they said she was not disabled. At work, the organisation did not engage Kinza in the conversation about the impact of poliovirus. The voice of those without polio was amplified to speak about disability whilst Kinza herself, who was living with polio and working as a consultant in the same organisation, was silenced. As such, Kinza described how the cultural myth of disability held her tightly in a way that defined her exclusively by the “*disability*” label, thus reducing her worth as a person and hindering her from being anything else she wanted to be.

In her narrative, Kinza described how she did not let the negative experience in Nigeria hold her back. Instead, she reframed her experience to present herself as a person who “*tried to find a way*”, got a university offer, and “*came to the UK*”. These practical strategies involved

a plan that indicated the extremes to which Kinza was willing to go, hence the painfulness of the situation that led her to these extremes. Kinza saved money from her work and came to study for a Master's degree in the UK. In one of her emails, she stated that her plan was not merely to get a higher degree but to settle in the UK after completing her studies. Kinza believed that her decision to move to the UK would enable her to construct the life that she wanted to live, a life in which she wanted to be happy and satisfied. The following sections discuss Kinza's experience in her new life context in the UK.

7.2 "I came to the UK": new life, new identities

"When I came to the UK, it was like *my eyes opened, my eyes opened* [emphasis by Kinza], you know. I went to the University of [name of city], and when I got there, I saw a couple of people, they were like 'oh, can you be our disabled [students] representative' to join the university team, executive team, so I didn't understand what is it all about, because I haven't done something like that before, so the president of the university he was like 'we need you, we need you, we need you', so they ran an election with another lady, and I won the election".

Kinza's early experience in the UK was life-changing. Her body occupied a new space in an environment where different bodies were classified as "*disabled*" and a potential "*representative*" of disability. Winning the disabled students' representative election at the university made Kinza feel needed and wanted for her potential and voice as a disabled person. As a disabled students representative, Kinza was asked "*to look around and find out how the accessibility is*" in the university. At that time, she started to use a powered wheelchair. Her role was to ensure the university's environment, facilities use, and participation of disabled students in the life of their university were accessible. The barriers that Kinza was looking for did not only include the physical environment, with difficulties in accessing the buildings, library and support services (Holloway 2001; Redpath et al. 2013). Barriers could also involve attitudinal barriers such as negative attitudes from non-disabled students (Liasidou 2014) and staff (Madriaga 2007). Kinza's role was to report any of these barriers. She said:

"If I find there is any problem, then I only meet in university once every month, so we will go, and I talk about the problems we had, and now they can be sorted, so that's how my voice started".

Representing disabled students at meetings with other students and staff from across the university contributed to building Kinza's voice, it engaged her in the decisions she made about herself and other disabled students. She described how this experience opened her eyes and changed the way she felt about herself. Whilst she was settling into life as a new student another opportunity arose, that of making her voice heard. The president of the

university asked Kinza to go to a student campaign conference. Kinza said she did not know what he was talking about. He replied, *“just go, you will know, don’t worry”*, he reassured her. So, Kinza went there, and it was a *“disabled student conference”*. Kinza sat between two students; one was *“White”* and the other was *“Asian”*, and she realised that she *“was the only Black lady there”*. At that moment, one of the students asked Kinza her name, and whether she knew about the election they ran at this campaign.

“I said, ‘what kind of election? I don’t understand what you guys talking about’, she said ‘we are looking for someone to be a Black representative in the disabled committee because we don’t have someone who is Black in the UK’ ... and they run an election, so from there I became an LGBT representative, it’s been like a journey, a real journey for me as an activist, so throughout this journey Amani, so that’s when I realised and I taught myself the truth that I’m disabled”.

The excerpt above highlighted the construction of some social identities for Kinza as she expressed them: a Black woman, an LGBT representative, an activist, and a disabled person. During the campaign’s meeting, Kinza found herself in a society where everyone was assigned a racial identity such as White, Asian or Black, whether they were aware of it or not. The phrase *“we don’t have someone who is Black”*, classified Kinza as a Black person due to her skin colour. The Black identity was externally imposed upon Kinza, or in her words, it is how others look *“for someone to be a Black representative”* in the UK. Therefore, Kinza had to learn how to live with her body image as a Black person, in Nigeria she had not identified as Black.

Kinza also described being able to speak and feeling that she was being listened to by those who wanted to have a positive impact on society. She told me, *“they want to make a change, Amani, so they listen to me”*. Kinza believed that the incident of the student campaign allowed her to get the recognition she needed in order to express her identity. Although the campaign was looking for a Black disabled person, it seemed that Kinza’s sexual identity was foregrounded. By choosing to be an LGBT representative, Kinza highlighted another social identity for herself. Throughout her narrative, Kinza used the term *“LGBT”* and *“queer”* interchangeably to refer to her sexual orientation, but she mainly described herself as a queer. Queer was not a new identity for Kinza, but she only identified herself as a queer when she came to the UK. As Kinza explained, queer sexuality is not aligned with/accepted by many Nigerian Muslims’ cultural values and the Islamic religion. Heterosexuality is identified as normative, while any other sexual identities and practices are prohibited and must be covered:

“In Nigeria, I can’t say I’m a queer because the law and the policy in LGBT in Nigeria were not approved, so you can’t be a Nigerian Muslim and say I’m a queer, you’re a bisexual, do you understand ... [so], my identity is like held together and put in a container and covered, but when I came to this country [the UK], I found that being an activist really helps me and helps my identity as a person and I’m proud of my identity”.

Kinza acknowledged that the society and culture in Nigeria influenced her beliefs and behaviours about what was right or wrong, adding that “*the culture of where we were born or our society, it governs us*”. Because of these cultural influences, she believed that her queer identity was hidden, “*put in a container and covered*”. Samuels (2017, p. 344) argued “*that most people with disabilities, like most queers, do not share their identity with immediate family members*”. Considering Kinza’s case, queer identity was not only deviant in the realm of the Nigerian law but it was also against the Islamic law. Nigeria has laws that criminalise homosexual acts (Okanlawon 2020). The Criminal Act stipulates a punishment of 14 years imprisonment for persons who engage in homosexual acts. In addition, Sharia (Islamic) law which is adopted in 12 states in Nigeria, criminalises homosexual acts with imprisonment or whipping for women and a maximum punishment of a death penalty for homosexual acts between men. Although no offenders have been sentenced to death, some Nigerians have been imprisoned for engaging in homosexual acts using these laws. The laws include one which was inherited from the British during colonialism, this law condemned homosexuality as sinful, immoral and illicit (Okanlawon 2020). These strict laws explained Kinza’s statement of why “*you can’t be a Nigerian Muslim and say I’m a queer*”.

But in the UK, Kinza stated, “*there is a freedom of speech*” which encouraged her to be an activist. She described how the activism work helped her and made up a significant part of her identity. When Kinza was asked to describe how she perceived herself, her response started with “*I’m a strong activist*”. Kinza’s activism work is best described as *coming out* (Samuels 2017). Coming out refers to the process of revealing and explaining one’s identity to others, rather than an act of acceptance facilitated by a disability or queer group. It includes the daily challenges of various acts, commitments and negotiations about bodily appearance and functions (Samuels 2017; Wendell 1996). For Kinza, the most crucial meaning of coming out, or in her word, “*being an activist*”, was to come to terms with her disabled identity.

“Now I look [in the mirror] and tell myself: you’re disabled, don’t deceive yourself ... so, that’s how I find my voice Amani, and I start to talk for organisations and everything, so it [activism] amplified my voice”.

According to Kinza, once she told herself the truth of her impairment and accepted it, she began to make a change and share her voice with various organisations. In other words, Kinza explained that understanding her disabled identity was enhanced by her engagement as an active subject in shaping her identity and contributing to making a better world for herself and others, in opposition to the dominant societal perception of disability and homosexuality. As Kinza said:

“I want to make a change, not for me, make a change for the next generation so that the next generation won't go through what we're going through now”.

Although the university provided the necessary climate for Kinza to share her voice, her activism movements were not only to speak for herself but also for the community. Kinza described demanding positive change to protect the future generations against the dominant societal norms that affected her life, such as disablism, racism, sexism and homophobia. Yet, Kinza described having two goals when she came to the UK as a student: pursuing her education and living with dignity, freedom, and respect. She told me, “*you will not understand the concept of freedom if you don't experience bondage*”. After acquiring her Master's degree and after the expiry of her student visa, Kinza applied for asylum so that she could stay in the UK.

“I went to a refugee centre to apply for asylum ... [but] I didn't have my papers, it was a really hard life for me, it was like everything was taken away from me, the home office took away my medications, I couldn't access or use anything there, it was really hard for me, so, yeah, I'm a survivor”.

The process of seeking asylum was not easy, as Kinza described in the above excerpt. First, Kinza had to provide documentary evidence to show she could not return to her country because she feared persecution. The documentary papers became an integral part of Kinza's identity. It was a medium required by the Home Office to prove her identity, review her case and check her circumstances, but Kinza did not have the papers to support her claim. As a result, she sent many appeals to inform the Home Office that she “*attempted suicide*” many times in Nigeria. Secondly, whilst her case was being considered, which usually takes several months due to lack of supporting documents, Kinza had to stay in a refugee and migrant centre, which was not accessible for physically disabled people.

Finally, medication was one of Kinza's basic needs in order for her to manage her symptoms and survive in the refugee centre, in addition to water, food and clothes. Kinza was left to manage her symptoms without medication. Also, to manage her fear that the Home Office would reject her claim, due to insufficient evidence, and she would have to go back to

Nigeria. Although it was “*really hard*” for Kinza to survive at the refugee centre with these difficulties, her case was eventually accepted, and she was given asylum. Owing to her experience of granting asylum, Kinza described herself as a “*survivor*” who managed to cope well during difficult times throughout her life. At the time of these interviews Kinza was living in a wheelchair-accessible flat in Southwest England.

7.3 Chapter Summary

Kinza’s attempt to engage with the world around her and to challenge the societal perception of disability constituted the core theme of her narrative. She portrayed herself as a survivor of her experience, focusing on coping with difficulties more than suffering. In Nigeria she felt that her voice had been silenced throughout her life. She felt compelled to act as an able-bodied person and not to stand out as being different in a society that was telling her “*you aren’t disabled*”. As a result, Kinza struggled to adapt to whatever her able-bodied counterparts were doing without asking for help or complaining, but her experience was often hard and challenging.

A different experience prevailed in the UK. Kinza found freedom of speech to adopt an activist identity where she continually negotiated her rights and others who were disabled, Black, and queer, as well as women’s rights. Her dream of living with respect, dignity and freedom was achieved, mainly due to the disability support she received from the university. In short, Kinza’s narrative illustrated that what can be deviated and undesired in a hostile social context can be normative and celebrated in another welcoming one. In the following chapter, the practices used by Farah, to challenge the dominant social perception of visual impairment and to celebrate her identity as a “*successful*” disabled Muslim woman, are highlighted.

CHAPTER EIGHT:

“I work so hard to ensure I am not known solely for my sight loss”

Farah is a woman in her mid-20s. She was diagnosed with visual impairment at three years old after she dropped money on a colourful marble flooring during a family visit in Pakistan and started to move her *“hand around on the floor to try to feel the money”*. Farah then underwent regular hospital admissions until the age of eleven, but she commented that doctors did not know what had caused her non-genetic visual impairment or the cure for her condition. Farah attended regular follow-up appointments to ensure that *“nothing has changed drastically”* in her eyesight, while all she knew was that she could lose her sight completely in the future. When I met Farah, she used a white cane and wore dark shades on her eyes, but she mentioned using them only two years before participating in this study. Her decision to use these assistive devices was not straightforward, as she described in the following excerpt:

“I use it [cane] all the time now. So, I think the change was that I just got out of my own head. I said, ‘the only person I’m making it hard for is myself if I don’t use my cane, and if I don’t ask for help’, umm, before this I, my confidence, I’m like, it comes in stages. It takes a very long time to actually think about from this side of the spectrum because when you’re young, you’re just like I want to be like everyone else, I don’t want anyone to know that I’ve got something wrong with me, umm. Then the older I got, I was like, *‘I don’t care what you think’* [emphasis by Farah] like now I would clearly identify myself as someone with a disability”.

Farah’s decision resulted from going through different stages of building her confidence to make her invisible disability visible as she said, *“my disability is a visible disability and invisible disability. So, it’s only my cane that will let you know that I’m partially sighted”*. She described shifting her thinking from perceiving her visual impairment as something that she had to hide *“to be like everyone else”* to something she would make as a visible part of her identity. For that reason, by identifying herself *“as someone with a disability”*, she identified herself as a person first and as a person with a disability second. During the interview, Farah described the choices and practices that enabled her to live her life as a valued human being. She attended a mainstream school and achieved the *“highest score”* among her classmates. She also expressed joy in spending time with her siblings and feeling proud to have a lot of friends on social media. Over the 18 months of her involvement with this study, Farah was training to become a barrister.

This chapter highlights Farah's desire to live her life without allowing her visual impairment to define her. It describes the challenges that Farah faced in everyday life whilst trying to engage in life roles in two contexts: at school and in the community. The practices that Farah used to challenge the dominant social perception regarding her visual impairment, and to celebrate her different identities at the university and on social media, are also discussed.

8.1 At school: "I didn't really like people knowing"

Farah attended a mainstream school, this meant she had to adapt to fit into an educational environment designed for students without visual (and other) impairments. "*Fitting in is an embodied dynamic of displaying bodies that appear able to do normal things and look normal*" (McLaughlin and Coleman-Fountain 2018, p. 166), but this, as Farah described, "*wasn't so easy*". In the following conversation, Farah told of the challenges that she encountered whilst at school.

Farah: "When I was in school, it wasn't so easy, I didn't use to use my cane and shades in school, and I didn't really like people knowing [silence 00:04]. So, I guess because of that, I was pulled at school as well because people thought I was faking being blind".

Amani: Your classmates, do you mean?

Farah: "Yeah, students at school they thought I was faking, umm like pretending to be blind, and I used to get a teacher in every class who would read the paper to me, and when I got the highest score on a test, girls on my school would say, 'oh the teacher was telling her answers', and for someone you know, who is struggling already with confidence at that age, like I was 16, 17, and then to achieve something hard and someone to say, 'oh no that wasn't actually her', it was, it wasn't nice".

Visibility of visual impairment and its associated differentness was a crucial factor that could reveal Farah's social identity at all times during her daily interaction with people she encountered at school. Goffman (1963, p. 66) argued that visibility must be understood based on its obtrusiveness in such a context because if it "*is immediately perceivable, the issue still remains as to how much it interferes with the flow of interaction*". Farah was aware that the visibility of her visual impairment could become relatively easy to disregard if she minimised the signs associated with it, so she avoided using the white cane and wearing the black shades. McLaughlin and Coleman-Fountain (2018), Fourie (2007), Goffman (1963) and Porkertová (2020) found that assistive devices, such as a white cane, can create an expression of disability. This expression is a sign which makes it easier to recognise visually impaired people, it can get in the way of them being perceived as autonomous and equal to others.

Farah described how she endeavoured to do all schoolwork by herself, but sometimes she required the support of a teacher, for example, to read the paper for her. In doing so, Farah was caught in a balance between support enabling her to do ordinary things, such as reading a paper in class and symbolising the difference she wished to minimise by doing such everyday things. Thus, Farah's use of teacher support involved some degree of obtrusiveness that repeatedly disturbed her practices to enact normality and presented a conflicting message to other students, marking her as different (Fourie 2007; Goffman 1963).

Because Farah's visual impairment was not immediately apparent, the signs of blindness (which would involve using a white cane) were not obvious, her condition could be perceived as fake and a pretence as has been reported by Southwell (2012), especially when she achieved the highest scores amongst her classmates. Farah expressed sadness that other students did not recognise her hard work, the materials and the environment she occupied were all designed for sighted students (Kleege 2017). Also, Farah was achieving the "highest score". In a study of the health of long-term incapacity benefit recipients in the UK, Garthwaite et al. (2014) maintained that being assessed as having partial capacity for work does not equate to being told that one's illness is 'fake'. Garthwaite et al. (2014) added that government rhetoric has led to sickness benefits recipients being placed in the latter position, that is, as faking it. This has a significant impact on their daily lives by generating feelings of shame and stigma. However, Farah did not report asking for special resources to accommodate her needs. As such, dealing with her visual impairment challenges, schoolwork, and classmates who denied her achievements, "*wasn't nice*" for Farah, who was trying to build her confidence to live with a visual impairment without letting it to affect her too much.

The main issue, however, was Farah's appearance. As Farah did not correspond to the stereotypical image of a visually impaired person and it was not obvious that she could not see, she described being bullied at school. According to Chatzitheochari et al. (2016), bullying can be regarded as one of the means by which children with particular impairments become disabled. Farah spoke about the way students singled her out, they thought she was pretending to be blind and assumed that the teacher was telling her the answers, suggesting the high scores were not due to her achievements. According to McLaughlin (2017), this kind of bullying is common in mainstream settings, such as schools.

Chatzitheochari et al. (2016) and Carter and Spencer (2006) reported that disabled students were more likely to be bullied than non-disabled students. This is because their impairments may disturb social interaction with other students or be linked to aspects of their physical appearance, an attribute related to beliefs about normality and difference due to which

disabled students are perceived as different and subject to bullying and victimisation (Chatzitheochari et al. 2016; Faris and Felmler 2014; Holt 2004; Lightfoot et al. 1998). Farah explained the relationship between the bullying she experienced and the social perception of her visual impairment:

“You know, I was doing good on my study and was doing good on my extra-curricular as well, and people [students] just couldn’t understand how that’s work if they see I can’t see I think they just expected me not to be able to do anything”.

Farah thought her visual impairment was perceived as a barrier to achieving academically, this has also been reported by Coleman-Brown (2017), that disabled children are not expected to achieve in the same manner as other children. The poignant issue for Farah was that her different way of doing things, different timing, spacing and resources of her embodied efforts and dedication at doing routine and extra-curricular tasks frequently remained unnoticed, invalidated and explained away by other students. Despite that, Farah recognised that whilst visual impairment had created some challenges, it had shaped her worldview and interaction with others. Farah refused to let herself be disabled or victimised by the bullying that could be overcome with adaptive responses. She said:

“Maybe it helps the fact that I have all these siblings. I’ve got four siblings older than me, and I’ve got three younger than me. So, I guess it helped a lot having people older than me who support because I was able to, so, when I used to get [bullying] comments like this. Yes, it affected me, and yes, I would get upset, but I wouldn’t drill on it, I would, you know just carry on, and I had a teaching assistant who I don’t think I would be able to get this far without her help, so whenever an incident like this happened, she would report them”.

Farah ignored the negative comments that upset her without thinking intensively about it or letting it affect her day. Research on the experiences of disabled children at mainstream schools found that children tried to ignore bullying comments or avoid situations that were likely to lead to bullying, such as not wearing optical glasses (Bourke and Burgman 2010; Lightfoot et al. 1998). In addition, Bourke and Burgman (2010) and Kanetsuna et al. (2005) found that disabled children appeared to turn to their teachers and friends for support, with the latter being one of the main coping strategies. Farah indicated the critical role that her teaching assistant played in supporting her to deal with bullying incidents. She, however, stated that her ability to respond to bullying was influenced by the assistance of her siblings, who created a supportive environment, particularly the older siblings.

8.2 In the community: “I can’t change people”

“I don’t think I’m much involved with my community, and I guess that’s because of Asians and stigma. I’m from an area where it’s heavily South Asian population ... So, for example, I don’t get to the mosque that much, I would love to go to the mosque but I just, I don’t know how I’m going to be treated there, I don’t know, and these are all fears that I’m overcoming now as I’m getting older because I love my religion, but I guess there are just people that don’t see you as a person when you have a disability, and you’re a Muslim”.

Farah described feeling excluded from multiple spheres of her community, the Asian community in general and the Muslim community at the mosque. She believed that exclusion, due to stigma associated with different bodies enacted in everyday situations, marginalised her from the community. Farah described herself as someone who loves “*to go to the mosque*”. But her statement “*I don’t know how I’m going to be treated*” can be interpreted as a barrier to going to the mosque. The issue was that Farah wanted to be seen as a Muslim person who wanted to perform religious rituals at the mosque like everyone else. But when she reported fear of people’s reaction towards her disability identity, she was rendered negatively visible. Farah believed that her visual impairment seemed to detract people’s attention from the fact that she was also Muslim. Her Muslim identity did not help her to feel she belonged. Instead, Farah stated that she did not feel accepted due to being entirely defined by her impairment. As a result she was excluded from the Muslim community that formed a significant part of her and her family’s identity. In a study of blind people’s body image in England, Kaplan-Myrth (2000, p. 288) reported the issue of “*not being two things at once*”. Two female participants in that study suggested that being blind seemed to distract people from noticing that they were also Pakistani (Kaplan-Myrth 2000).

Farah described another example of her everyday life in the community when she took a cab whilst using a cane. Her experience with the taxi driver was generally not pleasant, as she described in an email message.

“I took a cab today, and the conversation the driver tried to have with me has left me so angry. I don’t often admit when I’m angry, but wow, this was a whole new level of things not to say to a disabled person. Here let me demonstrate. Driver: ‘you have a stick, what’s wrong with you’, me: shocked at his audacity and tone, unable to form a response. Driver: ‘can you see a little bit’, me: yes. Driver: ‘oh, I’m so sorry’, me: ‘there is nothing to be sorry about’, silence for the rest of the journey. What I am angry about is that people feel it is okay to speak to disabled people in this way but take it from a disabled Muslim hijabi woman, IT IS NOT OKAY. I work so hard to ensure I am not known solely for my sight loss, but I can’t change people if all they choose to see is my disability. Like I’m training to be

a lawyer, but the cab driver would probably have never thought I could be capable of that and be successful”.

In relating the taxi driver incident, Farah expressed her anger about the conversation which had taken place between them. She stated that the taxi driver’s audacity to approach the conversation exceeded the accepted level of what to say or “*not to say to a disabled person*”. It was not only his audacity that made Farah feel angry but also his intrusive tone. She was left feeling shocked by his attitude. By saying, “*you have a stick, what’s wrong with you*”, he emphasised the fact that her stick was connected to something wrong with her body. It was interpreted as a negative connotation, meaning she was a different type of passenger, she was disabled. In this manner, the taxi driver abdicated Farah’s disability from her strength and ability to overcome visual impairment and travel independently, his emphasis was on her visual impairment as opposed to what she did about it.

Farah pointed out that the way the taxi driver asked this question was shocking to the extent that she could not form a response to answer him. At that moment, instead of stepping back from the conversation and understanding why the passenger kept silent, the taxi driver continued to question Farah’s visual impairment and whether she could “*see a little bit*” despite not speaking about her impairment. The expectation about Farah’s vision and her ability to see is related to the public misconception about a blind person as seeing nothing at all (Southwell 2012). When Farah answered with “yes”, she recalled how his reply with “*oh, I’m sorry*” formed another statement that left her feeling sad, angry and silent for the rest of the journey.

Farah’s anger was such that she affirmed “*IT IS NOT OKAY*” to speak with disabled people in this way, and more importantly not with “*a disabled Muslim hijabi woman*”. In other words, Farah’s affirmation pointed out that there are certain things that should not be said to a disabled person, such as “*what’s wrong with you*”. These things, Farah admitted, are more limited if the disabled person was a Muslim woman who wore a hijab. Farah wanted to emphasise that she did not accept being defined by her impairment, to think she was incapable, to question her condition, interfere, begin unnecessary conversation, or disturb her journey. She believed that there were boundaries in communicating professionally with a Muslim woman, and it was not permissible to push these boundaries.

Farah described working “*so hard*” to develop herself and demonstrate that her identity was more than a “*sight loss*” or a visually impaired person, but she acknowledged that she could not change people perceptions about disability. In the eyes of the taxi driver Farah was a disabled passenger. However, her self-inscribed identity was that of a “*successful*” woman who was “*training to be a lawyer*” to defend people for their rights to justice, she would

probably achieve far more than the taxi driver could imagine. Murugami (2009) argues that a disabled person can construct a self-identity not constituted in impairment but rather independent of it. Thus, Farah shared the taxi driver incident to define and set the boundaries of conversation with disabled Muslim hijabi women in public. The social contexts that encouraged Farah to construct her identity as a valued human being and to challenge the social perception of her visual impairment and Islamic identity are explored below.

8.3 At university and on social media: “I would tell them I’m partially sighted”

“I’m making the most of what I can with my life, I went to study Law at [name of university], and now I’m training to be a barrister, and I’m trying to show people that, you know, things like your disability shouldn’t hold you back, no matter if you’re a Muslim woman, no matter if you have a disability, no matter if you’re from a minority background”.

Farah described how she used every opportunity, in each day of her life, to create the best possible outcome. She graduated from law school and she was training to become a barrister. In doing so, Farah advanced the point that the loss of vision must not translate into an exclusive disability identity. Farah also realised that her life opportunities would be reduced due to the negative markers ascribed to her gender, race and religious identity. Thus, Farah shared her story to show how she constructed herself through these multiple identities. Murugami (2009) explained that one’s sense of self constantly evolves, and that people constantly reconfigure themselves through multiple identities.

Deegan (2010) also found that the interaction of multiple minority identities could be a source of new social standards and ways of being in the world. In other words, the management and commitment involved in constructing identity, with multiple markers of difference, going to university, choosing to become a barrister to speak on behalf of clients in court whilst using a white cane and wearing hijab, show the deeply embedded nature of Farah’s self-reliance in increasing people’s understanding of how she constructed herself as a valued disabled Muslim woman. In her efforts, Farah aimed to construct a new social identity of a “*successful*” disabled Muslim woman:

“I’ve done lots of stuff. It’s hard to keep all of them on two pages on my CV [laugh]. So, I’m kind of a success story”.

Farah spoke about various activities that she participated in during her time at the university. For example, Farah had chosen to be a “*student ambassador*”. She gave campus tours and talked to prospective students on the university’s open day. She recounted, “*I would tell them I’m partially sighted and aspiring barrister*”. Farah was also talking about her impairment to an organisation which had previously visited her school. She valued their

support, saying, “*they helped me learn braille, and they’re the ones who gave me my cane*”. Moreover, she mentioned being a part of the GCSE exam board broadcast programme to help students from disadvantaged backgrounds. Due to these achievements, Farah proudly described her experience as a “*success story*” of being a disabled Muslim woman. She also directed her story to other disabled Muslim women to demonstrate that success was not out of bounds. On one of her Instagram posts, Farah had a photo showing double sail flags at her university campus, one banner with her picture printed on, and the other quoting:

“A visually impaired aspiring barrister who acquired a placement before graduation as a caseworker at the House of Commons”.

Farah worked for a member of parliament and joined a group called “*partly able*” which advocates for disabled people. Farah was part of this group for one year, she talked about her journey through school and what she wanted to achieve. However, the presence of her body on the sail flags expressed a way that Sacks (1984), cited in Garland-Thomson (2011, p. 596), calls “*doing being ordinary*”. Such a presence yielded the privilege conferred by performing tasks and accessing spaces where people are not accustomed to seeing young Muslim women who wear hijab and walk alone with a white cane (i.e. in university and the parliament). For the banner Farah chose a photograph of herself standing with a white cane. The text she provided alongside the image acknowledged her visual impairment and stressed her focus on getting on with things and doing stuff that young students of her age at the university aim to do, such as aspiring to be a barrister.

Representation, according to Garland-Thomson (2017), attaches meaning to the body. Therefore, Garland-Thomson (2011) claims to make one’s identity more visible in order to transform their meanings so that they provide their bearers with a positive narrative from which one can launch subjectivity and agency. That is, Farah’s action represented her identity at once as performative (photo) and narrative (text), emerging as particular material bodies (sail flags) that interact in a particular social context (university campus) (Garland-Thomson 2011). Being seen as a Muslim woman who could achieve this was essential to Farah and influenced how she embraced her visual impairment and the “*struggles*” associated with it as a part of her everyday life. She said:

“You know, I try to post a lot, like actual struggles that we [disabled people] have, like you know, we’re just human as well. Like the other day, I posted a picture of my books and then, the next post was a video of my book being read out to me. Now that’s like an insight into how I study. Now people wouldn’t know that; they will just think, ‘oh, yeah, there is her iPad, she would probably just read them from her iPad’, but I don’t, my iPad reads to me, and I want them to know that”.

In her narrative Farah wanted to be seen as a person who overcame difficulties and learnt to deal with continuous challenges, not as a disabled body to which things were done passively. Her Instagram post about her way of reading a book corresponded with Garland-Thomson (2011) concept of fitting and misfitting that speak directly to the issue of materialisation and reshaping body and the world. Garland-Thomson (2011) argues that one of the fundamental premises of disability politics is that equal access and social justice should be achieved by changing the shape of the world, not changing the shape of our bodies. Farah, for example, could just have posted a picture of books to show she was reading, but she purposely posted a video demonstrating that her iPad reads for her rather than she reads from it. This directed attention towards environmental barriers rather than towards her impairment. In other words, when Farah encountered a printed text which she could not read; when she encountered a digital text, her "*book being read out to*" her. Thus, her shifting subject position from "*she would probably just read*" to "*my iPad reads to me*" created a fit between her and her world in what could have been an occurrence of misfitting.

Farah's video of her iPad reading also addressed the insider/outsider standpoint and the gap between representation and reality. That is the actual experience of disability is more complex and more dynamic than representation usually suggests (Garland-Thomson 2017). While sighted people read immediately from a printed text, Farah wanted to show that she had to prepare a digital text, use an iPad as a reader, make the iPad read to her and she had to listen to her iPad. Although this process is complex, it eased the material divergences between Farah's body and her environment, making misfits into fits. In such a process of reading Farah also pointed out to Kafer (2013) the concept of crip time, which emphasised recognising the notion of flexibility rather than just extra time for doing things. Farah related to crip time by making people watch the video so they would recognise that how long reading/things takes is dependent on particular bodies. People can then understand the flexibility of crip time as not only allowing more time, but also a challenge to normalising expectations of pace and accomplishment. Thus, rather than fitting disabled bodies to meet the clock, crip time fits the clock to meet the need of the disabled body (Kafer 2013).

Another reason for Farah posting on social media was her desire to share her image as a disabled Muslim woman.

"That's one of the reasons that I post a lot on my social media about my disability that I make sure you know, you can tell I'm a Muslim woman because I've got my headscarf on, and then you can tell that I'm, I've got a cane, so I'm disabled ... so I'm, you know, content with who I am".

Farah resorted to social media to convey that she was a woman, who was determined to live a fulfilling life by sharing a curated highlight reel of her life with a broader audience. She believed that her posts highlighted the figure of an “*ill-suited*” woman who was set apart from others on social media with her unusual body characteristics, these included a cane and headscarf (Garland-Thomson 2011, p. 593). Therefore, she tried to alternate modes of personhood and be agent of disabled Muslim women recognition by engaging and presenting herself in a challenging environment, filled with non-disabled women images, to accommodate her difference, promote human diversity (Garland-Thomson 2011), and celebrate her unique identity. She also described how her posts on social media played a critical role in connecting her to a large group of friends, those who were also Muslim and disabled women:

“That [post on social media] has worked, like so many people who are Muslim women and disabled have messaged me on Instagram, so you know, come out of their cave ... and that makes me very happy like I've got, I think I've made like wide social media friends”.

Farah's words reflected her desire to be part of a particular community, this desire was deeply felt where the bonds of such belonging emerged through the messages she received on Instagram. Throughout these messages Farah claimed a sense of agency by having the power to promote her identity and a purpose to encourage, communicate and make friends with those whose bodies and identities had been socially devalued, underrepresented and excluded from public life.

8.4 Chapter Summary

Farah's story evokes how a young disabled Muslim woman built her confidence until she became a professional solicitor. During her time at school, Farah described how she worked hard to complete her homework and to achieve the highest score among her sighted classmates. They denied her achievements and accused her of faking blindness. She also described feeling excluded and defined by her visual impairment in the community, even before using the white cane. As a result of these experiences, Farah realised that she could not change how people perceived her but instead she changed herself and constructed an identity other than the one conferred by her visual impairment.

Through the choices Farah made, mostly during her time at university, she endeavoured to construct her subjectivity as a woman who had a right to live a fulfilling life with, rather than despite having, a visual impairment. For Farah, being visually impaired did not mean having a limited life. It was about doing everyday things in a way that conformed with her visual requirements. Farah tried to construct a life that she would enjoy and an identity that she felt

proud of, based on what she could do, not how she could do it. For Farah, social media was a medium that enabled her to celebrate her difference, embrace her visual impairment as part of her identity, and alternate modes of personhood through deliberate provocation of misfitting acts. Yet, acquiring “*a placement before graduation as a caseworker at the House of Commons*” was a signpost vision for Farah’s future identity, the one that she has chosen in the midst of an environment which is hostile to body differences. The following chapter discusses how Zara felt socially included, excluded and “*vulnerable*” to sexual harassment due to general hostility towards body differences in her everyday life contexts.

CHAPTER NINE:

“People are staring at me, and I don’t know why they’re staring”

Zara was in her early 50s, married and had two children from a previous marriage. In 2003, Zara contracted HIV from her first husband. Following the HIV diagnosis Zara was diagnosed with a number of mental health conditions, these included bipolar and borderline personality disorder. At the same time, Zara described practising her religious traditions more, and began to wear a niqab. In 2009, Zara developed chronic back pain, osteoarthritis, chronic IBS (irritable bowel syndrome) and stomach ulcers. She was also diagnosed with fibromyalgia after suffering long-lasting pain, which affected her mobility. As a result, Zara had to use crutches to walk short distances both indoors and outdoors.

Zara described how she was frequently stared at because of the way she walked and because of other categories of her identity, such as being “*Black*” and a “*lady with a niqab*”. In spite of this, she described how she tried to cope with people staring, she hoped to present a positive image of herself as a disabled Muslim woman with a niqab but this was not always successful. This chapter describes Zara’s efforts to be independent, to cope with people staring and to present a positive image of herself. She felt socially included, excluded and ‘*vulnerable*’ to sexual harassment due to general hostility towards body differences in her everyday life contexts.

9.1 Zara’s upbringing and diagnosis

When Zara was six years old, and while playing with her siblings, she recounted that they used to have “*a very short person*” walking around in their neighbourhood. As children, Zara described how they tended to stare at this person and their facial expression was “*like, wow*”. In response to their behaviour, Zara stated that her

“mum used to say, don’t stare, don’t laugh at people because you don’t know what’s your future is going to be, so we were raised like that”.

Staring is fastening one’s eyes on someone as a way of strongly expressing response and reacting to others (Garland-Thomson 2006, 2009). It is a more sustained form of looking than glimpsing, gazing and other forms of normative looking, which registers intense interest and endows it with meaning. That interest can take many forms ranging from curiosity, wonder, disgust to hostility (Garland-Thomson 2006). Zara described how her mother always taught her and her siblings at an early age that anyone had the potential to become disabled or look different, including them, in the future. This familial context encouraged Zara to

volunteer her time after school and the weekend to look after “*the elderly, the disabled, people with learning disabilities, children, [and] teenagers with learning disabilities*”. Thus, she became a volunteer “*carer*” at the age of 16 years. Then, her experience of looking after people developed further during her university placement before working as a nurse in the NHS. She said:

“I worked for the NHS for 30 years. I’m proud of the things that I’ve contributed in the past”.

Zara was proud to work at NHS hospitals, where she looked after people for many years. She told me that she wanted to do a postgraduate course to specialise further in mental health nursing, but she felt that the mental health problems due to her first marriage stopped her from doing so. Zara found it difficult to talk about her own mental health.

Zara: “I wanted to specialise, and I wanted to do mental health, but I have a mental health issue”.

Amani: What mental health issue?

Zara: “So, basically a bipolar and then I have a borderline personality disorder, but I think, I have, I was married, I’m married now, but I was married before to someone else, and he was an HIV positive”.

In 1997, Zara got married. She stated that her first husband was HIV positive, but he did not inform her about his health condition when they got married. “*He kept it secret*”, she said. When Zara was expecting her second baby in 2003, she “*started to feel really sick*” and visited the hospital. She explained that she had a medical check, including a blood test, but they told her:

“You are okay. And then, two weeks later they called: ‘*you have to come back to the hospital now, now, now, now*’ [emphasis by Zara], so they can stop the baby from getting this [HIV] condition, so basically then I was diagnosed with post-traumatic stress disorder because of what he did”.

When Zara was first diagnosed with HIV, she described being “*very stressed out*”. The challenge was not merely accepting HIV and living with it but also what to do with her husband. She told me that her ex-husband was arrested and was taken to court. Going to trial in court was stressful for Zara, and the struggle was evident in her words when she spoke:

“The trial was like, made me, I was, I was very stressed out, they said, you have post-traumatic stress disorder, but I forgive him, and I leave it to Allah [God]”.

Following her diagnosis with post-traumatic stress disorder, Zara described how she resorted to two strategies: forgiveness and reliance on Allah. Worthington and Scherer

(2004) stated that forgiveness could be used as an emotion-focused coping strategy to reduce a stressful reaction to a transgression. Thus, forgiveness was a form of coping that Zara used to help alleviate the stress that resulted from the traumatic experience and affected her mental health. Secondly, Zara also credited her faith in God for getting her through that stressful time. She described laying her trust in “*Allah*” and leaving the rest to him because she believed nothing is difficult for Allah. Accordingly, after obtaining a divorce, Zara explained how she tried to start a new life.

“I moved and stayed with my two children. I just started to practice my deen [religion] more. I started wearing a niqab ... so now I wear a niqab, but I’m still the same person who goes to the shop, says good morning, and then the person there goes, ‘good morning, how are you?’, ‘I’m fine;’”

Underlying her actions of continuing to work, going to the shops, and moving with her children was a vision of life where being a HIV positive Muslim woman would not mean living in isolation. These actions enabled Zara to subvert the stigmatised identity of a Muslim woman who had HIV both for herself and others. Zara also described remaining “*the same person*” who loved interacting with others in the community. She believed that HIV and niqab did not change who she was regarding her social behaviour and interaction with other people in the community. In addition to HIV, Zara also developed chronic back pain, osteoarthritis, chronic IBS and stomach ulcers between 2009 and 2011. She described being in a lot of pain due to these medical conditions:

“The pain is like I’ve been stabbed with a knife and I would stay on this couch, and I can’t move, I can’t get up for salah [prayer], I can’t get up to go to the toilet, and I can’t even umm eat because of the pain”.

The pain did not only affect Zara’s everyday life activities, such as eating, toileting and praying; it also affected her ability to work. Zara had worked until 2012 when she retired on health grounds. “*That’s how bad it was all the pain in my body*”, she said. Therefore, Zara believed she was disabled from the time when she began to experience the pain in 2009, this had started several years after the HIV diagnosis. She explained that her support worker tried to help her apply for disability allowance, but she did not qualify at that time.

“They said that just because you are in pain doesn’t mean you can qualify for it, and PIP, which is personal independent payment, concentrates on your mobility”.

Zara did not qualify for the PIP, to help her with the extra cost of living with a disability, until fibromyalgia affected her mobility, a diagnosis which was confirmed in 2015. She described how pain due to fibromyalgia, combined with osteoarthritis, chronic back pain and stomach

ulcers, resulted in her having to use crutches and “*start to be very slow and then every step agony*”. As such, the following sections describe Zara’s experience of her identity as a Black disabled woman who wore niqab and used crutches in three different social contexts of her everyday life: community shop, HIV clinic and public transport.

9.2 Representing a positive image in the community

Zara spoke of her feelings about the way she walked and how people reacted toward her. She said:

“I feel awkward because of the way I’m walking, it’s like I’m walking down a hill, and the way I’m walking with my crutches is extremely slow, and people are staring at me, and I don’t know why they’re staring at me, I don’t know if they’re staring at me because of that or because I’m Black, or because I’m Muslim, or because of my disability [laugh]”.

At the heart of Zara’s words is the matter of her body appearance. Walking slowly, Black skin, niqab, and crutches – all of these are body characteristics and embodied practices. She began by describing her walking as “*extremely slow*”, which she believed to be a primary reason for people staring at her. Garland-Thomson (2017) argued that stare indicated disabled identity about the body when markers, such as Zara’s crutches, are conspicuous to people. In this case, Zara’s body disrupted the body norm expectations and invited the stare that constituted her as other. But Zara also said she was unsure if her disability was the only reason for being stared at. Her uncertainty was complicated by the presence of other categories of her identities, which she believed invited stare; namely, being a Black and Muslim woman with a niqab. Wilkinson (1969, p. 191) referred to situations in which Black people find themselves receiving the “*Black hate stare*” in various forms in public, such as frowns and glances. Zempi (2020) reported that Muslim women who wear the niqab in the UK experience staring from strangers in public places due to their visible religious identity and gender performance. In the following extract, Zara explained how she responded to people who stared at her in the local shop:

“I smile through my eyes, I smile at everybody, I say hello, good morning, hello, good morning, even the elderly lady she will be staring at you like this [widened her eyes], but I was trying you know good morning, and she will go good morning. Then, I have the child in the shop, and the child stares at me like ahh, then I go hey [waved her hands] and then the child goes hey and then the mum laughs and those who were there start laughing because I made her child laugh, you know they didn’t expect things like that because I want every time they leave me, they go away and say ‘oh I met this lady with a niqab, and she was so friendly’. Because most of us [Muslim women] we don’t talk and there is a reason, our voice shouldn’t go

loud but I was born here so I'm just same to everyone else except from my deen [religion] is different".

Zara's phrase "*smile through my eyes*" exemplified how she responded to people staring by using her eyes to smile, the only part of her face that others could see through her niqab. In her narrative, Zara revealed that a niqab was not a barrier in her interaction with others. She said, "*even when I'm talking to strangers, they can see past of my niqab as if my face is open they end up talking to me*". In retelling the elderly lady incident, Zara affirmed that she did not conform to her belief that Muslim women "*don't talk*" when she turned herself from a silent object of the stare into a speaking subject (Garland-Thomson 2000).

During our conversation, Zara widened her eyes to show me how the elderly lady stared at her. According to Garland-Thomson (2006), face to face staring is the most intense form of looking. Thus, by greeting the lady, Zara believed that she turned the stare back on those who were staring, upbraiding them for their intrusive staring eyes that made her feel "*awkward*". Furthermore, her self-representation highlighted a story of creating change, in which staring could be productive and enhance social inclusion rather than oppressive (Hammer 2016; Garland-Thomson 2006). In other words, Zara described using stare as a positive opportunity to teach others about her identity and interact with them in the community (Renwick et al. 2018; Garland-Thomson 2009). She transformed their objectifying stares into moments of her agency through the performative act of engaged staring and interaction with others (Eisenhauer 2007; Garland-Thomson 2006).

Engaged staring is a version of looking that mutually engages starrer and staree with one another rather than repelling the starrer (Garland-Thomson 2006; Garland-Thomson 2009). Garland-Thomson (2006) argued that the intensity of engaged staring arises not from hostility or enforced distance but from a pressing need to know and make sense of the object that attracts one's eyes. For example, Zara's performance with the child and his mother in the shop, hastened the movement away from sustained stare into didactic and engaged stares that she intended to share in a positive way with others in the shop. As a result, Zara described representing a "*friendly*" image of herself in her community and creating an environment in which she believed she had been socially included. She also believed that her interaction with others was mainly facilitated because she "*was born*" and grew up in the UK, a privilege unavailable to immigrant, disabled Muslim women. However, there were instances when Zara felt socially excluded, such as in the HIV clinic.

9.3 The HIV clinic: “I hate going there”

The time after the HIV diagnosis was difficult for Zara, with her trying to get over the shock of the diagnosis, separate from her husband and figure out what her life would be. She recounted the first few months as very stressful, which led her to a period of depression.

“I just found myself with this man. I was a bit too shocked, and as soon as I found out, I told my mum, my dad, my brothers, my friends, my colleagues at work, I just went boom [mimicking words vomit] straight because, in the beginning, I was very depressed about it”.

Zara described being open about her diagnosis to everyone. Badahdah and Pedersen (2011) and Hasnain (2005) report that women in Muslim culture are often reluctant to disclose their HIV status to family and friends due to fear of stigmatisation. On the contrary, Zara told her story to show that this situation had happened to other Muslim women, and she wanted people to know that there is no shame in that:

“I will tell everybody that I got this condition because no one want to talk about it as if it’s a shame, but I used to look after sisters who passed away, and they [also] got it from their husbands, and I felt so bad for them and then when I go to [HIV] clinic and there the entire waiting room, and I’m the only Muslim there ... I hate going there because of the stigma, and I felt that that’s the only time I felt bad being when sitting in the waiting room”.

Looking after Muslim women who were HIV-positive and being around them at an early age, helped Zara learn about their individual stories and realise that she was not the only person to be in this situation. Yet, although Zara believed she did not do anything wrong to acquire HIV or feel ashamed about it, she expressed her resentment of the HIV clinic’s waiting room. She explained that she hated going there and there were many reasons why she felt like that. At first, in a context where HIV as a condition was already subject to stigma regarding the behaviour associated with HIV transmission, such as sexual practices or drug use (Turan et al. 2019), Zara described feeling completely alone as a Muslim woman. She told me that she did not meet any Muslim woman at the HIV clinic. She said, “*I’m just alone*”, which made her subject to multiple stigmas, that of being a woman, Muslim and HIV-positive. She also said:

“They couldn’t see me as a Muslim before I wore, I started wearing a niqab in 2008 ... [But] the good thing is they have women’s waiting room and men’s waiting room, but in the women’s waiting room there someone will come with their boyfriends or their husbands, and they [male companion] are going to be in our waiting room looking at me, I will be self-conscious that I’m the only one in the niqab”.

Zara explained that she did not wear the hijab between 2003 and 2008, when she attended her appointments at the HIV clinic. As a result, she revealed that no one recognised her as a

Muslim woman, whilst sitting in the waiting room during that period. Zara said that when her cousin had come over from Ethiopia to visit them, the cousin wore a niqab. Zara liked her cousin's niqab and started to wear one herself in everyday life, except at work because niqab was not permitted to be worn in clinical practice (NHS Employers 2020). As a niqab symbolised a Muslim woman, Zara described how she felt stigmatised because of her Islamic visibility through which she believed she was constructed as 'the other' by women patients and their partners in the waiting room. She described feeling judged when she walked into the room "*for the same thing that everyone there for*" (HIV-positive status) just because she was a niqab wearing HIV woman.

The barriers that Zara encountered in trying to achieve social inclusion through equal access to healthcare are unique. The interaction of her identities as a Muslim woman with niqab and a person with HIV resulted in her experiencing social isolation. She was, therefore, excluded twice, once from the women patients on the grounds of her religion, and again from the HIV patients on the grounds of her gender. Because she was a Muslim woman, she was subject to the social perceptions that non-Muslim women were not. Because she had HIV, she experienced the dominant male gaze, which addressed women as spectacles who serve as "*an object of vision*" (Berger 1977, p. 47). As such, the stare associated with the stigma that Zara's niqab attracted stood in relation to Zara's otherness, indicating the ways in which gender, religion and disability converged to exclude her. She said:

"They stare as if Muslim women do not get this condition; we don't get HIV, yeah we do".

The stare that Zara experienced in this context differed from the one she received in the community. Here, she believed it related to an HIV-positive woman with a niqab instead of a woman with a niqab in the community. Consequently, she described the way she faced HIV stigma and the embarrassment she felt about the perception that associated this condition with her religious identity. When Zara was asked about her feelings while sitting there and how she responded to the stares, she said:

"I felt a shame, so much shame, I felt a shame when they stared at me, and when I walked to a one [waiting room], I go hello, but it's not like hellooo, it's like I sit down and I look at the floor".

The stare Zara received played an influential role in framing her feelings and reactions. She articulated how the assumptions people made, based on her niqab, excluded her from being considered as an equal HIV patient and made her feel ashamed. Berger (1996) suggested that the state of being stared at creates a sense of shame. Renwick et al. (2018) added that being stared at could be experienced as stigmatising, objectifying, a loss of power and a

reminder that one's body is different from dominant social standards. Thus, when Zara found that others in the waiting room had difficulty in ignoring her difference, she tried to help them by making a conscious effort to reduce tension. She recounted managing their stares by looking down at the floor. Garland-Thomson (2006) identified this coping strategy as a separated staring. It is a visual pushing away from those who cannot bear the surprising particularities of human embodiment. It is also a form of facilitating stare in which Zara understood what motivated the people who stared at her and sought to overcome their limited understanding of human differences (Garland-Thomson 2006; Garland-Thomson 2009). Yet, the negative aspect of stare also acted as a constant reminder of Zara's HIV-positive status and its associated stigma, which she believed related directly to her health, as a result she missed appointments and discontinued the HIV pills:

"I missed my appointments, so I didn't look after my health properly. They just sent me six months' worth of medicine. I was like, mum, they sent me six months! They got so fed up with this woman who doesn't come to the appointment, but this is the only medicine that I'm careless with, the one that would save my life and sometimes, although I'm on 22 pills a day ... I beg them to give me one pill for years when they find they can give me one pill, I didn't respect it".

Narrating what perhaps seemed mundane for others, such as attending or missing an appointment or swallowing a pill every day, was another way Zara retrieved her voice in the face of being excluded and socially stigmatised. For example, if service providers had engaged Zara in a conversation, they would have discovered why she missed her appointments and also why she used to "*beg them*" for giving her one pill. The problem, however, was not the frequency of the appointments nor the quantity of the medications. Instead, it was the negative attitudes she was subject to in the waiting room, she felt it reduced her whole being to the stigma associated with her identity as a niqab-wearing HIV positive woman and it prevented her from being equal to other patients. Thus, while staring represented one of the social barriers to healthcare accessibility for Zara (Spencer 2020), HIV-related stigma was internalised by Zara as a feeling of shame and distress that had a negative impact on the way she approached her illness and the choices that she made about seeking treatment (Earnshaw et al. 2013). According to Fife and Wright (2000), internalised HIV-related stigma increases the stress associated with HIV. Thus, not taking a pill was one way in which Zara tried to reduce her feelings of distress, despite acknowledging that this one pill in between the other 22 pills "*would save*" her life. However, Zara's experience of stare, stigma and other practices of hostility towards her multiple identities manifested in other public places of her everyday life, such as on the train.

9.4 On the train; ‘I realised I’m vulnerable’

“When I was on the train, I was sitting in a carriage where there was no one else and four rows ahead of me there was a man, this man came behind me by my seat and then he just didn’t talk but WOOH [loud voice expression], like that. I just went ahh [panic expression], he was holding his private part and staring at me. When I saw him holding his private part, I turned to look through the window, and when I was looking through the window, I couldn’t see if I can see anything, I stared at the window, and for me, it took like an hour, but it would be three minutes or so, and then while I was staring he was laughing. After three minutes of staring at the window, I finally could see his reflection. I don’t know whether because we entered to the tunnel and there was dark, and you can see, and it’s like a mirror now, it’s not like you’re looking to trees or anything, and he was shaking his private part and staring up and down at me”.

Blocking a person’s path, making sexual gestures through touching oneself around another person, and looking at a person up and down, are all non-verbal examples indicating Zara’s experience of sexual harassment on the train. Sexual harassment involves unsolicited and rejected verbal or nonverbal sexual gestures that happen in different ways by a male stranger towards a female, solely based on her sex, in a public place (Laniya 2005; Ludici et al. 2017; Mason-Bish and Zempi 2019). To understand any woman’s experience, Davis (1994) and Mason-Bish and Zempi (2019) emphasised the significance of thinking of her as embodied and not as a person experiencing sexual harassment on various, nonintersecting axes, and then thinking about the particular meanings assigned to that embodiment in her context.

Dalton et al. (2021) and Martin et al. (2006) found that non-White women were more likely to have experienced sexual assault and to have been judged unfairly and blamed for the occurrence of the assault. Disabled women were among those who suffered most from sexual crime in the transport environment as their impairment might limit their ability to defend themselves, leading the perpetrator to feel that disabled women would be relatively powerless to resist (Ludici et al. 2017; Martin et al. 2006; Casteel et al. 2008). On the other hand, Haddad et al. (2006) argued that Muslim women had been historically portrayed as either hypersexual women or silent images of oppressed victims of male brutality. Yet, women who wear the hijab, in particular, were subjected to sexual harassment based on stereotypes about their gender, religion and race, which position their bodies as passive and incapable of resisting male offence (Alimahomed-Wilson 2017). In this regard, wearing the niqab marked Muslim women more readily visible as soft, easy, and convenient targets for attack (Mason-Bish and Zempi 2019). During the incident, Zara acknowledged that she was vulnerable as a Black disabled Muslim woman with niqab who was travelling alone whilst the

train was empty. She described how she thought and responded to the man's behaviour during that moment on the train:

"I was just holding one hand on my bag and the other hand on my crutch. With my crutch, I thought in my head should I hit him with my stick? What if I hit him with a stick, he might get hold of the stick and beat me with the stick, so I can't hit him, I was frozen, and then he just walked away. So then I had my suitcase, the next stop I got off, and it took like maybe 20 minutes to get to the exit, for somebody that would take them five minutes. And as soon as I saw the person behind the window at the station, I burst into tears and I said please I need to report something to the police, and then I thought I should never get on the train again on my own for the rest of my life. Although I video what happened to prove this, and I thought maybe the video would be evidence to the police, and that's when I realised I'm vulnerable".

Zara's expression "*I was frozen*", meant she resorted to the fight, flight and freeze response in the presence of stressful threats (Samra 2019). At first, Zara described thinking about the fight response. She thought of hitting the man with her stick, but she realised she could not protect herself if he got the stick and started beating her. Bearing in mind that he was standing by her seat and she had to walk slowly on crutches, neither fight nor flight and escaping from him seemed possible. Thus, Zara described finding herself at a point where she could not act or move at all; she froze until the man walked away. Despite that, Zara did not present herself as a passive victim in the face of the perpetrator. On the contrary, during the stressful few minutes of her experience of sexual harassment, Zara recorded a video of what was happening to use it as evidence in police investigations since the carriage was empty and there were no witnesses. Then, when she managed to reach assistance at the station, she immediately reported the incident.

On reflection, Zara referred to herself as a "*strong person*". For Zara, being a strong person did not mean having physical strength. Rather, it meant having the confidence to make choices, have freedom of mobility, and travel independently by herself without requiring assistance, despite her physical impairment which limited her mobility and required using crutches. But upon this incident, Zara found herself in a socially vulnerable position, encapsulated in the case of sexual harassment that lowered her self-esteem and made her feel weak and devalued. Swinton (2012) argued that belonging is on a deeper level than inclusion; to belong, Zara needed to be seen as a human being, to be included, she just needed to be present so that the transport system fulfilled some social or legal standards of inclusion and diversity.

Zara described being a "*vulnerable*" commuter within the transport system, her belonging involved not only making the transport environment physically accessible, but also re-

emphasising the need for a monitoring system which would make public transport safe and accessible for her as a disabled and Muslim woman. As such, she believed she was vulnerable, she could not control these situations and could not shield herself adequately from their consequences. According to Arstein-Kerslake (2019) and Scully (2014, p. 3), disabled women are a group of people who, for some reason, are “*especially vulnerable*”, they are at greater risk of experiencing specific types of harm or being a victim of hate crime or abuse.

Scully (2014) identified two different types of vulnerability in relation to disability: inherent, and contingent vulnerabilities. Inherent vulnerabilities are those which are often due to a physiological or biological characteristics directly resulting from the impairment itself. For example, Zara’s impairments are associated with mobility problems such as poor balance and risk of fall when walking. Contingent vulnerabilities are those which are directly created by the social environment, they are contingent on social and cultural responses to embodied differences which instigate and perpetuate situations and create vulnerability (Scully 2014).

For example an environment, such as public transport, that has not been made emotionally safe to use for Zara, who used crutches and required another person to guard her during attack. This environment left Zara vulnerable to the perpetrator, because when she was faced with the need to feel secure or escape safely she was dependent on the presence of another person or other passengers on the train. But the train was empty and the perpetrator held power in this situation, she believed that he might abuse that power. This is the vulnerability that is contingent by inaccessible environment (Arstein-Kerslake 2019). If the public transport was made accessible with automated surveillance, disabled passenger alarms and other appropriate mechanisms to detect parameters such as unsafe behaviour, then Zara might be able to use the train on her own and would not need to depend on another person to guard her. Zara would, therefore, not be vulnerable to the potential for other people to use their position of power and to harm her. Against a background of such vulnerability, Zara was inherently and contingently vulnerable in the context of public transport.

Whilst it might not be possible for changes in the social environment to fully negate the impairment-related inherent vulnerabilities from the lives of disabled people, contingent vulnerabilities could, in principle at least, always be altered (Arstein-Kerslake 2019; Scully 2014). Thus, to eliminate her vulnerability, Zara described her decision not to “*get on the train again on [her] own for the rest of [her] life*”; this decision restricted Zara’s autonomy by limiting her independence in travelling alone. “*Under such circumstances, any inner reflections on who one is are eclipsed by the external definition of what one is in the eyes of*

others” (Jackson 2002, p. 68). Zara wanted to live in a way that positively acknowledged the difference of her religious tradition, ability and gender-based identity, but this was not to be everywhere.

9.5 Chapter summary

Gender, race, religion and disability augmented one another in Zara’s display of herself to form a spectacle of embodied otherness that is simultaneously sensational and pathological. As such, Zara shared her story to present a positive image of a disabled Muslim woman with a niqab, one who is independent, friendly, sociable and smiling at everyone through her eyes. She was also proud of being a nurse who had helped and made a difference in the lives of people for 30 years. In addition, Zara’s narrative touch upon her feelings of social inclusion, exclusion and vulnerability in different contexts of her everyday life, including community, medical clinic and public transport.

Zara located her narrative between these spaces, she highlights how one can be an actor and also a person who is acted upon. Also, Zara suggested that the bridge to accommodate her differences could be crossed through a context-specific sense of humanity, implying forgiveness, respect and ability to promote genuine harmony throughout the wider society. Yet, one of the main issues brought about by Zara’s identity was the introduction of a pervasive sense of vulnerability when she encountered a hostile environment. As a disabled Muslim woman with a niqab, Zara embodied a vulnerability that was directly linked to her appearance. For Zara, a social life was no longer hers to participate in and enjoy independently, it was dependent on how other people would perceive and react to her, also who would be available to accompany her. In the following chapter the stories of five women are discussed in relation to the objectives of this study. The implications of the study, its limitations, challenges, recommendations for future research and reflexivity within this study are discussed. This is followed by the thesis conclusion.

CHAPTER TEN: Discussion and Conclusion

10.1 Experiencing disability in the UK: Muslim women narratives

This thesis explored the experiences of Muslim women living with disability in the UK. In the preceding chapters, in-depth narrative interview data, semi-structured interviews, observation of nonverbal communication and note-taking have been drawn on to answer the following research question:

What stories do participants share and construct based on the experience of being a woman, Muslim and disabled in the UK?

Each narrative is unique in its power to illustrate the experience of a particular disabled Muslim woman in her specific social context. This chapter discusses how these narratives offer a response to the following objectives of the study:

1. To explore the experiences of daily life from the viewpoint of disabled Muslim women and how they perceive themselves when they are living with multiple identities of being a woman, Muslim and disabled in the UK.
2. To explore how the social and cultural contexts influence participants' identity, choices, decisions and actions.
3. To foreground what strategies those women developed to make sense, cope and adapt as disabled Muslim women in everyday life.

In recounting their narratives, participants in this study covered substantial ground to show that disability “*is a cultural interpretation of human variation rather than an inherent inferiority, a pathology to cure, or an undesirable trait to eliminate*” (Garland-Thomson 2005, p. 1557). In other words, they seek to demonstrate that disability is the result of “*interactions between [their] bodies and their social and material environments*” (Garland-Thomson 2005, p. 1557), and “*that nondisabled body develops as it interacts with the world built to accommodate it*” (Garland-Thomson 2015, p. 301).

These women highlighted issues related to gender, race and religious identity. They also described how additional identities, such as being a mother of disabled children, queer, HIV-positive, niqab wearer, or older woman, can further complicate those experiences. Much of the oppression and distress that they experienced were socially determined, both through direct discrimination and prejudicial attitudes, and indirectly through numerous instances of stigma and fear of others' unpredictable reactions to their identities. Nevertheless, these

women did not present themselves as victims. Instead, each one portrayed herself as a source of “*help*” (Samia), “*fighter*” (Nadia), “*activist*” (Kinza), “*successful*” (Farah) and “*friendly*” (Zara) woman who resisted and overcame daily social challenges to recreate a better world for herself, other disabled Muslim women, and the next generation of disabled people.

This chapter begins by unpacking two major themes emerging from the participants’ narratives: (1) modes of everyday disablism, and (2) activism and aspiration for social change. These themes were not exclusive, they overlapped in various ways due to *the “messy and embodied”* nature of intersectionality involved (Ahmed 2017, p.119). Yet, they were among the many other experiences and practices that the participants enacted to construct stories in which their actions could be understood as meaningful contributions to unfolding plots. Each participant arranged her actions in a sequence of events, in that sequence, she described how she constructed a version of herself, how she interacted with the social world in which she lived, and the moral of her story.

The first theme focuses on the complex ways in which the participants experienced intersecting modes of oppression and stigma in everyday life and the strategies they used to cope in the face of a challenging present and uncertain future. The second theme focuses on their personal efforts, attempts and desires for social change and the way those women developed creative ways to redefine, reconstruct, or celebrate their unique identity, as disabled Muslim women, who otherwise would be invisible or perceived negatively in their social world. It draws on various bodies of literature including but not limited to critical disability studies, antiracist feminism, and Islamic feminism in an attempt to make Muslim women’s “*absent voice*” heard (Mahmood 2005, p.6), and to explore their “*misrepresented experiences*” (Garland-Thomson 2005, p.1557) whilst living with a disability in the UK.

10.2 Modes of everyday disablism

Goodley (2014, p. xi) described disablism as “*the oppressive practices of contemporary society that threaten to exclude, eradicate and neutralise those individuals, bodies, minds and community practices that fail to fit the capitalist imperative*”. In a similar vein, Goodley (2014, p.xi) defined disability “*as an identity position, often a negative, marked and stigmatised social position*”. These are powerful definitions that reflect the experience of the disabled Muslim women since they have multiple negative and stigmatised social identities which contribute to their oppression in everyday life. Firstly, they are women who are oppressed and discriminated against in male dominated societies (Gimenez 2005; Shastri 2014). Secondly, they are Muslim women who are viewed as victims of religious and cultural

oppression and who face prejudice in the post 9-11 era, in particular due to wearing of the hijab (Barazangi 2008; Rahmath et al. 2016; Vintges 2012). Thirdly, they are women of colour who are facing violence as a product of intersecting patterns of sexism and racism (Crenshaw 1991). Fourthly, they are disabled in an able-bodied world, in which they “*are engaged in an asymmetrical power relationship with their temporarily able-bodied counterparts*” (Gerschick 2000, p. 1264).

Therefore, there is every possibility that women in this study would have to navigate the convergence of misogyny, racism, Islamophobia and ableism in isolation or simultaneously on any given day, which Collins (2014) described as intersecting oppressions. Whilst ‘oppression’, in a discursive sense, was not mentioned by the participants, it was heavily implied in their narratives through various modes of disablism which they described during their interviews. According to Thomas (1999), disablism can involve both external dimensions, such as physical or social barriers encountered, and internal dimensions, such as the negative effect that the experience of the physical or social barriers may have on an individual’s well-being. In this connection, the findings of this study demonstrate that the major problems of the participants were not physical but social.

Amongst all the narratives, only one participant reported on the physical barriers related to access and built environment in the UK, this problem occurred during her temporary stay at the refugee centre while she was seeking asylum to reside in the UK. On the contrary, however, all participants described various social barriers they experienced in striving for independent living, these were manifested in the discriminatory attitudes and behaviours of several health and social care professionals. They also experienced bullying, staring, and intrusive and violent behaviour from non-disabled people in public places. Similar physical and social barriers were highlighted by Dossa (2009) in the lives of immigrant Muslim women who shared their stories of disability whilst living in Canada.

These social barriers, it is argued, have a negative impact on the participants’ psycho-emotional well-being when they were denied equal access to health and social care services, or fell short of being socially accepted for participation in community life. In addition to focusing on environmental barriers, we should also adopt Morris’s (1993, p. 13) suggestion that we need to take more “*control of, the representation of the personal experience of disability – including the negative parts to the experience*” because “*in our attempts to challenge the medical and the ‘personal tragedy’ models of disability, we have sometimes tended to deny the personal experience of disability*”, which could be associated with other markers of difference such as gender, race and religious identity.

According to Goodley (2014, p.ix), there is an assumption, predominantly within disability studies “*at least in Britain*”, that race, gender, sexuality, class “*intersect with dis/ability in many complex ways but, too often, they are sidelined in pursuit of trying to understand the master signifier of disability*”. For that reason, this thesis explores the way these social markers of difference matter as much as the individual’s impairment and they cannot be dismissed under the category of disability. As such, despite some apparent differences in the experiences of the participants in this study, one common similarity between them was the stigma of their multiple embodied identities.

Mirroring Bowleg’s (2008) study with Black lesbian women, participants in this study stated that they did not know which aspect of their multiple identities is related to the way they have been treated. They talked of living within a society blighted by sexism, racism, disablism and Islamophobia. In the same way that Ahmed (2017, p. 230) discussed how we need intersectionality to know how power works and how we come into existence as a result of our interactions with the world around us and through our bodies:

“I am not a lesbian one moment and a person of colour the next and a feminist at another. I am all of these at every moment. And lesbian feminism of colour brings this all into existence, writing of all existence, with insistence, with persistence”.

To understand the participants’ experience of stigma, I draw on Turan et al.’s (2019) concept of intersectional stigma which characterises the convergence of multiple stigmatised identities and their effects. According to Turan et al. (2019), the experience of intersectional stigma depends on the stigmatised identity presented and the characteristics associated with that identity, that are perceived but not necessarily present. For example, Crandall (1991) reported that an emergency room surgeon would practice more social distancing by maintaining greater than usual physical distance from a person with AIDS/HIV who is a homosexual man or an IV drug user. Similarly, participants in this study recounted numerous instances of stigma whilst using public transport, whilst in the clinic, or out shopping. They believed that the manifestations of their experienced stigma were often framed through the negative stereotypes associated with their multiple identities.

For example, participants reported that disability identity is stereotyped as a “*curse or a taboo*”, a Muslim woman as someone who “*don’t talk*”, Asian as “*needy*”, and visually impaired person as someone who is expected “*not to be able to do anything*”. The stigma and discrimination which they confront is fed by collective hostilities. These are based on societal perception of disability as a deviance of human traits and a cultural misconception of Muslim women as symbols of religious fundamentalism, foreigners, outsiders and threat (Chapman 2016; Hussain 2005; Ryan 2011). Thus, by confronting the multiple stigmas of

their identities and the associated stereotypes, it is argued that disabled Muslim women experience a matrix of intersectional stigma which significantly influences their lives beyond or in addition to the bodily experience of the impairment itself.

Within the narratives, I explored the way that participants adopted coping strategies to confront or minimise the effect of the intersectional stigma. Firstly, some participants reported concealing, not disclosing their impairment or avoiding any sign that would manifest it (e.g. using a white cane). The purpose being to prevent the stigma associated with it or to prevent adding additional markers of difference to their stigmatised identities. These findings parallel Lekas et al.'s (2011) research, they found that women with HIV and hepatitis C virus infection reported concealing their hepatitis status to decrease encountered stigma, but for the participants in this study, the concealment strategy was not trouble-free. Those participants reported how, on top of their impairment and its effects, they had to live in a stressful situation and to perform painful physical activities in their attempt to avoid such stigma, much in the same sense discussed by Block (2020) regarding the precarity of spirit when a person's body-mind is under extreme stress due to a hostile living environment.

Participants reported feeling additional stress and the unnecessary physical effort required to perform tasks, in the same way that non-disabled people could, exacerbated the effect of their impairment. This was both physical, such as experiencing pain, fatigue, injury and fall, and psychologically, such as being bullied for asking for help or being discriminated against for their race and religion. Therefore, I argue that no matter how much effort disabled Muslim women make to reduce the encountered stigma, they will find it hard to fully fit into (a disablist) mainstream society. Even if they concealed their impairment, they would still be stigmatised for performing things in non-typical ways as non-disabled people do (Soorenia and Olsen 2021; Taub et al. 2003). In addition, they would also be stigmatised for their race or religious identity, both of which are relatively difficult to conceal from others due to the visibility of their non-white skin colour (Song 2020), and the practice of their Islamic dress, namely the hijab (Al Wazni 2015).

Secondly, finding solidarity and developing a sense of belonging was another coping strategy that some participants recounted in their narratives. They formulated friendships with other disabled Muslim women on social media platforms or communicated with Muslim women who were mothers of disabled children. This strategy reflects the lives of women raising children with Down's syndrome in Jordan, together they "*came to envision new possibilities, but also to appreciate the constraints that shaped their individual circumstances and those of their children*" by forming communities online through Facebook, YouTube, and other social platforms (Sargent 2020, p. 17). However, there was no evidence to suggest

that participants in this study formed meaningful relationships based upon mutual respect and support within their community in general. Instead, they reported instances of being denied opportunities to interact with others in their community, this was due to stigmatisation that excluded them and set them aside as less important due to their multiple identities, a situation which Oni-Eseleh (2021) described as social rejection.

The elements of social rejection that participants experienced included negative labelling, stereotyping based on cultural beliefs and attitudes and denial of access to equal opportunities within their communities. Knowles et al. (2014) found in their study that social rejection motivated people to distance themselves from the sources of rejection and brought them closer to those who accepted them. In the same way, some participants reported social separation from the Muslim community which formed a significant part of their identity. They described avoiding going to the mosque, they prayed at home instead despite the fact that they “*would love to go*”. This was due to their fear of Muslim women’s unpredictable reactions to their disability status, a significant issue that Islamic feminism studies should be looking at more carefully.

Adopting these coping efforts brings to the fore the idea that the goals of the stigmatisers are achieved but that they are hidden by the coping strategies of these participants, Link and Phelan (2014) term this stigma power. The essence of the stigma power concept is that stigmatisers have a strong interest or motivation “*to keep people down, in and/or away*” (Link and Phelan 2014, p. 30). Their motivation to stigmatise ranges between three generic ends: (1) keeping people down or domination, where one group dominates another (e.g. racial stigmatisation), (2) keeping people in or enforcement of social norms, when people construct written and unwritten rules regulating everything people do (e.g. constructed roles of what should women dress), and (3) keeping people away or avoidance of diseases in favour of a healthy appearance (Link and Phelan 2014). All the participants in this study acknowledged that their identity as a disabled Muslim (Black or Asian) woman could easily combine all the motivations at one time.

During face-to-face interaction, some participants described a third strategy in which they tried to dismantle ableist myths and show their ability to ‘get by’ with strangers in a disablist world. Such as performing “*a two-person job*”, or getting in a taxi or getting on the train alone despite the physical difficulties associated with their impairments (e.g. pain and fatigue) or their use of assistive devices (e.g. white cane or crutches). However, they commented that their efforts to ‘get by’ were not appreciated. Instead, they felt they were being judged on their appearance, race and religious identity. They reported adopting silence as an alternative strategy when their getting by strategy did not succeed. According to Edley

(2000) and Ellingson (2017), silence can be a form of resistance and agency as well as oppression. As a result, the participants in this study were, to varying degrees, caught in a constant oscillation between instances of stigma and oppression and between exercising power to control their lives as autonomous individuals and being objects over whom power is exercised. In other words, they were active and passive agents in their own lives.

10.3 Activism and aspiration for social change

The disabled Muslim women who participated in this study did so because they believed that by making their voices heard, they were doing something which could improve the lives of disabled Muslim women and in general, disabled people with similarly complex needs. Their activism work, defined in their own terms, was carried out in the midst of their struggles to create a space where they could have a sense of belonging as Muslim women and where their humanity was recognised. They were aware that they were not always heard when they spoke, but their words were an attempt to advance the cause of a just society, which might bring about progressive social change. Therefore, they were keen to ensure that their efforts did not remain within the discrete spaces of their communities.

However, while the issues of disability, gender and race are considered in feminist and disability studies, the subject of how they intersect with religion remains unaddressed (Dossa 2009; Samuels and Ross-Sheriff 2008). The participants in this study did not refer to gender, race, religion and disability in exclusive terms. Instead, they interwove these markers of difference in their lived realities with varying emphasis. A prominent example is manifested in Kinza's narrative. As an activist, Kinza described working towards the equality of Black women, LGBT and disabled people. Her efforts were informed through experiencing a lack of "*freedom of speech*" in Nigeria, this was due to hostility related to her disability and by the need to claim her rights as a human being.

Kinza perceived her rights as interwoven with those of her peers, regardless of their gender, race and disability. In other words, Kinza's narrative shows that an exclusive advocate for gender, race, or disability may lead to casting one's identities into a discrete sphere, where one is seen as an activist for one oppressed group only. Not wanting to remain within the confines of one discrete category, Kinza positioned herself as a Black, LGBT, and disabled people activist as well as feminist. Kinza's advocate for multiple stigmatised groups at one point indicates that activism movements, as well as studies of disability and feminism, should not be informed by one category but rather by considering intersecting categories of one's identities. In unpacking participant accounts, two areas of significance were identified with

regard to their activism work and aspirations for change: (1) improving healthcare services for minority groups, and (2) constructing diversity in social media images.

10.3.1 Improving healthcare services for minority groups

Nadia reflected upon her multiple roles and responsibilities under challenging conditions of discrimination and her sense of losing power within the health and social care context. She described how her race and religion intersected in a way that denied her the medical support she deserved as a disabled person and the social support she was entitled to as the mother of disabled children, affecting the quality of care she received. She shared her story to call for improvements in the health and social care system, particularly for disadvantaged people. In the light of her story, I argue to adopt Bauer (2014) and Blackie et al.'s (2019) suggestion to incorporate the intersectionality theory and narrative intersectionality approach in health research, medical education and care. In other words, assessment and intervention practices in healthcare should consider the complex challenges faced by people living at the intersection of multiple identities in their everyday lives, in their local contexts. This is not to suggest the pursuit of a longitudinal narrative from each patient, rather it implies a genuine and open discussion, developed over time, with people who have different identities, experiences and values to those of the healthcare professionals.

People have socially recognized races, they have gender, they have cultures, languages and religious traditions. They also have social roles to play, and these factors interact in dynamic, interconnected, and influential ways to shape their experiences with disability. Learning about these factors requires gathering information about the person in the clinical setting such as: what is your ethnicity/religion? Where do you live? With whom? What do you do? How are you managing your mental and physical health? It also requires listening carefully to what patients say, to encourage connection rather than hostility to those people's identities. This discussion can then help to create a big picture which addresses the whole person, including their physical, mental, and emotional health, whilst also taking into account the social factors.

The aim is to educate future healthcare professionals and caregivers to look beyond the pathology of the disease, towards counteracting a system that, as Linton (1998, p.80) puts it, "*perpetually casts people with disabilities in the role of patient*". Particularly, where "*institutional discrimination against disabled people is prevalent throughout British society*" (Barnes 1994, p.203), and when the "*UK adults belonging to ethnic minority groups who perceive racial discrimination experience poorer mental and physical health than those who do not*" belong to any minority group (Hackett et al. 2020, p. 1652). Also, to encourage them

to think holistically about how living with multiple stigmatised identities affects the lives of individuals and their health outcomes (Turan et al. 2019). This effect is mainly in social contexts where the interrelated system of power, processes of oppression, social position, institutional practice and discrimination are at play in determining access to health and social care.

Research has shown that healthcare students initially adhere to the medical model of disability, this views disability as something that must be fixed or cured in order for the disabled person to better fit into society and live a full life (Cuff et al. 2016; Hirschmann 2012). I would argue that focusing on the body, as a disabled body needing a cure, can undermine the social issues that disabled people experience. On the other hand, the social model of disability puts the onus of change on society, saying that inability to participate fully in social interaction is intrinsic to the society that is structurally, attitudinally and systemically inaccessible (Cuff et al. 2016). Yet, focusing exclusively on the social barriers in society obliterates the body from view, it overlooks the pain and suffering caused by the physical impairment that cannot be addressed through accessible society (Hirschmann 2012).

As Shakespeare and Watson (2001) argued, the distinction between impairment and disability can be demonstrated by understanding where impairment ends and disability starts. While impairment is often a cause of disability, disability may itself produce or exacerbate impairment (Shakespeare and Watson 2001). Therefore, incorporating the narrative intersectionality approach can develop a mutually beneficial integration of the two models, it creates a critical framework for discussing the medical and social factors that shape the individual experience of disability represented in each patient's account. It can also transform education and practice for social change.

In other words, people enter the healthcare context with a story about a particular complaint and how it affects their life. Through critical engagement with their narratives, healthcare professionals can better understand the perspectives of disabled people and balance the power in the clinic (Garden 2010). By accepting the authority of disabled people to explain what might work best for them in terms of communication, the physical examination, and the treatment plan, healthcare professionals can begin to bridge the boundary between the medical model and the social model of disability. They can start to view disabled people as whole beings: to recognise that not all disabled people experience the same multiple identities in the same ways; many encounter multiple forms of oppression, but not all are rendered powerless (Samuels and Ross-Sheriff 2008). As a result, healthcare professionals can become care partners rather than merely providers of care.

It is important to note that the narrative intersectionality approach rests heavily on the rights-based approach to disability, which is rooted in the principles of the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations 2006). The UNCRPD and its optional protocol is one of the most recent core UN international human rights conventions, which was agreed in 2006 and entered into force in 2008 (Kakoullis 2018; McCall-Smith 2020). Since the UNCRPD entered into force and became obligatory, 93% of the UN member states have joined the treaty and became 'States Parties', and thus, are obliged to implement the Convention (McCall-Smith 2020). The international framework offered by the UNCRPD consists of 50 articles, these aim "*to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity*" (United Nations 2006, p.4). As such, the UNCRPD emphasises a holistic understanding of how all disabled people should be empowered to activate their existing human rights and enjoy full and effective participation in society on an equal basis with others (McCall-Smith 2020; Nankervis and Chan 2021; United Nations 2006).

In Article 25, which concerns health, the convention calls States Parties to recognise that disabled people have the right to enjoy the same range, quality and high standards of health care and programmes as those provided to other non-disabled persons, without discrimination on the basis of disability. Meantime, the convention reinforces the recognition of the diversity of disabled people who are subject to multiple forms of discrimination based on their race, gender, religion or other status, also recognising that disabled women are often at greater risk of violence, injury, neglect or mistreatment, both within and outside the home (United Nations 2006).

Despite the fact that the UK ratified the UNCRPD in 2009 (Kakoullis 2018; McCall-Smith 2020), some disabled women who belong to minority groups due to their race or religion identity, such as Nadia, continue to experience barriers in accessing health and social care and human rights issues, including stigma and discrimination. Therefore, the narrative intersectionality approach is not about introducing something new, it is about implementing and building upon what is already in place, namely the UNCRPD. One of the key elements to implement the UNCRPD is training for healthcare professionals on the principles and values underpinning the UNCRPD human rights framework. Also, to monitor the impact of any rights based law or policy on the lives of disabled people, so that the effective implementation of the UNCRPD can be achieved (Kakoullis 2018; Lawson 2005).

However, my recommendation to incorporate the narrative intersectionality approach in health research, medical education and care does not suggest that narrative and

intersectionality theory is not considered in these fields. Several scholars have discussed the integration of narrative (Banerjee et al. 2020; Garden 2010; Holstein et al. 2016), intersectionality theory and intersectional framework (Bauer 2014; Fraser and MacDougall 2017; Nichols and Stahl 2019; Powell Sears 2012; Sepúlveda and Lizama-Loyola 2022; Monrouxe 2015; Veenstra 2011; Windsong 2016), in varied healthcare, health research design, medical education and higher education contexts to address how discrimination, stigmatisation and lack of accommodation is experienced across different groups of people.

My argument is that the focus of such research, when addressing intersectional categories, is mainly the intersection of gender/sex, race/ethnicity, class, age, disability and, sometimes, migrant status, but the religious identity is often neglected. Consequently, when I say 'narrative intersectionality', I mean rather than merely examining the effect of common categories, such as gender, race and disability, that we should focus on listening to those with neglected social identity, such as religious identity and understanding the set of unequal social relations and stereotypes that are associated with the traditions of such an identity. Hence, to examine the way that particular identities, which were socially constructed, have been neglected over time and attempt to reveal the inherent power inequalities that lie behind them.

For example, we can consider how a narrative intersectionality approach could have improved the quality of care that Zara received at the HIV clinic. For the healthcare providers, Zara is a niqab-wearing "*woman who doesn't come to the appointment*". For Zara, niqab is not simply a piece of cloth to cover her face, Zara believed that her niqab was related to her religious duties. She described feeling shame, embarrassment, stigma, hating to go to the HIV clinic and missing the medicine that she described would save her life. If healthcare providers had engaged Zara in conversation they would have discovered that her problem related to her intersectional identities, as a niqab-wearing HIV positive woman, and the stigma associated with the neglected category of her identity when sitting in the waiting room. This understanding could have resulted in better individual care and ultimately diminished the disparities in the clinic.

10.3.2 Constructing diversity in social media images

In her narrative Farah reported posting her photos on social media, where she made it obvious that she was a Muslim woman by wearing her hijab and a disabled person through using a white cane. Likewise, Zara described practising acts of kindness, such as smiling through her niqab, and greeting and interacting with others in the community. Both aimed to promote a positive image and message of social inclusion for women of colour who are

disabled, Muslim, and wearing hijab or niqab. Those women did not want to change their bodies or themselves; they wanted to change the collective negative perceptions of disability and Muslim women as members of minority groups.

They wanted people to see these facets of perception as socially constructed barriers and not as inevitable or natural. Accordingly, they did not only resist defining themselves in terms of the stereotypes and preconceptions, observable in wider society, but insisted that another socially positive identity was appropriately descriptive of them. Farah, for example, was adamant that she was a “*successful*” woman whose true identity would be redefined on her completion of her training:

“Now I’m training to be a barrister and I’m trying to show people that, you know things like your disability shouldn’t hold you back, no matter if you’re a Muslim woman, no matter if you have a disability, no matter if you’re from a minority background”.

Farah’s account is a version of what Riessman (2000) refers to as resistant thinking to destigmatise oneself, this involves both “*instances of resistance and victory*” (Allen 1996, p. 268). Thus, while they resist oppressive perceptions of their stigmatised identities, they also emphasised their achievements, privileges, and the positive aspects of these identities. Zara, for example, commented on the opportunity that being a nurse at “*the NHS for 30 years*” allowed her to help many people and be “*proud of the things*” she contributed to the community.

By portraying their lives in this way, these women asserted their agency in the sense that their resistance operates across the individual and collective levels and is enacted through self-reflection coupled with action (Gabel and Peters 2004). Through these acts of resistance they celebrated a unique version of their selves, as disabled Muslim women, which they reconstructed from the perception produced by society about their identities as invisible, negative, passive, oppressive or without agency as has been described by Turmusani (2001), particularly through social media platforms (Saki and Yasmeen 2016; Vintges 2012; Zempi 2016). Disabled women and Muslim women are underrepresented in media, and even when they are included, they are often represented in stereotypical ways (Baglieri and Lalvani 2019; Kabir 2016). Thus, the photos that Farah shared via Instagram platform demonstrated her subjectivity as a disabled Muslim woman who wanted to share her positive experience of everyday life with others (Zappavigna 2016).

According to Garland-Thomson (2002), images of disabled women in media can be seen as feminist disability activism, they can shake up established assumptions about the normal and the abnormal, and have great potential for shaping public consciousness. These images

“do the cultural work of integrating a previously excluded group into the dominant order —for better or worse — much like the inclusion of women in the military” (Garland-Thomson 2002, p. 25). Garland-Thomson (2002), also added that images of disabled women would enable them to imagine themselves as part of an ordinary world, rather than a special class of excluded and invisible people. Therefore, rather than concealing or normalising, these photos highlight new social categories, write new stories, and recover traditional ones.

While several pieces of research have highlighted the positive role of social media in affirming ethnic minority or disability image (Carney 2016; McMillen and Alter 2017; Myers et al. 2019; Zhang and Haller 2013), to date, images in social media represent only one or two disadvantaged identities, such as race and disability. Religious identity, such as Muslim women, is still represented in isolation with a mere focus on hijab as a mark of difference. I subsequently argue that diversity in images, including a combination of disability, ethnic minority, and religious identity, is required. However, some caution must be urged here.

Representation does not equate to tolerance and equality. In this study, Kinza recognised that she felt needed and wanted, and crucially that she had a voice as a disabled person, when appointed to positions in the University. These roles were transformative for Kinza, changing how she saw and felt about herself. However, the work of scholars like Sara Ahmed (2012) tempers such claims by recognising how EDI (Equality, Diversity and Inclusion) policies at University, and broader attempts to solicit the views and ideas of people of colour, has a dark side. Promoting a *“very diverse student body”* can be problematic, in ways, because *“if students come from diverse countries, then they can be apprehended and thus treated as a diverse body”* (Ahmed 2012, p. 58).

Ahmed’s work, then, recognises the potential for exploitation and appropriation. Consultation, according to Ahmed (2012), is often thought of as a technology of inclusion. It involves those who consult, and those who are consulted irrespective whether their views are actually included or not. When a higher education institution, such as Kinza’s university, consults students, it does not necessarily mean that it uses feedback to change what they are doing. Rather, Ahmed (2012, p.94) argues, universities can consult and involve *“the others”* for positive optics around inclusion and promoting equality, without necessarily engaging with the feedback they had received or making structural changes to address inequalities.

Indeed, the introduction of the Race Relations Act 2000 for the first time placed positive duties on public bodies, including higher education institutions in the UK, to eliminate racial discrimination and promote racial equality (Tate and Bagguley 2019). To meet these statutory

responsibilities, universities had established a formal race equality policy applicable to all staff and students, and approved a comprehensive implementation plan to meet the objectives of the policies. Appointing someone, such as Kinza, could be part of fulfilment of the equality duty when diversity became ticking the boxes. Ahmed (2012) argues, however, that the tick box and good practice can be seen as operating in the same zone rather than different zones, both enabled an organisation to *look good*. Given that Kinza “*was the only Black lady there*”, it was transparent that how the group was constituted — with other White and Asian ladies — replicated some of the problems they were trying to address (Ahmed 2012). Despite positive images and representations being ‘*easily recognizable as images of diversity*’ (Ahmed 2012, p. 52), I agree with the argument that:

“Diversity is like a big shiny red apple ... and it all looks wonderful, but if you actually cut into that apple there’s a rotten core in there and you know that it’s actually all rotting away and it’s not actually being addressed. It all looks wonderful, but the inequalities aren’t being addressed” (Ahmed (2012, p. 71, 72).

Therefore, while these representations and positions (like Kinza’s) might have some benefits by influencing others and engaging them to change their cultural perceptions about disabled Muslim women slightly, I argue that it does not address the reality of inequality which these women experience. Future research could explore this further.

10.4 Implications for the development of research methodologies

From a methodological perspective, this thesis illustrates the importance of using narrative intersectionality as an analytical approach with which to explore the experience of people living with multiple identities. This section reflects on the development of this research methodology and describes its usefulness in research on intersectionality. Whilst this study was being designed, I became aware of the need to craft a methodology that would capture the lived experience of the participants and be sensitive to their intersectional identities. My initial reason for using narrative interviews to collect data, was to allow the participants to project their stories in the way they wanted and also to explore how their identities were co/constructed in different social contexts. The challenge came when I started to analyse the data, as there is neither a single method for narrative analysis nor the analysis of the intersectional identities (Nasheeda et al. 2019; Turan et al. 2019).

At the beginning of the analysis process, I used thematic analysis. It then became clear that participants’ experiences and identities were essentially intersected, thus it became necessary to use a data analysis method that would be sensitive to this and would appreciate and respect this intersectionality in each narrative. In other words, I

acknowledged that grouping participants' experiences into a number of selected themes would enforce a system of categorisation which would ignore significant elements of such a person's complex life experiences and life worlds (Blackie et al. 2019). Therefore, I decided to develop a narrative intersectionality approach drawing from Blackie et al. (2019) and Chadwick's (2017) concept of narrative intersectionality. This approach allowed me to combine the entanglements produced by narrative inquiry with the intersectional experience of multiple identities that happened within a particular context. There were several practical reasons and steps which discussed in detail how I developed and used this approach to analyse the data collected for this study (see section 3.4.3 and 3.4.4). The next section discusses the methodological implications of using narrative intersectionality as an analytical approach.

10.4.1 Narrative intersectionality as an analytical approach

Narrative intersectionality acknowledges that more is going on in a person's life than any single category of identity can explain alone (Blackie et al. 2019). With such acknowledgement, McCall (2005, p.1781) argues that within the individual narrative, "*complexity drives from the analysis of a social location at the intersection of single dimensions of multiple categories, rather than at the intersection of the full range of dimensions of a full range of categories*". Accordingly, McCall emphasised that analysis of intersectionality requires the use of modelling, such as the contextual model, this can introduce more complexity in the interpretation of the categories than the additive linear model that sums all the categories. In other words, analysing the categories of identity per social context asks not simply about the experience of the intersection of gender, race and religion with a disability but how that experience can differ for the same person as social contexts change.

This research provides a concrete example of how the methodology of narrative intersectionality demonstrates that disabled Muslim women's experience of their multiple identities is not fixed, but dynamic and contextual. By adding the contextual component, I examined each participant's experience of her identities throughout her life and then synthesised this information into a configuration of narrative, a set of intersectional experiences across various social contexts. The main findings to note are that patterns of gender, racial, religious and disability identity are not the same across the social contexts. For example, Zara described her experience of feeling socially included in the local shop, excluded at the HIV clinic and vulnerable on public transport.

McCall (2005) argues that the complexity of the experience of intersectionality is not related to the subject but derives from different contexts that reveal different configurations of mistreatment, hostility and inequality to that person's identity. Using the narrative intersectionality approach, I concluded that no single context can adequately describe the disabled Muslim woman's whole experience of multiple, intersecting, and interweaving identities that converge uniquely in the story of a solitary life. To focus on one context is to oversimplify the complexities of the participant's overall experience. Using a narrative intersectionality approach enabled me to explore this complex and multi-faceted experience in different social contexts, this might have been difficult to capture through another data analysis method.

10.5 Limitations, challenges, and future research directions

This research has some limitations and methodological challenges that might influence suggestions for future research. Firstly, this research was designed specifically to explore the experiences of disabled Muslim women in the UK. I recognise that the number of participants is low. However, being a narrative study with a small number of participants, no attempts have been made to generalise findings beyond the original participants. My research was more concerned with presenting rich data and the data being considered trustworthy. Hence, rather than being a limitation or a weakness of the design, the small number of participants was one of the strengths of this study for a number of reasons.

Concentrating on a small number of women, I was able to collect in-depth data about each woman's experiences over a relatively long period of time during the 18-month period of my recruitment process. I was also able to accommodate the wishes, needs and preferences of each participant as to the frequency and timing of our meetings. In other words, I interviewed each participant on three occasions, each interview lasted between 45-90 minutes, which in total resulted in 15 in-depth interviews. Boddy (2016), suggests that the multiple of 12 in-depth interviews may be appropriate for qualitative research because as Guest et al. (2006) found, data saturation occurred within the first twelve interviews, although basic themes were present as early as six interviews. For Guest et al. (2006), twelve interviews should be sufficient to understand perceptions and experiences among a group of relatively homogeneous individuals.

Yet, the second and third interviews, which were conducted during the COVID-19 lockdown, were not always straightforward or completed as planned similar to the first interview. For example, with some participants, the second or third interview was completed over two to three meetings due to participants' family commitments. Sometimes we had to resume the

interrupted interview on the same day but at midnight after their children or family members had gone to bed. At other times we had to reschedule it for another day and time. The small number of participants enabled me to return to the participants several times and accommodate their needs and preferences, particularly during the COVID-19 lockdown when everyone, including the participants of this study, was trying to adjust to a massive change in their daily lives.

The small sample assisted me with building a relationship of trust with the participants, through maintaining engagement over several months. This in turn offered me the opportunity to seek additional information about their experiences, using multiple sources of data collection in the form of email, text messages, WhatsApp or Instagram messenger. In addition, although my sample size was small (5 participants), the participants had a diverse range of characteristics. It was comprised of disabled Muslim women whom I recruited from a range of locations in the UK. The sample included participants in their 20s, 30s, 40s, 50s, and 60s, single, married and widowed, heterosexual and homosexual, working women, housewife and retired, from different social backgrounds and ethnic groups and those bereaved due to different types of suicide attempts and traumatic incidence.

My focus in sampling was more on the richness of information that would sufficiently answer my research question and less on sample size, as has been suggested by O'Reilly and Parker (2012). Thus, I would consider this study to be the beginning of a body of work which focuses on the wider population of disabled Muslim women. The primary consideration was to obtain their experiences within the clinical and social settings in the UK. Further longitudinal research would be useful to identify changes in perceptions and experiences of a large sample, over a more extended period, when attempting to generalise the findings to disabled Muslim women across the whole of the UK.

Secondly, this study missed the opportunity to explore the experiences of isolated, hard to reach, highly vulnerable and reluctant to speak women, this could also be a limitation. As mentioned earlier, the recruitment process lasted for 18 months, during which time I tried to reach participants from across the whole of the UK. Only 14 potential participants expressed their interest in participating, and just 6 actually participated in the study. Afterwards, one woman withdrew from the study. This woman lived in a different part of the country. I interviewed her in a disability mobility shop as she did not want to reveal her home address. After one year of participation, she contacted me to express her decision to withdraw from the study due to privacy concerns. I reminded her that participation was entirely voluntary and that her story would not be included in the study.

Another potential participant withdrew before taking part in the study, this occurred on the day we agreed to meet at her home. Before discussing her concern with me, she contacted the School of Healthcare Sciences Director of Research Governance, fearing I would use her personal information to abuse her later. As Boulanouar et al. (2017) report, some Muslim women are conservative and notoriously hard to gain access to. I appear to have failed to reach and engage the interest of these women, and I acknowledge that the absence of their stories is a significant limitation. Further research could explore better ways to reach and access such participants.

Lastly, it is worth reiterating that my findings are socio-culturally-bound, the lived experiences of disabled Muslim women in Britain are likely to be very different to those of disabled Muslim women in other parts of the world. Certainly, they are likely to be very different to the experiences of women in countries with different cultural, legal, and social prescriptions regarding disability. However, understanding disabled Muslim women's experiences is long overdue; it is time for their stories to be heard in different parts of the world, and I intend this thesis to be one of the first contributions to this endeavour.

10.6 Reflexivity within this study

The variety of definitions of reflexivity suggests that there is no consensus concerning the meaning of reflexivity, its purpose, or how and when it can be employed in research studies (Darawsheh 2014). Darawsheh (2014) and Finlay (1998) argued that reflexivity is a key element of every research project (qualitative or quantitative) which can be used both as a tool to guide the research process and to limit the bias of the researcher and their subjectivity. Reflexivity, in general, refers to the examination of one's own beliefs, judgement, practices and position during the research process and how these may have influenced the researcher, the research participants and readers of research outputs (Holmes 2020). Reflexivity informs, develops and shapes positionality. Positionality refers to the ways in which the social-historical-political location of a researcher influences their orientations and the social process they study (Holmes 2020). In other words, if positionality refers to how we are situated in social space implying what we know and believe (Selka 2022), then reflexivity is about what we do with this knowledge within these spaces.

Reflexivity is essential throughout all phases of the research process, which Guillemin and Gillam (2004, p. 274) called a "*reflexive process*", including the formulation of research questions, data collection, data analysis, and drawing conclusions (Berger 2013). For example, the topic of my study was originally about the body image perceptions of the British disabled Muslim women, with a research question querying how they perceive their body

image when living with multiple identities of being a woman, Muslim and disabled. When I started interviewing my participants, however, I found that body image was not important to them as much as their value as a recognised member of the British society. Consequently, I shifted the focus of my study from exploring the participants' body image to understanding their lived experience. As Farah stated:

“I think my value as a person is more important than my body image because self-image you grow as a person, your ideas change, your thoughts change when you meet people. Whereas the body image is your appearance and yes that changes when you're [getting] older but it's quite subjective you know, like just all it does is you are going to grow old, but let's say you could be old and you're the most honest person ever or the most boring person ever that's down to your personality, so I think your personality is more adaptable, whereas you can't change the way you look but you could change the way you think”.

During data collection, being self-reflective helped me to re-evaluate questions and contents that I had tended to emphasise or shy away from, and to become aware of my own thoughts, emotions and reactions to participants, and their triggers (Berger 2013). In other words, I attempted to attain an insider perspective from the participant's narrative whilst stepping back to obtain an outsider view through “*a mindset that is critical, but from within*” (Tomkins and Eatough 2010, p. 177). Holmes (2020, p.6) described the insider as “*someone whose personal biography (gender, race, skin-color, class, sexual orientation and so on) gives them a 'lived familiarity' with and a priori knowledge of the group being researched*”. At the same time, the outsider is a person/researcher who does not have any previous intimate knowledge of the group being researched. Holmes (2020) emphasised that there are several advantages and disadvantages to each position. While the insider perspective probes the ability of the outsider researcher to understand the experiences of those inside the culture, the outsider perspective probes the ability of the insider researcher to detach themselves from this culture to avoid studying them with bias (Kusow 2003).

I came to the UK from Saudi Arabia in 2009 and started my degree in Occupational Therapy. At that time I met some unkind and unfriendly students at university. I was coping with the hardship of living in a culture and language which were not my own, and coming to terms with my dual identity as a disabled Muslim, I was not identified in this way in my home country. So, I undertook this present study as a disabled Muslim woman interviewing disabled Muslim women. The similarities in our gender, religious and disabled identities created a sense of belonging, building a spontaneous relationship with the women I was interviewing.

Having some analogous lived experiences with the study participants positioned me in the role of the 'insider', and thus created distinct advantages which guaranteed quicker access into my participants' culture, jargon and lived world. Another advantage was demonstrated in the personal stories of the participants and their acceptance. I had knowledge of their social world as indicated through unfinished sentences, shared laughter, use of Islamic terminology (e.g. Allah, Alhamdulillah), or discourse markers such as 'you know' (Laserna et al. 2014).

The women to whom I reached out, shared their lived experiences with me and were friendly and cooperative. They expressed confidence and trust that being a disabled Muslim woman myself, I would be able to understand and represent their experiences and struggles more effectively than a non-Muslim or non-disabled researcher would. In addition, they conveyed their desire to help a disabled Muslim 'sister' (i.e. myself) to achieve her goal. It also assisted in developing rapport and increasing participants' level of comfort, from the moment they heard the religious salutation for Muslims (As-salamu alaykum), one could hear the sigh of relief and feel the atmosphere relax as they considered me "*one of them*" (Davis 2020, p.40).

However, there are disadvantages of an insider position, depending on the specific circumstances of the research participant. This includes the difficulty to bring an external perspective to the conversation (Holmes 2020), especially when the participant reveals sensitive information that an insider researcher holds as cultural or religious belief. For instance, I discovered that one of my research participant (Kinza) was a queer woman. At that moment, Kinza spoke, quite painfully, about how difficult it was to handle certain emotions and how she had to cut off from Muslim community in Nigeria. Consequently, I needed to be sure that the information I received from the participants was not affected by my behaviour, thus influencing the direction of the study findings (Finlay 1998). For example, I realised that my participant had internalised the same message as myself about homosexuality in Islam when she explained the following to me:

"So you Amani, you are outside my door, and you are not doing anything to me, you might not say anything to me Amani, but because I'm a minority I think what is Amani thinking of me now, is she thinking of me as a lesbian, is she looking at me like oh why I'm a queer ... but you didn't say anything Amani".

I found myself being uncharacteristically challenged by her example, particularly because we had this conversation at her home. But I also saw that she would have been exposed to other ideologies, for instance how as a researcher I should be empathic, professional as well as in control of my feelings and behaviour. As a consequence, I realised that my negative reaction would probably reflect the Islamic society within which Kinza was struggling, and

continue to experience a significant degree of conflict (Siraj 2012). Having engaged in a reflexive practice, I followed Holmes (2020, p. 6) suggestion that “*a researcher may inhabit multiple positions ... at the same time*”, taking the role of insider and outsider, as a context-specific and researcher, with no clear-cut boundaries. I also followed the practice of “*bending back*” where an action is oriented according to the person who originated it as suggested by Tomkins and Eatough (2010, p. 175).

Throughout data analysis I attempted to bracket, or set aside, previous assumptions in order to attend genuinely and actively to the participants’ views and to reduce interpretation bias (Finlay 1998; Mercer 2007). At the same time, however, I needed to bear in mind that it was impossible to bracket my subjective responses completely. These responses can still influence the entire research process during the data collection, data analysis and conclusion. Maintaining a reflective diary, discussion with my supervisory team, engaging with other researchers in the school (Noble and Smith 2015), as well as a friend who is an outsider to the research (a native English Christian White woman), and presenting my findings at national and international conferences, were the techniques I employed to help me unravel the complexities of some preconceptions which arose within the interpretation phase.

Overall, by being reflexive, I became attentive to the interpretations and decision-making that emerged during the research process. I became attuned to my thoughts, beliefs, feelings and what was creating them. To me, reflexivity is a more fluid, dynamic and recurrent practice. I agree with Lumdsen (2018, p.4) who stated that reflexivity “*is not merely a quality of the researcher, but is a practice which must be honed, applied, and kept in mind throughout the research process*”. As such, it is not a guarantee of higher quality research, but a way of becoming a better qualitative researcher (Holmes 2020).

10.7 Thesis Conclusion

This research focused on five Muslim women’s everyday life and their struggles in the world in which they live, whilst living with a disability in the UK. Through their narratives I explored how disability is influenced by gender, race, and religion. I attempted to uncover the complex ways that disability intersects with other social identities to produce the multiple stigmatised images that haunt them. The outcome of the women’s narratives in this study is that there are important aspects of those experiences and coping strategies that cannot be recognised within what has been accepted as evidence and arguments used to validate the experience of disabled women or Muslim women in the UK.

Central to all their stories was a desire to maintain some sort of agency. The participants in this study were not exercising their agency fully, and even when they were actively involved in seeking justice for themselves or other disabled people or Muslim women, they feared that the convergence of their gender, race, religion, and disability identity were working against them. They shared their stories to show how they perceived and enacted their agency to resist or fight multiple forms of stigma and oppression in their everyday lives, working towards the construction of their unique identity, as disabled Muslim women in the UK, that otherwise would be invisible or perceived negatively in their social world.

In addressing the existing gaps in the literature, I argue that this thesis is located at the intersection of multiple bodies of knowledge situated in multiple disciplines including, but not limited to, critical disability studies, feminist studies, race studies as well as religion and disability studies. It is the first piece of research, as far as I am aware, which explores the lived experience of disabled Muslim women within the context of ongoing attempts to live with multiple stigmatised identities in the UK. My findings also suggest that the narrative intersectionality approach can be a useful analytical tool for research which explores the experience of individuals living with multiple identities and which calls attention to the complex socio-cultural impact on participants' experience within different social contexts.

As a final point, what is clear throughout this study is that there are complexities in the intersectionality between gender, race, religion and disability identity. While some policies exist in the UK, such as the UNCRPD, to address the intersected inequality of gender, race, religion, disability and other dimensions of difference, the results of this study show that disabled Muslim women are not benefitting optimally from these. These disabled women, therefore, need to be recognised as a group requiring specific consideration so that inequalities, disadvantages and discriminations on the basis of their multiple identities are addressed successfully. We need to hear the voices of disabled women who have lived and struggled through the social realities of their stories, and we as researchers need to emphasise the importance of speaking *with* them, not *for* them.

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APPENDICES

Appendix 1: The recruitment process

Recruitment source	Medium of contacting the source	Response	Medium of distributing the invitation letter	Medium that potential participants used to contact the researcher	Number of interested participants	Reason for not taking part	Number of participants in study
Disabled Organisations & networks							
The Sisters of Frida disabled women organisation (Online website)	Email	Yes	Emails to members	Email	1	N/A	1
The disabled Muslims network (Online website)	Email	No	N/A	N/A	N/A	N/A	N/A
Side by side disabled women's peer group (Online website)	Email	No	N/A	N/A	N/A	N/A	N/A
Ability for all 2018 Campaign	Instagram messenger	Yes	A post on the campaign's Instagram page	Email	2	Lack of interest	1
UCLDSN Disabled students network UCL	Instagram messenger	Yes	A post on network's Facebook & Instagram page	N/A	N/A	N/A	N/A
Disability & Feminism RG	Email	Yes	Emails to members	Email	1	N/A	1
Feminist Organisations & Groups							
The Fawcett society for gender equality and women's rights (Online website)	Email	No	N/A	N/A	N/A	N/A	N/A
Wonder foundation for empowering women through access to quality education (Online website)	Email	No	N/A	N/A	N/A	N/A	N/A
Amnesty International UK (Online website)	Email	Yes	They do not have the capacity to assist research students	N/A	N/A	N/A	N/A
London Feminist Network (Online website)	Email	No	N/A	N/A	N/A	N/A	N/A
FWSA Feminist and Women's Studies Association (Online website)	Filling a form on a FWSA page	No	N/A	N/A	N/A	N/A	N/A
Islamic Mosques & Centres							
Abu Bakr Islamic centre, Masjid Abu	Face-to-face with the	Yes	A copy was placed on the	None	0	N/A	0

Bakr, Oxford Road, Reading	mosque's Imam		mosque's note board				
Aisha Masjid & Islamic centre, London Road, Reading	Face-to-face with the mosque's Imam	Yes	A copy was placed on the mosque's note board	None	0	N/A	0
East London Mosque	Email	No	N/A	N/A	N/A	N/A	N/A
Muslim Women Networks							
Muslim women's network UK	Twitter messenger	No	N/A	N/A	N/A	N/A	N/A
Muslim women council	Twitter messenger	Yes	A post on Twitter and Facebook page	None	0	N/A	0
Women's Groups							
The Rose centre, Oxford Road community centre, Reading	Drop-in & Email	Yes	Emails to members / WhatsApp voice message	Whatsapp messenger	4	Relative's death and other unknown reason	2
Reading community learning centre for migration women	Drop-in & Email	No	N/A	N/A	N/A	N/A	N/A
Reading refugee support group	Drop-in & Email	No	N/A	N/A	N/A	N/A	N/A
Utulivu women's network	Drop-in & Email	No	N/A	N/A	N/A	N/A	N/A
Personal Contact & Snowball Sampling							
(Five) personal Instagram accounts of Muslim women who declare their disability on their page	Instagram messenger	Yes	Email	Instagram messenger/Email	2	Lack of interest	1
Referral by actual participants	Ask the participants after the interview	Yes	Participants' preference	Instagram messenger/Email/WhatsApp	4	1-Under the age of 18 3- Unwilling for face-to-face interview due to health/ trust concern	0
In the community (i.e. Mosque, neighbours and town centre)	Ask Muslim women	No	N/A	N/A	N/A	N/A	N/A
Number of interested participants: 14	Number of participants in the study: 6		Number of withdrawal participants: 1		Total number of participants in the study: 5		

Appendix 2: The interview process

The basic phases of the interview

Phases	Rules
1) Initiation	<ul style="list-style-type: none"> • Explain aim and context of the study • Explaining the interview process such as that the interview will last between 45-90 minutes, it will be audio-recorded and that the researcher would like to hear your story in your own words • Emphasising confidentiality and gaining signed consent • Start the tape recorder • Obtain participant's demographic information (age, ethnicity, type of disability, marital status, education, work situation)
2) Main narration	<ul style="list-style-type: none"> • Encourage participant to begin telling their stories by asking a broad general question of the topic (Can you tell me how do you see yourself as a disabled Muslim woman, when did it start and what has happened since then?) • Attentive listening and using non-verbal encouragement such as head nodding, smiles and showing interest by using (Hmm, yes, true, I see) • Elicit additional and new information by asking (Can you say a bit more about ..?) • Some of the following questions were asked if not covered in the main personal narrative including : <ol style="list-style-type: none"> 1. How do you think people seeing you? 2. How people in your life (family, husband, friends, strangers) affect your experience with a disability? 3. Have you been treated differently or received any advantages because you are a disabled Muslim woman? 4. What strategies you are using to cope with your identity as a disabled Muslim woman in everyday life?
3) Concluding talk	<ul style="list-style-type: none"> • Switch off the tape recorder • Discuss with participant (In your opinion what matters the most for you as a disabled Muslim woman in the UK, and why did you participate in this study?) • Ask if there is anything else the participant want to say • Thank participant and conclude the interview • Write the concluding talk and impressions in a notebook immediately after the interview

Appendix 3: Transcription convention

Laughter	Laugh
Loud/ Emphasis a short passage	CAPS
Transcriber's comment / non-verbal elements	[]
Material omitted	...

Appendix 4: Transcript example

Amani: What do you feel when you walk into a room with strangers?

Zara: I could say that I feel awkward, I never feel awkward in my life, yes because of the way I'm walking, it's like I'm walking down a hill and the way I'm walking is extremely slow, and people are staring at me and I don't know why they're staring at me, I don't know if they're staring at me because of that or because I'm Black, or because I'm Muslim, or because of my disability [laugh]

Amani: So what feeling do you have because of all these things?

Zara: [Sighs] I felt embarrassed now [silence 00:04], I feel embarrassed but I'm trying to move as much as I can even though the ones behind me are telling me to hurry up, it's just the way that I feel awkward and embarrassed

Amani: Are there anything you want to do but you're not feeling confident to do because of your current situation, because you're using crutches? Like going to the park? Is it affecting your daily activities?

Zara: Definitely, I can't do 90% of the thing I used to be able to do, now I can't do them, my husband even cook for me, I can't even do that, it's not only my disability physically, it's also the other conditions that I have when they say that some disabilities are not always visible.

Appendix 5: Physical audit trail



Supervision Meeting Record

Student Name	Amani Alnamnakani	Student Number	1243028		
Supervisor Name	Dr. Dikaios Sakellariou		<input checked="" type="checkbox"/>		
	Dr. Tina Gambling		<input checked="" type="checkbox"/>		
Date of Meeting	18/02/2020	Meeting Type	Skype	Meeting No	23

Matters Discussed:

- Analyze individual story separately, start coding process considering what is the main parts of the story? And what is important to know?
- Consider writing a section about “building trust” in the methodology to explain how hard it was to reach the participants
- Keep notes of how I kept in touch with the participants and use any data they may offered
- Consider the “Cumulative effect” of the disadvantaged in the analysis
- The possibility of conducting more than 2 interviews if required

Actions agreed:

- Carry out the 5th participant’s interview and transcription
- Continue data analysis as discussed above
- Complete the quality of the study section
- Email “Jane Davis” re: qualitative analysis training workshop

Next Meeting Date	09/03/2020	Time	11 am
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Appendix 6: Ethical approval

School of Healthcare Sciences
Head of School and Dean Professor David Whittaker

Ysgol Gwyddorau Gofal Iechyd
Pennaeth yr Ysgol a Deon Yr Athrawes David Whittaker



01 August 2019

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Amani Alhamnakani
Cardiff University
School of Healthcare Sciences

Dear Amani

Body Image Perception of British Disabled Muslim Women

At its meeting of 30 July 2019, the School's Research Ethics Committee considered your research proposal. The decision of the Committee is that your work should:

Pass –and that you proceed with your Research in collaboration with your supervisor

The Committee has asked that the lead reviewers' comments be passed onto you and your supervisor, please see attached.

Please note that if there are any subsequent major amendments to the project made following this approval you will be required to submit a revised proposal form. You are advised to contact me if this situation arises. In addition, in line with the University requirements, the project will be monitored on an annual basis by the Committee and an annual monitoring form will be despatched to you in approximately 11 months' time. If the project is completed before this time you should contact me to obtain a form for completion.

Please do not hesitate to contact me if you have any questions.

Yours sincerely

Mrs Liz Harmer – Griebel
Research Administration Manager

Cc : Dikaïos Sakellariou, Joanne Blake, Katie Featherstone

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Mae Prifysgol Caerdydd yn elusen gofrestrddig, rhif 1136855

Appendix 7: Participants information sheet (English)



Participant's Information Sheet

Dear Muslim Sister,

You are invited to take part in a research study, but before agreeing to take part please read the information below carefully.

Title of the study: Body Image Perception of British Disabled Muslim Women

What is the purpose of the study?

The aim for the study is to explore how the British disabled Muslim women perceive their body image. The researcher is interested to listen to your story and in exploring what strategies have you developed in order to make sense, cope and adapt with your body image in everyday life as a disabled Muslim woman.

Why have I been invited to participate?

You have been selected because you are an important member in the British society who has managed to be part of the women's group, disabled group as well as Muslim group. Therefore, you are likely to have a valuable experience of living with multiple identities of being a woman, disabled and Muslim. You are eligible to participate if you are at least 18 years old, speak English or Arabic, and have valuable information to give for the study about the lived experience of Muslim women with disability.

Do I have to take part?

Taking part is entirely voluntary; if you decide to take part in the study you will have the right to withdraw from the study at any time without the need to provide any reason.

What will happen to my data if I withdraw?

We will store all your identifiable data (i.e. contact details) securely, but we need to use the data you provided for analysis and reporting purposes.

What will I have to do?

With your agreement, the researcher will contact you to agree on a convenient time and place for you. The researcher will meet you two times for approximately 45-90 minutes. The researcher will ask you to participate in an informal interview and spend time with you to listen to your stories. The interview will be audio-taped, so the researcher can focus on what you are saying without distracting you by writing notes.

Version 2: 05.08.19

What are the benefits of taking part in this study?

There are no personal benefit but it is hoped that this study will give you the opportunity to reveal your experiences and stories of struggles and success. It is also hoped that the result will help to inform the social understanding about disabled Muslim women and add their unique experience to the theoretical discussion on disability within the field of disability, feminist and the Islamic feminism studies.

What are the risks of taking part in this study?

No risks are anticipated from taking part in this study. However, you may experience discomfort while sharing unpleasant experiences. If at any time you feel unwilling to share unpleasant experiences, you are free to discontinue. The researcher will give time until you feel well to continue, or may cease the interview and rearrange another meeting at a time which is convenient for you. If you are feeling that your discomfort persists, you may like to seek support from the following service if needed:

Muslim Community Helpline
Harrow, London
HA1 9DY
Phone: 02089 048193
Email: ess4m@btinternet.com

Will participation in this study be kept confidential?

All legal and ethical guidelines will be followed to protect your confidentiality during the study in accordance with the Data Protection Act 2018 and General Data Protection Regulation. Your identity will be protected by the use of pseudonyms. Your consent form will be scanned into a secure electronic system before being destroyed. Audiotaping of interviews, notes and any personal information relating to you will be kept strictly confidential between you and the research team at Cardiff University. This information will be saved securely on a password-protected computer.

What if there is a problem?

If you have a concern or a problem about any aspect of this study, you should speak to the principal researcher Amani Alnamnakani, and she will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting the School of Healthcare Sciences Director of Research Governance Dr Kate Button (buttonk@cardiff.ac.uk – 02920 687734).

What will happen to the results?

The result of the study will be submitted as a thesis to meet a requirement of a PhD degree in Healthcare Sciences for the principal researcher. The finding may also be published in a scientific journal. You will not be identified in any publication as pseudonyms will be used to protect your identity at all times. If you would like a copy of the results, please send an email to the principal researcher and the results can be sent to you after completion of the study.

Version 2: 05.08.19

Who will carry out the study?

The study will be carried out by Amani Alnamnakani, a Postgraduate Researcher in Healthcare Sciences at Cardiff University.

Who will monitor the study?

The study will be monitored and guided by the following academic supervisors at Cardiff University: Dr Dikaios Sakellariou, Dr Katie Featherstone and Dr Joanne Blake.

Who has reviewed the study?

The study has been reviewed by the Research Ethics Committee, School of Healthcare Sciences at Cardiff University.

Who is funding the research?

This study is funded by the principal researcher Amani Alnamnakani.

What do I do next?

If you are willing to take part, contact the researcher who will send you a consent form with pre-stamped envelope to be kindly signed before your participation. However, if you can't return the consent form you can also sign it before the interview.

Further information and contact details.

If you would like any further information about the study or have any questions please contact:

Amani Alnamnakani
Postgraduate Researcher in Healthcare Sciences
12th Floor, Eastgate House
School of Healthcare Sciences
35-43 Newport Road
Cardiff
CF24 0AB
Mobile: 07444564509
Email: AlnamnakaniAA@cardiff.ac.uk

Thank you for reading this information sheet.

Version 2: 05.08.19

Appendix 8: Participants information sheet (Arabic)



ورقة معلومات المشارك

عزيزتي أختي المسلمة،

أنتي مدعوه للمشاركة في دراسة بحثية ، ولكن قبل الموافقة على المشاركة ، يرجى قراءة المعلومات أدناه بعناية.

عنوان الدراسة: تصور صورة الجسد للمرأة المسلمة المعاقة البريطانية

ما هو الهدف من الدراسة؟

الهدف من الدراسة هو استكشاف كيف ترى النساء المسلمات المعاقات البريطانيات صورة جسدهن. الباحثة في هذه الدراسة مهتمة بالاستماع إلى قصتك واستكشاف الاستراتيجيات التي قمتي بتطويرها من أجل فهم صورة جسمك والتعامل معها والتكيف معها في الحياة اليومية كامرأة مسلمة معاقة.

لماذا دعيت للمشاركة؟

لقد تم اختيارك لأنك عضو مهم في المجتمع البريطاني وقد تمكنتي من ان تكوني جزءاً من المجموعة النسائية، مجموعة المعاقين وكذلك المجموعة المسلمة. لذلك ، من المحتمل أن تكون لديك تجربة قيمة في العيش بهويات متعددة لكونك امرأة ، معاقة ومسلمة. أنت مؤهلة للمشاركة إذا كان عمرك لا يقل عن 18 عاماً ، وتحدثين اللغة الإنجليزية أو العربية ، ولديك معلومات قيمة عن التجربة المعيشية للنساء المسلمات ذوات الإعاقة.

هل يجب علي المشاركة؟

المشاركة تطوعية تماماً ؛ إذا قررتي المشاركة في الدراسة ، فسيكون لك الحق في الانسحاب من الدراسة في أي وقت دون الحاجة إلى تقديم أي سبب. سنقوم بإتلاف جميع بياناتك التعريفية (تفاصيل الاتصال) ، لكننا سنحتاج إلى استخدام البيانات التي تم جمعها لأغراض تحليل الدراسة.

ماذا سيحدث لبياناتي إذا قمت بالانسحاب؟

سنقوم بتخزين جميع بياناتك التعريفية (مثل تفاصيل الاتصال) بشكل آمن ، لكننا نحتاج إلى استخدام البيانات التي قدمتها لأغراض التحليل والإبلاغ

ما الذي يمكنني القيام به؟

بموافقتك ، سوف تتصل بك الباحثة للاتفاق على وقت ومكان مناسب لك. سوف تقابلك الباحثة مرتين لمدة 45 إلى 90 دقيقة تقريباً. سنطلب منك الباحثة المشاركة في مقابلة غير رسمية وقضاء بعض الوقت معك للاستماع إلى قصصك. سيتم تسجيل المقابلة صوتياً بحيث يمكن للباحثة التركيز على ما تقولينه دون صرف انتباهك عند كتابة الملاحظات.

ما هي فوائد المشاركة في هذه الدراسة؟

لا يوجد أي منفعة شخصية ولكن من المأمول أن هذه الدراسة ستمنحك الفرصة للكشف عن تجاربك وقصص الكفاح والنجاح. ومن المأمول أيضاً أن تساعد النتيجة في تعميق الفهم الاجتماعي للمسلمات المعاقات وإضافة تجربتهن الفريدة إلى المناقشة النظرية حول الإعاقة في مجال الإعاقة والدراسات النسوية والنسوية المسلمة.

الإصدار 2: 05.08.2019

ما هي مخاطر المشاركة في هذه الدراسة؟

لا يوجد مخاطر متوقعة من المشاركة في هذه الدراسة. ومع ذلك ، قد تشعرى بعدم الإرتياح أثناء تبادل التجارب غير الجيدة. إذا شعرتى في أي وقت بعدم رغبتك في تبادل التجارب غير الجيدة ، لكي مطلق الحرية في التوقف. سوف تمنحك الباحثة الوقت حتى تشعرى بالقدرة على الاستمرار ، أو قد تتوقف عن المقابلة وتعيد ترتيب اجتماع آخر في وقت مناسب لك. إذا كان شعور عدم الراحة لديك مستمر ، فقد ترغيبين في طلب الدعم من خط المساعدة للمجتمع الإسلامي التالي إذا لزم الأمر:

Muslim Community Helpline
Harrow, London
HA1 9DY
Phone: 02089 048193
Email: ess4m@btinternet.com

هل تبقى المشاركة في هذه الدراسة سرية؟

سيتم إتباع جميع الإرشادات القانونية والأخلاقية لحماية سريتك أثناء الدراسة وفقاً لقانون حماية البيانات 2018 واللائحة العامة لحماية البيانات. سيتم حماية هويتك باستخدام الأسماء المستعارة. سيتم نسخ نموذج موافقتك في نظام إلكتروني آمن قبل إتلافه. سيتم حفظ التسجيل الصوتي للمقابلات والملاحظات وأي معلومات شخصية متعلقة بك بسرية تامة بينك وبين فريق البحث بجامعة كارديف. سيتم حفظ هذه المعلومات بشكل آمن على جهاز كمبيوتر محمي بكلمة مرور.

ما إذا كان هناك مشكلة؟

إذا كان لديك اهتمام أو مشكلة بشأن أي جانب من جوانب هذه الدراسة ، يجب عليك التحدث إلى الباحث الرئيسي أماني النمكاني ، وسوف تبدل قصارى جهدها للإجابة على أسئلتك. إذا كنتى لا تزالين غير سعيدة وترغيبين في تقديم شكوى رسمياً ، فيمكنك القيام بذلك عن طريق الاتصال بمدير حوكمة كلية العلوم الطبية الدكتور كيت باتون عن طريق:

buttonk@cardiff.ac.uk
أو الإتصال على 02920687734

ماذا سيحدث للنتائج؟

سيتم تقديم نتيجة الدراسة كرسالة لتلبية متطلبات درجة الدكتوراه في العلوم الصحية للباحث الرئيسي. يمكن أيضاً نشر النتيجة في مجلة علمية. لن يتم التعرف عليك في أي منشور حيث سيتم استخدام الأسماء المستعارة لحماية هويتك في جميع الأوقات. إذا كنتى ترغيبين في الحصول على نسخة من النتائج ، يرجى إرسال بريد إلكتروني إلى الباحث الرئيسي وسيتم إرسال النتائج إليك بعد الانتهاء من الدراسة.

من سيجري الدراسة؟

سيقوم بإجراء الدراسة أماني النمكاني ، باحث دراسات عليا في علوم الرعاية الصحية بجامعة كارديف

من سيراقب الدراسة؟

ستتم متابعة الدراسة وتوجيهها من قبل المشرفين الأكاديميين في جامعة كارديف: الدكتور ديكايوس ساكيلاريو ، والدكتورة كاتي فيذرستون والدكتورة جوان بليك.

من قيم هذه الدراسة؟

تمت مراجعة الدراسة من قبل لجنة أخلاقيات البحث ، كلية علوم الرعاية الصحية في جامعة كارديف

الإصدار 2: 05.08.2019

من يمول البحث؟

تم تمويل هذه الدراسة من قبل الباحث الرئيسي أمانى النمنكاني.

ماذا أفعل بعد ذلك؟

إذا كنتي على استعداد للمشاركة ، تواصلني مع الباحثة وسوف تقوم بإرسال نموذج الموافقة إليك مع مظهر مختوم مسبقاً لتوقيعه قبل مشاركتك. ومع ذلك ، إذا لم تتمكني من إرجاع نموذج الموافقة ، فيمكنك أيضاً التوقيع عليه قبل بدء المقابلة.

مزيد من المعلومات وتفاصيل الاتصال

إذا كنتي ترغبين في أي معلومات إضافية حول الدراسة أو لديك أي أسئلة يرجى التواصل علي:

Amani Alnamnakani
Postgraduate Researcher in Healthcare Sciences
12th Floor, Eastgate House
School of Healthcare Sciences
35-43 Newport Road
Cardiff
CF24 0AB
Mobile: 07444564509
Email: AlnamnakaniAA@cardiff.ac.uk

شكرا جزيلاً لقراءة ورقة المعلومات هذه

الإصدار 2: 05.08.2019

Appendix 9: Invitation letter (English)



Invitation to participate in a study

Title of the study: Body Image Perception of British Disabled Muslim Women.

I am inviting you to take part in a research study regarding the body image perception of the disabled Muslim women in the UK. The aim of this study is to explore how British disabled Muslim women perceive their body image, and how they cope in everyday life. I am inviting all Muslim women who are living with a disability to share their stories of struggles and successes. I hope that the result will help to raise awareness about the body image of disabled Muslim women in the UK and make their voice heard. It may also help to add your unique experience to the theoretical discussion on disability within the field of disability, feminist and the Islamic feminism studies.

Taking part in this study is entirely up to you but if you decide to do so, I will meet you two times at a time and place convenient to you. I will be asking you some questions and spend time with you to listen to your stories. The interview is informal, and it will last between 45-90 minutes. I am simply trying to explore your thoughts of your body image as being a woman, Muslim and disabled.

I have included detailed information in the attached information sheet. If you want to discuss any aspect of this research without any obligation to take part, please feel free at any time to contact me on (07444564509) and the following email: (AlnamnakaniAA@cardiff.ac.uk).

Looking forward to hearing from you soon.

Sincerely Yours,

Amani Alnamnakani

PhD Researcher at Cardiff University

Appendix 10: Invitation letter (Arabic)



دعوة للمشاركة في البحث العلمي

عنوان الدراسة: تصور صورة الجسد للمرأة المسلمة المعاقة البريطانية

أدعوكي للمشاركة في دراسة بحثية عن تصور صورة الجسد للنساء المسلمات المعاقات في المملكة المتحدة. الهدف من هذه الدراسة هو استكشاف كيف ترى النساء المسلمات المعاقات في بريطانيا صورة جسدهن وكيف يتعاملن مع الحياة اليومية. أدعو جميع النساء المسلمات اللاتي يعشن مع إعاقة إلى مشاركة قصصهن عن الكفاح والنجاحات. أمل أن تساعد النتيجة في زيادة الوعي بالصورة الجسدية للنساء المسلمات المعاقات في المملكة المتحدة وإسماع صوتهن. قد تساعد أيضاً في إضافة تجربتك الفريدة إلى المناقشة النظرية حول الإعاقة في مجال الإعاقة، الدراسات النسوية والدراسات النسوية المسلمة في المملكة المتحدة.

إن المشاركة في هذه الدراسة أمر إختياري متروك لك تماماً ، ولكن إذا قررتي القيام بذلك ، فسوف أقابلك مرتين في الوقت والمكان المناسب لكي. سأطرح عليك بعض الأسئلة وأقضي بعض الوقت معي للإستماع إلى قصصك. المقابلة غير رسمية وستستغرق ما بين 45 إلى 90 دقيقة. أحاول ببساطة استكشاف أفكارك حول صورة جسمك كأمرأة مسلمة ومعاقة.

لقد قمت بتضمين معلومات مفصلة في ورقة المعلومات المرفقة. إذا كنتي ترغبين في مناقشة أي جانب من جوانب هذا البحث دون أي التزام بالمشاركة، فضلاً لاتتردي في أي وقت للتواصل معي على (07444564509) و البريد الإلكتروني التالي:

AlnamnakaniAA@cardiff.ac.uk

أتطلع إلى الإستماع منك قريباً.

تحياتي المخلصة

أماني النمكاني
باحثة دكتوراة بجامعة كارديف

Appendix 11: Consent form (English)



Consent Form

Study Title: Body Image Perception of British Disabled Muslim Women

Name of Researcher: Amani Alnamnakani

Please Initial box

1- I confirm that I have read the information sheet dated 05.08.2019 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2- I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

3- I understand that the interview will be recorded on a digital recording device.

4- I understand that the direct quotations from my story and the findings and potentially secondary analysis of the findings and associated data from this study may be presented at conference and published in scientific journals. I understand that these will be used anonymously and that no individual respondent will be identified in such report.

5- I agree to take part in the above study

Name of Participant	Date	Signature
---------------------	------	-----------

Name of Person taking consent	Date	Signature
-------------------------------	------	-----------

Version 2: 05.08.19

Appendix 12: Consent form (Arabic)



نموذج الموافقة

عنوان الدراسة: تصور صورة الجسد للنساء المسلمات المعاقات في بريطانيا

اسم الباحث: امانى النمنكاني

يرجى اختيار المربع التالي:

1- أؤكد أنني قد قرأت ورقة المعلومات بتاريخ 05.08.2019 (الإصدار 2) للدراسة المذكورة أعلاه. لقد أتيت لي الفرصة للنظر في المعلومات ، وطرح الأسئلة وقد أجبت على نحو مرضي

2- أدرك أن مشاركتي تطوعية وأن لي مطلق الحرية في الانسحاب في أي وقت دون إبداء أي سبب

3- أفهم أنه سيتم تسجيل المقابلة على جهاز تسجيل رقمي

4- أفهم أن الاقتباسات المباشرة من قصتي والنتائج والتحليلات الثانوية المحتملة للنتائج والبيانات المرتبطة بها من هذه الدراسة قد يتم عرضها في مؤتمر ونشرها في المجلات العلمية. أدرك أنه سيتم استخدام هذه المعلومات دون الكشف عن هويتي ولن يتم تحديد أي فرد من المجيبين في هذا التقرير

5- أوافق على المشاركة في الدراسة أعلاه

اسم المشاركة _____ التاريخ _____ التوقيع _____

اسم الشخص الذي أخذ الموافقة _____ التاريخ _____ التوقيع _____

الإصدار 2: 05.08.2019

Appendix 13: Risk assessment and management



Risk Assessment and Management

Identified Risks	Potential Impact/Outcome Who might be harmed and how?	Risk Management/Precautions
The discussion of painful experience has a potential to cause distress to participant	Participant <ul style="list-style-type: none"> Psychological distress Researcher <ul style="list-style-type: none"> Anxiety about dealing with a difficult situation 	<ul style="list-style-type: none"> Calm the participant Offer to cease the interview Refer participant to the Muslim Community Helpline for support if needed
Working alone	Researcher <ul style="list-style-type: none"> Physical/psychological assault 	<ul style="list-style-type: none"> Gather some background information through the telephone call contact with the proposed participant In each interview, the researcher will phone someone (supervisor/family/friend) before and after the interview If the interview in non-public place such as participant's home, the researcher will inform someone (supervisor/family/friend) where the interview will be, where the researcher are going to be and for how long Identify the safe exit from participant's home as the researcher goes in
Domestic animal/Fire risk	Participant Researcher	<ul style="list-style-type: none"> Check that environment is safe before commencing the interview Identify location of fire alarm and the nearest fire exit
Noise/Loud sounds	Participant <ul style="list-style-type: none"> Distraction form talking Researcher <ul style="list-style-type: none"> Distraction from listening 	<ul style="list-style-type: none"> Checking that the interview environment is free from any potential disruptions and noise The researcher will take notes whenever the participant's sound is lost during the interview conversation

