Biopower, Biotechnologies, and the Biopolitics of Mothering: A Sociological Exploration of Maternal Subjectivities within UK Dwarfism Communities

KELLY-MAE SAVILLE

Doctor of Philosophy

ASTON UNIVERSITY

November 2024

ASTON UNIVERSITY

Biopower, Biotechnologies, and the Biopolitics of Mothering: A Sociological Exploration of Maternal Subjectivities within UK Dwarfism Communities

KELLY-MAE SAVILLE

DOCTOR OF PHILOSOPHY
November 2024

THESIS ABSTRACT

This thesis explores the subjective experiences of mothers who have children with dwarfism, drawing on in-depth qualitative interviews with 34 mothers in the United Kingdom (UK). The study includes 19 average-statured mothers and 15 mothers with dwarfism, all of whom are members of various dwarfism communities. Situated within the context of emerging biotechnological advances in growth treatments for children with achondroplasia, the research reveals how mothers within dwarfism communities negotiate (often competing) discourses on motherhood, dwarfism, and disability. The findings highlight how these processes fundamentally shape maternal subjectivities. The study's key contribution lies in exploring how mothers manage their identities in response to emerging biotechnological growth therapies for dwarfism; specifically, through examining the ways that they engage with the biopolitical dimensions of these treatments. The research exemplifies how biopower – particularly the experiences of judgement, social policing, and intense scrutiny – manifests through the prospect of maternal healthcare decisions. This thesis offers the first UK-based study to situate maternal subjectivities within the milieu of emerging biotechnological therapies in dwarfism healthcare. The research contributes new sociological insights by foregrounding the centrality of power in the complex and nuanced interplay of identity, stigma, and disability; demonstrating the ways that these dynamics intricately shape maternal subjectivities within dwarfism communities.

Keywords: Maternal Subjectivities, Identities, Achondroplasia, Dwarfism Communities, Vosoritide, Voxzogo, Disability, Stigma, 'Good' Mothering, Biopower, Biotechnologies, Biopolitics, Power/Knowledge Nexus

One of the most vital ways we sustain ourselves is by building communities of resistance, places where we know we are not alone.

bell hooks

Yearning: Race, Gender, and Cultural Politics
(2014: 227)

Dedication

I dedicate this work to my beloved children, my source of pure joy, and my entire world.

Bilal, Luqman & Hudayfa

You all have been present throughout this journey, and so this work has been as much a part of your lives as it has mine.
I love you, infinitely.
xxx

Acknowledgements

There are so many people to whom I owe a great deal of gratitude. As I reflect on this chapter of my life, I recognise that many of the ‘chances’ I have had were made possible by the kindness and generosity of others. So, grab a cuppa – this will be a long one!

I must start by acknowledging the abundance of personal and professional support I have received from various people within the dwarfism communities. Since I became a mother to a child with dwarfism, I have felt encouraged and supported by many in the dwarfism communities. Thank you for providing safer spaces for families like mine to thrive and flourish. It goes without saying that this research would not have been completed without the participants from the dwarfism communities. Thank you for giving me your time and sharing your very personal stories with me.

Financially, thanks also to Aston University, for awarding me a bursary as part of the celebrations for the 50th anniversary of the University Charter. Also, for allowing me to undertake this programme part-time. Without both of these components, I would not have been able to undertake this research.

This thesis would have never been completed without the motivation and support of my Supervisors. Admittedly, this research took me so long, I ended up going through four! First, I must thank Professor Chrissie Rogers, who started supervising me on this doctoral path. An infinitely inspirational, motivational, and encouraging scholar – without your support throughout my degrees, I would never have dreamt that I could do this. Thank you for seeing something in me, making me believe in myself. Second, I want to thank another of my Supervisors, Dr Sarah-Jane Page, for supervising the first half of my doctoral research. I am immensely grateful to you for reading through so many of my first drafts and supporting my scholarly development. Thanks to the robustness of your theoretical and methodological knowledge, I have gained a wealth of conceptual and sociological training that I will carry with me throughout my career. Third, with the deepest appreciation, I want to thank Dr Emily Christopher for taking up the baton during the latter phase of my project. You were really thrown in at the deep end, and I thank you for your endless enthusiasm; this was always welcomed and really helped, especially when I struggled to see the wood for the trees. Finally, Dr Pam Lowe, you have been here with me on this journey from the beginning. Thank you for having the literal patience of a saint. I know you have wanted to give me a good shake on more than one occasion. I will always be eternally grateful for everything that you have done for me.

I am also incredibly thankful to my examiners, Dr Katy Pilcher and Professor Felicity Boardman, for their time, kindness, and generous feedback during my viva. Your encouragement and enthusiasm for this research meant the world to me.

I also want to express my gratitude to the friends that I have made during my doctoral time at Aston. Too many to mention here, but especially Dr Amy Simmons, Dr Jai Mackenzie, and Dr Balgiisa Sheik Ahmed; all of whom continue to support me and are always only a text message, email, or Zoom call away. I want to say a special thank you to my fellow PhD peeps and dear friends from office NW801 – Dr Luke John Davis, Ms Cristina Greco, and Dr Kostas Plisiotis – you guys made the campus experience wonderful, and I miss our little office team!

Outside of academia, I want to thank my best friend, Magda Bystřická, who has been my wing-woman since childhood. Magda, very wisely during the latter stages of this project, gave up asking, '*How's the PhD going?*', as I would panic at its sheer mention. Instead, cautiously checked in on me with, 'Can I ask about the Three Letter Acronym yet?' Our babies, yours literal, mine metaphorical, both due on the same date was, of course, kismet.

I want to use this opportunity to recognise the significant and lasting impact some of my school teachers have had on me. My English teacher, Mrs Renn (Anne

Neville) – probably without ever realising it – provided a sense of stability and inspiration during a time when my childhood was marked by deep uncertainty. Ever the optimist, you believed in me and nurtured a love of language that I have carried with me throughout every stage of my education. The irony is not lost on me, as I have struggled to find the 'right' words to convey just how incredibly grateful I am to have had you as a teacher. You have shaped not only my love of language but also my belief in the power of compassionate teaching. I would also like to extend my gratitude to another one of my teachers; I am extremely thankful for the feminist awakening I experienced in the classroom of my first sociology teacher, Ms Paz (Laura Paz-Vites). Your infectious passion for, especially, Marxist feminist sociology, ignited my own love for the subject and has continued to significantly shape my life ever since.

I also want to use this chance to honour the influences of my late grandmothers, Rosemarie Hayes and Mary Kelly. Their legacies have profoundly shaped my life. Rosemarie, as a mother who had a disabled son – my late uncle, Alan Saville – I wish you could have lived to see my family flourish (and to read this thesis). Mary (Maisie) Kelly – the Irish matriarch whose name I carry – you passed before I was born, yet I have always felt your presence in my life. Forever my role model, you have lived on through the stories of others and in the legend of you that I have adoringly pieced together in my mind. As a woman and mother who ran a family newspaper business in Dublin's Northside, the strength, determination, and resilience you embodied have, in many ways, become the blueprint that continues to guide and drive me forward. Your small shoes remain some of the biggest to fill.

Most preciously, to my dear family – Ibrahim, Bilal, Luqman, and Hudayfa – thank you for your boundless love, support, and understanding. Somehow, we kept going, step by step, along this long and winding road. This journey was never mine alone – it was ours. I am deeply grateful to you, Ibrahim, for your infinite belief in me and for the personal and professional sacrifices you made to give me the time, space, and support to pursue my academic goals. Only we truly understand what it took to get me through, and you did most of the heavy lifting. Knowing the challenges we faced, and that my three boys were always watching, was all the motivation I needed to keep moving forward. So, as I sign off, here I am – incredibly proud to have persevered. Because, in the end, to invoke Confucius' wise words – *'It does not matter how slowly you go, as long as you do not stop'*.

Table of Contents

Abbreviations

Achon	Achondroplasia
DSA	Dwarf Sports Association
ELL	Extended Limb Lengthening
hGH	Human Growth Hormone
LPA	Little People of America
LPUK	Little People United Kingdom
RGA	Restricted Growth Association

Table of Tables

Chapter One – Introducing the Research Context

Situating the Research Context

Dwarfism is a broad term used to classify a range of medical conditions that inhibit growth, resulting in an adult height of less than 4ft 10in (1.47m) (Pritchard, 2021). Researchers estimate that there are fewer than 6000 people with dwarfism living in the United Kingdom (UK), making the condition both medically and socially 'rare' (Pritchard, 2021; Thompson et al., 2007). In the UK, previous studies have centred around the lives of dwarf adults, often highlighting the social inequalities and discrimination they routinely experienced (Pritchard, 2021, 2023; Shakespeare et al., 2010; Thompson et al., 2007).

The main medical conditions that result in dwarfism stem from two principal areas. First, genetic mutations that affect the chromosomes; the most common form of dwarfism, achondroplasia (accounting for around 80% of short statured people), falls into this category. Second, hormonal causes; the most common in this category being attributed to growth hormone deficiency (Unger et al., 2023). In the majority of cases, a 'spontaneous genetic mutation' during conception is often the principal cause of dwarfism; this means that the condition was not genetically present in either parent. As a result, around 80% of people born with dwarfism have average-statured parents (Pauli, 2019).

Clinical trials of the drug, Vosoritide, marketed under the brand name Voxzogo, are being offered to the dwarfism communities as a growth treatment for achondroplasia in children. Consequently, parents (where the majority do not have dwarfism) become the primary decision-makers at this pivotal juncture in the advancement of biotechnological therapies for dwarfism (Irving & Andrews, 2023; Savarirayan et al., 2024). As this thesis will explore, the prospect of modifying the body to increase height has long been a source of contention within dwarfism communities, and the scientific development of this non-surgical treatment has reignited these debates (Pritchard, 2023).

The purpose of this study is to explore the nuances of maternal subjectivities and experiences within UK dwarfism communities. The emergence of new growth therapies for children with dwarfism serves as a critical lens through which to examine the negotiation, disruption, and management of identities within dwarfism communities. Through this perspective, this research explores how maternal identities are constructed and contested around ideals of 'good' mothering. Rather than focusing solely on the healthcare decisions mothers ultimately decide, this study highlights the ways that maternal subjectivities are shaped through the very prospect of these new biotechnological developments in growth therapies for children with dwarfism. In foregrounding the centrality of power (Foucault, 1977), this research aims to illuminate the complex and nuanced interplay of gendered maternal identities (Hays, 1996), stigma (Goffman, 1963), and the sociocultural dimensions of dwarfism (Pritchard, 2023) that shape the experiences of these mothers.

Cultural Representations of Dwarfism

In regard to dwarfism, it is important to consider the dehumanising cultural discourses that surround the condition, enabling us to further contextualise the maternal subjectivities and prevailing norms that operate within the dwarfism communities. Cultural representations of dwarfism have evolved across time and geography; these discursively reflect a complex interplay of reverence, marginalisation, and spectacle. In Ancient Egypt, individuals with dwarfism were venerated, often seen as divine incarnations. The god, Bes, associated with midwifery, childbirth, and fertility, embodied the sacredness attributed to the dwarf body; a body that was revered for its symbolic ties to piety and magic (Adelson, 2005a; Dasen, 2013). Throughout the Middle Ages and into the Renaissance, 'court dwarfs' were employed in royal households across Russia, England, China, Spain, and Italy. Their social status was often determined by their relationship with the reigning monarchy; some were regarded as cherished companions, while others were treated as purely objects of possession. Adelson (2005a) and Dasen (2013) argued that the marginalisation of people with dwarfism mirrored the degrading societal attitudes that were also levied towards women, slaves, and other disadvantaged people. Like these groups, the treatment of people with dwarfism could range from indulgence to abuse and neglect. Some people with dwarfism were kept or gifted as ‘pets’, while others were valued (alongside jesters), primarily, for their role as court entertainers.

The rise of the freak show in the 19th century marked a significant shift in the public portrayal of people with dwarfism. The 'circus dwarf' became a staple of these spectacles, where individuals deemed 'abnormal' were displayed for public entertainment (Backstrom, 2012; Gerber, 1993). These exhibitions reinforced the societal links between dwarfism and the grotesque; thereby, further entrenching its connection to cultural myths and folklore. In doing so, they perpetuated negative cultural portrayals that continue to resonate in contemporary representations (Ablon, 1984; Adelson, 2005a, 2005b; Pritchard, 2021, 2023; Saville, 2018). Despite these challenges, recent decades have witnessed concerted efforts by members of the dwarfism communities and disability rights activists to push back against these entrenched cultural representations (Pritchard, 2023).

Positionality and Motivation: Mother-Researcher Reflexivity

I approach this research from a deeply personal perspective, shaped by my own maternal subjectivities and lived experiences, as an average-statured mother to a teenage son with achondroplasia. My mother-researcher positionality inherently intertwines with my personal and professional roles, reflecting Wright Mills’ (1959) connection with the ‘personal troubles of milieu’ and ‘public issues of social structure’ – I stake my claim here. I do not allege to be detached from the research process, its interpretations, or findings (Cooper & Rogers, 2015; Rogers, 2007). Instead, my subjectivities drive and inform my academic interests. This crossroads in the 'personal troubles' and 'public issues' is also reflected in the motivations of many scholars whose work is deeply rooted in their own experiences and identities (Adelson, 2005b; Pritchard, 2023; Shakespeare, 2006, 2013).

As an average-statured member of the dwarfism communities, my knowledge is empathetic – shaped by observation, interaction, and relationality, rather than obtained through an embodied experience of having dwarfism. This places me in a liminal space; I am neither entirely insider nor outsider (Saville, 2020). While I cannot *feel* the visceral realities of a society that often dehumanises people with dwarfism (Shakespeare et al., 2010), I have witnessed the discrimination through my son's experiences, and I have listened to the vivid accounts from others in the communities. These events have profoundly influenced how I interpret the nuanced complexities of subjective identities, belonging, and stigma within the dwarfism communities. That is to say, it drives me *towards* community.

I see my son's dwarfism as an integral part of his identity and, by extension, my own. Many of the activities he participates in are embedded within the dwarfism communities; a deliberate choice I made when he was born, to cocoon him (and me) from the world. The communities gifted us a sense of belonging; a space where his identity is normalised and, even, celebrated. Yet, this immersion is also about me. As a mother, I sought to 'heal' from the experiences of difference that having a disabled child invokes – from others (Landsman, 2009). Similar (m)others might recognise *that* gaze of pity; those sympathetic looks that seem to say: 'Thank God it's not me'. So, I say defiantly: No! *Thank God it IS me!* Such has been my experience of 'healing', the dwarfism communities have come to represent not only spaces for embracing his identity, but also sites for 'reclaiming' my own.

Recent developments in biotechnological therapies for dwarfism have offered parents the option of non-surgical treatments aimed at increasing growth in children with achondroplasia (Irving & Andrews, 2023; Savarirayan et al., 2024). The medication, Vosoritide, has changed the landscape of dwarf healthcare indefinitely. It has presented the dwarfism communities with unfamiliar complexities and nuances. Whether mothers seek it or not, every decision is laced with potential consequences. On the one side, the drug claims potential health benefits; suggesting a reduction in achondroplasia-related complications, without the need for invasive surgery. On the other side, it raises profound and challenging subjective questions about identity and the implications of altering the experiences of dwarfism. As a mother, like every participant in this research, I grapple with balancing my son's physical and mental well-being while also nurturing his sense of self. Personally, I have always feared how it would make him feel if we had wanted to pursue growth treatments. That by offering him a diverging route away from dwarfism, could inadvertently send him *that* message: his body, as it is, is not good enough. This internal conflict underscores the weight of maternal decision-making in the face of biotechnological advancements; here, the stakes are both deeply personal and, potentially, culturally significant. The emotional toll of navigating these decisions is immense, particularly within a society that continues to stigmatise dwarfism, often through mockery, abuse, and public curiosity (Pritchard, 2023; Shakespeare et al., 2010).

If the stories of disabled communities are left untold, their lived realities are silenced, perpetuating what Rogers (2020) identified as a form of sociopolitical death. To resist this erasure, it is imperative to amplify the (m)other(ed) voices within dwarfism communities, and to situate their experiences within the sociological landscape. My research seeks to explore these narratives, recognising the symbolic violence enacted when the stories of marginalised groups are silenced by their absence (Rogers, 2020). The maternal perspectives of participants (some of which contrasted with my own) challenged and motivated me to ensure that these women's 'voices' were sociologically 'heard', through their inclusion in this thesis. In line with my position as a feminist, the recognition of power relationships is acknowledged through reflexive approaches, which are woven throughout this thesis.

Feminist Foundations

This thesis underscores the centrality of power and gender in understanding the nuanced maternal experiences within dwarfism communities. The research positions mothers as gendered subjects who are shaped and regulated through the discursive regimes that are embedded in complex power relationships (Foucault, 1982; Hays, 1996). Theoretically, the study foregrounds how maternal decision-making is intricately shaped by the gendered expectations of 'good' mothering (Hays, 1996), the (re)production of regulatory discourses (Foucault, 1977, 1982), and the influences of social stigma (Goffman, 1963); thus, situating gender as a critical site for analytical scrutiny across all chapters. Gender, therefore, is not simply an element of the interpretation or analysis; it is the foundational premise for understanding the lived realities of these mothers and the sociological implications of their experiences.

Methodologically, the project is underpinned by qualitative approaches that integrate the subjective and relational dimensions of this study. To that end, my feminist outlook and subjective positionality guide me, 'from the margins' (hooks, 1984); facilitating the centring of maternal voices and their lived experiences (Ribbens, 1998). Hence, maternal in-depth interviews elicited rich and subjective narratives, enabling me to explore 'both margins and the centre' (hooks, 1984). As a mother-researcher, I am reflexive to the nature of this project, which necessitated continual self-interrogation about how my own assumptions, values, and experiences shaped the research. As such, this project is located within constructionist and interpretivist feminist paradigms. These subjectivist foundations necessitate the adoption of reflexivity, regarding the practice as central to the analytical processes, where themes are viewed as co-constructed (Braun & Clarke, 2006, 2022). A key strength of this methodological approach lies in its recognition of the presence of relational power in the construction of knowledge. Positionality is not minimised but acknowledged as integral to the co-creation of meaning within the research process. Being reflexive throughout this project has enabled me to remain critically aware of my mother-researcher status, as well as its implications for the research and the project's findings.

Dwarfism: Decisions on Terminology

There are distinctions in vocabulary and discursive constructions of identity between the different dwarfism communities. When considering the power of language and discourses, scholars in sociology, disability studies, and disability activists more generally, often reference the use of language relating to disability into two categories: person-first and identity-first language (Dunn & Andrews, 2015). The objective of person-first language is to untwine the individual from their (often stigmatised) associated characteristics, such as disability. The individual is centred as a person before their disability (Bogart & Dunn, 2019). Therefore, the use of phrases such as 'person with dwarfism' or 'people with restricted growth' is often employed as a discursive tool to separate the person from a defining characteristic. In contrast, the use of identity-first language is utilised to demonstrate how individuals' identities (and experiences as a person with these identities) are salient to their sense of self. The objective of identity-first language is not to detach the individual from their disability, but to signal that it forms a significant aspect of that person's identity and experience in the world. Therefore, phrases such as 'dwarfs' or 'dwarfism communities' are used to emphasise the experiences of that characteristic on an individual's sense of self. This also permits the focus to move beyond the individual; a discursive tool used by disability advocacy groups to describe groups of disabled people who claim disability as a central and prominent feature of their identity (Bogart & Dunn, 2019; Dunn & Andrews, 2015).

As is evident from the previous paragraphs, terminology is inherently contested and can be employed in various ways to reflect differing social, political, or medical perspectives. There is no universal consensus on its usage. Importantly, no term is truly 'neutral' or value-free; every linguistic choice reinforces or challenges the norms of dominant discourses (Foucault, 1988). In writing this thesis, my approach to terminology reflects the fluidity I embraced during fieldwork. As an average-statured mother, I consciously chose to mirror the language used by participants when referring to dwarfism. This decision allowed participants to define and relate to dwarfism in ways that best aligned with their perspectives. Consequently, both person-first and identity-first language are interwoven throughout this thesis, reflecting the diverse ways in which participants engaged with these terms. However, this is not to say that I have done so, completely impartially. Reflecting on my evolving maternal subjectivities, I acknowledge the shift in my own preferences since the beginning of my mothering journey. Initially, I favoured person-first language, believing it better centred the individual. Over time, my perspectives evolved, and I came to predominantly use identity-first language, which is demonstrably more prevalent in this thesis. This linguistic shift underscores the permeable nuances of researcher positionality and subjectivity. It illustrates how my understanding and engagement with terminology have been shaped by my experiences within the dwarfism communities, further highlighting the dynamic interplay between my mother-researcher positionality and my own maternal subjectivities.

Research Questions

The aim of this thesis is to address the following research questions:

1. How do mothers of children with dwarfism construct their identities and negotiate the stigmas attached to themselves and their children?

2. How and why do mothers of children with dwarfism engage with the dwarfism communities?

3. How do mothers of children with dwarfism make healthcare decisions and engage with the debates surrounding biotechnological advances that are designed to increase the height of those with dwarfism?

Outline of Thesis

Chapter Two – The literature review serves to contextualise the research by exploring the dominant ideologies that construct motherhood and define the cultural expectations of 'good' mothering in the Global North (Hays, 1996). The review then moves on to evaluate motherhood in relation to disability, where stigma has often been used to conceptually delineate the boundaries between 'normal' and 'abnormal' (Goffman, 1963). The review identifies that despite the centrality of parental caregiving concerning children with dwarfism, few scholars have offered a gendered analysis of maternal experiences. The review turns to assess the limited scholarship on mothers' subjective experiences within dwarfism communities, establishing that sociological literature has scarcely addressed the complex discussions surrounding the development of new biotechnological growth treatments for dwarf children. Theoretically, the review critically foregrounds the conceptual significance of power/knowledge as simultaneously (re)productive and regulatory (Foucault, 1977). Interlacing at the intersections of gendered moral imperatives towards children (Hays, 1996), identity stigma (Goffman, 1963), and power (Foucault, 1977), the review identifies how maternal subjectivities are (re)produced and constrained by regulatory forces.

Chapter Three – This chapter outlines the feminist epistemological and methodological principles that underpin this research, establishing the foundations for exploring the subjective experiences of participants. The study adopts qualitative methodologies, in line with feminist scholars such as hooks (1984) and Ribbens (1998); the research prioritises amplifying the voices of women through in-depth interviews, seeking to elicit rich and nuanced narratives. The chapter details the initial research design, the recruitment sites, the participants' profiles, the fieldwork, and how interviews were arranged. Situated within constructionist and interpretivist paradigms, the research emphasises the importance of subjective reflexivity in shaping both the research process and the co-construction of knowledge. Ethical considerations, such as ethical approval, consent, confidentiality, emotional risks, and limitations, are discussed. The subjective mother-researcher reflexive framework I embedded into this research stresses how my maternal subjectivities are inherent throughout the project. The study acknowledges my subjectivities as a mother-researcher, recognising how this dual identity influences data interpretation; subjectively shaping the co-production of knowledge. The chapter describes my personal reflections during the research and outlines some of the difficulties I faced. Reflexive thematic analysis and the data management software, NVivo, facilitated the iterative development of themes. Reflexivity is integral to the methodological approach, allowing for a dynamic and iterative process of analysis (Braun & Clarke, 2006, 2022). This approach explicitly recognises how knowledge is never neutral but is shaped by the positionality of both the researcher and participant.

Chapter Four – This initial data chapter delves into the intricate subjective experiences of women navigating motherhood through their positionalities as mothers of children with dwarfism. It examines the maternal responses to a dwarfism diagnosis, analysing the distinct, yet interrelated, experiences of both average-statured and dwarf mothers. The chapter explores how dominant discourses surrounding disability disrupt maternal identities, creating spaces of stigma and isolation, which profoundly shape mothers' subjectivities. Both average-statured mothers and mothers with dwarfism navigate the regulatory pressures of 'good' mothering, where their maternal decisions are politicised and scrutinised. The concept of 'good' mothering (Hays, 1996) underscores how women are held accountable for perceived adversities stemming from their children's disabilities; reinforcing the intersections of maternal responsibility, stigma, and blame. Building on the conceptual frameworks outlined in Chapter Two, this chapter weaves theoretical insights to contextualise and interpret the data. It illustrates how maternal subjectivities could be simultaneously regulated and resisted by the interplay of stigma (Goffman, 1963), powerful regulatory discourses (Foucault, 1977, 2008), and subjective agency.

Chapter Five – This second data chapter explores the motivations and experiences of mothers as they engage with dwarfism communities; revealing how the stigma associated with dwarfism (Goffman, 1963) disrupts maternal subjectivities, propelling mothers towards these communities as spaces of solidarity, validation, and belonging. These communities offer mothers spaces to manage and mitigate stigma through the sharing of experiences and distinct forms of experiential knowledge. However, as Foucault (1977) highlighted, such spaces are not free from power dynamics. The chapter considers the dual nature of dwarfism communities, portraying them as both supportive environments and regulatory spaces. While these communities provide resources and shared understandings, they are, nevertheless, shaped by power/knowledge dynamics that (re)produce specific values and norms; thereby, influencing maternal subjectivities. By documenting how mothers actively contribute to and are shaped by these discourses, the chapter explores the interplay between cultural narratives, community participation, and maternal agency. Central to this discussion is the pivotal role played by dwarf mothers, whose embodied experiences position them as key contributors to a specifically defined and highly valued, embodied form of experiential knowledge (Boardman, 2017). Their personal narratives and practices (re)produced cultural norms, while shaping collective understandings of dwarfism. The chapter goes on to consider the role of digital platforms as critical sites for cultural (re)production and resistance. These platforms allow mothers to share their lived realities, advocate for inclusion, and collectively challenge the stigma surrounding dwarfism. However, as Foucault's (1977) notion of surveillance suggests, digital spaces can also function as sites where mothers' practices may be scrutinised and regulated.

Chapter Six – This final data chapter examines how maternal subjectivities and healthcare decisions are disrupted through the interplay of ‘good’ mothering expectations, stigma, and community dynamics. Against the backdrop of emerging biotechnological therapies, the chapter explores the negotiation and management of identities within the context of motherhood, gender, dwarfism, and disability. The findings illuminate how biopolitics – particularly the intense pressures, experiences of judgement, and ‘policing’ – are brought to the forefront through the prospect of healthcare decisions. It explores the elevated status of embodied experiential knowledge, considering how it shapes and regulates the decision-making of mothers, often leading to forms of self-discipline and conformity with community norms. Violent discursive framings of external ‘threats’ to dwarf identities further reinforce these norms, creating a complex dynamic of resistance and regulation. A central focus of the chapter is the tension surrounding Vosoritide and its implications for maternal choices and dwarf identity. The temporal urgency in deciding whether to enrol in the drug trials before the closure of epiphyses (growth plates) (European Medicines Agency, 2024) places significant pressure on mothers. The chapter considers how these intersect with ideological debates about preserving cultural identity versus mitigating stigma and health risks. These decisions are often framed as deeply moral and ethical, amplifying the biopolitical pressures on mothers to balance safeguarding their child’s well-being with navigating community expectations. Goffman’s (1959, 1963) concepts of stigma, performance, and ‘back-stage’ behaviours illustrate how mothers strategically manage their decisions; at times concealing them to manage their 'face'. The chapter considers how the communities' concept of 'Dwarf Pride' can function as both a unifying device and a regulatory mechanism. The chapter also explores resistance within these dynamics, highlighting moments where mothers deviate from dominant norms. It underscores how the uncertainty surrounding Vosoritide's long-term effects results in many mothers feeling distressed and grappling with fears of making 'wrong' decisions.

<u>Chapter Seven</u> – This concluding chapter closes the research. It serves to synthesise the emerging themes and interpret the findings of the thesis. The chapter restates its purpose, addressing the project's research questions, and situates its contributions within the broader literature. Focusing on the intersecting influences of stigma, biopower, and biotechnological advancements, the findings reveal how participants' experiences, both societal and intra-community, become identity-shaping. This demonstrates how maternal subjectivity is performatively (re)produced through social norms and community relationships. The complex dynamics mothers navigate not only shape their sense of self but can also regulate their subjective maternal decision-making. Drawing on Foucault's (1977, 2008) concepts of power/knowledge and biopower, the research illustrates how dwarfism communities simultaneously provide support while also enacting forms of regulatory pressures. The tensions surrounding biotechnological advancements, such as Vosoritide, highlight how mothers

grapple with the dual imperatives to protect their child’s health while preserving cultural identity. This chapter also offers personal reflections on my mother-researcher positionality by acknowledging how my personal experiences shape the interpretive processes, and reaffirms the study’s feminist, interpretivist framework.

Chapter Two – Motherhood, Disability, and Dwarfism: Mapping the Conceptual Landscape in Academic Scholarship

Introduction

The purpose of this chapter is to critically examine some of the literature that has informed the direction of this project, so that I may position my thesis within these broader bodies of research. The overarching goal of my project is to contribute to sociological perspectives that explore the experiences of mothering children with dwarfism, within the backdrop of biotechnological medical advances in dwarfism healthcare. To this end, I focus on literature relevant to the studies of motherhood, disability, and dwarfism.

The chapter begins by delving into the social constructions of motherhood, highlighting the expectations and ideologies that shape cultural understandings of mothering (Hays, 1996). Motherhood is further explored in relation to disability, discussing the ways in which stigma has been used to define the limits of 'normal' and 'abnormal' (Goffman, 1963). The chapter continues by exploring studies that have considered how women who mother children with disabilities perceive their identities in relation to their disabled children (Ryan & Runswick-Cole, 2009).

Next, I turn to the dwarfism literature. I suggest that far less attention has been paid to the subjective experiences of mothers within dwarfism communities, particularly within a UK context. I identify how current literature examining the experiences of dwarfs, including from within UK dwarfism communities, has not adequately addressed the complex nuances that arise from the debates concerning the enrolment of dwarf children in trials of Vosoritide (Pritchard, 2023; Savarirayan et al., 2024).

Finally, I summarise the key elements of the literature review and suggest concepts that will help me to construct my project. Theoretically, I draw attention to the notions that surround 'good' mothering (Hays, 1996), stigma (Goffman, 1963), and the interplay between power relationships and dominant discourses (Foucault, 1977). I suggest where pertinent approaches might intersect, in ways that may bridge their conceptual limitations, and offer opportunities for new sociological insights.

Social Constructions of Motherhood

The concept of being a 'mother' is saturated with gendered implications and value judgements, making motherhood a substantially regulated social identity (Chodorow, 1978; Hays, 1996; Lowe, 2016; Minnotte, 2023). Hays (1996) argued that motherhood carried distinct, and heavier, cultural expectations than those which defined and regulated fatherhood. Therefore, the practice of mothering implies not only childbearing but also the expectation of extended maternal investment in the raising of children. Motherhood is, therefore, tied to societal expectations about morality and responsibility, where mothers are constructed as primarily responsible for their children's well-being, and women's worth as mothers is often judged based on how well they adhere to these socially regulated behaviours (Garwood, 2014). In the Global North, dominant ideologies are framed around the concept of the 'good' mother, which places immense pressure on women to conform to idealised, and often unattainable, standards of mothering (Hays, 1996).

Hays (1996) suggested that the ideology of intensive mothering was rooted in a 'logical' picture of family and private life that necessitated an almost moral duty towards 'relationships grounded in affection and mutual obligations' (Hays, 1996: 152). Moreover, Hays (1996) argued that this 'logical' foundation was often at odds with the realities and 'logic' found in other aspects of life, such as the economic and political arenas, which 'emphasises the individualistic, calculating, competitive pursuit of personal gain' (Hays, 1996: 152). Intensive motherhood rests on the premise that women will *want* to become pregnant, raise dependent children and, most notably, be satisfied in the role. Hays (1996) argued that society expected women to perform motherhood intensively; seeking expert advice regarding adherence to recognised child development stages and ensuring that they followed professional guidance, whereby the child's well-being remained paramount. Put plainly, an intensive mother desires, and should choose, to hold individual responsibility of her children for the enjoyment and privilege of shaping those children into the 'adults these children will become' (Hays, 1996: 108). Thus, in the late 20th century, when women were expected to undertake paid work outside of the home, they were still assumed to retain their responsibilities as the primary parent. It was this type of 'cultural contradiction' that Hays (1996) addressed: the intensity in mothering expectations occurred at a time when women were less available because of their presence in the public sphere. Hence, the ideology became a dominant discourse during a specific period, when traditional gendered expectations and roles of motherhood were seemingly threatened by women's increasing involvement in the workforce (Hays, 1996). Importantly, both stay-at-home mothers, as well as mothers in paid work, are affected by the intensive mothering ideology (Johnston & Swanson, 2006; Schmidt et al., 2023). The societal expectations forced upon women to be self-sacrificing (Arendell, 2000), emotionally invested, and child-centred (Hays, 1996) are often regarded as the minimum requirement for one to be considered a 'good' mother.

Research into the social construction of 'good' mothering has highlighted the experiences of women across the economic and social spectrum; demonstrating the widespread significance of gender in the regulation of expected maternal behaviours within society. For example, Lareau (2003) described how the American middle-class 'cultivated' their children's upbringing, by centring leisure activities in areas that would have the greatest (economic and social status) impact on their lives. Moreover, it was presumed that these mothers would use their advanced professional networks to introduce their children into cultural surroundings, where there was an expectation of financial benefit and academic success. In contrast, working-class mothers were judged on their (in)ability to live up to these practices due to their economic disparities (Lawler, 2000). Gillies (2007, 2008) and Jupp (2012) both identified how the creation of *Sure Start* centres, a UK Labour Party flagship family policy, introduced the surveillance and management of parenting within predominantly working-class communities. Here, 'parenting is created as a transferable (middle-class) "skill" imbued with cultural value that can be learnt and used for the "good'' society to prosper' (de Benedictis, 2012: 4). Mothers' attitudes concerning mothering expectations, and how closely (or not) they adhere to the ideology of good mothering, are often socially regarded as an individual's choice; disregarding the weight of social structures and cultural expectations, and how these go on to influence (and limit) mothering choices (Carter et al., 2018; Carter & Anthony, 2015; Smith-Oka, 2013; Wetterburg, 2004). Moreover, because a mother's choice is thought of as her sole individual responsibility, she is also presumed to accept all of the consequences of these decisions, regardless of any structural restrictions or other limitations she may have encountered (Hamilton, 2016).

Women who do not live up to the cultural expectations in mothering practices can struggle to be considered 'good' mothers (O'Reilly, 2021, 2024). The principles laid out for 'good' mothering are imposed on women regardless of the social, cultural, or economic context of their individual situation (Hays, 1996). While Hays (1996) acknowledged that variations in mothering practices existed, her cultural centring of intensive mothering norms has been criticised for (re)producing a universalised ideal, rooted in the experiences of White, middle-class women. Thus, the ideology positions these practices as the standard against which all mothers are judged, irrespective of their economic or racialised backgrounds (Dow, 2019; Minnotte, 2023; Verduzco-Baker, 2017). Even though many mothers across different social spectrums may outwardly reject intensive mothering, it is still upheld as the ideal concept of motherhood (Collins, 2000; Glenn, 2000; Minnotte, 2023). That is to say, it is pervasive in the sense that mothers may work to resist this narrative, yet as individuals, they cannot necessarily prevent being judged, due to its ideological dominance (Lowe, 2016). Minnotte (2023) described how American mothers from poor economic environments and ethnic minorities, especially Black women, often fell afoul of the ideology. Therefore, despite a cultural history tormented by slavery and racism, rendering the need for alternative approaches to mothering practices specific to these circumstances, the ideology remains hegemonic and applicable to *all* mothers, regardless of their views or subjective approaches to mothering practices.

Non-Disabled Women Mothering Disabled Children

Research into the lives of non-disabled women who mother disabled children has repeatedly demonstrated the heavy social and emotional strain that is experienced by this group of mothers (e.g., Guse & Harvey, 2006; Landsman, 2009; McKeever & Miller, 2004; McLaughlin et al., 2008; Rogers, 2007, 2013, 2016; Ryan & Runswick-Cole, 2008, 2009). Overwhelmingly, such research has established that there are substantial societal expectations, which go beyond the 'norms' associated with mothering children with disabilities, in terms of care and emotional labour (Kittay, 1999; Landsman, 2003, 2009; Lynch, 2007; McLaughlin et al., 2008; Rogers, 2007, 2013, 2016; Thomas, 2007).

The phrase 'emotional labour' was initially devised by Hochschild (1983), who had observed workplace processes whereby employees' feelings were managed in recognition of normative contextual practices. Focusing on social interaction, Hochschild (1983) used the example of female cabin crew who were expected to perform the mental and physical labour of their roles, as well as the management of their emotions, and how these were expressed outwardly. For example, the expectation of the female cabin crew to have 'smiling faces' when performing the role. Scully (2010) described the expectation to manage the discomfort of others as 'hidden labour'; motivated, in part, by a desire to resist the stigma attached to disabled bodies. Scully (2010) observed, however, how these strategies of performance management were regulated within the contexts of power relationships (Foucault, 1972, 1977, 1988; Traustadóttir & Sigurjónsdóttir, 2008). Drawing on the concept of performative emotional labour, Runswick-Cole (2013) observed how mothers of disabled children, as part of their mothering performance, engaged in emotional labour; even anticipating and managing other people's emotions while 'wearing it all with a smile'. Runswick-Cole (2013) argued that non-disabled mothers occupied a liminal position within disability spaces; at times described as 'oppressors' of their disabled children or, at best, merely their 'allies'. This was even though many mothers often experienced disablism and 'discrimination by association', due to their proximity and relationship with their disabled children (Runswick-Cole, 2013: 105).

Similarly, Rogers (2013) argued that due to the social constructions and discourses around having disabled children, the whole family may become 'disabled' by extension. This is because the same disablist narratives that are tied to disabled children's bodies also apply to their non-disabled parents (Singh, 2019). Goffman (1963) referred to this type of interplay as 'courtesy stigma'; a negative characteristic associated with a person through their proximity to a stigmatised individual. Extending on Goffman's (1963) concept of stigma, Scambler (1989, 2004, 2009) also made the distinction between 'felt' and 'enacted' forms of stigma in his work on epilepsy. 'Enacted' stigma refers to explicit and public examples of discrimination and abuse experienced by a person;

this distinction covers events such as bullying, harassment, and exclusion. In contrast, 'felt' stigma is the internalisation of a person's feelings; this can cover emotional responses, such as shame and embarrassment. Critically, for this study, 'felt' stigma can also refer to the anticipation of a stigmatising experience or event; for example, the fear of facing discrimination or social isolation from peers. While agency and resistance are prominent themes within research on direct forms of stigma (Shih, 2004; Thoits, 2011), studies regarding courtesy or 'affiliate' forms of stigma tend to explore the phenomenon through the lens of negotiated 'disclosure', and the mental health effects of stigma. For example, unlike disabled mothers, non-disabled mothers can 'manage' their stigmatised identity through anticipated disclosures, which can protect their mental health (Ali et al., 2012).

Women who mother disabled children are still regulated by the expectations derived from the intensive mothering ideology (Hays, 1996; Kibria & Becerra, 2021; Schmidt et al., 2023). Rogers (2011: 565 italics in original) argued that mothering disabled children 'involves a mass of skills that they [mothers] need to develop as *their unanticipated* journey begins'. These skills are *additional* responsibilities that women are expected to learn and undertake. To illustrate, research by Lutz et al. (2023) explored how, during the COVID-19 pandemic, *all* women with children were still expected to juggle their usual 'work' and 'home' responsibilities alongside the additional implementation of regulations, which required children's formal education to be continued through home-schooling: a ‘simultaneous shift’. For some mothers with disabled children, they were also assumed to have (or develop) the skills to step into even more specialised roles. For instance, as well as some mothers being tasked with adapting teaching provision if their disabled children had individualised education plans, some mothers were also responsible for providing their children with physical and health therapies. In contrast, most fathers’ responsibilities remained as they were before, regardless of whether they had children or if any children had disabilities (Lutz et al., 2023).

Alongside the expansion of motherhood work that often accompanies having a disabled child, there is the expectation that women, in particular, will provide more frequent forms of advocacy when dealing with a range of educational and healthcare professionals (Ryan & Runswick-Cole, 2009). Kibria & Becerra (2021) explored how the cultural expectations set out in Hays’ (1996) intensive mothering ideology, aligned and blended with the ideals of effective parent advocacy, resulting in the formation of what they coined, the ‘Good Advocate Mother’. Selflessly and determinedly, the ‘Good Advocate Mother’ tracked and managed the treatment and services for her disabled child; she remained hyper-vigilant and abreast of her child’s education, health, treatments, and progress. Intensive mothering practices are evident in how mothers of disabled children ‘plunge’ themselves into acquiring disability knowledge, such as advocacy capital, attending workshops, and maintaining a presence in parental advocacy support groups.

Disabled Women Mothering Disabled Children

As disabilities vary, so do the levels of stigmatisation levied towards disabled mothers (Frederick, 2014). For Goffman (1963), stigma referred to characteristics that indicated difference when compared to an assumed social 'norm' and were typically negatively judged. Goffman (1963) suggested that stigma formed an overarching narrative that discredited and 'spoiled' a person's identity and self. Thus, disabled mothers are judged (stigmatised) by their proximity (and distance) to the 'norm', as socially defined. Therefore, disabled mothers are subjected to these distinctive and intensified forms of stigma, which are (re)produced through an interlacing of cultural narratives that construct disability and motherhood as fundamentally incompatible (Frederick, 2015; Frederick et al., 2019). These women must navigate pervasive societal discourses that simultaneously stigmatise their bodies and cast doubt on their maternal competence, while still being judged by normative concepts of 'good' mothering; expectations that often demand significant personal sacrifice to their own health.

While discourses surrounding non-disabled women often narrate a 'moral imperative' to become mothers (Riessman, 2000), disabled women, in contrast, are frequently confronted with a societal imperative of childlessness (Frederick, 2017). This imperative is particularly pronounced for those with heritable conditions (Boardman, 2011). Dwarfism, a physical condition, falls under Goffman's (1963) classification of stigma, referred to as 'abominations of the body'; consequently, mothers with dwarfism are frequently affected by stigma. Culturally considered as incapable and dependent themselves, some disabled women are even perceived as a 'threat' to the well-being of children. Disabled mothers are more likely to be under the gaze of state institutions, as their parenting abilities are questioned, and they are presumed to have mothering deficits (Frederick, 2015; Frederick et al., 2019). Moreover, their mothering practices and individual behaviours, which some disabled mothers may utilise to care for their children, are often viewed as deficient, as they may deviate from the expectations of mothering values set out within the 'good' mothering concept.

Even the *bodies* of disabled women are perceived to be a barrier to a 'progressive future', which is to say, without disability; as disabled mothers are considered to pose potential 'risks' to children (Boardman, 2011; Frederick, 2017). Concerning children's health, Gillborn et al. (2022) observed how societal discourses often hold mothers responsible for their children's bodies. This responsibilisation, Gillborn et al. (2022) argued, functioned as a biopolitical tool, regulating the women's behaviour and that of their children; ensuring their adherence to these dominant cultural discourses and standards of health. Consequently, when considering the responsibilisation of women as mothers, normative discourses are (re)produced, regulating the narrative that women are the ones responsible for the health and well-being of children. This includes cases where genetic components are linked to certain disabilities, meaning that 'choices' regarding potential motherhood are already laden with stigma; as if these disabilities are inherited by the child, then the mother is held responsible for the child's disabilities (Gillborn et al., 2022). Disabled mothers have reported feeling under heightened surveillance, (re)producing discourses that some disabled women should not become pregnant because they may spread 'defective genes' (Frederick, 2015; Malacrida, 2009; Namkung et al., 2019). Additionally, if disabled mothers utilise support services, their mothering is regarded as deficient, as the assistance of community networks or public services contrasts with an idealised concept of the independent mother (Franklin et al., 2022). Moreover, if her children assist her with her own disabilities, inversing the roles within the concept of intensive mothering, she is considered as failing in some of her maternal responsibilities (Frederick et al., 2019). The notion of interdependency within the relationship is not recognised or valued (Kittay, 1999; Rogers, 2016), as the mother is always positioned in relation to her children's well-being, not the other way around (Hays, 1996).

Research has demonstrated that some disabled mothers may internalise these intensive mothering discourses (Elliott et al., 2015), resulting in a lack of self-esteem (Franklin et al., 2022). Over time, this constructs a 'reality' in which their disabilities are seen as signs of incompetence or defectiveness (Skinner, 2013), shaping how they perceive their own potential to be a 'good' mother; a label they strive to attain as part of strategies in identity management (Scully, 2010). This can also include attempts by disabled mothers to resist and lessen the perception of their own stigma, by distancing themselves from groups they deem more stigmatised than their own (Gibbon, 2010). Undeniably, disabled mothers have long faced profound marginalisation, shaped by dominant discursive constructions of both disability and motherhood. The internalisation of stigma (Pescosolido & Martin, 2015) exemplifies the (re)productive power of discourses that permeate communities, subtly regulating behaviours and subjectivities (Foucault, 1972, 1977).

To assist in contextualising our understandings of disabilities, the next section will focus on three overarching Models of Disability that are pertinent to the concepts and arguments which emerge from my data.

Disability Models

To be able to examine the themes raised in this thesis, it is beneficial to consider three key Models of Disability. In particular, the Medical, Social, and Embodied Ontological Models of Disability have, to different extents, influenced the theoretical terrain of this study.

The Medical Model of Disability

The Medical Model of Disability frames disability through layers of impairments residing within individual bodies and minds (Landsman, 2005). For example, this model would usually consider the specific impairments associated with dwarfism and try to medically 'treat' them through pharmaceutical and medicalised intervention. To illustrate, an achondroplastic child may have leg bowing and thus be offered eight-plate surgery[1] to guide growth, whereby the outcome to the individual may be straighter legs. The objective here is to align the human body to an idealised version of what 'normal' health should be, regardless of the common characteristics of particular disabilities. This approach was embraced during the development of medical and scientific technology that ensued after World War Two (Finkelstein, 1981), with advancements in 'corrective'[2] surgery (Priestley, 2003) and genetic technologies (Scully, 2009, 2017, 2018) employed to help prevent or alleviate impairment. The Medical Model of Disability is an individualistic approach, seeing defective bodies in need of medicalised intervention (Shakespeare, 1996). It considers all elements of impairment as problematic and in need of a cure, so that the individual can function in society (Oliver, 2004). Shakespeare (1996) observed how, through this model, the

---

[1] I will later discuss throughout the data chapters, how decisions regarding surgeries are more complex.

[2] The term 'corrective' usually describes interventions that are performed to align bodies closer to normative body standards regarding health. The term can be problematic as it produces 'incorrect' bodies that can be disciplined through 'corrective' treatment.

barriers that disabled people faced were limited to medical concerns that ignored the social and emotional aspects of their lived experiences.

As critics have argued, this medicalised approach cannot be reduced to just the issues of understanding illness and impairment through a narrow biological lens. Medical approaches govern the discourses surrounding how society perceives disabled people, including how they are expected to live their lives. Even so, there have been clear improvements to some disabled people's lives through this approach, such as in the development of life-sustaining drugs. However, there are also substantial limitations, and Critical Disability Studies approaches, in particular, have recognised them. These critical perspectives assert that disability is not wholly a medical issue; it has social and cultural implications.

The Social Model of Disability

The Social Model of Disability challenges the Medical Model's framing of disabled lives (Finkelstein, 2001; Oliver, 2013). Within the Social Model, disability is conceptualised in relation to wider societal dynamics, going beyond the individual's impairments. The concept proposes that the societal barriers that people with impairments face result in disability. Under this model, if those barriers were removed or if accessible solutions were in place, disability would no longer be disabling. In 1975, the Union of the Physically Impaired Against Segregation (UPIAS) presented their landmark Aims and Policy statement in

London. This was a culmination of the aims and future directions of the organisation, including their policies, as agreed upon by the membership (UPIAS, 1975). The following year, UPIAS published the Fundamental Principles of Disability (UPIAS, 1976). Here, it was recognised that there was a distinction between impairment and disability:

> In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society.
>
> (UPIAS, 1976: 14)

Building upon this approach, UPIAS made the following distinction between impairment (physical) and disability (social):

> Impairment [–] lacking part or all of a limb, or having a defective limb, organism or mechanism of the body; Disability [–] the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities.
>
> (UPIAS, 1976: 3-4)

Using this framework, for example, a dwarf is only disabled because the built environment was created for 'average-sized' bodies. If society accommodated dwarf bodies, then, by this definition, they would no longer be considered disabled (Pritchard, 2021). However, the definition of impairment does not cover body size, although it does refer to having a ‘defective limb’. Moreover, it is not clear how these distinctions can fully recognise and reflect the experiences of people with dwarfism.

More recent sociological understandings of the model have attempted to address these limitations by arguing that instead of abandoning the concept entirely, it could be strengthened to reflect the broader experiences of disabled people (Thorneycroft, 2024; Yang & Lin, 2023). Moreover, recognising the value that relational and embodied approaches could contribute to the concept, Introna (2023: 90) suggested that the COVID-19 pandemic demonstrated the ease with which ‘crip utopias of accessibility unfolded’ in society. When the risk of vulnerability became normalised and felt by the general (non-disabled) population, society offered emancipatory change and epistemic possibilities. This, Introna (2023) argued, demonstrated the possibilities of a ‘cripped’ Social Model of Disability, which centred around the plurality of embodied disabled lives.

The Embodied Ontological Model of Disability

The Embodied Ontological Model of Disability (Shakespeare & Watson, 2001) was built to reflect the plurality of embodied experiences of disabled lives. Earlier feminist perspectives sought to address the critiques of the Social Model (Morris, 1991), attempting to rework the concept to build on the inadequacies of the framework. However, Shakespeare & Watson (2001) argued that due to the binary distinctions of disability/impairment, which defined the foundations of the Social Model, the framework was beyond reform.

Shakespeare & Watson's (2001) Embodied Ontological Model of Disability sought to combine aspects from the other two earlier frameworks; this model 'neither reduces disability to an individual medical problem, nor neglects the predicament of bodily limitation and difference' (Shakespeare, 2006: 2). Within the framework, Shakespeare (2006) acknowledged the limitations that impairment and disability could cause on the body and person, while also recognising disability as a central component in the construction of identity. Therefore, in contrast to the Social Model of Disability, which forms distinctions between the physical and social experiences of disability and impairment, an Embodied Ontological Model recognises the salience of the embodied nature of impairment and how it is fundamental to understanding the nuanced complexities of disabled people's lived experiences:

> Our point is that everyone has limitations, and that everyone is vulnerable to more limitations and will, through the ageing process, inevitably experience functional loss and morbidity. Many of us will be supportive of attempts to minimise or eliminate these limitations, where possible, which does not mean 'cure at all costs' [...] It is very difficult to achieve a core definition of 'disabled people', because it is not clear who counts as disabled or not. This is because different societies treat particular groups of people with impairments in different ways.
>
> (Shakespeare & Watson, 2001: 24-25)

Shakespeare & Watson (2001) and Shakespeare (2006) highlighted how disability was just an aspect, not the only feature, in identity and the presentation of self. Critically, the concept accounts for the embodied experiences of pain, bodily limitations, and the progressive disablement associated with impairments, such as dwarfism. Moving beyond a binary approach, the embodied model simultaneously emphasises the role of disabilities in shaping identities and constructing communities. For instance, a person with dwarfism may, at some stage, become less mobile and undergo surgeries to maintain movement and manage their pain. At the same time, they could feel value in their dwarf identity and belonging to the wider disabled community. Critically, the framework recognises that disability is mutually shaped by its intersections with other axes of identity, such as class, race, and gender, resulting in a complex and deeply situated, embodied experience.

A feminist approach to the Embodied Ontological Model weaves in the gendered expectations around mothering, specifically, 'good' mothering (Hays, 1996), and the embodied experiences of disability (Shakespeare & Watson, 2001; Shakespeare, 2006). For example, the importance of dwarf identity and how this informs (and puts limits on) some women's decision-making regarding health choices. Here, 'right' decisions are measured against the notion of 'good' mothering; however, these may not align with ideals within particular dwarfism communities. Within this framework, it will be important to recognise the interplay between mothers and children, and the care-work needed for disabled children (Rogers, 2016). This involves examining how, for example, dwarf mothers interpret their embodied experiences as disabled individuals, mothering a child with dwarfism. Similarly, the ways that these experiences inform the decisions they make for their child, as well as how they engage with their own embodied knowledge of dwarfism.

The following section explores the existing literature (most notably from the Global North) that pertains to the dwarfism communities. The section examines some of the ways that the social and cultural, as well as the medical and biotechnological developments, have affected the lives and experiences of people with dwarfism.

Social Constructions of Dwarfism

Previous qualitative research has explored the lives of people with dwarfism within an American context (Ablon, 1984, 1988, 1990, 1994). In her research, Ablon (1984, 1988) focused on members of the organisation, 'Little People of America' (LPA). Her research was built on Goffman's (1963) assertion that most stigmatised individuals seek out organisations which provide social and emotional support; Ablon (1984, 1988, 1994) challenged the notion that dwarfism was a 'spoiled identity' by documenting the lived experiences of dwarfism through everyday encounters. While Ablon (1984, 1988, 1990, 1994) acknowledged the economic, political, and structural implications that formed the participants' views of their lives, it was her understanding of social interaction that led her to concentrate on the interpersonal relationships formed within the community, and exploring how these played out in their everyday experiences. My project aims to contribute empirically within this broader research context by offering novel insights into the experiences of mothers within UK dwarfism communities.

In attempting to address the lack of empirical data and nuanced interpretations of the historical and cultural perceptions of dwarfism, Adelson's (2005a, 2005b) research spanned the historical context of dwarfism in Ancient societies, up to more contemporary understandings and cultural representations that were present at the beginning of the 21st century in America. As a mother to an adult daughter with dwarfism, Adelson (2005b) approached her research reflectively. Significant contributions of her research concentrated on the multiple dimensions of living with dwarfism, including the emotional impact of the medical and psychosocial aspects of short stature. Her work documented the century that saw dwarfism communities evolve from the stereotypes depicted in the freak shows to the creation of dwarfism advocacy groups in the USA; these provided valuable resources to both the individuals with dwarfism and the medical professionals entrusted with their care. Adelson (2005b) documented how some early 21st century experiences of diagnosis took a holistic approach, such as through referrals to parent-led counselling, resulting in extra peer support for families. This was an important shift in the dynamic of interactions with healthcare professionals. Similar research findings have highlighted the significant contribution that lay expertise can provide families (Maslen & Lupton, 2019). Building on the previous literature, which illustrated the importance of advocacy groups and maternal support for disabled families, my project seeks to contribute to our understanding of the contemporary experiences of mothers within UK dwarfism communities, focusing on their perceptions of relationships and support within these groups.

Other dwarfism research has focused on the lived experiences of dwarf adults. For example, Shakespeare's (1994, 2013) work has largely drawn out the disabling aspects of dwarfism impairments and the repercussions of having to manoeuvre around average-statured environments as a dwarf. Considering spatial encounters with the public, Kruse (2001, 2002, 2010) and Pritchard (2019, 2021, 2023) observed how public spaces are built with average-statured people in mind. Consequently, people with dwarfism have unique perceptions and experiences of living space (Pritchard, 2021). Empirical research that concentrates on the spatial experiences of people with dwarfism offers some insight into the different ways body size influences social interaction. These perspectives uncovered how embodied experiences of stigmatisation and intimidation resulted in some individuals with dwarfism (and their families) avoiding spaces to mitigate the chances of public harassment (Pritchard, 2021).

As a woman with dwarfism, Pritchard (2023) asserted the legitimacy and status of personal narrative and subjectivity in the pursuit and construction of knowledge. A key strength in Pritchard's (2023) work is the recognition that for dwarfism research to evolve, specific frameworks for interpreting data and constructing knowledge need to be built around the acknowledgement that dwarfism is not offered the same status as other forms of disability; as cultural attitudes towards dwarfism still situate dwarf bodies as sites of ridicule. Pritchard's (2023) objective was not to necessarily claim a novel angle of analysis, but to highlight the importance of discourse when laying out a justification for her development of the term 'midgetism': an all-encompassing definition to describe the unique forms of disablism and discrimination faced by people with dwarfism. Pritchard's (2023) work here is important. In recognising the need to use 'midget', a word she admittedly despised, Pritchard (re)located the term away from, rather than upon, people with dwarfism. Thereby, inversing its meaning to describe the very types of discrimination and oppression that its original use was intended to invoke upon this marginalised community. Previously, scholarship has highlighted the impact of cultural representations on people with dwarfism and sought to recognise their experiences as forms of disablism and hate crimes (Shakespeare et al., 2010). However, until Pritchard (2023), scholarship had not adequately attempted to carve out a dwarfism-specific term, which could be utilised by academics to fully encapsulate the unique types of disablism faced by people with dwarfism.

Drawing on her positionality and experiences as an ‘embodied expert’, Pritchard (2023) employed a reflexive and analytical lens to interrogate midgetism, community, and activism. She critiqued the various dwarfism communities’ perceived (in)ability to cater for the needs of the very people they claimed to represent: those with dwarfism. In part, she argued, this was due to the oversaturation of average-statured parents involved in the associations, and their ‘silencing’ of the voices of people with dwarfism; consequently, ‘non-normative’ (dwarfism) spaces had become dominated by normative (average-statured/non-disabled) voices. Pritchard (2023: 102) was firm in her belief that, ‘One of the biggest divides between parents and people with dwarfism is the result of conflicting attitudes concerning treatments and possible cures for people with dwarfism’. This is where Pritchard’s (2023) observations and positionality exposed the tensions and complexities within this marginalised community. The subject of treatments and ‘cures’ for dwarfism is a very nuanced debate; one that she does not fully address in this work. However, pertinent to Pritchard’s (2023) broader argument was how normative discourses, which problematise and stigmatise the dwarf body, have infiltrated dwarf spaces, becoming a dominant discourse that may harm people with dwarfism inside of their very own non-normative space.

As I describe in the next section, recent advances in biotechnologies regarding the 'treatments' of achondroplastic children, such as Vosoritide, have yet to undergo sociological scrutiny with respect to parents' decision-making processes, and how societal attitudes to disability and dwarfism influence (or not) their choices. It is at this juncture where I situate my study. My research aims to address the intersections of identity, dwarfism, mothering, and medical decisions within an increasingly emergent, biotechnological society.

Biotechnological Advances in Dwarfism Healthcare

Stramondo (2017) has argued that medical technologies have been slow to consider how inequalities and the stigmatisation of disabled bodies are present in, for example, reproductive technologies. Stramondo (2017) attributed this to a hegemonic concept of ethics and morality that defined 'better offspring', as a minimum, to mean without a disability. Research has recognised that stigma could attach itself to a mother who *desired* their child to have a disability; these women may never be seen as 'good' mothers in the view of medical 'experts' (Frederick, 2017). The feelings of wanting a child with dwarfism are not dissimilar to other mothers, beyond the dwarfism communities, who wish their children to share a genetic similarity or component; it is, however, the specific issue of disability and dwarfism that stigmatises these mothers (Stramondo, 2017).

Medical professionals often become the gatekeepers in constructing a disability's range, defining the boundaries and limits regarding what is considered 'normal' and 'abnormal' (Stramondo, 2017). As Foucault suggested, this produces a docile body that can be 'subjected, used, transformed and improved' (Foucault, 1977: 136). The discursive processes that construct the 'normal' body generate power relations through which 'abnormal' bodies are (re)produced and regulated (Foucault, 1982). Disability is associated with the 'abnormal' and social deviancy, and it is these marginalised bodies that are labelled as the 'object' of treatment (Shildrick, 2005). Consequently, the 'treated' body has become a new way of being and, as such, is subjected to the biomedical technologies of the time (Sullivan & Nourry, 2005).

In many areas of health, advances in biomedical treatments have transitioned beyond the Medical Model of Disability, where intervention is understood as essential to health and well-being, and into the field of human enhancement; here, the goalposts have shifted, to make people 'better than well' (Almeida & Diogo, 2019; Elliott, 2004). While biotechnological advances in medicine have undoubtedly contributed to the eradication of widespread outbreaks of, for example, deadly diseases, such as smallpox, through national vaccination programmes, wider concerns regarding the benefits and continuing development of many technological advances remain (Holtug, 2011). In particular, the implications of biomedical interventions have raised suspicion and speculation amongst populations that have developed distinct cultural identities. In the D/deaf community, for example, where a unique social identity and pride has flourished through shared experiences of deafness in a majority hearing society, the availability of cochlear implants is still controversial for many (Tucker, 1998; Wallis, 2020). Cochlear implants are seen as an intervention that forces the assimilation of the D/deaf community into the hearing one; the implication being that their Deafness must be remedied (Hyde & Power, 2000, 2006; Lee, 2012). Similarly, the dwarfism communities have also come to the attention of scientists and medical practitioners in their quest to advance the treatment of health conditions (Irving & Andrews, 2023).

Formerly developed in 1985 from the pituitary gland of human cadavers, a synthetic form of human growth hormone (hGH) was marketed for an array of medical conditions. This expanded its potential for dwarfism treatments, as initially it was only available to those with growth hormone deficiency; subsequently, it was offered to children with unexplained dwarfism, such as Idiopathic Short Stature (Conrad & Potter, 2004). The continued practice of prescribing hGH to children with Idiopathic Short Stature, some argue, is a controversial one (Murano, 2019), as the ‘benefit’ of this line of treatment is based upon an envisioned discriminatory predicament, rather than a health rationale.

Recognising that societal discrimination and prejudice are an inevitability for those with dwarfism, one justification put forward was that children with dwarfism should be given the opportunity to remove that obstacle, as hGH treatment might lessen their experiences of discrimination (Conrad & Potter, 2004). Despite its popularity amongst some parents and professionals, other people within the dwarfism communities have raised concerns over the absence of data regarding the long-term effects of the drug, as well as the lack of evidence that hGH treatment will improve the psychological outcomes in affected children (Conrad & Potter, 2004). Notably, some research suggests that the use of hGH may increase psychological risks (Kelnar et al., 1999; Murano, 2019).

A more invasive procedure used by specialists to increase height is extended limb lengthening (ELL); the bones in the limbs are broken, pins are inserted, and, at regular intervals throughout the treatment, the bone is slowly expanded using external metal frames. This technique has been used since 1905; however, it only became readily accessible in the 1970s (Adelson, 2005b). Current research on the surgical outcomes of ELL on achondroplastic children in the UK puts medical complication rates at 70% (Donaldson et al., 2015).

Parens (2006) examined how normative discourses on the body and disability shaped parental decisions regarding ‘corrective’ surgery. Drawing parallels to the cosmetic industry, Parens (2006) highlighted a deeper concern: the emergence of treatments and therapies, including those for achondroplasia, might contribute to broader narratives surrounding the normalisation of ‘surgically shaping’ disabled children, in order to conform to non-disabled body standards. Hedley (2006), a mother to a daughter with achondroplasia, explained the emotional and psychological demands of mothering a child with dwarfism. She unpacked the decision-making processes and the various considerations that influenced her choices. As an average-statured mother, she was guided by her overarching apprehension, ‘the very message I know we must never send: we love you, you're perfect the way you are … now change’ (Hedley, 2006: 46). Contrastingly, Sullivan Sanford (2006), a dwarf adult who had previously made the decision as a child to undergo ELL surgeries, questioned her identity amid resistance and accusations of ‘cheating’ from within the dwarfism communities. She described being unsure of how to identify as a ‘dwarf’, now that she was closer to being average in stature. Crucially, her experiences of ELL and as someone raised within dwarfism communities cemented her view that subjective perceptions of dwarf identity were critical to healthcare decisions:

> I strongly recommend that parents delay decisions about limb lengthening until the child is aware of her identity as a dwarf, and can voice an opinion and participate in the decision regarding this potential alteration of her body and thus her identity.
>
> (Sullivan Sanford, 2006: 30)

Recently, international clinical trials of an experimental drug, Vosoritide, have reignited the tensions and debates that surround dwarfism therapies, especially as these growth treatments are designed for dwarf children. Vosoritide works by attaching itself to the receptor type B (NPR-B), which inhibits the fibroblast growth factor receptor 3 (FGFR3). FGFR3 is responsible for inhibiting cartilage within the body and transforming it into bone, containing specific proteins. Vosoritide is understood to attempt to control these pathways so that bone growth is allowed to thrive uninhibited. It is a treatment with a specific window of opportunity; it must be administered before the epiphyseal plates close, and the earlier treatment is started, the greater the potential for overall 'benefit' (growth) (European Medicines Agency, 2024; Savarirayan et al., 2024). Therefore, the targeted demographic for this treatment is achondroplastic children. Consequently, for mothers within the dwarfism communities, the opportunity for deciding to opt-in to this specific therapy is limited; clinical eligibility largely focuses on children from newborn to under 5 years of age (in part to mitigate the likelihood of existing health complications relating to achondroplasia) (European Medicines Agency, 2024). Hence, preferences to wait for children to become 'aware' of their identity (Sullivan Sanford, 2006) conflict with the timing and thus availability of the treatment as an option.

It is worth noting here that, as treatment is recommended to begin as soon as possible in children, some perceptions within the communities may add weight to

Pritchard's (2023) observations that (average-statured) parents' actions could be construed as reflecting discourses which problematise dwarf bodies. These normative discourses are operating within non-normative (dwarf) spaces, and this may be harmful to dwarfs who seek out 'safety' in these spaces. Jóhannsdóttir, Egilson & Haraldsdóttir (2022) observed that to resist the internalisation of ableism, disabled people need 'safer spaces' where communities can form systems of solidarity and support. They acknowledged the use of the word 'safer' instead of 'safe', as spaces are malleable and can be penetrated quickly by unsafe behaviours such as ableism, microaggression, and violence. Therefore, disabled spaces are not always safe. As observed in my own data, although disabled spaces within the dwarfism communities are 'safer', behaviours within the communities are still influenced by normative discourses from the outside and also have other conflicts within them.

For some, biotechnological advancements and the use of enhancement drugs may be considered a solution to the experiences of discrimination that their children may come to face in the future. For others in the communities, because dwarfism is perceived to be a distinct subculture, the widespread use of genetic screening and the development of biotechnologies that attempt to target growth are perceived as a potential threat to their very existence (Adelson, 2005b; Shakespeare, 2013). Clearly, decisions regarding Vosoritide are complex and nuanced, as are the attitudes and perspectives of the dwarfism communities.

Debates concerning what specific treatments may challenge the notion of 'dwarf identity' (Sullivan Sanford, 2006) are subjective in any case. As most mothers seek out the dwarfism communities at a time of confusion or shock, many perceive the communities as spaces of emotional and practical support (Adelson, 2005b).

It is important to explore the ways that Vosoritide might challenge the maternal perceptions of the dwarfism communities and also document, to what extent, mothers feel a sense of belonging and acceptance within these spaces. My project aims to empirically contribute to these discussions in light of these developing tensions. The next section goes on to consider how power and knowledge are relationally (re)produced and regulated through dominant discourses. Recognising the implications of power relationships is critical, as it offers a lens through which to map and interpret the subjectivities and maternal experiences of participants within particular contexts.

Power/Knowledge and Regulatory Discourses

Foucault (1972: 42) argued that discourses are productive forces, defined as 'practices that systematically form the objects of which they speak'. This definition centres the dimensions of discourses to (re)produce or (re)construct the social world and our perceptions of 'reality', 'knowledge', and what we believe to be 'truth'. We live as 'a society which is essentially defined by the norm' (Foucault, 1988: 197). These 'norms' are (re)produced and regulated through discourses that set limits on how we perceive our world and understand ourselves (Foucault, 1972, 1977, 1988). Subjectivity, therefore, denotes the formation of subjects through discursive frameworks (Lazard, 2022). All ‘knowledges’, such as ideas about mothering, dwarfism, and disability, are (re)produced through discourses; thus, subjects are formed, shaped, and disciplined through the boundaries of discursive frameworks.

Foucault (1977) argued that knowledge and power are mutually constitutive; knowledge about a condition, such as dwarfism, is shaped by societal power structures, which are, in turn, reinforced through the knowledge they generate. Power structures define what constitutes legitimate knowledge, and this knowledge serves to reinforce the power relationships. However, dwarfism communities resist these imposed narratives by cultivating discourses that operate through a power/knowledge nexus. Foucault (1977) recognised how power is not just a structure of oppression; it is in a state of (re)production. In shifting dynamics in relation to the social interactions that flow through bodies in action, power is (re)produced over multiple spaces. Foucault challenged the concepts of power that assume totalitarian and oppressive structures; instead, he recognised that while power can act repressively, the main focus should be in power’s position as a *regulatory* productive force that 'produces reality; it produces domains of objects and rituals of truth' (Foucault, 1977: 194).

Despite his useful contribution to theories of power and discourse, a major critique levied at Foucault is his absence of gender analysis within his theoretical concepts. In particular, the gendered dynamics of power production and bodily regulation (Butler, 1989; McLaughlin, 2003). Foucault also overlooked the importance of gendered relations in the development and production of subjectivity (McNay, 1992) and identity construction. However, though Foucault did not explore his concepts in relation to gendered understandings of power, his work and the paradigms he offered are relevant to feminist concepts and analysis.

McLaughlin (2003) identified how feminists can utilise Foucauldian concepts to expose the methods and mechanics of power; for instance, how power (re)produces gendered realities, while also exploring how gender shapes the dynamics of power. Butler (1999: 45) suggested that gender was a repeated performance and 'acts within a highly rigid regulatory frame'. Repeated 'performances' *produce* gender and regulate its image; prescribing the limits of the role and legitimising what we 'know' as 'reality'. The same paradigm has also been applied to feminist understandings of disciplinary power, surveillance, and the regulation of motherhood. For example, how state surveillance may operate in ways that regulate women's bodies and their mothering practices. This, in turn, (re)produces the concept of 'good' mothers who are compliant and conform to the state's expectations. For example, drawing on this point, Peckover (2002) and Peckover & Aston (2018) observed how the practices of Health Visitors in the UK acted as a regulatory tool of the state to police mothers. The aim was to (re)produce performances of 'good' mothering, which these mothers were expected to live up to and emulate. Likewise, Larsen et al. (2008) observed how women's postnatal bodies, specifically, their production and supply of breastmilk, were regulated. It was regarded as a mother's personal responsibility to make breastfeeding successful. Yet, this regulation through 'expert' discourses, such as described by Hays (1996), sought to shape women's behaviours and mothering practices through the marginalising of those who resisted, by undermining their confidence around feeding.

(Re)Producing Identities and Communities

Theoretically, Foucault (1980, 1982) argued that the self is shaped through power relations that produce knowledge. This knowledge forms the foundation on which the self can develop, by (re)producing regulatory discourses about what the self should, and can, become. Applying this theoretical lens, a dwarf identity is not inherent but emerges from the discursive environments where knowledge about dwarfism is (re)produced. So accordingly, the dwarf-self cannot detach its 'self' from the knowledge created through the previous iterations and discursive constructions that came before (Pritchard, 2021, 2023). Social identity is (re)produced through subjectivity that stems from the knowledge and realisation of a person's affiliation to a particular social group, alongside any emotional attachments to that membership (Masinga, 2022; Tajfel, 1974). Moreover, people's perception of their social identity is influenced by their social environment and the interactions that take place within these spaces (Guan & So, 2016; Tajfel & Turner, 1979). These interactions shape how we perceive ourselves and direct how we should think and what we should do (Haslam et al., 2009); Foucault (1982) argued that this knowledge offered limits of possibility for the self and functioned to govern its potential.

Research has shown that shared social identities can act as the basis for an individual's group membership and the adherence to accepted collective norms and behaviours (de Hoog & Pat-El, 2024; Tajfel & Turner, 1979). In addition, Begeny et al. (2022) observed that when individuals perceived a collective sense of identity and belonging to a group, they were less likely to leave and might even become more involved within the collective community. For a community to become and remain effective, it must construct a collective identity based on a commonality between its members. The identity process can involve systematically transferring the personal and embodied experiences of its members into action (Begeny et al., 2022; Moayerian et al., 2022). In their research concerning families with children with dwarfism, Adelson (2005b) and Ablon (1984, 1988, 1990, 1994) both remarked, how it was the combination of isolation and health professionals with limited experience of dwarfism, which motivated the parents to make a connection with others with the same condition. Through the sharing of experiences, some women may develop a politicised identity, which may later transition into collective action and become a movement (O'Reilly, 2010, 2016, 2021, 2024). Yet, given the divisions in the attitudes towards medical intervention even within these movements, this is likely to also be exclusionary for many.

Importantly, communities are defined by having boundaries and borders; they can only exist once these are established (Jones, 1999). This could be experiences of gender, disability, health, mothering, shared interests and/or values (Ali et al., 2023). As I have previously explored, the subject-positioning of women who are mothers is constrained by the spaces and discursive constructions that (re)produce our 'realities' (Foucault, 1982). Those mothers who recognise their own positionality within a discursive construction of disability are able to build shared identities with (m)others who they believe embody the same traits as themselves (Abdullah, 2012; Kong & Hooper, 2018; Longman et al., 2013). Participation in community groups can build social capital, and some members will forge stronger social ties (Malinen, 2015; Oliver, 1984). For example, Gibson & Martin (2019) discussed how 'information poverty' amongst parents who have children with Down Syndrome or Autism could be addressed by the knowledge exchanges undertaken within these distinctive communities. In return for admission, members were expected to adhere to community discourses (e.g., criteria of admission, rules of behaviour and terms of exclusion) (Malinen, 2015). Thus, to be accepted into a community involves self-regulating behaviours.

Foucault (1982) questioned why individuals would comply with the actions of self-surveillance and governance, especially if this limited their own potential. He concluded that by participating, even in heavily regulated spaces, individuals could carve out expressions of their identity (Foucault, 1982). To illustrate, Rizvi (2021), acknowledging the White-centredness of disability support groups in the UK, observed how British Muslim mothers negotiated disability, culture, race, and religion within institutions and networks where these mothers perceived White British 'values' to be prevalent. Rizvi (2021) described these interactions as 'mothering in cultural bubbles', observing how these mothers drew from their own cultural community spaces; therefore, equipping them to resist cultural and institutional exclusion.

Space, according to Massey (2005), is relational, dynamic, political, and produced through interactions that are shaped by power. Within community-based support groups, specific social norms, attitudes, and behaviours are (re)produced over time; like, for instance, collective agreements to resist the dominant cultural discourses in some dwarfism communities, or to reject the use of derogatory terms, such as 'midget' (Pritchard, 2021, 2023). Stets & Burke (2000) highlighted how even within groups, sub-sets could arise; individuals aligned themselves with those perceived as similar, forming an immediately recognisable 'in-group', while those who deviated were marked out as an 'out-group'. These distinct and opposing identities that are (re)produced within communities can act as barriers to experiential learning and also obstruct the sharing of knowledge (Chiu et al., 2006). Rabinow's (1996) concept of biosociality provides a valuable lens for understanding the complex dynamics within dwarfism communities. According to Rabinow (1996), biosociality refers to the processes and behaviours whereby social groups are shaped around their shared biological traits, producing novel forms of collective identities and relationships. Dwarfism communities exemplify biosocial collectives; uniting, not solely due to a shared biological trait, but through the (re)production of cultural identities that resist mainstream societal narratives (Pritchard, 2023).

The next section goes on to explore this concept in relation to how people may feel drawn together by their shared identity, and how this may shape the construction of virtual communities.

Virtual Space: Constructing a 'Social-Network' Community

Studies have shown that women, some of whom are presumably mothers, use social media forums at high rates (Mackenzie, 2017, 2019, 2020, 2023). Some research suggests that the internet can be used as an empowering and embodied space for women in which to engage in political issues, providing support, and sharing experiences (Lowe, 2005; Lowe et al., 2009; Mackenzie, 2020, 2023; Madge & O'Connor, 2006). In some cases, this can lead to a sense of commonality, community, and belonging (Mackenzie, 2020, 2023; Pudrovska & Ferree, 2004). Research undertaken by McDaniel, Coyne & Holmes (2012) found that women who were new mothers were spending in the region of three hours a day on the internet. Previously, Madge & O'Connor (2006) suggested that women utilised the internet to find support and solve problems while they were pregnant, and this habit was often followed through into motherhood.

Other scholarship has questioned whether digital inclusion for disabled communities could aid in resisting the social stigma of disability, as barriers that may contribute to physical, economic, and social exclusion are not as prohibitive online (Tsatsou, 2021). Ringland (2019) has previously argued that some online spaces can be an inclusive forum for disabled children to play, learn social skills, and assist with childhood development.

Shifting Space: Online Health Communities

As an extension to global digitisation, healthcare and community groups often establish online health communities (OHCs). In a similar vein to mothering communities that foster a shared sense of belonging and purpose, OHC groups are a collective of people who interact with each other online, in spaces and forums specific to a shared health issue:

> OHCs can provide peer health knowledge, emotional support, and improve self-care for patients with chronic diseases […] OHC users with chronic

> diseases become more knowledgeable, feel better socially supported, and have improved behavioral and clinical outcomes compared with nonusers.
>
> (Rezaei Aghdam et al., 2020: 2)

As this quotation illustrates, an OHC acts as a platform for members to share knowledge and experiences regarding a specific illness or disability, giving members the opportunity for support and a connection to others with the same health condition. As with other community groups, a shared social identity cements the bonds and influences the interactions within the space. For OHCs, the specific health condition becomes the unifying identity under which members connect (Rezaei Aghdam et al., 2020; Zhao et al., 2016; Zhang & Liu, 2022). Communities of mothers of disabled children have used the virtual structures of OHCs as a blueprint for their own disability-specific communities (Bristow et al., 2022). However, while OHCs can serve as valuable sources of support, they are not without their drawbacks. The boundaries of who belongs in these spaces are often tightly policed, leading to the exclusion or marginalisation of those deemed ‘outside’ of the community's norms. Additionally, participation in OHCs can sometimes provoke anxiety, as members may face judgement or criticism from others. The spread of misinformation is another concern, as unverified or inaccurate health advice circulates within these spaces (Boardman & Clark, 2022).

Foucault asserted that power and knowledge are intertwined; forces of power decide which knowledge is most legitimate and from which sources it can be derived (Foucault, 1972, 1977, 2008). Consequently, ‘truth’ and knowledge are (re)produced by power relationships that are formed within society; these are affected by their proximity to narratives of authority and legitimacy. This explanation of power and knowledge production led Foucault (1980) to dismiss the notion that science can produce objective 'truths' and understandings. To illustrate, some OHCs aim to produce progressive allegiances by challenging ‘expert’ authority around common health matters (Rezaei Aghdam et al., 2020), similar to how disabled mothering communities (even before the widespread availability of the internet) have utilised lay expertise to challenge authority (Johnson & Quinlan, 2019; Ryan & Runswick-Cole, 2008). The relationship between these groups sometimes appears paradoxical; communities will frequently rely on up-to-date scientific knowledge to further their agendas, while at the same time, critiquing dimensions of it (Archibald & Crabtree, 2010; Brown et al., 2004).

Conclusion

In this chapter, I have outlined the body of literature and theoretical landscape that informed the context of my project, and where I intend to situate my contributions to sociological research. The review has demonstrated how few studies have examined the lives of parents in dwarfism communities; where research does exist, it tends to centre on American dwarfism communities. Moreover, the investigative context can be quite broad, gathering insights from 'families' and 'parents' (Ablon, 1988, 1990; Adelson, 2005b). Far less attention has been paid to the subjective experiences of mothers within dwarfism communities, particularly within a UK context. The literature review highlights how, currently, research concerning the experiences of dwarfs, including from within UK dwarfism communities, has not adequately addressed the complex nuances that arise from the debates concerning the enrolment of dwarf children into trials of Vosoritide (Pritchard, 2023; Savarirayan et al., 2024). I have identified this underdeveloped area as a space where I can locate my thesis and contribute new sociological perspectives.

Turning to the conceptual dimensions, Goffman's (1963) theories of stigma have profoundly influenced much of the literature surrounding dwarfism (Ablon, 1988, 1990). His work remains critically relevant to this research area, offering insights into how perceptions of dwarfism are not merely shaped by social interactions but are also (re)produced through cultural representations. These cultural frameworks establish societal boundaries between what is deemed 'normal' and 'abnormal', shaping collective understandings and expectations. Crucially, these definitions inform and construct subjectivities, influencing how individuals perceive themselves in relation to dominant notions of 'normality' (Goffman, 1963). This theoretical lens provides a foundational understanding of the interplay between cultural discourse, social interactions, and identity formation in the context of dwarfism.

This review has highlighted a critical gap in existing research: the insufficient attention to how the theoretical constructions of gender may shape mothering practices and perspectives within dwarfism communities (Ablon, 1988, 1990; Adelson, 2005b). Despite the centrality of maternal identities and caregiving roles in navigating the challenges associated with dwarfism, gendered analyses of maternal experiences remain significantly underexplored. This is particularly apparent in the research context of emerging biotechnological advancements in dwarfism healthcare and the development of treatments for children. Key to this is the conceptualisation of power and how it operates through disciplinary regimes (Foucault, 1977) to regulate maternal identities and healthcare decisions. However, the review has highlighted the limitations of Foucauldian concepts in fully addressing the social disparities and gendered expectations that specifically impact mothers (Peckover & Aston, 2018). Therefore, having critically engaged with the existing body of literature and identified significant gaps, this research will integrate feminist conceptualisations of motherhood to illuminate how women's experiences of mothering are continually regulated and (re)produced within societal structures and discourses (Hays, 1996). This feminist lens provides a vital framework for interrogating the complex ways in which gendered subject-positions and maternal subjectivities are constructed, challenged, and negotiated within the specific context of dwarfism communities.

In foregrounding the role of power in shaping maternal subjectivities, my project seeks to explore the nuances of these experiences within dwarfism communities amid, often, competing pressures. Foucault's (1972, 1977, 1988) conceptualisation of power as relational and productive offers the theoretical underpinning for understanding how these mothers' subjectivities are constructed through their active participation in, and resistance to, dominant discourses. The recent advancements in biotechnological dwarfism therapies offer a lens through which maternal subjectivities can be examined. Through the processes of maternal healthcare decisions, this study seeks to explore how participants negotiated and managed their identities in the context of mothering, dwarfism, and disability. Maternal subjectivities are shaped by their proximity to stigma (Goffman, 1963), their engagement with notions of 'good' mothering (Hays, 1996), and their participation in dwarfism communities.

The following chapter transitions to the methodological components underpinning this thesis, detailing the research design that facilitated the exploration of maternal subjectivities and experiences within dwarfism communities.

Chapter Three – Methodology and Research Methods

Introduction

The purpose of this chapter is to outline the epistemological and practical considerations that informed the study's design and allowed me to address the project's research questions. In the previous chapter, I discussed the concepts that informed the theoretical elements of this research. I now move on to consider the empirical aspects of the project. I start by setting out the initial premise of my study and how it contributed to the practical elements of the research design. I discuss how my feminist stance has shaped the entire project, laying the groundwork for my analysis of the lived experiences of mothers of children with dwarfism. Through this lens, I offer original contributions to the current bodies of literature that surround the intersections of dwarfism, disability, motherhood, and the (re)production of communities.

This chapter offers a detailed overview of my chosen methods. I explain why I was drawn to qualitative approaches and discuss how this allowed for in-depth data to emerge from the maternal narratives. I go on to examine the ethical concerns and considerations related to the project. This includes reflections on consent, confidentiality, and the emotional 'risks' that can arise from research on sensitive topics. These ethical reflections are crucial to understanding how the findings of this study emerged, as they provide a foundation for the analysis, where I turn to the data and examine what it reveals about the central research questions.

In this chapter, I critically examine my own positionality as a mother-researcher and the broader implications of conducting 'insider' research. This section reflects on the benefits and challenges of conducting research within the communities where I share personal ties, exploring the ethical considerations of undertaking this research. I highlight how my dual role as both researcher and mother offered distinct insights but also required careful navigation. Finally, I discuss the project's limitations, which largely stemmed from decisions surrounding the recruitment of participants.

Research Design

The goal of this research was to investigate the experiences of mothers who have children with dwarfism. As the research was conducted within the context of new biotechnological advances in dwarfism healthcare, I decided to concentrate on mothers who may be most affected by these medical advances. Therefore, I knew that I needed to focus on mothers who had very young dwarf children. As a mother to a child with achondroplasia, I had previously carried out research with mothers in the dwarfism communities for my undergraduate and postgraduate dissertations. However, as my son was around seven years old at the time, the mothering networks I belonged to within the dwarfism communities were all older and, as such, very few in my networks, at that time, had any experience with the clinical trials of Vosoritide.

The scarcity of data relating to the clinical trials, from my previous dissertations, made me question whether mothers might be experiencing substantial maternal differences within the dwarfism communities. I wondered if (and to what extent) our maternal subjectivities were being shaped around the availability of Vosoritide, a drug that claimed to be able to offer growth in dwarf children (Irving & Andrews, 2023; Savarirayan et al., 2024). For example, when first available, the criteria for the drug trials were such that my son, and many of his peers, did not qualify for enrolment due to the list of exclusions (in order to operate an effective 'control' group) based on their previous surgeries. Therefore, the development of Vosoritide had no significant impact on our lives. Yet, I was aware that this was not the whole picture. Just as there were a number of families who would not fit the criteria for inclusion, there would be many (particularly newer/younger members) who did. I wanted to find out more about their experiences and perceptions of dwarfism, in light of these medical developments.

My project aimed to explore these nuances and to contribute to these debates through the perspectives of both average-statured and dwarf mothers within UK dwarfism communities. These maternal experiences were crucial; mothers were having to make decisions on behalf of their dwarf children while also trying to maintain community relationships, which could be fraught with a multitude of conflicting tensions. It was imperative that the perspectives of dwarf mothers were central to these discussions and wider conversations. Their views and experiences informed the broader debates, having experienced dwarfism from 'both' subject-positions. I thought there was value in research that centred on the maternal experiences inside of UK dwarfism communities, undertaken at a time of substantial biotechnological medical advances. I felt that the perspectives of mothers during this time in their lives could contribute significantly to both medical sociology and critical disability studies.

My initial thought was that mothers of younger children with dwarfism were operating within different discursive 'realities' from those of mothers of older children. Their 'realities' of what their children's futures could look like were being constructed through the possibilities of new embodied outcomes that they could opt to explore, unlike mothers with older children. The potential to *choose* to stay a dwarf, or not. To this end, the drug trials might form a substantial part of some mothers' lives while, simultaneously, be of absolutely no importance to the lives of other mothers.

Qualitative tools offer flexibility for researchers to interpret data and construct meaning through specific contexts (Given, 2008). I recognised how interpretivist paradigms held some advantages regarding feminist research, whereby the guiding principle was in how ‘best’ to represent and interpret the ‘voices’ of women (Gillies & Aldred, 2002; Meehan, 2024). While this project is driven by my feminist positionality, I acknowledge that my understanding and interpretation does not speak for all feminists. I take the stance that feminisms co-exist in various forms, and are fluid, with sometimes contrary epistemological positions (Brooks & Hesse-Biber, 2007; Enns, 2010; Griffiths, 1995). I consider this research experiential, focusing on the processes through which mothers make sense and come to understand, negotiate, and develop their own realities (Braun & Clarke, 2006, 2022).

Taking into consideration the above and to generate detailed and descriptive ‘rich’ data, I opted to undertake in-depth interviews with participants. Having discussed my methodological approach, the following section goes on to describe how I recruited participants, as well as issues surrounding contact and gatekeepers.

Participant Recruitment

As a collective, the dwarfism communities are not homogeneous in their values and beliefs pertaining to dwarfism as a medical condition, nor is there a homogeneous dwarfism culture. For example, the Restricted Growth Association (RGA) tends to lean into person-first language, whereas Little People UK (LPUK) and the Dwarf Sports Association (DSA) will almost always lean towards identity-first language. To be inclusive to the many 'voices' within the communities, the organisations chosen for recruitment broadly reflected the differing opinions regarding the construction of identities and disabilities within these complex communities. I also recognised that it was imperative that I approached members of the RGA, as this was the only one of the main UK charities that had provided the pharmaceutical company, BioMarin, a platform to disseminate and recruit for their trials of the drug, Vosoritide. The organisation, LPUK, offered an alternative set of norms and values to those that operated within the RGA. Unlike the RGA, LPUK had decided not to engage with the medical organisations running the trials. The community adopts identity-first language for their organisation; therefore, the language and terminologies that drive the discursive constructions of dwarfism are significantly different from those that are (re)produced within the RGA. Hence, it was crucial for this study to also collect perspectives from members who adopted this view of dwarf identity. Situated differently from the other charities, the aims and objectives of the DSA are based on sport participation. Therefore, it was a fairly neutral space for members of the dwarfism communities as it attracted people from both the RGA and LPUK.

Dwarfism amongst the general population is rare; thus, members of the dwarfism communities are geographically dispersed (Kruse, 2001). The only sensible way I could recruit for this project within the timeframe was to go through the UK dwarfism communities. However, this also led to the exclusion of mothers who were not active within dwarfism communities. Through my existing membership in online dwarfism communities, I was able to engage with mothers who showed interest in my research. Therefore, to reach as many potential participants as possible, I took a dual approach; combining 'venue-based sampling' (Rockliffe et al., 2018), recruiting directly from dwarfism events, as well as through 'purpose-based sampling' (Brickman-Bhutta, 2012), via the online dwarfism communities. Without my existing membership in social media groups for people within the dwarfism communities, it may have been much harder to recruit participants for this research. Brickman-Bhutta (2012: 79) noted that 'thanks to widespread use and niche groups, Facebook offers researchers a way to easily reach many otherwise hidden populations'.

As I later discuss in this chapter, I was perceived by some mothers as an 'insider'. This gave me invited access to private and 'secret' dwarfism groups hosted on the social networking site, Facebook. Before fieldwork, I had held membership in some of the groups; however, as my fieldwork progressed, I was invited into other groups I did not know existed. These groups were not always available to other researchers, as they exclusively targeted parents or people affected by dwarfism. Regarding my use of 'secret' Facebook groups, membership in these groups was by internal invitation only by other group members, which then needed 'screening' by a group admin (essentially ensuring I had dwarfism or was a relation to a person with dwarfism) before membership was approved. As word of my project spread through digital forums, I was either invited into more groups along the way or found that I had already been a member before the commencement of the project. By utilising these spaces, I employed a purposeful sampling approach, whereby I was able to directly contact mothers (Sargazi et al., 2024; Rogers & Ludhra, 2012), either through the group's 'post' feature or, if individuals had expressed an interest to engage further, through the private messaging feature.

During recruitment, I became very aware of the school term cycle, particularly around holidays. One of the more challenging aspects was the realisation that different local authorities had conflicting closure calendars, which I did not fully appreciate during my planning phase. For example, just because I was free to arrange an interview, this did not necessarily translate to a participant in the next county also being available. Moreover, non-emergency surgeries were almost always booked during lengthy school closures to lessen the impact on children's absence from education. Needless to say, this took precedence in the lives of my participants over their participation in my study. Additionally, the post-surgery recovery period also meant that participants were never truly 'free' or available to fit me into their lives, but many did juggle this, nevertheless (to which I am eternally grateful).

Appreciating that the challenges I was experiencing in recruitment may have been due to the complex and continuous caring cycle in maternal work, I quickly realised that I needed to adopt other methods to contact more participants. Recognising that participants could also be gatekeepers, in that they have access to other potential participants through their relationships and networks (Sanghera & Thaper-Bjokert, 2008), I asked my first few participants if they could send the participant information sheet (Appendix A) to any other mothers they knew in the communities. Interestingly, some mothers who had previously declined or ignored my offer of an interview reconsidered after same-social-circle participants approached them directly. Therefore, snowballing proved to be more useful in terms of recruitment numbers. This change in attitude may also have been because participants became aware of the general direction of my research questions via disclosures from the other mothers whom I had interviewed, easing any anxiety or hesitancy.

As this project aimed to recruit both disabled and non-disabled women who mother disabled children, accessibility was a key consideration. To reduce barriers to participation, I not only made myself available at community events, but I also travelled to participants' homes. This approach helped eliminate the financial and logistical burdens often associated with attending dwarfism events. Additionally, previous research with other disabled communities has shown that online communication can help to mitigate some of the inequalities and barriers to research participation (Cooper, 2014). Therefore, I also offered participants the option of online interviews via Skype if they were unable to be interviewed in person. This way, it was hoped that participants might not view my presence as imposing on the routine of their personal lives, as interviews could be conducted within a shared time and space.

Participant Profiles

The tables below illustrate important demographical information about the participants, leaving aside data that may make them identifiable (e.g., specific forms of dwarfism, age, employment, location, children's gender). As the dwarfism population is already modest and individuals were often well known to each other, especially when recruited from the same dwarfism space (Shakespeare et al., 2010), this extra precaution had to be employed to mitigate risks of breaching anonymity and confidentiality. The tables also help to contextualise the data by illustrating how, and in what locations, the participants' interviews were undertaken.

For ease of reference throughout this thesis, participants with dwarfism (15 in total) were assigned pseudonyms beginning with the letter R (Table 1) and average-statured participants (19 in total) were assigned pseudonyms beginning with the letter A (Table 2). Pseudonyms marked with an asterisk (*) indicate the participants whose children's fathers also had dwarfism. This background information was particularly important to note in relation to dwarf mothers, as experiences associated with double dominance[3] are unique to families where both parents have phenotypically similar types of dwarfism (Pauli, 2019). In addition, some contextual distinctions between participants have also been reflected in the categorisation used within the tables. For example, regarding dwarf mothers, Table 1 includes their level and/or length of community engagement. In contrast, these details were not included in Table 2, as all average-statured mothers' engagement and participation within dwarfism communities only commenced after the birth of their dwarf children.

---

[3] Where parents have the same or phenotypically similar dwarfing conditions (e.g., achondroplasia and hypochondroplasia), the term 'double dominance' is used within dwarfism communities to refer to the lethal risk (to a foetus) of dual genetic inheritance (Pauli, 2019).

Pseudonym	Interview Setting	Ethnicity	Community Engagement	Vosoritide Trial		
				Child/ren Eligible	Participant's Attitude	Child/ren on Vosoritide
Rosie*	Dwarfism event	White	Joined in childhood	No	Against	No
Radha	Home interview	BAME	Joined in childhood	Yes	Against	No
Roisin	Dwarfism event	White	Joined in childhood	Yes	Against	No
Rhia*	Dwarfism event	White	Joined in childhood	Yes	Against	No
Rachael*	Home interview	White	Joined in childhood	Yes	Against	No
Rebecca	Dwarfism event	White	Joined in childhood	No	Conflicted	No
Rabiya	Partial interview at dwarfism event + Skype	BAME	Joined as adult	Yes	Positive	Yes
Riley*	Skype	White	Joined in childhood	Yes	Against	No
Rhonda	Home interview	White	Joined in childhood	No	Against	No
Ruqayah	Home interview	BAME	Joined in childhood	Yes	Against	No
Remi*	Partial interview at dwarfism event + home interview	BAME	Joined as adult	Yes	Against	No
Reese	Home interview	White	Joined in childhood	Yes	Against	No
Rianne	Home interview	BAME	unclear	Yes	Positive	Yes
Ruby	Skype	White	Joined as adult	Yes	Against	No
Ruth*	Dwarfism event	BAME	Joined in childhood	Yes	Against	No

Table 1 Dwarf Participants

Pseudonym	Interview Setting	Ethnicity	Vosoritide Trial		
			Child Eligible	Participant's Attitude	Child on Vosoritide
Amyna	Partial interview at dwarfism event + home interview	BAME	Yes	Conflicted	No
Aoife	Partial interview at dwarfism event + home interview	White	Yes	Conflicted	No
Ashling	Home interview	White	Yes	Conflicted	No
Audrey	Partial interview at dwarfism event + home interview	White	Yes	Against	No
Alice	Skype	White	Yes	Against	No
Alma	Dwarfism event	White	No	Against	No
Allana	Home interview	White	No	Against	No
Alicia	Home interview	White	No	Against	No
Aria	Partial interview at dwarfism event + home interview	BAME	Yes	Conflicted	No
Ayaan	Home interview	BAME	No	Against	No
Addison	Partial interview at dwarfism event + home interview	White	Yes	Positive	Yes
Abbie	Home interview	White	Yes	Initially against, now regrets refusing	No
Amelia	Home interview	White	No	Against	No
Agatha*	Home interview	White	Yes	Positive	Yes
Amber	Skype	White	Yes	Against	No
Annabelle	Dwarfism event	White	No	Against	No
Áine	Partial interview at dwarfism event + Skype	BAME	Yes	Against	No
Athena	Home interview	White	Yes	Positive	Yes
Allison	Partial interview at dwarfism event + home interview	White	Yes	Conflicted	No

Table 2 Average Statured Participants

Data Collection

When discussing their preferred interview locations, many mothers requested that these take place during dwarfism event weekends. Interviews were usually conducted in their hotel rooms, away from the crowds, but were often interrupted by children or partners. As data collection progressed, I became increasingly aware of how the unpredictable and shifting nature of the field was shaping the research process. Participants had to navigate busy event schedules, often arranging interviews at the last minute to accommodate their limited availability. This sometimes resulted in interviews being abruptly paused mid-flow and resumed at a later time. The presence of others and the lack of privacy during some interviews may have influenced the data collected in these moments. As shown in the participant tables, some interviews had to be conducted over multiple sessions, as mothers found it challenging to fully engage amidst the demands of the dwarfism events. Balancing social commitments with participation in the study often led to distractions, necessitating the use of follow-up interviews. In such cases, recordings were paused, and alternative dates were arranged to ensure that participants did not feel rushed or interrupted. This might have impacted the 'final' data that was collected from these participants (but we will never know to what extent), as they may have, for example, omitted material when interviews were resumed.

For the most part, participants who wanted interviews away from dwarfism events requested that we make arrangements for me to travel to their homes. Initially, the most difficult obstacle to overcome in this research was navigating the geographical dispersion of participants. Fortunately, during this period in the field, online communication platforms, such as Skype, grew in popularity and had a positive snowballing effect on recruitment and data collection. Geographical location became less problematic; however, my perception of the differences was that participants tended to elicit more emotional responses during the in-person interviews than those which were conducted online. Harvey et al. (2024) suggested that communication medium can impact rapport building in qualitative interviewing and, as such, remote interviews may 'lose' some communicational features, which are important to the researcher in analysing discourse (this might also affect the length and depth of data from online methods). For example, the interviewer may be oblivious to the presence of others or distracted by sounds, smells, or objects in the room. To mitigate some of these recognised issues, when arranging Skype interviews, I communicated with participants the ideal of having a quiet and clear acoustic setting for the recording.

In light of my feminist driven perspectives, I drew upon frameworks inspired by life-story interviews (Hampshire et al., 2014) that seek to offer open spaces for women to voice their experiences (Griffiths, 1995; Ribbens, 1998), while facilitating greater turns to talk (Gubrium & Holstein, 2009; Riessman, 2008). At the start of each meeting, I requested permission to record the interviews, and all participants consented to this. Once participants were happy to proceed, I asked them to re-read the participant information sheet (Appendix A) and presented them with the research consent form (Appendix B). No participants withdrew after these steps.

The main topics I covered in the interviews were: (1) the dwarfism mothering journey; (2) connection/interaction with the dwarfism communities; and (3) medical decisions, and perspectives on surgeries and treatments. Furthermore, I offered the mothers a chance to add anything that they felt was pertinent but had not been covered during our interview.

The interviews always started with the opening question, '*Tell me about your journey with dwarfism, from the start*', which aimed to elicit a chronological life-story narrative from the subjective perspectives of the participants. This was a purposely broad question, as it allowed both dwarf mothers and average-statured mothers the same opportunity to offer their subjective experiences from their individual 'start' positions, recognising that dwarf mothers would have a different experience, perspective, and journey than those of average-statured participants. All narratives are inherently 're-'; they (re)tell, (re)construct, (re)produce, and (re)present our past experiences (Squire, 2008). Reflexive (memory) storytelling, as an extension, can be understood as an embodied expression; it is fundamental in how we communicate with others and ourselves about our lived experiences. Confronting our thoughts and co-constructing our 'realities', as we work through our feelings and beliefs within a particular time and space. Thus, this sharing of stories forms the structure for communicating our experiences and how we perceive the future, as well as how we engage in the moment (Smith et al., 2023).

Once participants had finished (re)telling their narrative, or if there was a natural pause or hesitation, I would follow up with probing questions by asking for clarification of some of the points that came up in the first narration. I aimed to make all interviews feel more like a natural conversation that a participant might have with a friend or acquaintance. I felt that a deeper focus on the emotional aspects of the project might be covered if participants felt that they were sharing this as part of a conversation. During the natural turn-taking of conversation, I would phrase a question to directly incorporate the next topic into the interview.

The spatial environments of the interviews did affect the data. My initial hotel room interview with Aoife, for example, had been going well until, when covering the topic of medical decisions, she asked to stop as she noticed her child had stopped playing and was 'listening in' on the conversation. Later, during her rearranged interview at home, she explained, *'I thought the kids would be engrossed in the events and not notice us, but I didn't want them having nightmares about the scary surgery stuff'*. Zimbalist (2022) noted how the presence of others typically resulted in bias or avoidance in reporting, especially with topics considered ‘sensitive’, as was the case with Aoife. The interviews that had taken place over Skype were all conducted in the evening, once children were preoccupied with other family members or asleep. The presence of other people in the background was evident in all cases; however, the potential impact this had on disclosure during the interviews is unknown, as I could not tell who was in the room at any one time, if at all.

No methodological approach is infallible to the inherent power relationships embedded in research. For example, a key issue that I felt I had to constantly manage during the data collection phase was the notion of ‘value’ judgements (Hoel, 2013), particularly in relation to the participants’ perception of me. I felt that some participants were trying to gauge my own personal opinions and positions concerning the topics raised during interviews. Some participants even turned the questions back on me, seeking consensus or even ‘approval’ that their actions aligned with their child’s best interest. Like other feminist researchers, when considering ethics and self-disclosure (Mapes, 2024; Oakley, 1981), I did my best to answer honestly about my own positions. Accordingly, when asked, I shared examples of how I had responded in similar situations, while emphasising that the research aimed to explore the diverse and subjective experiences within the communities as a whole, as opposed to prescribing or justifying a singular prevailing ‘right’ way to mother (Saville, 2020). Furthermore, participants were conscious and perceptive of others’ values within the communities, particularly when topics arose pertaining to medical decisions and treatments.

Feminists, such as Oakley (1981), advocated for self-disclosure as good practice in research, particularly in qualitative studies, as it fosters rapport and builds trust between researcher and participants. However, this practice comes with important limits. While self-disclosure can create a more equal and open research dynamic, it is crucial to maintain a balance to avoid leading participants or influencing their responses. In this study, I was mindful of the fine line between communicating personal experiences to build rapport and ensuring that participants’ perspectives remained the central focus. My approach was grounded in the awareness that excessive or strategically placed self-disclosure could inadvertently shape or steer participants' answers. The dwarfism communities I tended to engage with had expressed their concerns over the potential for harm towards dwarf bodies (and minds) in the discursive framing of topics related to medical issues and treatments. I deeply valued these communities, as during my own maternal experiences surrounding the medical difficulties of my son, these people with dwarfism had provided us with support that made us feel ‘normal’, at a time when we felt most vulnerable. Consequently, I sometimes felt defensive and protective towards these community perspectives. Reflecting on my positionality during the research, I carefully balanced my own sharing to avoid suggesting particular viewpoints or influencing the narratives that emerged. This allowed the participants to centre their own experiences, ensuring that their voices, rather than my own, led the research.

After conducting two interviews, I noticed, when listening back to the tapes, how our mutual understanding of context had offered up 'silences' and natural pauses in the audio recordings. For example, narratives that contained phrases like '*you know what I mean*' and other forms of shared or assumed knowledge created important absences in my data; absences that were significant to the 'stories' of the participants. I realised that I had to remain more alert throughout the interview process to these kinds of 'insider' pitfalls. To address these difficulties, I had to adjust my approach during interviews. I 'personified' my dictaphone that I used to do all the recordings. If I felt our dialogue was falling into 'mutual silences' and natural nods of understanding, I would stress, '*I know what you mean, but my dictaphone doesn't, so could you explain that to us like we're strangers and we don't know what you mean?*'. This was often followed up with laughter from both sides, as we felt silly in simplifying our conversation. However, this strategy worked to improve the richness and detail in the data generated.

The qualitative approach I utilised aided me in employing a variety of techniques, which resulted in generating rich, nuanced, and detailed data that was derived from context-specific personal stories. The stories were often co-constructed (Barkhuizen, 2013) as we took turns talking, co-producing the narrative together as we mirrored the flow of natural conversation (Mason, 2004). Consequently, I was embedded in the narration, either as a listener or as a co-participant. As a researcher, therefore, I recognise my part in the construction of these narratives (Riessman, 2008) and acknowledge my role as a contributor to the storytelling process. This approach facilitated a dynamic exchange of experiences and perspectives, enriching the depth and breadth of the data collected.

I made short recordings of my own thoughts via voice notes on my phone, which I later used to contextualise the research field. My experiences in the field assisted me in 'making sense' of how interaction formed part of the bigger 'story' (Barkhuizen, 2008). As a member of the communities I was researching, it is perhaps unsurprising that the boundaries between 'research work' and my own personal socialising, particularly within my support circles, were often fluid and difficult to delineate (Adler & Adler, 1997). Tedlock (1991) argued that the benefit to the observational researcher is that we can experience the shift from participant observation to observing participation and can witness our co-participation during an interaction. This resonated heavily with how I understood my embodied identities and the identity and role shift I was negotiating as a mother-researcher, which I discuss in greater depth later in this chapter. The research field permitted me opportunities to witness the 'social processes and circumstances through which narratives are constructed, promoted, and resisted' (Gubrium & Holstein, 2008: 256).

Braun & Clarke (2022), acknowledging the interaction between data collection and analysis, argued that such research was an 'iterative cycle'. Therefore, emerging themes and links across data sources were noted through 'inductive processes' during the data collection period. My fieldnotes also included several interpretations related to constructions of power, its relationality, and intersubjectivities. These notes fed into my data analysis and helped to drive the theoretical connections within the research.

Data Analysis

By the time I had finished actively collecting recorded interview data, the length of recordings ranged from 50 minutes to over three hours (with short rest breaks). Moreover, I had attended six dwarfism events during this period, conducting interviews and further recruiting for my study. After conducting the last of the interviews, I finished transcribing the recordings and checked the transcripts for accuracy. As previously described, the act of data collection was an 'iterative process' with simultaneous analysis (Braun & Clarke, 2022); therefore, most of my interviews had been transcribed along the way.

In line with interpretivist methodologies, which construct how we understand our social worlds, I chose to examine the data through a thematic analysis. I focused on examining the salient themes and patterns that were pivotal to how the participants understood and constructed their ‘realities’. In tune with my feminist interpretations of poststructuralism (Enns, 2010; Griffiths, 1995), the notion of objective ‘truths’ was rejected. The impetus of a reflexive approach to thematic analysis is its subjectivist foundations; the researcher’s positionality is recognised as contributing to the co-creation of meaning and knowledge within the research process (Braun & Clarke, 2006, 2022; Braun, Clarke & Hayfield, 2023). The interpretivist framework underpinning the analysis focused on uncovering the meanings individuals ascribed to their experiences. This meant that the analysis prioritised an understanding of how participants articulated their engagement with dwarfism communities, while also examining how these narratives were shaped by broader power relationships.

Reflexive thematic analysis, as conceptualised by Braun & Clarke (2022), is grounded in the notion that themes are not passively discovered but actively constructed through the researcher’s subjective interpretation. This reflexive method involves a recursive, non-linear process of coding and theme development. As such, this is a cycle that is continually informed by the researcher’s theoretical lens and evolving insights. This fluidity aligns well with an interpretivist paradigm, as it acknowledges the co-constructed nature of qualitative data and recognises the influence of the researcher’s positionality. Consequently, rather than attempting to minimise my own influence, the reflexive component became central to the analytical process. As the research progressed, I found that reflexive thematic analysis offered a malleable space for critically engaging with my own assumptions and 'realities', situating them alongside the conflicting or divergent experiences shared by participants.

Initially, I used the qualitative software package, NVivo, to organise the data. I began by reading through the transcriptions. I started coding each sentence of the data, originally grouping codes into broad categories. As the research progressed, I refined and sub-categorised these codes in response to the emerging conceptual relationships that developed between and within these thematic categories. Seven overarching themes have formed the direction of this thesis: ‘mothering’, ‘identity’, ‘intersubjectivities’, ‘dwarfism communities’, ‘dwarf culture’, ‘medical experiences’, and ‘decision-making’.

Researcher reflexivity was crucial as I navigated the tensions between my initial expectations and the data that emerged. The fluid adoption of grounded theory techniques (Charmaz, 2014), particularly constant comparison, enhanced the depth of the analysis by allowing me to iteratively test and refine themes against new data. As a result, the research did not aim to generate a singular or definitive account of the dwarfism communities, but instead to embrace the multiplicity of experiences and perspectives. This approach enabled a deeper exploration of how power relationships were negotiated within these communities and highlighted the complexity of maternal engagement, underscoring the need to account for the subjective and relational dimensions of the research process. By embedding reflexivity throughout the thematic analysis, I was able to critically examine how my interpretations were shaped by both my 'insider' status and the implementation of an interpretivist framework. This iterative process of self-reflection, coding, and theme development provided a rigorous yet flexible model for this project.

Mackenzie's (2019) interpretation of discourses stressed the subjective nature of its interpretation and how this can be affected by the analyst's positionality. Consequently, researchers do not only analyse participant narrative but also scrutinise the interplay of multiple contexts shaping narration, the researcher-participant relationships, their impact on data co-construction, and the ethical considerations in data selection and representation (Sharma, 2025). However, although as much as research reflects our own identities, it also engages with wider theoretical debates surrounding researchers who share commonalities with participants, and its influence on analysis and representation (Mauthner & Doucet, 1998, 2008). Thus, it is imperative to stress that the interpretations of the data within this thesis are mine. I align myself with Letherby's (2002: 53) perspective where 'presentation is filtered through my understandings, but at the same time I have made a self-conscious attempt to understand my respondents' understandings in their own terms'. In other words, an overriding research goal was to construct a space where participants felt that I had represented them fairly.

However, this does not mean that I have always agreed with the understandings that they had about themselves.

Ethical Considerations

This section outlines the ethical considerations that underpinned the research, as well as a reflexive account of my own subjective experiences as an ‘insider’ and mother-researcher. Ethical approval for this research project was granted by Aston University in 2017.

Risk of Harm to Participants

The topic of this research was always considered ‘sensitive’; therefore, participants were warned of the risk of emotional harm, as they would be sharing some very personal experiences and perspectives. Such topics can generate emotional responses and bring psychological harm to participants, particularly in areas of genetic technology and the participation of disabled people, where intrusive thoughts surrounding disability eradication and non-personhood may emerge (Shakespeare, 2008). To minimise this risk, interviews were designed to gradually cover these sensitive areas through a conversational interview design (Mason, 2004), at a location chosen by the participants. This method allowed participants to control their level of disclosure in a space where they felt comfortable. Additionally, participants were given time during and post-interview to reflect on their emotions regarding their experiences.

Risk of Harm to Researcher

There were both physical and emotional risks to navigate during the research. To mitigate any physical dangers to myself, if arrangements were made to meet at a participant's home, I would let my partner know the area, time, date and expected finish time of the interview. Additionally, he was able to track my smartphone location via an app. Importantly, within the spirit of confidentiality, I did not reveal who I was interviewing. After I had finished, I made a phone call or texted my partner to confirm I had left the site.

Being a mother to a child with dwarfism myself had, undeniably, the greatest impact on this research. It was this experience that drove and motivated me in all aspects, from theory to design. However, my positionality also delayed the progress of this research. The emotional toll that this took was more than I had accounted for. During the initial research design, I had felt an emotional distance from the whole topic of medical decisions. Personally, although our family had experiences of medical surgeries, for the most part, my son had recovered well. However, serious complications arose from a major surgery he underwent during my time in the field, resulting in a very traumatic and emotionally unstable time, not only for myself but for my whole family. At this time, I had little choice but to take a leave of absence from my PhD. After returning to the research over a year later, I found myself triggered and spiralling when immersed in the data. I felt that my 'home-life' was running in parallel to my 'work-life', and there was no separation or reprieve from my emotional suffering. The emotional recordings of mothers, having now experienced a traumatic medical procedure, made the whole topic a painful reminder as I struggled to manage emotionally detaching from these shared experiences.

Paradoxically, this time also deepened my understanding of participants' lives; it helped me grasp the magnitude and implications of mothering children with dwarfism during a period of significant biotechnological advances in healthcare. My experiences drove me to complete the research, as I appreciated its impact on experiential knowledge even more. However, the time it took to conclude this project resulted in a substantial and prolonged gap between conducting the interviews and writing up the thesis.

Therefore, reflecting back to my initial research design, I can now see that I did not give significant enough consideration to the risks I was taking to my own emotional well-being, even though this had been discussed with my Supervisors at the beginning of the project. As highlighted by Dickson-Swift et al. (2008), many researchers are drawn to areas that resonate with their own lives and experiences. A way to mitigate the risk of emotional harm, and one that I did take, was to adopt reflective practices throughout the research, which focus on the researcher's own experiences and emotions (Conolly et al., 2023). However, my own lived experiences as a mother to a son with dwarfism had also evolved from the time of the research proposal in 2015, as until 2020, most of the decisions I was making on his behalf had had no major lifelong consequences for his health and mental well-being. I had held a previously unacknowledged level of emotional distance between myself and my participants. I had believed that just reducing the number of participants from my own friendship and networking circles was ‘enough’ to create an emotional ‘buffer’. However, some experiences covered by participants during interviews became emotionally difficult for me to engage with during the data analysis. Listening back to tearful recollections, now having a different experience than I had at the time of the interview, raised new emotions and dilemmas for me. I struggled to gain a sense of perspective and found the whole project to be extremely emotionally draining to the point of near avoidance.

Confidentiality and Anonymity

The research process raised other ethical issues; for example, as the communities were comparatively small, there was always the possibility that participants knew each other (Shakespeare et al., 2010). The participants were all informed and warned throughout that this remained a risk, especially if participants came from close friendship circles. Therefore, confidentiality and anonymity became essential components. All identifiable features, such as names and, where appropriate, the number, ages, and genders of children, were altered or, in some cases, omitted entirely, to minimise the risk of identifying participants and their families. However, I acknowledge that in small or close-knit communities, complete anonymity can be difficult to guarantee, particularly when participants share distinctive features and life experiences.

To navigate these ethical complexities, I took additional steps by combining and/or generalising certain details. For example, by avoiding overly specific narratives and carefully selecting the excerpts for inclusion in quotations, thereby protecting the participants' identities, while preserving their 'voices'. As a feminist researcher, I was acutely aware of my ethical responsibility, not only in protecting the participants' anonymity, but also regarding the representation of their 'voices'. This required an iterative process of reflexive decision-making, in which I delicately balanced the pursuit of analytical depth with a sensitivity to the potential implications of representation. My aim was to ensure that the participants' 'voices' were both protected and meaningfully conveyed, in ways that remained authentic to their lived experiences, and the spirit of their narratives. Therefore, I informed participants that certain demographical characteristics presented in the research might be altered or omitted to protect their anonymity. However, these changes were cautiously considered to ensure that they did not compromise my interpretation of the data or misrepresent the 'voices' of the participants.

All data relating to this research was stored on my own password-secured drive, accessible only to me. Additionally, I stored a backup file of this data on the secure University virtual storage facility, OneDrive.

Informed Consent and Right to Withdraw

The British Sociological Association (BSA, 2017) outlined its expectations for ethical research, placing the responsibility for obtaining informed consent on the sociologist. However, the definition of 'consent' remains highly contested (Chase, 1996). In response to this ambiguity, I adopted Liamputtong's (2007) perspective that ethical research should be an ongoing process and also followed Miller & Bell's (2002) model of 'negotiated consent'. This approach views participation as entirely voluntary, allowing consent to be adapted and revised throughout the research process. For instance, during fieldwork, three participants were initially reluctant to take part in formal interviews. Their engagement began informally, but as our individual conversations progressed, it led to each participant consenting to take part in formal, recorded interviews. I regularly informed all participants verbally of their right to withdraw their consent at any time. All participants held copies of their own participant information sheet (Appendix A) and signed consent form (Appendix B).

In terms of communicating with the participants, I was mindful throughout that I was 'known' to the communities as a mother, not a researcher. Therefore, I had to be flexible in understanding that participants may have wanted to contact me through informal channels, such as Facebook, rather than my official university email address. To accommodate my participants' preferences, I followed a more informal approach to contact; communication and arrangements could be sought over the online support groups, as well as through my academic contact details on the participant information sheet (Appendix A).

Positionality: Reflexive Insider Research

My knowledge and understanding of the dwarfism communities are shaped through my own subjectivities, as an average-statured mother to a child with achondroplasia. As a mother, I have always encouraged my son to build relationships within the dwarfism communities, which, in turn, has deepened my own engagement and relationality with them. My awareness of the gap in the literature, which subsequently became the basis of this research, was informed through this personal involvement and proximity to the dwarfism communities. Ultimately, my relationality with these communities is what motivated me to design this research project. A reflexive approach to positionality is a way of describing how feminist researchers need to pay attention to the complexity of researcher/researched relationships. This involves not only recognising one's own embeddedness in the field but also acknowledging how knowledge is co-produced through these relational dynamics.

During fieldwork, I both experienced and witnessed how care-work was not only central but deeply entrenched in our everyday routines as mothers. This led me to reflect on the absence of substantial contemporary 'insider' research conducted by mothers within these communities, a gap that, given the demands on time and energy, seemed unsurprising. Negotiating the temporal constraints of this project alongside responsibilities for children, paid employment, domestic tasks and, for many of us, the cumulative emotional and physical exhaustion of constant caregiving, proved to be immensely challenging. These intersecting pressures illuminated the structural and embodied barriers that inhibited both the participation and production of this research. Reflecting on motherhood in academia, Jenkins (2020) highlighted how our constraints as mothers in the field influence who is able or unable to produce academic knowledge.

The beginning of my fieldwork and the recruitment of participants for this research was not the first time I had attended dwarfism community events; I had been embedded within these pockets of the dwarfism communities for six years or so prior to the project, even longer as an 'online' member. I had close friends, my own support network, and my sounding board in these spaces. These communities are important to me. They had supported me and my family during some of our most vulnerable moments. In particular, following my own experience of a 'biographical disruption' to my maternal identity (Bury, 1982), when on 30th September 2009, I received an unexpected prenatal diagnosis of dwarfism. It was the people within the dwarfism communities who had been able to step in and show us the mismatch between our cultural perceptions of dwarfism and their own lived experiences. Spending time within these spaces felt almost ‘healing’ for me. Largely, dwarfism was framed as a negative diagnosis during interactions in my everyday life; I recognised that by being in dwarf spaces with my son, I might be able to pre-emptively ‘protect’ him from the discourses that problematised his (beautifully perfect) dwarf body (Saville, 2020).

These deeply personal encounters not only shaped my relationship with the dwarfism communities, but they were also profoundly identity-shaping regarding my own maternal subjectivities. Consequently, my positionality and subjectivities heavily influenced the development of this research. I view my subjectivities not as a limitation, but as a valuable resource that brings emotional proximity, contextual sensitivity, and experiential knowledge to the research process (Boardman, 2017). Rather than striving for objectivity, I undertook the research reflexively, recognising the ways in which my lived experiences informed the research questions, interactions with participants, and analytical interpretation.

Goodley (1999: 36) has warned us, ‘when social contexts become research contexts, they are changed’. There have long been academic discussions surrounding the validity and ‘blurriness’ of so-called ‘insider’ research (Bulk & Collins, 2024; Cooper & Rogers, 2015; Griffith, 1998). In reflecting on my own identity, positionality, and theoretical leanings in this research, specifically, the Foucauldian and Goffmanian lenses through which I understand my own subjective experiences, I wrestled with the challenges to the relational dynamics and its influence on constructing our shared boundaries and realities in this study. This was most evident when I was undertaking the early analysis of the data; during PhD supervisions, my Supervisors would often find weaknesses or absences surrounding some of the more critical components of my interpretations. As a member of the dwarfism communities, I had aligned with many of their values. So initially, I easily overlooked many of the ways that power relationships operated within dwarfism communities.

Earlier, I discussed not knowing much about the clinical trials before starting this research; this was despite having undertaken two previous projects within the communities. I also discussed how only one out of three dwarfism organisations decided to offer the recruiter of the drug trials a platform at their conference. Offering a more critical reflection, it is important to acknowledge that *all* communities will actively shape the discursive boundaries of their spaces, and power operates to regulate the (re)production and circulation of knowledge within community contexts (Foucault, 1977). This underlines the embeddedness of power in seemingly supportive spaces, where the politics of representation and silence often reflect broader social hierarchies and normative discourses (Rabinow, 1996). Thus, representation is never neutral; it is always implicated in power, even within dwarfism communities. Hence, while the dwarfism communities provided essential support, some members felt constrained by what they were able to express, particularly around topics deemed too politically charged, emotionally difficult, or disruptive to community cohesion. In this sense, the communities determined which narratives were (re)produced, which were marginalised, and which were silenced. In doing so, they helped shape the normative discourses through which community members came to understand themselves and others. Recognising that these tensions exist does not diminish the value of the dwarfism communities. Rather, the research process challenged me to confront and critically reflect on how power operated within them, and how the knowledge they (re)produced was always shaped in relation to wider cultural, institutional, and biopolitical discourses (Rabinow, 1996).

Researcher positionality refers to a researcher's biography, emphasising the contexts that shape their identity, which in turn affects their perception and understanding of the social world. The researcher-participant relationship is a key aspect of reflexive practice, where different positionalities interact and shape the research process and potentially influence the data (Bukamal, 2022). In this vein, I recognise my own influence on the data presented, as it contains my own interpretation of our shared realities (Dinçer, 2019). However, Bulk & Collins (2024) argued that merely sharing characteristics was not sufficient enough to feel like or be perceived as an ‘insider’. They posited that an ‘insider’ is a nonbinary, fluid identity. It is an amalgamation of the complex subjectivities of researchers, participants, and their communities. One example of this amalgamation between relationality and positionality that I experienced was in the planning of the project’s timeline and research stages. My ‘insider’ status shaped not only the analytical and ethical dimensions of the project but also its more practical aspects. For instance, establishing clear boundaries for entering and exiting the research field were hard stages for me to define (Franco & Yang, 2021). As a member of multiple dwarfism communities, I was always, in some sense, ‘in’ the field. Even after formal data collection had ended, I never truly ‘exited’ the field; rather, I simply stopped conducting interviews and marked an end to my role as ‘researcher’.

The blurred boundary between fieldwork and ongoing community involvement complicates the linear framing of traditional research timelines, illustrating the enduring, relational nature of 'insider' research. However, as hooks (1984) so eloquently argued, when you live on the margins, you know *both* margins and the centre; it is from these oppositional positions that researchers can examine their own interconnected ‘realities’.

Similarly to others (e.g., Ademolu, 2023; Bulk & Collins, 2024), the question as to the extent to which I was seen as an ‘insider’ or an ‘outsider’ was fluid, and one that had to be continuously negotiated and reflected on. I could not deny or reduce the significance of my identity and positionality with respect to this project. Undoubtedly, *it did matter* to the success of this research how participants viewed me. Fundamental to these theoretical considerations is an acknowledgement of the presence of power in relationships and social interactions. Fayard & Van Maanen (2015: 11) asked, ‘Who are the insiders? The outsiders?’, arguing that often positions become ‘blurred and indistinct’. Without a doubt, my participants and the wider dwarfism communities *did* recognise me to various degrees as an ‘insider’. My own experiences reflected this sentiment. At times, I felt wholly an ‘insider’ within dwarfism spaces, especially when talking about our children. However, at times, this feeling would shift; as somebody without dwarfism, I was still considered an ‘outsider’ by some dwarf mothers.

As an average-statured mother, my proximity to dwarfism as an ‘observer’ of the ‘realities’ of dwarfism, rather than as a woman who had a lived, embodied experience of dwarfism, did become a topic of discussion during this research. For example, while negotiating contact and during interviews, some dwarf mothers shared their concerns around my ability to accurately portray their lives. We see these nuances drawn out, for example, in Chapter Five, with Ruth, where she discursively distanced her experiences as separated by our embodied realities as she justified her position with, ‘*No offence, but average-height mums don't have to deal with* […]’. At community events, some women with dwarfism would discuss my own positionality and question my ability to be an ‘expert’ on the topic of dwarfism, legitimately noting my stature and embodied identity as a limitation to my experiential knowledge. This was similar to Pritchard's (2023) experiences and argument. I felt that these negotiations were really about relational power, and *who* should qualify to 'share' with the world the discourses that construct the realities of dwarf lives. They did not implicitly state that I was an 'outsider' but implied the 'blurriness' of my status. In this sense, as I have previously reflected: 'I occupy a peculiar space: not quite insider, not quite outsider' (Saville, 2020: 634).

In contrast, I felt that average-statured mothers generally assumed that because I also had a child with dwarfism, I possessed adequate 'insider' knowledge and experiential competence to re(tell) their stories. As discussed earlier in this chapter, this dynamic became evident from the very first two interviews when, upon reviewing the recordings, I noticed that certain details had been left unspoken. The participants appeared to rely on our shared knowledge and, rather than offering fully elaborated narratives, had instead said things like, '*you know what I mean'*. These moments of interview 'silence', spaces where richer descriptive data might otherwise have been articulated, highlighted how our relationality, while fostering trust and rapport, also risked limiting the depth of description by allowing our shared understanding to stand in for explicit detail. I recognised that some 'missing data' arose as a consequence of my positionality and proximity to this topic of research.

Given the heightened recognition in sociology and critical disability studies of the importance of emancipatory and participatory research methods (Barton & Hayhoe, 2021), I realised that by acknowledging I occupied a 'simultaneously-both' insider/outsider position, the project could become:

> part of how I tried to challenge the insider/outsider dichotomy, as it presupposes that researchers in social structures cannot be located differently in terms of one social status, category, group affiliation, or even several categories; hence, they can be simultaneously both.
>
> (Jabiri, 2024: 87)

In acknowledging my own subjective self in the telling and (re)telling of other mothers' experiences, I accepted Charmaz's (2014: 14) invitation to consider my findings as interpretive constructions of our shared realities, rather than 'accurate renderings of these worlds'. Having explored my methodological decisions and positionality in relation to this research, the following section goes on to discuss some of the study's limitations.

Limitations of the Study

One of the primary limitations of this study was in how I recruited the participants. All mothers who took part in this research were members and involved (to different extents) with the dwarfism communities in the UK. This meant that the perspectives of mothers outside of the dwarfism communities did not form part of the data. To address this limitation, I reframed the scope of the project to consider the maternal experiences and perspectives of those mothers who were members of dwarfism communities. I was then able to theoretically explore the ways that some maternal behaviours were regulated through power relationships within dwarfism communities.

Moreover, participants were largely situated within a particular socioeconomic context; attendance at some of the dwarfism events can be financially exclusionary to some families. As I recruited from these communities, middle-class participants were largely over-represented in the data. While I offered to conduct interviews online and travel to participants' own locations to help mitigate the financial burden of participation, these measures did not address the underlying limitation, as all participants were already members of the dwarfism communities. Therefore, the maternal perspectives offered in this study may not reflect the experiences of mothers located in other social or cultural contexts.

In considering the limitations of this research, and in line with postmodern feminist understandings, the findings of this investigation do not attempt to make any claims of 'truth' representative of the dwarfism communities. The narratives examined within this work are the participants' own stories and experiences, unique to them. I have not attempted to make universal generalisations based on this study's findings; nevertheless, this research contributes important new perspectives and insights into an understudied population who are deserving of more empirical investigation.

Conclusion

This chapter has detailed the ontologies and interpretive feminist epistemologies that underpinned this research. The broad aim here was to implement qualitative methods that could help explore the maternal experiences of mothers within dwarfism communities. In this chapter, I have explained my methodological choices by considering the goals and aims of the project laid out in Chapter One. I also recognised the impact of power relationships in research and how this affected the study. To this end, and in alignment with feminist traditions that emphasised the importance of centring women's voices (Ribbens, 1998), I deemed in-depth interviews the most suitable method to gather participants' narratives. This method facilitated the elicitation of rich, nuanced accounts that captured the intricate and multifaceted nature of maternal subjectivities. By including both average-statured and dwarf mothers, the approach enabled a deeper and more nuanced exploration into how maternal subjectivities were (re)produced and negotiated within dwarfism communities. I discussed how I recruited for this project and the difficulties I faced during the fieldwork. I also drew attention to the ethical dimensions of this project, for instance, issues of consent, safety considerations in research, data handling, and confidentiality.

I have described the data analysis process; I discussed how I adopted a fluid approach to thematic analysis, which was supported by NVivo software to efficiently manage and organise the extensive dataset. This approach was particularly effective in identifying recurring patterns and discourses while remaining attuned to individual differences in participants' narratives (Braun & Clarke, 2006, 2022). The analysis framework aligned with poststructuralist feminist principles, which prioritised the lived experiences and voices of women, to critically examine the intersections of power, identity, and subjectivity. This framework was instrumental in unpacking how broader societal discourses and community norms intersected to shape maternal experiences. I have reflected on how the methodological approaches recognised my mother-researcher positionality and how it became a key element in the co-construction and interpretation of this project's data. I also considered my positionality in light of the critiques, ethical considerations, and implications of 'insider' research, as well as how my feminist perspectives drove the research design and decisions throughout the project. The findings that will be discussed in the following chapters are deeply rooted in the methodological decisions and perspectives outlined here.

Finally, this chapter reflected on the study's limitations, particularly regarding the recruitment of participants, which only included mothers who were embedded within dwarfism communities. Therefore, while valuable for understanding the maternal dynamics at play within dwarfism communities, it inevitably excluded the perspectives of mothers from outside these contexts.

The following three chapters of this thesis go on to present the data and findings of this research project. As a researcher, I have positioned myself alongside existing feminist understandings of ‘truths’; I have reiterated that this project does not attempt to make ‘absolute truth’ claims. Therefore, I restate the position of this research and its findings as interpretive constructions of our shared realities, rather than ‘accurate renderings of these worlds’ (Charmaz, 2014: 1).

Chapter Four – Maternal Subjectivities: Mothering Children with Dwarfism

Introduction

This first data chapter begins by exploring maternal experiences of a dwarfism diagnosis, analysing the distinct relational contexts of average-statured and dwarf mothers. Drawing on the conceptual frameworks outlined in Chapter Two, this chapter examines how ideals of 'good' mothering (Hays, 1996), stigma (Goffman, 1963), and regulatory discourses of power (Foucault, 1972, 1977, 1988) converge to (re)produce maternal subjectivities. The chapter explores the ways in which dominant discourses surrounding disability disrupt maternal identities, (re)producing stigma and feelings of isolation, which profoundly shape these mothers' subjectivities.

The following section draws attention to how the gendered construction of mothers mediates these experiences, with both average-statured and dwarf mothers encountering the regulatory pressures of 'good' mothering. Building on Hays' (1996) concept, this chapter underscores how women are held accountable for perceived adversities stemming from their children's disabilities; reinforcing the intersections of maternal responsibility, stigma, and blame. This view is then examined in relation to participants' profound desires for normality, focusing on their management of stigma and their public presentation of 'face' (Goffman, 1955, 1963). The strategies employed by some mothers can (re)produce a complex dynamic of (m)othering; while these strategies help mothers navigate stigma, they can inadvertently reinforce dominant narratives that marginalise disability (Rogers, 2007; Tringo, 1970).

Through an interpretive analysis of these dynamics, this chapter provides a nuanced exploration of the (re)production of maternal subjectivities. The findings illuminate the interplay between cultural discourses, embodied experiences, and maternal agency, offering sociological insights into the intricate power relationships at play. This first data chapter lays the groundwork for the subsequent chapters, which will build on the themes developed here; exploring how maternal experiences are influenced by dwarfism communities (Chapter Five), and how maternal healthcare decisions are an example of the way that subjectivities and biopower within the dwarfism communities are lived and negotiated (Chapter Six).

Un/Expecting Mothers: The Experiences of a Dwarfism Diagnosis

The experience of being given a diagnosis of dwarfism for their child varied considerably for mothers in this research. One of the key differences in receiving this information was driven by whether or not the mother (or father) had dwarfism themselves, due to hereditary instances of dwarfism being a distinct possibility in pregnancy for these parents. In these cases, women were usually offered early screening to ascertain: first, the viability of the pregnancy/foetus; if both parents have dwarfism, there is a 25% chance that the foetus will be incompatible with life (as I discuss below) and, as such, a termination is usually offered (Pauli, 2019). Second, if dwarfism is present, to monitor growth, have oversight of any of the common co-morbidities (such as hydrocephalus) related to dwarfism, and to prepare for any future intervention referrals post-pregnancy. Finally, to monitor the health of the mother and plan for the birth. As is the case for all women with dwarfism, a caesarean section is strongly recommended. This is largely driven by safety precautions based on dwarf physiology, for example, the pelvic size of dwarf women being smaller than average and not being compatible with the macrocephaly (enlarged head circumference) of dwarf babies (Brar et al., 2023; Ornitz & Legeai-Mallet, 2017).

The terms ‘double dominance’ and ‘double dose’ are commonly used within dwarfism communities to refer to the lethal risk of homozygous achondroplasia and phenotypically similar skeletal dysplasias (e.g., hypochondroplasia). When both parents have phenotypically similar dwarfing conditions, there is a 25% likelihood of homozygosity. This happens at conception, when the genetic mutation that results in skeletal dysplasia is inherited from both parents. The lethality associated with, for example, homozygous achondroplasia, is due to 'doubling' the severity of the existing significant health risks that are present in heterozygous achondroplasia, such as restrictive pulmonary disease and cranio-cervical junction constriction (Pauli, 2019).

Expecting: Dwarf Mothers' Experiences of a Dwarfism Diagnosis

During interviews with mothers where dwarfism was a known possibility (because they or their partner had the condition), women's encounters and their experiences of the diagnosis were often narratively retold to me, in the majority of cases, as uneventful, ordinary, and even expected. As Radha (whose partner was average-statured) remarked, '*completely expected, as well, because I have it, so I was prepared'*. This was often in sharp contrast to my interviews with average-statured women (with average-statured partners) who, as I will outline later, often experienced the process through a lens of shock and, for some, devastation. The majority of participants who had dwarfism described how the diagnosis journey, very quickly, took a medicalised route. Roisin, for example, expressed:

> The minute I was under a midwife, it was countless appointments which took away from my novelty of pregnancy. The hospital was really clinical, and I was constantly monitored and scanned; it really gave off the idea that I or she [the baby] was sick. They kept telling me stats and risk percentages.
>
> [Interview, 2018]

Roisin's narrative described how her endless hospital trips had overshadowed her '*novelty of pregnancy'*, as the persistence and intensity of her pregnancy became medicalised and '*gave off the idea that I or [the baby] was sick*'. Roisin's perceptions of her experiences drew parallels with previous findings by Daniels (2019), who argued that disabled pregnant women are subjected to increased medicalised surveillance. Of course, this is not to say that frequent visits do not also make up the experiences of other high-risk pregnancies in non-disabled women, and there can be clear medical justifications for this approach. For Roisin, however, her perception of the focus within these visits to reiterate '*stats and risk percentages'* (her partner was average-statured, so was not at risk of lethal double dominance) led her to the feeling that dwarfism itself was seen as being 'risky'. Through this lens, the very action of Roisin becoming pregnant, as a disabled woman, could have been judged as 'risky' behaviour as she could potentially pass on her 'spoiled identity' to her child. Thereby, contradicting the norms and expectations of 'good' potential mothers, who are expected to act and make decisions that minimise risk (Boardman, 2011; Frederick, 2017).

Like Roisin, Rhia, who had undergone genetic counselling during her journey to motherhood, felt that her pregnancies were frequently overshadowed and defined by 'risk' narratives. However, her pregnancy experiences were situated within a different context of 'risk'. As her partner also had dwarfism, she *wanted* to be monitored early, to avoid progressing with a pregnancy affected by lethal double dominance. She reflected back on these experiences:

> The sessions were all about the risk of inheriting achon [achondroplasia] and if I understood the outcomes. So, this one time [geneticist] asked if I understood what risks I was opening the baby up to [double dominance] […] but, like, what's the alternative if you're in a dwarf relationship? There was definitely a tinge of judgement there, like we brought this on ourselves.
>
> [Interview, 2018]

We can see from Rhia's narrative how she had a different view of medical surveillance. She saw advantages to early medical interventions because of how these could benefit her on her journey to motherhood. However, Rhia also felt that 'risk' was contextualised in the sessions to judge and assign blame towards her decisions. In Foucauldian terms, the biopolitical dimensions underscored the ways in which power operated through the regulation and management of Rhia's *individual* maternal behaviours and decisions, particularly in matters related to health and risk. However, Rhia's experience also challenged the notion of passive compliance with these discourses. Instead, she actively negotiated the complexities of these power relationships, demonstrating her agency in navigating healthcare systems to achieve her personal reproductive goals. By strategically engaging with and, at times, conforming to the labels of 'risk' assigned to her, Rhia's narrative demonstrated a nuanced form of healthcare agency. This agency involved not only resisting dominant narratives but also leveraging them to secure desired outcomes, even when doing so could subject her to forms of judgement. Rhia's narrative also revealed the complexity and interplay of power relationships, demonstrating how mothers managed their subjectivities and choices within the constraints of disciplinary regimes.

Describing their experiences of pregnancies affected by double dominance, two participants discussed how they managed the emotional and practical elements of being pregnant. Both had chosen to terminate, and both had gone on to have more children. Rhia described how, '*it's important when you're in an achon relationship, not to think of the [positive] pregnancy test as a definite'.* Here, Rhia discursively constructed a distinction and distance between having a pregnancy and expecting a baby. She further elaborated, '*if you take it on [being a dwarf couple], you accept that you might need a few goes [pregnancies]*'. Another participant, Rachael, had experienced multiple pregnancies affected by double dominance. She described the experiences of diagnosis as being '*routine'* in a methodical sense. Her medical team had got to know her family very well throughout this period, so whenever Rachael arranged to receive results, the same person was assigned to deliver this news. Again, Rachael approached this period in her life very systematically and retold her story with very little emotion, demonstrating, like Rhia, an ability to not invest emotionally in a pregnancy until the outcome of genetic testing was known.

Previously, research by Rothman (1986, 1993) examined how scientific advances in prenatal screening have changed women's experiences of their pregnancies.

This behaviour, defined by Rothman (1986, 1993) as a ‘tentative’ pregnancy, described how women managed early pregnancy through balancing emotional investment, with the risks associated with the loss of a pregnancy. She observed how pregnancies had to be tentative while waiting for amniocentesis results, in case women had to make abortion decisions. Similarly, Rhia and Rachael both described acting in ways that would minimise their emotional investment, until a time when they considered the balance of ‘risk’ to pregnancy to be reduced. However, it is important to highlight here that both participants had received an early prenatal diagnosis. Crucially, the experiences of women who discovered that they were affected by double dominance late into pregnancy, or after birth, did not form part of the data for this research. Therefore, analysis in this area of data is limited to the experiences of early detection.

Un/Expecting: Average Statured Mothers’ Experiences of a Dwarfism Diagnosis

As previously highlighted, cases of dwarfism are ‘rare’, with the most common form of dwarfism, achondroplasia, affecting only 1 in 25,000 births (Pauli, 2019). As such, it is not part of the routine NHS prenatal screening programme. Consequently, doctors might not have frequent encounters or experiences with diagnosing dwarfism. Therefore, when cases do occur, doctors may not have the resources available to support new mothers.

Aoife discussed how her feelings of anxiety were exacerbated by the lack of support during diagnosis:

> The geneticists, paediatrics, all of them, just gave us leaflets. We actually wanted to talk to somebody about this [a medical dwarfism expert] as it's all new to us, but they just said to call the RGA […] we came up against that frequently […] they tell you [at diagnosis] not to Google anything as it might be scary or wrong, but how else are you going to find out when the paediatricians don't even know about it?
>
> [Interview, 2018]

Aoife described feeling distressed by being handed leaflets during such a pivotal moment in her life. These materials not only failed to offer the depth of support she anticipated but also included directives discouraging her from independently seeking information online. Her experience highlights a critical tension: while some doctors remain sceptical of patients relying on 'Dr Google', as people turn to digital repositories in information-seeking behaviours, at the same time, there is official encouragement in the use of online systems (e.g., NHS App and nhs.uk) to alleviate pressures within healthcare organisations.

Experiences of pregnancy were different for average-statured mothers, as dwarfism was not usually an 'expected' outcome (except for women with dwarf partners). Therefore, when cases did arise, average-statured mothers usually found out postnatally, or late into pregnancy. As such, these 'un/expecting' mothers tended to recount their experiences through a lens of maternal identity disruption (Landsman, 2009). Here, I draw a parallel with 'biographical disruption', as theorised by Bury (1982). In his research, Bury (1982) conceptualised that becoming disabled or ill (he gave the example of having arthritis) was a 'critical' moment in the life-course; one which may challenge our imagined futures through our perceptions, our sense of self, as well as the relationships we build with others. The majority of average-statured mothers articulated, to some extent, how their feelings around diagnosis were influenced by the recognition that having a disabled child would cause a disruption to the 'norm'.

During the interviews, most average-statured mothers emotionally recounted the shock and subsequent disappointment they had experienced on learning that their child had dwarfism; this was irrespective of whether the diagnosis was confirmed pre or postnatally. As these narratives will illustrate, mothers often initially experienced the news as a loss of 'potential' in their future child; they would refer to the experience using words such as '*grief*' and '*loss*' to recount this time in their lives. There were often periods after diagnosis when mothers felt that they were going through a grieving process. One participant, Amyna, journalled her feelings at the time in a diary she kept throughout pregnancy. She described to me how she ended up burning the book in her kitchen sink (rather than, for example, throwing it away), due to the guilt she felt in what she had written, and fear that someone could find it and know the '*truth'* in how she felt about her child during the time of diagnosis. She was particularly scared about what her partner would think of her as a mother. Reflecting back, she was embarrassed about her feelings:

> Oh, the utter anguish, I can't describe; well, I can describe, but it's just awful saying it. Terrible saying it, but oh my God, the absolute devastation. The problem is, I'm there crumbling on the inside, but … if I look too freaked out and disgusted, then what's his dad and the doctors [going to] think of me as a mum? But like, oh my God, I'm young, like a teen mum, so I'm already being judged for that, but I'm thinking my first one was healthy and everything, and now this. And it doesn't even make sense because all the way through [pregnancy] the scans are fine, nothing was said, everything was perfect. How the actual fuck can this be happening?
>
> [Interview, 2018]

In this quote, Amyna described her feelings through multiple lenses of stigma, intersecting with an expectation that her actions and/or emotions may be damaging to her identity as a 'good' mother. First, she described being personally ashamed of her feelings of '*anguish*' and '*devastation*', which she attempted, as Goffman (1963) would suggest, to 'manage'. This involved resisting the external stigma and perceptions of others (namely her partner and the doctors) that her feelings were at odds, unacceptable even, to what a 'good' mother would feel in the same circumstances. Second, Amyna revealed that she felt *'judged'* as a '*teen'* mother. At the time of the interview, she had two children; her first was born during a time she called her '*Sixth Form years*'. Importantly, perhaps, was that although her child with dwarfism was born when she was in her early twenties, Amyna still perceived herself, in terms of her mothering identity, to be a 'teen' mother. She had internalised the judgement levied at herself and other teenage mothers, because 'teen' mothers are not discursively situated within the context of 'good' mothers (Varadi et al., 2020). Finally, by noting that she felt that she was '*already*' being judged as a teenage mother, Amyna also attempted to position herself as a 'good' mother by reinforcing that her first child was '*healthy*'. Her reference to '*now this*' identified the external narratives that may be threatening her position as a 'good' mother. Here, she could be attempting to demonstrate the distance she was trying to build between herself and the past stigmatising mothering identities. However, '*now this*' (having a disabled, dwarf child) challenged, yet again, Amyna's desire to experience idealised versions of 'good' motherhood that are constructed around healthy, non-disabled children.

Aoife's feelings echoed those of Amyna's. She too felt constrained by her concerns over others' perception of her emotions, not wanting to show her true feelings for fear of being judged by others, particularly her partner:

> When it was just the two of us at home together, he was there all swaddled up with just his face showing. His arms and legs were hidden by the blanket. Read into that what you will … but I would hold him and just cry. He would be there smiling up at me, not a worry in the world, and I hold onto him, rocking back and forth, looking into his face, just crying. One day, my partner walked in on

> me, and he must have seen it before, because he said, 'You need to stop doing this; stop feeling sorry and just take him as he is'. I don't know who I was feeling sorry for more, him [her child] or me. Thinking back, I still don't. It's become so much of a blur.
>
> [Interview, 2018]

While Aoife relayed her story, she also attempted to process her feelings, for example, her own admissions, '*read into that what you will'* and '*I don't know who I was feeling sorry for more [...] I still don't*'. As Aoife's narrative highlights, there can be feelings of shock and confusion that, to outsiders looking in, may present like a rejection of the situation, or even the child. Even within the confines of a confidential interview, Aoife attempted to avoid voicing her feelings honestly, as she expected judgement, recognising my own subject-position as a mother-researcher. Runswick-Cole (2013) explored the intensive emotional labour that mothers with disabled children must undertake to resist negative connotations and 'deficit' discourses getting attached to their experiences. Similar to Brock's (2015) findings on disabled motherhood, when reflecting on their sense of self, participants in this research rarely spoke about their position as partners in intimate relationships. Aoife's framing of her partner is significant, in that, like Amyna, she too felt as though she could not escape the judgement and expectations of what it meant to be a 'good' mother to a disabled child; as normative judgements surrounding the 'good' mother concept also operate within familial relationships and intimate partnerships.

The data here illustrates how maternal subjectivity involves a complex interplay that goes beyond the physical labour of caring for children; coined ‘maternal thinking’ by Ruddick (1980, 1989), the term describes the hidden emotional labour that women undertake due to normative expectations of gendered behaviour. This also includes the ‘appropriate’ management of feelings and emotions, for the benefit of others (Hochschild, 1983). In managing their identities as ‘good’ mothers, women like Amyna and Aoife (aware of how their emotional expressions may be perceived by others) will make attempts to mitigate stigma by masking their true feelings. Goffman (1963) noted that cases of stigma management were often undertaken by those who recognised their own stigmatised identity and would try to manage its effects on their perception of self, by undertaking ‘face-work’. This notion was also conceptualised by Foucault (1977), who posited that the panoptic society produces docile bodies; individuals who, having internalised disciplinary practices, behave as if perpetually under surveillance, even in its absence. Likewise, Budds et al. (2017: 347), for example, emphasised how mothers will discursively (re)produce ‘the expectations placed upon women to engage in a technology of the self – to act upon themselves and shape their subjectivities and practices in accordance with contemporary norms and expectations of motherhood’. For participants, such as Amyna and Aoife, their narratives revealed the powerful role of discursive forces in shaping maternal subjectivities and regulating gendered behaviours. Hence, whether they actually encountered external judgement or merely suspected it was almost inconsequential. Their perception of being under surveillance demonstrated how societal norms and expectations infiltrated maternal identities, influencing how mothers navigated their roles within these regulatory frameworks. Thus, their narratives underlined the pervasive impact of disciplinary power and cultural discourses in shaping their 'realities'.

These mothers' comments reflected existing findings from the wider bodies of literature that recount the subjective experiences of mothers who have disabled children, from the lesser explored perspective of dwarfism, and how these mothers managed and internalised stigma. The participants in this research demonstrated that their mothering practices often involved the complex interweaving of emotional investment, the careful management of self-presentation, and the challenging task of resisting dominant discourses while internalising a devalued social status. As Landsman (2009: 10) asserted, '(m)others of disabled children make their way within a society that devalues their children and in which their motherhood has 'failed' to follow the culturally appropriate trajectory'. The narratives of average-statured participants demonstrated how they understood their child's diagnosis as having disrupted normative discourses around idealised motherhood and, therefore, challenged their own perceptions of 'good' (normative) mothering practices, which they had imagined their futures would hold (Blum, 2015; Green, 2002; Landsman, 2009).

The following section further explores participants' experiences in relation to stigma. It illustrates how average-statured mothers, in managing their own stigma by distancing themselves from dominant discourses that marginalise disability, could inadvertently (re)produce the very hierarchies of disability that perpetuate cycles of stigmatisation (Rogers, 2007). The embodied positionality of dwarf mothers meant that, unlike average-statured mothers, they could not distance themselves from stigma in the same way. Some internalised this through self-stigma, while others sought to subvert it by distancing dwarfism from social constructions of disability. Therefore, showing how understandings of disability and dwarfism, even within similar communities, are nuanced, fluid, and subjective.

Maternal Subjectivities: Negotiating 'Normal'

The notion that there was a 'normal' motherhood was often assumed, and craved, by *all* the participants in this study. For example, there was often reference to 'normal', whether that was in the bounds of social activities, home/school equipment, or child development.

Subjective Experiences of Average Statured Mothers

It was the visibility of difference, of dwarfism, which contributed to the emotional feelings of disconnect from 'normal' motherhood; for many average-statured mothers, the use of the word 'normal' became a synonym for the absence of disability. For example, Aria told me, '*I just want people to see that we're normal, not a spectacle, but real people*'. Similarly, Allana also described the emotional and practical mothering work she undertook to shield her child from the unwanted attention that they received in public. She explained how her dwarf child had been given a birthday party invitation from a classmate, and had been extremely excited, and was looking forward to the day. However, she later discovered the party was at a theme park, and her child would not be able to meet the height requirements of the (age-appropriate) rides. To add further offence, a parent suggested that her child still attend, and classmates could 'take turns' to use the 'baby' rides with them. Clearly upset, she told me that the '*hidden'* parts of mothering, for example, having to mentally deduce the least '*disruptive'* ways her child could participate in '*normal'* activities, without having what she considered '*encroaching'* adjustments, took up her time. As her child knew of the party, it was not as easy to avoid the topic entirely. She was thinking of ways to balance going to the party with not '*standing out'*. If done 'well', she took fulfilment in the mundane enjoyment of normalcy. However, if things did not align with her hopes of '*normal'*, she feared the repercussions could fuel the notion that they were 'abnormal' and, consequently, she feared that her child might be ridiculed in public.

Again, it was as Goffman (1963) described, the stigma of difference, which exacerbated the detrimental feelings that mothers felt towards their circumstances. The normative expectations surrounding motherhood (Ginsburg & Rapp, 1995; Landsman, 2005, 2009), combined with the *perception* of stigma felt by participants, intensified mothering work and disrupted maternal subjectivities, shaping how they constructed their roles and identities (Landsman, 2009). Interestingly, these feelings were sometimes mirrored by participants onto other mothers within the wider disability community groups, as highlighted by Audrey:

> In the early days, we were referred by Portage or Early Support[4], I don't remember, [it was] one of them, to this baby group, just for babies with disabilities. I was new to the area. I didn't know anybody. None of the neighbours had children, and I'm not sociable at all, still not, and plus, Portage said that they would pay for the taxi every week to go to this baby centre and drop me home, as they saw it as a benefit. […] Well, the taxi started picking other mums up on the way, and I just started to sink, like my heart just dropped […] There was about 10 other mums with babies with all different disabilities, and I just felt like this wasn't me. My baby could sit up, smile, clap, drink from a bottle. Some babies had tubes coming out. I didn't fit in; I didn't want to fit in […] I remember saying to Portage, I didn't want to go again. […] When she asks why, what can I say? The truth? Nah, of course not […] I said the children there are way more disabled than my baby, and I know my baby has a disability, but it's not that bad where we need that kind of intervention.
>
> [Interview, 2018]

---

[4] Portage and Early Support are early interventions for disabled children. These provisions are usually referred on to by a Health Visitor.

The emotional anguish in Audrey's voice as she retold her story arose, predominantly, from an internalisation of the societal discourses that surround disability. Audrey described the conflicting emotions, '*I just felt like this wasn't me*', while also realising that she harboured internalised ableism through her own disclosure, '*what can I say? The truth? Nah, of course not*'. Although Audrey had initially avoided telling '*The truth*', she reversed this decision when she felt that her child was being associated with other disabled (stigmatised) children. Thereby, she attempts to manage their 'spoiled identity' by putting forward '*The truth*' and, as a result, positions disability through a hierarchical lens (Rogers, 2007; Tringo, 1970) when providing her justification, '*I said the children there are way more disabled than my baby, and I know my baby has a disability, but it's not that bad […]*'. Similar feelings have been previously highlighted by Yanes et al. (2024), who argued that the stigma of disability and the internalisation of ableism start before birth. However, resistance to these stigmas may also (re)produce forms of ableism, which are played out through interactions, as was evident in Audrey's interview. Audrey's narrative illustrates some of these complexities; attempts to manage her 'spoiled identity' further marginalise (m)others and children with different disabilities. Although not intentional, she had internalised and (re)produced a damaging narrative, which assumed the existence of disability hierarchies (Rogers, 2007; Tringo, 1970). As a consequence, Audrey attempts to manage her own stigma in relation to this.

As has been argued, ‘stigma is not solely the outcome of societal devaluations of differentness: in order for stigma to exist, individuals possessing such differentness must also accept this devaluation’ (Jacoby, 1994: 269). The data established that although mothers may not have considered dwarfism a ‘devalued’ identity, they acknowledged that, socially, dwarfism was perceived as devaluing; an association which could, in turn, devalue their own identities. Goffman (1963) observed how stigma also operates relationally; individuals in society are often judged by their proximity to it, a process he referred to as ‘courtesy stigma’. The participants’ narratives demonstrated the emergence of a dialetheic paradox: mothers acknowledged their devalued status while, simultaneously, resisting these discourses by immersing themselves in intensive maternal work. These behaviours reflect the influence of courtesy stigma, whereby mothers notice the negative social judgements directed at both themselves and their child, as a result of their association with a stigmatised group (Čolić & Milačić-Vidojević, 2021; Goffman, 1963).

The narratives of participants, as demonstrated in Aria’s comments, frequently portrayed a fluidity in the management of their subjective identities. Manoeuvring between both 'normal' and 'disabled' motherhood discourses signified the ongoing, iterative, and subjective processes through which mothers worked to make sense of the 'biographical disruption' they had previously encountered (Bury, 1982). By navigating the duality of 'disabled' and 'normal' motherhood, participants engaged in strategies to resist binaries, which facilitated a more intricate and nuanced representation of maternal subjectivities and lived experiences. These findings are consistent with prior research that highlighted women's strategic management of identity and their complex negotiation between subject-positions; endeavouring to make sense of, and construct meaning from, at times, traumatic, lived experiences (McKenzie-Mohr & Lafrance, 2011; Moran et al., 2024; Parton et al., 2019).

Subjective Experiences of Dwarf Mothers

The issues surrounding internalised ableism not only affected average-statured mothers; during interviews, a small minority of mothers with dwarfism (less than a quarter) had also described their struggles of receiving a prenatal diagnosis of dwarfism. One achondroplastic mother, Rabiya, held beliefs that achondroplasia was mostly a medical issue and, as such, did not want her children to inherit her condition. Rabiya explained:

> I'd do anything to not have achondroplasia. I never wanted a dwarf husband, or dwarf kids; like some actually seek out dwarf marriages, but I'm not my medical condition. I don't see it as some kind of sub-culture. All they're doing is condemning a child to a life of ridicule and arthritis. How is that fair? My husband's average-height, as soon as we got pregnant, we got tested. Positive for achondroplasia, every damn time. Not what we wanted.
>
> [Interview, 2018]

Rabiya described to me her deep desire for normality. To reconcile these feelings and to help her make sense of her experiences and condition, Rabiya had adopted a broadly Medical Model of Disability position. The confidentiality of the interview allowed Rabiya to reveal that the few times she has seen other people with achondroplasia in public, she had also stared and had felt an innate '*repulsion*' at the realisation that she too, '*looks like that'*. Similar feelings surrounding the experiences of some dwarf adults have previously described this internalised perception as a form of self-stigma (Pritchard, 2023). During our interview, she expressed deep unhappiness at having passed on her dwarfism condition to her children. Rabiya also implicated her husband as sharing in her perspective that achondroplasia was '*Not what we wanted'*. Interestingly, however, Rabiya did not express a desire to terminate any of her pregnancies. These feelings were relayed to me as more of a disappointment in passing on a stigmatised identity, bringing her further away from her desired 'normality', whereby her embodied and subjective experiences gave rise to a form of internalised mother-blame. The experiences of being stigmatised can reinforce the negative values that are forced upon one's social identity (Crocker & Major, 1989).

The awareness of a cultural stereotype towards a particular stigmatised group has a detrimental impact on how individuals value themselves and their identity, in relation to others (Link & Phelan, 2001). It was the awareness of her own precarious status of social identity, which had ongoing damaging repercussions in how Rabiya saw herself, ‘given that the stigmatised individual in our society acquires identity standards which he [sic] applies to himself [sic] in spite of failing to conform to them, it is inevitable that he [sic] will feel some ambivalence about his [sic] own self' (Goffman, 1963: 130). In Rabiya’s narrative, there was a strong theoretical alignment to Cooley’s (1902) work on ‘the looking-glass self’, in how her concept of self was perceived through the lens of other people, particularly in reference to her ‘*repulsion*’ remark around seeing others with the same condition as herself. Goffman's (1963) notion of ‘stigma’ was built upon the frameworks of Cooley (1902) and Mead (1934); through this lens, women may internalise their feelings of guilt, shame, and self-blame, causing mothers, like Rabiya, to be particularly vulnerable to this form of internalised stigma (Mueller et al., 2012).

Sinason (2001) argued that nowhere in the world would a parent wish for their child to have a disability. In contrast, my data documented multiple examples of women who, unlike Rabiya, wished for their children to inherit dwarfism. Ruqayah, for example, revealed that she would be ‘*disappointed’* if her children were ‘*average-height’*, as she desired the shared experience; envisioning herself taking on a mentoring role, due to already having this embodied expertise. Remi, similarly, told me she felt that the practical day-to-day tasks of lifting and managing a child, while being a dwarf, would be ‘*too hard’* and ‘*awkward’* when the child became a certain size. Reese, who already had two children at the time, said that being a dwarf was part of a different culture, and ‘*average-height people’* do not consider that aspect when they think of dwarfism. She perceived that the general public saw dwarfism as a '*disability or the seven dwarves'*; that is to say, a binary distinction between the medical condition and the characterisation from cultural representations. Interestingly, unlike research that suggested that the recognition of dwarfism as a disability was perceived as a source of validation (Adelson, 2005b), Reese's narrative offered a contrasting perspective. The way that Reese discursively constructs disability, in reference to her remark '*disability or the seven dwarves',* highlights how disability is not a static or universally agreed-upon concept, but one that is (re)produced by cultural, social, and individual contexts. This divergence underscored the complexity and fluidity in how dwarfism was framed and understood by participants. It was contingent upon the social context and relational dynamics in which it was situated, leaning towards a more embodied ontological understanding of disability, which is fluid and open to change (Shakespeare & Watson, 2001). Reese's experiences as a dwarf, raised within dwarfism communities, led her to consider this aspect as an extension to her cultural identity; comparable to her nationality, or being a woman. In addition, she felt that her experiences were '*unique to dwarfism'*. Moreover, as Reese could not position herself away from stigma in the same way as average-statured mothers, she discursively subverted it, distancing dwarfism from social constructions of disability. Therefore, demonstrating how even within communities, understandings of dwarfism and disability can be fluid, relationally complex, and nuanced.

Conclusion

The findings from the data examined in this chapter underscore how maternal subjectivities were fluid, relational, and deeply contextual. To situate my interpretation of the data within the distinct maternal context of this study, and to illustrate how the findings of this chapter have been established, this conclusion is organised into two sections. I will first discuss the findings that have emerged in this chapter in relation to average-statured mothers. I will then go on to consider the findings from the narratives drawn from the dwarf mothers.

I began this chapter by suggesting that for average-statured mothers, receiving a dwarfism diagnosis emerged as a pivotal moment in shaping maternal subjectivities. Many average-statured mothers articulated, to different extents, how their feelings around diagnosis were shaped by the recognition that having a disabled child would cause a disruption to the 'norm'. Signalling a profound interruption to their anticipated maternal journeys, I suggested how these findings echoed those of both Bury's (1982) concept of 'biographical disruption' and Landsman's (2009) notion of 'maternal disruption'. The data revealed how many of the average-statured participants had come to recognise that their initial reactions were mostly perpetuated through their own internalised biases, and what they previously 'knew' about dwarfism. Their subjective perspectives had already been shaped through dominant discourses, whereby dwarfism was culturally defined and regulated (Adelson, 2005a). The data also demonstrated how these defining and regulatory discourses implicated mothers through courtesy stigma (Goffman, 1963).

The findings of this chapter build on previous research (Ryan & Runswick-Cole, 2008), suggesting that the experience of diagnosis often initiates a complex negotiation of identity. This involved reconciling previous maternal expectations with the realities of mothering a disabled child. The data demonstrated how participants worked to integrate these new roles and responsibilities into their maternal identities. Therefore, illustrating how maternal subjectivity was not static but deeply influenced by societal narratives that reinforced normative expectations of motherhood (Hays, 1996). When negotiating their subjectivities in relation to their 'disruption' of identity, as gendered subjects, participants' efforts to maintain alignment with the ideals of 'good' mothering (Hays, 1996) persisted as a central feature of their maternal journeys. This is a testament to the pervasive strength of such discourses (Foucault, 1977, 1988).

The maternal adjustment process involved significant emotional labour, which I interpreted through Ruddick's (1980, 1989) concept of 'maternal thinking' and Hochschild's (1983) work on emotional labour. For instance, examining the narratives of Amyna and Aoife revealed that irrespective of a mother's emotional state, even in the context of traumatic experiences, the need to suppress or adapt their expressions exposed the emotional expense (hidden emotional labour) mothers sacrificed to their own well-being; an alignment with societal expectations of ‘good’ mothering (Hays, 1996). I explored how this emotional labour extended beyond the immediate care of their children, also encompassing the ongoing management of their maternal identities, as mothers navigated societal judgement, even from their own partners. Dominant discourses, as conceptualised by Foucault (1977), operated as regulatory forces, shaping and reinforcing standards of ‘good’ mothering (Hays, 1996), which participants felt compelled to uphold. Likewise, as Wilson’s (2007) research into women’s experiences of motherhood and HIV discovered, this concept can be useful in demonstrating the emotional reactions to participants’ intersubjective perspectives when considering stigmatising conditions. Wilson’s (2007) study found that when participants with stigmatised medical conditions sensed a disruption to their mothering identity, they felt the need to compensate with self-regulating behaviours to be perceived as ‘good’ mothers. I developed these conceptual observations further to suggest how they also intersect with Goffman’s (1955, 1963) notion of ‘face-work’, whereby individuals actively manage their impressions to navigate stigma. These strategies demonstrated how mothers actively resisted stigmatising discourses while, simultaneously, reinforcing normative ideals of motherhood. The duality of this resistance, both subversive and conforming, highlighted the complexity of maternal subjectivities in the context of disability and dwarfism. I explored how the discursive strategies that average-statured mothers, like Audrey, undertook to distance themselves from discourses that marginalised disability, could also, inadvertently, reinforce societal hierarchies; perpetuating cycles of stigma onto others (Rogers, 2007).

For dwarf mothers, the findings in the chapter demonstrated that their maternal subjectivities, particularly concerning pregnancy and the experience of receiving a dwarfism diagnosis, were distinctly constructed. The findings demonstrated how some dwarf mothers (with dwarf partners) adopted 'tentative' approaches to pregnancy. The emotional distancing was a deliberate strategy, aimed at minimising their emotional investment, recognising that they may have to make abortion decisions (Rothman, 1986, 1993). This finding also emphasised the critical significance of access to abortion in the reproductive lives of dwarf mothers, by situating it as fundamentally vital in their pursuit of motherhood.

The chapter also explored how dwarf mothers were aware that their pregnancies were regulated by discourses of 'risk'; however, I have argued that this does not imply that these mothers were passive recipients of medical surveillance (Daniels, 2019; Frederick, 2017). Instead, the findings suggested that dwarf mothers operated subjective agency within these structures; strategically engaging with and resisting medical narratives to achieve reproductive goals. Thus, the findings revealed a nuanced negotiation of power within maternal healthcare: a duality of compliance and resistance. I examined the ways that dwarf mothers strategically engaged with ‘risk’. This form of agency entailed not only resisting dominant narratives but also tactically leveraging them to achieve desired outcomes, even at the potential cost of being subjected to stigmatised judgements (Goffman, 1963). I argued that these experiences operated within a complex interplay of power relations (Foucault, 1982, 1988, 2008); thereby, illustrating how dwarf mothers navigated and negotiated their subjectivities and choices within the constraints enacted by disciplinary regimes (Foucault, 1977).

The data demonstrated that, unlike average-statured mothers, dwarf mothers could not distance themselves from stigma as easily, due to their embodied positionality. This gave rise to distinct subjective perceptions: some participants internalised stigma, aligning with the concept of self-stigma (Pritchard, 2023), while others, such as Reese, actively subverted it by reframing dwarfism as distinct from the stigmatised discourses of disability. This underscored the complexity of maternal subjectivities, demonstrating how disability and dwarfism were constructed in contextual and relational terms: fluid and dynamic, shaped by the interplay between subjective agency and the broader societal contexts in which they were embedded.

Theoretically, this chapter engaged with the key conceptual frameworks outlined in Chapter Two. I have interwoven these conceptual perspectives throughout the data chapters to explore and examine the data. My interpretations illustrated how maternal subjectivities were both constrained and enabled by the intricate interplay of stigma (Goffman, 1963), which was shaped by powerful regulatory discourses (Foucault, 1977, 2008), perspectives of 'good' mothering (Hays, 1996), and maternal perspectives of subjective agency. The findings underscored the fluid, relational, and deeply contextual nature of maternal subjectivities. The data illustrated how maternal identities were not merely passively shaped by societal discourses, but were actively negotiated, with opportunities to subvert and resist emerging within these power relationships. This chapter has critically examined the intricate ways in which a dwarfism diagnosis disrupted, reshaped, and (re)produced maternal identities.

This chapter has laid the groundwork for the next, where I will consider how participants' experience of 'maternal disruption' (Landsman, 2009) marked critical junctures in their lives, often driving them towards dwarfism communities. The following chapter further explores the themes that have arisen from the findings presented here. It builds on these subjective experiences by examining the (re)production of dwarfism communities, the motivations that drive mothers to seek membership, and the maternal experiences within these communities.

Chapter Five – Maternal Subjectivities: Mothering Children within Dwarfism Communities

Introduction

This second data chapter extends on Chapter Four's findings, which underscored the contextual and relational construction of maternal subjectivities, locating experiences of 'biographical disruption' (Bury, 1982) as fluid and shaped by the interplay of subjective agency and societal contexts. Here, the focus shifts to consider how the experiences of 'maternal disruption' (Landsman, 2009) and encounters with stigma (Goffman, 1963) prompt some mothers to seek support within dwarfism communities, and critically explores their interactions within these spaces.

The chapter begins by documenting the motivations and experiences of mothers as they engage with dwarfism communities. It examines how the stigma associated with dwarfism (Goffman, 1963) disrupts maternal subjectivities, propelling mothers towards these communities as spaces of solidarity, validation, and belonging. The chapter examines the dwarfism communities as sites of knowledge (re)production, where dwarf mothers do embodied work and (re)produce knowledge. Not free from the dynamics of power (Foucault, 1977), this chapter examines how a power/knowledge nexus operates within dwarfism communities, (re)producing specific forms of knowledge and values that regulate and shape the maternal subjectivities of mothers engaging within these spaces. The themes developed in this chapter will set the stage for the final data chapter (Chapter Six), where they are examined in relation to how these experiences within dwarfism communities disrupt subjective identities and shape maternal healthcare decisions.

(Re)Producing Dwarfism 'Communities'

Having experienced a 'biographical disruption' (Bury, 1982) to their mothering identity, average-statured mothers often sought out dwarfism communities as spaces to undertake relational meaning-making, seeking commonality in their mothering experiences. Many participants' motivation for joining the dwarfism communities was based on the realisation that their personal parenting journeys were developing differently from their other friends and family members, who had maternal experiences not based on disability or dwarfism. While trying to create an 'ideal' type of support network within their own families and communities, some participants found the reality to be '*isolating'* and othering, as Amber emotionally explained:

> There's no other relationship like it [motherhood within the dwarfism community]. It's so affirming. That's what it is, it's affirming. They say you become closer to your mother and sister when you have a baby, and I had that expectation [...] When [child] was diagnosed, we had to buy specialist equipment due to health and safety, you know. My mum and sister thought I was over the

> top; they would undermine me and brush off my feelings. They just didn't understand what all the 'fuss' was about for a baby. […] I felt that nobody understood. It was so isolating. This all changed when I met other mums [within the dwarfism communities]. They affirmed everything I had been told by the doctors; they understood emotionally the barriers I was facing with my family because they had felt the same. It's a really affirming group of parents, and I'd be lost without them.
>
> [Interview, 2018]

Amber's feelings of isolation within her own family and community of local friends highlighted how existing relationships became strained when disability, and in particular, dwarfism, was introduced. In Amber's experience as a first-time mother, her idealised vision of familial relationships with her own sister and mother was disrupted. There was a gulf in understanding of each other's positions, and this drove Amber further into relying on dwarfism groups for parenting advice, to the point that she no longer engaged with her family if it concerned dwarfism at all. Research concerning the mothers of disabled children frequently observed the creation of 'self-help' groups and other forms of support networks; these groups replicated, or replaced entirely, the sources through which emotional support was provided (Beresford et al., 2007; Runswick-Cole, 2007; Seligman & Darling, 2007). Moreover, this is not dissimilar to other mothering communities; digital research has demonstrated that mothers often sought out advice and shared experiences away from traditional family and friends, for example, through the online network 'Mumsnet' (Mackenzie, 2017, 2020). The shift towards the use of anonymous internet profiles also helped in the thwarting of unwanted advice or criticism for chosen parenting decisions, as the groups and circles mothers engaged with tended to align with their own styles and values; thus, creating an echo chamber of affirmation and support.

During her research into ‘militant lactivism’, attachment, and intensive mothering, Faircloth (2013) found that new mothers often had an ‘idealised’ vision of childrearing and motherhood. However, like Amber, these women would also often experience critical responses and resistance to their mothering practices from family and friends. Subsequently, this left them isolated and seeking support in the form of niche communities, where their mothering practices were reaffirmed and supported. Consequently, although the context of dwarfism is specific, Amber’s experience of seeking out and bonding with mothers she felt a commonality with is a frequent, rather than a unique, motherhood experience. Subsequently, her participation in dwarfism groups contributed to the (re)production of the dwarfism communities; in so far as to maintain their presence, these groups needed a continual accumulation of new members.

Many conversations held within the communities’ spaces, in person and online, focused on the lived experiences of dwarfism within public social life, and the effects that this had on the individual as well as the wider family unit. One participant, Amelia, discussed the (re)productive nature of the dwarfism communities, while also illustrating how mothering practices, and the respective norms and values, became embedded within each development and iteration of the communities:

> It started off as me joining for the support. I guess you could say I was a 'receiver' more than a 'giver' of the dwarfism charities, for maybe the first decade of [child's] life. Then it just naturally progressed, as people retired or dropped off the radar, because their children became adults, I started to get asked a lot more to volunteer. Until it became the norm. I find it really fulfilling that it's kind of come round 180°.
>
> [Interview, 2018]

Amelia's narrative alluded to 'receiving' from the dwarfism spaces and taking on responsibilities after 'learning the ropes' of the communities. She was then able to 'pass' these on to other members when they came into the spaces without this prior knowledge. It is this type of productive force within spaces that, Foucault (1977, 1988) argued, regulated discourses and the (re)production of power. Here, specific 'norms' of the communities were shared with the intention of (re)producing particular sets of values. Thus, the constructed communities were able to (re)produce their *realities* through the operation of a power/knowledge nexus. Most poignant in her reflection was how the cycle of (re)production emerges through a connection with others; she perceived the dwarfism communities as a stable source of support that remained in the background of people's lives.

Dwarfism Communities as Sites of Knowledge (Re)Production

Some participants discussed how their motivations for joining dwarfism communities were rooted in the recognition that the spaces offered a wealth of dwarfism-specific knowledge, which they could draw from. As Ruby reflected:

> One of the main reasons I joined the dwarfism community as an adult was that I wanted to start a family, and I felt that I'd need the support from other women with achon [achondroplasia]. It's not like I can just ask other friends [outside of the dwarfism communities], because they don't face the same struggles and experiences that I would have. Even having a smear test is completely different for achon women than it is for average-height. Our cervixes are really difficult to get to in a smear. The whole situation with pregnancy and the prenatal testing, and genetic counselling side takes over the whole pregnancy and dominates the experience, which is less than ideal, but it's what we have to go through if we want to become parents.
>
> [Interview, 2018]

Ruby's admission that she joined the dwarfism communities to seek out the experiences of other dwarf women is essential when exploring the interplay of power, which (re)produces and legitimises specific forms of knowledge (Foucault, 1972, 1977). Ruby's acknowledgement that maternal experiences remain distinct, even within the shared experiential context of dwarfism, underscored the deeply embodied nature of the dwarfism communities in the (re)production of knowledge. Ruby highlighted how the physical realities of dwarfism shaped specific aspects of her maternal journey, such as the gynaecological differences, which could not be fully understood by those outside of the *embodied* experience of *being* a dwarf. This distinction emphasised that even within communities formed around shared identities, there were nuanced complexities and differences. For Ruby, this deeply personal form of embodied experiential knowledge enabled mothers, like her, to understand the challenges and cultivate knowledge about their disability.

The concept of 'experiential knowledge' was a common theme that emerged during the research; as an encapsulating perspective, it was a highly valued resource within the communities. Conceptually, although it is widely recognised, it is not as easily defined as a framework, and there have been contested theoretical and practical applications (Boardman, 2014, 2017). Nevertheless, its value is recognised within dwarfism communities, and it was, arguably, one of the major drivers for community membership. Therefore, the definitions I use here are conceptually fluid, context-dependent, and shaped by individual subjectivities, embodied realities, and norms within the dwarfism communities. Engaging with these dynamics, we can explore the distinctions made between 'embodied' (direct bodily) and 'empathetic' (emotional ties) forms of experiential knowledge (Boardman, 2017), as they are navigated and constructed within dwarfism communities.

Generally, the acquisition of robust dwarfism-specific knowledge was considered very important by most of the participants, as it assisted mothers in making the 'right' decisions for their children. However, there were instances of contention, particularly from dwarf mothers, regarding who held the 'rights' to claim experiential knowledge of dwarfism (rejecting empathetic forms). People with dwarfism may experience complex medical interventions throughout their lives. As such, embodied experiential knowledge was viewed as a vital component in making healthcare decisions, meaning the ways in which mothers asserted or challenged these views were particularly important elements to this research. Rhia, for example, mostly sought medical advice from people with dwarfism, prizing the embodiment of dwarfism over other forms of experiential knowledge:

> If and when I need [dwarfism] advice, I'll ask other dwarfs. They'll know where I'm coming from and what side effects I might have […] It's important for me to take advice from people who have been in my shoes.
>
> [Interview, 2018]

Rhia's perspective that getting advice from other people with dwarfism was best, as dwarfs had particular experiences that could not be understood by those without dwarfism, was a very common theme across all mothers. In dwarf mothers, it was a majority view. However, Reese suggested it was also about familiarity:

> I’ve known some of these ladies since we were kids. Now we’re having our own, it’s just easier to ask them what they’re doing, like asking a friend, rather than strangers. Especially if it’s a sensitive or private topic.
>
> [Interview, 2018]

Rabiya felt that the added benefit of experience was also reassuring when it came to seeking advice or input from other mothers:

> It’s reassurance that I want from another [dwarf] mum. If they’ve had a procedure, or their kid, I know then that whatever they tell me is coming from a place of experience.
>
> [Interview, 2018]

For Rabiya, seeking out embodied experiential knowledge from other mothers with dwarfism reassured her that she was making informed decisions, aligning with ‘good’ mothering expectations. As the dwarfism communities were also spaces of knowledge production, the communities, likewise, could be seen to produce their own dwarf experts. The participants’ narratives also demonstrated the fluidity of power within a Foucauldian framework; power was not possessional, but relational, where all individuals were influenced by complex power relations (Foucault, 1982). This was illustrated, for example, in how knowledge was (re)produced, sought out, and given status within the communities by dwarf mothers. Ruth saw the dwarfism communities as a ‘*resource*’, but more importantly, as a support system able to guide her through uncharted waters. Ruth cherished the opportunity to share in this experience with other dwarf mums:

> Yes, medically, having a community of dwarf women going through this is super useful as a resource, because you can tap into that information for your own benefit to see likely outcomes. However, for me, it's that peer support that I cherish the most. I know that anytime I can call friends from the community, and they can listen to me and know what I've gone through and know what I feel because they've been there before […] Our babies die. No offence, but average-height mums don't have to deal with those statistics. I feel 100% confident speaking to dwarf mums who have had the same experience or face the same challenges. This is support I can't get outside of the community.
>
> [Interview, 2018]

For Ruth, her identity, as well as that of the other (dwarf) women, became a defining characteristic in her understanding of her embodied experiences. For example, she recognised me as not 'belonging' to that group of women, when remarking, '*No offence*', as I was not a dwarf. This was strong evidence of a distinction between mothers within the dwarfism communities; illustrating how the intersection of the body and lived experience produces knowledge, which is both personal and deeply situated. It demonstrated how power operated not only between dominant cultural discourses and marginalised groups, but also within marginalised communities themselves; where certain forms of knowledge, located through direct embodied experiences, could be highly valued and given more status within these spaces.

The relationship between embodiment and 'legitimacy' in occupying dwarf spaces further emerged in the perceptions of some average-statured mothers. Audrey, for example, perceived there to be divisions within *all* of the dwarfism communities, based on stature and hierarchies of stature. She described her feelings as '*paranoid*' but felt as though members in the groups tended to be broadly '*dwarf circle and average-height circl*e'. As an average-statured mother, she feared this created a subtle hierarchy, with potentially substantial ramifications to the children, as she explained:

> I've overheard the bigger kids asking the younger ones if their parents 'are average-height or dwarf'. There seems to be sub-groups and 'popularity', depending on if your parents have dwarfism or not. Like, you're 'more' entitled to hang out if you come from dwarf parents. I don't know if it's always been this way, but it made me feel pretty shitty about being here, if we're not welcome.
>
> [Interview, 2018]

Audrey narrated her experience through 'felt' stigma (Goffman, 1963; Scambler, 1989, 2004, 2009); her internalised emotional reaction to perceived judgement and stigmatisation, fearing that as an average-statured mother, the dwarf people within the space might not legitimise her presence or status (or that of her dwarf child). However, these instances could also be justified through the actions and motivations of dwarf mothers, like Ruth, as arising from the need for specific embodied experiential knowledge. Therefore, these infrequent events offered moments of limited opportunity for gathering this information. The shared feature of dwarfism positioned the body as a central site of meaning-making and relationality, which mothers, like Ruby, leaned on to carve out their own support system within a larger group of the dwarfism membership. Moreover, it demonstrated the relational context in which participants made decisions, through being selective of the types of information available within the space. Therefore, the maternal groups that emerged within the dwarfism communities (as earlier highlighted by Audrey) could also be productive when considering the various and multiple needs across the dwarfism communities.

My fieldnote describes a discussion about issues with cleanliness. Due to arm length, this can be more difficult for some dwarfs to undertake independently:

> We were discussing hygiene equipment [RGA event], and there's some recommended bottom wipers; however, [dwarf woman] told us about the toilet seat bidets available from Japan, and now a UK-based one that she reckons could be sourced by OT [occupational therapist]. One mother [average-statured] said they've only been offered stick types, and [another dwarf woman] had to message her privately [Facebook] because she couldn't work out the 'reach', so she ended up taking step-by-step pictures of herself in the poses so she could understand.
>
> [Fieldnote, 2018]

My fieldnote reflects on how average-statured people may lack the specific forms of knowledge that can only develop through the situational and embodied lived experiences of dwarfism. Thereby, emphasising how the embodied perspectives shared by dwarf mothers are pivotal to the contribution and (re)production of embodied experiential knowledge in dwarfism communities. This echoed findings from research with disabled women, which demonstrated how their embodied experiences produced a type of 'subjugated knowledge' (Garland-Thomson, 2011); knowledge that was formed through the lay experiences of disabled and marginalised people.

Having discussed how mothers seek out knowledge that is constructed and (re)produced within dwarfism communities, the following section delves deeper into the interplay of power and surveillance within online spaces. Drawing on Foucault's (1977) notion of disciplinary power, the next section examines how such mechanisms regulate, shape, and ultimately (re)produce maternal norms; thereby, aligning with socially constructed ideals of 'good' mothering (Hays, 1996).

Panopticons of Social Media: Performing 'Good' Mothering

Participants expressed an awareness of 'good' mothering ideals that were often being perpetuated by their dwarf friends through social media channels, such as Facebook. More than two-thirds of participants discussed their use of social media, and the behaviours that they observed and, at times, mimicked themselves. For example, Radha got into what she described as a '*habit*' of '*tagging*' herself into events and locations. She had initially observed the behaviour from her other friends:

> We went to [child dwarfism event], and [community] people tagged us, and I just got into the habit of tagging back, and it went from there. I loved it cos my average-height friends could see that we had a social life too. I think maybe they think [child] can't do things, but this shows them that we find a workaround.
>
> [Interview, 2018]

Radha's narrative demonstrated her desire to seek commonality and assimilate with mothering practices outside of disability spaces. In undertaking similar, yet different, activities with her child, Radha was undertaking relational meaning-making by attempting to normalise and share her own mothering experiences through internet 'tagging'. This echoed other research, which found that disabled communities would adopt 'tagging' and internet play to subvert and challenge the social discourses surrounding disability (Mitchell et al., 2019). Likewise, Audrey's narrative below refers to '*dance recitals*' and '*learning an instrument*', pastimes commonly associated with the middle-classes:

> It's really hard to join in other activities outside of the dwarfism community, in just the basic sense of being able to physically keep up, like join in […] Football club, swimming, dance recitals, learning an instrument. It's all very physical. You see these parents, racing from the school gates to get to Brownies or football club, and they will tell you there's not enough hours in the day […] It's all a performance, because secretly they love it. I know this because

> before [child] that was me. Now, finally, I've discovered the DSA, and [because of] the inclusive activities and sports they do, [child] and me finally get to do the headless chicken run! I'm now posting pictures, tagging Facebook, and doing the same things that I did before, but with the dwarfism twist.
>
> [Interview, 2018]

Audrey explained that due to the accessibility of dwarfism activities for children through the DSA, she could finally '*do the headless chicken run*'; a reference to the practices of mothers who were frequently seen to be sacrificing their time in the pursuit of child-centred activities (Hays, 1996). Lareau (2003) observed a distinct mothering practice utilised by the middle-classes, which she coined, 'concerted cultivation': the concept that mothers viewed their children as 'projects', which could be cultivated in their spare time, to enhance their intellect, social network, learn [middle-class] talents, and language skills. Building on Lareau's (2003) concept of 'concerted cultivation', through a Bourdieusian approach to habitus and field, Frederick (2018) examined how disabled middle-class mothers were excluded from these practices, as the 'fields' deemed positive for 'cultivation' were often inaccessible to physical disabilities. Likewise, it is important to highlight that this remains the case with working-class mothers and economic capital. However, disabled women tended to adapt by using 'tenets' of concerted cultivation as a way to resist disabling narratives. Similarly, mothers in this research employed adaptive approaches to maintain a semblance of 'normality' and adherence to expected mothering ideals.

Consequently, in response to the mothering expectations that were often being perpetuated through online dwarfism communities, some participants expressed a desire for comparably similar sustained and intensive child-centred activities. In interviews, these participants spoke about the heavily edited celebrity photoshopping of mothering practices and the unrealistic images that were (re)produced on social media. Paradoxically, the same participants often discussed generating their own social media posts, which perpetuated the intensive mothering ideals they had recognised were likely to be an unrealistic portrayal of family life. For example, some out-of-school extracurricular activities were inaccessible due to the medical risks associated with dwarfism, such as hydrocephalus and spinal stenosis. However, there were comparative dwarfism-centred activities that families could access; thereby, reconciling the 'good' mothering ideals perpetuated on Facebook and in their own social circles, with the realities of their lived experiences. While participants recognised the negative pressures that 'good' mothering ideals and other 'mommy blogging' (Doucet & Mauthner, 2013; Lopez, 2009; Scardigno et al., 2024) had on their lives, many still found themselves entangled in these norms – unable to reject participating in actions that were perceived by others as activities undertaken by 'good' mothers. Aoife discussed her 'performance' of routines:

> I feel like in the age of social media, you have to be 'seen' to be doing it all. We're all tagging hospital appointments with captions like,

> 'just did the 800-mile drive to London' [sarcastic laugh], then we're tagging in the swimming lesson, a quick picture of the home-made dinner, a moan about work and fitting in the kids' homework to boot. It's a theatrical performance. I'm just as guilty of doing this, but we need to stop; it's just not healthy. It's exhausting. And for what? Keeping up with the Joneses? The funny thing is, we're all projecting this life online, and it's a race to the bottom, because it's not beneficial to anyone. It's smoke and mirrors.
>
> [Interview, 2018]

Aoife recognised that her social media activity functioned as '*a theatrical performance*'; a means of publicly and positively 'front-staging' her mothering practices. Her use of the phrase '*smoke and mirrors*' suggested an awareness of the constructed nature of these portrayals, while her admission that '*we need to stop; it's just not healthy*' acknowledged the potentially damaging effects of such behaviours. Yet, despite this recognition, she continued to engage in these practices, highlighting the contradictions inherent in negotiating idealised motherhood. Moreover, these tensions between awareness and participation demonstrate how performances of ideal motherhood and childhood may function as strategies for deflecting cultural scrutiny. By carefully curating their online presence, mothers navigated and challenged dominant narratives that positioned disability as a site of deficiency or failure. Notably, these behaviours expose the broader social pressures that shaped maternal subjectivities within dwarfism communities.

That said, if engaging in 'too much' social media was understood by some participants to run counter to understandings of 'good' mothering, then some mothers could rationalise their online presence to justify time spent away from their children. Since, according to Hays (1996: 125), society views a 'bad' mother as 'a mother who neglects her kids for selfish reasons, because she is more concerned with her personal fulfilment, her leisure pursuits, her material possessions, and her status than she is with her children'. Rebecca explained:

> Facebook has been life-changing for me. Without it, who knows where we would have been medically? The community, the medical expertise is priceless. I easily spend 2 to 4 hours a day on dwarfism-related groups. But it's for [child's] benefit, and ours as parents and carers of a disabled child. It's not like I'm neglecting [child] playing Candy Crush [mobile app game]. I'm actually researching or talking to other parents who are newer in their journey; you know, giving them support, same like I had when I first joined [...] It's really no different than reading medical leaflets. So, this is exactly to the point, without having to waste time on irrelevant content.
>
> [Interview, 2018]

In addition to managing 'good' mothering ideals through the use of technology, some mothers, like Rebecca, adopted a medicalisation narrative as a means to justify time spent on social media. Furthermore, Rebecca associated her time spent online with performing labour on behalf of other members within the dwarfism communities; demonstrating both her sense of sacrifice, as well as the perceived social status this afforded her. In addition, by comparing technology use, for example, of mothers playing '*Candy Crush*', as a neglectful action, Rebecca also deployed a stigma-management strategy by self-regulating her own usage, to avoid the negative labels attached to women who she presumed were taking time away from their children. Consequently, she stigmatises forms of mothering through her discursive distinction between 'good' and 'bad' time away from child-centred activities. This highlighted the interplay between normative expectations of 'good' mothering practices (Hays, 1996), self-presentation (Goffman, 1959), and the management of identity through 'face-work' (Goffman, 1955).

Conclusion

I began this chapter by making the link between the findings from Chapter Four, which suggested that a dwarfism diagnosis resulted in a maternal form of 'biographical disruption' (Bury, 1982), prompting mothers to seek out dwarfism communities as spaces of relational meaning-making. The data highlighted how the realisation that participants' maternal journeys differed, at times significantly, from their (non-disabled) families and friends, had motivated mothers to seek commonality and support within the dwarfism communities. While some mothers, like Amber, initially turned to their existing familial relationships for support, they frequently experienced these networks to be isolating and othering. As I have sustained throughout, maternal subjectivities were deeply shaped by the discursive constructions that produced their realities (Foucault, 1982); the data demonstrated that mothers of children with dwarfism often recognised their positionality in relation to the stigma of disability (Goffman, 1963), using this relational awareness as a foundation to construct shared identities with others who embodied similar traits and experiences (Abdullah, 2012; Kong & Hooper, 2018; Longman et al., 2013). The findings highlighted how participation in these communities was not solely about belonging; they also entailed active engagement in the (re)production of the dwarfism communities themselves, reinforcing their norms and values.

The data in the chapter illustrated how both average-statured and dwarf mothers frequently formed connections with others who had shared embodied experiences, demonstrating a nuanced interplay around the (re)production of communities and maternal subjectivities. These findings signalled how engagement within dwarfism communities reflected a deeper drive for belonging, as mothers often sought solidarity among those whose embodied experiences mirrored their own. The findings from the data indicated how the cycle of receiving a dwarfism diagnosis and engaging in maternal support-seeking behaviours contributed to the (re)production of dwarfism communities. These spaces were dependent on the continuous participation of new members to sustain their existence, stressing their vital function as sites for shared identity, knowledge exchange, and emotional support. Thus, the cycle of dwarfism diagnoses in children entwined with the support-seeking behaviours of mothers (Abdullah, 2012; Kong & Hooper, 2018; Longman et al., 2013) contributed to the (re)production of dwarfism communities. These communities relied on the continued cycle of new mothers to sustain it, demonstrating a dynamic process of maternal (re)construction that shaped, (re)produced, and reinforced identities. Yuval-Davis (1989, 1996) argued that women are responsible for the *reproduction* and birth of nations. This is a useful perspective in which to draw comparisons, considering how mothers might (re)birth dwarfism communities and, in doing so, contribute to the (re)construction of 'realities', as well as the (re)definition and (re)production of normative discourses within these spaces.

The findings in this chapter expose the intricate processes through which dwarfism communities were constructed and (re)produced. Communities, by definition, exist through the establishment of boundaries and borders that define inclusion and exclusion (Jones, 1999). These boundaries may arise from shared identities, experiences, or values (Ali et al., 2023). Within the context of dwarfism communities, we can see how these boundaries were drawn around the shared experience of dwarfism, enabling members to cultivate maternal subjectivities embedded in commonality. Importantly, the findings have identified that for dwarf mothers, embodied familiarity also became a distinguishing component of why and how they engaged with dwarfism communities. The concept of biosociality provided a particularly useful lens for interpreting these dynamics (Rabinow, 1996). Biosociality explains the ways in which social groups form around shared biological traits, producing and defining new identities and relationships. Within dwarfism communities, the data demonstrated how shared biological and experiential realities served as the basis for the exchange of knowledge and the formation of social ties, particularly for dwarf mothers.

The findings of this chapter signalled that the dwarfism communities served as sites for knowledge (re)production, where the interplay of power and embodied experiences shaped maternal practices and perspectives on dwarfism knowledge. The data clearly demonstrated how average-statured mothers' interactions within dwarfism communities became a crucial means of accessing insights from dwarf mothers regarding their children's health. For average-statured mothers, whose (embodied) experiential resources were comparatively limited, these relationships were particularly significant. Drawing on Foucault's (1972, 1977) conceptualisation of power/knowledge, the findings demonstrated how dwarfism communities acted as sites where knowledge was not only shared but also legitimised and contested. Dwarf mothers often conveyed their motivations for engaging with knowledge (re)production within these communities as stemming from a recognition that dwarfism-specific insights were crucial for navigating life as a dwarf. The findings highlighted that for most mothers, embodied lived experiences were positioned as particularly authoritative sources of knowledge. Most participants prioritised guidance from dwarf mothers, in ways that aligned their decisions with the dominant expectations around seeking 'expert' advice; a key element in the ideology of 'good' mothering (Hays, 1996).

In terms of interpreting dwarf mothers' experiences through the perspectives of disability models, I suggested that for dwarf mothers, their embodied realities exemplified feminist critiques that highlighted the complex and nuanced layers of experience, which have proven difficult to conceptually map within the Social Model of Disability (Morris, 1991). A feminist approach to the Embodied Ontological Model of Disability provided a beneficial framework for understanding how embodied forms of experiential knowledge emerged and operated within dwarfism communities. This model recognised the interplay of physical embodiment, lived experiences, and structural contexts, offering a conceptual lens through which to explore how embodied experiential knowledge was constructed, validated, and shared. Within these communities, this framework illuminated how embodied knowledge was not only a personal resource but also a collective one; thereby shaping maternal practices, reinforcing community norms, and navigating the broader sociopolitical landscape of disability (Shakespeare & Watson, 2001; Shakespeare, 2006).

Maternal experiences remained distinct, even within the shared experiential context of dwarfism, underscoring the deeply embodied nature of subjective knowledge within these communities. Through power relationships, an ‘embodied experiential knowledge of dwarfism’ emerged; one that was distinctly defined to address and regulate the status of dwarf mothers within these communities. This echoed the more encompassing ‘embodied experiential knowledge of disability’, which has been proposed can co-exist within the nuanced interplay of embodied and empathetic forms of experiential knowledge (Boardman, 2017). For mothers, such embodied experiential knowledge served as a critical resource, allowing them to better understand the unique dimensions of their experiences and those of their children. However, it also delineated boundaries within the dwarfism communities, privileging those whose knowledge stemmed from their embodied experiences and, by extension, embedded hierarchies of expertise and authority within these communities. The interplay between empathetic and embodied experiential knowledge further exposed the complexity of maternal subjectivities within these spaces. While overall, having experiential knowledge offered invaluable insights for navigating the specific challenges associated with dwarfism, its validation within the communities was often contingent on the ‘embodied’ element. This demonstrated an implied hierarchy of expertise that could both include and exclude. For dwarf mothers, the recognition of their embodied experiential knowledge reinforced their status and, I suggested, legitimised their identity through their ‘face-work’ (Goffman, 1955). Conversely, for average-statured mothers, like Audrey, some interpreted the absence of embodied experience as a sense of *disembodiment* within the communities, inversing the concept of a discredited identity (Goffman, 1963).

The data demonstrated how dwarfism communities are fluid, co-productive, and operate through multiple mediums. It also revealed how, through digital platforms, mothers utilised these spaces to share lived experiences and challenge stigma. However, in line with Foucault's (1977) concept of surveillance, these spaces also functioned as sites where maternal actions and identities were open to scrutiny and regulation, from both the dwarfism communities and broader society.

The tension between projecting an idealised version of 'good' mothering (Hays, 1996) and maintaining a sense of agency, under the perception of constant scrutiny, was a key theme that emerged. Hence, social media became a battleground where mothers managed their maternal identities (Hays, 1996), navigating the pressures of self-regulation (Foucault, 1977) while, at the same time, resisting stigma (Goffman, 1963). Mothers used digital spaces to 'normalise' their children's dwarfism and to resist, or 'cool', their 'spoiled identity' (Goffman, 1952, 1963) by 'front-staging' (Goffman, 1959) their lives through visual mediums, engaging in practices such as 'tagging', and sharing personal experiences. These behaviours aligned with research by Mitchell et al. (2019), who highlighted how disabled individuals used internet play, such as 'hash-tagging', to shift dominant discourses away from medical model perceptions of disability. However, these performances of normalcy carry potential risks; digital visibility is a double-edged sword, where mothers seeking acceptance and normalisation are confronted with the ethical challenges of balancing their children's autonomy and privacy (Saville, 2020; Steinberg, 2017). These findings extend on Goffman's (1959, 1963) concepts regarding stigma management and identity performance; illustrating the ways that mothers of children with dwarfism engaged in identity work for themselves and their children, as processes of 'de-stigmatising identity work' (Fields, 2011).

This chapter provided a nuanced understanding of how dwarfism communities shaped the maternal subjectivities of the mothers who engaged and participated within them. It highlighted the complex interplay between cultural discourses, communal belonging, and maternal agency, setting the stage for the following chapters. This chapter has emphasised that mothers engaged with dwarfism communities, not merely as passive recipients of support, but as active participants whose experiences were shaped by, and in turn shaped, the broader discourses of power and regulation within these spaces (Foucault, 1977). This chapter has drawn attention to the ways that these communities were perceived as neither completely supportive nor wholly regulatory. Instead, it highlighted the relational nature of maternal participation within the dwarfism communities, where support and regulation were inextricably intertwined, and where maternal subjectivity could be both constrained and exercised in response to these dynamics.

This interpretive analysis furthers the groundwork for the final data chapter (Chapter Six), which will extend on the concepts developed here. As the findings of this chapter have demonstrated, participation in dwarfism communities was not without its complexities. Through a power/knowledge nexus, these communities generated their own norms and values, which regulated maternal practices and expectations. Building on the interplay of these themes, the next chapter illustrates how, in the context of biotechnological growth therapies, mothers' discussions of healthcare decisions offer insights into how biopower and maternal identities are disrupted, negotiated, and embodied in the dwarfism communities.

Chapter Six – Maternal Subjectivities: The Biopolitics of Biotechnologies in Dwarfism Healthcare

Introduction

This final data chapter builds on the findings of Chapters Four and Five, which explored the contextual and relational construction of maternal subjectivities in response to biographical disruptions of identity (Bury, 1982; Landsman, 2009) and the management of stigma (Goffman, 1963). This chapter extends the analyses of disability and identity by exploring how the biopolitical dimensions of the dwarfism communities and maternal subjectivities are simultaneously disrupted, regulated, and negotiated through the prospect of healthcare decisions.

This chapter begins by exploring the shifting perceptions of dwarfism healthcare among average-statured mothers as they deepen their engagement within the dwarfism communities. Consequently, as participants' maternal journeys developed, many critically reflected on their earlier decisions, increasingly drawing on the embodied experiential knowledge of dwarf mothers, whose perspectives often held elevated status within the communities. This reliance exposes the complex interdependence of maternal subjectivities and relationality within the communities. The chapter goes on to examine the ways that the use of violent language further reinforces the communities' norms by discursively constructing external ‘threats’ to dwarf bodies and identities, in ways that shape the dominant discourses within the dwarfism communities.

The chapter then focuses on the key theme of biotechnological advances in dwarfism healthcare. Regarding the drug trials, some mothers, fearing the threat of isolation and rejection, regulated their decisions to align with the dominant norms of the dwarfism communities. However, although this tended to influence the behaviours of many mothers, there were instances of resistance. The central aim of this chapter is not merely to examine the healthcare decisions participants ultimately made, but to critically explore how these decisions – and the processes through which they were made – reveal the nuances of identity management and biopolitics, and expose the subjective tensions shaped by the cultural and societal discourses surrounding ‘good’ mothering, disability, and dwarfism. In the context of emerging biotechnological therapies for dwarfism, such decisions shed light on how notions of ‘good’ mothering are constructed and contested by both mothers with dwarfism and those without, across both online and offline spaces. By situating maternal healthcare choices within a broader sociopolitical landscape, this chapter highlights how the biopolitics of dwarfism communities becomes visible and operates through (often competing) discourses regarding motherhood and disability; thereby, shaping and constraining maternal subjective agency.

The themes developed in this chapter will set the stage for the Conclusion (Chapter Seven), where they are examined in order to address the research questions raised in Chapter One.

Dwarf Bodies as Sites of Embodied Experiential Knowledge

A significant theme present in many of the experiences of average-statured participants was the evolution of their attitudes towards disability and, often, their acquisition of more in-depth knowledge regarding dwarfism. As was the case with many average-statured mothers, dwarfism-specific knowledge to help guide healthcare decisions was initially limited at the start of their mothering journeys. Significant healthcare decisions were often unavoidable and could have a specific window of time when they needed to be made. Usually, this was an area of concern in the lives of participants. Often their descriptions of these choices reflected the prevailing discourses of maternal responsibilisation; the expectation imposed on women to be 'good' mothers and to make the 'right' choices (Gillborn et al., 2022; Lowe, 2016). Over time, some participants, still desiring to align with 'good' mothering principles regarding adhering to experts, came to believe that the best way forward for their children's well-being was to switch, or broaden the definition of, who they considered held the monopoly on dwarfism expertise.

In Chapter Five, I discussed how specific forms of embodied knowledge were given heightened status within mothering groups in the communities. I now establish how some average-statured mothers leveraged this knowledge to help inform their decisions regarding their children's healthcare. For example, Ayaan positioned the status of dwarf embodied knowledge above that of the medical expertise she had previously followed. Ayaan described becoming reliant on the dwarfism communities as a source of expert knowledge:

> When he was born, we went down this medical pathway, where we had lots of appointments, and everything was about bent spines [and] bowed legs. We never had a chance to catch our breath. By the time we had met people with dwarfism, he had tubes in his ears, eight-plates in his legs, and a back brace. Once we had met the dwarfism community people, we realised the back brace probably wasn't even necessary, because a feature [normal physiological component] of achon is curvature of the spine. Same goes for the tubes in the ears.
>
> [Interview, 2018]

Average-statured mothers often described uncertainties around what constituted 'healthy' for dwarf children, as demonstrated by Ayaan's reflections on whether her decisions to treat certain features of dwarfism were '*necessary*'. Relying on the embodied experiential knowledge residing within dwarfism communities to guide her maternal choices revealed a critical dynamic: these communities operated as regulatory spaces where power/knowledge relationships shaped and normalised particular maternal behaviours. Annabelle also described the shifting of her attitude towards dwarf health and surgical decisions:

> It wasn't until [child] was aged 8 that it finally clicked [I understood] that no amount of surgeries was going to change the fact that [child's] physical complications were the least of the problems. All those times I was side-tracked with tonsil surgeries, eight-plates, you know, and yes, we'd like to have those, but in those days no one [medical experts] ever talked about the mental health component, the social component, the bullying, and what multiple surgeries and hospitalisations does to a child and their development. [Child] grew up thinking that they were sick and fragile, and that the doctors were going to make them 'better'. Our friends and neighbours all thought so too. I'm so angry. At the doctors, at myself.
>
> [Interview, 2018]

During her interview, Annabelle, evidently upset and emotional, expressed anger and regret at what she now perceived to be an exaggerated focus on the physical impairments associated with dwarfism. As a mother wanting to follow 'good' mothering practices, her feelings of regret and guilt illustrated the challenges and complexities regarding the many medical decisions expected of mothers within the dwarfism communities. Discovering that the surgery decisions she had made resulted in her child, and others, believing '*that they were sick and fragile, and that the doctors were going to make them "better"*', ultimately, resulted in a paradigm shift for Annabelle. In redefining what she considered to be detrimental to the health of people with dwarfism, Annabelle was able to discursively distance herself from her previous decisions. This included her lack of recognition regarding the aspect of hospitalisations; frequent occurrences would, evidently, impact children, to some extent. Even if she was angry at herself, she could, however, shift the blame and responsibility elsewhere. In this case, the blame was on the doctors.

Participants' maternal practices were often the subject of judgements, across both normative (non-dwarf) and non-normative (dwarf) spaces. Power and its resistance created the illusion of choice, yet mothers' actions were still governed by regulatory norms; for Foucault (1977), this is disciplinary, with surveillance being panoptic. To be considered a 'good' mother across these spaces, many participants found themselves straddling what were, often, very conflicting discourses; navigating tensions between adhering to medical recommendations and aligning with the norms of the dwarfism communities. Audrey explained her approach:

> Our child had eight-plate surgery when he was 7. He desperately needed it by that age, and they wouldn't do it before 5. His legs were so bowed and turned in, it was painful to watch. We just wanted that addressing. We're not interested in height, but the surgeon said straight legs gives him back 1-2 inches over time! [laughing] yay! [sarcasm] That's the only elective thing we'd do, oh and spine if needed. Everything else would have to be non-elective, like if you needed brain surgery, or decompression, or a shunt. Those aren't optional.
>
> [Interview, 2018]

Audrey's narrative illustrated how she categorised surgery interventions and healthcare decision-making in terms of '*elective*', which she deemed as '*optional*', and '*non-elective*', which she described as being in an emergency scenario. Audrey had chosen to adopt a 'pick 'n' mix' approach, enabling her to manage the 'good' mothering expectations across boundaries that (re)produced conflicting judgements on the 'right' types of medical interventions. By creating these discursive divisions, she self-regulated her mothering practices, and in doing so, acted in ways that could change to reflect the dominant discourses in dwarfism communities. Moreover, as these distinctions were defined by Audrey herself, it also meant that her actions and judgements could always be positioned *within* the prevailing norms and values of the dwarfism communities.

What these participants' narratives have in common is a shared sense of confusion and doubt regarding healthcare decisions. For example, Ayaan described how she felt rushed into making choices, having '*never had a chance to catch our breath',* while Annabelle felt '*side-tracked'*, and Alicia '*was so caught up with the diagnosis'* that she did not question the accuracy of the information she was given. Many average-statured mothers, therefore, described experiences of having to make often complex, difficult, and important decisions, from a position of having very little knowledge about any potential health repercussions.

The next section delves deeper into how mothers' subjectivities and decision-making were shaped and regulated by discourses that invoked violent imagery: a strategy employed to regulate and reinforce cultural norms.

Violent Imagery: The Discursive Regulation of Bodies and Identities

The dominant discourses used to regulate the cultural norms and boundaries of the dwarfism communities were, at times, quite violent and graphic. For example, a quarter of dwarf mothers drew on the use of violent and brutalising language to discursively situate particular strands of healthcare as *the cause of harm* to the dwarfism communities. Unlike average-statured mothers, some dwarf participants had histories and experiences that were extremely traumatic, which they used to support their views that particular healthcare decisions were a personal attack on dwarf identity. By framing individual medical interventions as having the potential for macro consequences for the entire dwarf population, these participants were (re)producing regulatory discourses, whereby blame and stigma could be levied against people who did not conform. To demonstrate, discourses that invoked violent imagery were sometimes used as a strategy to (re)produce 'threats' of harm against dwarfs. Radha described the use of ELL as a '*punishment'* for dwarf children:

> Limb lengthening is a cruel and unusual punishment. I don't know any other disability where the treatment options include breaking your legs and stretching those breaks out with pins and rods, only for them to heal, and forcibly, purposefully, be broken and stretched out again. It's beyond inhumane. It's certified medieval torture in the 21st century. Vocalising out loud the methods just drives home how insane this procedure is! Oh, and to add insult to injury, remember this is the child's treatment! These are kids who should be out playing. Instead, the NHS will spend the majority of their

> childhood breaking these kids' bones, and stretching them out, so they can look 'normal'.
>
> [Interview, 2018]

Radha used visceral and emotive language to describe ELL as akin to '*medieval torture'*. Associating this with NHS healthcare, as well as relating it to children's '*treatment'*, amplified her critique of institutional complicity in practices aimed, in her view, at enforcing the societal disciplining of dwarf bodies. Although a hostile view for some, Radha's perspective does invite a critical reflection regarding broader discussions on how people with dwarfism perceive the healthcare systems they navigate. Radha's beliefs echoed the concerns raised by Parens (2006), who questioned the ethics behind the use of some technologies where the objectives were in surgically shaping dwarf children to look 'normal'. Although ELL was still undertaken by some members of the communities, many participants in this study, such as Reese, found the surgery to be '*old-fashioned technology that doesn't really wash with the 21st century body positivity outlook'*. The American dwarfism organisation, the LPA, has discouraged surgeries like ELL, as it reinforces the hegemonic position that there is biologically and physiologically something wrong with the dwarf body (Kruse, 2003). Echoing more embodied considerations, aligning with Shakespeare & Watson's (2001) and Shakespeare's (2006) concept of the Embodied Ontological Model, members were more likely to consent to straightening procedures that may improve issues such as pain management or stamina, but not undertake surgery primarily for growth.

Employing similar discursive strategies to Radha, Remi discussed her own experiences of childhood and dwarfism, while being raised within a religious BAME community:

> In my [BAME] culture, community is everything; Church is everything. It's a big family. Representation is important because we get racism, so we know what it's like, we've got to stick together […] we're proud, you know. But disability isn't like that. You're not 100%, you understand? My youth was all about rejecting that side of me. Cutting it out. Bone by bone. My back, the arms, legs, it's all been done […] I tell the kids, now it ain't like that. Being [BAME] and being a dwarf is the same. No shame in any of it […] I'd not lighten their skin, so why I'm gonna cut the dwarf out of them?
>
> [Interview, 2018]

During her interview, Remi's descriptions were often graphic and indicative of trauma. For example, the description of '*cutting*' out the elements of dwarfism, of her visible disability, she understood as a form of rejection. As an adult, Remi noted the discrepancy in how various elements of her identity were perceived. Remi perceived that her BAME culture, which had worked hard to foster a sense of community and pride amongst the backdrop of racism, did not consider how other aspects of Remi's identity, specifically her disability, also contributed to her sense of self. As a mother, she had sought to address this issue with her children, arguing that both elements of their identity – disability and ethnicity – were equally important. The language utilised by both Radha and Remi is a demonstration of how powerful discourses were invoked to construct regulatory narratives. Soytemel & Saglam (2024) argued that such 'conspiratorial narratives' produce 'cultural repertories', which individuals use to shape their subjectivities, identities, and influence how they understand the social world. Conspiratorial narratives politicise the self and empower actors by challenging mainstream narratives. Likewise, the discursive environment in which dwarfism narratives operated exposed their relational context, in so far as participants were (re)producing specific subjectivities, knowledges, and cultural 'realities' about dwarfism.

Due to the strength of such discourses, several average-statured participants described feeling that their positions were not secure within the communities, resulting in some mothers feeling compelled to follow the behaviours of dwarf members, or risk exclusion and stigma. The following section explores how the perception of surveillance could produce docile, self-governing, maternal bodies.

Governing Growth: Panoptic Surveillance and Maternal Docility

Women's disproportionate responsibilities for children's well-being (Gillborn et al., 2022; Lowe, 2016) and the maintenance of community relationships (Doucet, 2015) meant that the powerful discourses that regulated membership of the dwarfism communities had a heightened influence on mothers, producing a form of maternal docility. To navigate their subject-positions as mothers responsible for their children's healthcare, and as members seeking acceptance within these communities, most participants (particularly those of average-stature) engaged in self-regulatory practices to maintain their sense of belonging. This dynamic highlighted the juxtaposition of medical and social pressures that mothers continuously negotiated. Amber, for example, expressed how membership of the communities had repercussions on the types of medical treatment she accepted for her child:

> We spoke to the Chairs [committee members/representatives] of a few [dwarfism] organisations, swapped numbers with a few mums. So, by the time we went back to the consultant, we knew in a kind of way what was good for health, like flat-based car seats, and what was not accepted wholeheartedly in the community, [such as] drug trials and limb lengthening […] I guess the risk all average-height parents who find out at the birth, is that the medical community will offer things, and as [average-statured] mums, we're not educated or have experience in this area; we trust and go along with it […] but what's recommended medically, may not be the 'thing' to do in the community.
>
> [Interview, 2018]

Amber's perception that some of the recommended healthcare options '*may not be the "thing" to do in the community*', indicated that membership in the communities was understood by some mothers to be conditional and regulated by the production of a set of rules. These dynamics also imposed constraints on mothers' decision-making, through internalised norms and self-regulation, producing a Foucauldian docility that shaped maternal subjectivities. For instance, Amyna reflected on how the presence of different people influenced what she felt could be discussed with her friends:

> I didn't realise [when first joining the communities] that you couldn't really talk about surgery procedures, or the medical trials, without getting lots of grief back in return. I had about a dozen people shoot me down when I asked about the new treatments.
>
> [Interview, 2018]

These accounts illustrated how mothers within dwarfism communities developed an awareness of this surveillance. As a result, they practised self-governance and self-censorship regarding what they felt could be openly shared. In comparison to dwarf mothers, average-statured mothers felt that their position, status, and presence within the dwarfism communities were not secure. Correspondingly, Allison said it was '*her number one fear*' not to feel part of the communities. Feeling that they had more to lose (having already experienced maternal marginalisation and isolation from their own relationships), many average-statured mothers often felt more pressure to comply with the expected norms of the dwarfism communities, fearing further rejection or expulsion.

Previously, Gillborn et al. (2022) have argued that in relation to health and children's pathologised bodies, cultural discourses hold mothers responsible.

This responsibilisation worked as a biopolitical tool, governing participants' decisions. In Amyna's experience of seeking out medical information and '*getting lots of grief*' in return, she recognised that to a certain extent, her options were being regulated by restricting what topics were open to discussion within the communities. Amyna reacted through compliance, as she stopped seeking answers to the topics that she perceived to be '*off limits*'. This finding also highlights the limitations regarding the usefulness of community membership, as it led to some mothers moving between, and even leaving, some communities. Amyna's narrative also clearly demonstrated that by silencing her questions, the dwarfism communities were valourising certain choices. Thereby, revealing how biopolitical identities were both constructed and contested in relation to notions of 'good' mothering, and making visible the biopolitical dynamics at play within dwarfism communities; hence, social norms were (re)produced through actions. Power operates through productive constraints: it permits subjects to act to constrain them (Tremain, 2002), giving the impression of choice. These participants' narratives uncovered the ways that panoptic surveillance was perceived. Consequently, the perception of surveillance subjected mothers in ways that could position them as 'threats' to disabled and dwarf bodies, within a cultural context which valued these characteristics.

One mother, Aoife, described how she '*just wish[ed] these decisions could be left until adulthood, as [child] could make up their own mind what was what*'. Aoife was reflecting on her inability to distance responsibility for decision-making away from herself. Early on in her mothering journey, Aoife had established a connection with the dwarfism organisations to seek out support. As her mothering evolved, she felt that she relied less on their support but intermittently maintained contact so that her child remained a member and could always attend functions, keeping future options open for her child and herself. In reference to Aoife not wanting to make medical decisions until her child could decide '*what was what*', she recognised that her child's attitude towards dwarfism was not determined. In adopting distance between herself and the dwarfism communities, Aoife was able to retain more autonomy than other participants, such as Amyna. However, delaying decisions could often rule out certain interventions. Thus, not deciding on some forms of treatment could, actually, be a firm decision.

Mothers' subjectivities, positionality, and decision-making were further complicated by the newly developed biotechnological advancements in drug treatments, which were in clinical trials. Developed for young children with the most common form of dwarfism, achondroplasia, the drug trials offered families a non-surgical route to increase growth (Savarirayan et al., 2024). The developments had ignited suspicions within some pockets of the dwarfism communities that the targeting of height 'treatment', specifically for the most common form of non-lethal dwarfism, was motivated by the desire to 'eliminate' dwarfism. The trials reinforced the notion that normative attitudes within medicine and society actually posed a ‘threat’ to dwarfs (Pritchard, 2023), and this suspicion added layers of complexity to the mothers’ subjectivities.

Maternal Decisions in the Context of the Clinical Trials of Vosoritide

A key contribution to the literature that this thesis makes is in exploring the profound tensions and divisions that have emerged within dwarfism communities. These have stemmed from the introduction of biotechnological medical advances in drug ‘treatments’ (Savarirayan et al., 2024), aimed at increasing growth in dwarf children. Almost all members had observed the divisive nature of healthcare decisions, in relation to the few drug trials that were alleged to perpetuate growth in children and adolescents with achondroplasia (Pritchard, 2023). The most common and well-known on the market, Vosoritide, promoted and sold under the brand name, Voxzogo, was created by the pharmaceutical company, BioMarin. In this section, I examine this issue in detail, arguing that these emergent therapies bring to light key debates and tensions, which are interwoven at the intersection of ‘good’ mothering, disability, and the negotiation of identities, as experienced by mothers within the dwarfism communities.

Dwarf Pride

It is tautological to mention it, but being a dwarf is central to the dwarfism communities. As the participants were all recruited from the communities, all were familiar with the concept of 'Dwarf Pride[5]'; although, to what extent they related to it within their own lives, varied among participants. The majority viewed it as beneficial, as it sought to frame dwarfism positively. For example, Alma outlined this common view on the relationship between the physical stature of a person, their connection to the dwarfism communities, and the way that the drug trials seemed to threaten this:

> As a rule of thumb, we address issues when they arise; for example, we've had eight-plates because of bowing in the legs […] I guess I want them to be as healthy as possible and still maintain a connection and pride within the dwarfism community. I don't think that's possible, if you are on a drug trial trying to make yourself taller, then go on to waving the 'Dwarf Pride' flag[6] at people or sign online [disability] acceptance petitions.
>
> [Interview, 2018]

Alma highlighted a perceived contradiction between having a desire for, and the pursuit of, physical growth – '*make yourself taller*' – and the founding ethos of the dwarfism communities, which are based on restricted growth. The sentiment of dwarfism pride and identity was also echoed by Alice, who was firm in her stance:

> I have no interest in putting my child on the drug trial. We've been offered it, but my child's dwarfism is an inherent part of their identity. I've asked them, and they say they love being a dwarf, […]

---

[5] The concept that dwarfs should celebrate and embrace their dwarf stature.

[6] Alma's reference to a 'Dwarf Pride' flag is metaphorical – no flags exist.

> wishes we were all dwarfs, and wouldn't want to do anything that would change that.
>
> [Interview, 2018]

The concept of 'Dwarf Pride', which both Alma and Alice referred to, is based on the acknowledgement and recognition of the unique experiences people with dwarfism face in society. Reflecting back, Riley described her perspectives on how this notion of 'Dwarf Pride' initially embedded itself into the discourses that operated within dwarfism communities:

> I was so excited to meet people with dwarfism that I talked about it for a good year, until the next conference. Back then, you had little choice but to make peace with it [having dwarfism before Vosoritide]. So, Dwarfism Awareness Month and 'Dwarf Pride' was that vehicle of acceptance for us.
>
> [Interview, 2018]

Riley considered how the concept of 'Dwarf Pride' might have emerged as a unifying mechanism within the communities, enabling members to embrace the inevitability of living with a disability that could not be changed. Previously, research explored how membership in dwarfism communities offered dwarfs the opportunity to challenge normative discourses on embodiment (Ablon, 1984, 1988, 1990, 1994; Kruse, 2003). Hence, for dwarfism communities, 'Dwarf Pride' was positioned as a subversive device, often in response to what they perceived to be unnecessary medical interventions and societal stigmas, relating to the historical and cultural representations of dwarfism that problematised dwarf bodies (Adelson, 2005a; Pritchard, 2023; Saville, 2018, 2020). The development of Vosoritide has changed the landscape of dwarfism healthcare in a way that destabilises the very foundational premise of 'Dwarf Pride', towards a context where dwarfism may not be so inevitable, and people may be able to have some choice over their stature, either way. Thus, the contemporary application of the concept of 'Dwarf Pride' appears to operate at an oppositional level to the current debates surrounding biotechnological growth therapies.

Furthermore, recognising the potential for 'pride', also underlined how mothers understood and defined the concept, in relation to their disabled children. As a marginalised identity, it may appear paradoxical to have 'pride' in the stigmatised attributes of dwarfism. However, in defiance of their previous experiences of disappointment and rejection (as described in Chapter Four and Chapter Five), some average-statured mothers, like Alma and Alice, sought a (re)definition that inversed what it meant to be disabled and proud. Thus, the contradictions surrounding marginalised identities were revised to normalise the dwarf body, legitimising their feelings of 'pride'. However, while perceived as positive, 'pride' could also be used to discursively regulate healthcare decisions, in so far as the presumption that if you 'treated' your child's dwarfism, then you could not claim to be 'proud' of your dwarf child.

Mothers Under Suspicion

Some participants felt that by engaging in the drug trials, they risked 'isolation' from some dwarfism communities. Through a regulatory 'gaze', some participants felt that they were being judged by their attitudes to drug 'treatments'. Their allegiances to the values of some communities were effectively questioned; a division had emerged among the membership. Illustrating how embedded this attitude is within the dwarfism communities, dwarfism scholar Pritchard (2023: 102) has argued that 'One of the biggest divides between parents and people with dwarfism is the result of conflicting attitudes concerning treatments and possible cures for people with dwarfism'. Significantly, Pritchard (2023) overlooked the possibility that some dwarf parents might have agreed with some of the medical treatments for dwarfism. Like, for instance, Rabiya from my data. Moreover, Pritchard's (2023) analysis did not consider that some average-statured parents might also reject treatments, as was the case, for instance, with both Alma and Alice from my data. These findings expose the complexity and diversity around maternal perspectives, which cannot be neatly mapped by stature alone.

The perception that the trials were being orchestrated through a demand from average-statured mothers to 'treat' their dwarf children was also expressed by over half of the dwarf mothers in this research, as Rosie insisted:

> It's average-height parents who can't accept their child is disabled. All the talk of BioMarin on Facebook is from parents [average-statured] wanting to know how to get it.
>
> [Interview, 2018]

Ruth held similar beliefs:

> I don't know any dwarf parents who have put their kids on the trial. I'd be surprised if there was. But all the ones who are on it have average-height parents.
>
> [Interview, 2018]

Both Rosie and Ruth formed their 'realities' through the regulatory gaze of mothers within the dwarfism communities. This is a clear example of how suspicion could be perpetuated and sustained through a power/knowledge nexus (Foucault, 1988), operating through 'conspiratorial narratives' that circulated within the communities (Soytemel & Saglam, 2024). Such narratives (re)produced the 'realities' of their lives.

Drawing on Goffman's (1955, 1963) concept of 'face-threatening' acts, these interactions demonstrated how stigma could be employed to regulate the decisions of average-statured mothers. The 'threatening' of these mothers' 'face' also disrupted their subjective sense of self and belonging within the dwarfism communities. Consequently, these 'conspiratorial narratives' (Soytemel & Saglam,

2024) developed into the dwarfism 'realities' that were (re)produced within the communities, risking the stigmatisation of the entire group of average-statured mothers. Additionally, this demonstrated why average-statured participants, unlike dwarf participants, felt that their position within the dwarfism communities was often at risk. As previously examined, most average-statured participants accepted that to be part of the communities, they had to align their behaviours, to some extent, with the dwarfism communities' norms. In contrast, no dwarf participants expressed the same beliefs. Instead, the expectation to conform was, almost entirely, levied towards average-statured mothers.

This is where my findings further deviated from the arguments put forward by Pritchard (2023), which linked the attitudes towards 'cures' to parental stature – it is not the divide my data suggests. In my research, I found that the motivation to pursue enrolment in drug trials was, not surprisingly, a lot more nuanced than a binary division between average-statured and dwarf parents. For example, Agatha explained to me that it was her dwarf husband who had initially tabled the idea:

> I usually go by [husband's] lead when it comes to dwarf-related things, as he is one! He had a lot of issues growing up. Very overweight, was bullied […] he didn't want that for [child], so we asked [hospital] and got enrolled.
>
> [Interview, 2018]

This is clearly in direct contrast to the assumptions made by Rosie and Ruth that dwarf parents were not involved. Similarly, her own experiences of childhood drew Rabiya towards looking at drug trial options for her children. It was also why she was motivated to advise others from the dwarfism communities about the trials:

> I was bullied throughout childhood, so I would've done the BioMarin trial if it was around when I was a child. I wanted it for my children [...] I'm in touch with other [dwarf] mums and will forward them the info, but they have to reach out first. It's a bit hush-hush, as I can't be public about it, because of the bullying and infighting by the charities. There's [several dwarf] families that I know who are on it, but it's not public.
>
> [Interview, 2018]

Childhood experiences of bullying was a common theme raised in the majority of interviews with dwarf participants. Previously, research with dwarfism communities demonstrated how dwarf parents drew on their lived experiences to inform their future parenting decisions (Ablon, 1984, 1988, 1990; Adelson, 2005b). Both Agatha and Rabiya discussed how their attitudes to the drug trials were influenced by bullying; in Agatha's narrative, it was in relation to her dwarf husband. Interestingly, Rabiya referred to '*the bullying and infighting by the charities*', illustrating the similarity in how the mechanisms of regulating 'deviancy' and enforcing conformity can operate punitively, in both normative and non-normative spaces. By examining Rabiya's narrative through a Goffmanian

(1959, 1963) perspective, it is clear that to manage her 'spoiled identity', Rabiya (aware of being observed) undertakes 'front-stage' and 'back-stage' behaviours; intentionally deciding what to bring to the public (front-stage) and what to keep private (back-stage).

Past research has argued that it is often mothers who are associated with the 'moral' stigma of having disabled children and are therefore culpable for their children's bodies and decisions (Davis & Manago, 2016). As previously addressed, violent language could be used as a tool to (re)produce norms and regulate accepted behaviours, which could stigmatise and other mothers. Given that the majority of average-statured mothers feared this type of isolation, this perceived 'threat' was usually effective at regulating behaviours or driving them 'back-stage'. For example, Addison was accused of '*eugenics through the back door*' by another member, who had discovered that her child was in the trials. Another mother, Allana, felt that '*all average-statured parents were under suspicion'* from some of the dwarfism communities. In agreement, Ashling, having witnessed the fractured infighting within the dwarfism communities, explained her predicament when making decisions regarding early access to enrolment in the drug trials:

> Back at the start of the BioMarin drug trial [Vosoritide], the online dwarfism community, you could say, took it very badly. Internationally, the community just imploded. The fights were the worst I've ever seen, beyond any accusation that is usually levied at

> those who've had limb lengthening. This was on another level. [Average-statured] Parents were being called Nazis, eugenicists [...] we were being watched […] accused of not accepting our children. The community was fractured. At the time, [child] was a toddler. We could have easily put them on the trial. But we were scared of the backlash. The dwarfism community has meant so much to us. It has supported us through life events, […] I just couldn't bear the thought that they might reject us if we put [child] on BioMarin [Vosoritide]. I just kept thinking, won't fit in at school, won't fit in with the dwarfism community. We'd risk complete isolation.
>
> [Interview, 2018]

Ashling's narrative illuminated how the surveillance and regulatory pressures enacted upon the membership could be extreme when the dwarfism communities felt threatened by normative medicalised discourses on dwarf embodiment. Through a Foucauldian lens, the data exemplifies the connection between power, the self, and community, suggesting that the dwarf body becomes a pivotal site in exercising power. Thus, Ashling's concerns around the potential '*backlash'* and her fears of social '*isolation'* within the dwarfism communities were not without substance. This was also evident, as discussed previously, in Alma's views on the irreconcilability of medically '*treating'* height, where she could not understand the desire to have growth treatment while maintaining membership in the dwarfism communities, which based their values on having short stature. Hence, by examining the data through the lens of biopower, the biopolitics of the dwarfism communities emerge. The data uncovers how identities were constructed and contested around ideals of 'good' mothering, exposing the biopolitical influences that shaped maternal subjectivities and experiences within dwarfism communities.

Healthcare Under Suspicion

A quarter of participants felt that the communication between the needs and wants of the dwarfism communities (as they saw them) and the pharmaceutical companies responsible for creating new-generation treatments was at a crossroads. Marred by suspicion over the healthcare options on offer, some participants in this research, such as Remi, felt that they were negotiating a healthcare pathway in which the medical experts were '*learning on the job'*. Remi felt that it was not clear to many where robust and scientifically backed healthcare ended, and '*experimentation'* through medical trials on dwarfs began. Remi's description of medical trials as '*experimentation'* is important. It is literal, as all medical trials are, by their nature, experiments that test medical developments to measure costs and benefits. However, '*experimentation'* also invoked a Frankensteinian image of untoward, or even horrific, embodied experiences. Once more, illustrating how violent imagery could (re)produce regulatory discourses within the communities.

Dwarf mothers, such as Rhonda, said that they had seen the popularity of medical treatments over the years '*come and go'*. Surgical treatments, such as ELL, had left a metaphorical scar on the communities. Other medical interventions that also targeted achondroplasia, such as the trials of Growth Hormone Injections, had never been regarded as ‘effective’ due to the biological components of the treatments not being able to alter the genetic structures, which resulted in that form of dwarfism (Murton et al., 2023). Now, in a new era of biotechnological advances in medicine, the dwarfism communities expressed a renewed concern for their existence and identity within modern society, as Riley explained:

> These drug trials symbolise the biggest threat to the dwarfism community in its history. All of the information and publications related to the trials only focus on the benefits to height velocity and growth; they don’t look at any other risk factors associated with dwarfism […] Nobody had asked for this.
>
> [Interview, 2018]

Riley, feeling that she could speak on behalf of the dwarfism communities, felt the companies formulating the treatments were working in opposition to what she thought the wants and needs of people with dwarfism were. She believed that this drug focused just on height, and this was not the dwarfism communities’ concern. She was not completely against medical interventions, but Riley felt that the new treatments should focus on the lethal complications that could arise from dwarfism. So far, as with all other previous attempts to formulate a drug regimen, she felt that pharmaceutical companies had worked in isolation from the dwarfism communities. They had, again, in Riley’s opinion, presumptively set their sights on height as the overarching ‘problem’ affecting people with dwarfism. The social beliefs, which situate height as the starting point for 'burden' in dwarfism healthcare, have continued to shape the direction of medical treatments (Murton et al., 2023).

Taking the long view, Aria believed that the tensions within the dwarfism organisations went deeper than healthcare or perspectives on identity:

> These are not new debates; just look at the D/deaf community around cochlear implants. Same conversations with regards to identity versus medical treatment for disability. You'll get the same ratios with people vehemently against and those who see it as beneficial to their daily lives [...]If the next generation of kids are put on Vosoritide, the community and dwarf identity as a 'thing' diminishes […] The disability support charities are never going to get behind something which removes the impairment, which is fundamental, you know, the 'selling point' to their existence. Think turkeys voting for Christmas.
>
> [Interview, 2018]

Aria reflected on the dwarfism debates in relation to other disabled communities who had experienced similar fractions within their healthcare options. Her perspective focused on the financial viability of disabled support charities, believing that some groups may be under pressure from new biotechnologies, which have the potential to alleviate the symptoms and medical conditions associated with the respective disabilities. She questioned whether the charities were more concerned about the future of '*their existence*', rather than the lived experiences of their dwarf members. Likewise, Ruqayah said, '*there's no point asking them [organisations]; if there's no dwarfs, there's no them. They'll never support the trials'*. The biosociality and characteristics of community are founded on shared features (Rabinow, 1996). In the case of the dwarfism communities, the feature is short stature, which Goffman (1963) categorised as a stigmatised identity. The findings suggest that the biopower of the dwarfism communities operated through the sharing of this stigmatised identity; subsequently, a biopolitical culture arose. As Aria's narrative illustrated, the new biotechnologies were situated as a 'threat' to this biopolitical identity and, by extension, the communities' organisations.

There were also discussions within the communities about what the drug could actually 'treat'. Rosie, for example, was less convinced that this new drug could help in the long-term with dwarfism complications, as the initial trials had to exclude many children with co-morbidities (required in order to operate an effective 'control' group). There were also criticisms concerning the communication and messages by the medical experts involved in the running of the UK-based trials. Áine, for example, had attended a dwarfism conference and believed that the drug trials' recruiters were reacting to the realisation that the communities were not going to 'buy-in', without there being tangible benefits to their health. She felt that they had realised that they had to pitch the drug to go beyond the issue of height, but that this was not very authentic:

> She, of course, made the position that it's about height and about associated benefits for things [such as] sleep apnoea, hydrocephalus, the usual. Then, she talked about having benefits [such as] being able to brush your hair, because you can reach the top of your head, and the benefits of independence with personal hygiene. However, when it came to the Q&A part, the guy next to me asked specifically if it addressed disproportionality in achondroplasia. She said no, it just accelerates growth in proportion to how you would already be growing. […] the guy next to me said, 'So, you're just making a generation of giant dwarfs, who still won't be able to brush the hair on the top of their head'. The whole room burst out into laughter.
>
> [Interview, 2018]

Áine's narrative reflected the general suspicions of some dwarfism communities regarding those involved in the trial's recruitment. Áine felt that in this case, the presenter was misleading about the potential benefits, to make it more difficult for people to oppose the treatment. Given the risks involved with surgical interventions that can alleviate health complications, the majority of participants agreed that non-surgical interventions would almost certainly have a higher uptake and make inroads in contemporary approaches to dwarf health.

The following section examines the narratives of mothers who made the decision, or expressed a desire, to join the clinical trials. It explores their motivations and experiences of this new medical route.

Clinical Trials: Maternal Motivations

The participants in this study were all recruited from various dwarfism communities; many were either explicitly against the drug trials or would only consider it beneficial if it cured the co-morbidities of dwarfism, which could be lethal (such as sleep apnoea and hydrocephalus). Hence, it was not a surprise that many of the mothers (over two-thirds) were against the trials. This section examines the motivations of participants who did not hold this position. These accounts often stressed the emotional feelings of the mother (e.g., hope, fear, guilt) and how this took precedence over their desire to appease the communities. For example, Addison weighed up the risk of isolation with the lived realities of dwarfism:

> The first day of school, first day of college or university, starting the world of work. Then the everyday stuff, going to the supermarket […] These are all areas of social life that is directly impacted by having achondroplasia. How can spending 10 days of the year [partaking in dwarfism community events], at most, justify living the other 355 days as an outsider […] It's not a rejection of dwarfism, disgust, or the like, which I've been directly accused of online. It's an acknowledgement of the difficulties that living with and having dwarfism puts you under. This trial is attempting to alleviate the difficulties associated with achondroplasia. It is not a rejection of the community – they, in fact, are rejecting us.
>
> [Interview, 2018]

Addison concluded that no matter what choice was made, there would be a compromise. The only choice was what, and how much, should be sacrificed.

Ultimately, she decided that as her child would be mostly impacted on a day-to-day basis, it made more sense to follow treatments that may '*alleviate the difficulties associated with dwarfism'*. Addison recognised that her choice placed her in opposition to the prevailing norms and attitudes of most dwarfism communities. However, she denied that this decision indicated her own rejection of the communities themselves. Instead, she saw it as an example of the communities' rejection of members who did not align with their values. Likewise, Rabiya understood that the trials were not popular and that there was a stigma associated with mothers who pursued the treatment:

> Apparently, [mothers] choosing BioMarin [for children] has dire consequences for the whole of dwarf humanity! [sarcasm]. I just rather not deal with people telling me what I should do with my children. I just keep this bit to myself […] I still like to participate [in dwarfism communities], but I decide what to share, and that is none of their concern.
>
> [Interview, 2018]

Rabiya perceived there to be a dominant discourse within the communities; that specific maternal healthcare decisions had '*dire consequences for the whole of dwarf humanity!*'. In her narrative, Rabiya described the negotiation of her subjective positionality, balancing her community participation and the conflicting tensions through a set of 'performances'. Understanding that she was being observed, Rabiya masked her 'stigmatising' behaviours (such as her attitude to the drug trials), locating them 'back-stage' (Goffman, 1959, 1963). Some mothers, like Rianne, were ‘*not concerned’* about potential backlashes from the communities, as it ‘*wasn’t them taking it’*. Rianne had decided to opt-in for the new biotechnology after fully weighing up the potential risks and benefits. Athena reasoned that she had ‘*nothing to lose*’ by enrolling in the trials since there was no data showing that the drug was dangerous. She felt that the potential positive outcomes might help to mitigate any of the possible negative social and lifestyle implications of achondroplasia:

> When we finally came to a decision, it was on the basis of safety and hope for the future. Number one, is the drug safe? Yes, it has passed mouse model trials, and nothing untoward happened. So, even if we get nothing out of this in 10 years' time [bone growth/height], we haven’t hurt [child]. Number two, if it does work, things become easier to manage: school, work, everyday independence. Ultimately, there was nothing to lose but potentially something extraordinary to gain.
>
> [Interview, 2018]

Some participants’ attitudes shifted over time. Abbie, for example, reflected on how her child’s experiences of invasive medical treatments and surgeries had changed her outlook on the new biotechnological therapies. Until serious illnesses had affected her family personally, she had tended to align her beliefs with the dominant values offered by the dwarfism communities. Previously, Abbie had been resistant to some forms of medical interventions and had declined participation in the trials:

> Up until that stage, there had been no, absolutely zero, medical complications associated with achondroplasia. Fast forward to now, and it's been pretty horrendous, to put it mildly […] If, and this is the allegation, the drug [Vosoritide] can alleviate the complications of achondroplasia by encouraging growth, which may widen the narrow spinal canal, airways, and the like, without the need for invasive and life-risking surgery, then it has to be worth it […] I was against the trial because I fully embraced the concept of 'Dwarf Pride' and the Social Model of Disability. But to see the pain this has caused my child, the actual pain that managing the side effects of having dwarfism has caused […] No 'pride' or theory is worth that. Every day, I look at the scars and I live with regret.
>
> [Interview, 2018]

Unlike both Áine and Rosie, who dismissed the potential health benefits as insufficient justification for pursuing drug treatments, Abbie, having seen her child experience traumatic health complications due to their dwarfism, developed a markedly different attitude. Motivated by hope for a healthier future, Abbie's emotional disclosure touchingly got to the heart of the subject: the dwarfism communities were experiencing a time of dramatic uncertainty; without the advantages of hindsight and foresight, most mothers were making these life-changing healthcare decisions under extreme time constraints (before children's epiphyseal plates closed), in an era of fast-paced technology, where information and data outcomes from the trials regarding these treatments could change quickly. Mothers were having to sift through (often contradictory) information from all directions, in pursuit of what they felt were the 'right' healthcare decisions for their children. Moreover, they lived with the fear of making mistakes in these evaluations, as we see in Abbie's narrative.

Conclusion

I began this chapter by making the connection between the maternal experiences of average-statured participants and their gradual acquisition of more nuanced knowledge about dwarfism. At the outset of their mothering journeys, many average-statured mothers reported limited knowledge of dwarfism-specific healthcare, yet they were often faced with significant and time-sensitive medical decisions. These decisions frequently caused anxiety, reflecting broader societal discourses of maternal responsibilisation and the expectation put on women to embody the 'good' mother, by making the 'right' choices (Gillborn et al., 2022; Hays, 1996).

Previously, in Chapter Five, I discussed how specific forms of embodied knowledge were highly valued within these groups, producing an alternative authority to conventional medical expertise. Recognising the diverse and nuanced range of dwarfism experts enabled some average-statured mothers to draw on embodied forms of knowledge to help facilitate their navigation of healthcare decisions. Their engagement with embodied lived experiences, as forms of expertise, underscored the relational dynamics of maternal subjectivities; in particular, this was evidenced through the ways that these community relationships shaped biopolitical identities, manifesting through specific healthcare ‘choices’. For example, it was illustrated in Ayaan’s narrative how she prioritised the embodied experiential knowledge of dwarf community members over the medical advice she had previously followed. This finding suggested that mothers were reconfiguring what, and whom, they perceived to constitute trustworthy and authoritative knowledge. I suggested that this also indicated the ways in which mothers still negotiated and attempted to align with ‘good’ mothering ideals, by following expert guidance on children’s well-being (Hays, 1996); the authoritative ‘experts’, now considered by many participants, were dwarf mothers.

Dwarf mothers also enjoyed this status, as it formed part of their ’face-work’ (Goffman, 1955, 1959); their embodied knowledge elevated the status of dwarfism and destigmatised their identities (Goffman, 1963). This chapter highlighted the mutual advantages of these relational encounters within this context; it was these initial experiences of maternal solidarity that mothers felt drawn to and prioritised, even amid, at times, what could feel like extremely hostile encounters.

As is the case with normative cultural expectations of mothering (Hays, 1996), the data also demonstrated how maternal practices were often subject to scrutiny; this intersected across both normative (non-dwarf) and non-normative (dwarf), online and offline spaces, illustrating how maternal actions were governed by an interlacing of regulatory discourses (Foucault, 1972, 1977). To be perceived as a 'good' mother in these interlacing spheres, participants often felt compelled to navigate conflicting expectations, balancing the healthcare recommendations of doctors with the norms and values upheld within dwarfism communities. This delicate negotiation highlighted how maternal agency could be constrained by broader discursive frameworks that governed participants' decisions.

The findings from this chapter revealed how the dominant discursive discourses, which regulated the cultural norms within the dwarfism communities, could, at times, be violent and graphic. For instance, the data demonstrated how some dwarf mothers employed language infused with violent imagery to depict certain healthcare decisions as harmful. Some dwarf participants drew on their personal histories – often involving trauma – to frame specific medical interventions as not just individual choices, but as existential 'threats' to dwarf identity. By positioning individual healthcare decisions as having significant ramifications for the entire dwarf population, these participants reinforced a discursive strategy where blame and stigma could be used as tools for enforcing conformity. The language used by some dwarf mothers, such as Remi, illustrated the power and potency of discourse, (re)producing regulatory narratives. I made the connection with Soytemel & Saglam's (2024) observations, suggesting that 'conspiratorial narratives' served as 'cultural repertoires', which individuals deployed to shape their subjectivities, identities, and interpretations of their social worlds. These narratives politicised the self, enabling individuals to challenge mainstream discourses while, simultaneously, reinforcing community norms. The regulatory role of 'conspiratorial narratives' (Soytemel & Saglam, 2024) further illustrates how powerful discourses shape the communities. For instance, framing average-statured mothers' involvement in ELL or drug trials as 'threats' to dwarf identity contributed to the (re)production of a 'reality' that fostered a divisive atmosphere, one that perpetuated suspicion and marginalisation. This demonstrated how power could be both productive and punitive, shaping maternal agency through the dual mechanisms of stigma (Goffman, 1963) and surveillance (Foucault, 1977).

The chapter examined how mothers' disproportionate responsibility to maintain community relationships (Doucet, 2015) heightened their vulnerability to the forces of power that regulated the membership of dwarfism communities. For many, particularly average-statured mothers, balancing responsibility for their children's healthcare, alongside their own personal aspirations for community acceptance, necessitated navigating stringent expectations, which could limit their autonomy and subjective agency in decision-making. Membership in dwarfism communities, as perceived by the participants, at times, felt conditional and was governed by expectations that required mothers to self-regulate. This was evident in accounts like Amyna's, who reflected on modifying her conversations, depending on the presence of certain individuals. Her narrative highlighted how mothers became hyper-aware of the surveillance that operated within these spaces, leading to self-censorship and a calculated negotiation of their own interactions. The findings suggest that for average-statured mothers, this pressure was amplified due to their relatively insecure status within the communities. Having frequently experienced maternal marginalisation and isolation in other (non-dwarf) contexts, they felt particularly threatened by the risks of rejection or expulsion from the dwarfism communities; this often prompted greater compliance with community norms. As Tremain (2002) suggested, power functions not only to constrain, but also to produce possibilities for action, giving the illusion of choice while, simultaneously, regulating it.

Consequently, maternal decisions were often embedded within a wider context of community, beyond a child's individual medical situation. This dynamic of panoptic surveillance subjected mothers to heightened scrutiny, framing some forms of dwarf healthcare as potential 'threats' to dwarf and disabled identities, within a cultural landscape that valued these embodied characteristics. Such surveillance reinforced maternal responsibilisation, while perpetuating exclusionary norms and power hierarchies; thereby, regulating the boundaries of community membership and shaping maternal subjectivities.

In this chapter, I explored the contradictory ways in which the concept of ‘Dwarf Pride’ functioned: perceived to be, at the same time, a unifying narrative and regulatory discourse. I discussed how, previously, it had served as a counter-hegemonic device to the inevitable, fixed, embodied realities of dwarfism. Earlier, the concept had enabled dwarfism communities to reject societal stigmas, and (re)produce dwarf identity as a ‘normal’ form of embodiment; a channel for ‘face-work’, and a mechanism to resist stigma (Goffman, 1955, 1959, 1963). However, I have suggested that the introduction of Vosoritide has disrupted this narrative and created a novel terrain of choice, where altering the embodied experiences of dwarfism becomes a new possibility. Crucially, as participants were overwhelmingly the decision-makers for their dwarf children, the future of the dwarfism communities was often perceived to be in the ‘control’ of the 80% of parents who were not dwarfs (Pauli, 2019). For those with dwarfism, this distinction was a significant element regarding the embodied realities of dwarfism; this specific context often fed into deeper community debates on biopolitical identities, and the discursive framing of eugenics, around the eradication of dwarf personhood (Shakespeare, 2008). It is perhaps unsurprising that the power/knowledge nexus, which operated within the dwarfism communities, (re)produced such regulatory strategies, aimed at identifying potential ‘threats’.

Moreover, the findings exposed the nuanced complexities and workings of biopolitics (Foucault, 2008) within the dwarfism communities. Hence, the concept of 'Dwarf Pride' illustrated the productive and constraining dimensions of power within these biosocial communities. While it offered a framework for resisting external stigmatisation, it could also function as a regulatory device, shaping maternal behaviours and healthcare decisions. Framing certain medical interventions, as antithetical to maternal 'pride', implicitly establishes boundaries around acceptable forms of maternal 'choice'. For instance, the suggestion that pursuing growth treatment could undermine maternal 'pride' in a child's identity, exerted pressure on mothers to conform to community values. This reflects how Foucault's (1977) concept of power operates through productive constraints, where the illusion of choice masks the underlying mechanisms of regulation and surveillance. However, the experiences of many participants also revealed moments of resistance to these constraints.

The findings suggest that attitudes towards drug trials were shaped less by a binary division of stature and more by the intersection of biopolitical identity, personal history, community norms, and dominant societal discourses. We can see how average-statured mothers, like Alma and Alice, rejected growth treatments, challenging the assumption that average-statured parents were spearheading the pursuit of medical treatments for growth. Conversely, Rabiya's willingness disrupted the assumption that dwarf parents were uniformly resistant to growth therapies. Ultimately, the findings of my data complicate the binary interpretations offered by Pritchard (2023) by highlighting the fluidity and diversity of attitudes within dwarfism communities.

Further, I have suggested that the emergence of Vosoritide represented a profound challenge to the biopolitical identities that underpinned many dwarfism communities. Grounded in the shared characteristic of short stature, these communities were constructed from a collective experience of stigma (Goffman, 1963), transforming a perceived deficit into a site of solidarity and resistance. The research findings exposed tensions: the perception that emerging biotechnologies threatened dwarf identity and could jeopardise the foundations of dwarfism communities, including its erasure (Shakespeare, 2008). As Rabinow (1996) argued, biosociality is rooted in shared biological traits; however, when these traits are framed as malleable or correctable through medical intervention, the very basis of collective identity is called into question. I uncovered how the availability of Vosoritide had illuminated the intricate conflicts between the biotechnological advancements in dwarf healthcare, subjective identities, and the power dynamics that operate within dwarfism communities. The drug's reliance on early enrolment, requiring administration before the closure of epiphyseal plates, placed an urgent demand on mothers' decision-making. I highlighted how this context conflicted with developmental approaches, which advocate for children's agency in understanding and embracing their identities, as discussed by Sullivan Sanford (2006). Within this temporal constraint, medical decisions were entangled with subjective perspectives on dwarf identities, presenting challenges to mothers that were not merely practical, but also deeply ideological for some. The changing landscape of biotechnological treatments exemplifies Vosoritide's potential to shift the boundaries of dwarf healthcare. The findings suggest that this also amplified community debates around cultural identities, exerting biopolitical pressure on mothers with dwarf children. Maternal decisions were imbued with a dual burden: the responsibility to safeguard their child's health (Hays, 1996), while navigating the expectations and judgements of the dwarfism communities. This reinforces Davis & Manago's (2016) argument that mothers of disabled children often bear the moral responsibility for their children's bodies.

The findings demonstrated the deeply emotional and subjective complexities of maternal decisions: for some, the promise of mitigating health complications and social stigma provided hope; for others, the fear of contributing to the loss of their child's cultural identity fostered resistance. Maternal concerns were compounded by the lack of definitive data on the long-term effects of Vosoritide, leaving some mothers in a perpetual state of distress, where they feared making the 'wrong' decisions. I suggested that this may have contributed to the reasons why some mothers managed their decisions in ways that shielded them from community backlash. For instance, by relegating behaviours that might be perceived as ‘stigmatising’ to the ‘back-stage’, mothers were able to maintain ‘face’ and community engagement; although this often required strategic concealment, aligning with Goffman’s (1955, 1959, 1963) concepts of performance and stigma.

The tensions surrounding Vosoritide functioned as a lens through which the evolving dynamics of identity, community, and medical advances could be critically examined, as I have done here. The findings underscored the role of biotechnological therapies, not only in shaping physical bodies but also in governing the discourses of communities, thereby influencing cultural identities and power relationships. The data demonstrated that for some mothers within dwarfism communities, these biotechnological therapies embodied a wider struggle over autonomy, belonging, and the preservation of dwarf identities. The emotional complexities faced by these mothers highlighted the pressures of navigating competing maternal expectations (Hays, 1996), where the potential for health ‘improvement’ intersected with cultural fears of erasure (Shakespeare, 2008).

The themes explored in this chapter furthers the groundwork for the Conclusion (Chapter Seven), which will draw on the concepts developed here to situate my final interpretations of the project’s findings. As the findings of this chapter have demonstrated, individual maternal decisions were not without their own intricacies; it is clear that mothers navigated complex healthcare decisions while, simultaneously, seeking a sense of belonging within the dwarfism communities. However, for some, this desire for inclusion was overshadowed by previous experiences of exclusion. Hence, power operated subtly, yet forcefully, regulating maternal subjectivities through the ever-present risk of community stigma. Thus, the very spaces that were sought out for support and solidarity could, paradoxically, become sites of tension. Far from being static or one-dimensional, maternal subjective perspectives emphasised the complexity of navigating belonging within dwarfism communities, where solidarity and regulation co-existed.

In the following chapter, I engage in a reflexive analysis of my research journey by examining some of the methodological and conceptual challenges I encountered along the way. I then move on to revisit the central aims of the study, exploring how the emerging themes of the project addressed the research questions raised in Chapter One.

Chapter Seven – Concluding the Research

Introduction

In this concluding chapter, I will fulfil the purpose of this thesis by situating the findings of this project in relation to the research questions proposed in Chapter One. In Chapter Two, I discussed how this project developed in response to the sparse literature on mothering children with dwarfism, especially amid its immense transformation, which was marked by the development of biotechnological growth treatments. Notably, sociological research had yet to engage with this terrain, regarding maternal experiences within UK-based dwarfism communities.

The scarcity of empirical research in this area was increasingly pronounced, especially when considering that the clinical trials of Vosoritide had represented a significant shift in the medical landscape. These developments offered transformative possibilities, potentially altering the lived experiences and future trajectories of the next generation of individuals with dwarfism. It is within this critical juncture of social and medical change that this thesis makes its contribution. Hence, this thesis constitutes the first UK-based sociological study to examine these issues from the perspectives of the maternal subjectivities of mothers within dwarfism communities.

I begin this chapter with a final reflection, where I examine my personal development as a researcher throughout this academic journey. This includes an exploration of how my positionality and assumptions evolved, influencing the study's trajectory. By situating my own experiences within the context of the research process, I aim to provide transparency regarding the ways in which my perspectives have shaped the interpretation and representation of the research findings.

I will then revisit the central themes and insights that have emerged from my thesis, locating them within the context of the research questions (Chapter One). Finally, in closing the research, I offer some concluding remarks that will encapsulate the substance of this thesis.

Positionality: My Reflexive Research Journey

The research process necessitated a profound confrontation with my positionality and the assumptions I held about dwarfism communities. Specifically, my own maternal subjectivities, as an average-statured mother, where my personal experiences had shaped my views of these communities. Having relied heavily on the support and welcoming nature of the dwarfism communities during a particularly vulnerable time in my life, I approached the fieldwork with a strong sense of loyalty and protectiveness. The dwarfism communities had provided me with a vital source of emotional support and practical guidance when I needed it most, and I carried this gratitude into my research. However, as I listened to some of the participants' narratives, I was forced to grapple with a set of experiences that diverged markedly from my own. A few mothers (average-statured and dwarf) had described instances of hostility and social policing within the communities; experiences that challenged the idealised view I had brought into the field.

This disjuncture led me to interrogate my own complicity in perpetuating a singular, perhaps sentimentalised, narrative of the dwarfism communities. My initial tendency was to think about these dwarfism communities as explicitly supportive spaces, where the potential for maternal 'healing' could take place. This all drew from my own, overwhelmingly positive experiences. Yet, some participants' narratives suggested that the spaces and discourses, which produced these communities, were more complex and nuanced. Hence, the very structures intended to foster support could also exclude and (re)produce forms of discursive regulation. The discomfort I felt in acknowledging this discrepancy spoke to the broader challenges of conducting research as an 'insider', with my own vested emotional interests. My subjectivities, as a mother who had benefited immensely from the dwarfism communities' support, made it difficult to reconcile these conflicting narratives, prompting me to develop a deeper, more critical engagement with my positionality.

In attempting to understand what compelled mothers to engage with dwarfism communities, it was necessary to move beyond my own understandings and examine the broader motivations at play. Many participants (both average-statured and with dwarfism) spoke of a strong 'pull' towards the communities, driven broadly by the need for emotional relationships and access to specialised knowledge about dwarfism. This mirrored my own initial motivations, yet the stories of surveillance and regulatory tensions indicated to me that these experiences were examples of deeper power relationships, which operated within dwarfism communities. In Foucauldian terms, these narratives demonstrated the ways that power relationships could (re)produce the communities' behaviours, regulating cultural norms, and the construction of maternal subjectivities. Hence, the communities appeared to be experienced as contested spaces, where support and regulation co-existed, often uneasily. For some participants, the communities' support was perceived as being contingent upon conforming to certain norms or expectations, signifying an undercurrent of biopower at work.

I came to view these maternal experiences (both positive and negative) as being shaped by a complex interplay of power relationships, rather than as purely individual or distinct in nature. Foucault's (1977) concept of disciplinary power, where power operates through everyday practices and norms rather than through overt coercion, offered this project a useful framework for demonstrating and interpreting these relationships. It provided an explanation for the participants' inconsistent and contested feelings towards the dwarfism communities. Dwarfism communities occupied a complex and often contradictory position; they were simultaneously perceived as spaces of safety and support, while also functioning as sites where maternal behaviours and choices could be closely monitored and regulated. Power, in this context, was not an external force imposed, but rather a relational construct, emerging through the everyday interactions and discourses within the communities. Power was enacted in subtle and pervasive ways, shaping maternal subjectivities and influencing how dwarfism was perceived and understood. Rather than being a monolithic mechanism, power relationships were fluid and co-produced through the lived experiences of the communities' members. Thereby, revealing the intricate ways in which social norms and expectations were negotiated and contested.

The variability in participants' experiences also signalled that power did not operate uniformly across different contexts or communities. My initial impulse was to generalise from my own positive experiences, yet the research process highlighted the contingent and fluid nature of power relations. Some mothers articulated a willingness to overlook or justify the instances of hostility they encountered, framing these tensions as a necessary part of participating in the communities that offered significant emotional and informational support. This echoed Foucault's (1977) argument that disciplinary power was effective, not because it overtly coerced, but because individuals often consented to its workings, believing it served a broader benefit. In this context, maternal emotions, particularly the desire for support and connection, became a crucial mechanism through which power could be negotiated and enacted.

Reflecting on my positionality as a mother-researcher, it is evident that my own emotional investment shaped not only my expectations but also my interpretation of the data. The protective instinct I felt towards the communities initially obscured their more ambivalent and negative aspects, which some participants described having experienced. Acknowledging this required me to confront the ways in which my own perspectives drove my analysis. The process of critically engaging with these themes, even when they contradicted my own perceptions, allowed me to gain a distinct understanding of the complex nuances of power relationships at play.

Ultimately, this critical reflection foregrounds the importance of examining how relational power operates within these communities, and how maternal subjectivities – including my own, as a mother-researcher embedded in and engaged with dwarfism communities – were shaped in relation to these dynamics. In the following section, I offer my interpretation of the research findings.

Revisiting the Central Themes: Key Findings

Reiterating the goals of the research discussed in Chapter One, the central questions this study sought to address were:

1. How do mothers of children with dwarfism construct their identities and negotiate the stigmas attached to themselves and their children?
2. How and why do mothers of children with dwarfism engage with the dwarfism communities?
3. How do mothers of children with dwarfism make healthcare decisions and engage with the debates surrounding biotechnological advances that are designed to increase the height of those with dwarfism?

In foregrounding the role of power in shaping maternal subjectivities, this thesis has explored how mothers navigated their subjective positionalities amid intersecting discourses of cultural stigma (Goffman, 1963) and the norms established within dwarfism communities. Drawing on Foucault's (1972, 1977, 1988) conceptualisation of power as relational and productive, this research illuminated the dynamic processes through which maternal identities were disrupted, negotiated, and reshaped by both compliance with and resistance to regulatory discourses. Maternal subjectivities were deeply influenced by their proximity to stigma (Goffman, 1963), their engagement with the societal ideals of 'good' mothering (Hays, 1996), and their active participation in dwarfism communities. Together, these dynamics revealed the intricate interplay of external pressures, community expectations, and subjective agency, which shaped the lived realities of these mothers. In the following section, I offer my interpretation of the findings, framing them around the central themes of this study, and discuss the insights that have emerged from the research.

Maternal Identities and Stigma Negotiation

The findings demonstrated how mothers of children with dwarfism navigated a complex landscape of stigma, which extended beyond their child's condition to include their own self-perceptions. This affected all mothers, dwarf mothers as well as average-statured mothers, raising dwarf children. The data suggested that participants often perceived a dual layer of stigma: one linked directly to their child's dwarfism, and the other associated with societal judgements regarding an implied, maternal (in)adequacy. These findings supported the argument that expectations of 'good' mothering placed additional responsibilities on mothers (Hays, 1996). In the context of this research, a child's disability could be perceived as a reflection of maternal (in)adequacy, and a failure to meet culturally prescribed ideals of 'good' motherhood.

The topic of maternal (in)adequacy was raised by many dwarf mothers, who also reported a heightened sense of blame for their child's condition. These mothers described facing implicit and explicit scrutiny from both medical professionals and wider society. They felt that there was an assumption that their choice to become a mother, particularly if they had expressed a desire for a child with dwarfism, was in some way irresponsible or selfish. These findings offer a nuanced understanding of how maternal subjectivities are co-constructed within the context of power relationships, underscoring the fluidity of maternal identities. Furthermore, the findings exemplify how participants negotiated maternal subjective agency in the ways that mothers complied with, and resisted, normative discourses surrounding ‘good’ mothering (Hays, 1996). These findings provide a contribution to feminist perspectives on motherhood as a site of contested power; at this intersection, identities and maternal subjectivities are disrupted and shaped through dominant discourses, which medicalise the body and govern constructions of gender and disabilities.

The research explored the ways that dwarf mothers navigated stigma and negotiated identity through intricate and nuanced strategies, shaped by their embodied positionality. Dwarf mothers were unable to distance themselves from stigma, in the same way that some average-statured mothers could, as their physical embodiment, inherently, tied them to the dehumanising societal discourses surrounding dwarfism and disability (Ablon, 1984; Adelson, 2005b; Goffman, 1963). In these instances, this led to the internalisation of stigma, which was experienced by some participants as self-stigma (Pritchard, 2023). Conversely, other dwarf mothers actively challenged and subverted these discourses; one way mothers enacted resistance was through the reframing of dwarfism, by distancing it away from traditional constructions of disability. This reframing reflected an effort to disrupt dominant discourses by reasserting mothers' subjective agency over their identities and the identities of their children. Such practices illustrated the nuanced, fluid, and subjective perceptions of disability and dwarfism. Furthermore, the findings underscore the diverse ways in which dwarf mothers engaged with and contested stigma. Thus, revealing the complex interplay of identities, subjective agency, and the dominant discourses that shape experiences of dwarfism.

Some average-statured mothers navigated their maternal identities through an ongoing, (re)productive cycle. For example, some participants described their need to reconcile their personal expectations of motherhood with the 'biographical disruption' (Bury, 1982) they had experienced as a result of their child's dwarfism diagnosis. This echoed the findings of Landsman (2009), who described this experience as a form of 'maternal disruption', and also Ryan & Runswick-Cole (2008), who argued that the arrival of a disabled child often brought a profound shift in maternal identity and disrupted the preconceived notions of what it meant to be a 'good' mother.

Several average-statured mothers expressed ambivalence and uncertainty following the diagnosis, which was shaped through an acute awareness of the societal perceptions of dwarfism as a stigmatising condition (Ablon, 1984, 1988; Adelson, 2005a, 2005b; Pritchard, 2021, 2023; Shakespeare et al., 2010). This recognition not only highlighted the marginalisation of their children but also generated tensions between their own maternal subject-positions. For many participants, such tensions were mediated through the stigmatising discourses they encountered; thereby, also posing a threat to their own sense of identity. These findings aligned with Goffman's (1963) analysis of courtesy stigma, illustrating how the proximity of a non-stigmatised individual (the mother) to a stigmatised person (the child) extended the risk of stigma. Hence, reinforcing the feelings of social exclusion and identity disruption.

In efforts to manage stigma, some average-statured mothers inadvertently reinforced hierarchical discourses of disability (Rogers, 2007). For instance, participants who framed dwarfism as a manageable or less severe condition, attempting to elevate its status by distancing it from other forms of disability, (re)produced a hierarchy of impairments (Tringo, 1970). This underscores the paradoxical nature of stigma management: efforts to manage, or 'cool' stigma (Goffman, 1952, 1959, 1963), can also reinforce the very same dominant discourses that produce it.

The research illustrated how mothers often resisted stigma through forms of 'face-work'. Drawing on Goffman's (1963) concepts of stigma, the findings demonstrated how some mothers resisted marginalising discourses by 'front-staging' (Goffman, 1955, 1959) dwarfism through, for instance, curated portrayals on social media. However, in attempting to 'normalise' their lives through ‘front-staging’ (Goffman, 1955, 1959), mothers could inadvertently encroach on their children’s privacy and right to consent (Saville, 2020; Steinberg, 2017). These visual practices aligned closely with observations made by Thomas (2021), who, when referring to Down’s Syndrome, argued that parents will often seek to reposition disability as a normal and mundane feature of their everyday life. Another significant finding was regarding the maternal actions that resituated the ‘gaze’, exposing how mothers used everyday visuals and interactions from their own lives to help resist and challenge the dominant cultural representations of dwarfism. These actions also uncover the paradoxes that construct the ‘realities’ of dwarfism: many mothers within the dwarfism communities had blamed social media for the precarious positioning of dwarfism in the first place.

Mothers in this study recognised dwarfism as both a biological reality and a social construct, which had been shaped through the cultural forces of knowledge (re)production and medical discourses. This echoed Rabinow’s (1996) notion of biosociality, demonstrating the intricate link that biological features can have on the construction of our subjective selves. The processes through which mothers managed stigma and produced their identities reflected a biopolitical struggle, whereby mothers asserted their agency within a system that often disciplined and regulated their experiences of motherhood. Given the frequent emergence of embodiment-related themes throughout this project, the Embodied Ontological Model of Disability (Shakespeare & Watson, 2001) offered a compelling framework for mapping the interplay between physical embodiment, lived experiences, and structural contexts. This model supported my perspectives and interpretations of disability, dwarfism, and identity as deeply relational and embodied constructs (Shakespeare & Watson, 2001; Shakespeare, 2006).

Maternal Engagement with Dwarfism Communities

The data suggested that the dwarfism communities (re)produced a power/knowledge nexus, which was maintained and managed through the collective sharing of maternal knowledge. The findings also highlighted how 'embodied' and 'empathetic' experiential forms of knowledge were distinctly positioned (Boardman, 2014, 2017). The research uncovered how engagement with dwarfism communities allowed many dwarf mothers to undertake forms of 'face-work' (Goffman, 1959), reconstructing their (stigmatised) identities by situating their dwarf bodies as sites of authority. While this dynamic was (re)affirming for many dwarf mothers' sense of self, some average-statured mothers pushed back, believing that it reinforced a hierarchy of stature, which in turn, challenged the legitimacy of their own embodied positions within dwarfism communities.

Moreover, the data illustrated how dwarf mothers (most of whom had been engaged in the communities since childhood) were perceived to be dwarfism 'experts' through their embodied lived experiences. This was despite lacking formal medical or professional credentials. In contrast, average-statured mothers (all of whom had only entered the communities after the birth of their dwarf child) did not possess the same depth of relational or experiential capital. As dwarf mothers asserted their subjective knowledge, their longevity and status within the communities positioned them as ‘embodied experts’, affording them considerable influence in shaping and regulating community norms. This extended to the regulation of healthcare decisions, exemplifying the cyclical and hierarchical nature of experiential knowledge (re)production within dwarfism communities. Hence, bodily experiences and community embeddedness were mutually reinforcing. However, this dynamic also intensified the tensions regarding *which* bodies had the power to define community norms, (re)produce 'expert' knowledge, and influence maternal subjectivities. Through this lens, the regulation of dwarfism narratives and maternal practices within the communities can be understood as an exercise of biopower, where bodies, health, and identities were (re)produced and enacted through community norms.

A key motivation for mothers’ engagement with communities was the desire to protect their children. As previously discussed, mothers perceived the communities as spaces of knowledge, helping to navigate issues such as bullying, discrimination, and social exclusion. Mothers drew on the resources and collective knowledge within the communities to help their children develop a positive sense of identity, equipping them to navigate a world that often viewed dwarfism through a stigmatised lens. However, while many mothers did receive these forms of support, there were drawbacks. Many mothers felt that their presence within the communities was conditional. For example, certain topics, particularly around healthcare, became contentious and could risk community isolation, thereby regulating maternal behaviours.

In relation to the construction of online dwarfism communities, the findings reflected broader trends in how communities leveraged digital networks for support, contributing to the literature on internet behaviour and information-seeking (Mackenzie, 2017, 2020). The findings suggest that the online spaces served as mostly positive platforms for mothers of children with dwarfism; participants utilised the medium to share knowledge, build solidarity, and advocate for their children. These virtual spaces not only facilitated the exchange of practical advice but also acted as important sites for community building and resistance. This perspective contributes to our understanding of how digital communities can serve as productive spaces for marginalised groups by (re)producing identities and knowledge in ways that challenge dominant societal narratives. Digital spaces were integral to how mothers navigated both intensive mothering ideals (Hays, 1996) and the stigma attached to their children's condition (Goffman, 1963). However, the findings also indicate the ways that online communities could function, not only as spaces of support and knowledge, but also as sites of regulation, policing behaviours in line with dominant community norms. This demonstrated the ways that online dwarfism communities could be perceived as both supportive spaces and sites of surveillance (Foucault, 1977), reinforcing the boundaries around dwarfism, identity, and ‘good’ mothering practices.

Additionally, the findings of this research have contributed to stigma theory, illustrating how stigmatisation can occur *within* marginalised communities, as mothers felt internal judgement for considering biotechnological growth interventions. This challenges the traditional understanding of stigma, as something imposed solely by the dominant society; it reveals how intra-community surveillance can also (re)produce stigma and regulate maternal decision-making.

Maternal Healthcare Decisions and Debates on Growth Therapies

The research highlighted instances where mothers in this study felt intense scrutiny when making decisions related to biotechnological dwarfism therapies, such as whether to enrol their children in BioMarin’s clinical trial of Vosoritide. The debates surrounding this drug, which suggests it may enhance growth in children with dwarfism, sparked significant divisions within the communities. Some participants supported these advances, viewing them as a potential way to improve their children's lives by addressing the challenges associated with dwarfism. Conversely, others viewed them as inherently problematic, interpreting the drug's development as an attempt to 'fix' dwarfism, something they felt challenged the notions of 'Dwarf Pride' and identity, which were embedded within the dwarfism communities. Therefore, the findings demonstrated how healthcare decisions in the context of dwarfism communities were profoundly shaped by both the communities' dynamics and the complex power/knowledge nexus, which regulated the communities' norms and discourses.

Interestingly, while the findings indicate that attitudes toward drug trials were not strictly determined by a binary division of stature, a notable divergence emerged between the perspectives of mothers with dwarfism and those of average-stature, concerning the development of biotechnological growth therapies. Mothers with dwarfism were more likely to articulate clear and consistent views of the trials, with only one participant expressing uncertainty. In contrast, average-statured mothers more frequently reported conflicted or evolving positions. This difference may be linked to their varying stages of identity formation and levels of engagement with the dwarfism communities. Mothers with dwarfism often reported longstanding involvement in these communities, and demonstrated more established biopolitical identities, and perspectives on disability, dwarfism, and embodiment. Conversely, average-statured mothers were more likely to be actively negotiating their understandings of disability and their maternal roles in the context of their child's dwarfism. This ongoing process of identity negotiation may account for their more fluid or conflicted responses to biotechnological drug therapies. These findings build on the theoretical understandings of Foucault's (2008) concept of biopower and its relevance to modern healthcare decision-making in biosocial communities. My analysis of participants' narratives revealed clear examples of how biopower operated, not only through medical institutions but also through community-based discourses. Consequently, shaping subjective identities and maternal healthcare choices through social norms and stigma.

The findings illustrate that healthcare decisions were not solely clinical or rational; rather, they were deeply infused by maternal subjectivities and were understood to bear significant regulatory, social, and cultural implications within community spaces. However, mothers in dwarfism communities were not simply passive recipients of these regulatory discourses; many actively engaged with the expertise and norms that were (re)produced within dwarfism communities, shaping their healthcare decisions. As such, this research calls for a more nuanced understanding of healthcare agency, one attuned to the ways that individuals negotiate complex power relationships between medical and community gatekeepers. This could facilitate the development of more inclusive healthcare practices that engage with community knowledge systems and also contribute to sociological understandings of how these productive forces operate within biosocial communities (Rabinow, 1996).

With respect to health decisions, some mothers described feeling caught between medical and embodied forms of expertise. Many sought to balance the advice of healthcare professionals, alongside the experiences and advice shared within the dwarfism communities. The BioMarin Vosoritide trials exemplified how mothers grappled with medical advancements that promised physical ‘improvements’, while raising broader concerns about identity, stigma, and the implications of ‘treating’ dwarfism. In some cases, participants actively sought out the latest information on biotechnological advances to make informed decisions about their children's healthcare. However, this information-seeking process was complicated by what participants perceived to be conflicting messages from healthcare professionals and community members.

Some average-statured mothers felt further scrutiny as ‘outsiders’ to the embodied experiences of dwarfism. Their decisions were sometimes viewed with suspicion or mistrust, and these mothers often feared making the ‘wrong’ decisions, which could lead to long-term consequences for their child’s physical health or social acceptance within the communities.

The decision to enrol in the clinical trials of Vosoritide was often framed as a balancing act between improving the child’s health outcomes and protecting their social identity. Some participants described feeling overwhelmed by the enormity of these choices, with few even expressing feelings of guilt, if they believed their decisions might cause harm, either physically or socially, to their children. This dimension of decision-making illuminates the emotional strain of navigating the intersection of biological health, perceptions of 'good' mothering, biopolitical identity, and community belonging. Some mothers discussed having to make sense of conflicting narratives, often negotiating their healthcare decisions by adopting middle-ground positions. Choosing, for example, to pursue some medical interventions, while rejecting others that were perceived as 'more' invasive or identity-altering.

Mothers' healthcare decisions were significantly influenced by their membership within dwarfism communities. A key finding of this research was in how the concept of 'pride' could be used as a regulatory tool, where some dwarfism communities encouraged mothers to avoid medical interventions, which could be perceived as diminishing dwarf embodiment. This created pressure to conform to certain norms that valued dwarfism as an identity, rather than, for example, as a condition to be 'treated'.

Mothers who considered enrolling their children in the BioMarin Vosoritide trials described experiences of hostility and judgements from within the communities. This resulted in feelings of guilt and anxiety among some mothers, who feared being ostracised from the communities for making decisions that conflicted with their norms. However, these mothers still expressed a desire to belong to the communities, indicating that their sense of belonging and the support they received from the communities outweighed their experiences of hostility. This complex relationship between the dwarfism communities' support and cultural norms exposed the tensions and effects of power.

Theoretically, the interweaving of the conceptualisations of power (Foucault, 1977, 2008), stigma (Goffman, 1963), and 'good' mothering (Hays, 1996) provided new insights into how marginalised maternal identities were shaped. Maternal subjectivities were formed through both external forces (such as societal stigmatisation) and the relational power dynamics within dwarfism communities (such as 'pride' and gatekeeping). Therefore, the research demonstrated that mothers' healthcare decisions were deeply influenced by their desire to manage stigma and construct a socially acceptable identity, both for themselves and their children.

Concluding Remarks

In drawing this thesis to a close, I offer my final thoughts: rather than viewing participants' experiences and decisions as individual behaviours and choices, we need to recognise the deep nuances that intersect within the operation of power relationships. Ultimately, this study revealed how all mothers were having to manage complex healthcare decisions within communities, in which they desired to feel a sense of belonging. At times, however, some mothers described experiencing the opposite; as power often operated through regulatory forces that attempted to define the boundaries of dwarfism communities. Thus, some mothers may have felt that their choices were limited due to the risk of stigmatisation and fear of community isolation. Having sought out communities within these non-normative (dwarf) spaces, these threats to maternal identity and belonging (re)produced a docility in some mothers, as they tried to conform to the values of the communities. Nevertheless, these mothers chose to still engage with the dwarfism communities, regardless of, at times, the hostilities that were invoked. It is these nuanced discourses of power that (re)produced and defined the intricate details of maternal experiences within dwarfism communities.

Given the exploratory nature of this study, as well as the scarcity of research within the context of experiences of mothering within dwarfism communities, this thesis offers the first sociological exploration into the experiences of maternal subjectivities within the context of UK-based dwarfism communities. In addressing the aims and questions of this research, this study meaningfully enhances our understanding of how biotechnological advances, community norms, and power dynamics intersect to shape healthcare decisions within marginalised, dwarfism communities. The research offers original contributions to the fields of medical sociology, digital sociology, motherhood studies, disability studies, and theories on the formation of identities and communities, providing new insights into the complex power relationships that are (re)produced between the dwarfism communities and their membership. By examining how mothers in dwarfism communities navigated healthcare decisions, in the context of advancing biotechnologies, the study contributes to a deeper understanding of the social and emotional dimensions of medical decision-making, particularly in communities where identity and stigma play a central role. Moreover, it underscores how maternal identities are constructed and negotiated in relation to ideals of ‘good’ mothering, exposing the biopolitical forces that shape experiences within dwarfism communities.

References

Abdullah, M. (2012) ‘Womanist Mothering: Loving and Raising the Revolution’, *Western Journal of Black Studies*, 36 (1), pp. 57-67.

Ablon, J. (1984) *Little People in America: The Social Dimensions of Dwarfism,* New York: Praeger.

Ablon, J. (1988) *Living with Difference: Families with Dwarf Children*, New York: Praeger.

Ablon, J. (1990) ‘Ambiguity and Difference: Families with Dwarf Children’, *Social Science and Medicine*, 30 (8), pp. 879-887.

Ablon, J. (1994) ‘Reflections on Fieldwork with Little People of America: Myths and Methods’, in Don. D. Fowler and Donald L. Hardesty, (ed.) *Others Knowing Others: Perspectives on Ethnographic Careers*, Washington, DC: Smithsonian Institution Press, pp. 195-210.

Adelson, B. (2005a) *The Lives of Dwarfs: Their Journey from Public Curiosity toward Social Liberation*, New Jersey: Rutgers University Press.

Adelson, B. (2005b) *Dwarfism: Medical and Psychosocial Aspects of Profound Short Stature*, Baltimore: The Johns Hopkins University Press.

Ademolu, E. (2024) ‘Birds of a Feather (Don’t Always) Flock Together: Critical Reflexivity of “Outsiderness” as an “Insider” doing Qualitative Research with One’s “Own People”’, *Qualitative Research*, 24 (2), pp. 344-366.

Adler, P. and Adler, P. (1997) ‘Parent-as-Researcher: The Politics of Researching in the Personal Life’, in R. Hertz, (ed.) *Reflexivity and Voice*, London: Sage Publications, pp. 21-44.

Ali, A., Hassiotis, A., Strydom, A. and King, M. (2012) ‘Self Stigma in People with Intellectual Disabilities and Courtesy Stigma in Family Carers: A Systematic Review’, *Research in Developmental Disabilities*, 33 (6), pp. 2122-2140.

Ali, D. A., Figley, C. R., Tedeschi, R. G., Galarneau, D. and Amara, S. (2023) ‘Shared Trauma, Resilience, and Growth: A Roadmap Toward Transcultural Conceptualization’, *Psychological Trauma: Theory, Research, Practice, and Policy*, 15 (1), pp. 45-55.

Almeida, M. and Diogo, R. (2019) ‘Human Enhancement: Genetic Engineering and Evolution’, *Evolution, Medicine, and Public Health*, 2019 (1), pp. 183-189.

Ames, S. G., Delaney, R. K., Houtrow, A. J., Delgado-Corcoran, C., Alvey, J., Watt, M. H. and Murphy, N. (2023) ‘Perceived Disability-Based Discrimination in Health Care for Children with Medical Complexity’, *Pediatrics*, 152 (1), e. 2022060975.

Archibald, M. and Crabtree, C. (2010) ‘Health Social Movements in the United States: An Overview’, *Sociology Compass*, 4 (5), pp. 334-343.

Arendell, T. (2000) ‘Conceiving and Investigating Motherhood: The Decade's Scholarship’, *Journal of Marriage and Family*, 62 (4), pp. 1192–1207.

Backstrom, L. (2012) ‘From the Freak Show to the Living Room: Cultural Representations of Dwarfism and Obesity’, *Sociological Forum*, 27 (3), pp. 682-706.

Barkhuizen, G. (2008) ‘A Narrative Approach to Exploring Context in Language Teaching’, *ELT Journal*, 62 (3), pp. 231-239.

Barkhuizen, G. (2013) ‘Maintenance, Identity and Social Inclusion Narratives of an Afrikaans Speaker Living in New Zealand’, *International Journal of the Sociology of Language*, 2013 (222), pp. 77-100.

Barton, J. and Hayhoe, S. (2021) *Emancipatory and Participatory Research for Emerging Educational Researchers: Theory and Case Studies of Research in Disabled Communities*, Abingdon: Routledge.

Begeny, C. T., van Breen, J., Leach, C. W., van Zomeren, M. and Iyer, A. (2022) ‘The Power of the Ingroup for Promoting Collective Action: How Distinctive Treatment from Fellow Minority Members Motivates Collective Action’, *Journal of Experimental Social Psychology*, 101 (2022), e. 104346.

Beresford, B., Rabiee, P. and Sloper, P. (2007) ‘Outcomes for Parents with Disabled Children’, *Research Works: Research Findings from the Social Policy Research Unit*, 2007 (3), pp. 1-4.

Blum, L. M. (2015) *Raising Generation Rx: Mothering Kids with Invisible Disabilities in an Age of Inequality*, New York: New York University Press.

Boardman, F. (2011) ‘Negotiating Discourses of Maternal Responsibility, Disability and Reprogenetics’, in C. Lewiecki-Wilson and J. Cellio, (ed.), *Disability and Mothering: Liminal Spaces of Embodied Knowledge*, New York, NY: Syracuse University Press, pp. 34-49.

Boardman, F. K. (2014) ‘Knowledge is Power? The Role of Experiential Knowledge in Genetically “Risky” Reproductive Decisions’, *Sociology of Health & Illness*, 36 (1), pp.137-150.

Boardman, F. K. (2017) ‘Experience as Knowledge: Disability, Distillation and (Reprogenetic) Decision-Making’, *Social Science & Medicine*, 191, pp. 186-193.

Boardman, F. and Clark, C. (2022) ‘We're Kind of Like Genetic Nomads': Parents' Experiences of Biographical Disruption and Uncertainty Following In/Conclusive Results from Newborn Cystic Fibrosis Screening’, *Social Science & Medicine*, 301, e. 114972.

Bogart, K. R. and Dunn, D. S. (2019) ‘Ableism Special Issue Introduction’, *The Journal of Social Issues*, 75 (3), pp. 650–664.

Brar, B., Hoover-Fong, J. E., Gough, E., Hashmi, S. S., Hecht, J. T., Legare, J. M., Dujmusic, L., Little, M. E., Modaff, P., Pauli, R. M. and Rodriguez–Buritica, D. (2023) ‘Impact of Delivery Route on Postnatal Surgical Morbidity in Fetal Achondroplasia: A Multicenter Cohort Study’, *American Journal of Obstetrics & Gynecology*, 228 (1), e. S612.

Braun, V. and Clarke, V. (2006) ‘Using Thematic Analysis in Psychology’, *Qualitative Research in Psychology*, 3 (2), pp. 77-101.

Braun, V. and Clarke, V. (2022) *Thematic Analysis: A Practical Guide*, London: Sage Publications.

Brickman-Bhutta, C. (2012) ‘Not by the Book: Facebook as a Sampling Frame’, *Sociological Methods and Research,* 41 (1), pp. 57-88.

Bristow, S., Usher, K., Power, T. and Jackson, D. (2022) ‘Understanding Maternal Resilience; Lesson Learnt from Rural Mothers Caring for a Child with a Chronic Health Condition’, *Journal of Clinical Nursing*, 31 (17-18), pp. 2593-2604.

British Sociological Association. (2017) ‘BSA Statement of Ethical Practice’ [online], Available from: https://www.britsoc.co.uk/media/24310/bsa_statement_of_ethical_practice.pdf [Last accessed on 10/10/2024].

Brock, S. A. M. (2015) ‘The Individualization Thesis and Mothering Children with Disabilities’, *Journal of Family Studies*, 21 (3), pp. 261-281.

Brooks A. and Hesse-Biber S. N. (2007) ‘An Invitation to Feminist Research’, in S. N. Hesse-Biber and P. L. Leavy, (ed.) *Feminist Research Practice*, Thousand Oaks, CA: Sage Publications, pp. 1-24.

Brown, P., Zavestoski, S., McCormick, S., Mayer, B., Morello Frasch, R. and Gasior Altman, R. (2004) ‘Embodied Health Movements: New Approaches to Social Movements in Health’, *Sociology of Health and Illness*, 26 (1), pp. 50-80.

Budds, K., Hogg, M. K., Banister, E. N. and Dixon, M. (2017) ‘Parenting Agendas: An Empirical Study of Intensive Mothering and Infant Cognitive Development’, *The Sociological Review*, 65 (2), pp. 336-352.

Bukamal, H. (2022) ‘Deconstructing Insider–Outsider Researcher Positionality’, *British Journal of Special Education*, 49 (3), pp. 327-349.

Bulk, L. Y. and Collins, B. (2024) ‘Blurry Lines: Reflections on “insider” Research’, *Qualitative Inquiry*, 30 (7), pp. 568-576.

Bury, M. (1982) ‘Chronic Illness as Biographical Disruption’, *Sociology of Health & Illness*, 4 (2), pp. 167-182.

Butler, J. (1989) ‘Foucault and the Paradox of Bodily Inscriptions’, *The Journal of Philosophy*, 86 (11), pp. 601–607.

Butler, J. (1999) *Gender Trouble: Feminism and the Subversion of Identity*, New York: Routledge.

Carter, S. K. and Anthony, A. K. (2015) ‘Good, Bad, and Extraordinary Mothers: Infant Feeding and Mothering in African American Mothers’ Breastfeeding Narratives’, *Sociology of Race and Ethnicity*, 1 (4), pp. 517-531.

Carter, S. K., Reyes-Foster, B. M. and Carter, J. S. (2018) ‘“Breast is Best, Donor next”’: Peer Breastmilk Sharing in Contemporary Western Motherhood’, *Sociological Inquiry*, 88 (4), pp. 673-695.

Charmaz, K. (2014) *Constructing Grounded Theory*, London: Sage Publications.

Chase, S.E. (1996) ‘Personal Vulnerability and Interpretive Authority in Narrative Research’ in R. Josselson, (ed.) *Ethics and Process in the Narrative Study of Lives Volume 4*, Thousand Oaks, CA: Sage Publications, pp. 45-59.

Chiu, C. M., Hsu, M. H. and Wang, E. T. (2006) ‘Understanding Knowledge Sharing in Virtual Communities: An Integration of Social Capital and Social Cognitive Theories’, *Decision Support Systems*, 42 (3), pp. 1872-1888.

Chodorow, N. (1978) *The Reproduction of Mothering: Psychoanalysis and the Sociology of Gender*, California: The Regents of the University of California.

Čolić, M. and Milačić-Vidojević, I. (2021) ‘Perceived Stigma among Serbian Parents of Children with Autism Spectrum Disorder and Children with Physical Disabilities: Validation of a New Instrument’, *Journal of Autism and Developmental Disorders*, 51 (2), pp. 501-513.

Collins, P. H. (2000) *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*, Abingdon: Routledge.

Conolly, A., Rowland, E., Abrams, R., Harris, R., Kelly, D., Kent, B. and Maben, J. (2023) ‘“Pretty Cathartic Actually”: Reflections on the Attempt to Reduce Re-

Traumatization of Researchers and Nurses taking part in a Longitudinal Interview Study', *Journal of Advanced Nursing*, 79 (11), pp. 4196-4206.

Conrad, P. and Potter, D. (2004) 'Human Growth Hormone and the Temptations of Biomedical Enhancement', *Sociology of Health & Illness*, 26 (2), pp. 184–215.

Cooley, C. H. (1902) *Human Nature and the Social Order*, New York: Charles Scribner's Sons.

Cooper, M. (2014) 'Meeting the Needs of Disabled Students in Online Distance Education – An Institutional Case Study from The Open University, UK', *Distance Education in China*, 2014 (12), pp. 18-27.

Cooper, L. and Rogers, C. (2015) 'Mothering and "Insider" Dilemmas: Feminist Sociologists in the Research Process', *Sociological Research Online,* 20 (2) pp. 14-26.

Crocker, J. and Major, B. (1989) 'Social Stigma and Self-Esteem: The Self-Protective Properties of Stigma', *Psychological Review*, 96 (4), pp. 608-630.

Daniels, J. N. (2019) 'Disabled Mothering? Outlawed, Overlooked and Severely Prohibited: Interrogating Ableism in Motherhood', Social Inclusion, 7 (1), pp. 114-123.

Dasen, V. (2013) *Dwarfs in Ancient Egypt and Greece*, Oxford: Oxford University Press.

Davis, J. L. and Manago, B. (2016) 'Motherhood and Associative Moral Stigma: The Moral Double Bind', *Stigma and Health*, 1 (2), pp. 72-86.

De Benedictis, S. (2012) Feral Parents: Austerity Parenting under Neoliberalism', *Studies in the Maternal*, 4 (2), pp. 1–21.

De Hoog, N. and Pat-El, R. (2024) 'Social Identity and Health-Related Behavior: A Systematic Review and Meta-Analysis', *Social Science & Medicine*, 344 (2024), e. 116629.

Dickson-Swift, V., James, E., L., Kippen, S. and Liamputtong, P. (2008) ‘Risk to Researchers in Qualitative Research on Sensitive Topics: Issues and Strategies’, *Qualitative Health Research*, 18 (1), pp. 133-144.

Dinçer, P. (2019) ‘Being an Insider and/or Outsider in Feminist Research: Reflexivity as a Bridge between Academia and Activism’, *Manas Sosyal Araştırmalar Dergisi*, 8 (4), pp. 3728-3745.

Donaldson, J., Aftab, S. and Bradish, C. (2015) 'Achondroplasia and Limb Lengthening: Results in a UK Cohort and Review of the Literature', *Journal of Orthopaedics*, 12 (1), pp. 31-34.

Doucet, A. (2015) ‘Parental Responsibilities: Dilemmas of Measurement and Gender Equality’, *Journal of Marriage and Family*, 77 (1), pp. 224-242.

Doucet, A. and Mauthner, N. (2013) ‘Tea and Tupperware: Mommy Blogging as Care, Work, and Consumption’ in C. Rogers and S. Weller, (ed.) *Critical Approaches to Care: Understanding Caring Relations, Identities and Cultures,* Abingdon: Routledge, pp. 92-104.

Dow, D. M. (2019) *Mothering While Black: Boundaries and Burdens of Middle-Class Parenthood*, California: University of California Press.

Dunn, D. S., and Andrews, E. E. (2015) ‘Person-First and Identity-First Language: Developing Psychologists' Cultural Competence using Disability Language’, *The American Psychologist*, 70 (3), pp 255–264.

Elliott, C. (2004) *Better Than Well: American Medicine Meets the American Dream*, New York: WW Norton & Company.

Elliott, S., Powell, R., and Brenton, J. (2015) ‘Being a Good Mom: Low-Income, Black Single Mothers Negotiate Intensive Mothering’, *Journal of Family Issues*, 36 (3), pp. 351-370.

Enns, C. Z. (2010) ‘Locational Feminisms and Feminist Social Identity Analysis’, *Professional Psychology: Research and Practice*, 41 (4), pp. 333-339.

European Medicines Agency. (2024) ‘Voxzogo (Vosoritide)’ [online], Available from: https://www.ema.europa.eu/en/medicines/human/EPAR/voxzogo#overview [Last accessed on 10/10/2024].

Faircloth, C. (2013) *Militant Lactivism? Attachment Parenting and Intensive Motherhood in the UK and France*, Oxford: Berghahn Books.

Fayard, A. L. and Van Maanen, J. (2015) ‘Making Culture Visible: Reflections on Corporate Ethnography’, *Journal of Organizational Ethnography*, 4 (1), pp. 4-27.

Fields, J. (2001) ‘Normal Queers: Straight Parents Respond to Their Children's “Coming Out”’, *Symbolic Interaction*, 24 (2), pp. 165-167.

Finkelstein, V. (1981) ‘To Deny or Not to Deny Disability’, in A. L. Brechin, P. Liddiard, and J. Swain, (ed.) *Handicap in a Social World*, Sevenoaks: Hodder and Stoughton.

Finkelstein, V. (2001) ‘The Social Model of Disability Repossessed’, *Manchester Coalition of Disabled People*, 1, pp. 1-5.

Foucault, M. (1972) *The Archaeology of Knowledge*, New York: Pantheon Books.

Foucault, M. (1977) *Discipline and Punish: The Birth of the Prison*, New York: Vintage Books.

Foucault, M. (1980) ‘Truth and Power’, in C. Gordon, (ed.) *Power/Knowledge: Selected Interviews and Other Writings, 1972-1977*, New York: Random House, pp. 109–133.

Foucault, M. (1982) ‘The Subject and Power’, *Critical Inquiry*, 8 (4), pp. 777-795.

Foucault, M. (1988) *Power Knowledge*, New York: Random House.

Foucault, M. (2008) *The Birth of Biopolitics: Lectures at the Collège de France, 1978-1979*, Basingstoke: Palgrave Macmillan.

Franco, P. and Yang, Y. (2021) ‘Exiting Fieldwork “With Grace”: Reflections on the Unintended Consequences of Participant Observation and Researcher-Participant Relationships’, *Qualitative Market Research: An International Journal*, 24 (3), pp. 358-374.

Franklin, L., Theodore, K., Foulds, D., Cooper, M., Mallaghan, L., Wilshaw, P., Colbo rne, A., Flower, E., Dickinson, D. and Lee, J. N. Y. (2022) ‘“They Don't Think I Can Cope, because I Have Got a Learning Disability…”: Experiences of Stigma in the Lives of Parents with Learning Disabilities’, *Journal of Applied Research in Intellectual Disabilities*, 35 (4), pp. 935–947.

Frederick, A. (2014) ‘Mothering while Disabled’, *Contexts*, 13 (4), pp. 30-35.

Frederick, A. (2015) ‘Between Stigma and Mother-Blame: Blind Mothers' Experiences in USA Hospital Postnatal Care’, *Sociology of Health & Illness*, 37 (8), pp. 1127-1141.

Frederick, A. (2017) ‘Risky Mothers and the Normalcy Project: Women with Disabilities Negotiate Scientific Motherhood’, *Gender & Society*, 31 (1), pp. 74-95.

Frederick, A. (2018) ‘Disabling Fields, Enabling Capital: Mothers with Disabilities and the Concerted Cultivation Habitus’, *Disability Studies Quarterly*, 38 (4), e. Fall 2018.

Frederick, A., Leyva, K. and Lavin, G. (2019) ‘The Double Edge of Legitimacy: How Women with Disabilities Interpret Good Mothering’, *Social Currents*, 6 (2), pp. 163-176.

Garland-Thomson, R. (2011) ‘Misfits: A Feminist Materialist Disability Concept’, *Hypatia,* 26 (3), pp. 591-609.

Garwood, E. (2014) ‘Regulating Motherhood: A Foucauldian Analysis of the Social Construction of the Mother’, *The New Birmingham Review*, 1 (1), pp. 19-28.

Gerber, D. (1993) ‘Interpreting the Freak Show and *Freak Show’*, *Disability, Handicap and Society*, 8 (4), pp. 435-436.

Gibbon, H. F. (2010) ‘Learning to Mother: The Definition of Motherhood by Participants in a Welfare Reform Parenting Class’, *International Journal of Sociology of the Family*, 36 (1), pp. 49-63.

Gibson, A. N. and Martin III, J. D. (2019) ‘Re-Situating Information Poverty: Information Marginalization and Parents of Individuals with Disabilities’, *Journal of the Association for Information Science and Technology*, 70 (5), pp. 476-487.

Gillborn, S., Rickett, B. and Woolhouse, M. (2022) ‘A Feminist Relational Discourse Analysis of Mothers’ Voiced Accounts of the “Duty to Protect” Children from Fatness and Fatphobia’, *Feminism & Psychology*, 32 (2), pp. 224-245.

Gillies, V. (2007). *Marginalised Mothers: Exploring Working Class Experiences of Parenting*, Abingdon: Routledge.

Gillies, V. (2008) ‘Childrearing, Class and the New Politics of Parenting’, *Sociology Compass*, 2/3, pp 1079–1095.

Gillies, V. and Alldred, P. (2002) ‘The Ethics of Intention: Research as a Political Tool’, in M. Mauthner, M. Birch, J. Jessop and T. Miller, (ed.) *Ethics in Qualitative Research*, London: Sage Publications, pp. 32–52.

Ginsburg, F. D. and Rapp, R. (1995) ‘Introduction’, in F. D. Ginsburg and R. Rapp, (ed.) *Conceiving the New World Order: The Global Politics of Reproduction*, Berkeley: University of California Press, pp. 1-17.

Given, L. M. (2008) *The Sage Encyclopedia of Qualitative Research Methods*, London: Sage Publications.

Glenn, E. N. (2000) ‘Creating a Caring Society’, *Contemporary Sociology*, 29 (1), pp. 84-94.

Goodley, D. (1999) ‘Disability Research and the “Researcher Template”: Reflections on Grounded Subjectivity in Ethnographic Research’, *Qualitative Inquiry*, 5 (1), pp. 24-46.

Goffman, E. (1952) ‘On Cooling the Mark Out: Some Aspects of Adaptation to Failure’, *Psychiatry*, 15 (4), pp. 451-463.

Goffman, E. (1955) ‘On Face-Work: An Analysis of Ritual Elements in Social Interaction’, *Psychiatry*, 18 (3), pp. 213–231.

Goffman, E. (1959) *The Presentation of Self in Everyday Life*, New York: Bantam Doubleday Dell.

Goffman, E. (1963) *Stigma: Notes on the Management of Spoiled Identity*, Harmondsworth: Penguin.

Green, S. E. (2002) ‘Mothering Amanda: Musings on the Experience of Raising a Child with Cerebral Palsy’, *Journal of Loss and Trauma*, 7 (1), pp. 21-34.

Griffith, A. (1998) ‘Insider/Outsider: Epistemological Privilege and Mothering Work’, *Human Studies,* 21 (4), pp. 361–376.

Griffiths, M. (1995) ‘Making a Difference: Feminism, Post-modernism and the Methodology of Educational Research’, *British Educational Research Journal*, 21 (2) pp. 219-235.

Guan, M. and So, J. (2016) ‘Influence of Social Identity on Self-Efficacy Beliefs through Perceived Social Support: A Social Identity Theory Perspective’, *Communication Studies*, 67 (5), pp. 588-604.

Gubrium, J.F. and Holstein, J.A. (2008) ‘Narrative Ethnography’, in S.N. Hesse-Biber and P. Leavy, (ed.) *Handbook of Emergent Methods*, New York: The Guilford Press: pp. 241–264.

Gubrium, J. F. and Holstein, J. A. (2009) *Analyzing Narrative Reality*, London: Sage Publications.

Guse, T. and Harvey, C. (2006) ‘Growing Up with a Sibling with Dwarfism: Perceptions of Adult Non-Dwarf Siblings’, *Disability & Society*, 25 (3), pp. 387-401.

Hamilton, P. (2016) ‘The “good” Attached Mother: An Analysis of Postmaternal and Postracial Thinking in Birth and Breastfeeding Policy in Neoliberal Britain’, *Australian Feminist Studies*, 31 (90), pp. 410–431.

Hampshire, K., Iqbal, N., Blell, M. and Simpson, B. (2014) 'The Interview as Narrative Ethnography: Seeking and Shaping Connections in Qualitative Research', *International Journal of Social Research Methodology*, 17 (3), pp. 215-231.

Harvey, O., van Teijlingen, E. and Parrish, M. (2024) 'Using a Range of Communication Tools to Interview a Hard-to-Reach Population', *Sociological Research Online*, 29 (1), pp. 221-232.

Haslam, S. A., Jetten, J., Postmes, T. and Haslam, C. (2009) 'Social Identity, Health and Well-Being: An Emerging Agenda for Applied Psychology', *Applied Psychology-an International Review,* 58(1), pp. 1-23.

Hays, S. (1996) *The Cultural Contradictions of Motherhood*, New Haven, CT: Yale University Press.

Hedley, L. A. (2006) 'The Seduction of the Surgical Fix', in E. Parens, (ed.) *Surgically Shaping Children: Technology, Ethics, and the Pursuit of Normality,* Baltimore: Johns Hopkins University Press, pp. 43-50.

Hesse-Biber, S. N. and Leavy, P. (2010) *The Practice of Qualitative Research*, London: Sage Publications.

Hochschild, A. R. (1983) *The Managed Heart: The Commercialization of Human Feeling*, Berkeley: University of California Press.

Hoel, N. (2013) 'Embodying the Field: A Researcher's Reflections on Power Dynamics, Positionality and the Nature of Research Relationships', *Fieldwork in Religion*, 8 (1), pp. 27-49.

Holtug, N. (2011) 'Equality and the Treatment-Enhancement Distinction', *Bioethics*, 25 (3), pp. 137-144.

hooks, b. (1984) *Feminist Theory: From Margin to Center,* Boston: South End.

Hyde, M. and Power, D. (2000) 'Informed Parental Consent for Cochlear Implantation of Deaf Children', *Australian Journal of Social Issues*, 35 (2), pp. 117-128.

Introna, A. (2023) 'Pandemic Lived Experience, Crip Utopias, and Dismodernist Revolutions: For a More-Than-Social Model of Disability', *Social Inclusion,* 11 (1), pp. 82-91.

Irving, M. and Andrews, M., (2023) 'A Caregiver and Physician Perspective on the Role of Vosoritide in the Treatment of Achondroplasia: An Interview with Mary Andrews and Melita Irving', *Future Rare Diseases*, 3 (2), e. FRD37.

Jabiri, A. (2024) 'The Continuity of Othering in Feminist Methodology: Activist-Scholar and the Insider/Outsider Dynamics', *Third World Quarterly*, 45 (1), pp. 79-94.

Jacoby, A. (1994) 'Felt Versus Enacted Stigma: A Concept Revisited: Evidence from a Study of People with Epilepsy in Remission', *Social Science & Medicine*, 38 (2), pp. 269-274.

Jenkins, K. (2020) 'Academic Motherhood and Fieldwork: Juggling Time, Emotions, and Competing Demands', *Transactions of the Institute of British Geographers*, 45 (3), pp. 693-704.

Jóhannsdóttir, Á., Egilson, S. Þ. and Haraldsdóttir, F. (2022) 'Implications of Internalised Ableism for the Health and Wellbeing of Disabled Young People', *Sociology of Health & Illness*, 44 (2), pp. 360-376.

Johnson, B. L. and Quinlan, M. M. (2019) *You're Doing it Wrong!: Mothering, Media, and Medical Expertise*, New Brunswick, NJ: Rutgers University Press.

Johnston, D. D., and Swanson, D. H. (2006) 'Constructing the "Good Mother": The Experience of Mothering Ideologies by Work Status', *Sex Roles*, 54 (7–8), pp. 509–519.

Jones, G. (1999) '"The Same People in the Same Places"? Socio-Spatial Identities and Migration in Youth', *Sociology*, 33 (1), pp. 1-22.

Jupp, E. (2012) ‘Parenting Policy and the Geographies of Friendship: Encounters in a Sure Start Children's Centre’, in P. Kraftl and J. Horton, (ed.) *Critical Geographies of Childhood and Youth*, Bristol: Policy Press, pp. 215–229.

Kelnar, C. J. H., Albertsson-Wikland, K., Hintz, R. L., Ranke, M. B., and Rosenfeld, R. G. (1999) ‘Should We Treat Children with Idiopathic Short Stature?’, Workshop Held in St.-Paul-de-Vence, France, April 18-19, 1999, *Hormone Research in Paediatrics*, 52 (3), pp. 150-157.

Kibria, N., and Becerra, W. S. (2021) ‘Deserving Immigrants and Good Advocate Mothers: Immigrant Mothers’ Negotiations of Special Education Systems for Children with Disabilities’, *Social problems*, 68 (3), pp. 591-607.

Kittay, E. F. (1999) *Love’s Labor: Essays on Women, Equality and Dependency*, New York: Routledge.

Kong, S-T. and Hooper, C. A. (2018) ‘Building a Community of Practice for Transforming “Mothering” of Abused Women into a “Mutual Care Project”: A New Focus on Partnership and Mutuality’, *British Journal of Social Work*, 48 (3), pp. 633-655.

Kruse, R. (2001) ‘Activity Spaces of Dwarfs’, *The Geographic Bulletin*, 43 (1), pp. 7-15.

Kruse, R. (2002) ‘Social Spaces of Little People: The Experiences of the Jamisons’, *Social and Cultural Geography*, 3 (2), pp. 175-191.

Kruse, R. (2003) ‘Narrating Intersections of Gender and Dwarfism in Everyday Spaces’, *The Canadian Geographer*, 47 (4), pp. 494-508.

Kruse, R. (2010) ‘Placing Little People: Dwarfism and Geographies of Everyday Life’ in V. Chouinard, E. Hall, and R. Wilton, (ed.) *Towards Enabling Geographies*, Surrey: Ashgate, pp. 183-219.

Landsman, G. (2003) ‘Emplotting Children's Lives: Developmental Delay vs. Disability’, *Social Science and Medicine*, 56 (9), pp. 1947-1960.

Landsman, G. (2005) ‘Mothers and Models of Disability’, *The Journal of Medical Humanities,* 26 (2-3), pp. 121–139.

Landsman, G. (2009) *Reconstructing Motherhood and Disability in the Age of ‘Perfect’ Babies*, New York: Routledge.

Larsen, J. S., Hall, E. O. and Aagaard, H. (2008) ‘Shattered Expectations: When Mothers’ Confidence in Breastfeeding is Undermined – A Metasynthesis’, *Scandinavian Journal of Caring Sciences*, 22 (4), pp. 653-661.

Lareau, A. (2003) *Unequal Childhoods: Class, Race, and Family Life,* Berkeley: University of California Press.

Lawler, S. (2000) *Mothering the Self: Mothers, Daughters, Subjects*, New York: Routledge.

Lazard, L. (2022) ‘Digital Mothering: Sharenting, Family Selfies and Online Affective-Discursive Practices’, *Feminism & Psychology*, 32 (4), pp. 540-558.

Lee, C. (2012) ‘Deafness and Cochlear Implants: A Deaf Scholar’s Perspective’, *Journal of Child Neurology*, 27 (6), pp. 821-823.

Letherby, G. (2002) ‘Claims and Disclaimers: Knowledge, Reflexivity and Representation in Feminist Research’, *Sociological Research Online*, 6 (4), p. 81-93.

Liamputtong, P. (2007) *Researching the Vulnerable*, London: Sage Publications.

Link, B. G. and Phelan, J. C. (2001) ‘Conceptualizing Stigma’, *Annual Review of Sociology*, 27 (1), pp. 363-385.

Link, B. G. and Phelan, J. C. (2014) ‘Stigma Power’, *Social Science & Medicine*, 103 (2014), pp. 24-32.

Longman, C., De Graeve, K. and Brouckaert, T. (2013) ‘Mothering as a Citizenship Practice: An Intersectional Analysis of “Carework” and “Culturework” in Non-Normative Mother–Child Identities’, *Citizenship Studies*, 17 (3-4), pp. 385-399.

Lopez, L. K. (2009) ‘The Radical Act of “Mommy Blogging”: Redefining Motherhood through the Blogosphere’, *New Media & Society*, 11 (5), pp. 729-747.

Lowe, P. (2005) ‘Embodied Expertise: Women’s Perceptions of Contraception Consultation’, *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine,* 9 (3), pp. 361–378.

Lowe, P., Powell, J., Griffiths, F., Thorogood, M. and Locock, L. (2009) ‘Making it All Normal’: The Role of the Internet in Problematic Pregnancy’, *Qualitative Health Research*, 19 (10), pp. 1476-1484.

Lowe, P. (2016) *Reproductive Health and Maternal Sacrifice*, London: Palgrave Macmillan.

Lutz, A., Lee, S. and Bokayev, B. (2023) ‘Intensive Mothering in the Time of Coronavirus’, *Journal of Social Issues*, 79 (3), pp. 997-1021.

Lynch, K. (2007) ‘Love Labour as a Distinct and Non-commodifiable Form of Care Labour’, *Sociological Review,* 55 (3), pp. 550-570.

Mackenzie, J. (2017) ‘“Can We Have a Child Exchange?” Constructing and Subverting the “Good Mother” through Play in Mumsnet Talk’, *Discourse & Society,* 28 (3), pp. 296-312.

Mackenzie, J. (2019) *Language, Gender and Parenthood Online: Negotiating Motherhood in Mumsnet Talk*, Oxon and New York: Routledge.

Mackenzie, J. (2020) ‘Digital Interaction’, in S. Adolphs and D. Knight, (ed.) *The Routledge Handbook of English Language and Digital Humanities*, Abingdon: Routledge, pp. 49-65.

Mackenzie, J. (2023) *Connected Parenting: Digital Discourse and Diverse Family Practices,* London and New York: Bloomsbury.

Madge, C. and O'Connor, H. (2006) ‘Parenting Gone Wired: Empowerment of New Mothers on the Internet?’, *Social & Cultural Geography*, 7 (2), pp. 199-220.

Malacrida, C. (2009) ‘Performing Motherhood in a Disablist World: Dilemmas of Motherhood, Femininity and Disability’, *International Journal of Qualitative Studies in Education*, 22 (1), pp. 99-117.

Malinen, S. (2015) ‘Understanding User Participation in Online Communities: A Systematic Literature Review of Empirical Studies’, *Computers in Human Behavior*, 46 (2015), pp. 228-238.

Mapes, M. (2024) ‘Radical Self-Disclosure as Abolitionist Agitation’, *Women's Studies in Communication*, 47 (2), pp. 126-132.

Masinga, N. C. (2022) ‘Social Identity for Social Change’, *Routledge Resources Online - Psychology in the Real World* [online], Available from: https://www.taylorfrancis.com/entries/10.4324/9780367198459-REPRW102-1/social-identity-social-change-nonhlanhla-masinga?context=rroprw, [Last accessed on 11/10/2024].

Maslen, S. and Lupton, D. (2019) ‘“Keeping it Real”: Women's Enactments of Lay Health Knowledges and Expertise on Facebook’, *Sociology of Health & Illness*, 41 (8), pp. 1637-1651.

Mason, J. (2004) ‘Personal Narratives, Relational Selves: Residential Histories in the Living and Telling’, *The Sociological Review*, 52 (2), pp. 162-179.

Massey, D. (2005) *For Space*, London: Sage Publications.

Mauthner, N. S. and Doucet, A. (1998) ‘Reflections on a Voice-Centred Relational Method of Data Analysis: Analysing Maternal and Domestic Voices’, in J. Ribbens and R. Edwards, (ed.) *Feminist Dilemmas in Qualitative Research: Private Lives and Public Texts*, London: Sage Publications, pp. 119–144.

Mauthner, N. S. and Doucet, A. (2008) ‘“Knowledge Once Divided Can Be Hard to Put Together Again”: An Epistemological Critique of Collaborative and Team-Based Research Practices’, *Sociology*, 42 (5), pp. 971-985.

McDaniel, B. T., Coyne, S. M. and Holmes, E. K. (2012) ‘New Mothers and Media Use: Associations between Blogging, Social Networking, and Maternal Well-Being’, *Maternal and Child Health Journal*, 16 (7), pp. 1509-1517.

McKeever, P. and Miller, K. (2004) ‘Mothering Children who have Disabilities: A Bourdieusian Interpretation of Maternal Practices’, *Social Science and Medicine*, 59 (6), pp. 1177-1191.

McKenzie-Mohr, S. and Lafrance, M. N. (2011) ‘Telling Stories without the Words: “Tightrope Talk” in Women’s Accounts of Coming to Live Well after Rape or Depression’, *Feminism & Psychology*, 21 (1), pp. 49-73.

McLaughlin, J. (2003) ‘Screening Networks: Shared Agendas in Feminist and Disability Movement Challenges to Antenatal Screening and Abortion’, *Disability & Society*, 18 (3), pp. 297-310.

McLaughlin, J., Goodley, D., Clavering, E. and Fisher, P. (2008) *Families Raising Disabled Children: Enabling Care and Social Justice*, Basingstoke: Palgrave Macmillan.

McNay, L. (1992) ‘The Problems of the Self in Foucault's Ethics of the Self’, *Third Text*, 6 (19), pp. 3-8.

Mead, G. H. (1934) *Mind, Self and Society*, Chicago: University of Chicago Press.

Meehan, G. (2024) ‘Research with Deaf and Hard-of-Hearing Women: Reimagining Social Justice as Flourishing’, in K. McGarry, C. Bradley and G. Kirwan, (ed.)
Rights and Social Justice in Research, Bristol: Policy Press, pp. 99-119.

Miller, T. and Bell, L. (2002) ‘Consenting to What? Issues of Access, Gate-Keeping and ‘Informed’ Consent’, in M. Mauthner, M. Birch, J. Jessop and T. Miller, (ed.) *Ethics in Qualitative Research*, London: Sage Publications, pp. 53-69.

Minnotte, K. L. (2023) ‘Decentering Intensive Mothering: More Fully Accounting for Race and Class in Motherhood Norms’, *Sociology Compass*, 17 (8), e. 13095.

Mitchell, F. R., Santarossa, S., Ramawickrama, I. L., Rankin, E. F., Yaciuk, J. A., McMahon, E. R. and van Wyk, P. M. (2019) ‘An Evaluation of Social Media Images Portrayal of Disability Discourse: #amputeefitness’, *European Journal of Adapted Physical Activity*, 12 (2), pp. 1-15.

Moayerian, N., McGehee, N. G. and Stephenson Jr, M. O. (2022) 'Community Cultural Development: Exploring the Connections between Collective Art Making, Capacity Building and Sustainable Community-Based Tourism', *Annals of Tourism Research*, 93 (2022), e. 103355.

Moran, R. J., Martin, R. and Ridley, S. (2024) '"It Helped Me Open My Eyes": Incorporating Lived Experience Perspectives in Social Work Education', *Affilia*, 39 (1), pp. 78-93.

Morris, J. (1991) *Pride Against Prejudice*, London: Women's Press.

Mueller, A. K., Fuermaier, A. B., Koerts, J. and Tucha, L. (2012) 'Stigma in Attention Deficit Hyperactivity Disorder', *ADHD Attention Deficit and Hyperactivity Disorders*, 4 (3), pp. 101-114.

Murano, M. C. (2019) *Critical Paediatric Bioethics and the Treatment of Short Stature: An Interdisciplinary Study*, Sweden: Linköping University Electronic Press.

Murton, M. C., Drane, E. L., Goff-Leggett, D. M., Shediac, R., O'Hara, J., Irving, M. and Butt, T. J. (2023) 'Burden and Treatment of Achondroplasia: A Systematic Literature Review', *Advances in Therapy*, 40 (9), pp. 3639-3680.

Namkung, E. H., Mitra, M., and Nicholson, J. (2019) 'Do Disability, Parenthood, and Gender Matter for Health Disparities?: A US Population-Based Study', *Disability and Health Journal*, 12 (4), pp. 594-601.

Oakley, A. (1981) 'Interviewing Women: A Contradiction in Terms', in H. Roberts, (ed.) *Doing Feminist Research*, London: Routledge and Kegan Paul, pp. 30-61.

Oliver, M. (2004) 'The Social Model in Action: If I Had a Hammer', in C. Barnes and G. Mercer, (ed.) *Implementing the Social Model of Disability: Theory and Research*, Leeds: The Disability Press, pp. 18–31.

Oliver, M. (2013) 'The Social Model of Disability: Thirty Years On', *Disability & Society*, 28 (7), pp. 1024-1026.

Oliver, P. (1984) '"If You Don't Do It, Nobody Else Will": Active and Token Contributors to Local Collective Action', *American Sociological Review*, 49 (5), pp. 601-610.

O'Reilly, A. (2010) 'Outlaw(ing) Motherhood: A Theory and Politic of Maternal Empowerment for the Twenty-First Century' [Paper in: Focus on Mothering], *Hecate*, 36 (1/2), pp. 17-29.

O'Reilly A. (2016) 'We Need to Talk about Patriarchal Motherhood: Essentialization, Naturalization and Idealization in Lionel Shriver's *We Need to Talk about Kevin*', *Journal of the Motherhood Initiative,* 7 (1), pp. 64-81.

O'Reilly, A. (2021) *Matricentric Feminism: Theory, Activism, Practice*, Ontario: Demeter Press.

O'Reilly, A. (2024) *In (M)other Words: Writings on Mothering and Motherhood, 2009-2024*, Ontario: Demeter Press.

Ornitz, D. M. and Legeai-Mallet, L. (2017) 'Achondroplasia: Development, Pathogenesis, and Therapy', *Developmental Dynamics*, 246 (4), pp. 291-309.

Parens, E. (2006) *Surgically Shaping Children: Technology, Ethics, and the Pursuit of Normality* (ed.), Baltimore: Johns Hopkins University Press.

Parton, C., Katz, T. and Ussher, J. M. (2019) '"Normal' and "Failing" Mothers: Women's Constructions of Maternal Subjectivity while Living with Multiple Sclerosis', *Health*, 23 (5), pp. 516-532.

Pauli, R. M. (2019) 'Achondroplasia: A Comprehensive Clinical Review', *Orphanet Journal of Rare Diseases*, 14 (1), pp.1-49.

Peckover, S. (2002) 'Supporting and Policing Mothers: An Analysis of the Disciplinary Practices of Health Visiting', *Journal of Advanced Nursing*, 38 (4), pp. 369-377.

Peckover, S., and Aston, M. (2018) 'Examining the Social Construction of Surveillance: A Critical Issue for Health Visitors and Public Health Nurses

Working with Mothers and Children', *Journal of Clinical Nursing*, 27 (1-2), pp. 379-389.

Pescosolido, B. A., and Martin, J. K. (2015) 'The Stigma Complex', *Annual Review of Sociology*, 41 (1), pp. 87-116.

Priestley, M. (2003) *Disability: A Life Course Approach*, Cambridge: Polity Press.

Pritchard, E. (2019) 'Hate Speech and Dwarfism: The influence of Cultural Representations', in M. Sherry, T. Olsen, J. Vedeler and J. Eriksen, (ed.) *Disability Hate Speech: Social, Cultural and Political Contexts*, Abingdon: Routledge, pp.116-128.

Pritchard, E. (2021) *Dwarfism, Spatiality and Disabling Experiences*, Abingdon: Routledge.

Pritchard, E. (2023) *Midgetism: The Exploitation and Discrimination of People with Dwarfism*, Abingdon: Routledge.

Pudrovska, T. and Ferree, M. M. (2004) 'Global Activism in "Virtual Space": The European Women's Lobby in the Network of Transnational Women's NGOs on the Web', *Social Politics: International Studies in Gender, State & Society*, 11 (1), pp. 117-143.

Rabinow, P. (1996) 'Artificiality and Enlightenment: From Sociobiology to Biosociality', in P. Rabinow, (ed.) *Essays on the Anthropology of Reason*, New Jersey: Princeton University Press, pp. 91–111.

Rezaei Aghdam, A., Watson, J., Cliff, C. and Miah, S. J. (2020) 'Improving the Theoretical Understanding toward Patient-Driven Health Care Innovation through Online Value Cocreation: Systematic Review', *Journal of Medical Internet Research*, 22 (4), e. 16324.

Ribbens, J. (1998) 'Hearing my Feeling Voice? An Autobiographical Discussion of Motherhood', in J. Ribbens and R. Edwards, (ed.) *Feminist Dilemmas in Qualitative Research: Public Knowledge and Private Lives*, London: Sage Publications, pp. 24-38.

Riessman, C. K. (2000) ‘Stigma and Everyday Resistance Practices: Childless Women in South India’, *Gender & Society*, 14 (1), pp. 111-135.

Riessman, C. K. (2008) *Narrative Methods for the Human Sciences*. London: Sage Publications.

Ringland, K. E. (2019) ‘A Place to Play: The (Dis)abled Embodied Experience for Autistic Children in Online Spaces’, *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, pp. 1–14.

Rizvi, S. (2021) ‘Mothering in Cultural Bubbles’, in S. Rizvi, (ed.) *Undoing Whiteness in Disability Studies: The Special Education System and British South Asian Mothers*, Basingstoke: Palgrave Macmillan, pp. 33-90.

Rockliffe, L., Chorley, A. J., Marlow, L. A. and Forster, A. S. (2018) ‘It’s Hard to Reach the “Hard-to-Reach”: The Challenges of Recruiting People who do not Access Preventative Healthcare Services into Interview Studies’, *International Journal of Qualitative Studies on Health and Well-Being*, 13 (1), e. 1479582.

Rogers, C. (2007) *Parenting and Inclusive Education: Discovering Difference, Experiencing Difficulty*, Houndmills: Palgrave Macmillan.

Rogers, C. (2011) ‘Mothering and Intellectual Disability: Partnership Rhetoric?’, *British Journal of Sociology of Education*, 32 (4), pp. 563-581.

Rogers, C. (2013) ‘Intellectual Disability and Mothering: An Engagement with Ethics of Care and Emotional Work’ in C. Rogers and S. Weller, (ed.) *Critical Approaches to Care: Understanding Caring Relations, Identities and Cultures*, London: Routledge, pp. 132-143.

Rogers, C. (2016) *Intellectual Disability and Being Human: A Care Ethics Model*, London: Routledge.

Rogers, C. (2020) ‘Missing Data and Socio-Political Death: The Sociological Imagination Beyond the Crime’, in J. M. Parsons and A. Chappell, (ed.) *The Palgrave Handbook of Auto/Biography*, Basingstoke: Palgrave Macmillan, Springer International Publishing, pp. 609-631.

Rogers, C. and Ludhra, G. (2012) 'Research Ethics: Participation, Social Difference and Informed Consent' in S. Bradford and F. Cullen, (ed.) Research and Research Methods for Youth Practitioners, Abingdon: Routledge, pp. 43-65.

Rothman, B. K. (1986) *The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood*, New York: Viking Press.

Rothman, B. K. (1993) *The Tentative Pregnancy: How Amniocentesis Changes the Experience of Motherhood*, New York: WW Norton & Company.

Ruddick, S. (1980) 'Maternal Thinking', *Feminist Studies*, 6 (3), pp. 213-230.

Ruddick, S. (1989) *Maternal Thinking: Toward a Politics of Peace*, Boston: Beacon Press.

Runswick-Cole, K. (2007) '"The Tribunal was the Most Stressful Thing: More Stressful than my Son's Diagnosis or Behaviour": The Experiences of Families who go to the Special Educational Needs and Disability Tribunal (SENDisT)', *Disability & Society*, 22 (3), pp. 315-328.

Runswick-Cole, K. (2013) '"Wearing it all with a Smile": Emotional Labour in the Lives of Mothers and Disabled Children', in T. Curran and K. Runswick-Cole, (ed.) *Disabled Children's Childhood Studies: Critical Approaches in a Global Context*, London: Palgrave Macmillan, pp. 105-118.

Ryan, S. and Runswick-Cole, K. (2008) 'Repositioning Mothers: Mothers, Disabled Children, and Disabled Studies', *Disability & Society*, 23 (3), pp. 199-210.

Ryan, S. and Runswick-Cole, K. (2009) 'From Advocate to Activist? Mapping the Experiences of Mothers of Children on the Autism Spectrum', *Journal of Applied Research in Intellectual Disabilities*, 22 (1), pp. 43-53.

Sanghera, S.G. and Thaper-Bjokert, S. (2008) 'Methodological Dilemmas: Gatekeepers and Positionality in Bradford', *Ethnic and Racial Studies*, 31 (3) pp. 543-562.

Sargazi, S., Yamani, N. and Najimi, A. (2024) 'Voices Unheard, Insights into the Lives of People with Disabilities: A Needs Assessment Study', *Journal of Education and Health Promotion*, 13 (1), pp. 157 (1-7).

Savarirayan, R., Hoover-Fong, J., Yap, P. and Fredwall, S. O. (2024) 'New Treatments for Children with Achondroplasia', *The Lancet Child & Adolescent Health*, 8 (4), pp. 301-310.

Saville, K-M. (2018) 'Dwarfism: Wrestling Show will Simply Reinforce Prejudice', *The Conversation* [online], Available from: https://theconversation.com/dwarfism-wrestling-show-will-simply-reinforce-prejudice-103628#:~:text=The%20Dwarfanators%20wrestling%20show%20has, [Last accessed on 08/10/2024].

Saville, K-M. (2020) 'Co-Constructed Auto/Biographies in Dwarfism Mothering Research: Imagining Opportunities for Social Justice', in J. M. Parsons and A. Chappell, (ed.), *The Palgrave Handbook of Auto/Biography*, Basingstoke: Palgrave Macmillan, Springer International Publishing, pp. 633–656.

Scambler, G. (1989) *Epilepsy*, London: Routledge.

Scambler, G. (2004) 'Re-Framing Stigma: Felt and Enacted Stigma and Challenges to the Sociology of Chronic and Disabling Conditions', *Social Theory & Health*, 2 (1), pp. 29-46.

Scambler, G. (2009) 'Health-Related Stigma', *Sociology of Health & Illness*, 31 (3), pp. 441-455.

Scardigno, R., Sportelli, C., Cicirelli, P. G., Lops, A. and D'Errico, F. (2024) 'Online Mothering: The Empowering Nature of a Hashtag Movement Founded on Social Sharing and Stereotype Deconstruction', *Societies*, 14 (5), pp. 67-83.

Schmidt, E.-M., Décieux, F., Zartler, U., and Schnor, C. (2023) 'What Makes a Good Mother? Two Decades of Research Reflecting Social Norms of Motherhood', *Journal of Family Theory & Review*, 15 (1), pp. 57–77.

Scully, J. L. (2009) ‘Towards a Bioethics of Disability and Impairment’, in P. Atkinson, P. Glasner, and M. Lock, (ed.) *Handbook of Genetics and Society: Mapping the Genomic Era*, Londen: Routledge, pp. 367-381.

Scully, J. L. (2010) ‘Hidden Labor: Disabled/Nondisabled Encounters, Agency, and Autonomy’, *International Journal of Feminist Approaches to Bioethics*, 3 (2), pp. 25-42.

Scully, J. L. (2017) ‘A Mitochondrial Story: Mitochondrial Replacement, Identity and Narrative’, *Bioethics*, 31 (1), pp. 37-45.

Scully, J. L. (2018) ‘Disability and the Challenge of Genomics’, in S. Gibbon, B. Prainsack, S. Hilgartner, and J. Lamoreaux, (ed.) *Routledge Handbook of Genomics, Health and Society*, London: Routledge, pp. 186-194.

Seligman, M. and Darling, R. B. (2007) *Ordinary Families, Special Children: A Systems Approach to Childhood Disability*, New York: Guilford Press.

Shakespeare, T. (1994) ‘Cultural Representation of Disabled People: Dustbins for Disavowal’, *Disability & Society*, 9 (3), pp. 283-299.

Shakespeare, T. (1996) ‘Disability, Identity, and Difference’, in C. Barnes and G. Mercer, (ed.) *Exploring the Divide*, Leeds: The Disability Press, pp. 94-113.

Shakespeare, T. (1998) ‘Choices and Rights? Eugenics, Genetics and Disability Equality’, *Disability & Society*, 13 (5), pp 665–681.

Shakespeare, T. (2004) ‘Social Models of Disability and Other Life Strategies’, *Scandinavian Journal of Disability Research*, 6 (1), p. 8-21.

Shakespeare, T. (2006) *Disability Rights and Wrongs*, Abingdon: Routledge.

Shakespeare, T. (2008) ‘Debating Disability’, *Journal of Medical Ethics*, 34 (1), p. 11-14.

Shakespeare, T. (2010) ‘It’s the Economy, Stupid! The Ironic Absence of Class Analysis in British Disability Studies’ in A. Matsui, O. Nagase and A. Sheldon, (ed.)

Creating a Society for All: Disability and Economy, Leeds: The Disability Press, pp. 56-69.

Shakespeare, T. (2013) *Disability Rights and Wrongs Revisited*, Abingdon: Routledge.

Shakespeare, T. Thompson, S. and Wright, M. (2010) ‘No Laughing Matter: Medical and Social Experiences of Restricted Growth’, *Scandinavian Journal of Disability Research*, 12 (1), pp. 19-31.

Shakespeare, T. and Watson, N. (2001) ‘The Social Model of Disability: An Outdated Ideology?’, in S.N. Barnartt and B.M. Altman, (ed.) *Exploring Theories and Expanding Methodologies: Where We Are and Where We Need to Go*, Leeds: Emerald Group Publishing Limited (Research in Social Science and Disability), pp. 9–28.

Sharma, D. (2025) *The Illustrated Guide to Social Science Research*, Abingdon: Routledge.

Shih, M. (2004) ‘Positive Stigma: Examining Resilience and Empowerment in Overcoming Stigma’, *The ANNALS of the American Academy of Political and Social Science*, 591 (1), pp. 175-185.

Shildrick, M. (2005) ‘The Disabled Body, Genealogy and Undecidability’, *Cultural Studies*, 19 (6), pp. 755-770.

Sinason, V. (2001) ‘Abuse and Handicap: South Africa’s Dangerous Legacy’, *Plenary Address: Psycho-Analytic Psychotherapy in South Africa*, 9 (2), pp. 1-12.

Skinner, T. (2013) ‘Women’s Perceptions of How their Dyslexia Impacts on their Mothering’, *Disability & Society*, 28 (1), pp. 81-95.

Smith, K. A., Widger, K., Arbour-Nicitopoulos, K. P. and Gibson, B. E. (2023) ‘The Sensory Experience of Waiting for Parents of Children Awaiting Transplant: A Narrative Ethnography’, *Qualitative Health Research*, 33 (8-9), pp. 801-810.

Smith-Oka, V. (2013) *Shaping the Motherhood of Indigenous Mexico*, Tennessee: Vanderbilt University Press.

Soytemel, E. and Saglam, E. (2024) ‘Conspiratorial Narratives as Cultural Repertoires and Methodological Tools’, *The British Journal of Sociology*, [online early view ahead of issue], pp. 1-15.

Steinberg, S. B. (2017) ‘Sharenting: Children's Privacy in the Age of Social Media’, *Emory Law Journal,* 66 (4), pp. 839-884.

Stets, J. E. and Burke, P. J. (2000) ‘Identity Theory and Social Identity Theory’, *Social Psychology Quarterly*, 63 (3), pp. 224-237.

Stramondo, J. (2017) ‘Disabled by Design: Justifying and Limiting Parental Authority to Choose Future Children with Pre-Implantation Genetic Diagnosis’, *Kennedy Institute of Ethics Journal*, 27 (4), pp. 475-500.

Sullivan, N. and Nourry, D. (2005) ‘Body Politics: Introduction’, *Continuum*, 19 (3), pp. 323-324.

Sullivan Sanford, E. (2006) ‘My Shoe Size Stayed the Same: Maintaining a Positive Sense of Identity with Achondroplasia and Limb-Lengthening Surgeries’, in E. Parens, (ed.) *Surgically Shaping Children: Technology, Ethics, and the Pursuit of Normality,* Baltimore: Johns Hopkins University Press, pp. 29-42.

Tajfel, H. (1974) ‘Social Identity and Intergroup Behavior’, *Social Science Information*, 13 (2), pp. 65–93.

Tajfel, H. and Turner, J. C. (1979) ‘An Integrative Theory of Intergroup Conflict’, in W. G. Austin and S. Worchel, (ed.) *The Social Psychology of Intergroup Relations,* Monterey, CA: Brooks-Cole, pp. 33–47.

Tedlock, B. (1991) ‘From Participant Observation to the Observation of Participation: The Emergence of Narrative Ethnography’, *Journal of Anthropological Research*, 47 (1), pp. 69-94.

Thoits, P. A. (2011) ‘Resisting the Stigma of Mental Illness’, *Social Psychology Quarterly*, 74 (1), pp. 6-28.

Thomas, C. (2007) *Sociologies of Disability and Illness: Contested Ideas in Disability Studies and Medical Sociology*, Basingstoke: Palgrave Macmillan.

Thomas, G. M. (2021) 'Dis-Mantling Stigma: Parenting Disabled Children in an Age of 'Neoliberal-Ableism', *The Sociological Review*, 69 (2), pp. 451-467.

Thompson, S., Shakespeare, T. and Wright, M. (2007) *A Small Matter of Equality: Living with Restricted Growth*, Newcastle: Newcastle University Press and the Restricted Growth Association.

Thorneycroft, R. (2024) 'Screwing the Social Model of Disability', *Scandinavian Journal of Disability Research*, 26 (1), pp. 286–299.

Traustadóttir, R and Sigurjónsdóttir, H. B. (2008) 'The "Mother" Behind the Mother: Three Generations of Mothers with Intellectual Disabilities and their Family Support Networks', *Journal of Applied Research in Intellectual Disabilities*, 21 (4), pp. 331-340.

Tremain, S. (2002) 'On the Subject of Impairment', in M. Corker and T. Shakespeare, (ed.) *Disability/Postmodernity: Embodying Disability Theory*, London: Continuum, pp. 32-47.

Tringo, J. L. (1970) 'The Hierarchy of Preference toward Disability Groups', *The Journal of Special Education*, 4 (3), pp. 295-306.

Tsatsou, P. (2021) 'Is Digital Inclusion Fighting Disability Stigma? Opportunities, Barriers, and Recommendations', *Disability & Society*, 36 (5), pp, 702-729.

Tucker, B. P. (1998) 'Deaf Culture, Cochlear Implants, and Elective Disability', *Hastings Center Report*, 28 (4), pp. 6-14.

Unger, S., Ferreira, C.R., Mortier, G.R., Ali, H., Bertola, D.R., Calder, A., Cohn, D.H., Cormier-Daire, V., Girisha, K.M., Hall, C. and Krakow, D. (2023) 'Nosology of Genetic Skeletal Disorders: 2023 Revision', *American Journal of Medical Genetics Part A*, 191 (5), pp.1164-1209.

Union of the Physically Impaired Against Segregation. (1975) *Aims and Policy Statement* [online], Available from: https://tonybaldwinson.com/wp-content/uploads/2014/06/upias-aims-and-policy-statement.pdf, [Last accessed on 10/10/2024].

Union of the Physically Impaired Against Segregation. (1976) *Fundamental Principles of Disability* [online], Available from: https://disabledpeoplesarchive.com/wp-content/uploads/sites/39/2021/01/001-FundamentalPrinciplesOfDisability-UPIAS-DA-22Nov1975.pdf, [Last accessed on 10/10/2024].

Varadi, A.-L., Raby, R. and Tardif-Williams, C. (2020) 'Discourses of Good Motherhood and the Policing of Young Parenthood', *Women & Criminal*, 30 (5), pp. 374-390.

Verduzco-Baker, L. (2017) '"I Don't Want Them to be a Statistic": Mothering Practices of Low-Income Women', *Journal of Family Issues*, 37 (7), pp. 1010-1038.

Wallis, J. M. (2020) 'Is it Ever Morally Permissible to Select for Deafness in One's Child?', *Medicine, Health Care and Philosophy*, 23 (1), pp. 3-15.

Wilson, S. (2007) '"When You Have Children, You're Obliged to Live": Motherhood, Chronic Illness and Biographical Disruption', *Sociology of Health & Illness*, 29 (4), pp. 610-626.

Wright Mills, C. (1959) *The Sociological Imagination*, New York: Oxford University Press.

Yanes, T., Nathan, V., Wallingford, C., Faragher, R., Nankervis, K., Jacobs, C., Vassos, M., Boyle, F., Carroll, A., Smith, S. and McInerney-Leo, A. (2024) 'Australasian Genetic Counselors' Attitudes toward Disability and Prenatal Testing: Findings from a Cross-Sectional Survey', *Journal of Genetic Counseling*, 33 (4), pp. 822-833.

Yang, L. and Lin, Z., (2023) 'The Re-Imagined Social Model: The Disabling Space of Disabled People during the Pandemic', *Disability & Society*, 14, pp.1-20.

Yuval-Davis, N. (1989) 'National Reproduction and "The Demographic Race" in Israel', in N. Yuval-Davis, F. Anthias and J. Campling, (ed.) *Woman-Nation-State*, New York: Palgrave Macmillan, pp. 92-109.

Yuval-Davis, N. (1996) 'Women and the Biological Reproduction of "The Nation"', *Women's Studies International Forum*, 19 (1-2), pp. 17-24.

Zhang, X. and Liu, S. (2022) 'Understanding Relationship Commitment and Continuous Knowledge Sharing in Online Health Communities: A Social Exchange Perspective', *Journal of Knowledge Management*, 26 (3), pp. 592-614.

Zhao, J., Ha, S. and Widdows, R. (2016) 'The Influence of Social Capital on Knowledge Creation in Online Health Communities', *Information Technology and Management*, 17 (4), pp. 311-321.

Zimbalist, Z. (2022) 'Bystanders and Response Bias in Face-to-Face Surveys in Africa', *International Journal of Social Research Methodology*, 25 (3), pp. 361-377.

Appendices

Appendix A – Participant Information Sheet

Participant Information Sheet

Mothering Children with Dwarfism in an Age of Bio- Technological 'Advances': An exploration into the (Non) Mythical

Invitation

I am writing to invite you to participate in the above mentioned research study. I intend to conduct qualitative interviews around the theme of mothering children with dwarfism. This research will be carried out by myself, Kelly-Mae Saville, a doctoral student at Aston University, Birmingham. This project has been approved by the Aston University Research Ethics Committee. This research is being supervised by academics, Dr Pam Lowe and Dr Sarah-Jane Page, in the School of Languages and Social Sciences.

Why have I been chosen?

As a woman who has a child with dwarfism, you have been asked to contribute to this research in order to share your viewpoints and experiences around mothering within this community.

Aims of the Research:

1. To document and explore the experiences of mothering a child with dwarfism

2. To explore how some mothers interact (or not) with the online dwarfism community spaces (for example, Facebook groups)
3. To examine the motivations of mothers who interact and communicate in the dwarfism community spaces (for example, through charity-based events)
4. Through maternal accounts, exploring the choices, decisions and consequences of biotechnological advances in the dwarfism community (such as making decisions around healthcare)

Researcher: Kelly-Mae Saville **Email:** savillkm@aston.ac.uk

Academic Research Supervisors:

Dr Pam Lowe **Email:** p.k.lowe@aston.ac.uk

Dr Sarah-Jane Page **Email:** s.page1@aston.ac.uk

What happens if I take part?

If you do decide to contribute to this project, you will be required to read this information sheet and sign the accompanying consent form. Shortly after, the researcher will make arrangements to collect the paperwork and interview you. If you give permission, the interview will be recorded using a digital recorder.

What happens if I do not wish to participate, or I change my mind?

Your participation in this research project is completely voluntary. As such, should you decide to withdraw consent, you have the full right and freedom to do so. You can withdraw your consent at any time before submission of the thesis and/or publication of the data. If you decide to withdraw after publication and/or the thesis has been submitted, any subsequent publications will not use your interview data.

Are there any potential risks in talking part in the study?

There are no known risks associated with this research. However, as some topics may include the retelling of emotional or upsetting experiences, some aspects may be emotionally uncomfortable.

Expenses and payments

Participation is voluntary. There are no financial benefits tied to this research.

Will my taking part in this study be kept confidential?

All of your information will be confidential. Recognisable aspects of your personal identity will be anonymised or excluded from any publications linked to the research. A pseudonym will be used in place of your name. All data will be securely stored on password-protected files and any printed data will be locked in a filing cabinet within Aston University.

What will happen to the results of the research study?

The findings of this research will be included in the researcher's doctoral thesis and in publications and presentations related to this research.

Who has reviewed the study?

The research has been approved by Aston University's Ethics Committee.

What if I have further questions or concerns?

If you have any concerns about the way in which the study has been conducted, you should contact the Secretary of the University Ethics Committee on j.g.walter@aston.ac.uk or telephone 0121 2044869.

If you would like to participate in this research study or require further information, please find my email address at the top of this letter.

Sincerely,
Kelly-Mae Saville

Appendix B – Consent Form

Aston University
Birmingham

Consent Form

Mothering Children with Dwarfism in an Age of Bio- Technological 'Advances': An exploration into the (Non) Mythical

Researcher: Kelly-Mae Saville **Email:** savillkm@aston.ac.uk
Academic Research Supervisors:
Dr Pam Lowe **Email:** p.k.lowe@aston.ac.uk
Dr Sarah-Jane Page **Email:** s.page1@aston.ac.uk

1. Purpose of the Research: This research aims to explore and document women's experiences in mothering children with dwarfism.

2. Elements of the Research Process: You have been asked to participate in a qualitative interview, the objective of which is to identify some of the issues that arise from your position as a mother to a child with dwarfism.

3. Risks and Discomforts in the Research Process: There is no risk to yourself by participating in this research project. As this research encompasses private and personal experiences, there may be questions that you find upsetting, this may cause discomfort to yourself. You are not obligated to respond to any of my questions and you have the right to cease the interview at any stage.

4. Benefits of the Research Process: There is no monetary benefit to participating in this study. If you request, I can make available to you a summary of the findings three months after my work has been submitted.

5. Statement of Confidentiality and Anonymity: Your participation in this research study is confidential and as such provisions will be made to safeguard your privacy. All personal information will be anonymised, and a pseudonym will be used in place of your real name. The data from this project will be securely stored on password protected databases only accessible by me.

6. Voluntary Participation: Your participation in this research project is entirely voluntary and as such you can stop and withdraw at any time up to publication/thesis submission. You do not have to answer any questions you do not wish to answer. You will be reminded of your right to withdraw during the start of each stage of the interviewing process.

7. Inquires or Complaints: Please contact the Secretary of the University Ethics Committee on j.g.walter@aston.ac.uk or telephone 0121 2044869 if you have any complaints or concerns about this research.

8. Statement of Consent: By agreeing to take part in this project you are confirming the following statements:

I have read and understood the information sheet for the above project	
I understand that participation in this research is completely voluntary and as such I am free to withdraw, without giving reason, my consent at any time before submission of the thesis/publication	
I understand that the researcher will use pseudonyms, and that my real name will not be used in any publication	

I agree for the interview to be recorded and that the data will be kept by the researcher in a secure database	
I agree to take part in this research	
I agree to the use of my anonymised quotes in future publications	

You must be 18 years of age or older to consent to and take part in this research process. If you agree to participate in this study and agree to the terms outlined above, please sign your name and date this form in the spaces provided below.

You will be given a copy of this form for your records.

Participant’s Signature: Date:
Researcher’s Signature: Date: