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Investigating the Role of Healthcare in the Construction of Lay Experience of Physical Disability: A Multimethod Qualitative Study of People Living with Dystonia

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Contents

Diagrams

Table

Abbreviations

BoNT – Botulinum toxin injection therapy

Botox – Botulinum toxin injection therapy

CAM – Complementary and Alternative Medicine

DBS – Deep Brain Stimulation

MRI – Magnetic Resonance Imaging

MUS – Medically Unexplained Symptoms

NHS – National Health Service

NRES – National Research Ethics Service

REC – Research Ethics Committee

SMA – Spinal Muscular Atrophy

SGm – Support group member

SGr – Support group representative

WADSS – The Warwick Dystonia Self-Management Study

This thesis is dedicated to the memory of my grandparents: Len, Leslie, Millie, and Sophie. They taught me so much.

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together and the moments that we have shared pondering life's unanswered mysteries. Thank you to Lesley and Rob Moseley for keeping me fed with their delicious dinners throughout this long journey. You have both shown me such warmth and friendship. And last, but certainly not least, I would like to thank my wonderful and supportive partner, Joseph Edward Moseley, for his patience and reassurance. I would have felt extremely lost and alone without you being there for me over the last five years. Looking to the future, I am incredibly excited about opening the next chapter of our lives together.

<u>Declaration</u>

This thesis is submitted to the University of Warwick in support of my application for the degree of Doctor of Philosophy. It has been composed by myself and has not been submitted in any previous application for any degree.

The work presented (including data generated and data analysis) was carried out by the author except in the case outlined below:

> The semi-structured interviews from NHS Hospital 2 were conducted in collaboration with Dr David Ellard and Dr Harbinder Sandhu from The Warwick Dystonia Self-Management Study, Warwick Clinical Trials Unit.

Abstract

The notion of 'experiential knowledge', or knowledge that is derived through and from people's direct or indirect experience of a condition, has been elusively defined, particularly its relationship to biomedicine. While some researchers argue that this episteme exists independently of expert models of disease, others maintain that it develops alongside and/or through the pervasive hegemonic framework of biomedicine. This research makes a novel contribution to the aforementioned debates by analysing the various ways in which the relationship between experiential and medical knowledge can be both synergistic and epistemologically (dis)similar. This argument is developed through an exploration of the everyday experiences and experiences of healthcare of 42 individuals living with, and managing, the hyperkinetic movement disorder known as dystonia. In many cases of this condition, effective treatment options are limited and prognoses uncertain. Qualitative data were gathered through group and individual interviews and thematically analysed for patterns and relationships, as well as deviant cases. It was found that participants interpreted their experiential knowledge of dystonia in confluence with medical knowledge and their everyday realities. The dynamism of this interrelationship fluctuated in intensity according to the extent to which participants felt that biomedicine could provide them with a socially legitimated explanation of their visceral experiences across different contexts. For example, the negotiation of a diagnosis and/or treatment plan were sites where this interrelationship became particularly fraught resulting in varying dynamic synergies between the two forms of knowledge, which I have termed *dissonant* and *resonant synergies*. Through these novel concepts, I demonstrate how the relationship between experiential and medical knowledge transforms and shifts across the disease trajectory of a contested and complex condition like dystonia. In addition to these conceptual insights, a consideration of how health professionals could strive to resonate their knowledge with that of their patients' is presented.

Chapter 1

Introduction

Study outline: why research dystonia?

Academic rationale

Dystonia syndromes[1] are a diverse and complex collection of hyperkinetic movement
disorders (Albanese et al 2013; Jinnah et al 2013: 927). They do, however, share
broad neurologic features such as uncontrolled and sometimes painful muscle spasms
and contractions triggering repetitive, twisting postures and/or contorted movements,
which can fluctuate and/or deteriorate over time (*ibid*). Medical researchers argue
that individuals with dystonia report a poorer health-related quality of life[2] compared
to the general population due to the potentially restrictive and stigmatising nature of
the condition (Papathanasiou et al 2001; Ben-Shlomo et al 2002; Rinnerthaler et al
2006; Stamelou et al 2012; Werle et al 2014; De Pauw et al 2017a). Though dystonia
is considered 'rare' since its prevalence is below 50/100,000 (European Commission
2008), the syndrome is still the third most commonly diagnosed movement disorder
after Parkinson's disease and essential tremor (Defazio 2010). In fact, while Steeves
et al (2012) have suggested that the global prevalence of the dystonia disorders is
16.43/100,000, they believe that this number is probably much higher. The true
figure is unknown because of high misdiagnosis rates and methodologically weak
prevalence studies (Defazio 2010; Steeves et al 2012; Defazio et al 2013). Given its

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[1] A syndrome denotes a cluster of symptoms and signs, often associated with multiple phenotypes and
aetiologies (Fung et al 2013: 891).
[2] This construct is usually measured using questionnaires comprising different questions about various
aspects of life with a long-term medical problem (e.g. mood, wellbeing, physical and social function)
(Camfield 2002: 7). After respondents rate each area, their scores are then calculated to generate an
overall quality of life score (*ibid.*).

clinically heterogeneous and poorly understood status within lay and medical

domains, I decided to use dystonia as an example through which to examine the way

people living with it variously mobilise their experiential knowledge, or knowledge

that is constructed through the particularities of everyday life (Abel and Browner

1998), to negotiate suitable forms of care and support.

Owing to the complexity of the dystonia disorders and the fact that most cannot be

medically confirmed with a diagnostic test or procedure, clinical scientists view the

process of diagnosis as 'challenging' (Fung et al 2013: 889). Having observed the

patient's movements and considered dystonia, the specialist neurologist then uses the

Movement Disorder Society's revised framework on phenotype and aetiology to

formulate the specific syndrome (Albanese et al 2013; Jinnah 2015). Depending on

which type they have, neurologists may, for example, refer patients for neuroimaging

to detect possible causes such as brain tumours or organ damage (*ibid.*). Diagnoses

may need to be changed as new clinical features develop over time (e.g. the

combined dystonia syndromes[3] may initially present as an isolated dystonia[4]) (Jinnah

2015: 79). Yet, the lack of established diagnostic guidelines surrounding dystonia

coupled with the condition's unusual and varied presentation (Fung et al 2013: 889;

Jinnah 2015: 78) mean that health professionals (e.g. GPs, non-specialist

neurologists) often struggle to recognise its defining characteristics (Logroscino et al

2003; Tiderington et al 2013).

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[3] Dystonic symptoms predominate alongside other movement disorders (Albanese et al 2013).
[4] Dystonia presents as the sole clinical feature with or without tremor (*ibid.*).

Dystonia is currently incurable and no universal approach to treatment exists (Roubertie et al 2000; Termsarasab et al 2016). The majority of medical interventions for dystonia also lack reliable clinical evidence (Delnooz and van de Warrenburg 2012). Commonly used treatments include medication (e.g. (anti)dopaminergic agents, anticholinergics, baclofen, and benzodiazepines (Greene 2007: 183-186)), surgery (e.g. Deep Brain Stimulation [DBS]), and botulinum toxin injection therapy (BoNT) (Termsarasab et al 2016) (for further details on dystonia treatment options see appendix 1). In general, these methods aim to reduce pain, correct abnormal muscle spasms, and improve quality of life (Delnooz et al 2009: 2187). Moreover, there has been some evidence to suggest that people with dystonia use paramedical therapies (e.g. physical and occupational therapy) and/or Complementary and Alternative Medicine (CAM) (e.g. acupuncture, aromatherapy) alongside orthodox medical interventions to improve mood and decrease the intensity of the involuntary muscle (Junker et al 2004; Lim 2007; Delnooz et al 2009; Fleming et al 2012; Bernstein et al 2016). However, data on the effectiveness of these treatments is limited and of poor methodological quality (*ibid.*). Yet, approximately 65% of surveyed respondents with dystonia found relaxation and mindfulness exercises helpful and just under half had used CAM, suggesting that such interventions may be beneficial (Dystonia Society 2014). Choosing a particular treatment depends predominately on key clinical features like symptom severity and body distribution, as well as tolerance to any side effects (Cloud and Jinnah 2010; Termsarasab et al 2016). Consequently, knowing which strategy will be the most effective for reducing the prominence of the physical symptoms is very much a process of trial and error (Morishita et al 2009: 7-9).

Researchers have highlighted the way physical function, body concept, and symptom visibility all have implications for mood and psychosocial wellbeing in dystonic populations (Jahanshahi and Marsden 1988; 1989; Jahanshahi 1991; Jahanshahi 2000; Papathanasiou et al 2001; Moraru et al 2002; Rinnerthaler et al 2006; Page et al 2007; Skogseid et al 2007; Kuyper et al 2011; Stamelou et al 2012; Werle et al 2014; Hertenstein et al 2016; De Pauw et al 2017a). Supporting this viewpoint, several qualitative researchers have found that individuals (and/or their families) affected by dystonia often feel incompetent and powerless to cope with the physically disfiguring and uncontrollable nature of the motor effects of the condition (MacLean Caldwell 2001; Camfield 2002; Camfield 2004; Hariz et al 2011; Zosso and Schoeb 2012; Austin 2015; Austin et al 2017). Moreover, since members of society are expected to regulate and be in control of their own bodily movements and behaviours, any individual believed to deviate away from socially acceptable standards surrounding corporeal normalcy and control may experience profound levels of stigmatisation (Camfield 2002).

Interestingly, due to the unpredictability and perceived peculiarity of dystonia, cultural depictions of it can be traced back as far as to the 14th century (Albanese 2017: 1). For example, post-medieval artist, Dante Alighieri, and Victorian author, Charles Dickens, variously referred to dystonia as an intriguing but grotesque and serious disorder that closely resembled evilness and punishment (Schoffer and O'Sullivan 2006; Garcia-Ruiz et al 2015; Albanese 2017). Of late, there have been a number of films (e.g. Twisted n.da), theatrical performances (e.g. Sadlers Wells n.d), and televised documentaries (e.g. This Morning 2017) all featuring dystonia. Some

of these communications media have depicted the condition as a 'demonic force', an outer bodily experience, and one that nobody would ever wish to get (Twisted n.db). Arguably, this reflects the broad ways in which contemporary, Western societies attribute very particular meanings to noticeably non-normative types of bodies (Oliver 1990). Exploring the ways in which agents' felt experiences and day-to-day visceral realities intersect with wider social structures and discourses would, thus, reveal something meaningful about how this group manages and processes their illness across their lived trajectories.

Sociologists argue that the medical profession occupies a paradoxical role within society; while the media and patient charities often invest a great amount of faith and hope in medical bodies of evidence, in reality, these offer very little in the way of providing cures for prevalent and chronic illnesses such as cancer or neurological disease (e.g. Williams, G 1991: 519; Gwyn 2001; Fox 2002; Collins and Pinch 2005; Griffiths et al 2005; Shakespeare 2006; 2014; Novas 2007; Thomas 2007: 14; Conrad 2013). As such, citizens' projected expectations and ideas about modern medicine may conflict with what it can practicably and dependably offer (Fox 2002). Individuals living with dystonia may, however, experience these tensions particularly intensely. Despite the fact that patients may perceive their clinicians to be knowledgeable about their problem, as documented earlier, professional practitioners attempting to decipher a person's dystonic movements may be left feeling perplexed by the peculiarity of the complaint (Marsden and Harrison 1974: 805; Fahn 1988). Doctors may also lack specialist knowledge of the phenotypic diversities of dystonia because they do not come across it that often in clinical practice (Tiderington et al

2013: 3; Neurological Alliance 2017). This may mean that they are unable to provide a diagnosis, offer advice, and/or make a (correct) referral (*ibid.*). In fact, a recent report published by The Neurological Alliance (2017) found that 55% of surveyed participants with dystonia reported visiting their GP five times or more before getting a definitive diagnosis (*ibid.*). Even though a training module was set up by the *British Medical Journal* (2018) in 2010 to educate primary care providers on dystonia, the average time from symptom onset to diagnosis for cervical dystonia, the most common type that typically affects the muscles in the neck, is still four – six years (Jinnah 2015: 80). This indeterminacy may, thus, produce a notable impact on patients' experiences and perceptions of medical services (Lim 2007).

As well as delays to diagnosis, individuals may also feel dissatisfied with the treatments that they receive (The Neurological Alliance 2017). Indeed, despite the notable impact of dystonia on everyday life, medical interventions remain limited to palliative options and do not improve motor symptoms in all cases (Roubertie et al 2000; Termsarasab et al 2016). Research from a health sciences perspective has explored the ways in which patients and/or their relatives try to manage some of these difficulties in the context of DBS decision-making (Hariz et al 2011; Austin 2015; Austin et al 2017). Specifically, Hariz et al (2011) have investigated adult patients' decisions to have DBS for generalised[5], myoclonus[6], or focal[7] dystonia. The authors found that the 'disabling' and 'disfiguring' nature of these disorders

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[5] This clinically severe type usually starts in early childhood and slowly affects both the trunk and (upper and/or lower) limbs (Albanese et al 2013; Klein 2014: 138).
[6] This combined type of dystonia often causes rapid, jerky movements and twitches in the neck, arms, and trunk (Fung et al 2013).
[7] The focal dystonias usually develop sporadically during adulthood and involve one specific body part such as the neck (cervical dystonia) or eyes (blepharospasm) (Albanese et al 2013; Klein 2014: 138).

influenced decision-making (*ibid.*). Unsuccessful attempts at trialling other treatments and viewing surgery as 'a last hope' were also salient predicators (Hariz et al 2011: 2103). Furthering this line of analysis, the subjective experience of looking after a child with secondary dystonia[8] and wishing to do the best for them has been revealed to influence DBS decision-making in families affected by the condition (Austin 2015; Austin et al 2017). Parents may also rely on the authority and power of health professionals to assist them with this crucial decision (Austin 2015; Austin et al 2017: 190). They may do this even at times when clinicians struggle to guarantee a positive result because of the complexities and uncertainties of both dystonia and the procedure (*ibid.*). In an international survey of 1,071 individuals with cervical dystonia, Comella and Bhatia (2015: 842) found that 'expectations of treatment were high with almost two-thirds expecting to be "free" of spasms or pain.' Yet, '49% of patients were either equivocal or dissatisfied with their treatment outcome', mainly because they did not perceive a positive change in their symptoms (*ibid.*). Despite the fact that the gap between participants' views and actual uses of therapy contributed to alterations in mood and general wellbeing, the authors observed that 98% of respondents continued to access healthcare services in the hope of finding a treatment that would dramatically decrease the disquieting effects of their impairment (*ibid.*). Consequently, recent research has pointed to tensions between the need to manage problematic and stigmatising dystonic movements, on the one hand, and the lack of reliably effective medical interventions, on the other.

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[8] A clinically severe form of the disorder that co-exists in confluence with other (non)neurological conditions or disease processes, although cerebral palsy is the main cause in the majority of cases (Austin et al 2017: 186).

Overall, the wider literature on decision-making in relation to healthcare for dystonia has shown that a range of contextual factors (personal, familial, clinical) shape individuals' thoughts and feelings about treatment (e.g. Austin et al 2017). Researchers have also emphasised the physically and emotionally disruptive nature of this condition (e.g. MacLean Caldwell 2001). However, in spite of these insights, researchers have tended to examine one particular type of dystonia and/or therapeutic intervention, usually DBS. This is an important point to consider because the lived and living experience of dystonia has interconnecting social components related to stigma and shame (Camfield 2002). Indeed, the dystonic body often contravenes hegemonic expectations surrounding carnal normalcy, making it difficult for members of the public to interpret (*ibid.*). Since the idea of medicine as a source of certainty is the dominant discourse in contemporary society (Fox 2002; Griffiths et al 2005), those with dystonia typically expect their symptoms to be completely ameliorated through their cooperation with medical practitioners (Comella and Bhatia 2015). Yet, most feel dissatisfied and upset if doctors are unable to diagnose them and/or cannot provide an effective therapy (Comella and Bhatia 2015). Given that there has been sparse data investigating the experience of different types of dystonia *and* associated treatments, there remains questions around how people diagnosed with some forms of the condition manage it in the face of persistent stigmatisation and limited effective therapeutic options at various points across their lived trajectories. Exploring a divergent range of dystonic presentations and severities is important in order to understand various forms and uses of experiential knowledge. Thus, the ideas presented in the subsequent chapters document the ways in which individuals' experiential knowledge of dystonia is deciphered, evaluated,

and mobilised alongside expert medical discourses and practices in the negotiation of support and healthcare provision.

Personal experiences of dystonia

In addition to the academic justification, my status as a person who lives with dystonia has also shaped my choice of research topic and the framing of the research aims and questions. I was diagnosed with the condition at the age of 11 years old, after several relatives and teachers noticed my 'peculiar' gait and tightened writing posture. Having examined my 'unruly' right arm and leg in his consultation one afternoon in 2000, my GP at the time quickly referred me on to a neurologist for further investigations (an experience that starkly contrasts with the accounts of many participants in my research (chapter 5)). Soon after meeting with a paediatric neurologist, I was told that I had torsion dystonia (currently termed early-onset generalised isolated dystonia (Albanese et al 2013)) due to a mutation in one of my genes. Yet, the fluctuating nature of my symptoms has raised questions about whether these can neatly be contained within the finite boundaries of this particular diagnostic label. Torsion dystonia is regarded as one of the most medically debilitating types but because the severity of my impairment effects varies across contexts, clinicians have described me as an 'unusual' case. For example, I often appear less impaired when I am typing or sitting down at my desk and more impaired when walking or handwriting. This also means that strangers struggle to make sense of my bodily signifiers, an experience that many participants also reported in their accounts of life with dystonia (chapter 6). I am frequently stared at in public and

have even been asked whether I am inebriated or on drugs. At other times, however, the visibility of my symptoms may lessen or disappear temporarily.

The only medicine that I have thus far taken for my dystonia has been the synthetic dopamine drug levodopa to rule out dopamine-responsive dystonia (a combined form of the condition). After I did not respond successfully to this drug at the age of 11, I decided not to use any further treatments, partly because of my anxieties surrounding possible side effects. As somebody who has always struggled to participate in sport and physical activity, my interests at school and beyond were mostly academic and so, I was worried whether taking tablets that alter brain activity would also affect my cognitive abilities and concentration levels. Currently, my neurologist recommends that I trial BoNT to correct the spasms in my right hand, and in turn, make handwriting easier but once again I am unsure whether the risks outweigh the benefits. When I express my concerns about treatment to the medical profession, doctors usually tell me to try it first before making a judgment. While I understand their reasoning, my passion and enthusiasm for sociology and disability studies has enabled me to reflect on my own experiences from a political vantage point and consider other ways of managing and thinking about disablement. Therefore, I am approaching this study both with an academic interest in a relatively under-researched topic area, but also as a person with a particular experience of dystonia who has largely chosen to avoid medical intervention (I return to the issue of reflexivity in chapter 4).

Thesis structure

This thesis contains eight chapters. Following the introduction, chapter 2 provides an historical account of dystonia through an examination of the way this diagnostic label has changed through time. Firstly, it documents how medical scientists from mainly neurological and psychiatric disciplines have inconsistently defined and classified dystonia over the course of almost 200 years. Secondly, the main epistemic disputes surrounding aetiology and explanation are considered. By noting dystonia's tempestuous relationship with the medical profession, this chapter argues that patients' experiences of healthcare may inadvertently be affected.

Chapter 3 sets out the literature on the interplay between two salient bodies of knowledge, experiential and medical, in order to consider the different ways in which scholars have conceptualised these epistemic sources. Specifically, it highlights how the rise in consumerist healthcare modalities has led to a decline in paternalistic medicine, subsequently changing the nature of the patient-doctor relationship. Since these developments have also spurred sociological interest in the notion of experiential knowledge, the next part discusses how different writers have applied this term in their work and thought about its political consequences, namely, for challenging professional frameworks.

I describe the methodological assumptions supporting the research study, as well as my approach to data collection and analysis in chapter 4. Further, I provide details of recruitment procedures, sampling techniques, and ethical issues. I then offer a

reflexive account of the ways in which my disabled embodiment and personal experiences of dystonia invariably impacted on the findings from the study.

Chapter 5 examines the medicalisation of dystonia. In particular, it concentrates on participants' experiences of getting a diagnosis and treatment plan, as well as their beliefs and expectations of medicine. This chapter also demonstrates the various ways in which participants used their experiential knowledge in conjunction with medicalised constructs to make sense of their inexplicable symptoms and seek appropriate care. Consequently, participants' varied emotional responses to the medicalisation process are considered.

Chapter 6 explores participants' experiences of adjusting to a body that is predictable in its unpredictability. It also highlights the ways in which participants' personal understandings of suffering intermeshed with wider disablist and medico-popular discourses and practices across their lived trajectories.

Chapter 7 discusses the co-developmental impact of embodiment and medical knowledge on the (dis)assembly of shared patient identities. By concentrating on (the threats to) lay identification, this chapter argues that medical notions of health and disease underpinned participants' decisions to (dis)connect with other people with dystonia. In fact, despite the significance of social oppression on their day-to-day lives (chapter 6), there was little evidence of political mobilisation at the support groups.

Weaving together the analysis from the aforementioned results chapters (chapters 5-7), within chapter 8 I contend that participants used medicalised ideas about the body to interpret their condition. However, the way participants ordered different knowledge claims, experiential and medical, changed across various contexts. My findings demonstrate that the relationship between these two resources is both synergistic *and* epistemologically (dis)similar according to how far these knowledges *resonate* with the subjective experience of living in a body affected by dystonia. The final part of this chapter evaluates the strengths and limitations of the study before suggesting possible avenues for further research.

Chapter 2

Setting the scene: the history of dystonia

This chapter examines various conceptualisations of dystonia in order to position the research within the literature. Specifically, I document the ways in which dystonia has emerged as a disorder not only from disputes and tensions taking place within biomedicine, but also from the interests and practices of quasi-medical organisations like The Dystonia Society.[9] Taking into consideration the dynamism of dystonia's rich and diverse past, it represents an exemplar disease in which to carry out my research.

I conducted a scoping review using mostly websites (e.g. The Dystonia Society) and secondary sources (e.g. neurology textbooks, historical accounts) to discuss the history of defining and understanding dystonia. While the principal limitation of this analysis is the lack of systematic reviewing around the area of dystonia, I critically consider the way medical definitions have emerged and evolved in relation to a range of factors and circumstances.

Though there are several medical papers on the history of dystonia, these tend to provide readers with a descriptive account of the development of the condition. In particular, the dominant narrative of these reviews is that, before the early part of the twentieth century, the term dystonia was unknown but its clinical appearances (e.g.

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[9]The Dystonia Society is the largest patient advocacy organisation for dystonia in the UK and aims to promote the rights and interests of individuals affected by the condition (Camfield 2002). It also promulgates medical research and education on dystonia and has set up 40 local support groups nationwide for those living with the condition, which are run and coordinated by volunteers.

abnormal movements) were deemed to be largely representative of hysterical disease (Fahn 2006; Goetz 2006). Tensions over important issues such as terminology and nosology (classification) persisted throughout much of this period (Fahn 2006; Goetz 2006; Albanese et al 2013). In recent times, health professionals have debated whether dystonia should be considered a disease in its own right or rather, a collection of separate signs and symptoms associated with other conditions (e.g. Albanese 2017).

Arguably, the history of dystonia is presented as a linear process of discovery and not as a series of iterations or 'inventions' (Bury 1986: 137). While the medical profession admits that there are gaps within its own knowledge base (e.g. genetics) (e.g. Charlesworth et al 2013; Jinnah et al 2013; Albanese 2017), dystonia groups and clinical researchers often present these limitations as temporary. Indeed, it is believed that through 'continuous development driven by good science, beneficent medicine and committed specialists', new discoveries and innovations will eventually be made (Gardner 2014: 69). The idea that the medical profession can be trusted to gather evidence about the nature of disease demonstrates the authority invested in its abilities and skills (chapters 3 and 5) (e.g. Griffiths et al 2005). Yet, this hegemonic representation overlooks the ways in which the advancement of medical knowledge is linked to, and influenced by, a divergent range of cultural and political factors (Bury 1986; Nicolson and McLaughlin 1988; Berg 1992).

More specifically, sociologists have examined the process through which disparate ('objectively' observed) signs and ('subjectively' experienced) symptoms are 'neatly'

ordered and transformed into single disease entities (Bowker and Star 1999; Aronowitz 2001). Blaxter (1978: 10), for example, has noted that the system of biomedicine moves 'from the parts to the whole, building layer upon successive layer and reorganising only partially and intermittently.' In fact, as the case of dystonia demonstrates, symptoms *are* the disease until a formal classificatory system is established (*ibid.*). Arguably, 'defining the phenomenon under consideration – "disease" – and then sub-dividing it into components, proceeding from the whole to the parts' would generate a more proficient diagnostic framework (*ibid.*). However, due to the complex nature and protracted history of medicine, this approach is largely untenable (*ibid.*). Nevertheless, visual mediums (e.g. autopsies, observations, neuroimaging) are employed as 'reliable' tools to detect pathologies and assist with the codification of disease, even though these techniques can introduce new problems and concerns for both patients and doctors (Rhodes et al 1999; MacNeela et al 2010).

Nosology remains a fundamental part of the operation of biomedicine since its linguistic tools provide a degree of coherency to the uncertainties and complexities of expert medical knowledge (Jutel 2009: 280, 281). Yet, classificatory schemas are neither neutral nor stable since their definitions and meanings change continually through time (Bowker and Star 1999; Hedgecoe 2002; 2003; Jutel 2009: 293). For example, seemingly fixed diagnoses like diabetes mellitus and cystic fibrosis have emerged from disagreements and 'negotiated compromises' between various stakeholders (e.g. medical researchers, clinicians, patient support groups) (Stockdale 1999; Aronowitz 2001; Hedgecoe 2002; 2003; see also Brown 1995; Brown and

Zavestoski 2004; Brown et al 2004; Zavestoski et al 2004). While each of these groups may have different and competing viewpoints and agendas, medical claims usually come to dominate because of the way social structures (e.g. the media) generate a great amount of 'hype' and excitement around the alleged benefits of scientific technologies (Stockdale 1999). Furthermore, powerful pharmaceutical firms perform a key role in creating, expanding, and/or retracting the boundary of what is deemed to be 'normal' and 'pathological', most notably, by lobbying central government and patient support groups for funding and/or endorsement (Abraham 2010; Areheart 2011; Conrad 2013). Finally, some sociologists argue that diagnostic labels and practices carry out key regulatory and monitoring functions through the way they sort and sift body-subjects into particular groups (Meekosha and Shuttleworth 2009; Areheart 2011). This demarcation is usually based on the extent to which an individual's capacities and abilities (physical, cognitive, etc.) comply with an arbitrarily defined norm that is created in confluence with social power and authoritative discourses around medicine and disability (*ibid.*).

Using the sociology of diagnosis and expert knowledge literature as a point of departure, I demonstrate within this chapter that medical beliefs have conflicted, converged, and intersected with each other over the last two centuries, constituting and re-comprising hegemonic notions of dystonia. These varied transformations and inconsistencies affect how health professionals subsequently treat and make sense of this highly complex and contested condition.

Medical definitions and practices of dystonia: from the mid-nineteenth century to the present

Describing dystonia

According to contemporaneous medical conceptualisations, dystonia (*dys* – abnormal*; tonia* – muscular tone) is a syndrome or hyperkinetic movement disorder, which is associated with a range of aetiological and pathophysiological features (Steeves et al 2012; Albanese et al 2013; Albanese 2017; Mezaki 2017; Quartarone and Ruge 2018). Mezaki (2017) has also hypothesised that dystonia is not only characterised by 'muscle overflow' (contractions, involuntary movements) but also by 'flow failure' (known as 'negative dystonia'); meaning, the inability to activate certain muscles and successfully execute tasks. Observing the interconnected nature of these aspects, he has argued that dystonia can be viewed 'as a phenotype resulting from the patterned motor "malflow" due to the loss of motor control' (*ibid.*). Given the complexity of dystonia, modern-day clinicians note that 'there is no combination of physical signs that accommodates for all' its syndromes and symptoms (Albanese 2017: 10). Historically speaking, these diversities have meant that dystonia has been poorly defined and understood within scientific circles.

Before its introduction in 1911 by well-known German neurologist Hermann Oppenheim, the term dystonia was medically unknown (Fahn 2011; Klein and Fahn 2013; Poisson et al 2012; Camargo and Teive 2014; Albanese 2017). Indeed, from the fourteenth century up until Oppenheim's breakthrough, various artists and physicians employed a conjunction of descriptors in order to interpret its phenomenological variability (*ibid.*). For example, sixteenth century physician and

dramatist François Rabelais initially coined the term 'torticollis' to refer to twisted or contorted neck muscles (Poisson et al 2012: 1581; Camargo and Teive 2014: 559; Broussolle et al 2015: 3; Albanese 2017: 1-2). This label was frequently invoked throughout the twentieth century. However, given that it vaguely denotes a symptom of varied origin, which can present in both dystonic and non-dystonic movement disorders, the term has largely been replaced with the name 'adult-onset idiopathic cervical dystonia' (Martin 1982: 251; Dauer et al 1998: 548; Poisson et al 2012: 1581). As well as using the neologism torticollis, nineteenth century health professionals also discussed patients' 'unusual' (dystonic) movements and postures in terms of 'tics', 'tremors', 'contractions', and '(functional or progressive) muscle spasms' (Goetz 2006; Klein and Fahn 2013: 851-852). In addition, eminent neurologist Jean-Martin Charcot attempted to subsume these multiple signs and symptoms within distinct categories known as 'hysteria' and 'the neurosis' (see 'disputing the cause' section) (Goetz 2006). Interestingly, medical historians speculate that descriptions of dystonic movements probably date back to the time of the Romans in which the emperor Tiberius Claudius Drusus Nero Germanicus (born in 10 BC) reportedly experienced a speech impediment, gait disturbance, and involuntary muscle spasms in his neck and limbs (Rice 2000; Camargo and Teive 2014: 559). Since this case was most likely the first reported account of a person living with dystonia (*ibid.*), there was (limited) recognition of the problem long before clinicians formally defined and categorised its prominent manifestations (Albanese 2017: 1-2).

Though nineteenth century doctors used various labels and definitions to describe

dystonic postures and tremors, the German psychiatrist Markus Walter Schwalbe is believed to have actually discovered the disorder in 1908 (Grundmann 2005: 683). While he was the first physician to detail the appearances of dystonia and recognise its possible familial genesis (see 'disputing the cause' section), Schwalbe also thought that the condition was partly psychogenic and subsequently termed it 'tonic cramps syndrome with hysterical symptoms' (Grundmann 2005: 683; Klein and Fahn 2013: 851; Camargo and Teive 2014: 559-560). Later, Oppenheim invented the term 'dystonia' in his 1911 publication discussing four unrelated Jewish children with unprecedented spasms and contortions (Grundmann 2005: 682; Fahn 2011: 950; Klein and Fahn 2013: 851). Initially, however, he could not determine if the patients' symptoms related to hysteria or idiopathic bilateral athetosis (another type of movement disorder) (Klein and Fahn 2013: 851, 853-854). Afterwards, Oppenheim deduced that neither of these diagnoses was relevant since he regarded the problem to be in the muscle (rather than the mind), and that further, he could not find conclusive evidence of athetotic movements (i.e. slow and writhing) (Fahn 1988: 1-2; Grundmann 2005: 682; Klein and Fahn 2013). As such, Oppenheim began to establish his own diagnostic category, but this task also proved difficult (*ibid.*). Given that the children's 'unusual' movements were marked by a steadily worsening gait and abnormal posture (lordosis), Oppenheim formulated the term 'dysbasia lordotica progressiva' (Klein and Fahn 2013). Yet, he also noted that the patients' lower limb muscles often alternated between hypotonia and hypertonia states, depending on their activity levels at a given time (*ibid.*). This observation prompted Oppenheim to propose the neologism 'dystonia musculorum deformans' as another possible option (*ibid.*). Since he believed that variations in lower limb muscle tone were the key

clinical features of the condition, he finally decided to use the latter concept (*ibid.*).

Many specialists around the world would subsequently come to adopt the label

dystonia musculorum deformans (Klein and Fahn 2013: 851). This was not only

because Oppenheim felt that it provided an accurate description of the phenomenon

under consideration but also because he was a highly respected professor of

neurology (Klein and Fahn 2013: 851; Albanese 2017: 2). Indeed, Oppenheim was

well-recognised among international scholars who trusted him and used his ideas and

hypotheses as springboards for their own related research on the condition (*ibid.*). As

he is regarded as the 'father' of dystonia, it is no surprise that his initial observations

are still considered prototypical of all the dystonia states[10] (Standaert 2011: 3).

Despite the significance of Oppenheim's term, the publication of his article initially

aroused criticism from lesser-known neurologists. For example, early twentieth

century Polish physicians Flatau and Sterling believed that it placed too much

emphasis on fluctuating muscle tone (Grundmann 2005: 682). In contrast, they

observed dystonic movements in the lower *and* upper extremities with no sign of

hypotonia in two Jewish children (Grundmann 2005: 682-683). From their

observational studies, they deduced that the hallmark characteristic of the condition

was the presence of deteriorating muscle contortions (*ibid.*). Consequently, Flatau

and Sterling rejected both of Oppenheim's concepts (i.e. dysbasia lordotica

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[10] The term dystonia musculorum deformans has variously been updated to: generalised torsion dystonia (introduced by geneticist Gregor Mendel in 1919 who wanted to demonstrate the condition's distinctiveness from other involuntary movement conditions like hysteria and chorea) (Fahn and Eldridge 1976; Albanese 2017: 3), idiopathic generalised torsion dystonia (Marsden 1976a; 1976b; Sheehy and Marsden 1982), Oppenheim dystonia (Klein and Fahn 2013: 852), DYT1 or DYT-TOR1A dystonia (named after the gene and locus responsible for the condition) (Ozelius et al 1989; 1992; 1997), and more recently, early-onset generalised isolated dystonia (Albanese et al 2013; Klein 2014).

progressiva and dystonia musculorum deformans) and instead, proposed the term 'progressive torsion spasm' (*ibid.*). While other labels were also put forward in the same year as Oppenheim's publication[11], some contemporary medical researchers have argued that Flatau and Sterling's definition would have provided a more precise representation of the disease's complex nature compared to Oppenheim's now well-established neologism (Grundmann 2005: 683).

The label dystonia musculorum deformans was also considered problematic because Oppenheim 'never concisely separated the phenomenon of dystonia from the disease entity he described, so that dual use of the term dystonia in referring to a sign and a syndrome produced nosologic confusion for many years' (Grundmann 2005: 682). As a result of this ambiguity, the possibility that dystonia could be a discrete disease entity was overwhelmingly rejected in 1929 at the Tenth International Neurological Reunion in Paris (Grundmann 2005: 683; Poisson et al 2012: 1582-1583; Broussolle et al 2015: 10). Only one delegate, Henry Meige, objected to the ruling for reasons that will subsequently be discussed (Poisson et al 2012: 1582-1583; Broussolle et al 2015: 10). Instead, the majority of attendees concluded that dystonic phenotypes were associated with different syndromes and underlying psychiatric factors (Grundmann 2005: 683; Poission et al 2012: 1582-1583; Broussolle et al 2015: 10). Yet, mid-twentieth century neurologist Ernst Herz (1944a; 1944b) advocated the view that dystonia was a distinct 'clinical entity', not only characterised by slow, continuous movements but also related to an organic genesis (regrettably, he only studied generalised dystonia) (Albanese 2017: 6). Despite Herz's (1944a; 1944b)

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[11] For example, Ziehen applied the label 'torsion neurosis' to denote cases of abnormal, idiosyncratic movements with psychogenic origin (Klein and Fahn 2013: 851).

alternative perspective, the mainstream of medicine uncritically accepted the belief that dystonia was a neurologic sign of emotional origin for several decades, which, as will be noted in due course, affected the ways in which clinicians treated patients presenting with 'unusual' movements and postures.

Throughout the twentieth century, Oppenheim's original term evolved to encompass a range of different manifestations and types (e.g. focal, multifocal[12], hemidystonia[13]) (Fahn 1988; Albanese et al 2013). In 1984, a panel of experts brought together by the Dystonia Medical Research Foundation (henceforth, referred to as the 'Foundation committee') delivered a consensus view of dystonia as 'a syndrome of sustained muscle contractions, frequently causing twisting and repetitive movements, or abnormal postures' (Fahn 1988: 2). Up until fairly recently, clinicians had employed this description in both research and healthcare settings given that it provided a more comprehensive and accurate understanding than previous definitions (e.g. Oppenheim's belief that dystonia was a disorder exclusively of the muscle (Fahn 1988: 1-2)) (Albanese et al 2013: 2). Yet, disputes around the clinical and nosologic appearance of dystonia persisted. In fact, over the years, several researchers have (re)assessed the degree to which the dystonias ought to be considered a single clinical entity or a collection of separate problems (Fahn and Eldridge 1976; Marsden 1976a; 1976b; Sheehy and Marsden 1982; Jinnah et al 2013; Albanese 2017; Quartarone and Ruge 2018). On the one hand, focal and generalised forms of dystonia have been found to differ with respect to

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[12] This type involves two or more body parts.
[13] This type of dystonia affects either the left or right side of the body (e.g. left/right leg, left/right arm, and, in some cases, the left/right side of the face, too) (Dystonia Society n.da).

phenomenology, epidemiology, and/or cause (Fahn and Eldridge 1976; Quartarone and Ruge 2018). On the other, scientists have observed certain commonalities such as shared symptom manifestation (e.g. involuntary muscle spasms), molecular pathways (e.g. dysfunctions in dopamine signalling and ion channels), anatomical circuitry (e.g. disturbances in the brain), physiological substrates (e.g. malfunctioning neural plasticity), and genetics (Marsden 1976a; 1976b; Sheehy and Marsden 1982; Mink 2003; Jinnah et al 2013: 932-933). Due to the fact that epistemic ambiguities remain, it is still unclear whether the dystonias should be subsumed within a distinct disease category or conversely, broken up into multiple disorders (Jinnah et al 2013; Albanese 2017; Quartarone and Ruge 2018).

Thus far, I have provided an historical overview of the ways in which dystonia has medically been defined and described. In doing so, my intention has been to disrupt taken-for-granted understandings of this condition by demonstrating the saliency of professional interests in contributing to commonly held truth claims (Aronowitz 2001). This view also links to previous research on the social construction of diagnosis, and in particular, the ways in which diseases emerge from numerous epistemic revisions, modifications, and compromises (Hedgecoe 2002; 2003). As biomedicine has found it difficult to grapple with the dynamism of dystonia, medical tensions have invariably followed. In turn, this has necessitated that researchers fall back on the perceived credibility of certain clinicians' judgments in order to make sense of the condition's inexplicable appearances. The complex reality of dystonia not only reflects the ways in which it has been (re)defined over the years but also classified and grouped together into clinically significant categories, as will be

examined in the next part.

The classification of dystonia

Up until now, I have demonstrated the various obstacles that doctors have encountered in establishing a clear and concise description of dystonia. Closely related to the problem of definition is categorisation, and in particular, the process through which diverse medical conceptualisations are brought together and organised under specific categories (Blaxter 1978; Brown 1995). Consequently, I think through the ways in which seemingly 'rational' and elaborate classificatory schemas (Jutel 2009: 280) of dystonia have not only emerged over the last 50 years but, due to the aforementioned disputes surrounding phenotypic manifestation, have also been subject to various limitations and changes.

Given the broad range of definitions employed by both nineteenth and twentieth century physicians, subsequent health professionals and researchers have attempted to make sense of these descriptions by devising their own classificatory frameworks (Klein 2014: 137; Albanese 2017). Principally, Fahn and Eldridge (1976) were among the first to design a comprehensive schema of dystonia, largely by demarcating between primary dystonia (with or without a genetic basis), secondary dystonia (concomitant with another hereditary neurological disorder or triggered by a known environmental insult), and, in rare cases, psychogenic dystonia (*ibid.*). Despite aiming to create a holistic classificatory account of the various dystonic states, Fahn and Eldridge (1976) recognised that modifications would most likely be required. In response, the 1984 Foundation committee used their revised definition of

dystonia (as described in the previous section) to distinguish between age at onset (early/childhood or late/adult onset), body distribution (e.g. focal or generalised), and cause (primary or secondary) (Fahn 1988). Having also come across multiple cases of patients with psychogenic dystonia (Fahn et al 1983), the panel realised that this disorder was more common than Fahn and Eldridge's (1976) original assertion (Munts and Koehler 2010: 1554). Consequently, a separate classification for psychogenic dystonia was created based on phenotypic manifestation (e.g. neurologic signs that are clearly psychogenic such as false weakness or self-inflicted injuries), and origin (i.e. the presence of a psychiatric disturbance) (Fahn and Williams 1988; Munts and Koehler 2010). Later, specialists updated and clarified prevailing classificatory concepts, as well as added new ones to the growing list such as 'dystonia-plus' and 'heredodegenerative'[14] to refer to conditions that existed in confluence with another movement disorder and/or were progressive, respectively (Albanese et al 2013: 2). Additionally, some neurologists retained the original primary dystonia label but changed the secondary dystonia term to include dystonia-plus and heredodegenerative types (Grundmann 2005: 684; Albanese et al 2013: 2). Though Albanese et al (2013: 2) have described the modification of dystonia nosologic systems as an inevitable response to emerging developments within the field of neurology, I would also argue that these revisions epitomise the ways in which reductive medical concepts have struggled to interpret the intricacies and complexities of this specific condition.

In 2013, an international panel of specialists re-evaluated the mainstream definition

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[14] The heredodegenerative dystonias are considered extremely rare and usually associated with metabolic disturbances (Gardner 2014: 17).

and classification of dystonia, which had originally been proposed by the Foundation committee (Albanese et al 2013). Principally, the point of this exercise was to clarify the terms primary dystonia and secondary dystonia since these had been employed inconsistently (*ibid.*). Indeed, primary dystonia had, among other applications, been used to refer to either 'phenotypes of relatively pure forms of dystonia'[15] or an absence of visible brain abnormalities (Albanese et al 2013: 3). On the other hand, secondary dystonia had confusingly described 'non-isolated dystonia, a defined pathology or more generally a known etiology' (*ibid.*). In an attempt to resolve these issues, Albanese et al (2013) devised a diagnostic system in which dystonia could be interpreted along two main axes: clinical features (axis I)[16] and aetiology (axis II).[17] Supplementing axis I, Klein et al (2017) added the characteristic 'complex' to denote acquired or combined forms of dystonia, whereby dystonic features are not predominately involved and are comprised of a variety of neurologic and non-neurologic signs (Klein 2014). While it can be argued that these frameworks and latest revisions have enabled clinicians and researchers to formulate the dystonia syndromes more precisely (e.g. early-onset generalised isolated dystonia) (Klein 2014: 138), such modifications also highlight the profound difficulties for those attempting to classify and examine its complexities (Austin 2015: 12).

I have demonstrated the ways in which health professionals have assembled and employed a divergent range of classificatory systems in order to provide a degree of

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[15] Although this type can also co-exist with tremors (Albanese et al 2013: 3).
[16] These include: age at onset, body distribution, temporal pattern (i.e. whether the condition progresses. remains static, or varies momentarily in relation to voluntary actions or 'sensory tricks'), isolated (formerly, primary dystonia) or combined (formerly, dystonia-plus) features (Albanese et al 2013).
[17] These include: inherited/genetics, acquired (including psychogenic cases), or idiopathic (familial and sporadic) causes (*ibid.*).

cohesion to the fragmentary nature of dystonia. However, as sociologists have noted, diagnoses are complex entities and composed of multiple elements (Blaxter 1978; Jutel 2009: 282). In fact, this section has highlighted the ways in which dystonia schemas have been constructed in relation to, among other components, temporal pattern, body distribution, and cause. Arguably, my analysis reveals a tension between the need to consider the striking phenotypic diversities of dystonia, on the one hand, and the need to unify these into a coherent diagnostic framework, on the other. Compounding the issue, dystonia specialists are aware that 'there is no pathognomonic presentation that allows for reliable clinical-etiological correlations, either for genetic or for environmental forms' (Albanese et al 2013: 9). This is because some dystonias are associated with a structural, biochemical, and/or molecular abnormality, whereas other types 'have no apparent pathology in the' body (Jinnah 2015: 78). Yet, aetiology is often considered important for enabling clinicians and patients to make sense of the problem. In fact, both parties usually rely on the use of medical technologies (genetic sequencing, neuroimaging) not only to locate visible pathological markers but also to prove the existence of disease (the implications of this for patients will be discussed in subsequent chapters) (Rhodes et al 1999). In the context of dystonia, its variability threatens hegemonic assumptions surrounding the trustworthiness of these tools and the established boundary between neurologic and psychogenic aetiologies (Munts and Koehler 2010). Thus, a final area of contestation that I examine relates to the genesis of dystonia and the problems doctors have faced in trying to establish its cause.

Disputing the cause

Given that the origin of dystonia has variously been attributed to both the brain (in terms of neurologic and/or psychiatric factors), and more recently, mutations in specific genes, this section explores key epistemic disagreements around each of these causes.

Neurologic versus psychiatric explanations

Prior to the emergence of dystonia as a medical label, well-known nineteenth century neurologist Jean-Martin Charcot set out his own theories and ideas about the nature of patients' varied and dynamic muscular symptoms (Goetz 2006). In his neurological department at a hospital in France, Charcot clinically observed several patients with various kinds of neurologic movement disorders (e.g. dystonic spasms and tics, Parkinson's disease), which 'were described by large categories of symptoms and not by anatomical lesions' (Goetz 2006: 4). Using his clinical skills and judgment, Charcot applied the familiar 'anatomo-clinical method' to help him identify the underlying organic genesis of numerous neurological diseases (*ibid.*). This approach involved two parts: firstly, Charcot studied the evolution of patients' symptoms over a given period and secondly, he performed autopsy examinations of nervous system tissue on the recently deceased (Goetz 2006: 4-5). In doing so, Charcot was able to cross-reference visible anatomical pathologies to the symptoms witnessed during the time that the patient was alive (Goetz 2006: 5). While this sophisticated technique allowed Charcot to reveal that spasticity in amyotrophic lateral sclerosis correlated with neuron lesions, which in turn inspired further anatomo-clinical research into other health contexts, his postmortem observations did not always lead to such definitive insights (chapter 3 discusses the significance of the

medical gaze and experimental method within clinical settings) (*ibid.*). For example, he was unable to locate any anatomical pathology for several movement disorders such as Parkinson's disease, chorea, and dystonic spasms (*ibid.*). Thus, to classify neurologic symptoms and conditions that were clinically familiar but anatomically unidentifiable, Charcot invented a tentative label known as the neuroses ('névroses') (*ibid.*). He believed that this category would one day be supplanted by further work into the location of structural lesions (*ibid.*). However, this ambition was never realised in Charcot's lifetime and he died without knowing the origin of these mysterious complaints (Nettleton et al 2004: 63).

From the 1870s onwards, Charcot subsumed the specific symptoms classically associated with neurotic disorders such as spasms and tremors under the broader and well-recognised category of 'hysteria' (Goetz 2006: 7). Yet, this term was confusingly applied to movement disorders of both neurologic (anatomical and non-anatomical) and non-neurologic (psychogenic) appearance, although it was largely discussed within neurological publications (Fahn 2006; Goetz 2006). This was because the specialties of psychiatry and neurology were viewed and practiced more or less separately: whereas the former was connected with insanity-causing diseases, the latter dealt predominately with internal processes (Goetz 2006: 3-4). Medical sociologists have, however, observed striking ambiguities between the two disciplines, including the ways in which both are concerned with the brain and nervous system, but that further, seek different explanations of the problem (e.g. biochemical or emotional disturbances for psychiatry and structural injuries or physiological changes for neurology) (Nettleton et al 2004: 63; Halpin 2011: 858;

Jackson 2011). Compounding the issue, nineteenth century neurologists and psychiatrists often worked together as editors on various medical journals and thus, would have most certainly exchanged ideas and concepts related to the nature of Medically Unexplained Symptoms (MUS) and contested conditions (i.e. illnesses that lack a pathological marker) (Nettleton et al 2004: 63). While neurology and psychiatry are still considered distinct disciplines, Fein (2012) and Rapp (2012) have maintained that traditional mind-based theories of mental illness are gradually being replaced with material (neurologic) explanations (chapter 3). Consequently, the demarcation between these two branches of medicine may be difficult to uphold in practice (Nettleton et al 2004).

Charcot and others, following in the tradition of nineteenth century medicine, examined hysteria as a movement disorder with emotional consequences but, unlike some of his contemporaries, he never believed that it was triggered exclusively by stress or trauma (Goetz 2006). Instead, Charcot advocated the view that patients with a variant of neurosis or hysteria inherited it from a familial 'weakness' (known as a *tache*), as well as from frequent exposure to environmental insults (Goetz 2006: 6). While exogenous factors alone could not trigger the onset of a neurotic condition, these could provide a certain degree of protection in families with a history of the problem (*ibid.*). Charcot also attempted to 'prove' the organic nature of hysteria through the use of hypnosis, whereby he noted several improvements in many of his patients (Goetz 2006: 7). Despite the fact that Charcot initially used male participants to demonstrate the symptoms of hysteria during his clinical lectures, he subsequently employed only female patients, who, feminist theorists argue, 'came to epitomize the

hysteric' within these spaces (Devereux 2014: 24). Later, Sigmund Freud, one of

Charcot's students, famously defined hysteria as a form of repression and psychic

scarring: a view that he strongly linked to women (Devereux 2014: 24-25).

Specifically, Freud maintained that women were emotionally unstable compared to

men due to the seemingly 'castrated' nature of their bodies (*ibid.*). To overcome

profound feelings of loss and anxiety, he recommended that they find a husband with

whom to bear children (*ibid.*). By staunchly believing that the genesis of hysteria lay

in the mind (psyche), rather than the brain (anatomy), Freud reassessed previously

taken-for-granted understandings of this 'disease', and by proxy, strengthened the

border between psychiatry and neurology (Nettleton et al 2004: 63). Given the ways

in which definitions of hysteria have changed through time and space, sociologists

have referred to it as a 'transient diagnosis' (Hacking 1999) that has performed a

significant impact on medical perspectives of dystonia.

In contrast to Charcot's assertion that dystonic movements were organic (Goetz

2006), nineteenth century French physician Edouard Brissaud proffered the term

'mental torticollis' ('torticolis mental') since he believed that its origin was psychical

after witnessing several patients temporarily reverse their neck contractions by

lightly touching the affected area (Poisson et al 2012; Broussolle et al 2015). In

1902, his students, Henry Meige and Eugène Louis Clément Feindel, called this

voluntary movement the 'antagonistic gesture' ('geste antagoniste') (*ibid.*). More

contemporary scientists have, however, renamed it a 'sensory trick' or 'alleviating

manoeuvre' (Ochudlo et al 2007; Patel et al 2014; Broussolle et al 2015). Though

this gesture is commonly associated with torticollis, it has also been observed in

patients with more clinically severe forms of dystonia, albeit a more forceful motion is often used (sometimes termed a 'forcible trick') (Ochudlo et al 2007; Poisson et al 2012: 1582). Brissaud thought that this 'bizarre' mannerism was a 'childish' and 'pathologically imaginary' movement, which 'proved' the psychogenicity of the condition[18] (Poisson et al 2012; Broussolle et al 2015). His well-respected commentary on the emotional origin of mental torticollis went virtually uncontested for several decades, although some research conducted in the early to mid-part of the twentieth century proffered contrasting perspectives (Poisson et al 2012: 1582-1583 e.g. Wilson 1927; Foerster 1933; Herz 1944a; 1944b). For example, Foerster (1933) maintained that the pathological progression of torticollis was an angiomatous one; meaning, a condition associated with dilated blood or lymph vessels in certain parts of the body. Nevertheless, it would take up until the middle of the 1970s before the highly reputable neurologist, Charles David Marsden (1976a; 1976b), used physiological evidence on disrupted basal ganglia[19] activity to allude to dystonia as a single clinical entity with organic genesis. In this way, his work would come to be viewed as a major contributor to the field of movement disorders, dispelling previously held 'truths' about the disparate and psychogenic nature of the dystonia syndromes (Brooks 1999; Quinn et al 2012; Broussolle et al 2015; Albanese 2017).

Assessing paediatric patients in his private clinic at the turn of the twentieth century, Oppenheim thought about some of the possible causes of dystonia musculorum deformans (Klein and Fahn 2013: 852). As was reflective of the period, he initially

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[18] Ironically, recent research has shown that the antagonistic gesture is usually found in cases of organic dystonia and not psychogenic forms (Schrag 2006: 57; Poisson et al 2012; Broussolle et al 2015).
[19] An area of the brain that is thought to be associated with motor movements (Mink 2003).

believed that the children might be suffering from a psychogenic problem but later

changed his mind when he could not find any evidence to support this view (*ibid.*).

Principally, Oppenheim identified several physical signs, which indicated that

dystonia could be an organic disorder (e.g. fluctuating muscle states that were 'not

suggestible, not altered by trickery (e.g. applying a magnet to the body), not altered

by distraction or hypnosis') (*ibid.*). He also noted that the patients did not display any

clear 'emotional factors' (*ibid.*). To substantiate his claim, Oppenheim compared

dystonia to 'Parkinson's disease as an example of another [neurological] condition

without any "obvious pathology"' but which clinicians still agreed was organic

(Klein and Fahn 2013: 853). In doing so, Oppenheim tried to provide compelling

arguments for the material origin of dystonic movements but, unlike the relative

popularity of his dystonia musculorum deformans term, this would take a lot more

convincing.

Though, as previously mentioned, Flatau and Sterling contested Oppenheim's

terminology, the authors agreed that dystonia was organic because none of the

patients that they observed displayed any signs of mental illness (Grundmann 2005:

283). Similarly, some researchers interested in the origin of torticollis (as it was

known at the time) disputed the psychogenicity of the disorder by proposing a link

between the symptom and various other conditions such as definite pyramidal

diseases (related to the nervous system, cerebral cortex, and brainstem), organic

paraplegia, or, in rare cases, mild encephalitis (brain swelling) (Wilson 1927). While

Meige and Feindel published a monograph in 1902 on the psychical origin of mental

torticollis, the dissemination of Oppenheim's work subsequently prompted Meige to

reconsider his original perspective (Poisson et al 2012: 1582). In fact, during the Tenth International Neurological Reunion in Paris, Meige was the only attending neurologist to argue that abnormalities in the basal ganglia were most likely responsible for the onset of the disorder (Poisson et al 2012: 1583). Furthermore, Meige identified several variants among torticollis such as writer's cramp and facial spasms (later known as Meige's syndrome or orofacial dystonia[20]) (Poisson et al 2012: 1583). Specifically, he noted similarities between these different forms and proposed the term 'focal dystonia as part of the clinical spectrum of Oppenheim's generalized dystonia' (*ibid.*), a belief that would also be echoed by Marsden[21] (e.g. 1976a; 1976b; Sheehy and Marsden 1982) in subsequent decades. In this way, Meige advocated the view that dystonia was not only a chronic disease in its own right but also had an organic genesis (Poisson et al 2012: 1583). However, many twentieth century clinicians drew on Meige and Feindel's earlier work on sensory tricks to emphasise the emotional nature of dystonia and the ways in which it could potentially be treated with different psychological approaches (e.g. systematic desensitisation – Meares 1973).

Bowker and Star (1999) have argued that medical conceptualisations of disease are negotiated and complex since only certain perspectives come to be regarded as 'true' at particular times and contexts. For example, widespread disputes taking place between early twentieth century neuropsychiatrists operating in different fields such

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[20] This type affects the jaw, tongue, and eyes. Sometimes the muscles in the neck may also be involved.
[21] In particular, Marsden (1976a; 1976b) maintained that focal and generalised kinds should be grouped together and placed under the broader diagnostic category of '(idiopathic torsion) dystonia' (Sheehy and Marsden 1982).

as biology and psychology led to passionate debates about the nature of various unexplained conditions (Munts and Koehler 2010: 1560). In the case of dystonia, the mainstream of medicine overshadowed dissenting voices that promoted a neurologic understanding of the problem, particularly as psychodynamic theories had increased in popularity and a somatic substrate remained unconfirmed (*ibid.*). In fact, strongly influenced by the views and hypotheses of the Freudian school of psychoanalysis, many twentieth century clinicians treated dystonic movements and postures as symptoms of emotional disorders (Dauer et al 1998: 548; Grundmann 2005: 683; Munts and Koehler 2010: 1554; Poisson et al 2012; Camargo and Teive 2014: 560; Broussolle et al 2015). Most notably, several psychiatrists such as Cleveland (1959) and Diamond et al (1984) maintained that focal dystonia manifests as a result of unconscious conflicts and repressed sexual desires, 'the stiff neck [for example] depicting an erect phallus or a symbolic turning away from the world' (Dauer et al 1998: 548). Despite a propensity towards Freudian psychoanalysis, some considered this approach 'rather vague' and lacking in any robust empirical evidence (Martin 1982: 257). Nevertheless, some branches of the medical profession remained certain that a psychological mechanism would be found. In particular, followers of the behavioural school of psychology contended that the unpredictable head movement in torticollis/cervical dystonia produced high levels of anxiety, which the resulting spasm temporarily relieved (Martin 1982: 258; Brierly 1967; Meares 1973). In this way, behaviourists observed that dystonic movements were gradually conditioned and reinforced over time, particularly during moments of profound tension and stress (Meares 1973). To treat the problem, researchers recommended that patients were desensitised 'to the anxiety evoked by the head movements' by, for example,

delivering a series of low-grade electrical shocks each time the symptoms occurred (Martin 1982: 258; e.g. Brierly 1967). However, the findings from these studies have largely been rejected on the basis of their limited samples and ambiguous findings (Martin 1982: 258). More recently, psychological research on dystonia has focused on the impact of the condition on mood (e.g. Werle et al 2014) and the possible ways in which the application of a combined cognitive behavioural and mindfulness programme may improve wellbeing for people with the disorder (Sandhu et al 2016). In other words, there has been a move away from attributing the causes of dystonia to emotional factors to examining the psychosocial consequences of its physical manifestations.

While dystonia had often been misinterpreted for a psychiatric disease due to its 'bizarre' presentations, fluctuating movements, and seeming lack of a physiological pathology (Ganos et al 2014), Marsden (1976a: 259) refuted the belief that these characteristics alone were 'decisive evidence in favor of a psychogenic origin.' Instead, Marsden and colleagues (1985) conducted research on the pathological features of some forms of dystonia in which they detected lesions in the basal ganglia (Marsden 1976a; 1976b). Though Marsden and Quinn (1990: 142) noted that Magnetic Resonance Imaging (MRI) scanners[22] were unable to detect structural pathologies in patients with idiopathic generalised or focal torsion dystonia, they nevertheless surmised that some unknown biochemical disturbance in the basal ganglia was most likely responsible. This was largely because several electrophysiological studies had demonstrated the occurrence of 'distorted

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[22] This technology uses radio waves and magnetic fields to generate highly detailed images of the internal organs in the body, usually for diagnostic purposes (National Health Service Choices 2015).

descending basal ganglia drive' in these types (*ibid.*). Due to Marsden's belief in the material nature of dystonia, the pendulum swung in favour of this view (Munts and Koehler 2010). In fact, the possibility that the disease could be psychogenic was dismissed as an aberrant phenomenon (Fahn and Eldridge 1976); somatic explanations had become the mainstream.

However, in recent years, dystonia clinicians have begun to reassess the established border between neurology and psychiatry (Munts and Koehler 2010). This has been due to several notable developments. Firstly, in spite of initial reports by Fahn and Eldridge (1976), psychogenic dystonia is a fairly common problem and regularly seen in specialist movement disorder clinics (Schrag 2006: 54; Munts and Koehler 2010: 1561). Medical scientists suggest that psychogenic dystonia accounts for 20%–50% of all reported cases of movement disorders with an emotional genesis, although, due to difficulties with diagnosis, this figure may be higher (Miyasaki et al 2003; Hallett 2006; Schrag 2006: 54). Psychogenic dystonia is also a complex condition that requires the mutual expertise of neurologists and psychiatrists to diagnose and treat effectively (Hallett 2006; Peckham and Hallett 2009). Interestingly, modern-day researchers speculate that the condition may be triggered by both emotional conflicts and changes in the activity of certain areas of the brain (Munts and Koehler 2010). For example, using imaging techniques on patients affected by either organic or psychogenic dystonia, as well as on healthy controls, Schrag and colleagues (2013) detected various abnormalities in the prefrontal cortex (e.g. cerebellum, basal ganglia) in the dystonic group compared to the controls, and that further, these changes diverged significantly from each other. Secondly, it has

been hypothesised that a malfunction of sensorimotor circulation and control (De Pauw et al 2017b), in conjunction with various exogenous factors like stress and trauma, may affect the performance of the central nervous system (Munts and Koehler 2010: 1560, 1561). These combined aspects may potentially carry out a salient role in the physiopathology of organic dystonia (*ibid.*). In view of that, the medical profession has come full circle. Clinicians rely on neuroimaging techniques to confirm the presence of neuroanatomical factors in some of the dystonia syndromes (e.g. children and adults with suspected hemidystonia or generalised dystonia) (Jinnah 2015: 79), while also noting the possible aetiological impact of environmental insults: a proposition that Charcot originally stated nearly 200 years ago (Goetz 2006: 12-13). Still, little research has definitively established the origin of the dystonia states, but many clinicians suggest that multiple biologic and psychogenic factors most likely contribute to the majority of cases (Munts and Koehler 2010).

Though current medical definitions and explanations of dystonia are contested, they all largely refer to it as a movement disorder associated with varied origin and phenotypic manifestations (e.g. Albanese 2017; Mezaki 2017). While The Dystonia Society also acknowledges dystonia as a diverse condition with a range of presentations and severities, this complexity is often lost in its representations of affected individuals in fund raising and awareness raising campaigns[23] (Camfield

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[23] The following extract demonstrates the way dystonia is described on The Dystonia Society's website (Dystonia Society n.db): 'a neurological condition characterised by involuntary and sustained muscle spasms which can force affected parts of the body into abnormal movements or postures.' It also states that 'there is now a unanimous view that focal and generalised dystonia are organic brain disorders' (*ibid.*). Elsewhere, the organisation recognises the emotional impact of dystonia, as well as its heterogenous nature (e.g. Dystonia Society n.dc; n.dd; n.de).

2002: 100). As was discussed, dystonic symptoms can be triggered by a physical and/or psychiatric disturbance, demonstrating its aetiological variability (Fahn 2006; Hallett 2006; Munts and Koehler 2010; Schrag et al 2013). Despite recognising that patients with functional (psychogenic) dystonia sometimes report previous experiences of trauma (Dystonia Society 2015), The Society still prioritises organic explanations over emotional ones. This is perhaps unsurprising given that Marsden was a prominent figure in setting up the charity in the 1980s (Dystonia Society n.df). The Dystonia Society also benefits from advocating the view that dystonia is a biological disease because of the wider socio-political milieu within which physical conditions are accorded a higher status than psychogenic ones. As I explore in further detail in later chapters, the label of mental illness is often equated with deplorable personality traits like dishonesty and individual irresponsibility (Goffman 1963). People displaying inexplicable, erratic, or difficult to read physical symptoms may be regarded as 'mad' and blamed for their deviant behaviours (e.g. Corrigan 2007). In contrast, somatic conditions are perceived as more legitimate and authentic than psychiatric ones because the causes are usually attributed to fixed and material biological systems (e.g. the brain) rather than the individual's supposed lack of morality or psychological coping mechanisms (I return to these points in the subsequent chapters) (Fein 2012). Consequently, The Dystonia Society draws selectively on specific ideas about dystonia that are in line with current medical thinking to promulgate a particular perspective of the condition, which is also socially acceptable and concomitant with its own needs and values (e.g. fund raising) (Camfield 2002). Indeed, it has been noted that lay movements often perform a significant role in *promoting* and *reproducing* medicalised notions of disease and the

body (Brown 1995; Barker 2008; Jutel 2009: 283).

Continuing with our exploration of the aetiology of dystonia, the next part examines the growing field of genetics and its impact on past and current understandings of this particular disease.

The geneticisation[24] of dystonia

There have been numerous uncertainties around 'the importance and precise nature of genetic mechanisms in dystonia' (Fahn 1993: 140). During the early part of the twentieth century, some doctors believed that heredity factors could be responsible for triggering the condition (Grundmann 2005: 684). At this time, medical researchers were greatly influenced by eminent nineteenth century scientist Gregor Mendel's theory of inheritance and often used it to identify 'genetic defectives' (Conrad and Gabe 1999: 505). For example, Schwalbe and Flatau and Sterling suspected that dystonia was genetic with an autosomal recessive[25] mode of inheritance because of its 'familial occurrence and an ethnic predilection to occur in Jews of eastern European ancestry' (Grundmann 2005: 684). However, though Mendelian genetics had routinely been used to understand the mechanisms of dystonia, the perceived psychogenicity of the disorder coupled with the rise of Nazi propaganda during the 1930s and 40s, tangibly obstructed clinical recognition of its role for several decades (Grundmann 2005: 684). In fact, Herz (1944b: 352) refused

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[24] Geneticisation describes the process whereby human characteristics, behaviours, and differences are defined and understood in relation to genetic theories and ideas (e.g. deoxyribonucleic acid codes) (Hedgecoe 2009).
[25] Autosomal means that the non-sex chromosomes are involved. A recessive mode of inheritance indicates that two versions of the mutated gene must exist in order for the disease to manifest.

to attribute dystonia to one particular ethnic group due to the horrifying consequences of Nazi eugenic policies, despite the fact that he noted hereditary patterns in the families of Russian Jews. Interestingly, medical sociologists Peter Conrad and Jonathan Gabe (1999: 505) have noted that 'geneticists moved to separate themselves from the pseudo-science of eugenics' following the end of World War II. In this way, it can be argued that wider social and cultural factors have performed a notable role in shaping the scientific community's attitudes towards genetic medicine, and in particular, their understandings of the genesis of dystonia.

It was not until the 1960s and 70s that medical researchers reconsidered the hereditary nature of the dystonia syndromes (Grundmann 2005: 684; Klein and Fahn 2013: 852). Zeman and Dyken's (1967) classic review of the genetic and pathological features of idiopathic torsion dystonia established its mode of inheritance as autosomal dominant with reduced penetrance[26] given the incidence of the condition in successive family members. The authors also noted a 'higher gene frequency of dystonia in Jews' compared to non-Jews, albeit 'they did not construe a distinct disease gene […] for this population' (Fahn 1993: 141). However, at the end of the 1980s, Ozelius et al (1989) located the first torsion dystonia locus (DYT1) to chromosome region 9q32-34 in non-Jewish families. In addition, researchers showed that the same chromosome linkage and gene locus was also present in European Jewish populations (Kramer et al 1990; Ozelius et al 1992). Later, the gene

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[26] An autosomal dominant mode of inheritance indicates that only one copy of the defected gene is required to transmit the disease. Reduced penetrance means that not all mutation carriers will be symptomatic. Researchers estimate a reduced penetrance of approximately 30% in patients with torsion dystonia (Pauls and Korczyn 1990). In other words, only 30% of defective gene carriers will be symptomatic (Klein 2014: 140).

responsible for torsion dystonia (*TOR1A*) was identified (Ozelius et al 1997). Since the mutated *TOR1A* gene causes it to encode a protein known as torsin A abnormally (*ibid.*), these incorrect pathways interfere with the brain's ability to communicate properly with muscles, henceforth causing them to spasm and contort uncontrollably (Charlesworth et al 2013: 2023; Dystonia Society n.dg). Modern-day researchers suggest that this gene is responsible for 80% of all isolated forms of childhood-onset dystonia in Jewish populations and 50% of the same type in non-Jewish groups (Charlesworth et al 2013: 2023). Though the field of dystonia genetics has expanded since the publication of Ozelius et al's (1989) landmark paper, the scientific community is still unsure of how molecular changes in certain genes produce (un)detectable structural abnormalities in particular areas of the brain (Standaert 2011: 2; Charlesworth et al 2013: 2023).

Of late, medical researchers have mapped over 20 different genetic loci (DYT1, DYT2, etc) linked to the onset of monogenic[27] isolated dystonia[28] (Charlesworth et al 2013; Lohmann and Klein 2013; Moghimi et al 2013; Dystonia Society n.dg; Klein 2014; Klein et al 2017). Clinicians have also noted that some complex forms of dystonia can be X-linked recessive (e.g. Lesch-Nyhan syndrome) or mitochondrial-based (Albanese et al 2013; Klein et al 2017), demonstrating the molecular heterogeneity of these disorders. The number of identified genes will probably rise as developments in genetic sequencing become more advanced and lead to new interpretations and ideas (Charlesworth et al 2013). In fact, while the majority of

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[27] This term describes single gene mutations.
[28] Although the genes for some reported loci have not yet been found (Charlesworth et al 2013; Klein 2014).

adult-onset focal isolated dystonias were customarily thought to be idiopathic, contemporary scientists believe that these types may occur as a result of 'susceptibility genes'[29], although these are yet to be identified (Steeves et al 2012: 1789; Lohmann and Klein 2013: 900; The Dystonia Society n.dg). Despite the fact that genetic testing may be performed in some types of dystonia (e.g. the early-onset isolated ones), this is not usually done for individuals with focal forms unless there is a known family history (Jinnah 2015: 79).

Genetic conceptualisations of dystonia have produced dramatic effects on the ways in which diagnoses are made (e.g. genetic testing) and treatments and cures are developed. While there is currently no cure for dystonia and modern-day therapeutic interventions only address the external symptoms (e.g. muscle spasms) (chapter 1) (Roubertie et al 2000; Termsarasab et al 2016), some work has been done to identify key biochemical abnormalities that could potentially be corrected with the administration of appropriate treatment (Dystonia Society n.dg). One area of research that has proved successful in this objective has been the location of the cellular mechanism of dopamine-responsive dystonia[30], which is widely recognised within the medical community and can effectively be treated with regular doses of levodopa (Segawa et al 1976). More recently, researchers have proposed an untested link between deficiencies in eIF2α signalling and a malfunctioning DYT-TOR1A gene (Rittiner et al 2016; Calakos 2017). The authors have predicted that increasing the

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[29] It is thought that exposure to certain exogenous factors like stress or trauma may trigger mutations in particular genes.
[30] This rare type of dystonia (also known as Segawa syndrome) is characterised by an abnormal gait with diurnal fluctuation (Segawa et al 1976). The muscles of the upper extremities and trunk may also be contorted (*ibid.*). The most common type of dopamine-responsive dystonia is triggered by mutations in either the *GCH1* or *TH* gene (Klein 2014: 140).

activity of this specific pathway (in mice) could produce promising results for patients in the future (*ibid.*). Nevertheless, not only is their hypothesis in its embryonic stages (they have, thus far, developed a DYT1 dystonia assay) but little is known about the relevance of cellular pathways in various types of dystonia (*ibid.*).

Aside from the aforementioned research developments, early-onset dystonia is also listed among the 'rare diseases' currently being studied through the 100,000 Genomes[31] sequencing project, which is currently operating and has received substantial funding from the Department of Health and Social Care (Genomics England n.db). In the long-term, this work aims to expedite diagnosis and provide patients affected by rare diseases or cancer with treatments uniquely tailored to their genetic compositions (Genomics England n.da). Closely related to the rise of chromosomal testing is the availability of reproductive technologies designed to prevent future generations from inheriting genetic disease. At present, the Human Fertilisation and Embryology Authority (n.d) has approved the use of pre-implantation genetic diagnosis[32] for autosomal recessive dopamine-responsive dystonia, early-onset torsion dystonia, and myoclonus dystonia. Developments in prenatal screening technologies are often regarded as useful for accelerating access to genetic counselling and helping would-be parents make informed reproductive decisions (Charlesworth et al 2013). Yet, social scientists suggest that the benefits of genomic and reproductive medicine are being exaggerated and heralded as revolutions in healthcare, often without reasonable consideration for potential

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[31] A genome refers to a complete set of genes combined with 'the DNA between the genes' within most cells in the human body (Genomics England n.da).
[32] Embryos are created through in vitro fertilisation (i.e. gametes are fertilised outside the body) and tested for genetic mutations. Healthy embryos are then implanted into the uterus for development.

drawbacks, uncertainties, and alternative ideas (Deans et al 2013; Samuel and

Farsides 2017).

A final issue related to the proliferation of genetic medicine is the formation of

patient identities (Novas 2007). Even though The Dystonia Society aims to build a

shared identity around what is essentially a complex and diverse disorder (Camfield

2002: 100), it looks to genetic research as a way of unifying these multiplicities by

claiming, for example, that the identification of the DYT-TOR1A gene 'will [one

day] be applicable to all dystonia patients' (Dystonia Society n.dh). In doing so, The

Society advocates the view that advances in genetic technologies will open new ways

for the effective treatment of dystonia in the future. Social scientists maintain that

patient charities often take an active role in creating and developing potentially

beneficial therapies for chronic conditions by, for example, funding medical research

and promulgating scientific agendas at group meetings (e.g. Brown 1995;

Rabeharisoa 2003; Shakespeare 2006; 2014; Novas 2007). For The Dystonia Society,

and its locally-run support groups, by (re)producing information on dystonia that

aligns with the viewpoints and perspectives of genetic (and neurologic) medicine,

they are able to shape the development of dystonia and promote their own

understandings of how the disorder should be treated and managed. Novas (2007)

has referred to these sorts of activities as 'the governance of genetic diseases',

whereby patient organisations perform a key role in fundamentally altering the

course and direction of scientific research efforts to expedite the advancement of

curative treatment. Central to the process of medical discoveries is the *hope* that

science will one day eradicate disease and provide accessible technologies and forms

of expertise to all (Shakespeare 2006; 2014; Novas 2007). Thus, the trust and authority placed in the medical profession, namely, to discover a cure, provide answers, and offer a positive vision for the future (Novas 2007) means that the ethos of medicine persists and endures within lay dystonia support spaces, amid the continual uncertainty and instability of expert bodies of evidence (chapters 5 and 7).

Conclusions

In conclusion, this chapter has presented some of the tensions and mediating factors that have shaped expert medical knowledge of dystonia for nearly 200 years. Specifically, competing medicalised perspectives from both within and between neurology and psychiatry have influenced contemporary understandings of this poorly defined condition.

The uncertainties and limitations inherent within medical conceptualisations of dystonia have primarily generated contestation around its phenotypic and classificatory features (Albanese 2017). It has also raised the issue of whether novel medical technologies like neuroimaging and genetic sequencing can feasibly resolve nosologic confusion, as well as effectively treat and predict the condition. While new developments within the field of genetics and other specialties have looked to establish the fundamental principles of dystonia, these have ironically introduced new challenges and problems, particularly in situations where a pathological marker cannot be identified (as will be discussed throughout this thesis). Thus, even though expert medical knowledge of dystonia has dramatically increased since the middle of

the nineteenth century, this disorder remains a medical enigma with many questions still left unanswered (*ibid.*).

Through my historical overview, I have interrogated the process of categorisation in order to explore the circumstances that have influenced modern-day health professionals' and patient advocacy groups' understandings of dystonia. Consequently, I have highlighted the problematic nature of medical bodies of knowledge for clinicians and lay campaigners aiming to represent its diversities (Camfield 2002; Austin 2015: 12). Moreover, epistemological doubt and disagreement may also have a profound impact on patients' experiences of dystonia, with varying outcomes for health-seeking behaviour. For example, this turbulence may shape the ways in which patients use professional knowledge sources to process and interpret both their own sense of embodiments and day-to-day lives with the illness. Accordingly, the indeterminacy of medicine may inadvertently affect the nature of the relationship between lay and expert knowledge, as will now be explored in chapter 3.

Chapter 3

Conceptualising the relationship between experiential and medical knowledge

Through this chapter, my research examines the ways in which individuals living with and managing chronic and contested conditions like dystonia make decisions about their healthcare and support-related needs. Consequently, I critically consider the following strands of thought. Firstly, I evaluate the traditional role of expert medical knowledge, and in particular, examine the extent to which its authoritative status has been affected by the emergence of neoliberal and consumerist processes. Secondly, I discuss the way these developments have prompted sociologists to assess how far 'lay' and 'experiential knowledge', or bodies of knowledge that are derived from lived experience, can be used to challenge, supplant, or augment dominant medical epistemologies (Blume 2016). Finally, I draw upon the feminist and disability studies literature in order to consider the key ontological and political implications of experiential knowledge. Overall, by using these explorative components, the evolving literature on the relationship between lay and professional knowledge as a hierarchical dynamic to a synergistic and mutually co-constitutive one is presented.

The nature and status of expert medical knowledge

Medical knowledge as a dominant epistemic source

Since the mid-twentieth century, theoretical developments within medical sociology have produced rich and diverse understandings 'of health, illness and medicine',

particularly in the context of the patient-doctor relationship (Bury 1997: 82). One of the first sociologists to consider these issues in significant detail was functionalist scholar Talcott Parsons (1951). According to the author, patients have little power to direct consultations and influence clinical outcomes primarily because of their lack of technical expertise (*ibid.*). As a result, Parsons (*ibid.*) argued that the positions doctors and patients typically occupy were starkly contrasting, but that further, this asymmetry helped to maintain wider social cohesion due to a process commonly referred to as the 'sick role' (Bury 1997: 82-87). This role denotes the responsibilities and rights delegated to patients and health professionals during the period that a person feels unwell (Parsons 1951; Turner 1987; Bury 1997: 82-87). Though patients have the right to withdraw temporarily from social activities and receive certain benefits (e.g. sick leave), they also have the moral responsibility to obtain appropriate healthcare and comply with 'doctor's orders' in order to get better as quickly as possible (*ibid.*). In addition, health professionals must minimise patients' recovery period by providing a diagnosis and effective treatment in order for social functions and roles to continue as before (*ibid.*). While later sections consider the limitations of the sick role in relation to the MUS and contested conditions literature, Parsons' (1951) consensual model of the medical profession illuminates the ways in which this institution restores economic and social productivity, otherwise lost due to an acute bout of illness, through seemingly benevolent medical practices like rehabilitation and recovery.

In contrast, several sociologists have generated profoundly critical accounts of Parson's understandings of the patient-doctor dynamic (Bury 1997). Well-established

medical sociologist Elliot Freidson (1970), for example, has contended that the caring profession is able to define and demarcate 'the healthy' from 'the ill' because of the authority society places in its (incomplete) perspectives (Bury 1997: 22). Indeed, despite the limitations of medical knowledge, social actors often perceive its specialist language and use of 'rational' methodologies to codify disease as more legitimate than lay notions of illness (Twaddle 1980; Mishler 1984; Kleinman 1988). In view of that, patients are encouraged to consult with knowledgeable health professionals, rather than proffer their own 'illogical' beliefs about what could be wrong (Freidson 1970; Jewson 1976). This epistemic hierarchy means that the medical profession inevitably comes to wield momentous power and control over those entrusted in its care (Bury 1997: Ch 1, 3). Adding to this strand of thought, Marxist theorists argue that the medical profession acts on behalf of the interests of the capitalist (dominant) classes (Navarro 1976; Waitzkin 1989; Taussig 1980). Such a function is made possible through the creation and use of supposedly apolitical bodies of knowledge in which clinicians place the locus of the problem firmly on to the perceived deficiencies of the person and not wider forms of social inequalities adversely effecting health (*ibid.*). Consequently, critical sociologists maintain that the socially controlling and opaque nature of the medical profession means that individuals are rendered impotent to manage their own healthcare requirements (Illich 1976).

Feminist theorists have also made important contributions to the aforementioned debates, most notably, through their analysis of the clinical encounter as a site of male domination and control (Bury 1997: 91). For example, Graham and Oakley

(1981) have maintained that lay and expert understandings of naturally occurring events such as pregnancy and childbirth compete for power within a particular 'frame of reference', or set of values and beliefs, whereby mothers and (male) doctors variously perceive these experiences but only the perspectives of health professionals come to dominate. The authority invested in medicine to transform the (non-medical) concerns of laities, and in particular, women into medical ones has been termed 'medicalisation' and arguably allows this institution to increase jurisdiction into further facets of social life (Zola 1972; 1975; Illich 1976; Riessman 1983). In addition, it can be contended that making women reliant on the advice and expertise of clinicians reproduces the perceived passivity of female behaviour *per se* within therapeutic spaces (Riessman 1983; Bell 1987; Bury 1997: 91). Therefore, older theories have in more or less certain ways characterised the relationship between lay and expert sources as hierarchical in which medical (male) power constrains and undermines patients' sense of agency.

However, it has been argued that a major limitation associated with the consensus and conflict models is that they both over-determine the influence and power of medicine, without considering patients' abilities to dispute such dominance (Ainsworth-Vaughn 1995; Bury 1997: 92). Addressing this issue, Stimson (1974) and Stimson and Webb (1975) have suggested that patients are not passive recipients of healthcare but rather, attempt to negotiate their role in accordance with prevailing interactional constraints. For example, patients may rehearse what they want to say to the doctor before attending their consultation in order to appear knowledgeable and prepared (*ibid.*). On the other hand, various aspects of the patient-doctor

dynamic such as time keeping, the location of the consultation, and the fact that the clinician acts as a gatekeeper for further services and benefits severely restrict patients from exerting full control over their healthcare needs (*ibid.*). Scholars also contend that a perceived 'competency gap' exists between the authoritative perspectives of doctors and the 'unreliable' ones of patients in which medical knowledge ultimately comes to preside over any final healthcare decision (*ibid.*). While negotiation theorists have avoided describing the relationship between patients and doctors as intrinsically hierarchical, by pointing to the various constraints imposed on laities' active involvement in healthcare, they still conceptualise this negotiated interaction as divergent and antagonistic (Bury 1997: 97).

Medical knowledge and experiential knowledge as equal epistemic sources
One of the problems with several of the aforementioned perspectives has been a failure to acknowledge the rapid changes taking place within Western healthcare systems over the last 50 years (Bury 1997: 96, 98). Most notably, the accelerated rise of consumerism and neoliberalism during the 1960s and beyond led to the transformation of a 'passive patient' into an informed and expert one (Fox and Ward 2006). Specifically, these political agendas cast both patients and doctors as active and autonomous agents, equally responsible for the delivery of high-quality healthcare (Beisecker and Beisecker 1993; Bury 1997: 98; 2010; Charles et al 1997; 1999; McGregor 2001; Mold 2010). Such changes also echo broader shifts within society more generally (Blume 2016). In an era currently underpinned by great swathes of uncertainty, medical knowledge is no longer viewed as an infallible epistemic source (Davis 1960; Kelleher et al 1994; Williams and Calnan 1996a;

1996b; Mechanic 1998: 663; Monaghan 1999; Fox 2002; Griffiths et al 2005; Hinote and Wasserman 2013; Baillergeau and Duyvendak 2016). Giddens, for example, (1991) has noted that late modernity has made it easier and more accessible for individuals to consider the risks and limitations associated with abstract bodies of knowledge. In fact, reflexive agents are often encouraged to use their own experiences and re-appropriate health-related information from various outlets such as the media in order to make informed decisions about treatment (Giddens 1991; Williams and Calnan 1996a; 1996b; Monaghan 1999; Sulik and Eich-Krohm 2008). While several decision-making paradigms have emerged out of this modified socio-political landscape (e.g. the patient-led decision-making model), consumer rights advocates tend to favour the shared decision-making model as the most appropriate for effectively empowering patients to assess the usefulness of various therapeutic options and take control of their own healthcare needs (Quill 1983; Charles et al 1997: 681, 683; Mead and Bower 2000). That is, such an approach refers to the way patients and doctors should both be sufficiently informed to arrive at mutually agreed decisions, principally through the exchange and deliberation of knowledge (Charles et al 1997; Elwyn and Charles 2009: 117). Thus, the main aim of this paradigm is to enable patients to 'participate as equal partners in decisions about the healthcare they receive' (Paterson, B 2001: 574; Mead and Bower 2000).

Closely related to the shared-decision making model is the patient-centered care and communication approach (Stewart and Brown 2001: 105). This paradigm assumes that it is both clinically and morally important for clinicians to construct empathetic, collaborative, and reciprocal relationships with patients, as well as listen attentively

to their illness beliefs and concerns (Coulter 1999; 2002; Elwyn and Gwyn 1998; Mead and Bower 2000; Elwyn and Charles 2001: 134, 135; Stewart and Brown 2001; Greenhalgh 2001; Bissell et al 2004; Ong and Hooper 2006; Latter et al 2007; Berwick 2009; Epstein and Street 2011; Wrede-Sach et al 2013; Elwyn et al 2014; Greenfield et al 2014; Crawford et al 2017; Munro 2017). Drawing on this literature, Elywn et al (2014) have argued that healthcare communication could be improved if doctors engaged in a process of 'deliberate collaboration.' This is where health professionals offer alternative plans of action and integrate patients' goals, priorities, and preferences into the entire decision-making process (*ibid.*). By providing the (physical and psychological) 'space' for patients to express their concerns and experiences means that decisions can not only be made in relation to these aspects (Greenfield et al 2014), but that further, the medical encounter can be directed to issues most important to them (Coulter 2002). In doing so, the patient can be framed 'as a co-producer, whose views need to be actively sought, informed [and] respected' (Elywn et al 2014: 159). Supporting this position, Stewart and Brown (2001) have contended that enacting patient-centered practices can allow patients and doctors to reach 'common ground', whereby both parties can agree on how to tackle complex situations together. As a result, proponents of patient-centered approaches suggest that these apparatuses can create a more supportive and open environment in which the rights and interests of patients are valued and deemed to be important for the generation of compassionate medical provision (e.g. Wrede-Sach et al 2013; Greenfield et al 2014).

Despite a propensity towards the patient-centered care and shared decision-making paradigm, it has been argued that this approach is paradoxical and constrained by a number of political and practical factors, most notably, its connections with the medical profession and wider consumerist frameworks (Opie 1998; Thomas 2001; Whitehead and Williams 2001; Henwood et al 2003; Bissell et al 2004; Wilson et al 2007; Sulik and Eich-Krohm 2008; Ward et al 2009; Greenhalgh et al 2014). Indeed, the decisions that patients make about their medical needs are not done in a vacuum but rather, co-depend on the caring institution, which determines 'the types of choices available' (Sulik and Eich-Krohm 2008: 8; Greenhalgh et al 2014). This unequal practice is accepted, however, because of the perceived authority placed in the specialist and esoteric nature of medicine (Sulik and Eich-Krohm 2008). Although patients may attempt to re-appropriate medical vocabulary in order to appear 'credible' to clinicians (Barry et al 2001; Latter et al 2007), professional epistemic sources remain largely inaccessible to them (Kingfisher and Millard 1998; Paterson, B 2001; Henwood et al 2003; Wilson et al 2007). Thus, having expertise in medicine equips health professionals with the power to eclipse patients' subjective knowledge with their more 'objective' – viz. valued – perspectives (*ibid.*).

Research within the social sciences has noted that clinicians tend to view shared decision-making as a linear or static practice, which is definitively accomplished at discrete moments in time (Paterson, B 2001; Sulik and Eich-Krohm 2008; Epstein and Street 2011; Swinglehurst et al 2012; Greenhalgh et al 2014). It has been argued, however, that patients' treatment choices and experiences of healthcare often fluctuate throughout their disease trajectories and, in doing so, contravene

established understandings around patient involvement in medicine (*ibid.*). Due to laities' lack of formal medical training, physicians may also view lay narratives as uninformed and clinically insignificant (Munro 2017). Indeed, doctors may over-rely on the use of algorithms and decision support systems to obtain clinical evidence rather than ask open-ended questions about lived experience (Swinglehurst et al 2012; Greenhalgh et al 2014). The combination of these factors may lead to the creation of a discordant and uncooperative therapeutic relationship in which laities feel that they are not listened to or able to take an active role within consultations (Mead and Bower 2000; Bissell et al 2004; Ong and Hooper 2006; Latter et al 2007; Sulik and Eich-Krohm 2008).

However, health professionals often believe that their communication styles are sufficiently patient-centered (Opie 1998). Compounding the issue, doctors rarely evaluate the usefulness of biomedical model-derived conceptualisations of disease and illness, primarily because their training has socialised them into viewing these reductive perspectives as highly prestigious (Hadler 1996; Good 1994; Paterson, B 2001; Wilson et al 2007; Jutel 2010). This profound lack of practitioner reflexivity may result in the dissolution of key patient-centered principles like empathy, compassion, and respect, particularly in situations where medicalised frameworks cannot meet the needs of patients or provide them with sufficient resources to make informed decisions (as will be discussed later in the context of MUS) (Kingfisher and Millard 1998; Opie 1998; Paterson, B 2001; Wileman et al 2002; Nettleton 2006; Skuladottir and Halldorsdottir 2008).

In terms of links with consumerism, proponents of the mutualistic care model have applied such concepts as 'patient choice' and 'patient autonomy' to promote empowerment within the therapeutic encounter (and beyond). Indeed, by drawing on consumerist terminology, patients are encouraged to appraise and reflect on their own medical decisions as they would any other choice (Bury 2010). Yet, there are some problems with this line of thinking. Firstly, individuals cannot consume or use healthcare in the same way as they do everyday products such as food or clothes (Bury 2010: 174-175). It would be absurd to suggest that a patient could return a healthcare procedure or request that the 'manufacturer' gives them a refund or substitution (*ibid.*). Consumerist discourses are also inconsistently invoked since they hold lay actors accountable for the 'choices' they make about their healthcare, even though such decisions are co-produced in relation to a plethora of external social and material contingencies (e.g. poverty, low health literacy) (Bissell et al 2004; Boardman 2010; Hinder and Greenhalgh 2012). Secondly, the rhetoric of patient choice assumes that laities can or want to take responsibility for their own healthcare needs but much research has indicated the limitations of these suppositions (Lupton 1997a; Leydon et al 2000; Henwood et al 2003; Ziebland et al 2006; Ziebland and Herxheimer 2008; Sulik and Eich-Krohm 2008). For example, in cases of medical emergencies, doctors may have to make healthcare decisions quickly, usually without exploring patients' ideas about treatment beforehand (Lupton 1997a; Ziebland et al 2006; Ziebland and Herxheimer 2008: 438). Individuals may also prefer to relinquish power back to the doctor because their medical condition leaves them feeling too unwell and vulnerable to make informed decisions (Lupton 1997a; Ziebland et al 2006; Ziebland and Herxheimer 2008: 438).

Similarly, they may decline taking a proactive or shared role in consultations due to their faith in medical authority and/or desire to avoid acquiring potentially distressing health-related information (Leydon et al 2000). Thus, since possessing '"rights" carry "responsibilities"', patients may feel pressured into making decisions that they would much rather delegate to professional practitioners (Henwood et al 2003: 604; Sulik and Eich-Krohm 2008; Seear 2009).

On a structural level, dominant corporate interests perform a significant impact on the development of healthcare resources (Abraham 1995; 2008). As pharmaceutical companies, for example, are motivated predominately by the pursuit of profit, this industry has been known to invent diseases (Moynihan et al 2002), as well as refuse to treat pre-existing ones on the basis of their perceived financial cost (Abraham 2010; Conrad 2013). This pattern of activity demonstrates the degree to which corporations have the power to expand and retract pharmaceutical-directed medicalisation in certain areas of social life (Conrad and Schneider 1980; 1992; Clarke et al 2003; Conrad 2005; 2013; Abraham 2010; Clarke and Shim 2011; Medina and McCranie 2011; Padamsee 2011; Williams et al 2017). Thus, it can be argued that the notion of the informed patient is nothing more than a buzzword for money-making firms to create particular expectations about a given product based on its potential profitability (Rose 2007; Sulik and Eich-Krohm 2008: 8). Finally, consumerist healthcare has intensified the volume of bureaucracy surrounding resource management and spending (Camfield 2002; Bury 2010: 175). In fact, an emphasis on health self-management programmes and interventions[33] has equipped

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[33] These aim to educate and empower patients about how to make informed decisions and take responsibility for their illness both within and outside of the consultation (e.g. Funnell et al 1991).

policy-makers and clinicians with the power to employ 'standardized and carefully costed treatment modalities' that control the overall production and consumption of healthcare (Bury 2010: 175). In this way, state-sponsored organisations, profitable health companies, and medical systems frame contemporary/consumerist styles of support (Sulik and Eich-Krohm 2008; Wilson et al 2007; Bury 2010). Ironically, this bolsters the power and legitimacy of these institutions and limits the amount of agency that patients have over the management of their condition (*ibid.*).

Aside from the paradoxical nature of consumerist healthcare (Opie 1998; Paterson, B 2001; Wilson et al 2007; Bury 2010), its application has also been constrained by the paucity of a concise and coherent explanation (Robinson et al 2008; Hawkes 2015). Though the main aim of the patient-centered care model is to attend to lived experience (Paterson, B 2001; Stewart and Brown 2001; Robinson et al 2008), this modality's close affiliations with private enterprise and bureaucratic agencies produces conceptual ambiguity, which in turn makes it difficult to consistently implement in practice (Robinson et al 2008; Sulik and Eich-Krohm 2008; Bury 2010). However, in an attempt to respond to the critical reception surrounding contemporary healthcare paradigms, Stewart and Brown (2001: 97) have renounced the language of consumerism and maintained that these holistically 'capture the illness experience of patients and the suffering they endure.' The authors have, thus, tried to highlight the compassionate, rather than corporate, side of equalitarian styles of healthcare (*ibid.*). Similarly, Coulter (1999) has argued that while consumerist policies may sometimes overlook the importance of reciprocity, upholding the principles of patient-centered care ensure medical services follow ethical guidelines.

Nevertheless, for Bury (2010: 175-176), the apparent contradictions within consumerist healthcare are politically significant since they help to sustain corporate agendas surrounding cost management by promulgating the view that 'something positive [and democratic] is being put in [the] place' of hierarchical and anachronistic medical systems (Bury 2010: 175). In addition, as patient-centered care and shared decision-making models originated from the 1960s' and 70s' consumer backlash against paternalism and medico-centric approaches, it is hardly surprising that these paradigms have been informed by this particular socio-political milieu (Mead and Bower 2000: 1090; Robinson et al 2008: 601; Dahlberg et al 2009). Consequently, it may be difficult to separate consumerist sensibilities from the more favourable rhetoric of patient-centered care and shared decision-making (Dahlberg et al 2009).

Related to the critique of mutualistic healthcare provision, several sociological writers have also adopted the work of post-structuralist thinker Michel Foucault (1973) in order to demonstrate the ways in which this paradigm obfuscates and reinforces medical power (Armstrong 1983; 1995; Arney and Bergen 1983; Silverman 1987; Lupton 1997b; Wilson et al 2007). According to Foucault (1973), the authority of medicine is reproduced and enacted through a coercive technology of power known as the medical gaze. In particular, the growth and application of anatomical science and the experimental method (e.g. observations, dissections) during the eighteenth century and beyond enabled the medical gaze to infiltrate the inner workings of the body to visualise its contents and identify the existence of organic/disease-causing pathologies (Rhodes et al 1999: 1192). However, throughout

the middle part of the twentieth century, the power of the medical gaze extended

from the anatomical body 'to every tiny nuance on the social horizon' (Arney and

Bergen 1983: 20). In doing so, it both encapsulated the complexity of patient care

(Armstrong 1983), as well as rendered 'the "whole" person an object of medical

attention' (Arney and Bergen 1983: 18). In fact, the aim of contemporary medicine is

to remain humane and liberating, while simultaneously encroaching into various

aspects of life, primarily by joining care with cure and compassion with assessment

(Arney and Bergen 1983). For example, Gardner (2014; 2016; 2017a; 2017b) found

that clinicians used a 'broad' medical gaze in order to examine not only the biologic

features of patients' dystonia but also the extent to which this condition performed a

detrimental impact on their physical and emotional wellbeing. Through the

enactment of patient-centered care principles, health professionals (e.g. neurologists,

physiotherapists, psychologists, speech and occupational therapists) obtained a

comprehensive understanding of each individual's unique goals and priorities (*ibid.*).

In view of that, Foucauldian theorists maintain that patients may find it difficult to

dismantle the pervasive nature of medicine because it 'exercises a positive [and

elliptical] power of influence' over their day-to-day lives (Noorani 2013: 57-58;

Armstrong 1983; 1995; Arney and Bergen 1983; Lupton 1997b; Wilson et al 2007;

Gardner 2014; 2016).

It has been argued that the proliferation of neoliberal and consumerist paradigms

within Western healthcare systems has widened the medical gaze beyond the clinical

domain by invoking new moralistic qualities about illness management (McGregor

2001; Galvin 2002; Aujoulat et al 2008; Seear 2009; Ayo 2012; Murdoch et al 2013;

Broom et al 2015). Since the dynamic of neoliberalism focuses on the perceived virtues of individual responsibility, self-surveillance, and corporeal discipline, it encourages citizens to monitor their own emotions and bodily behaviours through the consumption of health-related technologies and practices (McGregor 2001; Rose 2001; Galvin 2002; Ayo 2012). Along these lines, individuals come to view their lives as personal projects, which they must work on and manipulate for the benefit of their own wellbeing (Giddens 1991). Furthermore, the authority of these discursive contexts is bolstered through government and media agencies, which draw on expert medical knowledge to disseminate the belief that adopting a 'healthy' lifestyle is empowering (Finerman and Bennett 1995). However, the re-appropriation of the medical gaze within everyday spaces inadvertently reinforces discriminatory (disablist) attitudes about the lives of disabled people (Mitchell 2001; Reeve 2002; Zitzelsberger 2005; Lightman et al 2009). This is because cultural notions of corporeal desirability and normality inform the application of the gaze and as such, make those living with socially visible impairments particularly vulnerable to its regulatory power (Hughes 1999; Reeve 2002; Shakespeare et al 2010). For example, though some individuals with perceptible impairments may choose not to identify with the disabled label due to its negative connotations, the pervasive nature of the gaze may compel them to confront their carnal differentness, with adverse implications for wellbeing (Mitchell 2001; Watson 2002; Shakespeare 2006; 2014). While they may endeavour to manage the visible elements of their symptoms to reduce stigmatisation (Goffman 1963), this desire is closely incited through particular moralistic frameworks related to aestheticism and shame (Broom et al 2015). Indeed, the promulgation of healthy lifestyle messages and body modification

procedures has meant that disabled people no longer have a 'valid excuse' to look 'abnormal' or speak (at length) about their intractable forms of suffering (Higgs 2003: 186; Werner et al 2004). Instead, they must try to do all they can to erase the noticeable effects of their impairment in order to adhere to acceptable notions of 'responsible citizenship' (Rose 2001; Murdoch et al 2013; Broom et al 2015). As a result, individuals who cannot meet the prescribed (aesthetic) requirements of neoliberalism are chided for their perceived lack of personal (bodily) control (Ayo 2012; MacGregor and Wathen 2014).

Another illustration of the medical gaze that I would like to examine relates to hidden impairments. Much research has shown that individuals living with chronic pain, for example, feel that their 'private' experiences of suffering are not taken seriously or believed by health professionals and/or members of the public (Scarry 1985; Borkan et al 1995; Bendelow 1996; Rhodes et al 1999; Åsbring and Närvänen 2002; Glenton 2003; Lillrank 2003; Werner and Malterud 2003; Werner et al 2003; 2004; Jackson 2005; 2011; Clarke 2007; Skuladottir and Halldorsdottir 2008; Broom et al 2015). More specifically, they are often told that their problems are illusory or a result of poor self-management (*ibid.*). Such an occurrence happens because of the ways in which the medical gaze attributes values to particular body types (Hughes 1999). Indeed, while those living with socially imperceptible impairments may appear more carnally 'desirable' – viz. healthy – than individuals affected by visible medical conditions, their 'normal' outwardly presentation may make it difficult for them to describe aspects of their lived experience and/or access the kinds of help they require (Goffman 1963; Glassner 1992; Little et al 1998; Mitchell 2001; Reeve

2002; Stone 2005; Zitzelsberger 2005; Lightman et al 2009; Chaudoir et al 2013: 79-80; Broom et al 2015). The problems associated with biomedical/dualistic notions of disease and health also relate to the fact that individuals with imperceptible (as well as perceptible) illnesses may experience a divergent range of physical and/or emotional problems (Lupton 1997a; 2012; Glenton 2003; Henwood et al 2003; Fisher 2007; Lightman et al 2009; Broom et al 2015). These difficulties may palpably limit patients from (fully) adhering to the accepted mandates of neoliberalism and consumerism (*ibid.*). In spite of the severity of their symptoms, however, others may judge the 'normal' embodiments of those with invisible medical conditions as a sign that they can implement a 'will to health' (Rose 2001) but choose not to out of 'laziness' (Werner et al 2004). Consequently, as individuals are encouraged to pursue healthy lifestyles (MacGregor and Wathen 2014: 9), not being able to meet normative standards is viewed as an example of 'failed' citizenship (Broom et al 2015: 723). To circumvent stigmatisation, those with (im)perceptible medical problems may decide to adopt a resilient or stoical attitude in which they repress their real experiential difficulties and 'just get on' with 'privately' managing their problems as best they can (Charmaz 1994; Williams, G 1993; Evangelista et al 2001; King et al 2002; Boardman et al 2011; Broom et al 2015: 723; Griffiths et al 2015). In doing so, they may be able to exercise the duties and demands of healthism but usually at the expense of their own wellbeing, whereby engaging in consumer-led practices may contribute to an overwhelming sense of isolation and entrapment (Broom et al 2015).

Thus far, I have demonstrated the ways in which proponents of neoliberalism and consumerism describe the perspectives of health professionals and patients as different but equal in status (Edgar 2005; Pols 2014: 78). This symmetrical conceptualisation of the relationship between lay and expert knowledge opposes earlier work, which posited such epistemes in contention with each other, competing for power and existing entirely separately (e.g. Freidson 1970). While supporters of consumerist healthcare have maintained that medical systems can perform more democratically if patients are educated about the nature of their condition (e.g. Funnell et al 1991), I have examined some of the limitations associated with these ideas. For example, 'holistic' modalities such as patient-centered care and shared decision-making are not only vaguely defined but also shaped by the economic and political tenants of neoliberal, consumer capitalism, which prioritises resource efficiency above the subjective experience of illness (Paterson, B 2001; Sulik and Eich-Krohm 2008; Ward et al 2009; Robinson et al 2008; Bury 2010; Hawkes 2015). Still, the enveloping nature of the neoliberal turn and its focus on patient autonomy and patient expertise has inspired much debate within the social sciences surrounding the extent to which lay actors' everyday stocks of knowledge can pose a substantial threat to the status of medicine (Noorani 2013; Blume 2016: 2-3). Most notably, these political developments have led sociologists to describe individuals' illness subjectivities and healthcare decisions in relation to the concept of 'experiential knowledge' (Blume 2016). With this in mind, the next section examines the way people draw on their intricate biographies and sense of embodiments in order to attribute meaning and understanding to abstract medical systems.

Defining experiential knowledge

Experiential knowledge as a privileged epistemic source

Over the last four decades, the growing literature on experiential knowledge has illuminated the way it informs individuals' treatment decisions in various health-related contexts (Blume 2016 e.g. patient collectivities in Borkman 1976; 1990; Rabeharisoa 2003; Bülow 2004; Caron-Flinterman et al 2005; Whelan 2007; Akrich 2010; Locock and Brown 2010; Barker and Galardi 2011; Entwistle et al 2011; Mazanderani et al 2012; Edwards et al 2014; Rabeharisoa et al 2014; Britten and Maguire 2016; Foster 2017; pregnancy and dementia in Abel and Browner 1998; hereditary cancer in d'Agincourt-Canning 2003; 2005; childhood disability in Fisher 2007; pre-natal testing in Kay and Kingston 2002; Etchegary 2008; Potter et al 2008; Boardman 2010; 2014a; 2014b; 2017; Markens et al 1999; 2010; France et al 2011a; 2011b; Boardman et al 2017; Rubel et al 2017; mental health in Beresford 2002; 2005; 2013; Wittink et al 2008; Noorani 2013; Baillergeau and Duyvendak 2016; Voronka 2016; Faulkner 2017; contraception use in Lowe 2005; illicit substance use in Casey and McGregor 2012; lung disease in Pols 2014; health valuation research in Cubi-Molla et al 2018; abortion regret in Doan et al 2018). In particular, Borkman (1976) first introduced this term as a novel analytical concept to refer to the concrete and commonsensical forms of knowledge that are derived from reflecting on, and obtaining awareness of, personal involvement in a given phenomenon. According to this view, holistic experiential epistemes not only challenge the reductive and inaccessible knowledge of health professionals (Borkman 1976; Fisher 2007) but are also 'a primary source of truth in' patient support groups (Borkman 1976: 446). Similarly, Whelan's (2007) exploratory study of women with endometriosis found

that they formed 'epistemological communities' by sharing and transforming their raw experiences into a valuable resource. These collectivities emanated directly from a united identity based on a shared diagnosis and set of common understandings that helped the women to privilege and affirm their own knowledgeability, as well as confront the limitations of professional expertise (*ibid.*). This phenomenon also relates to Borkman's (1990) notion of 'experiential authority' in which knowledge acquired from lived experience is considered real, legitimate, and authentic. More recently, Noorani (2013) and Faulkner (2017) have re-appropriated this concept to emphasise the collective power of experiential knowledge among mental health service users. Indeed, through the 'connective logic' of this epistemology (Barker and Galardi 2011), survivors are better placed to develop credible strategies to manage moments of distress and contest biomedical representations in novel and creative ways (Noorani 2013). As such, these authors have drawn attention to the pragmatic uses of experiential knowledge (Borkman 1976; Bülow 2004; Whelan 2007; Ziebland and Herxheimer 2008; Barker and Galardi 2011; Noorani 2013; Faulkner 2017); most notably, they have observed the ways in which it is converted into a specific set of coping techniques, which are subsequently brought together at support group sites for the purposes of assessing, challenging and ultimately, improving dissatisfactory medicalised discourses and practices (*ibid.*).

Related to the experiential knowledge concept is lay knowledge and lay expertise. These terms have been extensively researched within medical sociology and denote the ways in which individuals acquire knowledge through the meanings that they attribute to their illness narratives (Prior 2003: 53). Like the concept experiential

knowledge, lay knowledge refers to the subjective and multifaceted qualities of lived experience, which in turn exposes the fallible and restricted nature of professional epistemic sources (Williams and Popay 1994: 120, 123; Popay and Williams 1996; Kerr et al 1998). At the centre of accepting experience rests the belief that lay knowledge can provide plausible understandings 'of the causes of disease in relation to the experience of its impact' (Williams and Popay 1994: 122). For example, this research has examined the valuable and relevant contributions that lay and 'insider' knowledge can make to the construction of scientific perspectives in the context of contested illnesses (e.g. Repetitive Strain Injury in Arksey 1994; fibromyalgia syndrome in Barker 2002). In addition, other studies have noted the way patient support groups often use lay knowledge for cathartic purposes. Since living with an illness can be biographically disruptive and diminish one's sense of self (Bury 1982; Charmaz 1983), sharing narratives and reflexive accounts based on a common set of values or experiences (usually a diagnosis) (Rapp 1999; Rapp et al 2001; Barker 2002; 2008; Whelan 2007) can perform a restorative role in understanding and overcoming adversity (Williams, G 1984; Bülow 2004; Frank 2013). Such collectivities can also be used to challenge inequitable forms of healthcare provision and/or achieve recognition of medically uncertified problems (e.g. Brown 1995; Brown and Zavestoski 2004; Brown et al 2004; Zavestoski et al 2004; Faulkner 2017). Consequently, researchers maintain that the fluid dimensions of lay knowledge provide an alternative and contrasting view of illness, which may also play into the wider deprofessionalisation agenda arguably taking place within contemporary, Western societies (Kelleher 1994; Kelleher et al 1994; Williams and

Popay 1994; Popay and Williams 1996; Williams and Calnan 1996a; 1996b; Radin 2006; Boardman 2017).

In spite of its many applications, however, writers such as Collins and Evans (2002: 238) have argued that the lay expert concept is a contradiction in terms (i.e. how can it be possible for somebody to be a non-expert expert?), which undermines the special nature of expertise (*ibid.*). As an alternative to the oxymoron, the authors have used the terms 'experience-based expertise' and 'interactional expert' (*ibid.*). These concepts specifically define patient expertise in terms of personal knowledge that is derived from ordinary experience not formally recognised by educational degrees or certificates (Collins and Evans 2002; Prior 2003). In support of this view, Rabeharisoa (2003) has referred to those with rare diseases as 'experiential experts' to denote the way they share their experiences of everyday life with similarly affected people and, in doing so, become more knowledgeable about their condition. Further, 'to avoid any suggestion of inferiority' associated with the notion of lay knowledge, Caron-Flinterman et al (2005: 2576) have applied the expression experiential knowledge. Indeed, it is important for health researchers and policy makers to use terms that capture the centrality of experience, including the way patients may accept or challenge medical treatments through reference to their own personal stocks of knowledge (Caron-Flinterman et al 2005; Wittink et al 2008).

While sociologists have debated *how* the emotional and epistemic contributions of social actors should be referenced (Britten and Maguire 2016: 78), the aforementioned research has largely described lay and experiential knowledge as a

model for action (e.g. Borkman 1976; Kelleher 1994). However, other researchers have moved away from these resource-oriented definitions in order to emphasise the subjective and unconscious qualities of experiential knowledge, including the different forms it may take in various scenarios (Abel and Browner 1998). For example, in an investigation of women's experiences of pregnancy, on the one hand, and looking after family members with dementia, on the other, Abel and Browner (*ibid.*) have distinguished between two types of experiential knowledge: embodied knowledge and empathetic knowledge. Whereas the former refers to experience that is derived directly from carnal sensations, the latter – empathetic experiential knowledge – is acquired through proxy experience of the visceral realities of other people (*ibid.*). In this way, the authors have described experiential knowledge as a complex process, which is formed from individuals' subjectivities, and that further, can be used to resist inappropriate types of professional expertise at different times and contexts (Abel and Browner 1998).

Drawing on Abel and Browner's (1998) conceptual typology, d'Agincourt-Canning (2003) has examined the ways in which individuals with inheritable ovarian/breast cancer and their families use their experiences in order to decipher genetic counselling and testing. She has described embodied knowledge as direct knowledge that is derived from the actual experience of cancer and empathetic knowledge as subjective knowledge that is acquired from one's close emotional connections with somebody with the disease (d'Agincourt-Canning 2003). Though the author has differentiated between these concepts in order to highlight the interplay between them, d'Agincourt-Canning (*ibid.*) found that embodied knowledge and empathetic

knowledge were equally valuable in individuals' accounts of healthcare decision-making. For example, a person's ability to live with cancer may be influenced by the experiences of previously affected family members (*ibid.*). In addition, relatives' interactions with those managing the condition may cause them to re-evaluate their own bodies and selves (*ibid.*). d'Agincourt-Canning (*ibid.*) has also argued that four different types of empathetic knowledge exist depending on one's 'closeness' or 'distance' from a particular phenomenon. Whereas 'tangible knowledge' refers to subjective information that is obtained from close ties with somebody living with cancer, 'recent knowledge' denotes personal knowledge of 'cancer as something new to the family' (d'Agincourt-Canning 2003: 124). 'Distant knowledge' is derived through stories about unknown relatives and finally, 'accidental knowledge' of hereditary cancer is obtained from chance discussions with other family members (d'Agincourt-Canning 2003: 124-125). The proximities associated with these various forms of experiential knowledge suggest that individuals may use it in order to evaluate (their risk of getting) cancer, depending on the degree to which they perceive this episteme to be credible (d'Agincourt-Canning 2003). Similarly, in the context of female carriers' experiences of X-linked diseases, Kay and Kingston (2002) found that obtaining knowledge about the condition through a first-degree relative, rather than a more distant family member, intensified feelings of apprehension surrounding reproductive and genetic decision-making. In support of these perspectives, Etchegary et al (2008) and Potter et al (2008) have noted the ways in which women often invoke embodied and/or empathetic notions of experience to make 'informed decisions' about prenatal screening. Specifically, Etchegary et al (2008) have set out two types of empathetic knowledge, 'vivid' and

'vague', to examine the process through which women evaluate their choices around testing. Vivid empathetic knowledge refers to personal knowledge of taking care of somebody with a medical condition, while vague empathetic knowledge signifies distant knowledge that is derived from hearsay or media reports (*ibid.*). Overall, these studies raise awareness of the important role that contextual factors perform in shaping families' perceptions of a given medical decision or test (Kay and Kingston 2002; d'Agincourt-Canning 2003; 2005; Etchegary et al 2008; Potter et al 2008).

In terms of more recent work focusing on the value of experiential knowledge, Mazanderani et al (2012) and Rabeharisoa et al (2014) have documented the mechanisms through which this episteme is converted into a credible resource that can be distributed and applied among members of a support group. Most notably, Mazanderani et al (2012: 547) have suggested that the individual obtaining the experience-derived 'information must identify with the person providing it.' Even in situations where members feel unable to express a sense of belonging and experience an 'identity tension', they have to learn to negotiate this conflict 'in order […] to be able to engage and benefit from experiential information sharing' (Mazanderani et al 2012: 549). In particular, individuals may carefully select an appropriate medium through which to share their embodied experiences with other people (Mazanderani et al 2012). For example, since acquiring information about others' personal experiences through virtual mediums (i.e. a vague empathetic experiential knowledge source (Etchegary et al 2008)) may allay any fears about having to see somebody with a more severe type of impairment, individuals may come to view the support and health-related advice that they receive online positively (Mazanderani et

al 2012). In doing so, they may choose to foster a shared (empathetic) embodied identity via these specific mediums (Locock and Brown 2010; Mazanderani et al 2012).

Experiential knowledge as a limited or uncertain epistemic source

Conceptualising lay and experiential knowledge as privileged standpoints through which people can appraise and resist medicalised frameworks (e.g. Whelan 2007), arguably romanticises the value of these resources (Abel and Browner 1998; Collins and Evans 2002; Prior 2003; Pols 2014: 77). In fact, the way experience comes to be viewed as authentic often depends on various external contingencies (Blume 2016). Firstly, its authority may be shaped by the social status of the communicator at support group sites since these collectivities are often populated by white, middle class women (Rapp 1999; Rapp et al 2001; Stockdale and Terry 2002; Blume 2016: 8), who are more likely to assume professional identities and accept specialised forms of support (Rapp et al 2001). Borkman (1976) has recognised that while every person possesses experiences, they may not necessarily have the same opportunities or capabilities to mobilise them. Hence, the author has used the term 'experiential expertise' in order to refer to those individuals who have enough skills to describe and share their stories with others (*ibid.*).

Secondly, Boardman (2014a: 139) found that families' experiential ideas about illness generated 'contrasting ways of knowing' Spinal Muscular Atrophy (SMA) based on the 'proximity to the experience of the condition.' Some individuals who questioned the validity of relatives' experiential knowledge or felt unsure about their

own viewed this episteme as an unhelpful and restricted resource, which contributed to, rather than alleviated, unresolved dilemmas surrounding the emotionally charged issue of reproductive decision-making (Boardman 2010; 2014a). Powerful medical, commercial, and social interests may further determine 'whose experiences' are privileged and 'achieve the status of "experiential knowledge"' (Blume 2016: 11; Casey and McGregor 2012). For example, Hogle (2002) found that in spite of activists mobilising their experiential expertise to resist the pharmaceutical company's aggressive marketing of the breast cancer drug tamoxifen, patients thought that their agendas were patronising and fanatical. Instead, by activating the informed patient discourse in confluence with their own sense of embodiments, the women disregarded the activists' knowledge and used industry-provided information to justify their decisions to take the treatment (*ibid.*). In addition, research has shown that male and female activists opposed to abortion disregard alternative perspectives by viewing their own embodied and/or empathetic anecdotes as proffering the 'truth' about the alleged dangers of this procedure (Doan et al 2018). Whereas researchers who have privileged experiential knowledge assume 'that there is an authentic voice to hear once […] the obstacles to hearing it' are removed (Pols 2014: 77), scholars such as Boardman (2010; 2014a; 2017) and Blume (2016) have drawn attention to the way this epistemic source is variously distilled, diluted, and constrained within different contexts (e.g. support groups, families). In doing so, they have challenged the view that it holds universal legitimacy and can automatically be used to contest medical knowledge (*ibid*).

A further limitation of experiential knowledge relates to the way it is often subject to revisions and modifications (Abel and Browner 1998), most of which can leave individuals feeling unsure about their future prognosis (Boardman 2010; 2014a; 2014b). Pain and corporeal deterioration, for example, may prevent social actors from participating in support group meetings (Ussher et al 2008) or possessing sufficient embodied resources to perform everyday tasks (Reeve et al 2010; Ong et al 2011; Cassidy 2012). Meeting other people with more severe symptoms may also lead to the creation of a negative 'downward social comparison' (Festinger 1954; Wills 1981) in which the less afflicted individual refuses to form a shared experiential identity with the worse off due to concerns about the possible future deterioration of their own condition (Carmack Taylor et al 2007; Locock and Brown 2010; Mazanderani et al 2012; Holbrey and Coulson 2013; Heaton 2015). Since the severity of a given illness may change over the course of a person's lifespan (Lindgren 2004; Shakespeare 2006; 2014), individuals living with a particular health problem along with their families may need to re-evaluate, albeit never fully resolve, new embodied dilemmas and concerns (Boardman 2010; 2014a; 2014b). In this sense, the fluidity of experiential knowledge can introduce an overwhelming sense of fear, which renders its potentially assistive qualities unstable and obsolete from time-to-time (*ibid.*).

Theorists contend that distinguishing between embodied knowledge and empathetic knowledge is a misnomer, as it struggles to account for the complexities located within the realm of the experiential (Boardman 2010; Mazanderani et al 2012). It also unwittingly sustains a false dichotomy between these two interpenetrating terms

(*ibid*). With this in mind, Boardman (2017) and Faulkner (2017) have posited a critique of the experiential knowledge concept, maintaining that it fails to address the nuanced aspects of individuals' subjectivities. Furthermore, to avoid overlooking or misrepresenting the differences among people deemed to be in possession of 'lived experience', Voronka (2016) has maintained that experiential knowledge should not be theorised as an essentialist category nor should it be used to unify these variations. Instead, it has recently been suggested that researchers should apply the term 'experiential knowledges' (Faulkner 2017) to capture the dynamism of everyday experience as it changes over various timeframes and contexts between and within lay people's illness narratives.

Collins and Evans (2002) and Prior (2003) have argued that the privileging of lay knowledge as a challenge to, or replacement for, medical expertise risks overplaying its usefulness. Indeed, as the properties of this epistemic source are intrinsically particularistic and limited, individuals 'can often be plain wrong about the causes, course and management of common forms of disease and illness' (Prior 2003: 45). In contrast, other writers argue that agents' seemingly contradictory or incomplete illness accounts reflect the intricacies of social life (Todres 2004; Werner et al 2004; Nordgren et al 2008; Baillergeau and Duyvendak 2016). Even if patient narratives consist of myths and exaggerations, individuals' intimate knowledge of a given condition can still illuminate the way they make sense of their experiences in relation to pre-existing social contingencies (e.g. unemployment) (Baillergeau and Duyvendak 2016). In turn, this knowledge can help health professionals to obtain a more comprehensive account of the issues contributing to social actors' problems

(*ibid.*). Thus, to move away from the idea that experiential knowledge can be wrong, it has been argued that researchers should refer to this episteme as 'knowing otherwise' (Walklate and Mythen 2011; Baillergeau and Duyvendak 2016). By viewing individuals' subjective knowledge in this way, researchers and professional practitioners may be in a much better position to understand how it can be used as a genuine 'resource for the development of self-resilience in situations of adversity' (Baillergeau and Duyvendak 2016: 5). This is not to suggest that the limitations of lay sources should be ignored given that agents' lack of technical expertise can produce a palpable effect on their perceived ability to cope (Prior 2003: 45). Rather, '"knowing otherwise" entails taking "wrong knowledge" to be neither totally fictional nor wholly embracing experiential knowledge as a resource for action' (Baillergeau and Duyvendak 2016: 5).

Experiential knowledge and medical knowledge as co-developmental epistemic sources

Until now, this section has reviewed previous research examining the extent to which lay and experiential knowledge can challenge the hegemony of medicine. However, such an exploration has often posited a conceptual gulf between the intimate experiences of patients and the esoteric understandings of clinicians (e.g. Arksey 1994). Pols (2014) has argued that one of the problems with distinguishing between medical knowledge and experiential or, what she has termed, patient knowledge (derived from the techniques and strategies used to cope with a particular condition) is that it ignores professional influences entwined within the voices and stories of individuals. Indeed, since the reliance on, and authority invested in, medical

knowledge influences the ways in which lay experts come to know and manage their illness, the boundary between these two epistemologies is blurred and exists as a hybrid of the other (Gwyn 2001; Shaw 2002; Kangas 2002; McClean and Shaw 2005).

Related to this issue, research on the embodied understandings of pregnant women who accept or decline prenatal screening showed that these decisions occur in confluence with medicalised agendas (Markens et al 1999; 2010). Indeed, whereas some women refused to be tested on the basis that they believed their pregnancy was (clinically) 'healthy' and 'safe', others justified its use on account of the fact they feared something was 'wrong' with the developing foetus (*ibid.*). As such, the women mobilised their subjective knowledge to evaluate the experiential relevance of professional discourses and practices, which in turn adjudicated and framed their appraisals of genetic testing in tandem with their own sense of pregnancy (*ibid.*). In view of that, Markens et al (2010) have described the association between experiential and medical knowledge as a *dynamic, complex, and synergistic interrelationship*. Similarly, Boardman's (2010: 310) research on the reproductive decisions of individuals and their families living with, or at risk of, SMA found that experiential and medical epistemes 'existed as parallel sources, crossing, intersecting and weaving together at various points.' Researchers also note that patients mitigate uncertainties around expert practices (e.g. treatment, genetic screening) by combining their personal stocks of knowledge with embodied, familial, spiritual, and/or medical notions of health (Sulik and Eich-Krohm 2008; Armstrong and Murphy 2008; Wittink et al 2008; France et al 2011a; Rubel et al 2017). Rubel et al

(2017) have argued that these multiple and intersecting forms of evidence contribute to individuals' 'cultural expert knowledge.' Furthermore, the entanglement of lay and medical epistemic sources arguably raises questions concerning the role of experience within patient collectivities (Rabeharisoa et al 2014). Most notably, Rabeharisoa et al (*ibid.*) have suggested that support group members do not merely juxtapose their experiential knowledge with more formalised frameworks but rather, produce and mobilise credible health-related evidence by bringing together these different knowledges. Several theorists also contend that the promotion of medicalisation within lay spaces (Barker 2008; Barker and Galardi 2011) has diluted the unique properties of experiential knowledge and subsequently, limited the degree to which it can pose a challenge to professional paradigms (Caron-Flinterman 2005: 2582; Blume 2016). Therefore, Pols (2014: 77) has argued that patient knowledge should be regarded as context-dependent, whereby its properties are made and altered in confluence with the established permeation of biomedical science.

Aside from the ways in which lay knowledge is shaped by medical knowledge, part of professional expertise is also experiential. Indeed, several researchers argue that clinicians learn about their work through both medical training and 'tacit knowledge', or knowledge that is obtained from intuition and unconscious, bodily behaviours assimilated through repetitive action and practice (Carlsson et al 2002; May et al 2004: 152; Kontos and Naglie 2009; Gardner 2014; Hurst and Mickan 2017). In particular, the core tenants of tacit knowledge are acquired twofold within clinical and non-clinical domains through the primordial and socio-political importance of 'embodied selfhood' (Kontos and Naglie 2009). This concept refers to

the culturally-informed 'habits, movements, and other physical cues' that health professionals use to form emotional connections with patients with dementia (Kontos and Naglie 2009: 689). That is, care-work 'emanates from the body's ability to tacitly apprehend and convey meaning' (Kontos and Naglie 2009: 697). In line with this corporeal view of clinical practice, Morse and Mitcham (1997) have argued that nurses come to know illness through 'compathising' with their patients. Whereas empathy describes the shared emotional bond between caregiver and receiver, 'compathy' denotes a mutual somatic state in which both parties experience similar physical or 'compatheic' bodily responses (e.g. feeling nauseous in the presence of somebody vomiting) (*ibid.*). Compathy also performs a vital role in care provision since it can motivate or inhibit clinicians' abilities to look after others (Morse and Mitcham 1997: 653-654). For example, research on the everyday practices of physiotherapists caring for children with dystonia found that their tacit knowledge (experiences, skills, perceptions) together with the application of material objects (e.g. adaptable couches) and professional protocols helped them to decipher patients' momentarily-induced symptoms (Gardner 2014: Ch 5). In doing so, the physiotherapists were able to appraise the children's eligibility for surgery, consider how well they would respond to undergoing such a procedure and most crucially, share this clinical information with other health experts at team meetings (e.g. neurologists) (*ibid.*). As a result, it has been argued that tacit knowledge of caring should be conceptualised as an ensemble of interrelating, rather than separate, epistemic sources (Gardner 2014; Hurst and Mickan 2017).

While the dynamism of the relationship between lay and expert knowledge is an

important part of its constitution, this particular association nevertheless changes in degrees and intensities over the course of a person's trajectory (Boardman 2010; Markens et al 2010; France et al 2011a; Pols 2014). Those who live with a contested form of dystonia (e.g. idiopathic cervical dystonia, psychogenic dystonia) for which a 'real' pathological marker cannot be identified may be one such context (Camfield 2002). Other examples may also include contestation around the role the environment performs in disease (Kroll-Smith and Floyd 1997), the issue of whether mammograms should be used in younger women (Barker and Galardi 2011), and tensions between medical scientists' 'perceptions of the potential benefits of, and their actual practices in relation to, consumer involvement' in health research (Ward et al 2009: 63). In fact, Ward et al (2009) have referred to researchers' negative views of lay engagement as 'epistemological dissonance' to demonstrate the way they perceive their own professional bodies of knowledge as more legitimate and informed than consumers' experiential ones. With regards to people with uncertain medical conditions, May et al (2004) have suggested that lay and expert models of these particular problems are usually incongruent and lead to conflicted patient-doctor relationships. The reason for this tension is because clinicians tend to deploy 'invalid' psychosocial explanations, whereas patients often use organic ones in order to bolster the credibility of their inexplicable embodiments (*ibid.*). In other words, disputation occurs when expert medical knowledge cannot legitimately confirm the reality of patients' troubling symptoms (Hadler 1996; Rhodes et al 1999; Whitehead and Williams 2001; Fox 2002; Nettleton et al 2004; Nettleton 2006). Congruence between these perspectives, however, may variously be restored if doctors are able to locate a biological pathology (high alignment) or recognise the physiological

consequences of the embodied discomfort (e.g. sleep disturbance resulting in depression) (low alignment) (May et al 2004). Developing a cooperative patient-doctor dynamic, thus, depends on the degree to which individuals believe that authoritative medical frameworks can provide accurate explanations of their concerns (Sulik and Eich-Krohm 2008). In this way, patients use their experiential knowledge in various contexts (e.g. support groups, consultations) to sustain normative assumptions about the productivity of expert knowledge, particularly its perceived ability to cure and care (Rhodes et al 1999: 1200; Werner and Malterud 2003; Collins and Pinch 2005; Griffiths et al 2005; Barker 2008; Barker and Galardi 2011; Daker-White et al 2011; Lupton 2012).

The idea that the lived and living experience of illness can only be confirmed through the visualisation of the body characterises much of biomedicine and contemporary clinical practice (Foucault 1973). Since the Enlightenment period, the medical gaze has increasingly come to define and understand individuals' subjectivities (*ibid.*). Indeed, visual mediums and tools such as clinical observations and MRI machines have enabled clinicians to 'create an "inside" body, another world that can be seen, accurately represented […] and, ultimately, manipulated' (Rhodes et al 1999: 1192). These ocularcentric practices have not only allowed the medical profession to verify the presence of disease 'objectively' (Rhodes et al 1999) but have also provided patients with the means through which to integrate these concrete images into their illness narratives (Good 1994). Despite the potential benefits of using diagnostic technologies, clinicians rely on these interventions even when the existence or progression of disease cannot be graphically confirmed (Hadler 1996;

Paterson, B 2001; Jutel 2010). Such knowledge is prioritised due to prevailing ideological frameworks within medicine (and society), which uphold 'the cultural model of the visible body' (Rhodes et al 1999). At the root of this reductive approach rests the belief that the reality of disease can only be aetiologically corroborated through the use of visual mediums (*ibid.*). Non-organic illnesses defined solely on the basis of symptom presentation are, thus, discredited and deemed to be of lower social status than pathologically visible diseases (Nettleton et al 2004; Rosendal et al 2017). As such, these culturally entrenched dualisms have reproduced an illness hierarchy 'between the "medically explained" and "medically unexplained symptoms"', with palpable consequences for the ways in which patients with inexplicable problems experience their healthcare trajectories (Nettleton et al 2004: 48).

Since 'patients are both enmeshed with and estranged from' the hegemonic belief that medicine will 'find the answer' to their problem (Rhodes et al 1999: 1200), the emotional and social implications of not receiving a legitimated – viz. organic – diagnosis and associated prognosis can be immense (e.g. Grace 1998; Åsbring and Närvänen 2002; Glenton 2003; Lillrank 2003; Werner and Malterud 2003; Nettleton et al 2004; Dumit 2006; Clarke 2007; Rosendal et al 2017). In fact, 'the absence of diagnosis denies the patient an explanatory framework, a treatment, access to the sick role and legitimisation of the complaint' (Jutel 2010: 230). Furthermore, without any 'objective' data to indicate an underlying abnormality or disease, doctors may misappropriate psychosomatic explanations ('you're just tired') and, in doing so, undermine the severity of patients' concerns (e.g. Rhodes et al 1999; Lillrank 2003;

Clarke 2007; Holm et al 2014). These outcomes may leave social actors feeling profoundly frustrated with the medical profession (e.g. *ibid.*). Patients may also feel alienated from their own bodies and doubt the 'reality' of their experiences, as well as question the usefulness of their personal stocks of knowledge (Lillrank 2003; Jackson 2005; Nettleton et al 2004; 2005; Nettleton 2006; Daker-White et al 2011; Holm et al 2014). Of course, there may be situations where doctors believe that a person with uncertain symptoms is unwell. A psychiatric diagnosis, for example, may be made on the basis that all other explanations have been excluded, reinstating 'the infallibility of the physician and the omnipresence of medicine' (Jutel 2010: 237). Despite receiving a clinically valid diagnosis, however, patients may refuse to accept having their embodied discomforts located in psychiatry because of the stigma surrounding mental illness (e.g. Sayre 2000; Jutel 2010). Indeed, the widespread belief that this condition is triggered by a lack of personal responsibility and can simply be reversed by adopting a more constructive attitude may prompt individuals to seek a less stigmatising explanation of their presenting complaint (Rhodes et al 1999; Sayre 2000; Camfield 2002; Corrigan 2007; Garand et al 2009; Jutel 2010: 236; Halpin 2011; Fein 2012; Lupton 2012; Rapp 2012). Overall, these issues may mean that patients with rare and/or contested conditions go through a relatively long 'diagnostic odyssey' in which they make repeated efforts to find a health professional who has sufficient knowledge of their problem and can situate it within a socially legitimated framework (Robinson 1988; Cox et al 2003; Budych et al 2012; Pavey et al 2013; Ashtiani et al 2014).

Sociologists examining the cultural relevance of the neurosciences argue that this

highly prestigious and influential branch of medicine has gained considerable

traction within technologically democratic societies (Pickersgill and Van Keulen

2012). In fact, contemporary notions of self and personhood have become closely

defined in relation to cerebral-based classificatory frameworks and practices (Rose

2003; Fein 2012; Gardner 2014). According to Fein (2012), neurological diagnoses

are perceived more positively than psychiatric ones because of the ways in which

they refer to the brain as an organic, fixed entity regulated by physiological, as

opposed to psychological (viz. mutable and illusory), processes. In this way, the

emblematic motifs of neurological medicine (e.g. reductionism, determinism)

reinforce key mind/body dualisms (Pickersgill and Van Keulen 2012). Yet, despite

the restrictive nature of the neurosciences, patients willingly draw on its perceived

authority. In a study examining medical and social representations of dystonia,

Camfield (2002) found that media articles reported the various difficulties people

typically experience with trying to obtain a neurological diagnosis and the

subsequent relief they feel when they do so. In particular, these reports showed that

patients are usually disbelieved by their GP or inappropriately referred for

psychiatric help and as a result, struggle 'to describe what [is] happening to' their

troublesome bodies (Camfield 2002: 38), a phenomenon that Jackson (2005) has

defined as experiencing an uncomfortable 'betwixt and between' existence.

Consequently, the usefulness of different knowledge sources is weighed up in

contexts where patients feel they have little power to exercise control but believe that

neurologic notions of health and disease can appropriately address both the

unintentional and real aspects of their (disputed) problems.

The literature on feminist epistemologies has examined the issue of 'epistemic privilege' and status (Hartstock 1983; 1997; Hekman 1997; Casey and McGregor 2012). According to Waugh (1992), for example, feminism has traditionally pushed against the intellectual ideas of modernism and its focus on 'objectivity' by pointing to the ways in which the production of knowledge is socially situated (Haraway 1988). In particular, standpoint feminists have maintained that exploring the perspectives of marginalised groups such as women is politically important for revealing the inequitable structures contributing to and underlying their oppression (Hartstock 1983; 1997; Hill-Collins 1986; 1997). Consequently, the role of feminist researchers is to use these standpoints in order to dismantle and transform hierarchical power relations (*ibid.*). Issues around equality and justice have also been examined by disability rights scholars who argue that individuals with impairments can mobilise their personal stocks of knowledge to put forward alternative ideas about disablement (Morris 1991; 1992; Crow 1992; 1996). With this in mind, the next section explores the politics of experience and considers how agents can privilege particular epistemologies at various timeframes given its socially constructed character (Haraway 1988).

The political implications of experiential knowledge

Feminism and experience

With the rise of scientific and technological discoveries in the eighteenth and nineteenth centuries, medical definitions of bodily experience have traditionally been understood in relation to reductionist, biological theories. One particular approach that encapsulates much of Western, Enlightenment philosophy is the Cartesian

dualist model, which refers to the body and mind as separate entities (Turner 1992: 32; Williams and Bendelow 1996: 25-26). According to this view, consciousness and cognitive activity are praised as necessary contingencies for the progress of humanity and scientific endeavour, while the body is conceptualised as an irrational, transgressive, and unstable entity that is capable of habouring disease and illness (Williams and Bendelow 1996: 25-26; 2000). Given that a considerable amount of medical work has been influenced by such dualistic thinking (Nettleton et al 2004), feminist scholars have paid attention to the ways in which discourses within medicine negatively conceptualise the female body and its associated functions (e.g. menstruation, lactation) as uncontained and amorphous (Battersby 1993; Williams and Bendelow 1998: Ch 6; 2000; Hallam et al 1999: 11). Indeed, as a result of the perceived unpredictability and 'leakiness' of these biological events, women are reified into the social order as risky and intellectually inferior, deemed to be of lower social worth than men (*ibid.*). On the other hand, medical (masculinist) modes of knowledge construct male carnalities as predictable and sanitised entities in which the self is believed to be neatly contained within the boundaries of the disciplined body (*ibid.*). Thus, through its signification of the body/self as a nucleated and unified container, the Cartesian dualist model represents female (fluid) forms of embodiment as a deviation from, and fundamental threat to, the symbolic order of hygiene and carnal integration and control (Lawton 1998).

To oppose reductive conceptualisations of personhood, feminist researchers argue that an ontological continuum exists between the body/self and society, whereby 'meaning […] resides in the body, and the body resides in the world' (Williams and

Bendelow 1998: 54). This embodied position denotes the interactions between the felt experiences of individuals and the broader social, cultural, and political systems that contextualise their subjectivities (Williams and Bendelow 1998: 8). Feminist scholar Elizabeth Grosz (1994: xii) has fruitfully contributed to these debates, maintaining that somatic experiences closely interrelate with patriarchal oppression (Thomas 2007: 139). For Grosz (1994: xii), the fluidity between body, mind, and society suggests that none of the components are reducible since each part is an inflection of the other (*ibid.*). In support of this view, phenomenologist writer Thomas Csordas (1994) has argued that the interdependent body/self entity forms the material basis of culture and history. For example, as individuals draw on prevailing meanings in order to interpret their corporeal experiences, language becomes a thoroughly embodied tool through which the immediacy of their experiential concerns or 'being-in-the-world' are explained (rather than simply represented) (*ibid.*). In this sense, the embodied elaboration of culture means that individuals can (de)value particular epistemic or linguistic sources based on their perceived (in)significance (*ibid.*). Arguably, this demonstrates the power of the experiential for dismantling and revising previously taken-for-granted epistemological frameworks (Boardman 2010: 49).

Within the feminist epistemology community, and in particular, within postmodern circles, concerns have been raised as to whether scholars should decide on the 'truthfulness' of different knowledge claims (Hekman 1997). These debates have developed from the understanding that knowledge is partial, infinite, and complex, making it difficult to decipher the authenticity of particular sources at any one time (Haraway 1988; Flax 1990; Yeatman 1994; Hekman 1997). In addition, attempts to

determine epistemic reliability may risk (re)producing hegemonic power relations since other versions of 'reality', which differ from or contest these beliefs, may be silenced (Hawkesworth 1989: 554; Yeatman 1994). While postmodern feminists have rightly warned against the problems of privileging one particular strand of knowledge above the other, critics have nevertheless accused such theorising of potentially eliding into relativism (Hawkesworth 1989; Fricker 1994; Mangena 1994; Strickland 1994). This is an important point to consider given that a fragmentary view of knowledge may make it difficult for researchers and policy-makers to tackle and transform 'the realities that circumscribe women's lives' (Hawkesworth 1989: 555). To address this limitation, standpoint feminists have argued that knowledge can be both socially situated *and* real (Hartstock 1983; Hill-Collins 1997). Indeed, they suggest that the multiplicities of interplays between different forms of experiences, structures, and power relations (e.g. patriarchy, racism) mean that 'the standpoints of some groups are most certainly privileged over others' and should be disputed, using experiential information, on the grounds that they push against equality-promoting agendas (Hartstock 1983; Hill-Collins 1997: 380). Related to this issue, Kokushkin (2014: 15-16) has argued that 'standpoint approaches allow the creation of alternative knowledge' by destabilising dominant and powerful epistemes in 'fields dominated by positivist [or institutional] thinking.' As the proliferation of reductive kinds of knowledge like medicine encroach further into social actors' everyday lives (e.g. Barker 2010; Barker and Galardi 2011), the ways in which individuals attempt to mobilise their own intimate stocks of knowledge and challenge such jurisdiction, demonstrates the emancipatory potential of this experiential epistemic source (Boardman 2010; 2014a; Kokushkin 2014).

Disability studies and experience

As well as the feminist critique of professional knowledge in female-related domains like menstruation and pregnancy (e.g. Williams and Bendelow 1998: Ch 6), disability rights activists have also raised concerns about the effects of medicine on the subjective realities of disabled people (Barnes and Mercer 2010: 29). Most notably, they argue that proponents of the medical and personal tragedy models of disability, which are supported by reductive and dominant (expert) agendas, view this phenomenon as an individual defect and aberration from an assumed norm (Oliver 1990; 1996a; 2009; Brisenden 1986; Morris 1991; 1992; Crow 1996: 64; Paterson, K 2001; Boxall and Beresford 2013). In fact, campaigners contend that defining disability as an intrinsically tragic and negative experience has enabled health professionals to classify and treat those with impairments in isolation from the rest of society, further subjecting them 'to control and exclusion' (Oliver and Barnes 2012: 83). Accordingly, the medical model is perceived as a powerful, anachronistic, and oppressive framework, continually interfering and intervening in the lives of disabled people (Thomas 2001; Whitehead and Williams 2001; Oliver and Barnes 2012: 84-85).

As well as disability rights activists' general distrust of medicalised approaches, they also maintain that the widespread promotion of therapeutic interventions and cures naturalises and sustains disabled people's inferiority (Charlton 2006). Supporting this viewpoint, it has been argued that much of the thinking around disability relates to the notion of social competency, whereby the perceived failings of one's body are used as 'aesthetic "evidence"' to discredit their sense of agency and ability to

perform tasks (Paterson, K 2001: 94). Medical discourses and practices, thus, aim to reduce the stigma and shame often thought to be connected with disablement by manipulating individuals' 'deviant' bodies in confluence with mainstream definitions of bodily comportment (Paterson, K 2001: 83). Consequently, the role of the medical profession is not only to define impaired bodies/minds as pathological but also to fix and rehabilitate them 'to as near as normal functioning as possible' (Thomas 1999: 17).

However, grassroots organisations campaigning in the 1960s and beyond transformed outdated medicalised understandings of disability into something much more radical and democratic (Hunt 1966; Finkelstein 1980; Oliver 1990; Morris 1991; 1992; Beresford 2002; 2005; 2013; Boxall and Beresford 2013). Indeed, these innovators helped to generate and/or promote the social model of disability: a politicised framework that distinguishes between anatomically created impairments and culturally constituted disabilities (*ibid.*). According to social model notions, the challenges that disabled people often face are not related to their biological limitations but rather, to wider environmental, attitudinal, and cultural barriers excluding them from participating fully in social life (Oliver 1990). In this way, the notion of disability has political connotations in which disabled people's subjugated positions develop from asymmetrical power relations and widespread forms of discrimination (Charlton 2006). In response, social modellists argue that society should make concerted efforts to create more egalitarian polices, which emphasise inclusivity, celebrate bodily diversity (Corbett 1994; Swain and Cameron 1999), and most crucially, seek to remove any barriers impeding the needs and requirements of

those with health problems (Thomas 2004; Beresford 2002; 2005; 2013; Boxall and Beresford 2013).

Though supporters of the social model of disability have made great progress from campaigning tirelessly for the rights of disabled people, their work has also received a great deal of criticism, most notably, for overlooking the important issue of embodiment (e.g. Morris 1991; 1992; Crow 1992; 1996; Williams, SJ 1999; Shakespeare 2006; 2014; Thomas 2007; 2008; Hughes 2009). Indeed, by differentiating between the 'impaired body' (biological) and the 'disabled body' (social), various social scientists maintain that the social model does not account for the ways in which those with medical conditions experience embodied markers like fatigue and pain (*ibid.*). Having equal access to society is also difficult because there is incompatibility between the embodied needs of people from different impairment groups, and that further, there are some bodily differences that society simply cannot accommodate due to natural geographical barriers (Shakespeare 2006; 2014). As a result, critics have accused proponents of materialist approaches of producing an over-socialised view of disability and one largely dismissive of the corporeal impact of different health problems (Williams, G 1996; 1998; Williams, SJ 1999; Bury 1997; Hughes 2009).

To circumvent the perils and pitfalls of cultural determinism and incorporate the lived and living experience of impairment into the agendas of mainstream society, Morris (1991; 1992) and Crow (1992; 1996) have argued that it is important for disabled people to speak openly about their unique sense of embodiments. Taking

this perspective forward, disability rights campaigner Mike Oliver (1996b) has proposed the creation of a social model of *impairment*. He has suggested that activists and medical sociologists, examining the everyday realities of chronic illness, should engage in a meaningful dialogue about how to locate the lived body within a contextual framework. In response, various writers across the social sciences have fleshed out Oliver's (*ibid.*) call for a more carnally-informed understanding of disablement. For example, disability sociologists Bill Hughes and Kevin Paterson (1997) have argued that disabled people's experiences of wider forms of social oppression are palpably felt in their 'flesh and bones' (Paterson and Hughes 1999: 606). Similarly, Gareth Williams (1996; 1998) has suggested that researchers ought to adopt a materialist phenomenological perspective of disability, whereby lived experience and structure are examined dialectically. Continuing with the theme of the politicisation of experience, disability feminist Carol Thomas (1999; 2007; 2010; 2012) has put forward a social relational model of impairment and disability in order to account for the intersection between 'impairment, impairment effects [biosocial symptoms] and disablism' (Thomas 2007: 137). She has also acknowledged the ways in which oppressive practices can heighten the severity of one's health problem, as well as produce very real psycho-emotional consequences (Thomas 1999; 2007). Thus, for Thomas (2002), it is important that researchers examine the impaired body in confluence with disablist discourses and practices to comprehensively capture the textured experience of disablement.

Within disability studies, much discussion has focused on the ways in which the impairment and disability terms should be defined and incorporated into the

experiential accounts of disabled people (Crow 1996). However, less attention has been given to exploring the theoretical divisions existing between impairment and illness (Boardman 2014b: 4). As a result, the boundaries between these concepts have been poorly conceptualised and applied within both medical sociology and disability studies (Mulvany 2000; de Wolfe 2002; Boardman 2014b: 4). Indeed, whereas sociologists have typically used the aforementioned terms (including disability) interchangeably to denote suffering and bodily discomfort (e.g. biographical disruption – Bury 1982), social modellists have suggested that disability, or the social and political oppression of people with a given impairment, should be prioritised (e.g. Oliver 1990).

To provide some clarity, De Wolfe (2002) has argued that a conceptual distinction ought to be made between the impairment and illness terms. Most notably, she has maintained that though impairments are experienced in a variety of different ways, illnesses always represent intolerable and intractable forms of suffering (De Wolfe 2002: 262). This view of illness also supports the writings of sociologists Elaine Scarry (1985) and Simon Williams (1996), who have spoken about the incontestably real nature of pain and its impact on the disintegration of the body/self-continuum. More recently, Boardman (2010; 2014b) has developed an experiential typology of the many ways in which individuals and their families come to know SMA (e.g. through social exclusion, the premature death of a child, and/or the experience of mobility difficulties). In fact, the findings draw attention to the dynamism of experiential knowledge in the context of one particular health problem, as well as the way certain medical decisions may be made or rejected on the perceived inevitability

of suffering and decline (*ibid.*). Similarly, Shakespeare (2006; 2014) has set out an interactional model of disability in order to examine the ways in which the subjectivities of disabled people and the choices they make about treatment are co-shaped by a combination of intrinsic (e.g. symptoms, personal qualities, and opinions) and/or extrinsic factors (e.g. views of others, dis/enabling structures, and environments). In other words, he has argued that individual and/or social aspects perform a tangible impact on disabled people's functioning capacities, and that further, impairments can be disabling (Shakespeare 2006; 2014; see also: Vehmas and Watson 2014). With respect to this literature, disabled people may decide to locate their embodied discomforts within medicine and place a great amount of hope in the development of a cure because they want to minimise suffering and live without the intolerable effects of their condition, rather than specifically dismantle the political agendas of disability rights campaigners: one is not necessarily contrary to the other (Williams, SJ 1999; Beauchamp-Pryor 2011; Shakespeare 2006; 2014). That is, accepting medical knowledge and seeking an effective treatment may be viewed as emancipatory (*ibid.*). Accordingly, through an acknowledgement of the ways in which the limitations of embodiments may form a central part of the subjective realities of disabled people, policy makers and health professionals may be able to provide such individuals with better access to life-enhancing modes of support and advice (medical and social) (Shakespeare 2006; 2014).

Conclusions

This chapter has set out the conceptual framework for my research through a detailed examination of the relevant bodies of evidence exploring the nature of experiential

and medical knowledge, as well as the possible types of relationships existing between these two epistemic sources. While previous theorising has referred to this interplay as hierarchical, with varying implications for the patient-doctor dynamic (e.g. Parsons 1951), the promulgation of consumerist and patient-centered frameworks and practices occurring within and outside of healthcare settings from the 1960s and beyond prompted a reconsideration of medical power and authority (Bury 1997). Supporters of these equalitarian approaches to care and communication view professional knowledge sources as discrete but, nevertheless, symmetrical and equivalent to experiential ones (Pols 2014: 78-79). Namely, it is assumed that medical knowledge and information ought to be made easily accessible to patients so that they can implement this advice and seek appropriate treatment from health professionals (Fox and Ward 2006; Pols 2014). However, others maintain that some patients may find it burdensome to participate as equal partners in consultations and/or take responsibility for their medical needs (e.g. Sulik and Eich-Krohm 2008: 22). Furthermore, researchers suggest that clinicians have defined accepted definitions of participatory decision-making and health self-management in terms of how far patients and doctors are able to make definitive and 'rational' evaluations about treatment (Paterson, B 2001; Wilson et al 2007; Sulik and Eich-Krohm 2008; Epstein and Street 2011; Hinder and Greenhalgh 2012; Swinglehurst et al 2012; Greenhalgh et al 2014). Arguably, such an understanding not only undermines the principles of patient empowerment but also overlooks the ways in which the dynamism of lived experience affects laities' perceptions of healthcare over time, as well as their abilities to implement previously agreed choices (*ibid.*).

Still, in spite of these problems, the decline of traditional paternalistic styles of healthcare coupled with the rise of lay support groups and growing trends in acceptance of the rights of patients as '"health care consumers"' have led sociologists to consider the constitution, value, and status of experiential knowledge, or knowledge that is grounded in and through the vicissitudes of everyday life (Blume 2016: 2). In particular, several writers have conceptualised this type of knowledge as a privileged source that is fundamentally different from reductive medical notions of disease and the body (e.g. Whelan 2007). For others, the association between these two types of knowledge is synergistic and mutually co-constitutive, whereby patient and expert ideas about illness overlap and weave together across a divergent range of contexts and timeframes (e.g. Markens et al 2010). In examining the different ways in which scholars have imagined a relationship between experiential and medical knowledge, I have drawn attention to the complex and fraught nature of this phenomenon for sociological analysis.

Part of the complexity associated with the lay – expert interplay relates to the ways in which patients may use their knowledge to resist experientially inappropriate medical explanations and treatments at the same time as mobilising more suitable ones (e.g. Rhodes et al 1999). For example, as those living with chronic health problems like dystonia have to make complex decisions about their medical needs, usually in situations where their symptoms cannot be explained through pathological analysis alone, this interaction is typically experienced as a site of profound negotiation (Camfield 2002). To manage any disputes emerging from this, feminist and disability theorists argue that individuals appraise the relevance and accuracy of

medical explanations primarily by drawing on their everyday stocks of knowledge. In doing so, agents may (un)wittingly utilise their experiences to reinforce or supplant the narrowly defined and disembodied parameters of biomedicine.

Despite this growing literature, however, little research on dystonia has made specific reference to the notion of experiential knowledge and the ways in which it relates to professional bodies of evidence. It is important to explore this phenomenon because effective medical options for dystonia are limited but the visceral everyday experience of this complex condition can produce a notable impact on social life (chapter 1). The concept of experiential knowledge has also been poorly defined and understood within academic circles. My own research, thus, explores medical decision-making in adults affected by some form of dystonia by bringing together various social scientific perspectives on the complex interplay between patient and professional notions of illness. In view of that, the next chapter outlines the key theoretical and methodological principles underlying the design and conduct of this study.

Chapter 4

Methodology and methods: investigating lived experience in dystonia

In this chapter, I provide a detailed account of how I explored the embodied experience of dystonia. The first part sets out the research aims and questions before discussing some of the key theoretical assumptions underlying this study. Furthermore, I discuss my choice of study criteria, recruitment techniques, and research methods. The second part explores pertinent ethical and political issues influencing the outcomes of the research. Finally, I consider the impact of my own role throughout the research process and the measures I took to ensure the quality and credibility of the findings.

Research aims

This research project sought to understand:

1) The various ways in which individuals use their experiential knowledge to adjust to dystonia throughout their lives;

2) How people decipher and assess the relevance of a divergent range of medical services, therapies, and treatments.

Research questions

I investigated the following research questions:

1) What are individuals' views and experiences of dystonia?

2) What role do medicalised understandings and practices perform in individuals' experiences of living with and managing dystonia?

3) How do social constructions of (ab)normality and (dis)ability within (quasi)medical establishments and wider society influence individuals' experiences of dystonia?

4) Does a shared patient identity exist among individuals with dystonia? Why(not)?

Whereas question one focuses on individuals' subjective meanings, questions two and three make explicit the connections between one's personal experience with dystonia and the wider socio-cultural milieu within which it is situated. Furthermore, considering that support groups often unite around shared experiences in order to offer support and promulgate illness-specific medicalised information (e.g. Barker 2002), question four was designed to examine whether people with dystonia use their experiential knowledge to (dis)assemble a collective identity and why(not). By developing broad research questions around the lived and living experience of dystonia, I was able to examine how far participants valued their own stocks of knowledge, and that further, used these perspectives to make sense of treatment decisions.

Theoretical background

Given that the main aim of my research was to explore the subjective meaning of dystonia, I decided to implement a qualitative research design to achieve this goal. Qualitative approaches are considered particularly useful for capturing and

documenting the divergent range of viewpoints and sense-making schemas that

agents attribute to their everyday lives (Pope and Mays 2006: 4). Informing any

(qualitative) approach to research are the social scientist's ontological (reality) and

epistemological (knowledge) assumptions (Pope and Mays 2006; Carter and Little

2007). Since I required an intellectual framework that accommodated the dynamism

of lived experience, I decided that the application of an interpretative epistemic

stance, which enables social scientists to harness the concerns and shared belief-

systems of individuals, would be the most appropriate (Schutz 1953; Bryman 1988;

Pope and Mays 2006: 4; Cohen and Crabtree 2008; Brown 2015).

However, critics of the interpretative paradigm have expressed considerable concern

at the way this approach conceptualises reality as nothing more than a product 'of

meaning[s], conventions, morals and discursive practices' (Cromby and Nightingale

1999: 4). Indeed, a strong focus on the ways in which the subjectivities of agents can

only be known via these social processes arguably reduces their embodied actualities

to discourse alone (Cromby and Nightingale 1999). Conversely, my research regards

lived experience as a material foundation for knowledge (Madill et al 2000: 12) in

which the fleshiness of the body produces tangible outcomes and informs agents'

interpretive devices (and vice versa) (e.g. Williams, G 1996; Williams and Bendelow

1998; Thomas 1999; 2007; Williams, SJ 1999). Loyally ascribing to a socially

constructionist/relativist ontology would have, thus, conflicted with these theoretical

suppositions. To mitigate this problem, I required a framework that viewed reality as

both referential and examinable, 'though always partial, limited, and' grounded in

language and culture (Nightingale and Cromby 2002: 710; Willig 1999). For those

reasons, I decided to implement a contextualist approach within an interpretive epistemic stance (Ussher 1999; Madill et al 2000; Huxley et al 2014: 276). Contextualism requires the researcher to acknowledge that the ontology of 'the things of experience' is real 'but the meaning of a particular thing (e.g. this desk, this illness) is' perspectival and mediated by a conjunction of personal, discursive, methodological, and wider socio-political factors (Cassidy 2012: 78; Ussher 1999). As such, this framework rests in-between a realist and relativist ontological stance, whereby agents' meaning-rich accounts illuminate the realm of the experiential but not in any straightforward way (Cassidy 2012: 78-79).

Selecting an approach

The choice of research methods, especially for analysis, is often informed by the social scientist's theoretical ideas and assumptions (Pope and Mays 2006: 2). In the context of my own research, I decided that an inductive thematic approach to analysis would be the most suitable because of my exploratory research aims and eclectic contextualist framework (Braun and Clarke 2006). Indeed, this analytical method is compatible with a 'meditative view' of ontology (Woolgar 1996: 17) because it 'works both to reflect reality and to unpick or unravel the surface of "reality"' (Braun and Clarke 2006: 81). Consequently, I decided to identify the themes at the 'latent (interpretive) level' of meaning, whereby I considered the impact of dominant discourses and ideologies on the way participants were able to construct their experiential accounts (Braun and Clarke 2006: 84).

Aside from its theoretical compatibility, my approach to analysis also enabled me to highlight thematic similarities and variations across different cases (King 2004: 257). Elaborating on the content of the emergent themes in relation to particular circumstances and phenomena (e.g. evaluating the effects of treatment) helped to build a comprehensive understanding of participants' accounts of reality. It also allowed me to weave together significant themes in order to pay attention to salient data patterns and connections (Braun and Clarke 2006). Therefore, I was able to produce a richly contextualised interpretation of experiential knowledge in dystonia rather than focus intensely on the individual biographies of each participant, which may have obscured the identification of deviant cases or broader thematic relationships (*ibid.*).

Study inclusion and exclusion criteria

Individuals had to meet the following criteria to be included in the study:

- *Adults (i.e. 18 years+) living with dystonia.*

- *The person has been diagnosed with dystonia for at least two years or more.* It was anticipated that individuals who had recently been diagnosed with dystonia would still be adjusting to it (Bury 1982). Thus, they may not have had much experience with treatment or enough time to make sense of their impairment.

- *They are able to travel to the support groups (support group attendees) or currently reside within the city boundary of National Health Service (NHS) Hospital 1 (patients).* Since I am unable to drive and experience the effects of

dystonia in my arms and legs, it was important that fieldwork sites were relatively easy for me to travel to.

- *The person must be able to engage in an interview and have capacity of concurrent consent.* This was to minimise the risk of coercion and ensure that consent was both informed and given freely (although I discuss some of the limits of informed consent in the 'ethical issues' section).

In addition to the primary research work, I attained a pre-existing qualitative interview dataset from members of The Warwick Dystonia Self-Management Study (WADSS) team at Warwick Clinical Trials Unit. WADSS explored the acceptability of delivering a residential-based treatment intervention, using behavioural principles and mindfulness practice, to assist individuals coping with dystonia (see 'recruitment and data collection procedures' section) (Sandhu et al 2016).

The study criteria for WADSS were:

- *English-speaking adults aged 18 years old or over with capacity of concurrent consent.*

- *The person has been diagnosed with isolated dystonia for at least one year or more.*

- *Participants are self-caring and able to travel to a 3-day residential course in January 2015.* The intervention sought to encourage effective self-management and the formation of social support networks. Thus, this required participants to stay over for the duration of the course.

- *Participants must be able and willing to take part in the intervention activities.*

- *They must not have a diagnosis of a serious mental illness or live with an acquired dystonia (e.g. that is caused by exposure to psychotropic medicine or psychological trauma).* The intervention aimed to alleviate stress and discomfort brought on by dystonia-specific symptoms rather than the combined effects of another medical problem.

Recruitment and data collection procedures

Multiple qualitative methods and a diversity of recruitment sites were used to gather the data about life with dystonia. These research techniques included: group interviews, semi-structured interviews, and secondary analysis. Fieldwork took place between October 2014 – August 2015 and detailed observational and reflexive notes were kept throughout this period. I also made a series of analytic memos during the transcription and analysis stages in order to supplement the thematic coding (see 'data analysis' section).

I employed a broad purposive sampling strategy to obtain a diversity of opinion about the management of dystonia. This technique is useful for selecting 'information-rich' cases, or individuals who possess in-depth knowledge of the research topic (Patton 1990; Holloway and Wheeler 2010: 138). Phenomenal categories were, thus, pre-determined and chosen on the basis that they would proffer meaningful information on the experience of dystonia (Sandelowski 1995: 180-181). As is common with qualitative research studies, the demographic details of people in

and of themselves are of relative unimportance (Mays and Pope 1995; Sandelowski 1995: 180-181). Rather, the processes, meanings, and experiences underlying individuals' demographic histories are evaluated (*ibid.*).

A multiple approach to sampling is often employed in qualitative research projects investigating sensitive topics and/or unknown phenomena (Lee 1993). This can mitigate low recruitment rates among difficult to reach populations, and reduce the risk of sample bias (Lee 1993; Thompson and Phillips 2007). Given that my research dwelled into the emotive issue of lived experience in a rare condition, I applied various techniques within my broad purposive sampling strategy to maximise recruitment opportunities.

In the subsequent sections, I describe my recruitment strategies and method choices, as well as outline my reasons for using them within my research. I also critically consider how far my choice of methods and approach to data collection has helped to generate a holistic and nuanced account of the dystonia experience.

Group interviews

The group interview is a specific type of interviewing procedure in which several individuals are asked simultaneously to share their opinions about a given subject matter (Frey and Fontana 1991: 175; Liamputtong 2011: 48). Like other qualitative research techniques, group interviews can allow health service-users with a given impairment to discuss excluded or unknown perspectives (Kroll et al 2007: 690). While the group interview method is a variant of the well-established focus group

interview, a notable difference is that priority is usually given to the semantic content of the conversation as opposed to group dynamics and interactions (Frey and Fontana 1991: 175; Liamputtong 2011: 48).

To gain access to local dystonia support groups, I contacted The Dystonia Society about my research and they agreed to assist. I then spoke to several attendees at two of The Society's groups: 'Support Group 1' and 'Support Group 2.' These groups are fairly accessible via public transport and are active providers of information and support for people with dystonia. Both groups are also located in different parts of the United Kingdom, thus increasing sampling diversity. Due to their connections with The Dystonia Society and the medical profession, I conceptualised them as 'quasi-medical.'

Given that a substantial number of members belong to Support Group 1 (approx. 100) and up to 35 people regularly attend their tri-annual meetings, I decided to conduct three separate group interviews over as many sessions (i.e. one at the end of October 2014 and two in mid-November 2014). Holding the group interviews over three sessions meant that I could recruit a sensible number of people per group (e.g. 5 – 10), most likely from the pool of 30 (approx.) regular members (Brown 1999: 118). In contrast to the relatively large number of people who belong to Support Group 1, around 20 – 30 members are registered on the mailing list of Support Group 2 and up to 10 regularly meet three – five times a year. I, thus, planned to conduct one group interview with Support Group 2 attendees.

The representative from Support Group 1 invited me to their summer barbecue in July 2014, whereby I was able to chat informally with members about my research. The Dystonia Society then posted and/or emailed the study documents for the group interviews between September and October 2014 to all potential participants on both support groups' mailing lists. This meant that everybody registered with the groups had an equal chance of being asked to participate (Patton 1990). Since every person on the groups' mailing lists was assumed to be an 'information-rich' case by virtue of them living with dystonia and being an associate of a local dystonia support group, my strategy adhered to the logic of sampling purposefully, strategically, and fairly (*ibid.*). Anybody interested in participating was invited to contact me directly either via email, over the telephone, and/or at the support group meetings.

Twenty-seven members from Support Group 1 responded to The Dystonia Society's group interview mail-out. However, 15 of the 27 later declined participation for personal reasons. The first group interview went ahead in October 2014 with seven of the 12 potential participants. Ten members from Support Group 2 agreed to participate in the group interview in early November 2014.

In order to boost recruitment rates, I decided to supplement the mail-outs with a snowball sampling strategy. Paige, the Support Group 1 representative, volunteered to remind members about the study at one of their meetings at the beginning of November 2014. This strategy extended the sample of participants who agreed to take part in the group interviews by four. While Paige's involvement in the research study helped to increase the size of my sample, some degree of bias may have been

introduced from employing a snowball strategy (Thompson and Phillips 2007). For example, the people who she 'snowballed' into the study may well have been individuals who knew her or who shared her particular view of the group. They may have also been at a certain point in their dystonia journey to be able to attend the support group meetings in the first instance (Ussher et al 2008).

Since the location of the group interview can markedly influence participation rates, it has been argued that researchers should pay attention to this issue prior to entering the field (Liamputtong 2011: 57-60). I conducted all group (and semi-structured) interviews with attendees in a private room at their regular meeting site to facilitate access and participation. In doing so, I was able to obtain a sense of how they behaved and interacted with each other in a relatively 'natural' and familiar setting (Frey and Fontana 1991).

Initially, I intended to use group interviews to explore the various ways in which Dystonia Society support group attendees considered, communicated, and used lay information and support. In particular, I sought to explore their collective views of The Dystonia Society meetings and so designed the interview schedule for this purpose (appendix 2). Yet, during the discussions, participants spoke a great deal about their *personal* experiences of dystonia and healthcare alongside their shared understandings and opinions of the group. Rather than interrupt the flow of the conversations, I let these develop organically and allowed participants to talk about the issues that they wished to discuss.

I ran each group interview according to recommendations set out by Bryman (2008: 485). Having introduced the study and the purpose and structure of the group interview, I informed attendees that it would be audio-recorded with their permission so that I could acquire an accurate record of the discussion (Braun and Clarke 2006: 87). I also reminded participants not to disclose the content of the interviews to anybody else in order to preserve, as far as possible, anonymity and confidentiality. I politely requested that each group respect everybody's' opinions and refrain from speaking over each other. Next, I invited any questions, obtained informed written consent from each person, and assigned an ID number to them. Finally, I requested that participants wear name tags to facilitate group cohesiveness (Liamputtong 2011: 73).

At the start of each group interview, I asked each participant to state their first name and something about how they had found out about The Dystonia Society and/or local support group. This introductory question was designed to be simple and allow participants to ease into the discussions (Liamputtong 2011: 76). It also helped to generate information around what participants already knew and provided a 'safe space' for everybody to contribute (*ibid.*). In addition, it facilitated transcription, enabling me to distinguish between the different voices (*ibid.*).

Towards the end of each interview, I asked participants if they had any outstanding issues or points that they wished to discuss. I then switched the audio-recorder off, debriefed participants on what would happen next (e.g. analysis, dissemination), and invited any questions from the floor.

I conducted four group interviews with a total of 26 participants, of which 17 were female. Interviews lasted between 30 mins (Support Group 2, group interview 2) and 1 hour 18 mins (Support Group 1, group interview 3).

Semi-structured interviews

Unlike the group interview, the semi-structured interview is performed with one participant at a time (Wilkinson 1998) and produces rich textual data about a person's unique understandings of a given phenomenon (Lawler 2002: 255; Kelly 2010: 307). It is also a flexible type of interviewing method, whereby the researcher has a broad idea of which themes they would like to cover but still allows the participant to diverge or digress on to other areas (Britten 2006: 13).

To add to the aforementioned dataset and broaden the scope of my research, I carried out semi-structured interviews with support group attendees (n=10) and NHS patients (n=2). In addition, this study is built on a secondary analysis of 21 pre-existing semi-structured interviews originally conducted with 13 NHS patients living with some form of dystonia (mostly, cervical dystonia). Qualitative secondary analysis means that researchers retrieve data initially gathered from previous studies, often to explore different research aims and questions (Heaton 2008: 506, 510).

All attendees of Support Groups 1 and 2 received an invitation to a semi-structured interview between December 2014 and January 2015. Eleven Support Group 1 attendees and two attendees from Support Group 2 responded to The Dystonia

Society's mail-out and agreed to take part. However, three Support Group 1 members later declined participation for personal reasons.

I introduced each semi-structured interview as I did for the group interviews by explaining withdrawal rights, inviting any questions, and taking informed written consent. In a similar way to the group interviews, I initially sought to use semi-structured interviews with attendees to (further) explore their viewpoints of their local dystonia support group. However, participants also spoke about the relevance of their healthcare in relation to their biographical trajectories. As per the interview schedules for representatives (appendix 3) and members (appendix 4), I began each interview by asking about participants' roles within, and opinions of, the meetings. These introductory questions enabled me to obtain a sense of how attendees identified with other people with dystonia, as well as provided support to each other.

A total of 10 support group attendees participated in a semi-structured interview between February and March 2015. The sample included: two representatives (one from each support group) and eight members (seven members from Support Group 1 and one member from Support Group 2). Interviews lasted between 21 minutes (Support Group 2 representative) and 43 minutes and 47 seconds (Support Group 1 member).

To recruit patient participants into the study, I made initial contact with members of staff in 'NHS Hospital 1' trust prior to obtaining permission from the Research Ethics Committee (REC). This hospital provides multiple types of treatment for

those individuals affected by dystonia. Following ethical clearance, I liaised with the Principal Investigator – a specialist in dystonia – about possible recruitment strategies. I initially requested that different health professionals (e.g. neuro-surgeons, neurologists, movement disorder nurses) consecutively identify potentially eligible individuals from each of their outpatient appointment lists. Potential participants would then be given the study documents and between two – four weeks to consider their participation. However, this sampling strategy raised a number of practical issues given that I found it difficult to contact the clinicians. Despite attempts to sample patients from both DBS surgery *and* BoNT clinics, only one health professional from the latter identified and distributed the study documents to 30 patients for their participation in a semi-structured interview.

In total, three patients from NHS Hospital 1 responded to the mail-out via telephone call and two agreed to participate in a semi-structured interview. The REC and I agreed that only potential participants (patients and support group attendees) who approached or contacted me directly would be considered for inclusion. Thus, I had to exclude one patient because they were too ill to speak to me about the research and had relied on the assistance of their husband to perform this task.

The interviews took place between February and March 2015. The shortest interview lasted 46 minutes and the longest 1 hour and 9 minutes. Patient participants chose to have their interview conducted in their own homes.

I intended the semi-structured interview schedule for NHS patients to focus specifically on the lived and living experience of dystonia (appendix 5). Given that the semi-structured interview schedule for patients had initially been designed to be more in-depth than the ones for support group participants, I conducted a pilot interview with a university student living with dystonia in June 2013 to assess its relevance. Based on participant feedback, I later refined some of my interview questions. For example, I changed the wording of the stigma-related questions so that they better reflected the concerns of participants. I also included areas that emphasised the variability of dystonia. In addition, conducting a pilot interview meant that I could practice my interviewing technique under the guidance of one of my academic supervisors.

Having obtained informed written consent, I requested that NHS patient participants tell me something about themselves, including any current hobbies or activities. This 'ice-breaker' not only enabled me to obtain important demographic information (see 'participant demographics' section) but also helped them to relax into the discussions. I then asked participants how they came to be diagnosed with dystonia in order to elicit broad responses before following this up with more specific prompts (e.g. what their life was like prior to getting the diagnosis). The rest of the interview focused on their sense of embodiments and experiences with any treatment and/or lay-led support.

To mitigate relatively low participant recruitment rates, I decided to perform a secondary analysis on a pre-existing semi-structured interview dataset that was not only relevant to the aims of the primary study but was also readily available to use.

I accessed the interviews from Warwick Clinical Trials Unit in August 2015. Given that members of the WADSS team agreed to share the dataset directly with me – the primary WADSS researcher – 'informal data sharing' methods were employed (Heaton 2008: 509). This technique is rising in popularity among qualitative secondary analysts interested in health and illness topics (*ibid.*). Indeed, it enables researchers to obtain the data within a relatively short amount of time, meaning that the findings will still be relevant to the phenomenon under exploration (Hinds et al 1997: 415; Heaton 2008: 515). While a potential limitation of informal data sharing is that the dataset 'may not be prepared to as high a standard as in an archive' (Heaton 2008: 515), my approach to analysis involved verifying the accuracy of each transcript against each audio-recording (see 'data analysis' section). Consequently, I ensured that all the datasets had suitably been prepared *before* I proceeded to thematically code the transcripts.

The semi-structured interviews were conducted as part of a proof-of-concept study investigating the feasibility and suitability of a combined cognitive-behavioural and mindfulness programme for people living with dystonia[34] (for full study details see Sandhu et al 2016). As mentioned, I was the primary WADSS researcher and recruited all participants from a single BoNT outpatient's clinic at 'NHS Hospital

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[34] The Dystonia Society funded WADSS.

2.'[35] I also conducted many of the interviews (n=15) either alone over the telephone or with another team member[36] at participants' homes or in an office at Warwick Clinical Trials Unit. While all participants had provided their informed written consent before the start of the pre-intervention interviews[37], a reiteration of their rights was also given with the opportunity to ask any questions.

In the pre-intervention interviews (conducted between November 2014 – early January 2015), participants were asked to provide a 'potted history' of their dystonia journey, including how they came to be diagnosed and treated with the condition. They were also invited to speak about their daily activities, coping strategies, and relationships with family and friends. Towards the end of each interview, each participant was requested to answer a pre-scheduled question related to his or her expectations of the intervention. Though this question bore no direct relevance to the aims of my research, in practice, many participants struggled to provide an answer and subsequently continued to talk about their personal difficulties with dystonia. In situations where participants did provide a more detailed response to the intervention question, they would often describe their thoughts and feelings towards meeting other people affected by dystonia. While the post-intervention interviews (carried out between February and March 2015) used a different guide in order to obtain participants' reflections of the course, most digressed on to other topic areas relevant to the primary work such as the shared and changed nature of embodied experience

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[35] A neurologist initially screened their appointment lists for patients who met the study criteria (Sandhu et al 2016).
[36] They are referred to as 'I' for interviewer in the subsequent results chapters.
[37] For the majority of participants, their consent was obtained in the clinic some weeks prior to the first round of interviews. For a minority, this was done at their homes either sometime before or at the point of interview.

across various temporalities. Due to the fact that all the datasets featured similar topics of conversation, I decided to integrate them within my analysis.

Interviews lasted between 11 minutes and 52 seconds (post-intervention interview) and 57 minutes and 11 seconds (pre-intervention interview). Even though the post-intervention interviews were designed to last 20 minutes, in practice, many participants (except for two people) felt comfortable in speaking about their experiences of dystonia and the intervention beyond this timeframe.

In addition to the interviews, participants were asked to complete three separate sets of questionnaires about their dystonia symptoms and emotional wellbeing (at baseline and at 1- and 3-months after the delivery of the intervention). Experts in neurology, psychology, and mindfulness practice delivered the 3-day intervention to participants at a residential setting in mid-January 2015 (Sandhu et al 2016). A colleague and I observed all aspects of the course and made a series of detailed fieldnotes. However, I excluded these data from my research because they related specifically to the psychology intervention and not lived experience. As Heaton (2008: 509) has argued, 'single or multiple datasets can be shared, and re-used in full or in part, depending on the aims and scope of the secondary research.'

Arguably, a potential limitation of secondary analysis is that it may distance the investigator from the data due to their lack of personal involvement in the field (West and Oldfather 1995: 456; Heaton 2008: 511). Yet, being present throughout the design and implementation of WADSS meant that I had in-depth experience and

knowledge of the entire research process and could assess the quality and suitability of the interview datasets, as well as reflect on the various stages of the fieldwork (Hinds et al 1997: 418; Heaton 2008: 509, 511, 515). Furthermore, carrying out a secondary analysis in addition to the primary work meant that sufficient and detailed information on the phenomenon under consideration was obtained. Consequently, I ceased fieldwork upon receipt of the semi-structured interview dataset from members of the WADSS research team.

Flow Diagram 1: Overview

Support Group 1
n=17

↓

Support Group 2
n=10

↓

NHS Hospital 1
n=2

↓

NHS Hospital 2
n=13

↓

Sample size
n=42
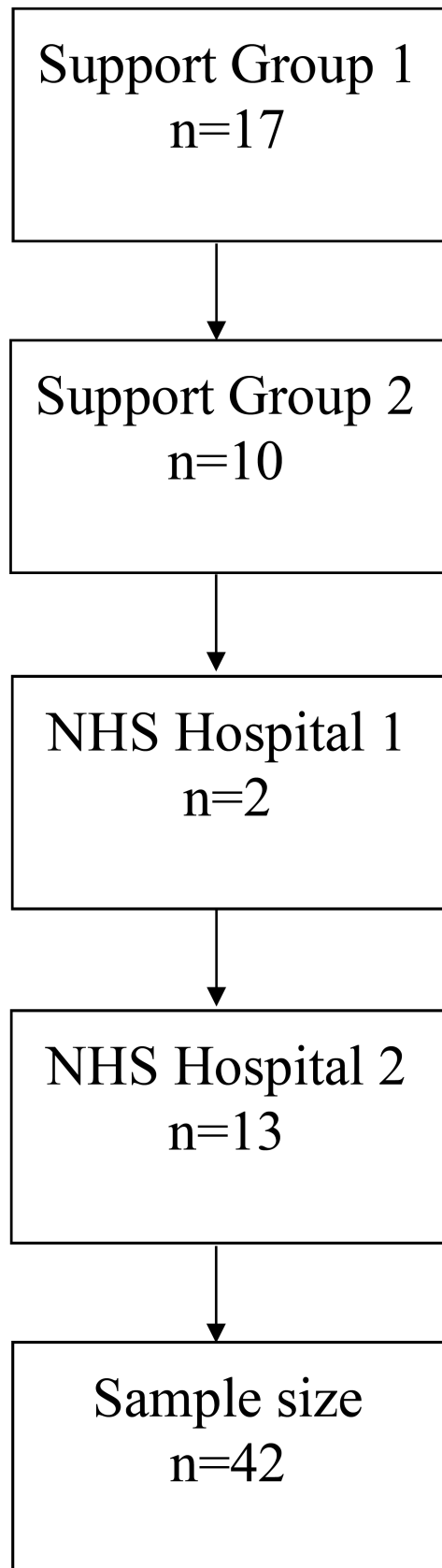
Flow Diagram 2: Dystonia Society Support Groups

Support Group 1
n=17

Group interviews
n=3
Participant numbers
n=7 n=4 n=5

7 participants who participated in a group interview also took part in a semi-structured interview. The 9 remaining participants agreed to participate in a group interview only

Semi-structured
interviews
n=8

1 participant took part in a semi-structured interview only

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┌─────────────────────────┐
│                         │
│    Support Group 2      │
│       n=10              │
│                         │
│                         │
└─────────────────────────┘
            │
            ▼
┌─────────────────────────┐        ┌────────────────────────────────┐
│                         │        │ 2 participants who participated in a │
│    Group interview      │        │ group interview also took part in a  │
│        n=1              │───────▶│ semi-structured interview. The 8     │
│   Participant numbers   │        │ remaining participants agreed to     │
│        n=10             │        │ participate in a group interview only │
│                         │        └────────────────────────────────┘
└─────────────────────────┘
            │
            ▼
┌─────────────────────────┐
│                         │
│    Semi-structured      │
│     interviews          │
│        n=2              │
│                         │
│                         │
└─────────────────────────┘
```

Flow Diagram 3: NHS Hospitals

NHS Hospital 1

Number approached
n=30

Number of contacts
received by researcher
n=3

Number of contacts
excluded by researcher
n=1

Patient herself too
unwell to speak to
researcher

Number of participants
interviewed
n=2
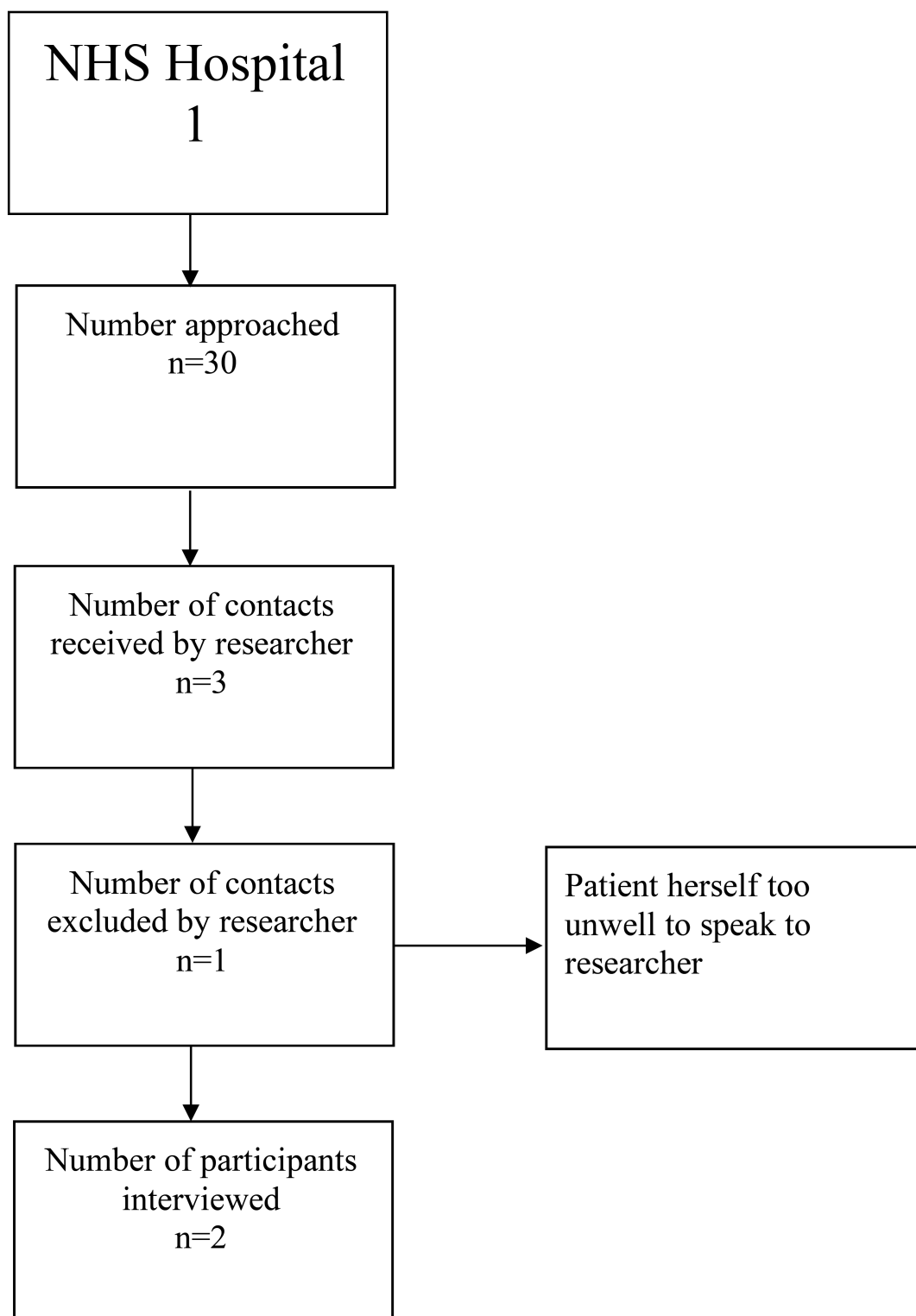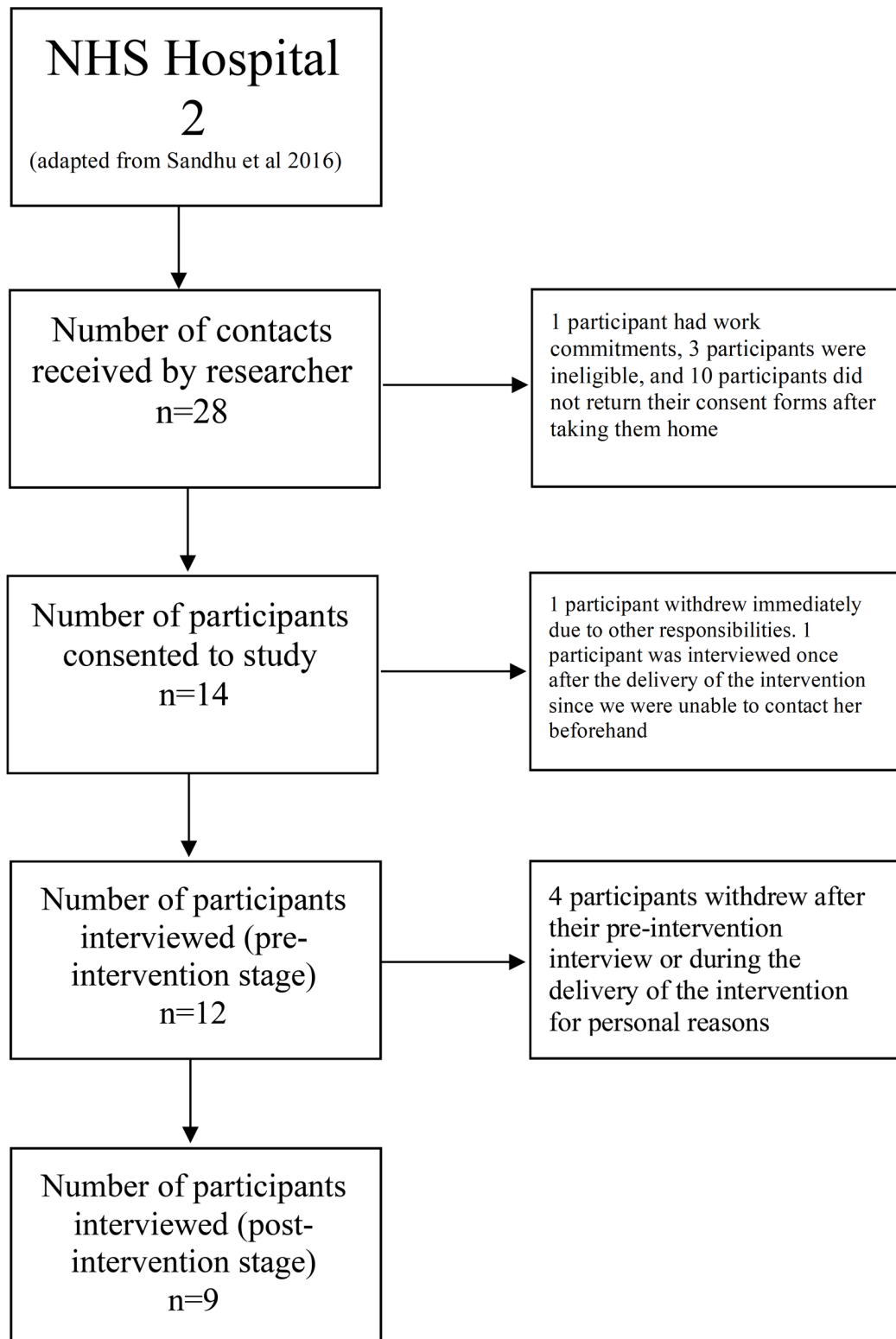
Data recording and transcription

Each interview from each study was audio-recorded with a high-quality dictaphone and transcribed verbatim. I listened carefully to all the recordings in order to verify the 'accuracy' of the transcripts, as well as to remove or change any identifiable information (Braun and Clarke 2006).

Verbatim accounts of both verbal (e.g. talk, overlapping talk) and non-verbal utterances (e.g. coughs, laughter, and emphasis) were documented. Recording these details meant that the content and tone of the interviews, as well as participants' affective states could be captured (Oliver et al 2005: 4; Braun and Clarke 2006: 88). It is not usually advised that researchers, adopting a thematic approach to analysis, use highly detailed transcripts such as those commonly produced for conversation analytic studies (Braun and Clarke 2006: 88). While supporters of this technique interpret 'the intricacies of spoken language', thematic analysts concentrate on the broader meanings constituting participants' responses (Braun and Clarke 2006: 87-88).

Participants from the primary project were asked if they would like to receive a copy of their interview transcript(s) (group and/or individual) in order to check over and, if necessary, change certain segments. They were also instructed to submit any amendments or queries within a reasonable two – four week timeframe so as not to delay data analysis. One participant sent back two revisions clarifying some points that she had made during the group interview. I added these to the original transcript and documented where they had come from. I phoned the nine remaining WADSS

participants who completed the intervention and discussed the themes that had

emerged from their interviews.[38] I then asked each participant if they would like to

receive a hard-copy of their interview transcript(s). One participant agreed but later

made no revisions to the text. Contacting the primary and secondary research

participants at the end meant that they could ask me any questions about the

respective studies.

Participant demographics

Information on participants' gender, age, ethnicity, socio-economic position (i.e.

work status and/or occupation), and dystonia type were obtained in several ways (for

a detailed breakdown of the sample see appendix 6). Group interview participants

were asked to complete an anonymised demographics form prior to the discussions.

Some details were also provided in the interviews. For the one primary study

participant (Dawn) who only took part in a semi-structured interview, her details

were collected at various points throughout the conversation. She did not receive a

demographics form because these were given to group interview participants only.

Each participant from NHS Hospital 1 was asked about their demographics at the

start of each semi-structured interview. Finally, details about WADSS participants

were obtained from the baseline questionnaires and pre-intervention interviews.

Since one participant (Zara) did not complete a baseline questionnaire, her

demographic details were obtained exclusively during the pre-intervention interview.

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[38] While members of the WADSS research team were allowed to use data from participants who had
withdrawn, they were not permitted to make any further contact with them.

Of the 42 participants who were interviewed, 29 were female and 13 were male. While the majority of participants described their ethnicity as white British (n=35; 83.3%), four (9.5%) defined themselves as white Irish, two as mixed ethnicities (4.8%), and one as black other (2.4%). These demographics seem to be broadly representative of the dystonic population. Marras et al's (2007) incidence study, for example, found that cervical dystonia most commonly affects women (1.14 vs 0.45 for men per 100,000 person-years) and white people from North America (1.23 vs 0.15 for black and ethnic minority individuals per 100,000 person-years). Moreover, in a review of the epidemiology of dystonia, the prevalence of people with an early-onset form of the condition was higher in the Ashkenazi Jewish group (44 per million people) than in the rest of the population (24 per million people) (Defazio et al 2004). Late-onset dystonia, the most common type, was predominately found to affect white Europeans (283 per million people) compared to individuals from Asian and black backgrounds (34 per million people) (*ibid.*).

Job status and/or occupation were used as proxies for participants' socio-economic background. Of the 25 participants who reported that they were retired, 12 provided information on their previous careers (e.g. two had worked for private car firms and one had been a director of his own company, suggesting that these participants were financially stable) (appendix 6). Five of the eight participants who said that they were currently in full-time employment had an office-based job. The relatively low number of individuals working full-time may be due to the over-representation of older people in the sample (see next paragraph). Three participants were unemployed and four worked part-time (e.g. one was a social worker and another a secretary).

The work status and occupation of one participant, Dawn, was not obtained during her semi-structured interview. Another participant, Zara, said that she worked as a pub chef but did not mention whether this was full- or part-time. Ten participants had used private healthcare insurance or paid to see an alternative therapist (e.g. homeopathist) to manage their symptoms at some point during their disease trajectories (chapter 5). Consequently, there was evidence within the sample that access to financial resources had an impact on health-seeking behaviours. However, though I considered the political implications of private healthcare consumption for therapeutic decision-making, I chose not to examine socio-economic status systematically as a separate line of analysis. This was because I wanted to focus my interpretation on personal understandings of dystonia and the medical profession, issues that cut across social class and background.

I have reported the ages of the primary and secondary research participants in intervals of 10, ranging from '18-28 years old' up to '62 years old or over.' The majority of participants across both studies fell into the '62 years old or over' age bracket (n=26; 62%) with only one primary research participant reporting an age range of between '29-39 years old' (2.4%). Interestingly, out of the 10 participants who attended Support Group 2, eight were listed as aged 62 years old or over. The next most frequent age group was the '51-61 years old' bracket (n=8; 19%) followed by the '40-50 years old' category (n=5; 12%). The age range of two participants was not obtained.

The sample was somewhat heterogeneous in terms of the type(s) of dystonia affecting participants. More than half said that they lived with a definitive diagnosis

of some form of focal dystonia either in their neck (cervical dystonia) (n=18; 42.9%), eye (blepharospasm) (n=3; 7.1%), voice (laryngeal dystonia) (n=1; 2.4%), hand (writer's cramp) (n=1; 2.4%), or mouth, tongue, and/or jaw (oromandibular dystonia) (n=2; 4.8%). As is reflective of my sample, cervical dystonia is regarded as the most common type of focal dystonia with a range of 23 –130 cases per million people followed by blepharospasm (17 – 133 cases per million people) (Defazio et al 2007). Recent estimates have indicated that adult-onset focal dystonia is more prevalent than childhood-onset generalised dystonia with a range of 30 – 7320 per million people compared to 2 – 50 per million people, respectively (Defazio 2010). Furthermore, it is perhaps unsurprising that all patient participants from the primary and secondary research studies reported various problems with their neck given that they were recruited from clinics that mainly treat these types of symptoms. Aside from its relatively rare nature, my sample may not have included psychogenic dystonia because it is under-represented at local support groups and not usually linked to focal types (Albanese et al 2013).

Despite the fact that a large proportion of my sample lived exclusively with a focal dystonia (n=25; 59.5%), some participants also reported a diagnosis of generalised dystonia (n=3; 7.1%) and dopamine-responsive dystonia (n=1; 2.4%). In addition, other participants reported different combinations of dystonia such as oromandibular dystonia and paroxysmal dystonia (Charlotte), cranial dystonia with some cervical dystonia (Miranda), and focal hand and oromandibular dystonia (Allen) (appendix 6). Arguably, these cases demonstrate the wide-ranging physical consequences of the condition, as well as the difficulties with attributing dystonia-specific symptoms to a

particular medical label (chapter 6). Due to the divergent range of categories assigned to dystonia (chapter 2), I have reported participants' diagnoses in their own words in the subsequent data analysis chapters.

Though I have tried to be consistent with my reporting of participants' demographics, some details are missing. One Support Group 2 member, Agnes, did not specify which type of dystonia she lived with, although referred to her experiences of the condition in the group interview. To comply with NHS procedures, the primary and secondary studies asked clinicians to identify patients according to the aforementioned inclusion and exclusion criteria. However, one WADSS participant, William, said that he experienced tremors (rather than dystonia) in his hand and neck. Another WADSS participant, Zara, described living with head tremors and dystonia, which I have subsequently interpreted as cervical dystonia. Finally, one person from WADSS, Olivia, said that she was not aware she had dystonia until meeting me in the clinic (I discuss the ethical implications of this later). Thus, I am not sure which type of dystonia she lived with or even if she had a definitive diagnosis of the condition. On the other hand, she mentioned that her neck frequently shook and her leg sometimes went into spasm. Consequently, I have incorporated the accounts of these participants into the analysis because they described living with dystonia and/or dystonia-related symptoms (e.g. tremors, shaking, spasms).

Ethical issues

The National Research Ethics Service (NRES) Committee London – Riverside gave ethics approval for the primary research project in May 2014, REC reference

number: 14/LO/0305. WADSS was reviewed and given favourable ethical opinion by the NRES Committee East Midlands – Leicester in September 2014, REC reference number: 14/EM/1091.

For the primary research, I obtained ethics approval for observing dystonia support group meetings and consultations with patients and clinicians, as well as for conducting semi-structured interviews with health professionals. However, these aspects are not associated with the analysis reported in this thesis but are stated here because they are specified in the REC approval letter (appendix 7).

Despite the importance of procedural guidelines, these cannot be taken as ends in themselves due to the socially situated nature of ethics (Skeggs 2001: 433-435; Guillemin and Gillam 2004). Indeed, ensuring the ethicality of one's research necessitates an ongoing, reflexive approach (*ibid.*). Given the delicacy of my topic, I carefully considered my own actions throughout the research process in order to protect, as far as possible, participants' wellbeing. While I adhered to the regulations set out by the REC (e.g. the right to withdraw, the provision of voluntary consent), I also reflected on those 'ethically important moments' that unfolded over the course of my research (Guillemin and Gillam 2004). With this in mind, I discuss four important ethical issues: emotional harm, anonymity and confidentiality, lone research, and informed consent.

Emotional harm

Given that I carried out qualitative interviews to concentrate on the emotional and deeply personal aspects of individuals' illness experiences, my research may be regarded as 'sensitive' (Lee 1993). As well as the topic area, the ethicality of the chosen research techniques for both studies can also be examined. For example, scholars argue that the open and flexible nature of qualitative interviews may compel participants to reveal more about their lives than previously expected (Brannen 1988; Bornat 2008). In fact, since I had anticipated that participants might be left feeling distressed and vulnerable during the interview situation, I put in place a number of safeguarding strategies prior to starting my fieldwork.

I reminded each participant at the start of each interview that they could skip over distressing topics or direct the conversation to issues they preferred to discuss. I also reiterated these points to those participants who became visibly distressed during their interview, suggesting that they take a break or stop completely. While none made use of these options and continued to talk about the struggles that they (had) faced, this did not mean that I had been absolved of ethical responsibility. Indeed, I questioned afterwards whether I had done enough to protect participants from emotional harm or whether I had come across too detached and 'professional' to appear caring and compassionate. I also feel somewhat guilty about the fact that I have used academic language to theorise and reduce participants' inner thoughts and feelings to a particular analytic interpretation (O'Connell Davidson 2008), a phenomenon that Dickson-Swift et al (2008: 50-51) have termed 'the ethical hangover.' In counterargument, many participants said that they found the interviews

therapeutic and hoped their participation would help other people with dystonia in the future (Pillow 2003). Furthermore, the fact that I carried out a secondary analysis might be viewed as ethically counter-balancing since it not only reduced the risk of the datasets being underused but also limited other people's exposure to the potentially intrusive nature of social scientific research.

Another way I tried to manage the impact of emotional harm was by informing participants of The Dystonia Society's support helpline and/or by handing them a leaflet on dystonia and mental health at the end of their interview. In addition, WADSS participants were able to speak to the project leader – a qualified health psychologist – about any personal issues related to their participation in the study. Primary and secondary research participants were also asked if they had any questions about their involvement. They were then informed of what would happen next in order to reduce potential feelings of uncertainty or anxiety. When I contacted participants about their transcripts, I also asked if they had any questions or concerns about any aspects of the primary or secondary research work. Yet, I did not invite participants to speak about their affective states because I was concerned that doing so might blur the boundary between researcher and counsellor (Dickson-Swift et al 2008: Ch 4).

Aside from the risk to the participant, conducting sensitive research can also have a negative impact on the emotional wellbeing of the researcher who is continually exposed to distressing stimuli (Dickson-Swift et al 2008; Woodby et al 2011). Indeed, while immersion in one's research is considered useful for obtaining a better

insight into the dataset(s), being involved with the project from inception to completion often makes researchers vulnerable to a range of psychological problems (*ibid.*). To safeguard my own emotional wellbeing, I intentionally foregrounded a researcher identity in the field and regularly 'offloaded' my concerns to relatives and colleagues (Woodby et al 2011). Finally, I kept an emotional diary and recorded my experiences throughout the various stages of both research studies in order to reach some kind of resolution, as well as reflect on the possible ways in which my preconceptions and ideas about dystonia might have informed my interpretation of the data (Dickson-Swift et al 2008).

Preserving anonymity and confidentiality

Related to the issue of emotional harm is the preservation of anonymity and confidentiality. While I adhered to secure file transfer and storage procedures, my sample contained a large number of support group attendees who knew about each other's personal experiences and sometimes made reference to these in the (group and/or semi-structured) interviews. This meant that participants' accounts included information about their views of other people's experiences of dystonia, most of whom had not been present in the interviews. Similarly, Boardman (2010: 93-94) became acutely aware that using a patient support organisation to recruit participants meant that the majority recounted other members' stories during their interview(s) and/or recognised each other's narratives through research outputs. Though I randomly assigned pseudonyms to all persons who were mentioned in the interviews and omitted the parts of the country where I collected the data, my attempts to obscure the identities of those individuals who had not provided their consent but yet

still featured in the analysis remains a contentious issue (Murphy and Dingwall 2001: 341). When I presented the findings at Support Group 1 and Support Group 2 in order to provide feedback to (non)participants and field questions about the study from the floor, I also requested that they did not try to guess whose (anonymised) interview extracts belonged to who. Yet, as I am not entirely sure whether attendees did this within their own private friendship groups at the end of the meetings, my concerns arguably illustrate some of the difficulties with safeguarding participants' anonymity and keeping their stories confidential (*ibid.*).

Conducting lone research

Even though I took a series of measures to protect my emotional health, I still found the experience of carrying out lone research an incredibly isolating one. In addition to the psychological implications of conducting research alone, I also had to look after my own safety. While I aimed to be as flexible as possible over where the primary research interviews were conducted, I checked with participants that the research sites (houses, support group meeting rooms) could all be easily accessible via public transport before making any formal arrangements. This strategy minimised the amount of walking I needed to do and meant that I could prepare my journeys in advance. I also arranged the interviews in daylight hours to avoid travelling on public transport at night when services are usually less frequent. Moreover, I contacted each onsite manager at each of the support group venues in advance of my visits so that they were aware of when I would most likely arrive. Before entering participants' homes, I informed one of my supervisors of where I was going and how long I intended to stay. I also contacted my supervisor again once I had left. Though the

concepts of 'risk' and 'safety' are culturally contingent and not always known beforehand (Kenyon and Hawker 1999), putting into place several measures to protect my welfare was not only important for reducing physical threats but also for making me feel comfortable enough to carry out my research duties effectively.

In the context of WADSS, one of the reasons that a colleague and I conducted many of the face-to-face interviews together was to protect our own safety. My colleague followed similar procedures to the ones previously mentioned when they occasionally home interviewed participants alone.

Problematising informed consent

While I obtained informed written consent from all primary and secondary research participants, the principles and practices underlying this concept remain contested within social scientific research (Stark and Hedgecoe 2010: 590-591). Specifically, it has been argued that the ethical recommendations set out by the REC neglect to take into account the wider social milieu in which decisions about participation are made (Corrigan 2003). For example, when I initially met support group attendees at their meetings, some spoke to me about their personal experiences of dystonia and thanked me for taking an interest in their condition. Afterwards, I considered whether participants had decided to take part not because they had read the Participant Information Sheets but because they felt obligated to do so on account of the fact that my research contributes to the nascent field of dystonia. Some may have also hoped that the research would give them a chance to talk about their relatively unknown and unheard viewpoints. In fact, as several participants described the interviews as

'cathartic' (Pillow 2003), they may have temporarily forgotten that they were taking part in research or misunderstood the difference between a research interview and a therapeutic one (O'Connell Davidson 2008). In an attempt to deal with these issues, I kept the audio-recorder visible during face-to-face discussions and reminded those individuals taking part in a telephone interview that they were participating in a research study. Furthermore, one WADSS participant informed my colleague that she had never heard of dystonia before meeting me in the clinic to discuss the project and provide her consent (Olivia). I later reflected on whether this participant had fully understood the aims of the study or why she had been approached in the first instance. Perhaps somewhat more worryingly, I questioned whether I had unwittingly given her a *de facto* medical diagnosis. Overall, these fieldwork experiences demonstrate the ways in which the complex and unpredictable nature of social life may contradict the received wisdom upheld by ethics committees oriented towards a reductive and biomedical understanding of consent (Corrigan 2003).

While the Chief Investigator for WADSS confirmed that the consent forms included information on data sharing and secondary analysis, none of the participants were aware of how this would be done. Grinyer (2009) has raised the issue of whether 'renewed informed consent' is required given that little guidance currently exists for researchers carrying out a secondary analysis. Yet, continually seeking agreement from participants each time their data is shared may put additional demands on them, although would ensure that they are aware of the aims of the other researcher's study (Grinyer 2009: 2; Heaton 2008). On balance, however, WADSS participants knew that in addition to my role as a Research Associate I was also a PhD student studying

people's experiences of dystonia. Furthermore, since members of the WADSS research team had specified in the Participant Information Sheet that contact would cease following the end of the study (i.e. after all the 3-month questionnaires had been returned in April 2015) and I did not receive the interview datasets until August, any further communication was deemed to be unethical.

Writing the embodied self into research: the importance of reflexivity

In chapter 1, I reflected on the way one particular aspect of my identity (disability) informed the development of the research aims and questions. The notion of reflexivity refers to the various ways in which social scientists critically assess the impact of their identities, volitions, and everyday experiences on the research process (Stanley and Wise 1983; Finlay 2002; Ellingson 2006; Seymour 2007). In particular, this concept allows investigators to render their 'invisible' preconceptions and assumptions about the social world transparent so that others can examine how far their analytic accounts are slanted towards a particular perspective (Finlay 2002). Feminist scholars have also applied the term 'embodied self' to illuminate the way identities are constituted in and through the fleshy contours of the body (Ellingson 2006). This feminist characterisation of embodiment strongly focuses on the collective, fluid, and permeable nature of the body and self (Hallam et al 1999: 9-10). Though some scholars contend that reflexivity encourages researchers to become self-absorbed and egoistic (Clifford 1986: 12-13; Patai 1994), paying close attention to the link between embodiment and interpretation arguably generates more authentic and trustworthy narratives that can illuminate important dimensions of the social world (Stanley and Wise 1983; Finlay 2002; Ellingson 2006; Mays and Pope

2006: 89; Seymour 2007; Cohen and Crabtree 2008). Given my unique experiences and understandings of dystonia (chapter 1), it was important that I reflected on these throughout the research process and considered alternative perspectives. Consequently, I document the impact of my own bodily experiences on the data collection and analysis process.

The 'impaired body' has been relatively underexplored within the literature on reflexivity, particularly in contrast to gendered or racialised carnalities (Ellingson 2006). Yet, reflecting on my identity as both a disabled person and an individual with dystonia was important given the changing social (in)visibility of my symptoms. In particular, I thought about the impact of this on the play of power within the interview situation. While much has been written about the relative (dis)advantages of choosing (not) to reveal one's disabled identity, researchers maintain that either decision will significantly inform field relations and the production of knowledge (Andrews 2005; Tregaskis and Goodley 2005; Seymour 2007; Boardman 2010: 98-100; Brown and Boardman 2011; Sheldon 2017). Specifically, some researchers suggest that sharing personal information can dismantle the operation of power within the field and promote reciprocal relationships (Andrews 2005; Tregaskis and Goodley 2005; Seymour 2007; Boardman 2010: 98; Brown and Boardman 2011). In counterargument, disabled researchers might feel compelled to reveal certain aspects of their lives that they had not previously been prepared to discuss (Brown and Boardman 2011; Sheldon 2017). Alternatively, deciding not to disclose one's disabled identity may allow participants to position themselves as 'experts' (Brown and Boardman 2011). On the other hand, participants may feel betrayed or guilty if

they later find out that they had been talking to a 'closeted' disabled person the entire time, particularly about disability-related issues (*ibid.*). Taking these dilemmas into account, social scientists should use their own intuition and skillset to determine how much information they wish to disclose about themselves, ensuring that they consider the impact of their decision on data collection (*ibid.*).

As was previously mentioned, I purposefully tried to foreground a researcher identity in order to mitigate emotional harm and appear professional while in the field (Woodby et al 2011). However, due to the unpredictable nature of my impairment, some participants from both the primary and secondary research studies asked if I lived with dystonia after noticing my claw-like grip and upturned elbow as we signed and dated the consent forms. Another WADSS participant also asked me personal questions about my dystonia during the pre-intervention interview and later told my colleague that they had been (unbeknown to me at the time) observing my gait during the delivery of the course. I would argue that in each of these situations the power dynamic between the participant and I shifted dramatically since I not only felt embarrassed by their curiosity and re-appropriation of the gaze but also incapable of doing anything about it, apart from to ask them to save their questions until the end of the interview. Despite personal feelings of objectification and vulnerability, these scenarios also provided me with a direct insight into how participants may have felt while being interviewed. It also revealed something interesting about participants' attitudes towards disability. In particular, my tacit experience of being stared at echoed what participants said in the interviews about how they would often watch other people with dystonia in order to ascertain the severity of their condition.

In other words, the effects of my body on data gathering provided me with a more complete or comprehensive understanding of participants' views of other people with dystonia (chapter 7). Indeed, participants' re-appropriation of the gaze was something that I had directly experienced and reflected on during fieldwork, as well as observed in my data.

Though I only know of a few participants who were explicitly aware of my dystonia, I am not sure if they later relayed this information to others at the support groups and/or intervention site. I am also uncertain about whether those participants who did not comment on my body had still noticed that I lived with dystonia. These are interesting points to consider given that more participants than perhaps I had realised at the time might have known about my condition, inadvertently affecting the kinds of data that I obtained. Further, I was not always sure if and when my disabled identity would be revealed because of the nature of my dystonic symptoms. Thus, preparing what I was willing to disclose to participants in advance of our discussions was difficult. I also wondered if telling participants that I would answer their queries at the end of the interview, when the audio-recorder was switched off, was the most ethical approach. Would it have been more appropriate if I had disclosed something about my experiences when I had been asked, particularly as I expected participants to do the same? Alternatively, would I have felt compelled to reveal more about my life than previously anticipated or influenced participants in a certain direction? Consequently, engaging in reflexive practice was not only important for bolstering the credibility of my findings but also for illuminating the range of ethical and methodological dilemmas that I had to negotiate during my time in the field.

Data analysis

I thematically analysed the aforementioned datasets as one whole set. I also decided to view all the datasets as 'equal in status' and integrate them within the analysis to proffer a comprehensive narrative of participants' understandings of reality (Madill et al 2000; Mays and Pope 2006: 87-88; Lambert and Loiselle 2008: 231). I was able to do this because all the interviews explored participants' everyday experiences of dystonia and the impact of support and healthcare provision on their unique perspectives.

I followed Braun and Clarke's (2006) recommendations for carrying out an inductive thematic approach to analysis at the latent level in order to interpret all the interview data systematically and robustly (see 'selecting an approach' section). This method allowed me to create a 'template' of 'data-driven' codes and themes, which were closely guided by participants' viewpoints and not pre-existing theory (King 2004; Gibbs 2007: 45). Of course, this is not to say that my template was 'uncontaminated' by my intellectual commitments or background in sociology (Braun and Clarke 2006: 83-84; Gibbs 2007: 46). Rather, I took several measures to consider new ideas, and in turn, enhance the quality of my research (e.g. by generating analytic memos, reading through previous reflections, and using supervisors to check my developing interpretations) (*ibid.*). In fact, I found that storing and organising the data in Nvivo 10 permitted me to link memos to various transcripts, themes, and data extracts (Bazeley 2007). Doing so also provided me with a better understanding of participants' accounts and the connections emerging between concepts (*ibid.*).

Though following Braun and Clarke's (2006) guidelines may appear prescriptive, each broadly defined step directed me through the data analysis process without placing restrictions on my creativity. As I gathered more interview data from the primary and secondary research work, coding the transcripts became a highly recursive procedure in which previously completed steps were revisited so that new themes could be created and older ones renamed, combined, and/or discarded (*ibid.*). Thus, while I present my approach to analysis as a series of consecutive phases, in reality, thematically coding all the data took a relatively long time. I began the analysis early on during data collection in October 2014 and stopped when all themes and concepts had been fully developed and did not reveal any new dimensions in May 2016 (Charmaz 2006).

To obtain immersion in, and familiarity with, the data, each audio-recording was not only listened to at least once but each completed transcript was also read and re-read multiple times. In addition, this meant that I was able to assess the compatibility of the WADSS dataset and confirm that it comprised rich information on the lived and living experience of dystonia (Hinds et al 1997: 418; Heaton 2008: 511, 515). During this initial phase, I highlighted particularly interesting phrases, words, or sentences and made a note of any tentative codes immediately jumping out at me at the end of each transcript. By recording my thoughts and feelings about the data, I was able to compare these to new insights during the second reading.

The next stage involved systematically attributing 'initial codes' to each pertinent segment of data in the transcripts (e.g. a sentence, a paragraph, multiple segments) (King 2004: 258; Braun and Clarke 2006: 88, 89). I coded some segments multiple times in order to remain open to a variety of interpretations (*ibid.*). To code, I highlighted a relevant portion of the text and marked it with a (descriptive) label until I had a comprehensive list of several unorganised codes (e.g. 'medical cures', 'uncertainty', 'hope').

Thirdly, I identified several themes by collating the free codes into broader but more concise categories, which in turn illuminated particular aspects of experience. Since this phase was not definitive, I decided to keep any code that could not (yet) be transformed into a theme or integrated with other codes until a later stage of analysis. Part of this phase also involved the development of a hierarchical coding tree, whereby I placed general themes at the top and inserted more specific sub-themes underneath in order to think through the properties of each label (King 2004; Gibbs 2007: 74). This method of organisation meant that I could categorise sub-themes under related themes and also reflect on their possible links to other concepts elsewhere in the coding tree (e.g. I placed the codes 'arriving at a diagnosis of dystonia' and 'negotiating treatment' under the broad theme 'medicalisation' and considered their possible associations with the free category 'information-seeking behaviours'). These tentative reflections also formed the basis of my results chapters, which I subsequently reworked as the thematic coding of the transcripts progressed. Yet, as I still had a large quantity of themes and sub-themes (as well as a few free codes), I began to refine and revise my previous template. This meant reading each of the data extracts assigned to each theme, sub-theme, and code in order to assess

their relevance and fit to the dataset. I also examined how each theme related to the broader coding tree, whereby any data items and/or themes that did not belong in the hierarchy were reworked, placed somewhere else, or discarded (Braun and Clarke 2006).

To reflect the essence of the data, this stage involved further revisions to the themes through a review of current names and definitions (Braun and Clarke 2006). I evaluated the connections between themes and the relevance of their thematic descriptions to the collated data extracts in order to identify any repetition, ambiguity, and/or unfounded categories in the coding tree (*ibid.*). My descriptions and analytic memos helped to determine which concepts were most significant and indicative of the experience of dystonia. I also considered how themes could be contextualised by the literature in order to elevate these to a more abstract level.

The final stage of coding consisted of drawing on the key themes in order to weave together a compelling and persuasive analytic narrative (Braun and Clarke 2006). Though I had begun to draft my results chapters earlier on in the coding process, having 'a set of fully worked-out themes' helped me to produce a convincing and intricate account of the ways in which participants evaluated their experiences of dystonia across different contexts (medicalisation in chapter 5; everyday life in chapter 6; support groups in chapter 7) (Braun and Clarke 2006: 93). In particular, I used my developing coding tree and analytic reflections to think through the crucial link between embodied experience and healthcare, as well as consider how my analysis related to, and also went beyond, the literature on experiential knowledge

(chapter 8). While thematic analysis anchors the researcher towards 'things said' rather than unsaid (Carter 2006), I created a 'group interview dynamics' code to discuss, where appropriate, the impact of these on the semantic features of the data, thereby adding another aspect to the final analysis (Moen et al 2010).

Conclusions

In conclusion, I have discussed the key methodological principles and practices underlying my research on dystonia. Firstly, I set out my contextualist approach and considered its suitability to the aims of this project. Secondly, I described the study criteria, recruitment procedures, and research design. I then examined the impact of several ethical and practical dilemmas on the production of knowledge. I also provided an account of my own identity as a disabled researcher and the ways in which this informed the outcomes of the study. Finally, I offered a step-by-step guide for how I interpreted participants' perspectives and considered the reasons for combining the different datasets. Having outlined the research process through its different phases, the three successive chapters present and discuss the data from the primary and secondary work in order to explore participants' experiential realities and the relationship of these to medical decision-making.

Chapter 5

The idea of medicine and medicine in practice

I analysed the group and individual interview data in accordance with the technique outlined in chapter 4 to develop several themes around the lay experience of dystonia. In particular, this chapter explores the association between the embodied knowledge of people affected by the condition to their understandings and experiences of medicalisation and healthcare decision-making. The way dystonia has been defined has changed through time, with dramatic implications for patient experience (chapter 2). Arguably, the fraught interconnection between dystonia and medicine illuminates the broader context within which individuals with the disorder come to approach decisions about treatment, as well as evaluate and respond to medicalised frameworks. In view of that, I examine the various ways in which participants' perceptions and actual uses of healthcare intersected with medical bodies of knowledge throughout the past, present, and future.

This chapter is set out in two sections. In the first part, I discuss participants' turbulent experiences of negotiating an appropriate diagnosis and treatment plan. The second part then moves on to explore the extent to which they sustained the idea of expert medical knowledge as a 'vehicle' for eliminating suffering and pain (Conrad 2013). Throughout this chapter, participants' emotional responses to their interactions with, and expectations of, the medical profession is emphasised. Even though, for practical purposes, the themes are structured and defined in a linear manner (e.g. moving from a diagnosis to a treatment plan), participants did not pass through these different stages straightforwardly but rather, used their experiential knowledge to

question, re-evaluate, and directly challenge the suitability of previously established explanations and/or therapies. Overall, by presenting data on participants' accounts of medicine, I will frame a later analysis of the ways in which these experiences shaped their understandings of their own embodied subjectivities (chapter 6), as well as their perceptions of lay identification (chapter 7).

Utilising expert medical knowledge to interpret and manage dystonia

As discussed in my literature review (chapter 3), recent conceptions of the experiential-expert interplay have emphasised its dynamic, synergistic, and fluid dimensions (Armstrong and Murphy 2008; Boardman 2010; Markens et al 2010; Barker and Galardi 2011; France et al 2011a; Pols 2014). Specifically, researchers argue that medical knowledge is the lens through which individuals affected by a chronic condition can make sense of their own experiences and weave together a coherent and acceptable account of healthcare, which also supports their own illness beliefs (*ibid.*). In other words, one's ability to combine, supplant, and/or modify certain aspects of professional epistemic sources occurs in confluence with a sensate embodied self (Wittink et al 2008). Building on these ideas, this section explores participants' experiences of approaching decisions about healthcare. I begin by detailing the problems that many participants in my research reported during the negotiation of an appropriate explanation of their enigmatic symptoms. I then move on to compare these (disquieting) experiences with the (eventual) arrival of a diagnosis of dystonia. The final part examines participants' views of dystonia treatment and the ways in which they coped with issues such as therapeutic (in)effectiveness and/or medical (mis)management (e.g. health professionals

sidelining their concerns). In doing so, I argue that the degree to which lay and medical bodies of knowledge harmoniously aligned during medical encounters varied considerably across participants' dystonia trajectories, influencing therapeutic dynamics and outcomes.

Negotiating a diagnosis

Medicalisation describes the point at which non-medical problems become re-defined and understood as medical complaints (e.g. Jutel 2009). Diagnostic tests and explanations are key classificatory tools of this process (e.g. *ibid.*). Successfully negotiating a diagnosis is important for patients, especially with MUS and/or contested conditions, because it can transform their inexplicable experiences into something much more acceptable (e.g. Nettleton et al 2005; Nettleton 2006; Jutel 2009: 278; Mik-Meyer and Obling 2012). Yet, sociologists have used the notion of the 'diagnostic odyssey' or 'medical merry-go-round' to describe the length of time that patients with these problems often have to wait before getting a firm diagnosis due to delays, not being believed, and/or having to undergo unnecessary tests (Robinson 1988; Cox et al 2003; Budych et al 2012; Pavey et at 2013; Ashtiani et al 2014). This medical merry-go-round may involve numerous meetings with different clinicians in order to overcome epistemic discrepancies between one's sense of embodiment 'and medical explanations of them' (Robinson 1988: 23). Patients with contested illnesses may also demand that physicians comply with their requests for referrals, at the same time as challenging the advice of those clinicians who fail to act in accordance with their requirements (Barker 2008). The process of arriving at an

appropriate diagnosis may, thus, be experienced as a 'battle' that individuals affected by these particular types of conditions have to 'fight' to get (Dumit 2006).

As has already been found in relation to dystonia (Camfield 2002) and other movement disorders (e.g. ataxia in Daker-White et al 2011; Cassidy 2012; Huntington disease in Halpin 2011; motor neurone disease in Pavey et al 2013), the majority of participants (n=30) in my research described a circuitous journey towards diagnosis, with varying implications for emotional wellbeing. In some cases, participants reported that they had received more than one 'wrong' diagnosis before getting a definitive label of their dystonia type. Furthermore, one participant, Olivia, had not been aware that she lived with dystonia prior to consenting to WADSS due to poor patient-doctor communication (chapter 4). She had, however, visited her GP on two separate occasions before finally being referred to a neurologist for BoNT treatment. In contrast to these issues, four participants did not report any difficulties with getting a firm explanation given that they saw a private specialist without any delays (Zara, William, and Allen) or were quickly referred, through the NHS, to a neuro-physiotherapist (Irene). A further seven participants did not mention their diagnostic experiences.

Though not every participant provided details, 10 described their frustration at waiting one – eight years after presenting to their primary care physician to receive an explanation of dystonia from a specialist neurologist. This finding aligns with previous research, which estimates that patients with cervical dystonia usually wait between four – six years before receiving a diagnosis (Jinnah 2015: 80). Some

participants also said that they had lived with a range of troublesome symptoms for several years before seeking help from the medical profession since they had not immediately viewed these as clinical problems (e.g. Cassie).

During the negotiation of a medically valid explanation, some participants reported that they had been tested for and/or misdiagnosed with a psychiatric problem (n=15). Amber, for example, is aged 62 years old or over and lives with cervical and myoclonus dystonia. Throughout the process of diagnosis, she said that she had been walking strangely and experiencing muscle contortions in her neck. Though Amber '*knew there was something the matter*' with her body during this time, she still felt unable to explain exactly what was wrong to her family and friends. Consequently, Amber endeavoured to obtain answers from the medical profession, who she thought would be able to provide a suitable account of her inexplicable symptoms. However, as can be demonstrated from the following excerpt, these attempts introduced a range of problems and difficulties:

> Amber: I was in the [hospital name] it was a psychiatric hospital actually […] we were in different wards and er my husband was alive and he was a bus driver, he used to come in and a lot of his friends used to come in and they'd say 'Amber what are you doing here?' […] They said 'get out of here' and I'd be just there you know listening away to them and when I came on a bus on the way to my doctor and of course you have a lot of forms delivered. He said to me 'it's all in your mind' and I feel like thumping him [Faye: Yeah] (louder) I feel like thumping him really [Faye: Yeah exactly!] but I wasn't that natured […] but to be told that it's all in your mind [Faye: Dreadful] there's

nothing wrong with my mind (laughs) it's an insult isn't it but they didn't understand did they. [Support Group 1 member, group interview 4]

Arguably, individuals may struggle to make sense of their corporeal sensations because of the idiosyncratic and uncertain nature of experiential knowledge (e.g. Abel and Browner 1998; Prior 2003). This raises questions about the degree to which it can automatically be considered an informative and helpful resource in healthcare decision-making (e.g. Massé et al 2001; Henwood et al 2003; Boardman 2010; 2014a; 2014b; Baillergeau and Duyvendak 2016). While Amber categorically knew that her symptoms were independent of psychiatric causes, she still lacked a socially acceptable code in which to make sense of her disquieting experiences and subsequently, searched for an appropriate medical diagnosis to mitigate her concerns. Yet, despite her efforts, health professionals' understandings repeatedly failed to tally with Amber's experiential knowledge; the tension between knowing what she did not have (i.e. a mental health condition) and not being able to obtain a suitable explanation of what could be wrong heightened. Supporting this finding, Jackson (2005) has suggested that people with MUS and/or contested conditions frequently experience a liminal ontology in which they must learn to manage an uncomfortable 'betwixt and between' state of knowing and not knowing. Given that this particular status can make it difficult for patients to feel empowered, Amber struggled to use her experiential knowledge to generate alternative ways of thinking about her symptoms. Instead, she invested a great amount of time and energy in the medical profession to provide a suitable explanation of what was going on in her body due to its powerful position within society (Robinson 1988: 23).

The degree to which laities perceive particular explanations as (il)legitimate depends upon the different kinds of meanings that they ascribe to them (Bendelow 1996; Nettleton et al 2004: 49; Jackson 2005; 2011). Indeed, while individuals may trust the medical profession to provide them with a (socially legitimated) diagnosis, these hopes may be confounded by the arrival of a stigmatising label like mental illness (Goffman 1963; Sayre 2000; Gray 2002; Lillrank 2003; Huibers and Wessely 2006; Corrigan 2007; Garand et al 2009; Jutel 2010; Halpin 2011; Jackson 2005; 2011; Lupton 2012). This is because psychiatric disorders are inextricably linked to moral discourses surrounding fraudulence, incompetency, and personal irresponsibility (*ibid.*). Arguably, Amber's relatives and friends had expressed surprise at her mental illness label because they believed that she did not possess any of the qualities typically attributed to individuals with this particular diagnosis. Consequently, they reinforced stereotypical beliefs about the dispositions of all people affected by a psychiatric problem.

As well as her social familiars, Amber also sustained anti-psychiatric attitudes by feeling offended at the arrival of a mental illness diagnosis. This may have been because patients living with a mental health condition are often viewed as possessing deficient personality types and occupying a different social status from the rest of society (Corrigan 2007). Camfield (2002: 38-39) has also noted that people with dystonia often 'reiterate popular prejudices: that psychiatric illness is not genuine, can be controlled, and is a legitimate cause of guilt.' These beliefs, sustained by Cartesian dualist ideas about the reality of mental (viz. intangible) and physical (viz. tangible) health, also affected how participants in my research experienced and

understood medical knowledge throughout their lived trajectories (Bendelow 1996; Lambert and Rose 1996; Nettleton et al 2004; Fein 2012). Amber attempted to present a moral self by remaining calm and not becoming physically aggressive towards the doctor who had insulted her. However, Amber's attempts to resist psychological explanations because she thought these did not align with her bodily experiences made her feel distressed and estranged from the medical profession. In this way, obtaining a psychiatric label had a palpable impact on her sense of self and belonging in the world.

In addition to reinforcing negative ideas about mental illness, participants also challenged the legitimacy of a psychiatric diagnosis because of the aetiological ambiguity surrounding this category (Barker 2010). Roberta is aged between 51-61 years old and lives with cervical dystonia, a diagnosis that had taken her over two years to obtain. Before arriving at this label, however, she had visited her GP several times complaining of a tremor in her neck. The doctor repeatedly said that her shakes were a result of depression and '*extreme stress*' and would eventually subside. While Roberta had been going through a stressful time at home during the negotiation of her diagnosis, she emphatically dismissed the view that her symptoms were related to psychological factors:

> Roberta: I wasn't happy with what my GP was telling me er because I kne-
> although I was under stress at the time, I knew there was something wrong
> urm don't ask me how I knew but I *just* knew that there was something going
> on with me physically that wasn't to do with urm as me GP put it at the time
> er psychological stress […] I found it very distressing urm I was- I did at that

time urm (pause) I had things going on in my private life as well as knowing

that there was something medically, physically wrong with me […] I was

diagnosed with depression because I- I just could not urm find out what was

wrong. Urm my GP had me almost believing that it- it was- I'd got this

tremor on urm because of my urm home situation, so I- I found it very

distressing urm GP had not particularly taken notice of what I was saying

[…] because of the tremor urm obviously I've tried different ways of

stopping it urm to no avail obviously because it's- it's just not going to stop.

Yeah, I knew there was something wrong but the GP was trying to convince

me otherwise, he was saying that I'd developed this tremor urm because urm

of the stress that I was under. Urm and if I removed the stress from my life

then the tremor would just go away […] I couldn't understand at the time

why is my GP not taking any notice? And in fact I actually felt that I was

being a nuisance. [WADSS participant, pre-intervention interview]

Contemporary Western societies are extremely ocularcentric since they classify

bodies according to hegemonic principles of 'visual perception' (chapter 6)

(Zitzelsberger 2005: 393; Hughes 1999). In fact, from the nineteenth century

onwards, the medical profession began to interpret individuals' forms of embodiment

through optical methods that rendered previously unseen bodily spaces visible and

known to the observer (Foucault 1973). Medicine still relies heavily on technological

mediums to classify and treat patients' symptoms (Rhodes et al 1999; Nettleton et al

2004; 2005; Anspach 2011: xxiv). Though psychological explanations are clinically

valid, there often remains controversy around the cause of these problems given that

no (obvious) structural pathology can be detected (Fahn 2006: 24-25). Organic structures like the brain are clearly visible on medical scanners (e.g. MRI machines) and deemed to be fixed and real, whereas the invisible and intangible nature of the mind means that health professionals struggle to authenticate the existence of mental health conditions (Rhodes 1999; Fein 2012). This inadvertently reinforces the commonly held view that mental illness is caused through irresponsible lifestyle practices (Pollock 1993; Mulvany 2000; Glenton 2003; Rose 2003; Fein 2012). As such, patients with MUS and/or contested illnesses often see the process of having their problems located within psychiatry 'as an expressly delegitimating' one (Dumit 2006: 583).

Related to these ideas, Roberta rejected expert understandings of her enigmatic symptoms because she felt that these had undermined the reality of her suffering. By drawing on her own embodied experiences, she knew that the tremors in her neck would not be improved through relaxation practices. Yet, given that the doctor continued to sideline her concerns, Roberta believed that he had viewed her as a '*nuisance*.' This paternalistic experience of healthcare echoes a study by Ward et al (2009), who have put forward the notion of 'epistemological dissonance.' Such a concept refers to the ways in which medical scientists position their own professional expertise as a privileged type of understanding compared to lay perspectives, despite the fact that recent consumerist agendas emphasise the importance of involving patients in research (*ibid.*). For Roberta, the tension between experiential and medical knowledge during the negotiation of her diagnosis caused her to feel extremely upset, arguably leading to a 'discordant therapeutic encounter' (Mead and

Bower 2000; Barry et al 2001; Bissell et al 2004; Ong and Hooper 2006; Latter et al 2007; Sulik and Eich-Krohm 2008). Yet, since she desperately wanted to absolve responsibility for her disrupted carnality, Roberta continued to emphasise the *involuntary* nature of her embodied subjectivity to the medical profession.

Though some participants said that they had been given a psychiatric explanation, a minority (n=4) had (also) obtained a (tentative) diagnosis of an acute physiological condition. Eric, for example, is aged between 51-61 years old and lives with cervical dystonia. Like Roberta, Eric's experiences of negotiating this label involved repeated visits to the GP for about a year before obtaining a diagnosis. In spite of his attempts to inform the GP of the persistently uncontrollable nature of his embodied discomforts, he kept being told that he had strained a muscle in his neck:

> Eric: […] I was getting creams for urm a- a strained neck, because I was
> weight lifting which, I said to the doctor, 'you could see I do not do weight
> lifting, but I'll try this- try this cream.' And then another doctor was giving
> me pain-killers and anti-depressants, which is, it's not for depression, it's
> usually the muscle relaxant […] and I was going back saying 'well this
> shoulder is about an inch, sometimes two inches higher than that one, all this
> side pulls up' and she'd [GP] say 'take your shirt off. No I can't – I can't see
> what you're on about.' I said (abruptly) 'look! Just look you know it's- it's
> like that.' 'So what we'll do we'll- we'll double the pain killers and we'll
> double the- the er anti-depressants.' I was on two lots of them, and I said
> 'look, you're- you're not treating the problem you know you're- you're you

know like icing over it you're *not* doing nothing.' [WADSS participant, pre-intervention interview]

The sick role describes the point at which individuals' personal experiences of illness are clinically validated, thereby exempting them from carrying out daily routines and activities (chapter 3) (Parsons 1951; Turner 1987; Glenton 2003: 2244). Part of this role not only involves patients taking responsibility for their own recovery but also submitting to the authority of the doctor, while simultaneously having their rights to withdraw from 'normal' social engagements temporarily upheld (*ibid.*). However, the chronicity of their symptoms prompted Roberta and Eric to reject their physicians' explanations and doggedly pursue another diagnosis that aligned with how they were experiencing their bodies from the inside. Researchers contend that the arrival of an appropriate clinical explanation creates epistemic congruity between lay and expert knowledge (May et al 2004). It also permits the adoption of 'acceptable' sick role behaviour in which patients feel that doctors and relatives are taking their concerns seriously (Stewart and Sullivan 1982: 1401; Robinson 1988: 23; Dumit 2006; Lupton 2012). Even though they had technically been granted permission into the sick role on account of their ('wrong') diagnostic labels, Roberta and Eric failed to enter into this position because they had not accepted their clinicians' judgments or ideas about their complaint (Stewart and Sullivan 1982: 1401; Turner 1987). Moreover, Eric generated his own version of the sick role by assuming that successive GPs had violated a key criterion of it: to provide an appropriate explanation of his peculiar and sporadic movements so that he could get better and not feel responsible for his illness. Murdoch et al (2013: 458) found that one of their participants invoked a

modified version of the sick role discourse by exempting herself of accountability for deciding not to take her asthma medication on the basis that it made her feel worse. This participant viewed health professionals as having provided incompetent assistance and ineffective therapeutic interventions (*ibid.*). In a similar way, Eric (and Roberta) failed to accept and enact sick role behaviour, blaming the medical profession for their repeated lack of proficient help in providing an apposite diagnosis of their disruptive symptoms.

In contrast to Eric's distressed reaction to the arrival of a physiological diagnosis, another participant, Larry, was much more understanding and accepting of this label:

> Larry: […] I was just trying to think from when I first had it (dystonia) I noticed I got this problem like I couldn't understand why my head keep- kept moving urm and I'd gone to the doctor and I'd des- I'd gone to the doctor describing it and we'd sort of gone through 'well is it this, is it that?' you know, 'have you strained your neck?' and things you know so we'd gone through the usual you know sort of usual things urm 'cause it's not the sort of thing (brief pause) a doctor would zero in on straight away unless I think unless he'd seen it. [WADSS participant, aged 62 years old or over with cervical dystonia, post-intervention interview, 2 months after initial interview].

Arguably, Larry recognised that dystonia was not an obvious disorder GPs would be able to identify or diagnose straightaway due to their lack of specialist knowledge around elusive and relatively rare medical conditions. While Camfield (2002: 39) has

noted that the general ignorance surrounding dystonia usually contributes to individuals' isolation and suffering, for Larry, using this explanation to vindicate his GP's tendency towards an acute physical problem helped him to make sense of a potentially distressing situation and accept it as a matter-of-course. In some respects, the presentation of a stoical attitude helped him to circumvent feelings of alienation and commit to a socially acceptable form of citizenship (chapter 6). It also enabled Larry to continue searching for assistance from the medical profession without too much disruption to his sense of self. Furthermore, whereas Eric felt that his GP had dismissed the perpetuity of his discomforts and given him an inappropriate diagnosis of, and treatment plan for, strained muscles, Larry's doctor seemed somewhat more inquisitive and open to other possibilities and ideas ('*we'd sort of gone through 'well is it this, is it that?'*'). Greenfield et al (2014) have recently argued that patients report better therapeutic outcomes when healthcare providers give them a 'space' to vocalise their physical and psychological concerns. It can be contended that, unlike Larry, Eric felt his GP had denied him a space to be heard and understood. Overall, by accepting the limitations of expert knowledge at the same time as also feeling listened to (i.e. Larry's doctor did not continually push for a physical diagnosis), he reacted to the prospect that he might have an acute problem in a far less negative way than Eric.

While every participant apart from one (Cassie) experienced the arrival of a (provisional) psychiatric explanation highly disruptively, some who had been tested for a 'wrong' neurological disease (e.g. Parkinson's disease, multiple sclerosis, stroke) all accepted that this was part of the medicalisation process (n=7). Like Larry,

they believed that healthcare providers might not have been able to identify their symptoms correctly straightaway because of a lack of awareness around dystonia and the fact that dystonic symptoms appear similar to other neurological conditions. One WADSS participant with cervical dystonia also said that she had given her GP the benefit of the doubt when he had tentatively diagnosed her with a neurological problem (e.g. Edna: '*Oh like er the doctor said er 'I [think] you've probably got benign shaking syndrome' [...] so I'll give him his due.*' [Post-intervention interview, two months after initial interview]). These participants may have been more tolerant of obtaining a (provisional) diagnosis of a neurological disease in comparison to many of those who had received a psychiatric one because of the authority invested in brain-based explanations (see 'arriving at a diagnosis of dystonia' section) (e.g. Pickersgill and Van Keulen 2012).

Though many participants had obtained at least one ('wrong') diagnosis before (eventually) getting the label of dystonia, some reported that they had initially been unable to acquire any medical explanation whatsoever (n=7). This phenomenon has been referred to as 'demedicalisation', or the point at which 'a problem is no longer defined in medical terms and medical treatments are no longer seen as directly relevant to its solution' (Conrad and Schneider 1992: 255). For participants, this meant that they were denied access to care and support, as well as the right to make sense of their bodily experiences through an authoritative medicalised lens (Lillrank 2003; Dumit 2006; Nettleton 2006; Jutel 2010). A minority of participants absolved the medical profession of responsibility for these issues by recognising that there was a dearth of information and awareness surrounding dystonia (e.g. Bella: '*the GPs*

didn't have any knowledge of the situation […] there's not been a lot of awareness or understanding, I don't think.' [WADSS participant, post-intervention interview]). Yet, other participants struggled to accept or 'rationalise' this unfavourable reality and subsequently, experienced a discordant therapeutic relationship (e.g. Ong and Hooper 2006). Rachael is aged 62 years old or over and lives with oromandibular dystonia. She described her route towards getting a clinically valid diagnosis as deeply frustrating and distressing given that her GP had repeatedly failed to act empathetically or engage in a meaningful discussion about her embodied concerns:

> Rachael: […] they (the medical profession) took about between four and five years to diagnose urm they just kept saying that they couldn't see anything, but he's (GP) sitting with his computer here and he's typing away, I was hoping he was actually listening but I wasn't sure and uhm at the end of me telling my story to him, he said 'well I can't see anything' which I thought was like a big put me down. So he'd never heard of it and it turned out that in my er medical practice where my GP is, they've only got one other patient with –with dystonia, so it's very hard to get er some attention […] At the beginning you know you're battling like mad to get the diagnosis […] I would be sitting in our dining room making the call (to The Dystonia Society's helpline) and at the same time just *streaming* with tears. [Support Group 2 member, group interview 2]

It can be contended that Rachael's preference to fall under medical surveillance collided with her GP's ignorant and dismissive attitude, which disallowed her from obtaining a desperately sought-after explanation of her presenting complaint. That

Rachael felt her GP had limited knowledge of her symptoms was apparent in the way he had used the medical gaze to misinterpret her (temporarily) ordered body as 'normal.' Broom and Woodward (1996) have suggested that researchers ought to demarcate between the terms 'medicalisation' and 'medical dominance.' Whereas the former can be experienced and perceived in various ways, the latter, medical dominance, is always problematic (Maseide 1991; Broom and Woodward 1996; Massé et al 2001; Prior 2003; Busfield 2017). Arguably, the doctor had acted as a dominant player in the consultation by privileging medical (visual) means above Rachael's sensate and dynamic experiences. Since specialist and generalist doctors have been found to make female patients feel guilty for demanding an explanation of their mysterious symptoms, Thomas (2001) has pointed to the intersection of disablism and sexism within medical encounters (see also May 2007). Indeed, the GP's flippant attitude not only contributed to a fractious and unequal patient-doctor relationship but also left Rachael feeling upset and neglected, without any support or help to make her life more tolerable. Compounding the problem, Rachael's GP had reproduced a 'myth of certainty' around the medical implausibility of her symptoms, despite the fact that he had not properly listened to her or referred her for further tests and investigations (Fox 2002; Griffiths et al 2005). Werner and Malterud (2003) have argued that women living with chronic pain experience high levels of indignity and shame because of the ways in which doctors question the authenticity of their claims to be in the sick role. As such, female patients often attempt to make their 'private' experiences of illness socially noticeable during consultations (e.g. by not wearing make-up or smart clothes) in order to be taken seriously and considered 'credible patients' who adhere to socially acceptable ideas about coping and recovery (*ibid.*).

In fact, many participants, including Rachael, performed several strategies such as seeking a second opinion from a private and/or NHS doctor to get their internal experiences of suffering believed and authenticated.

Interestingly, a minority of participants (n=2) reported that, after receiving a diagnosis of cervical dystonia from a specialist, another neurologist retracted this label completely and told them that they were imagining their symptoms (Larry and Liam, same doctor). While Liam reluctantly accepted the judgment of the second specialist, he refrained from using the internet to gather additional health-related information in case it revealed something serious:

> Liam: I did avoid researching [online] because I didn't wanna pick up on something that was- that would be urm affect me you know be er suggestible and put- plant an idea in my mind and that sort of thing that this is what I am experiencing. [WADSS participant, pre-intervention interview])

Due to the fact that his embodied discomforts persisted, Liam returned to his GP a couple of years later and was referred to another neurologist who reconfirmed his original explanation of cervical dystonia. As a result, Liam said that he is not '*well disposed to*' the physician who withdrew his diagnosis but continues to see him for treatment because '*he does a good job.*' Larry had initially been diagnosed with cervical dystonia by a private neurologist courtesy of his company's insurance scheme. This doctor then referred him on to the same NHS physician as Liam for BoNT treatment who also told Larry that his symptoms were '*just a habit*' but administered the injections anyway. In the meantime, Larry went to see another

private neurologist who reconfirmed his original diagnosis. Though he had experienced a circuitous route towards getting a definitive explanation, Larry did not report any ill feelings towards the neurologist who had doubted his dystonia label since he was pleased to have had it verified and been referred for treatment. In a similar way to Leydon et al (2000), who found that patients with cancer relied heavily on the expertise and experience of their physicians to help them get better, Larry also preferred his doctors to take an active role in decision-making rather than engage directly in this process himself:

> Larry: She [1st private neurologist] told me it was dystonia and torticollis [cervical dystonia] and I didn't (pause) I didn't look it up, I didn't- I didn't really want to know anything about it in my own mind. It was a bit like 'okay I've got it. Give me this injection and let's get rid of it.' That was my approach and I really didn't want to know. [WADSS participant aged 62 years old or over, post-intervention interview, 2 months after initial interview]

Recent shifts in healthcare policy concerning the patient-doctor relationship have transformed the landscape of medicine, and by proxy, laities' experiences of provision (Mold 2010). Previously considered the exclusive domain of the (paternalistic) medical profession from the eighteenth to the first half of the twentieth century, patients and clinicians are currently expected to proffer their own views of treatment and act as cooperative partners within consultations (Armstrong 1984; Mead and Bower 2000; Bissell et al 2004; Sulik and Eich-Krohm 2008). Indeed, one Support Group 2 participant, Allen, willingly and enthusiastically took an active role in his healthcare by attending support group meetings, collating archival information

on dystonia, and keeping a week-by-week diary of his symptoms ('*I try and give as much useful information to him [neurologist] so that he's got more to work on. I don't think you can afford to be vague when you've got dystonia, I think you've got to be proactive.*' [Semi-structured interview]). In this way, Allen developed an 'expert patient' health identity in which he provided his doctor with information on his disorder (Fox and Ward 2006). This type of medicalised identity is 'part of a much larger trend that is demanding change throughout medicine' (Taylor and Bury 2007: 41). It is particularly common among individuals with rare diseases, who often become expert patients on their condition because of the insufficient expertise of their clinicians (Budych et al 2012). Yet, researchers also note that not every person wishes to take responsibility for the management of their illness (e.g. Lupton 1997a, Leydon et al 2000; Henwood et al 2003; Sulik and Eich-Krohm 2008; Seear 2009). In fact, Larry preferred to relinquish power back to the various clinicians looking after him to avoid thinking about his condition, although he still performed an active, consumer-led role by seeking a second opinion from a private doctor. However, upon meeting the physician, he then wanted them to take control of the situation and solve his undesirable problem so that he could return, as far as possible, to his pre-dystonia self. Frank (2013) has referred to this stoical understanding of illness as a 'restitution narrative' in which individuals accept that they are presently unwell but hope to revert to a state of normality in the not too distant future. Arguably, Larry's stoicism and belief in the medical profession to alleviate his symptoms enabled him to circumvent feelings of distress and abandonment in the face of clinical ambiguity. This may have been made somewhat easier by the fact that he was able to use private healthcare insurance and eliminate uncertainty fairly swiftly in comparison to other

participants who did not have access to this resource. Thus, concordant therapeutic

encounters may develop from social inequalities operating within and outside of

medical systems, indicating a possible drawback of positive healthcare outcomes

(Ong and Hooper 2006).

This section has explored participants' accounts of negotiating a clinically valid

diagnosis that also aligned with their unique sense of embodiments. Some

participants were able to justify the limited and uncertain nature of expert medical

knowledge of dystonia, and in turn, circumvent or reduce feelings of distress and

isolation. However, many participants became alienated from the domain of

medicine and felt unable to move forward with their lives, particularly upon hearing

that they were mentally unwell or simply imagining their symptoms. Still, all

participants who came up against the boundary of medicine in some way used their

experiential knowledge to cope with their disruptive bodies alongside their

negotiation of a suitable diagnosis. This finding supports Cassidy's (2012) study on

the subjective experience of ataxia in which individuals with this neurological

disease often have to self-manage their condition given that clinicians do not listen to

their perspectives or take much interest in their personal viewpoints. My research

also demonstrates that the degree to which participants felt physically and

emotionally able to 'carry on' with their lives, regardless of encountering a range of

obstacles, significantly varied according to the meanings they ascribed to particular

diagnoses. For example, whereas disorders of the mind were mostly viewed as

illusory and amenable to improvement through the responsible self (Rose 2003; Fein

2012), participants subjected ('wrong') brain-based explanations to less scrutiny and

criticism because they felt that these had absolved them of blame for their troubling symptoms (Fein 2012). Since participants' perceptions of particular diagnostic labels shaped their experiences of medicine, they used these understandings to search for more appropriate and/or definitive explanations of their enigmatic complaints. In this way, participants' experiential knowledge intersected with authoritative medicalised frameworks and ideas throughout their lived trajectories, even at times when they pushed against particular expert judgments (e.g. see Markens et al 2010).

Arriving at a diagnosis of dystonia

Receiving a socially legitimated diagnosis can provide patients with several benefits such as psychological relief and access to treatment(s) (Peters et al 1998; Rhodes et al 1999; Glenton 2003; Lillrank 2003; Nettleton et al 2004; 2005; Huibers and Wessely 2006; Nettleton 2006; Broom et al 2015). In addition to this, it can inspire the formation of collective patient identities (chapter 7) (Rapp 1999; Rapp et al 2001). While agents may find that the path towards diagnosis is difficult and circuitous, acquiring a label that not only aligns with their subjective experiences but also emphasises the biological attributions of their symptoms may offer some clarity and respite from stigma and shame (Huibers and Wessely 2006).

As noted in my background chapter (chapter 2), diagnoses are discursive concepts that develop in confluence with a range of epistemic (dis)agreements occurring within and between (quasi)medical institutions (e.g. Stockdale 1999; Hedgecoe 2003). Moreover, they are 'embodied modalities' that disclose something meaningful about an individual's life context and way-of-being in the world (Csordas 1994;

Csordas et al 2008). Indeed, many participants felt comforted by the fact that their symptoms had (finally) been located in the organic structure of the brain. The arrival of a *neurological* diagnosis, therefore, lessened feelings of culpability and confirmed the existence of their troublesome experiences (Pollock 1993: 56; Bendelow 1996; Camfield 2002: 38-39; Glenton 2003; Rose 2003; Huibers and Wessely 2006; Fein 2012). For example, Kim is aged 62 years old or over and has been diagnosed with dopamine-responsive dystonia. Like some of the other participants in my research, doctors (and social familiars) thought that she was psychologically unwell before a neurologist eventually confirmed the problem. Prior to the arrival of her dystonia label, however, Kim almost conceded to the view that her mental state had caused her muscles to spasm since she lacked an alternative (medical) explanation. Lillrank (2003: 1051) also found that some female patients reluctantly began to believe their pain was psychosomatic after doctors suggested they had imagined it. Nevertheless, Kim recalled her relief and satisfaction at finally receiving her dystonia label given that it tallied with the ways in which she experienced her body:

> Kim: […] before I had a diagnosis for my dystonia, because I struggled for years with it. Uhm so many people told me it was all in my mind that I almost began to believe it. And uhm I- it was a relief to get a diagnosis because now I can tell people that it's neurological you know it's not in my mind. [Support Group 1 member, group interview 3]

Interestingly, another participant, Cassie, insinuated that getting her diagnosis of dystonia had proved the reality of her physical symptoms:

Cassie: I was actually going to the (hospital name) and the psychiatrist I was seeing wanted to check up whether it was nerves or- I was shaking I have writers tremor uhm whether that was just nervous or whether it was real and so she sent me off to a neurologist who said it was real. [Support Group 2 member aged 62 years old or over with focal hand dystonia, group interview 2]

Sociologists maintain that contemporary medicine defines individuals' dynamic subjectivities in relation to cerebral explanations because of the power invested in neurotechnologies to detect visible pathologies (Vidal 2009; Fein 2012; Rapp 2012; Singh 2012; Pickersgill and Van Keulen 2012; Gardner 2014). Gardner (2014) has coined the term 'neurosociality' to denote the ways in which dominant neuro-discourses and practices produce a profound impact on patients' accounts of health and disease. Whereas psychiatric illness attributions may be viewed as problematic due to their associations with personal defectiveness and accountability, neurological explanations refer to symptoms as originating within a physical system that is deemed to be immutable, morally blameless, and regulated by predictable biological processes (Fein 2012). The brain is also considered a Western motif for intellectualism and rationality, an understanding that is entirely different from the supposedly feckless and unstable mind (Camfield 2002: 16; Rose 2003; Jackson 2005; 2011; Vidal 2009; Fein 2012). In fact, participants praised the medical profession – particularly neurological medicine – for legitimating their embodied concerns at the point of a diagnosis of dystonia because it had absolved them of responsibility for their 'deviant' and erratic bodily behaviours (Pollock 1993: 56;

Bendelow 1996; Camfield 2002: 38-39; Glenton 2003; Rose 2003; Fein 2012). The uncontrollability of Kim and Cassie's shakes and spasms demonstrated the immunity of their symptoms from personal and external factors. That is, by agreeing with health professionals that the origin of their dystonia was in the robustly physical brain and not the unpredictable mind enabled Kim and Cassie to conceptualise the disciplines of psychiatry and neurology as irrevocable 'rivals' (Camfield 2002: 88). They also used the theoretical suppositions underlying cerebral explanations to demonstrate to social familiars that their symptoms were a result of a malfunctioning brain that could not be altered through the adoption of responsible lifestyle practices (albeit, as will be discussed in chapter 6, participants activated health self-management discourses to cope with their condition).

However, given that the idiopathic and genetic dystonias are often difficult to identify on MRI scanners (Standaert 2011; Albanese et al 2013: 11; Jinnah 2015), this ambiguity can open up questions surrounding the usefulness of neurologic discourses and practices. During a group discussion on the experience of getting a dystonia diagnosis, Kim tried to convince a participant in his early thirties (Oscar) that medical technologies struggle to display the basal ganglia:

Kim: Of course it's (dystonia) uhm it's difficult to diagnose 'cause it doesn't show on neurological tests does it? (Matt: No) This is the trouble so it is difficult –

Oscar: I don't know.

Kim: No, no it doesn't show.

Oscar: In what sense? You mean the sort of brain scan type -

Kim: Well yeah like brain scans, MRIs it wouldn't show up. You know 'cause everything comes from the basal ganglia doesn't it and that wouldn't show up would it? [Support Group 1 members, group interview 3]

As demonstrated previously, Kim viewed her neurological diagnosis positively because of its biological attributions. Despite the fact that some dystonias can be 'confirmed' as organic through a gene test (Charlesworth et al 2013), she still believed that a malfunctioning in the basal ganglia was primarily responsible for causing dystonia. However, the perceived lack of clinical data supporting this explanation threatened Kim's understanding of it as a biological (viz. socially legitimated) condition. Yet, she continued to invest power in (unverifiable) neurologic perspectives at the same time as resisting psychiatric ones, probably because of the stigma surrounding mental illness (e.g. Camfield 2002). Indeed, while she reported that neurological tests are unable to identify pathological abnormalities in the brain, the basal ganglia still held significance since it facilitated her belief in the reality of dystonia. This can be noted from the persistent way Kim reiterated these points to Oscar, who admitted that he had not previously known about them. Oscar's (generalised) dystonia had been caused by a lack of oxygen to his brain at birth. Unlike Kim who had initially been misdiagnosed with a psychiatric problem, Oscar had always known from early childhood that he had dystonia. Despite the fact that the problems he faced was getting the medical profession to decide which type he had, Oscar had accepted this uncertainty and used his dystonia diagnosis to make sense of his condition. Arguably, these reasons may potentially explain why he had not previously considered the issues with diagnostic imaging particularly notable,

demonstrating the degree to which he regarded some neuroscientific constructs as more relevant to his experiences than others.

While most participants experienced a discordant therapeutic relationship during the negotiation of a diagnosis (Ong and Hooper 2006), a minority (also) perceived the arrival of a definitive dystonia label extremely negatively (n=3). For example, Megan is aged between 51-61 years old and has been diagnosed with cervical dystonia. After experiencing painful tremors and shakes in her neck in late December 2012, she decided to visit her GP to find out what was wrong. Since he was concerned that she might have something serious, the GP referred her on to an emergency doctor for further investigations. At the hospital, clinicians tested her for different neurological conditions such as stroke and Parkinson's disease but concluded that she did not have any of these illnesses and so, sent her away with a prescription for painkillers. In the meantime, Megan checked her symptoms online to try to ascertain what they could be. Having been directed to The Dystonia Society's website, she thought that she might have dystonia and felt reassured that a range of treatments were available ('*I read a lot and I knew that there was treatment that you could have [...] I knew there was ways possible ways through it.*' [WADSS participant, pre-intervention interview]). Arguably, this demonstrates that the internet can produce a profound impact on patients' perceptions of their symptoms and abilities to cope (Hardey 1999; Eysenbach 2000; Ball and Lillis 2001; Collins and Evans 2002; Dolan et al 2004; Ziebland et al 2004; Fox et al 2005; Broom 2005; Wald et al 2007; Ziebland and Herxheimer 2008). Megan then went back to her GP after none of her symptoms had improved and got referred to a junior neurologist in

February 2013. The doctor looked at the posture of Megan's neck and could tell '*within a minute*' what she had but wanted to consult with her superior before officially confirming the diagnosis. That same day, a consultant neurologist formalised Megan's diagnosis. Even though she had been aware that she might have dystonia, Megan described getting it medically verified adversely:

> Megan: Once I you know I-I- once I knew that that's what I'd got (dystonia), then I'd got to think about what- 'well, how I'm going to live with it you know, what- what's it going to do (to) me? Is it going to-' because I was told it could get worse, so or we might be able to make it better, which obviously it has become a lot better. But urm yeah […] I did as I say I did reach some deep parts and I thought 'how is this gonna affect the rest of my life?' […] but urm as I said I'm in a lot better place than I was because I didn't you know didn't kno- what- what was gonna happen in the future and whether I was gonna be like this forever, was it going to get any better? [WADSS participant, pre-intervention interview]

Clinical labels are interpreted in and through an embodied self that variously responds to these medicalised constructs (Wittink et al 2008). In particular, the arrival of Megan's diagnosis generated a range of existential uncertainties concerning her future life with dystonia, including whether it would worsen and how she would cope if it did. Bury (1982) has argued that the arrival of a diagnosis can be emotionally upsetting and 'biographically disruptive.' This is because it can threaten an individual's previous stocks of knowledge and require them to re-work their identity in light of new information and ideas (Bury 1982; Pinder 1992; Tobin and

Begley 2008; Balmer et al 2015). Megan's negative experiences of getting her dystonia diagnosis may have been further compounded by the fact that she received it relatively quickly (i.e. within a couple of months), although, as with many of the participants in my research, her route towards diagnosis was still circuitous. Ashtiani et al (2014) found that timing was crucial in determining parents' responses to receiving their child's genetic diagnosis. Indeed, parents who experienced a shorter diagnostic odyssey were less prepared to receive the news than those who were told about their child's illness much later (*ibid.*). Similarly, for Megan, the expedient arrival of her diagnostic label marked an 'experientially incoherent' time in her life (Pinder 1992) since she had not previously considered how the chronicity of her complaint would affect day-to-day functioning.

Megan's experiences align with those of Eric who suspected that he might have dystonia after researching his symptoms online but became upset when a neurologist verified the news (*'just it's- it's strange because you know that you had it, but the minute you get diagnosed, it's ten times worse.'* [WADSS participant, pre-intervention interview]). Eric might have felt emotionally distressed at the point of diagnosis because the faith that he had invested in the medical profession made it seem more serious and real. Tobin and Begley (2008: 36) have noted the 'transformative power of diagnosis' for patients with cancer, whereby receiving one metaphorically moves them 'from personhood to pathology to a new perspective of personhood.' These changes 'brought about through labelling' can leave individuals feeling disoriented and disempowered, as well as unsure of how to integrate their new diagnostic embodiments within their day-to-day lives (*ibid.*). Similarly, Megan

and Eric's negative experiences demonstrate the degree to which obtaining a diagnosis can be an incredibly exhausting and strenuous time (Pinder 1992; Tobin and Begley 2008; Cassidy 2012). However, despite the fact that a minority felt uncertain about their (future) lives as a result of the information they had been given, all later came to appreciate the benefits of having a definitive diagnosis of dystonia (e.g. Megan received valuable advice at a seminar organised by The Dystonia Society).

This section has examined participants' experiences and understandings of getting a firm diagnosis of dystonia. Since receiving a clinically valid label permits individuals access to medical therapies (e.g. Dumit 2006), the next part explores participants' perceptions and actual uses of treatment.

Experiencing dystonia treatment

Receiving a dystonia diagnosis enabled participants to trial a range of therapies that had previously been inaccessible to them (e.g. medication, surgery, BoNT, and/or CAM). In particular, participants reported that they had decided to engage with treatment in order to manage their disrupted carnalities. Only two participants, Sheila and Oscar, said that they had stopped using orthodox medical interventions after they found none were effective. However, Sheila still took homeopathic remedies and attended support group meetings in the hope of listening to medical speakers present new information on orthodox treatment. Participants' experiences of (un)orthodox therapeutic approaches changed across different contexts and varied significantly based on their personal histories, fluctuating impairment effects, and particular

healthcare needs at specific temporal locations. During a group discussion between Support Group 2 attendees, for example, some participants emphasised the positive bodily transformations that one member, Xavier, had gone through since undergoing surgery to alleviate his dystonic movements:

Xavier: Well in the last year or two I've had a – a neurological operation on the brain, with what's called (Deep) Brain Stimulation […] I've enjoyed sharing my experiences [of having DBS] with the members of the group.

Charlotte: Sure.

Xavier: You know the problems and the (pauses) the benefits.

Cassie: We could see what a dramatic effect it was having.

Charlotte: I was just thinking actually, when you were talking, I was having flashbacks to those early days and the body movement and – and the body language and how *completely* different and relaxed you've been now to back then. (Group members make agreeing sounds)

Xavier: Yes, yes I'm a lot stiller, I'm a lot freer from pain –

Charlotte and Jasmine: (In unison) Yes.

Xavier: But there is still movements and difficulties.

Jasmine: Course.

Charlotte: Yeah. But his facial expression is much happier –

Jasmine: Yes.

Charlotte: And the sparkle has come back in your eyes.

Jasmine: You don't look so –

Miranda: And I think you've put on a little bit if weight as well.

Jasmine: Tense, does he?

Rachael: (To Miranda) Yeah.

Jasmine: Fabulous! (Laughs)

Charlotte: It is.

Jasmine: I think we could all do with a dose of that. [Group interview 2]

Camfield (2002: 41) has argued that the ways in which therapies are communicated to people with dystonia typically focus on the positive aspects 'of overcoming [the condition] and normalisation which perpetuate negative stereotypes of people with disabilities.' This is not to suggest that participants' engagement with therapy did not improve uncomfortable or painful bodily sensations. Rather, while Xavier created a relatively measured account of therapeutic outcome, other participants used their perceptions of his less noticeable, post-surgery body in order to recast his treatment experiences positively (I return to the issue of the changing social (in)visibility of disability in chapter 6) (Goffman 1963). Through this particular group interaction, Charlotte, Cassie, Jasmine, Miranda, and Rachael pooled together their experiential (empathetic) knowledge to frame their understandings of Xavier's DBS journey in a somewhat different light to him. Indeed, Xavier said that he has to manage ongoing challenges that are perhaps no longer as visible to other people but yet still as problematic as before he had surgery. Even though Jasmine briefly acknowledges this comment, she ends the conversation agreeing with the viewpoints of the other female attendees. This is because their focus on the seemingly beneficial outcomes of Xavier's treatment helps to create and sustain a collective support group identity that is characterised by the re-appropriation of medical knowledge (chapter 7). Indeed, these Support Group 2 participants attributed a particular meaning to Xavier's

experiences of treatment by communicating their experiential knowledge in a quasi-medical setting and forming a shared patient identity built closely around medicalised agendas.

Other participants' personal narratives of medical therapy demonstrated the ways in which their perceptions aligned with socially constructed notions of bodily 'competency' and 'desirability' (chapter 6) (Paterson, K 2001; Zitzelsberger 2005). Ruby, for example, has been diagnosed with cervical dystonia and currently uses BoNT in order to treat the spasms in her neck. She reported that this treatment has helped to correct her affected muscles and subsequently enabled her to regain a sense of control over her body:

> Ruby: I couldn't keep it [head] straight you know on its own and most of me photos me head's (laughs) all you know all like that you know I try and keep it where it should be like you know.
>
> Celia: Yeah and how did that make you feel?
>
> Ruby: It was a bit embarrassing really because you know if […] I met somebody I've gotta have them so they was right on me left 'cause I had to look that way to 'em I couldn't have sat really much like you know stood like this now […]
>
> Celia: How do your current symptoms compare to before you had them [BoNT]?
>
> Ruby: Oh a lot better [Celia: Okay] I couldn't have of sat now [Celia: Yeah] I mean I think I'm more or less straight now but you know within a few

seconds it (head) would have gone you know without me [Botulinum]

injections – I do need me injections. [NHS Hospital 1 patient]

There is a substantial corpus of literature around the issue of unified selves and
bounded bodies that denotes the ways in which these types of carnalities and
identities map on to Westernised notions of order and containment (e.g. Williams and
Bendelow 1998; 2000). Indeed, embodiment authors suggest that female bodies are
considered corporeally transgressive because of 'uncontainable' and 'unhygienic'
fluids produced during natural events such as menstruation and childbirth (Battersby
1993; Lawton 1998; Williams and Bendelow 1998: Ch 6; 2000; Hallam et al 1999:
11). Arguably, corporeal (un)predictability echoes social (dis)order (*ibid.*) and resides
in moralistic ideas about the social worth of those who can(not) control their bodies
(Lawton 1998). Before using BoNT, Ruby said that she found it difficult to interact
with other people since the unintentional consequences of her impairment flouted
taken-for-granted rules and protocols underlying 'polite' social behaviour (Paterson,
K 2001). In contrast, however, she reported that using BoNT has transformed her
previously uncontrollable corporeality into a more manageable one. As such, Ruby's
engagement with treatment has enabled her to perform a more bounded – and hence,
socially competent – identity in which she feels less stigmatised than before. This
also highlights the wider political implications of treatment for normalising
'uncontainable' and 'undesirable' bodies (Brisenden 1986; Oliver 1990; Barnes
1992; Camfield 2002: 41; Swain et al 2003).

Bury (1991) and Calnan and Williams (1996) have maintained that using treatment is usually experienced turbulently because of fluctuating therapeutic outcomes. Indeed, even though many participants reported that having treatment had successfully reduced the presence of their symptoms (e.g. pain, spasms), others also noted the ways in which its therapeutic effects had gradually worn off over time and produced experiential uncertainty (e.g. Beth: 'w*ell it [BoNT] worked very well when I went initially and urm I thought I was virtually cured [...] but just lately it's got worse and I'm wondering if I've got sort of immune [resistance] to it.*' [NHS Hospital 1 patient]). Compounding the problem, participants spoke about having to adjust to adverse side effects and/or negotiate more effective forms of treatment. Participants adopted a range of strategies and responses in order to manage these ongoing challenges and create harmonious interactions with clinicians. Zara, for example, experiences spasms in her neck and currently has BoNT to reduce these symptoms. However, much to her dissatisfaction, a neurologist told her to take medication because he thought she would not benefit from BoNT:

> Zara: Urm I was only ever offered tablets [from the medical profession]. Now, I don't even take a tablet for a headache; I've got a very bad swallow so to take anything I have to put it into a banana and eat it that way, that's the only the way I can take anything er medication. So and because the tablets- I did try the tablets for a little while but they made me very drowsy and because I- I work split shifts you know I can't be like that, I've got to be alert especially with fryers and ovens and grills you know so I went back and urm I actually went to see a consultant in (city) because I had a pub in (city) at the time and I asked him if there was anything else they could do for me and

they- because this lady I'd been to, she told me that Botox [botulinum toxin injection therapy] could help and he said 'we wouldn't even consider doing Botox.' He said 'we'll consider giving you medication' but I explained the medication made me drowsy it didn't make me you know I wasn't alert to be in kitchens busy kitchens and I said- and then he said 'no, but it will get a lot worse for you.' And I actually did walk out of there you know I just said 'well, if that's all you can offer me then I- sorry I won't be coming back to ya.' So I've lived with it [dystonia] for quite a lot of years then you know the situation was there […] I mean I went to a doctor in (county) about a year and a half ago and I was telling him, this is when I was trying to get Botox urm done […] I got the Botox it just made me feel so much better. [WADSS participant, pre-intervention interview]

While I return to Zara's everyday experiences of dystonia in chapter 6 to explore the difficulties that she faced in spite of using BoNT (which she feels has become less effective in recent times), it is clear that she viewed this treatment more favourably than taking tablets. Since using medication brought up various problems and interfered with her day-to-day life, Zara mobilised these troublesome experiences to reject the first neurologist's advice and search for more suitable care elsewhere. In addition to the uncontrollable effects of her dystonia (chapter 6), the medication also prevented Zara from performing a professional identity because she felt drowsy and unable to execute her expected duties as a pub chef. Consequently, Zara's personal experiences of using treatment allowed her to accept specific kinds of expert understandings and practices that directly corresponded with her subjective

perspectives (i.e. BoNT). Markens et al (2010) found that pregnant women used a conjunction of medical and experiential knowledge sources to interpret their reproductive risk and make decisions about prenatal testing. Indeed, though agents often privilege their subjective experiences to challenge expert explanations and practices that are not consonant with their life contexts, they still frame and structure their understandings of embodiment in medical terms (Boardman 2010; Markens et al 2010). For example, participants in Boardman's (2010) study refuted certain kinds of medicalised definitions of SMA (e.g. muscle wastage) at the same time as absorbing more relevant scientific descriptions into their illness accounts (e.g. muscle weakness as a result of the ageing process). Similarly, Zara challenged the experientially unacceptable judgments of one doctor and agreed with the recommendations of another, thereby enabling her to re-appropriate medicalised frameworks and remain firmly within the cultural perimeters of medicine.

In addition to their subjective experiences and perceptions of treatment, participants said that *how* their care was delivered was as important as whether it was successful. For instance, two support group participants reported that a range of health professionals (GPs, neurologists) had lacked empathy and understanding of their situation, repeatedly failing to consider the impact of their condition on their daily lives (Kim and Matt). Another support group participant, Irene, also became annoyed when her neurologist made a flippant remark about the fact that her head kept moving backwards after having BoNT ('*I told them about this and the man [neurologist] all he said was "well it just shows it's (BoNT) working then isn't it?" He said and he sort of laughed it off which I wasn't too happy about.*' [Semi-

structured interview]). Others had been fortunate enough to receive treatment from an empathetic and knowledgeable doctor relatively quickly. Malcolm, for example, reported highly positive interactions with his neuro-surgeon, leading to a harmonious and informed consultation:

> Malcolm: I had an operation with Mr (neurosurgeon's name) at (hospital) and before the operation he sat down with me for an *hour* and insisted that my wife come in as well. For an hour just talking he could not have been more sympathetic […] and you didn't feel as though he was in a rush to get away. He said 'sit down, let's talk about this.' He was wonderful. [Support Group 1 member, group interview 1]

Consequently, the interviews revealed that participants valued empathetic interactions with health professionals who also had sufficient knowledge of their condition. This was important for enabling participants to discuss their embodied needs and preferences during consultations, although not necessarily the impact of social stigma on their day-to-day lives (chapter 6).

Some participants said that they utilised CAM (e.g. meditation, acupuncture, homeopathy) alongside or instead of orthodox therapies in order to obtain treatment that aligned with their embodied experiences (n=8). Participants also mentioned that they used 'integrative medicines' like physiotherapy, hard neck collars, and/or tinted glasses with positive therapeutic outcomes. In addition, nine participants found their participation in a combined cognitive behavioural and mindfulness programme mostly beneficial (Sandhu et al 2016). While one support group participant, Ollie,

had unsuccessfully trialled several (non)orthodox therapies, he positively described going to meet a counsellor to discuss his distressed feelings about living with dystonia:

> Ollie: […] And then I had uhm (Botulinum) injections in my back tried that no good and I tried osteopaths and all sorts of things like that. I got a bit low for a while so I had to see a nice lady who tried to say 'don't do away with yourself, you've got plenty to look forward to.' [Support Group 1 member, group interview 3]

After speaking with the counsellor, Ollie felt more emotionally prepared to return to his GP and request a referral to a specialist, who subsequently prescribed him some medication that quickly improved his dystonic symptoms ('*I took those [trihexyphenidyl tablets] home and the next morning I took them and they worked pretty much straight away.*'). Arguably, using a talking therapy enabled him to feel less upset about his life and more empowered to take a pro-active role within the orthodox medical structure, prompting clinicians to provide care that was commensurate with his sense of embodiment. Lowenberg and Davis (1994) have argued that non-orthodox support is often an extension of medicalisation given that it co-exists within the same cultural system as orthodox expert frameworks (Sharma 1996; Cant and Sharma 2014). This can also be noted from the ways in which alternative practices are conceptualised as 'treatments', 'therapies', or 'medicines', echoing traditional biomedical agendas (Sharma 1996; Cant and Sharma 2014). In fact, participants' belief in the power of (non)orthodox approaches (e.g. pharmaceuticals, counselling, acupuncture, meditation) to resolve or improve

embodied suffering, demonstrated the authority and legitimacy that they afforded to both.

Scholars have debated how far holistic practice challenges the operation of social power within and outside of the therapeutic encounter, as well as exists as a substitute to the hegemony of orthodox medicine (Kelleher et al 1994; Saks 1994; Sharma 1996; Scott 1998; Coulter and Willis 2004). My data highlights that the boundary between the two is difficult to determine since none of the participants reported that they used alternative therapies to reject orthodox medical agendas or collectivise against wider forms of oppression. This was because they wanted their healers to treat their complaint rather than undertake political action, even though issues of discrimination and social inequality negatively affected wellbeing (chapter 6). Specifically, participants used non-orthodox approaches to improve their physical symptoms (e.g. Sheila: '*I think I'd reached the point then where the homeopathy was starting to have an effect.*' [Support Group 1 member, semi-structured interview]) and/or obtain professional recognition of the daily impact of their disorder (e.g. Matt: '*I've actually sat down with a psychologist for an hour and that's [...] helpful [...] just to speak to someone [...] who just listens to you and you know doesn't judge and can understand.*' [Support Group 1 member, semi-structured interview]). Contemporary (non)orthodox clinicians (are expected to) consider patients' bodies *and* their emotional responses to illness (Zollman and Vickers 1999). Arney and Bergen (1983) have also argued that the rise in patient-centered medicine and the emphasis on patient-centered practice has endowed the medical profession with further authority to define and treat people's physical, emotional, and social

experiences under the benevolent rubric of 'individual choice' and 'democratic healthcare.' Orthodox and alternative systems sustain hegemonic ideas about self-responsibility and autonomy to varying degrees and intensities, whereby agents usually decide to use healers and/or clinicians to proffer individual solutions to personal issues (Sharma 1996: 252-253). Indeed, as discussed throughout this thesis, participants situated their 'private' suffering firmly within an individual (medical) framework in which their decisions to utilise (non)orthodox interventions related to the amelioration of their physical and/or psychological difficulties and not 'the social restrictions imposed by society' (Oliver 1990: 58).

Thus far, I have described participants' experiences of negotiating an appropriate diagnosis and treatment plan. Given that participants experienced several problems with using dystonia therapies, their faith in the integrity of the medical profession could sometimes become threatened. However, as I now move on to explore, they drew on positive representations of Western medicine to reduce feelings of distress and justify their ongoing engagement in treatment.

Reimagining medicine

Despite participants' efforts to obtain suitable healthcare provision, their optimism around medicine closely intertwined with their embodied need to control, and most crucially, erase their dystonic symptoms (I also examine support groups' interpretations of cures in chapter 7). Yet, since chronic conditions fluctuate over time and space (chapter 6) (Shakespeare 1996; 2006; 2014; Lindgren 2004; Thomas 2007; Larsson and Grassman 2012; Karlsson et al 2014; Kimbell et al 2015), patients

and health professionals may be unable to arrive at a reliable prognosis and treatment plan (Davis 1960; Fox 2002). In order to cope with this uncertainty, Davis (1960) has argued that patients often transform their emotionally turbulent experiences into positive understandings of the future. Matt, for example, reported that he had been experiencing several difficulties with living with cervical dystonia. Consequently, he turned to the medical profession to help him manage the spasms in his neck. Though he found BoNT ineffective, he continued to attend appointments in order to allay any fears about his dystonia worsening. For Matt, retaining a profound sense of hope in the medical profession enabled him to feel more in control of his uncertain future:

> Matt: […] urm like you (Ollie) said I mean when- when like you get low you think there's nothing that can be done or I mean even going to see (BoNT injector) gives you a bit of hope doesn't it?
>
> Ollie: Yep.
>
> Matt: So I mean that's why I go and see her as well – […] Well I asked him (neurologist)- I asked him for this review so that I could possibly see (BoNT injector) and that and urm he'd got a new strain of urm Botox [Kim: Yeah] because he knew the other stuff wasn't working with me and he went 'this is your review' and that was it and so he normally only gives me three injections but he gave me six that day.
>
> Kim: Did they work?
>
> Matt: No but then it's the- you wonder if you don't go you'll be worse-
>
> Kim: Worse, yeah […]

Matt: I mean what- what we all want really is a cure [Kim: Mmm] but you

know probably not in our lifetime but you know you hope. [Support Group 1

members, group interview 3]

Within the literature, there has been a range of debates surrounding the socio-

political implications of medical cures for people living with chronic conditions.

Disability rights scholars, for example, argue that the cure discourse is indicative of

disablism within Western societies that seek to 'normalise' and correct socially

'undesirable' bodies (Brisenden 1986; Oliver 1990; 1996a; 2009; Finkelstein 1998;

Boxall and Beresford 2013: 592). Yet, Gwyn (2001) has noted that the altruistic

character of medicine often appears 'charming' to patients in need of respite from the

intolerable effects of their illness (see also de Wolfe 2002; Shakespeare 2006; 2014;

Boardman 2010; 2014b; Beauchamp-Prior 2011). Similarly, Matt's sense of

embodiment was an important motivating factor in the way he approached and

interpreted decisions about healthcare (e.g. see Ziebland and Herxheimer 2008),

despite the fact that he had not yet found an effective therapy to correct the

involuntary muscles in his neck. Nevertheless, Matt wanted to continue using

treatment because hegemonic medical discourses about recovery tallied with his

dynamic subjectivity of not wanting to live in a disrupted body. His enduring belief

in the productivity of medicine also corresponds with Britten's (1996) notion of

'orthodox' medical accounts. This idea refers to the ways in which individuals

validate medical knowledge by presenting 'a taken-for-granted view of drugs and

medicine' (Britten 1996: 68). Where Matt did challenge his treatment experiences, he

did so in relation to its ineffectiveness rather than move beyond the perimeters of

medical knowledge or generate any broad critique of the nature of medicine *per se* (Britten 1996). Furthermore, he tried to avoid entering into an uncomfortable state of 'cognitive dissonance' (Festinger 1962) by relying on the medical profession to provide a cure and proffer appropriate help, even though his experiences of having treatment repeatedly contravened this underlying expectation. In fact, it can be argued that many participants attempted to lessen the negative impact of cognitive dissonance on their sense of self through a core belief in the legitimating role of medicine, particularly as their turbulent experiences of it did not dissuade them from seeking concordant therapeutic relationships (Ong and Hooper 2006).

While Matt reasoned that it would be unlikely for a cure to materialise in his lifetime, he still believed that this would happen at some unspecified point in the future. However, another participant, William, could not fathom any situation in which the prospect of a cure would ever come to fruition partly because of his own previous experiences unsuccessfully trialling medication. Taking the advice of his GP, William decided to self-manage his symptoms as best he could. In this way, William's account of healthcare remained firmly 'stuck' within the present in the sense that he could not imagine a life (his or anybody else's) without dystonia:

> William: One of the problems I've got with the issues – or the condition I've got is that there seems to be very little research into […] any medical cure or help that can be given to er people in my situation. You know, I go to the doctor and I've been going to the doctor for what, 30 years now, but all he says is 'oh it's a tremor' and that's it and urm you've got to live with it basically […] urm but (sighs) no matter who you talk to it's – you've got to

live with it, there's nothing that can be done about it basically. […] I've been and had these Botox injections in- in the hope that they will help but urm the- the jury's out yet, I'm not sure. Urm I've gone through a year of trying to take different pills recommended by er the consultant and neurologist at (city name), but they have so many negative side effects that I decided it just wasn't worth the er the improvement I saw was very short lived and then it started to develop in the end. So I decided that it wasn't worth pursuing the- the drugs related route, so I pulled out of that because of- as I said, the side effects that it was having on me. Urm so now I'm down to Botox really to see if it- if it will help. […] I went back to the GP and then they started this last 12 months at urm (town) with urm Dr (name) and now Dr (name) er with Botox. Urm I don't know, like I said, the jury's out, I'm not sure whether – I've certainly knocked on the head anything to do with drugs. [WADSS participant aged between 51-61 years old with head and hand tremors, pre-intervention interview]

In contrast to many participants' ideas about medical knowledge, William's account demonstrates the ways in which he fatalistically accepted that there would always be limited support for people with dystonia. Nevertheless, he hoped that using BoNT and taking personal responsibility for the management of his condition would help to improve his troubling symptoms. William's stoic and enduring outlook arguably relates to King et al's (2002) study on people living with diabetic renal disease. More specifically, the authors found that individuals reflected nonchalantly on their ongoing adjustment strategies to aid effective self-management (*ibid.*). Arguably,

people's stoical acceptance of living with a chronic condition is often the only 'morally viable' option available to them within Western societies, which emphasise the importance of health self-management and personal responsibility (chapter 6) (Williams, G 1993; King et al 2002). Since individuals usually live with their condition for all or most of their lives, enacting an expert patient identity by, for example, monitoring the effects of their problem (Newbould et al 2006) and remaining stoic about the future, psychologically protects them from becoming (further) distressed (Williams, G 1993; King et al 2002). Similarly, William presented a stoical stance to construct a socially acceptable method of coping that would shield him from further emotional anguish. It also enabled William to try to accept the limitations of medical knowledge as they occurred throughout his lived trajectory.

As was mentioned, William's stoical observations did not preclude him from using medical treatments or placing a certain degree of hope in their effectiveness. While he confidently asserted that using medication had been a resounding failure, he remained uncertain about the benefits of having BoNT. Yet, he still obtained advice from his GP and continued to search for medical interventions in the hope that one might work. Indeed, participants (as demonstrated earlier with Matt's account) invested faith in the legitimacy of medical knowledge to circumvent, as far as possible, feelings of distress. Despite the fact that participants strove to reconcile enduring tensions between experiential and medical knowledge, this was more successfully achieved if they were able to select and incorporate acceptable aspects of professional understandings (e.g. the cure discourse) fairly straightforwardly into

their life-worlds.

Conclusions

In conclusion, this chapter has presented the different ways in which participants spoke about, and reflected on, their diagnosis and treatment experiences. The interviews revealed that participants prioritised their embodied knowledge over other explanations when they needed to manage negative experiences of healthcare by, for example, seeking a second opinion or taking personal responsibility for the management of their condition. Even though participants challenged and resisted inappropriate medical epistemic sources, they still used professional agendas to decipher their everyday experiences of dystonia, as well as retain a sense of hope in clinicians' expertise and/or the future development of a cure. Building on the work of Markens et al (2010), I have demonstrated that the relationship between experiential and expert medical knowledge in the context of dystonia is synergistic and dynamic. The nature of this interplay also has a profound impact on emotional wellbeing (and vice versa), depending on how far these two knowledges tally with each other within the medical encounter (May et al 2004; Ong and Hooper 2006).

While I have analysed the ways in which participants drew on their own experiences and understandings in order to find appropriate healthcare, the following chapter explores their visceral realities of living with and managing dystonia outside of the consultation. The way disablist and medico-popular representations surrounding corporeal normalcy (Davis 1995) contributed to participants' personal stocks of knowledge across their lived trajectories is also considered. Finally, within chapter 7,

I examine the extent to which participants used experiential and professional notions

of health and the body to (de)mobilise shared patient identities.

Chapter 6

Narratives of body, self, and society

In the preceding chapter, I explored the way participants used their subjective perspectives as a means through which to obtain appropriate healthcare provision. Furthering this line of analysis, I investigate the ways in which participants coped with their dystonia throughout their everyday lives. The interviews revealed the impact of participants' physical, emotional, and social experiences of dystonia on their richly textured accounts. As was discussed, this is called 'embodied experiential knowledge' and refers to a particular type of understanding that individuals acquire from living 'in' a body affected by a given experience (chapter 3) (Abel and Browner 1998). Embodied knowledge enabled participants to adjust to the fluctuating effects of their impairment, as well as come to terms with varying degrees of stigma and social oppression. Moreover, participants interpreted their own personal stocks of knowledge in confluence with the wider social acceptability of illness management (e.g. coping with pain privately, adopting a stoical attitude), even though these strategies often left them feeling (further) isolated and distressed. Building on these findings, I explore the content of participants' lay knowledge of dystonia in order to illuminate the complex interactions between individual experience and socio-political structure.

In the first part, 'embodying dystonia', I examine the way medical and social frameworks informed participants' conceptualisations and experiences of their condition. The second section, 'transformative identities and dystonia', discusses the impact that participants' disruptive symptoms had on their sense of self. While the

superordinate themes were not necessarily experienced separately, I have organised them sequentially in order to highlight the way each one builds upon and interacts with the other. In this chapter, I present the various ways in which participants negotiated and responded to their diverse corporeal and emotional experiences within different spaces and contexts. Consequently, I maintain that dystonia is a 'social disability' (Nijhof 1995), which cannot be reduced to its clinical components.

Embodying dystonia

Chapter 2 demonstrated some of the problems with the existing scientific knowledge on dystonia, most notably, that there has been controversy within the medical profession itself about how this condition ought to be categorised. Yet, medical knowledge was the lens though which participants created their experiential ideas about dystonia, even though abstract constructs did not always tally with their embodied sense of illness (chapter 5). In fact, as can be demonstrated from the following interview extract, some participants struggled to identify with the neologism dystonia and questioned the usefulness of subsuming its phenotypic diversities into one category (n=10):

> Paige: It's (dystonia) a weird condition really that it presents itself quite differently to – in many patients and yet it's under the same umbrella of dystonia. Patients get presented with different – different difficulties, different challenges I suppose, depending on where your dystonia is and how severely you're affected. [Support Group 1 representative, aged 62 years old or over, diagnosed with cervical dystonia, semi-structured interview]

Research has shown that medical typologies of the genetic condition SMA do not completely align with the visceral day-to-day realities of it (Boardman 2010; 2014b). This is because each person's experience produces specific and unique understandings of the disease, which cannot be comprehensively represented within fixed and reductive medical labels (*ibid.*). Similarly, Paige criticised medical notions of dystonia based on the belief that these did not encapsulate her or other individuals' divergent range of experiences. Differing levels of difficulty, for example, illuminated the complexities of dystonia and challenged the view that these could be lumped together within the same diagnostic category. In fact, while the dystonia syndromes share certain clinical features (Albanese et al 2013; Jinnah et al 2013: 927), 'there is no unique etiology or pathophysiology' that unites all of them together (chapter 2) (Albanese 2017: 9). Consequently, medical scientists have debated the extent to which dystonia can be viewed as a single clinical entity or a collection of separate disorders (Jinnah et al 2013; Albanese 2017).

Even though participants identified some limitations with medical concepts, they still sustained biologically derived descriptors like 'severity' and 'body distribution.' This enabled them not only to substantiate their own views on the heterogeneity of dystonia but also interpret their involuntary movements as a physical symptom of a disease process (e.g. Beth: '*I told her [friend] it [dystonia] was to do with the nerves […] the nerves in in my neck weren't getting the right messages from the brain urm and I just described some of the symptoms.*' [NHS Hospital 1 patient]). Drawing on biomedical explanations and categories, including the dystonia label itself, also facilitated the assembly of shared patient identities since many participants used

these to frame their own and others' unique experiences (chapter 7) (e.g. see Rapp 1999; Rapp et al 2001). Markens et al (2010) found that while some pregnant women drew on their own sense of embodiments (e.g. feeling foetal movements) to confirm the health of their pregnancy and reject prenatal screening, their subjective understandings, nonetheless, paralleled authoritative medical discourses surrounding the nature of 'safe' pregnancies. Similarly, despite the fact that participants used their personal stocks of knowledge to challenge inappropriate medical conceptualisations, they still developed a health identity that was firmly structured around scientific ideas about physiopathology, treatment, and recovery (chapter 5). Yet, given that the medical profession has not looked at the everyday experience of dystonia satisfactorily, the rest of this chapter concentrates on what it is like to live in a body that is predictable in its unpredictability.

Experiences of pain and fatigue

Participants reported that the uncontrollable somatic aspects of their condition had an important part in shaping their experiential knowledge. In some respects, this shared experience aligns with the view from within the medical profession that dystonia is a disorder of movement and physicality (Geyer and Bressman 2007: 1). However, as well as experiencing the particular bodily effects associated with their specific type, participants also reported a range of widespread symptoms, including: pain, fatigue, tremors, shaking, poor posture, and/or balance. Moreover, participants' visceral experiences of these impairment effects interlaced with a wider cultural context that had a profound impact on their emotional and social wellbeing (discussed throughout this chapter). Sensate embodied understandings were, thus, holistic and challenged

the usefulness of prevailing medical typologies, which are based on where, as opposed to how, a person experiences their condition (Boardman 2010).

The majority of participants in my research negatively experienced a range of 'invisible' symptoms like pain and fatigue sometimes with(out) more perceptible bodily changes (e.g. involuntary muscle spasms) (n=30). Irene, for example, is aged 62 years old or over and lives with cervical dystonia. Despite the fact that this condition is regarded as a focal type since it affects a specific part of the body (Albanese et al 2013), she described the way the spasms in her neck used to produce other symptoms and discomforts:

> Celia: So how would you say that you experience living with your condition overall?
>
> Irene: I found it very difficult before these urm [BoNT] injections kicked in because my head – I used to sit up 'till all hours of the morning 'till I really tired myself out because my head was continually pulling right into the pillow and it was like this all the time and I was really worn out. [Support Group 1 member, group interview 4]

It is evident that, before Irene felt the effects of her treatment, the uncontrollability of her head movement coupled with her attempts to keep awake at night until the spasms eased off caused her to experience systemic symptoms (fatigue). These discomforts moved beyond the fixed disease boundary of her specific diagnosis given that tiredness is not typically understood as a clinical feature of dystonia (De Pauw et al 2017a). Further, the way she described her head as '*continually pulling*

right into the pillow' suggests that this part of her body was acting completely

independently of her own sense of self-control. It has been argued that individuals

with chronic illnesses experience their bodies as 'alien-like' since their carnal

discomforts threaten previously integrated states of embodiment (Leder 1990;

Williams, SJ 1996). Scholars refer to this phenomenon as 'dys-embodiment', or the

unwelcome presence of the body in distress (*ibid.*). Previous research on dystonia has

found that individuals with this condition often feel powerless to manage their

altered carnalities and subsequently, experience corporeal fragmentation in which

'dystonic body parts are separated from the whole' (Camfield 2002: 61). In a recent

study on parents' experiences of caring for a young person affected by secondary

dystonia, Austin (2015) found that mothers and fathers described the condition as an

unpredictable and difficult disorder to manage due to the ways in which it appeared

to 'trap' and 'imprison' their child within their own body (see also Austin et al 2017).

Since dystonia can affect a range of muscles that are assumed to be under a person's

control, experiencing or witnessing a body that 'displays a frightening "will of its

own"' (Williams and Bendelow 2000: 53) can invoke palpable fears around

helplessness and mental illness (e.g. Camfield 2002; Austin 2015). This is because

psychological problems are linked to the notion of personal irresponsibility: an

attribution that is negatively perceived within Western societies that value the body

and mind as obedient, controlled, and disciplined (discussed later in this chapter)

(e.g. Williams and Bendelow 1998; 2000; Ayo 2012). Seeing as the need for

corporeal control affects emotional wellbeing (Camfield 2002: 61), the parents in

Austin's (2015) study found it incredibly difficult to watch their child's distressed

expressions and involuntary movements (see also Austin et al 2017). Supporting

these findings, not only did the spasms in Irene's neck cause her to become physically and mentally exhausted but also made her feel powerless to stop its uncontrollable effects, further compounding her distress and suffering.

Many participants spoke about the significant impact that their (im)perceptible symptoms had on their abilities to navigate particular social spaces and environments. Whitney is aged between 51-61 years old and has been diagnosed with various types dystonia (e.g. cervical dystonia, laryngeal dystonia), although she later questioned the accuracy of this information during one of the group interviews. She had an accident while studying at university and fell on to the back of her neck, injuring various parts of her body, which her relatives believe triggered the onset of her dystonia. However, before this point, Whitney was placed into a convalescence school for children because she had been experiencing clumsiness, painful legs, and difficulties with walking. Given that these problems still pervade her day-to-day life, she sometimes uses crutches and/or a wheelchair to get around. Nevertheless, she struggles to perform routine tasks and participate in social activities because of the wide-ranging, varied effects of her condition:

> Whitney: I've tried all that [heated neck cushions to alleviate pain]. But I put it in the microwave and it set fire so (group laughter) me husband said I was not to be trusted! […] 'Cause some days I'm completely (pause) what can I say? Cloth-headed. When I haven't sort of got me (pause) you know you get in that much pain and you get that fatigued and tiredness as you probably all know (looks around at the other group members), you don't know what you'll doing anyway, do ya? You just wanna be pain free. So me husband

won't allow me in the kitchen 'cause I'm quite dangerous with saucepans and stuff. [Support Group 1 member, group interview 1]

Whitney: The muscle spasms can be really bad, where it affects not just my neck now but my lumber spine where I completely go into spasm [Celia: Right] my foot went into spasm just before Christmas so we had to phone the doctor and I had to have pregabalin tablets for the pain […] I've got problems with walking, balance, co-ordination, going to the dentist, 'aving my hair done. [Semi-structured interview]

Through their exploration of one individual's experience of living with Parkinson's disease, Bramley and Eatough (2005) found that their participant described problems with physical and mental functioning. Echoing Whitney's understanding of '*cloth-headiness*', the participant in Bramley and Eatough's (*ibid.*) study said that she often experienced a '*fog*' before taking her medication. Whitney's discomforts also intermeshed with day-to-day tasks like cooking, which worsened her symptoms and limited physical functioning. Thomas (2007: 136) has argued that impairments and their effects are both embodied and dependent on wider socio-spatial factors. Specifically, within contemporary Western societies, it is expected for people to have kitchens containing an assortment of appliances and pans to prepare and cook food (*ibid.*). Yet, disabled people may find it difficult to make meals in this prescribed way because of the physical and/or cognitive consequences of their impairment (*ibid.*). Due to their 'deviant' bodies, such individuals may also be viewed as 'incompetent' and prevented 'from taking up social activities and roles' (Thomas 2007: 136;

Paterson, K 2001). Since Whitney's symptoms restricted her from cooking with saucepans and safely operating electrical devices, her husband decided that she was not allowed to enter into the kitchen and so, excluded her from socially participating within this particular space. Arguably, this demonstrates the ways in which 'the bodily action involved is *itself* a socially [and environmentally] contingent one: the embodied act is thus bio-social' (Thomas 2007: 136 emphasis original).

Through their accounts of dystonia, participants described the various ways in which they adapted to the embodied impact of their condition. Within the sociology of health and chronic illness, a large corpus of studies has emerged exploring personal experiences of coping with, and adjusting to, various medical problems (Wiener 1975; Ben-Shira 1984; Scambler 1984; Robinson 1988; Radley 1989; Bury 1991; Charmaz 1995; King et al 2002; Sanderson et al 2011). Classical work within this body of literature includes research conducted by Wiener (1975) who found that living with arthritis requires individuals to cope with the continually uncertain nature of their illness. Further work has indicated that managing a condition or disrupted body is closely interwoven with the situated temporalities and contexts of social actors (Radley 1989). Similarly, participants' accounts of coping were 'dynamic' and 'multidimensional' (Reeve et al 2010; Ong et al 2011; Cassidy 2012), firmly understood and evaluated in relation to the changing physical and emotional effects of their dystonia. In fact, every participant employed a range of coping strategies in order to manage perpetual forms of suffering and discomfort, albeit with varying levels of success (see 'transformative identities and dystonia' section). Despite the consequences, participants' abilities to adjust adhered to socially acceptable ideas

about illness and recovery. Ava is aged between 40-50 years old and lives with cervical dystonia. She reported that her symptoms first onset 26 years ago when other people noticed the spasms in her neck. While her visible symptoms disappeared for a few years, they then returned without warning and are now controlled with BoNT. Still, Ava described the unexpected sense of loss (Charmaz 1983) that she felt when she had to give up her job as a full-time hairdresser because the dystonia had caused a range of problems in various parts of her body (head, arms, lower back). At present, she experiences frequent bouts of depression and pain, particularly when coming towards the end of a treatment cycle. However, as a single parent, Ava emphasised her duties and obligations as a mother and the importance of leading a normalising existence for both she and her family:

> Ava: […] When you're in pain it's really miserable and you do get into a hole and you do think how am I going to get out? But you know you have to pick yourself up and […] I think if I didn't have- have my family then yes it would be very easy to wallow. You know the other thing that pushed me forward, I have to do X, Y and Z, I have to go to work to provide for my family and myself so […] I could very easily get into that place where I'm in pain, I feel dark, I feel miserable, but if I don't – I could easily sit in this house for a week and not see or speak to (laughs slightly) anybody, but I feel that I have to push myself because it's a vicious circle-cycle isn't it? […] My friends don't- like it's not something I really discuss, but they don't understand if I'm having a bad day, well actually I'm not feeling it, because I look perfectly fine, they don't know what's going on inside but they've kind of learnt to

understand that if I need time out, I need time out and they don't ask

questions. [WADSS participant, pre-intervention interview]

Parsons (1951) has contended that ill people are required to perform the sick role in order to recover and carry on with 'normal' activities as soon as possible (chapter 3). However, people living with acute or long-term medical conditions often have to negotiate this expectation in tandem with their own bodily discomforts (e.g. Glenton 2003; Lightmann et al 2009). This is because the severity of their problem may prohibit the adoption of established social customs surrounding recuperation (*ibid.*) Compounding the issue, agents may be denied help on the basis that other people misinterpret their socially invisible symptoms as unreal or indicative of generic non-medical complaints (Rhodes et al 1999; Stone 2005; Dumit 2006; Lightman et al 2009; Broom et al 2015). Decisions about who qualifies as 'ill' are often based on reductive and medically oriented notions of bodies and minds 'as *either* able (and employable) or disabled (and unemployable)' (Lightman et al 2009 emphasis original). Despite the fact that it may create or sustain distress, however, individuals may attempt to manage their condition on their own to adhere to moral understandings of individual agency, responsibility, and autonomy (Williams, G 1993; King et al 2002; Boardman et al 2011; Ayo 2012; Broom et al 2015). The adoption of a stoical or resilient attitude may also emotionally protect social actors from other people's hostile reactions to their 'normal' carnalities, although, in doing so, may push their embodied concerns further into the private domain and intensify feelings of isolation and emptiness (Rhodes et al 1999; Boardman et al 2011; Broom et al 2015). Since many types of chronic conditions, including dystonia, do not

conform to the expected trajectory of the sick role (i.e. illness, recuperation, complete recovery), people often struggle to have their concerns taken seriously, and by proxy, get the support they require from their family and friends (e.g. Lightman et al 2009). Correspondingly, Ava existed in a liminal space of neither 'complete wellness' nor 'complete illness' (Jackson 2005), whereby her 'normal' physical functioning meant that she did not receive enough help and understanding from her social familiars. Nevertheless, Ava viewed being 'trapped in a dysfunctional, painful body' as a source of shame, indignity, and 'moral failure', which shaped her mood, social relationships, and engagement in day-to-day activities (Broom et al 2015: 723, 728). Yet, in order to adhere to social expectations surrounding responsible citizenship and motherhood, Ava felt that she had little choice but to monitor and repress her feelings irrespective of its impact on her general wellbeing. As Camfield (2002: 61) has noted, 'the imperative of [bodily] control is also extended to the emotions, which should be experienced and displayed according to dominant models' of coping and adjustment.

Though participants sustained moralising discourses and practices surrounding health self-management, their efforts were not always successful. While many participants reported that social familiars eventually became more supportive once they had a better understanding of the complexities of their condition, for some, this remained perpetually absent. In the following extract, Oscar and Matt discuss the problems of trying to assimilate with their friends:

> Oscar: But I find it quite frustrating when I'm sort of – I don't know maybe I
> don't do this enough even. When I'm out with friends and they would –

maybe we'd go to (city name) for a few hours and then either come back or stay in (city name) but sort of (pauses) as if they sort of expect to do something else after that –

Matt: Yeah. Yes.

Oscar: There's (laughs loudly) just no chance, just that main event (Matt: Yeah) is what I've been planning in my head for months and stuff trying to (Matt: Yeah) trying to limit my activity either side of it. […] I think that's - that's also a danger I sort of- if – if you are out and say like sort of a hypothetical situation where I'm out with my friends and my friends say 'let's go to do this?' I'm – I'm easily persuaded (Matt: Yeah) and I might try to do it and I might think 'well I'm ok at the moment' (Matt: Yeah) it's the day after that's sort of –

Matt: Yeah, you suffer (Oscar: Yeah) and that's the bit they don't see either, isn't it?

Oscar: Yes exactly, they possibly think that it's not serious. It's not –

Matt: They say 'well you're ok' (Oscar: Yeah, yeah) 'w-what's the problem?' Yeah, I get that a lot.

Oscar: Yeah.

Celia: And how do you feel about this?

Matt: I think it's just personally, I just think it's because it's so difficult to – to get somebody else to understand it, people that – that know you. [Support Group 1 members, group interview 3]

Heaton (2015) has observed that individuals coping with a chronic illness often distinguish themselves from their non-disabled peers in order to emphasise key experiential differences. In particular, they recognise the pressures of having to act like their healthy friends, even though their embodied discomforts (e.g. fatigue) make it difficult for them to adhere to normative expectations surrounding ability and performance (*ibid.*). Similarly, participants recognised that other people's way of life was incompatible with their own on account of the fact that they had to negotiate a range of adversities, often inconceivable to those unaffected by dystonia. Yet, as can be noted from Oscar's account, participants made several efforts to go along with what their friends wanted to do in order to be seen as performing an autonomous self that 'fitted in' with group norms. This generated palpable tensions between their carnal limitations and how they felt they had to behave in social situations, as well as between their claims to have a serious condition and coming across in public as perceptibly healthy. Little et al (1998) have argued that people with colorectal cancer usually find it difficult to communicate the devastating effects of their illness to family and friends, who similarly do not know how to respond (appropriately) to their condition. This sense of misidentification results in 'communicative alienation' and feelings of seclusion and distress (*ibid.*). It can be argued that Oscar and Matt had become alienated from their social familiars' lack of understanding surrounding their 'private' experiences of suffering. Indeed, these participants were frustrated by the fact that their friends had made little attempts to recognise or take seriously the disquieting and fluctuating effects of their dystonia. In addition to these issues, Matt and Oscar generated several upward social comparisons with negative consequences for their emotional wellbeing, whereby they saw themselves as inhabiting a more

limited body than their friends. Austin (2015) and Heaton (2015) have suggested that these types of evaluations help individuals with medical problems to demonstrate how much more difficult their lives are in contrast to their non-disabled peers. Since upward evaluations can make them more aware of their own corporeal difficulties, these often perform a negative impact on emotional and social wellbeing (*ibid.*). For participants like Oscar and Matt, invoking upward comparisons enabled them to emphasise the harmful aspects of their friends' inabilities to fathom the significance of their embodied discomforts, which they subsequently had to manage alone and out of sight of other people.

The interviews revealed that participants attempted to comply with Western expectations of autonomy and self-discipline by relegating their inner thoughts and feelings to the 'private' sphere. However, they longed for other people to empathise with their emotional problems and understand the day-to-day struggles that they faced. Based on this analysis, I would argue that Thomas' (1999; 2007; 2010; 2012) social relational model of disability, which refers to the ways in which impairments and their effects intersect with wider forms of oppression (chapter 3), is relevant to dystonia. This is because the political dynamic of individual responsibility not only intensified physical and emotional suffering but it also framed and structured participants' responses to their experiences of embodiment, demonstrating the social dimensions of impairment and illness. Though participants would have most certainly struggled with pain and fatigue irrespective of context, hegemonic ideas about coping and adjustment nevertheless mediated the very particular ways in which they managed and evaluated their personal realities of suffering (Thomas

1999; 2007; 2010; 2012; Shakespeare 2006; 2014). In fact, normative agendas sidelined participants' material needs for support, inclusion, and perhaps most crucially of all, legitimacy (de Wolfe 2002).

Given that dystonia is predominately defined as a hyperkinetic movement disorder (Albanese et al 2013), many participants' socially invisible experiences of suffering intersected with more perceptible impairment effects like twisting body postures and contorted movements (e.g. Irene). While their 'internal' embodied discomforts went mostly unnoticed (until they posed a threat to themselves and others [e.g. Whitney]), participants struggled to 'pass' for 'normal' during intense episodes of dystonic attacks and spasms (Goffman 1963). Since some participants' visible difficulties temporarily disappeared from time-to-time, social (un)familiars frequently questioned their claims to be in the sick role. The disruptive nature of participants' daily corporeal *and* psychological variations meant that different strategies had to be applied in order to cope effectively with these fluctuations. In view of that, the next section explores participants' everyday experiences of adjusting to uncontrollable motor symptoms within a society fixated on corporeal aesthetics and desirability.

Experiences of muscle spasms and contortions

Whereas many participants reported that they lived with pain and/or fatigue on a regular basis, all had experienced problems with movement (past and/or current) due to the presence of noticeable and involuntary muscle spasms, shakes, and/or tremors. Participants endeavoured to control and accommodate changes to their embodied selves by mobilising self-care practices (e.g. exercising, performing 'sensory tricks',

searching for information on dystonia online). Cassidy (2012: 128) found that individuals with ataxia became aware of their disrupted bodies predominately through their day-to-day management of it. While adjusting to the consequences of their condition could alleviate corporeal discomforts like disordered walking and poor coordination, such attempts could also deplete physical and mental resources 'to the point of exhaustion' (*ibid.*). Similarly, participants reported that continually having to monitor and think about their carnal behaviours in public intensified feelings of anxiety and embarrassment. Olivia is aged 62 years old or over and experiences head shakes and tremors, as well as more recent difficulties with walking due to the spasms and '*unbearable*' pain in one of her legs (reported in the post-intervention interview, 2 months after initial interview). These wide-ranging symptoms have interfered with her ability to perform everyday tasks such as eating and moving around. Nevertheless, Olivia said that she has not let her symptoms stop her from being independent and professionally caring for elderly people in their homes. However, the uncontrollability of her body can sometimes make it difficult for her to conceal and predict when her movements are likely to disrupt 'normal' social functioning:

> I: How did you manage your life then? Did it (dystonia) make you feel depressed?
>
> Olivia: Er not so much depressed because I am one of them persons that wouldn't let anything beat me, but I was more mad and embarrassed.
>
> I: Right, okay, embarrassed.
>
> Olivia: Embarrassed. If you go to the pub say- if I go to the pub, very rarely, but if I go to the pub I probably won't shake, but there's always that chance

that I shake and hold it together, I can get out of it because I can always say 'well, I'm drunk!' […]

I: It (dystonia) could have stopped you going out, I suppose?

Olivia: (Louder) Oh it could have stopped me, yeah because like I said I'm very embarrassed when I shake. Many times when I go to somebody's house [as a carer] and they says 'do you want coffee or tea?' I'm thirsty as anything and I go 'no' (laughs) Do you know what I mean? […] The *more* I shake the more I keep thinking they're noticing that and that, and I'm getting worse, I get worse then. I get really worse. I probably will shake in a minute.

[WADSS participant, pre-intervention interview]

As was discussed in chapters 3 and 5, feminist theorists argue that patriarchal societies value contained and disciplined forms of embodiment that do not transgress or threaten corporeal boundaries (Battersby 1993; Williams and Bendelow 1998: Ch 6; 2000; Lawton 1998; Hallam et al 1999: 11). A body that is deemed to be 'leaky' or disordered is usually subjected to harsher controls and regulations than one that is not (*ibid.*). Since the dystonia syndromes involve noticeable muscle spasms and tremors, these disorders are 'obviously more disabling in a society that emphasises appearance, bodily control and containment' (Camfield 2002: 60). Managing the body in dystonia may, thus, be necessary to conform to the customs of mainstream society and minimise the harmful effects of psycho-emotional disablism (i.e. discrimination-related distress) (Thomas 1999; 2007; Reeve 2002). In fact, Olivia took several measures to manage other people's perceptions of her in order to be socially accepted and enjoy the benefits of 'passing' for 'normal, most notably, by

using 'plausible' explanations to justify 'rule-breaking behaviour' (e.g. pretending to be drunk in a pub) or avoiding certain tasks that she knew would trigger her symptoms (e.g. using a teacup) (Goffman 1963; Robinson 1988; Nijhof 1995). Yet, she still felt frustrated that her body frequently shook because of the way it discredited her identity (Goffman 1963) and interfered with her engagement in various social activities (e.g. drinking tea with other people). Due to the unpredictable nature of her impairment effects, she also worried that these would unintentionally reveal a 'spoiled identity' (*ibid.*). Paterson and Hughes (1999: 603) have maintained that disablist societies define and reinforce socially acceptable codes of behaviour, which in turn exclude individuals displaying 'non-conforming forms of physicality.' This phenomenon has been referred to as 'carnal alienation', meaning that the protocols and conventions underlying 'correct' types of social interaction marginalise impaired bodies (Paterson, K 2001). Carnal alienation may also trigger or increase suffering through a process known as 'dys-appearance' in which disabled people become more conscious of certain aspects of their embodiments (Paterson and Hughes 1999; Paterson, K 2001). Similarly, Olivia found it difficult to adapt to the dominance of established norms governing corporeal performance, and by proxy, became highly self-conscious of her body (Butler and Bowlby 1997; Paterson and Hughes 1999; Paterson, K 2001; Zitzelsberger 2005; Thomas 2007). Being uncomfortably aware of her disrupted carnality in certain social spaces (e.g. the pub, clients' homes) not only affected her emotional wellbeing but also heightened the physical effects of her tremors, causing her to become further distressed and anxious. In this way, participants experienced disablist interactive regimes and practices *through* their bodies, which were located within particular

sociomaterial spaces and discursive contexts suited predominately for non-disabled embodiments (Butler and Bowlby 1997; Paterson and Hughes 1999; Thomas 1999; 2007; 2012; Paterson, K 2001; Reeve 2002).

As with other long-term medical problems, the embodied experience of dystonia was fraught with conflict surrounding identity and stigma (e.g. multiple sclerosis in Robinson 1988; chronic back pain in Glenton 2003; Broom et al 2015; ataxia in Cassidy 2012). On the one hand, participants made concerted attempts to conceal their 'spoiled identities' in order to appear less different and evade social recognition of their impairment (Larry: '*if I'm sitting down at a table I always tend to prefer to be on the left so that I am naturally turning towards them […] I obviously wanted to fit in as a normal person.*' [WADSS participant, pre-intervention interview]). Yet, on the other, they desperately wanted other people to see and validate their lives, struggles, and desires. In certain situations, a different kind of issue arose, whereby concealment was not a conscious decision to conform to socially acceptable notions of corporeal desirability but rather, an unintentional outcome of the dystonic body becoming less noticeable. Oscar is aged between 29-39 years old and has a diagnosis of childhood-onset generalised dystonia. Given that he found it incredibly difficult and painful to walk up until he started university, Oscar used to get around in a wheelchair. He now walks without the help of any mobility aids but still experiences visible and uncontrollable spasms in his legs. Since the motor effects of his condition can also fluctuate across different contexts, Oscar recalled a time in his life when his disrupted physicality temporarily disappeared:

Oscar: […] You sort of feel a bit self-conscious when- when I don't look

disabled, sometimes parking in with disabled badges, I wonder if- I have been

challenged actually about- by some so called do gooder, 'you shouldn't park

there unless you've got something wrong with your legs' he said, well

actually I have but (laughs loudly) you just haven't noticed yet! [Support

Group 1 member, group interview 3)

Drawing on Foucault's (1973) notion of the 'medical gaze' (chapter 3), these authors

argue that this technology of power monitors and classifies bodies according to

narrowly defined ideas about corporeal performance and aestheticism (Hughes 1999;

Reeve 2002; Stone 2005; Zitzelsberger 2005; Lightman et al 2009). Through the

stranger's application of the gaze within a specific socio-spatial location (a car park),

Oscar's carnality became 'known to the viewer' who then used this information to

invalidate Oscar's claim to be in the sick role (Reeve 2002: 498). While the observer

had wrongly believed that Oscar was healthy, Oscar recognised his own physical

limitations and needs because he had intimate, embodied knowledge of these

corporeal dimensions. Though Oscar felt self-conscious of his 'normal' bodily

appearance, he mocked the stranger's ignorant and '*do-gooder*' attitude to reduce

psychological harm. In addition to this, Oscar accounted for the stranger's misguided

view of his bodily comportment by drawing on reductive notions of disability and

difference ('*when I don't look disabled'*), thereby sustaining the power of the

medico-popular gaze (Reeve 2002). Hughes (1999) and Zitzelsberger (2005) have

maintained that stereotypical views of disablement separate disabled people's

carnalities from their sense of self and, in doing so, undermine their life contexts and

embodied concerns. Accordingly, stigmatisation may not only become an issue for those deemed to be 'abnormal' but also for those with fluctuating or 'episodic conditions' in which their embodied markers may diminish from time-to-time or appear less noticeable, bringing into question their need for support and assistance (Robinson 1988; Reeve 2002; Stone 2005; Grytten and Måseide 2006: 200; Lightman et al 2009). In short, living with a *dis*-appearing corporeality does not necessarily mean that disabled people will benefit from 'passing' for 'normal' (Goffman 1963): sometimes the body in (temporary) health can *dys*-appear as much as the body in pain and/or spasm.

The aforementioned data extracts highlight the way participants came to know their impairment effects directly through their own sense of embodiments interacting with wider disablist structures and practices (Thomas 1999; 2007; 2010; 2012). In contrast, however, nine participants said that they sometimes recognised their motor symptoms exclusively through other people's reactions to their disordered carnalities. Zara, who lives with varying levels of pain and tremors in her neck, is a qualified chef and pub landlady. This means that she regularly has to serve and interact with a range of customers, some of whom have suspected that she may be an alcoholic because of the perceived peculiarity of her symptoms. Zara reported that BoNT has diminished the intensity of her embodied markers and made her feel more confident meeting people in her private and professional life. However, in more recent times, its effects have not been as good as when she first started treatment. Consequently, as the following extract demonstrates, she often worries that her body is moving uncontrollably without her realising it:

Zara: […] When I went to- for the (job) interview for (city name) I actually had a committee man come and ask me what my problem was with the tremor in my head. He said 'what have you actually got?' And I said, 'oh, I've got dystonia' because I've never been embarrassed about *saying* it, but I do get embarrassed because you do get people that look at ya and I think sometimes I'm not doing it but I am doing it. But then when they look at you in a certain way you know you are doing it, but I can't stop it you know […] you know when you meet new people or like urm (pause) this came up quite a few times, my husband will probably be able to tell you more about it than me but you know I'll say to him like if we go somewhere 'my head's not shaking a lot is it?' And he'll go 'no, no, you're alright.' And I'll say 'well if it does will you just sort of nudge me?' Because I do try to stop it […] I've had somebody one time say 'you're like a nodding dog you know that you get in a car' you know but that's ignorance of people isn't it? I mean it's like everything in life isn't it? People say things and […] you know with different things that people say and urm that's very upsetting and then when people look at you as well. [WADSS participant, pre-intervention interview]

Zara's embodied markers frequently attracted the attention of others who deemed her bodily behaviours 'disordered' and/or 'strange.' Due to the impact of the dystonic body on social life, Camfield (2002: 60) has argued that 'much of this disability is not caused by the condition but by external reactions to it.' Indeed, cultural perceptions surrounding normality had a very real effect on how Zara experienced and managed her dystonia across various contexts, as well as how she felt about her

physical symptoms. While Zara was not aware that she had come across as impaired or 'socially incompetent' when, for example, she had attended a job interview, it was other people that had perceived her in these ways. Watson (2002) has observed that individuals affected by a chronic condition may choose not to incorporate the notion of 'disability' within their sense of self and identity due to the negative connotations associated with it. In this manner, being reminded of the fact that one looks different when they feel normal can have devasting psycho-emotional consequences (Reeve 2002; Watson 2002). Zara found this particularly distressing because she did not always know when she would appear different. In an effort to manage other people's perceptions of her, Zara asked her husband to interpret the severity of her tremor through the re-appropriation of the gaze. She also told people who asked about her symptoms that she lived with dystonia, thereby accepting a 'discredited identity' (Goffman 1963). This strategy, however, absolved Zara of responsibility for her 'undesired differentness' given that she had provided a 'plausible' account of the problem (Grytten and Måseide 2006: 196).[39] It is usually expected that individuals with impairments reveal highly personal details of their lives to justify their disrupted bodies to non-disabled people, and in turn, be accepted into mainstream society (Oliver 1990; Reeve 2002; Zitzelsberger 2005; Grytten and Måseide 2006). Furthermore, Zara said that working in pubs made her feel self-conscious because of the 'shame' associated with the noticeable effects of her condition. She and many other participants in my research often retreated into the 'private' sphere in order to minimise stigmatisation (e.g. Mandy: *if I do go out shopping I'm as quick as I can*

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[39] However, some participants reported that their friends and family would often 'tactfully avoid' asking them questions about their condition in order to circumvent awkwardness and emotive subject matters (Goffman 1963; Grytten and Måseide 2006: 200).

and back again into the house [...] because (laughs) I know there're [strangers]

looking at me.' [Support Group Member 1, group interview 4]). Even if participants

did not immediately experience their differences through their own bodies, they still

sensed the menacing and unwelcoming stare of other people (Scambler and Hopkins

1986; Jacoby 1994; Major and O'Brien 2005). The self-surveillance of the

'disordered' and/or 'incompetent' corporeal self was, thus, interwoven with

internalised oppression (self-stigma) and the medico-popular gaze (Marks 1999;

Reeve 2002: 501; Olney and Brockman 2003).

As well as strangers and distant acquaintances (e.g. job interviewers), participants

also reported that family members found it challenging to 'read' their very particular

impairment effects. One support group member, Miranda, who is aged 62 years old

or over and has been diagnosed with cranial and slight anterior cervical dystonia,

said that her husband used to find it difficult to make sense of her 'erratic'

movements:

> Miranda: On the way home [from a support group meeting] he [husband]
>
> didn't stop talking about, 'oh that lady there, her eyes do the same she's-',
>
> you know 'cause he used to tell me off 'cause I would stop walking across the
>
> road, because when your eyes close you automatically stop don't you?
>
> Charlotte: Mmm hmm.
>
> Miranda: So he'd say 'don't stop not in the middle of the road!' (Rachael
>
> laughs slightly) and he was – so I think it helped him [going to the support
>
> group meetings] as much as it helped me. 'Cause he then understood that
>
> (pause) well, it wasn't in my mind, if you like, it was actually uhm you know

a serious thing. [Support Group 2 members and representative, group interview 2]

Dumit (2006: 581) has noted that the formation of patient collectivities, united around the shared experience of suffering, helps to validate agents' concerns and deflect psychological blame (e.g. 'it's all in your mind'). By visibly seeing other people experience similar impairment effects to his wife and listening to their day-to-day difficulties with dystonia at a support group meeting, Miranda's husband eventually came to authenticate her condition. Yet, the fact that he had previously questioned the reality of her symptoms echoed many participants' turbulent experiences of negotiating a socially legitimated medical diagnosis (chapter 5). It also demonstrated the ways in which Miranda's husband misused psychological explanations to account for her seemingly aberrant and dangerous behaviours (e.g. stopping in the middle of a road). Research has shown that the mental illness label is often used synonymously with those deemed to display strange, defective, and/or inconsistent behaviours (Goffman 1963; Pollock 1993; Camfield 2002: 38-39; Mulvany 2000; Rose 2003; Jackson 2005; 2011; Corrigan 2007; Garand et al 2009; Jutel 2010; Fein 2012; Lupton 2012). This term may also be applied in situations where individuals are thought to lack personal responsibility and control over their 'unruly' corporeal selves (e.g. Lupton 2012). As was noted, being seen as 'mad' may be particularly devastating in a society that values self-discipline and autonomy (e.g. Ayo 2012). Due to the negative connotations associated with psychiatric disorders, Dear et al (1997) have observed that these conditions are one of the least accepted types of impairment within Western societies. Having their embodied discomforts

labelled as 'imaginary' or 'illogical' can, thus, leave individuals with contested and/or mental health conditions feeling worthless and disrespected (e.g. Corrigan and Watson 2002; Corrigan 2007). Consequently, they may internalise other people's antagonistic responses and distinguish themselves from the mental illness category (Goffman 1963; Corrigan and Watson 2002; Corrigan 2007; Lupton 2012). Agents may also do this to emphasise the *uncontrollability* of their behaviours, thereby sustaining stereotypical judgments about the realities of those individuals affected by (more severe) psychiatric conditions (*ibid.*). Further, belonging to a support group and witnessing other people experience a similar problem may help individuals and their families come to terms with it, as well as deal with persistent forms of stigmatisation (chapter 7) (Crocker and Major 1989; Dumit 2006; Blume 2016: 3). For Miranda and her husband, attending a local dystonia support group was beneficial given that both became more understanding of the complex and unpredictable consequences of her disorder. It also enabled Miranda's husband to recognise her concerns, and in turn, develop a more empathetic and supportive attitude.

This section has outlined the various ways in which the changing (in)visibility of participants' impairment effects had a profound impact on their wellbeing and experiential realities. Indeed, living with the dynamic consequences of dystonia intermeshed with acceptable ideas about performance and ability. Negotiating a disablist society heightened participants' sense of bodily awareness and, as I further discuss in the next part, influenced their constructions of self and identity at various times and contexts. While participants adopted creative strategies to manage their

dystonia, they often evaluated these in confluence with hegemonic expectations around corporeal desirability, normality, and containment. Yet, participants' internalisation of society's obsession with the ideal body type often caused them to become distressed and alienated from their own embodied subjectivities. In this way, coping with the physical and emotional dimensions of dystonia intersected with wider hegemonic beliefs about how (non)impaired carnalities ought to look and behave within ocularcentric cultures.

Transformative identities and dystonia

As well as experiencing the embodied consequences of their illness across various contexts, participants also reflected on the ways in which these aspects had shaped their identity and sense of self over multiple timeframes. Phenomenologist scholar Kay Toombs (1993) has argued that temporality forms a key experiential and perceptual component of agents' unique situations and biographies. Similarly, this modality became highly salient in relation to participants' subjective experiences and evaluations of their changed life contexts since developing dystonia and having to adjust to 'transitions in daily life, family life, working life and social life' (Asbring 2001: 313). Participants may have found it important to compare their lives and management strategies at different time-points given that all of them, except for one, had acquired dystonia in adulthood and hence, had some experience of living as a non-disabled person. In addition to this, many participants spoke about the fluidity of the effects of their impairment with respect to two types of corporeal change: deterioration and improvement. They also discussed the impact that these variations had on their identity as a person with dystonia and ability to come to terms with their

condition. With this in mind, I document the ways in which participants described their search for control and meaning in the face of illness and suffering.

Evaluating the loss of the pre-onset-of-illness self

Charmaz (1983) has argued that individuals often report a 'loss of self' and 'crumbling away' of previously valued identities due to the ways in which the embodied dimensions of their illness cause them to experience restricted and isolated lives. While every participant described several challenges associated with their condition, they still presented a stoical attitude in order to accept their bodily changes and make sense of their current dystonia identities (Trystan: '*[It's] a little bit disappoint[ing] that you can't do the things you did with your children when you've got grandchildren because [...] it's impractical [...] but you just find other things to do, find ways round it.*' [Support Group 1 member, semi-structured interview]). However, 12 participants reported that they sometimes found it incredibly difficult to come to terms with the 'negative ways in which their life had changed since the onset of their illness' (Heaton 2015: 343). For example, Liam is aged between 40-50 years old and has a diagnosis of cervical dystonia. He reported that frequent exposure to stressful situations often intensify the awkward effects of his condition, particularly when he has to stay late at work. Though Liam used to enjoy going cycling and taking long walks in the countryside to unwind, problems of mobility have made it increasingly difficult for him to perform these activities successfully:

> Liam: I think in some small ways I've got a bit better [managing dystonia
> since onset] but- but not fundamentally you know some small ways I've
> adapted […] The dystonia was more sort of urm being you know awkward

sort of walking around and- and you know getting photographed (laughs slightly) and- and er and urm cycling and that sort of thing more- more it made that more difficult […] In terms of actual pleasure cycling, I don't seem to really do that but as much urn the big difference is until- until certainly until you know 2010 [when his symptoms first started] I would happily do 20 or 30 mile walks, and that sort of thing, and now it's more of a struggle to do really even just four or five you know it is quite a struggle urm so that- that's a pleasure gone really […] that is quite a wrench really, you know urm being- because I'm an outdoor person and- but it's hard to be outdoors if you haven't got a sort of over-riding reason to do it urm to just hang about outside. I mean I suppose actually urm I moved here about 18 months ago, now I've got a bit of garden to potter about in, and that sort of thing urm but urm urm but yeah, it is quite a wrench not being able to or feeling not being able to go for the long hikes I used to over mountains and what not and that sort of thing.

I: Do you think it's your condition stopping you doing that or is it?

Liam: Well it's- it's quite an effort, I just urm it's sort of- I just don't feel right. [WADSS participant, pre-intervention interview]

Larsson and Grassman (2012) have suggested that the chronicity of long-term illness can produce multiple and continually disruptive effects on an individual's biography and sense of self. Moving beyond the Buryian (1982) notion of 'biographical disruption', whereby the onset of a health problem is experienced as a single, unexpected disjuncture within a person's life, Larsson and Grassman (2012) have argued that this can be repeatedly troublesome. Indeed, Liam found it emotionally

distressing to think about his pre-dystonia capabilities and performances. Heaton (2015: 343) has maintained that people with chronic conditions often invoke temporal self-contrasts by using themselves as 'foils' to emphasise the ways in which their carnal abilities have altered throughout their lives. Similarly, by generating an upward temporal comparison and portraying himself as a foil of his pre-symptomatic self (Heaton 2015), Liam viewed his life before dystonia in a much more positive light compared to the on-going challenges that he currently has to negotiate. Yet, Liam still attempted to preserve a sense of stability by recapturing his past self and continuing to work as an IT developer ('*I didn't actually take any time off you know, ever, I worked through it all*'). Supporting this finding, Asbring (2001: 315) has used the term 'partial transformation of identity' to refer to the ways in which people strive 'to continue living much the same as they did prior to becoming ill' in order to limit, as far as possible, the intrusive nature of their condition. On the other hand, Liam's efforts to carry on as 'normal' and retain his former identity were somewhat curtailed by his disrupted body and on-going mobility difficulties, which negatively impacted on his self-concept and caused him to become distraught. In spite of managing his condition more effectively than when he first developed it in 2010, the physical and emotional dimensions of Liam's dystonia had 'crumbled away' his previously valued 'outdoor' self-image (Charmaz 1983). Given that this left him feeling unable to completely accept his impairment, he failed to commit to a socially satisfactory form of individual agency and citizenship (Rose 2001; Broom et al 2015).

Charmaz (1994) and Smith and Sparkes (2002) have argued that men often

experience profound physical, psychological, and social losses as a result of the way illness erodes their sense of masculinity and mastery over their lives. This is because they are perceived to own orderly and contained bodies that conform to established notions of competency and autonomy (e.g. Charmaz 1994; Williams and Bendelow 1998: Ch 6; Smith and Sparkes 2002). In fact, several male participants described the challenges of adjusting not only to their corporeal changes but also to the collapse of a previously integrated and joyful self (e.g. Eric: *'I don't think there's a day that goes by when I wish I hadn't got it [dystonia] [...] I'm very urm you know outgoing comical person, but I lost all my- completely lost it, everything, but it has come back now.'* [WADSS participant, pre-intervention interview]). Eric's subjective experience of living in an uncontrollable body caused him to go through a *de facto* grieving process in which he mourned for his past life without dystonia by invoking disablist terminology to describe his distress (*'at the time [of his dystonia starting] I thought I was a cripple so I don't want to be a cripple.'*). Women also felt ashamed and alienated from their disrupted forms of embodiment. One female participant insinuated that her dystonic symptoms had prevented her from entering into a romantic relationship (Aileen: *'I've met some nice guys but then once- once they you know they obviously want an intimate side [...] I pull away because I [...] don't think it's worth it [the physical and emotional pain afterwards].'* [WADSS participant, pre-intervention interview]). Bramley and Eatough (2005: 229) have argued that women come to view the effects of their movement disorder as an assault on their 'feminine persona' and former lives because of normative expectations surrounding femaleness and sexuality. Arguably, these examples highlight the gendered aspects of carnal change in dystonia for both men and women.

The fluidity of impairment: corporeal deterioration and improvement

Unlike participants who sometimes viewed their altered states of embodiment as a threat to their current way of being in the world, a minority were able to harness their past experiences of suffering and convert them into something much more positive (n=4). Arguably, this was made easier by the fact that they chose to compare the initial onset of their condition to their present situation, which had been made relatively more tolerable with appropriate healthcare provision (chapter 5). Participants also accepted the uncertainty of their impairment and its fluctuating effects throughout their lives, believing these aspects to be more bearable than their previous experiences of suffering. Roberta is aged between 51-61 years old and lives with cervical dystonia. As was mentioned in chapter 5, she experienced profound upheavals during the negotiation of a diagnosis of her enigmatic symptoms. Yet, not only did Roberta encounter problems with convincing doctors of the reality of her complaint but also her family, who thought that her tremors and jerky movements would go away if she ignored them. As such, Roberta reported how her experiences of bodily change and deterioration significantly impacted on her familial relationships, eventually leading to the breakdown of her marriage. Due to the visibility of her constant head tremor, she rarely ventured outside her house and requested sick leave from work for six months. Roberta felt completely isolated and alone during the initial onset of her condition, unable to carry on with her 'normal' routines or fathom a life without disruption. In contrast, however, she described her present situation in the following ways:

> Roberta: Once the Botox starts running out the pain is so great that I- I can't

drive, I can't concentrate so I'm not going to put myself and the general

public at risk by driving during those few weeks but it was six weeks before I

can turn my head enough to be able to see into my wing mirror and also what

was behind me […] The dystonia is mine and it's part of who I am and I-I've

had some terrible experiences because of it but it's also given me a better

understanding of the people that I work with who 'ave also got long term

conditions, I have more empathy than I had before and owning my dystonia,

it's me, gives me that strength to know that my life can still be good and it is

still good, my life isn't over because I've got dystonia, so. [WADSS

participant, pre-intervention interview]

Roberta: My confidence grew, went back to work you know I-I've took

students from universities er you know urm on placements and I do all that

with my dystonia now. I'm back to where I was *but* I've more empathy.

[Post-intervention interview, 1 month after initial interview]

In spite of having to adjust to the variable effects of her treatment and the changes

that this subsequently produces in her body on a regular basis, Roberta had still

gained something valuable and fulfilling from her dystonia experiences. Frank

(2013) has referred to this phenomenon as a 'quest narrative' since it provides 'the

opportunity for body-selves to be restored in ways that link the individual to a sense

of progress' (Smith and Sparkes 2004: 611). Viewing illness as a source of strength

also demonstrates its moral and empowering dimensions, most notably, that

individuals are attune to the needs of others and capable of healing alongside their

'lives of disquiet and hardship' (Frank 1997: 146). Accordingly, the quest narrative permits individuals to feel re-embodied and able to align 'body, self and society' (Williams, SJ 1996: 23).

Some researchers have noted that the reconstruction of the self in illness can generate dramatic and radical changes to one's identity (Frank 1993; Asbring 2001; Clarke and James 2003). Furthering this line of analysis, Aujoulat et al (2008) have argued that people affected by chronic illness creatively adapt to their disrupted identities through a complex process of personal transformation. This consists of 'holding on' to former self-images and concepts in order to obtain a sense of control over the illness, while simultaneously 'letting go' and relinquishing restraint (*ibid.*). Similarly, Roberta returned to her pre-onset-of-condition self ('*I'm back to where I was*') at the same time as using her previous knowledge of suffering to produce an enhanced self-concept, namely, one that was more empathetic and understanding of other people. She was also able to adopt a stoical attitude and take responsibility for recovery, inventing herself as an 'agent of change' (Broom et al 2015: 714). While Reeve et al (2010) and Cassidy (2012) have suggested that individuals attempt to cope with everyday difficulties brought on by the physical and emotional effects of their condition, participants in my research generated a range of cognitive biographies and reflections *alongside* the practical management of their immediate discomforts. For Roberta, the creation of a revised self-identity that was different from, but closely related to, her former life before dystonia positively enabled her to claim ownership of past and present struggles, as well as ask for help from relatives and colleagues (e.g. Roberta informed her employer that she would require adaptations to her work

station). In fact, by believing that she had gained something new and beneficial from living with dystonia, Roberta felt able to cope with continuing problems and construct a far more valued self-identity compared to the initial phases of her illness.

One participant, Jasmine, described herself as '*lucky*' because she had been in remission from blepharospasm since 2001. Yet, she still felt psychologically harmed by her past experiences of stigma, recalling negative comments from social (un)familiars about her former dystonic body. Further, another participant's conceptions of corporeal improvement occurred in confluence with continual suffering and decline. Ollie is aged between 51-61 years old and was originally diagnosed with segmental dystonia[40] in the early 2000s. Health professionals, however, now think that his condition has progressed to a more generalised form of the disorder due to worsening spasms in his back and both legs. The changing nature of dystonia meant that some participants' original diagnostic type had become defunct and needed revising in light of new symptoms and experiences. Though he and his doctors believe that his dystonia has started to deteriorate, Ollie still felt that his bodily changes have improved his outlook on life and views of other people with impairments:

> Ollie: […] It's (dystonia) made me a better person in some ways. [Kim: Yeah] I shouldn't call it disabled but it's made me look at disabled people [Kim: Yes] in a different light now.
>
> Kim: Well it is a disability it is a type of disability isn't it?

---

[40] This type affects two contiguous body parts (e.g. neck and arms or eyes and mouth) (Albanese et al 2013).

Ollie: Yes we are all – we are all [Kim: Yes] I go out of my way to help somebody if I see problems all over. [Support Group 1 members, group interview 3]

In addition to Roberta's personal account of transformation, Ollie reported that living with dystonia has made him more attentive to the physical and emotional needs of disabled people, particularly as he used to feel suicidal and depressed. Distinguishing himself from his pre-dystonia, less empathetic self has also helped him to cope with the uncertain and deteriorating nature of his condition. Since his illness has given him something emotionally and morally fulfilling, in spite of its continually worsening effects, Ollie felt more positive about coping with the future and meeting 'suffering head on' (Smith and Sparkes 2004: 607). The use of confrontation imagery to describe coping with or overcoming a condition has been shown to assist disabled men in their expressions of identity (Smith and Sparkes 2004). This is because battle metaphors are 'crucial rhetorical resources in Western cultures for mobilizing the patriarchal values that construct' and reinforce heroic and dominant types of masculinities (Smith and Sparkes 2004: 607). These resources may help men to perform socially acceptable identities in disquieting situations that would otherwise reveal emotional and vulnerable selves (Smith and Sparkes 2004: 604). Furthermore, the application of the quest narrative to emphasise the gains made from the illness experience allow individuals to face up to their suffering, as well as journey from a place of relative instability and chaos to one of progress and enlightenment (Smith and Sparkes 2004: 607-610; Frank 2013). In fact, Ollie was able to focus on what he had achieved rather than lost as a result of becoming ill, enabling him to redefine his

dystonia trajectory as a considerable 'success' (Frank 1997).

Smith and Sparkes (2004: 600) have argued that disabled people's use of metaphorical devices (e.g. the quest narrative (Frank 2013)) to account for their changing sense of embodiments are thoroughly crisscrossed with, and circumscribed by, wider disablist protocols and belief-systems. Indeed, hegemonic Western narratives significantly influence common types of body metaphors, shaping and contributing to disabled people's communicative styles (Smith and Sparkes 2004). In particular, cultural references to disabled people often invoke tragic imagery in which they are viewed as burdensome or heroic 'and courageously struggling against the odds' (Smith and Sparkes 2004: 600; Oliver 1990; Barnes 1992; Shakespeare 1994). On the one hand, Roberta and Ollie re-evaluated their self-identities in relation to the management of the unexpected and disruptive consequences of their dystonia. They used their experiential knowledge to build a counter-narrative around the idea that disabled people are inherently pitiful and inferior (Smith and Sparkes 2004: 610), namely, by viewing themselves as occupying a higher moral status than before the onset of their illness. Further, given that expert knowledge had not been able to provide reliable treatments or determine an accurate diagnosis due to continual bodily decline, Roberta and Ollie's positive self-reflections helped them to bolster a sense of progress and justify their continual engagement with the medical profession. That is, they felt that at least this structure had made some improvement to their lives compared to when they had negotiated a diagnosis and/or treatment plan. Related to this, Roberta and Ollie demonstrated the problems with medical typologies and/or medicalised ideas about improvement and deterioration, namely

that the presence of illness does not automatically lead to a negative outlook (Reeve et al 2010; Cassidy 2012).

However, Camfield (2002: 59) has suggested that the healing and achievement narrative in dystonia 'can ultimately be limiting if it "naturalises" an intolerable situation.' Drawing on normative 'expectations of individual agentic potential' (Broom et al 2015: 728) in confluence with their embodied knowledge may have permitted participants like Roberta and Ollie to accept deterioration and suffering more easily. Finally, they did not challenge conventional notions of disability and difference or consider other interpretations of these terms. Ollie eventually conceded to the view that he and other people with dystonia were disabled on account of their (visibly) malfunctioning bodies. In fact, Roberta and Ollie reinforced a tragic understanding of disablement by projecting their past experiences of suffering on to other disabled people and assuming that their lives would be similarly distressing.

Conclusions

In conclusion, by conceptually distinguishing between various experiential dimensions, this chapter has demonstrated the complex and intricate meanings underlying participants' embodied accounts. It has also provided a holistic and nuanced interpretation of the body in dystonia and the ways in which this entity interlaces with wider socio-political discourses and agendas.

The data indicates that living with dystonia had widespread and far-reaching consequences for participants' lives, which could not easily be subsumed within

reductive medical categories. Indeed, the similarities and differences existing

between and within participants' accounts reveal the vast array of challenges and

achievements that they experienced with dystonia, irrespective of diagnosis.

Furthermore, for some participants, the fluctuating and unpredictable nature of their

experiences threatened the embodied relevance of their original diagnostic label.

Corporeal transformations, therefore, highlighted the permeability of fixed medical

boundaries and the potential of 'passing' from one diagnostic category into another.

Moreover, participants with focal or generalised forms of dystonia reported living

with multiple somatic effects, even though the former category involves only one

specific body part or region (chapter 2) (Morishita et al 2009: 3). Despite the limited

applicability of medical labels, participants still used these as critical reference points

to make sense of the uncertainties of their condition (chapter 5). In fact, as is argued

throughout this thesis, medical explanations dovetailed with participants' experiential

knowledge of dystonia, and by proxy, formed an integral part of their accounts.

Whereas the 'internal' and 'external' bodily experience of dystonia produced

somewhat different management strategies, it can be argued that both dimensions

imbued a cultural character. Indeed, dualistic notions of (dis)ability mediated

participants' embodied knowledge, despite the fact that their fluid and unpredictable

carnalities transcended demarcation (Jackson 2005; Stone 2005; Zitzelsberger 2005;

Lightman et al 2009). Due to the changing (in)visibility of their condition,

participants occupied a liminal and marginalised status, resting in-between

hegemonic orderings of sickness and wellness, competency and deviancy,

illegitimacy and validation (*ibid.*). Irrespective of the (im)perceptibility of their

symptoms, participants adjusted to enacted and/or felt stigmatisation by taking responsibility for their disrupted lives and placing the onus on them to monitor their bodily abilities and appearances. Even in situations where participants endeavoured to forge positive self-identities in order to mitigate embodied concerns about uncertainty, their sense of progress was wrapped up with Western moralities of performance and autonomy. Thus, it can be argued that this constrained the degree to which their counter-narratives resisted dominant ideas about disability and difference.

This chapter points to the ways in which participants' embodied knowledge intersected with a range of intrinsic (e.g. impairment severity) *and* extrinsic (e.g. social attitudes, dis/abling environments) factors (Shakespeare 2006; 2014). More specifically, as exclusionary discourses and practices formed an important modulation aspect in the lived and living experience of dystonia, my findings support the work of Thomas (1999; 2007; 2008; 2010; 2012), who has maintained that the notion of disability ought to be regarded as a form of social oppression that intermeshes with the embodied experience of impairment and illness. Arguably, applying these conceptualisations to the findings presented in this chapter reveal novel insights into the profound and disabling effects of neoliberal rationalities like self-management and individualisation on dystonic personhoods and identities across the life-course. With this in mind, the next chapter explores participants' perceptions of lay identification, and in particular, the ways in which they used normative ideas about illness and coping to frame their accounts of peer support.

Chapter 7

Exploring the role of experiential knowledge in (dis)assembling a shared patient identity

Chapters 5 and 6 demonstrated the way participants drew on experiential and medical bodies of knowledge to approach complex decisions about healthcare (chapter 5) and make sense of their day-to-day realities with dystonia (chapter 6), despite the fact that these sources did not always align straightforwardly with each other. Within this chapter, I further develop my analysis of the ways in which participants deciphered and gathered information on dystonia through an examination of their experiences and perceptions of peer support. In particular, I focus on shared identity across all participant groups: support group attendees, NHS patients, and those from WADSS, a 3-day residential group-based treatment intervention that had links with The Dystonia Society.

This chapter is presented as follows. I discuss the various ways in which participants formed shared identities with other people with dystonia in the context of a support group or intervention setting, before moving on to a consideration of how these could become threatened and/or fractured at different points in their trajectories. In doing so, I illuminate the sociological complexity of (mis)identification in lay-led provision across different social contexts.

Mobilising lay knowledge

Over the last five decades, patient support groups have become an important mediatory link for individuals to obtain information on the management of their specific condition and collectivise around medicalised agendas (Allsop et al 2004; Novas 2007; Mold 2010; Blume 2016). While feminists and disability rights activists created grass-roots organisations in the 1960s and beyond to emphasise issues of power and inequality operating within social systems (e.g. Hunt 1966; Morris 1992), biology focused discourses and practices have increasingly become the dominant form of identity politics governing the lives of disabled people today (Rapp 1999; Rapp et al 2001; Beresford 2002; Rose and Novas 2005; Novas 2007; Barker 2008; Sulik and Eich-Krohm 2008; Hughes 2009; Oliver 2009). In particular, support groups often perform a salient role in involving members in biomedical research activities and lobbying (non)governmental agencies for funding (Novas 2007: 14). Such collectivities may also provide opportunities for individuals to share their embodied experiences with experts and patients alike in order to address and take possible action against epistemological deficits existing within healthcare institutions (e.g. Borkman 1976; Epstein 1996; Kroll-Smith and Floyd 1997; Barker 2002; 2008; Allsop et al 2004; Whelan 2007; Sulik and Eich-Krohm 2008; Akrich 2010; Locock and Brown 2010; Barker and Galardi 2011; Blume 2016). These practices and strategies arguably offer hope and new possibilities for those affected by chronic conditions (Rose and Novas 2005; Shakespeare 2006; 2014; Novas 2007), albeit do not necessarily address the complex social and moral debates underlying medicalised agendas (e.g. Oliver 1990; 2009). Overall, by positioning lay knowledge as a 'credible' and holistic resource that can be mobilised within patient-led spaces (e.g.

Ziebland and Herxheimer 2008), the aim of many charities is to support those living with a particular medical problem manage the day-to-day effects of their condition (Kerr et al 1998; Finn 1999; Allsop et al 2004; Radin 2006; Sandaunet 2008; van Uden-Kraan et al 2008; Percy et al 2009; Holbrey and Coulson 2013).

With this in mind, I examine participants' experiences of mobilising their knowledge and expertise with other people with dystonia using the following thematic sub-headings: 'adopting medical terminology' and 'obtaining social support.' These categories focus on the various ways in which participants reinforced individual (medical) notions of disability and difference through their sense of belonging to a dystonia support group and/or group-based treatment intervention course. Peer support helped participants to integrate medical discourses and practices within their experiential accounts. It also allowed them to transform their embodied experiences into an epistemologically meaningful resource (Mazanderani et al 2012) that emphasised the dynamic of autonomy and individualisation. Arguably, this led to the creation of widely acceptable ideas about coping.

Adopting medical terminology
The interviews revealed that the majority of participants re-appropriated medical ideas about dystonia at the support groups or intervention site and, in doing so, generated their own particular brand of information and knowledge. In particular, inviting medical speakers to present enabled participants to share their experiences of these events and form an 'epistemological community' (Whelan 2007; Akrich 2010), which collectively reflected their awareness of, and faith invested in, expert bodies of

knowledge. Every support group participant, apart from Oscar who rarely attends

meetings (discussed later), said that clinicians and healers from different professional

backgrounds (e.g. neurology, physiotherapy, aromatherapy) were regularly asked to

give talks about the management of dystonia and field general questions from the

floor (n=26). Moreover, some participants reported that they enjoyed sharing stories

with other members about the content of the speakers' presentations (e.g. Faye: '*any*

kind of information is useful you know that you get and you can share it with other

people, I think that's wonderful [...] I thought the last meeting that we had where we

had the nurse and the physiotherapist were very helpful.' [Support Group 1 member,

group interview 4]). As part of the psychology intervention, a neurologist came to

speak to the nine remaining WADSS participants in order to inform them about the

biological aspects of dystonia (Sandhu et al 2016). They also received information on

effective self-management from two health psychologists and an expert in

mindfulness (*ibid.*). Consequently, the presence of (non)orthodox speakers gave

many WADSS participants a conversational reference point in which they obtained a

shared experience of meeting and liaising with the same specialists. This also

enabled them to discuss these talks among themselves during the breaks and develop

individually focused adjustment strategies (Ava: '*a couple of the other people were*

saying that (neurologist at WADSS) had shown them some- some exercises which

obviously seem to be paying off.' [WADSS participant, post-intervention interview, 1

month after initial interview]). Researchers note that patient organisations are helpful

for enabling members to come to terms with the disquieting effects of their illness

(Williams, G 1984; Bülow 2004; Frank 2013), as well as manage difficulties with

clinicians by sharing and selecting particular strands of knowledge that closely align

with the accepted values of the group (Barker 2002; 2008; Allsop et al 2004; Radin 2006; Whelan 2007; van Uden-Kraan et al 2008). Similarly, using peer support to obtain appropriate forms of medical information on dystonia meant that many WADSS and support group participants shared and united around a similar set of beliefs, namely, to repair epistemic fractures existing between experiential and expert knowledge (chapter 5). Tristan, who regularly attends support group meetings, is aged between 40-50 years old and has been diagnosed with generalised dystonia. In spite of the fact that a blood test indicated his type would not be responsive to the dopamine drug levodopa, Tristan adamantly believed that all individuals with dystonia should undergo the same assessment. This was because he had come across various types of medical information, including from the support group, which suggested levodopa was a highly effective treatment for those with dopamine-responsive dystonia:

> Paige: […] We don't give each other any advice as such, do we? At the support meetings…
>
> Tristan: I – (louder) I do! I do! I do occasionally!
>
> Paige: (laughing) You do!
>
> Tristan: (laughing) Sorry, I do! I do! Urm…
>
> Paige: Do we take it though!
>
> Tristan: Well yeah Jason has took it. About the benzhexol [dystonia medication] and stuff er (looking at Jason) the - the - the dopamine you took that advice didn't ya?
>
> Jason: Yeah, yeah.
>
> Tristan: I mean this is just something I pass on to Jason 'cause we had

(neurologist) who came [to the group] and did the talk and remember

(neurologist) said -

Paige: I don't.

Tristan: That he gave one of his patients a dopamine and he made an

appointment to see him the next month and he never turned up and he - he

saw the patient six months later and he said 'well why didn't you come?' He

said 'because its sort - I'm alright now.' 'Cause dopamine is a miracle cure

for dystonia. It will work in a very small number of people.

Paige: For some patients.

Tristan: For a very minute number of patients. But it will work instantly and

it's a miracle cure. And um I could never understand why when I first met

Jason that he had never even been trialled on the dopamine by (another

neurologist). Urm and I thought 'oh why not?' It's the - it's the cheapest cure.

It's the best cure. But obviously it doesn't work for 99% of people it won't

work but for 1% of people it will. And that's the advice I gave to Jason and

said 'well why haven't you trialled the dopamine?' [Support Group 1

members and representative, group interview 1]

Individuals with rare diseases often become expert patients on their condition

because of the knowledge that they have accumulated from living with it (Budych et

al 2012). This may lead them to question medical decisions and collectively vocalise

their requests for appropriate treatment within authoritative healthcare systems (Kerr

et al 1998; Rabeharisoa 2003). While Tristan and Paige noted that only a small

number of people with dystonia benefit from taking levodopa, Tristan still felt

obliged to inform other members of its potential effectiveness. In fact, drawing on his own personal experiences of treatment coupled with the information that he obtained from the group permitted Tristan to inform others about their healthcare options. Arguably, this meant that he positioned himself as a 'lay' (Prior 2003) or 'interactional expert': a type of person who has acquired specific information about a scientific discipline but cannot formally practice it (Collins and Evans 2002; Collins 2004; Collins and Pinch 2005). Exercising this type of expertise enabled Tristan to suggest, rather than prescribe, levodopa to other people with dystonia, extending their knowledge of potentially beneficial medications. The existence of levodopa also sustained the commonly held view that similarly effective treatments could be found for other types of dystonia in the future. Indeed, affiliating with medical speakers and disseminating their ethos to other attendees was widely indicative of the group's shared optimism. Through the mobilisation of medical knowledge, Tristan communicated and forged supportive alliances with some members at the support group. In doing so, he helped to transform their hopes into a reality, offer some certainty to the question of whether a possible treatment could help people with dystonia, and most crucially, make it seem more likely that the development of a cure was 'just around the corner' (Shakespeare 2006: 1013).

Many primary and secondary research participants found the groups beneficial for restoring their collective faith in the future productivity of medicine. Even though there are no curative options currently available for individuals living with dystonia and the effectiveness of prescribed treatments vary greatly (chapter 1) (e.g. Cloud and Jinnah 2010), some participants reported that they and others attend Support

Group 1 meetings in order to receive updates about potentially beneficial medical therapies:

> Celia: Paige said that health professionals enable more people to attend the group. Why do you think that is? (Pause) Why do you think that -
>
> Paige: I think people think they're going to learn something maybe an update maybe they even think they'll get -
>
> Jason: Quest for knowledge -
>
> Paige: News of a cure […]
>
> Whitney: I sort of keep up on to that hoping that someday we're all gonna be lucky and get a complete cure. (Laughs)
>
> Tristan: Mmm. [Members and representative, group interview 1]

This conversation demonstrates that participants valued medical speakers because their notions of health and the body closely aligned with the group's narrative surrounding acceptable dystonia therapeutic strategies. Indeed, acquiring information on dystonia from health providers enabled members to share and collectivise around medicalised discourses and practices, as well as create a sense of identification based on these particular ideologies. In this way, the interviews revealed the permeability of scientific knowledge into non-established medical organisations.

Support groups often 'embrace the biological reductionism of medicine and promote rather than deflect medicalization' (Barker 2008: 29). Specifically, members of support groups often weave together dissimilar understandings through the mobilisation of a shared medical diagnosis and permissive illness story that glosses

over the variability of experience (Borkman 1976; Barker 2002; 2008; Whelan 2007; Locock and Brown 2010). Attendees also collectively promulgate individualist ideas about the assumed suffering of disabled people in order to acquire funds and raise the profile of a given health problem (Stockdale 1999; Camfield 2002). Yet, through their adoption of a 'tragedy' approach to disability, support groups de-emphasise policies aimed at reducing inequalities within healthcare (Stockdale 1999) and the experience of disablism *per se* (Morris 1992; Drake 1996; Jones 2007; Oliver 2009). Instead, patient alliances reinforce the dominant idea that members' impairment effects are inherently problematic and require the implementation of a definitive (medical) solution (e.g. cure) to correct or erase (Morris 1992; Drake 1996; Camfield 2002; Sulik and Eich-Krohm 2008; Oliver 2009). In view of that, Barker (2008) has argued that support groups can be limited in terms of their capacity to construct truly open and collaborative spaces for members to put forward alternative agendas and ideas about disability. While Support Group 2 participants said that non-medical speakers (e.g. welfare officers) sometimes visited alongside health professionals, there was no evidence to suggest that any of the participants rejected the personal tragedy and medical models of disability. In fact, unlike Paige's surprise response to Tristan, none of the participants contested receiving advice from a medical speaker. Furthermore, many participants like Tristan used expert language in their accounts to view individuals affected by dystonia as automatic recipients of healthcare, as well as to emphasise the relevance of medicalised discursive frameworks to their everyday lives ('*for a very minute number of patients.*'). As The Dystonia Society (and WADSS) became a point of access to the medical profession, these quasi-clinical settings helped to promote dominant, medico-popular attitudes towards the

management of the condition.

However, researchers also maintain that disabled people's positive understandings of medical cures and therapies do not merely occur as a result of Western societies' enduring belief in the usefulness of expert knowledge (Beauchamp-Pryor 2011). As was documented in chapter 6, experiences of impairment can sometimes generate intolerable and disquieting effects, which may be unresolvable through the implementation of egalitarian policies alone (de Wolfe 2002; Shakespeare 2006; 2014; Boardman 2010; 2014b; Beauchamp-Pryor 2011). Obtaining updates about potentially beneficial treatments may be one of the few ways in which individuals feel that they can perform an active and autonomous role in managing their insurmountable experiences of suffering (*ibid.*). Consequently, this demonstrates the degree to which medicalised agendas produce and structure acceptable responses to illness.

Obtaining social support

Though the majority of participants drew on medical knowledge at the groups or intervention site to establish a 'credible' patient identity, others (also) said that sharing personal experiences of stigma could enhance their social and emotional wellbeing. For example, one WADSS participant, Roberta, said that she took part in the course in order to derive satisfaction from helping other people going through similar experiences to what she went through during the negotiation of a diagnosis (chapter 5) ('*I'm quite mindful that there'll be a lot of people who are currently experiencing what I experienced years ago and that if I can do anything to go up and*

support them, I would want to do that.' [Pre-intervention interview]). Research on

patient support groups has found that transforming experiences into trustworthy

epistemic sources and strategies can lessen the damaging effects of stigmatisation

and empower individuals to cope more effectively within their social environments

(Crocker and Major 1989; Kerr et al 1998; Finn 1999; Radin 2006; Sandaunet 2008;

van Uden-Kraan et al 2008; Percy et al 2009; Locock and Brown 2012; Mazanderani

et al 2012; Holbrey and Coulson 2013; Heaton 2015). Similarly, participants felt that

the groups acted as an antidote to uncomfortable feelings of social exclusion because

they could obtain temporary relief from not having to worry about looking 'odd' or

appearing different:

> Nicola: […] The thing I get out of meetings the most is being with people
>
> who understand your condition, you don't have to explain it, you don't have to
>
> let them know that you go through this, it's just a place to come and you can
>
> relax and just be yourself -
>
> Charlotte: Sure.
>
> Nicola: You're not constantly tensed wondering what people are thinking of
>
> you.
>
> Charlotte: Absolutely.
>
> Cassie: […] I'm rather the same, I come [to the support group] because it's so
>
> relaxing not to have to pretend not to have dystonia (agreeing sounds from
>
> Charlotte and Miranda) [Support Group 2 members and representative, group
>
> interview 2]

Disability rights scholars have debated how far individuals living with an impairment

can sufficiently mobilise a shared 'disabled identity' that challenges dominant understandings of disablement (Morris 1992; Shakespeare 1993; 1996; Beresford 2002; Galvin 2005; Hughes 2009; Beauchamp-Pryor 2011; Noorani 2013). One way agents may forge alternative health identities is through the rejection of 'an anti-medical and "anti-recovery" ethos' in which they value their illness (e.g. anorexia nervosa) and prefer not to take an active role in erasing its effects (Fox and Ward 2006: 471). Fox and Ward (2006) have maintained that this outlook supplants a strong focus on recuperation and personal responsibility with subjective notions of embodiment. As I argued in chapter 6, hegemonic qualities surrounding coping such as individual agency and health self-management (e.g. Murdoch et al 2013; Broom et al 2015) impacted on many participants' experiences of distress and isolation. This was because these moral discourses often undermined the perpetual and intractable consequences of their dystonia. Indeed, such ideologies contributed to the view that participants ought to take an active and autonomous role in getting better rather than ask for support or openly disclose their suffering to social familiars (e.g. Ava). In contrast, talking openly and candidly about their everyday stocks of knowledge and opting not to conceal their 'abnormal' bodies at the groups (Cassie: '*it's so relaxing not to have to pretend not to have dystonia.*') enabled many participants to authenticate their experiences and challenge the perception that they should manage these within the 'private' sphere. Displaying a sense of solidarity and describing their feelings of suffering and abandonment in public also allowed participants to derive emotional benefit from repeatedly sharing their condition-specific experiences with other members who had similar understandings.

However, the extent to which the mobilisation of experiential knowledge sufficiently enabled participants to resist normative ideas about the management of chronic illness was somewhat constrained through the groups' adherence to a consumerist, neo-liberal agenda (Drake 1996; Stockdale 1999; Sulik and Eich-Krohm 2008; Oliver 2009; Mold 2010; Beauchamp-Pryor 2011: 10). This ideological framework severs personal experiences of health from the wider social milieu within which they are created, limiting the formation of overtly political identities (McGregor 2001; Sulik and Eich-Krohm 2008). As was outlined earlier in this chapter, The Dystonia Society and other patient support groups are often charities and as such, they rely on presenting members in particular ways to control the public profile of the disease and generate funds (Drake 1996; Camfield 2002). Specifically, attention is placed on empowering and increasing the self-esteem of dystonia members rather than encouraging them to take political action against social injustices and wider forms of discrimination (Camfield 2002). In fact, participants' struggles with appearing 'normal' in public meant that they used the groups to vocalise their frustrations and feel more included instead of uniting against the promulgation of socially oppressive discourses and practices, even though these produced a negative impact on general wellbeing (chapter 6).

Until now, participants' abilities to create a shared identity have been presented as relatively uncomplicated, i.e. it has been premised on a shared diagnostic category. The next section considers the various ways in which this sense of identification could become compromised or fail to develop in the first place, thereby demonstrating its complexity in the context of dystonia.

Threats to the formation of a shared patient identity

As well as many participants' positive accounts of mobilising a shared identity (n=35), some (also) reported several barriers (potentially) preventing them from identifying with other people with dystonia. Interestingly, none of the participants recruited from NHS Hospital 1 showed a sense of unity around dystonia or engaged in Dystonia Society events partly because they viewed their condition as relatively mild (discussed later) (n=2). While one support group attendee, Oscar, who is aged between 29-39 years old and has been diagnosed with generalised dystonia, belonged to The Dystonia Society, he said that he rarely goes along to the meetings because he prefers not to label himself as 'incapable.' However, Oscar somewhat retracted this comment after another participant questioned his perceptions of peer support:

> Oscar: I do consider myself disabled but not particularly badly […] maybe one of the reasons I don't come to the dystonia group is I just- I don't try to label myself I try to just do what's in front of me, my academic career and things rather than (pause) thinking too carefully about why I can't do things but that sort of- it does come back to haunt me really. It's uhm-
>
> Matt: Do you think that if you came to the meetings it would make you feel uhm like you're putting a label on yourself, like you're saying 'oh yes I'm going?'
>
> Oscar: I wouldn't worry about that label because I do of course think- (laughs) I'm reminded every time that I can't do something, I'm reminded that there is something wrong. So I'm not- I'm not sort of saying that I'm too proud to come [Matt: Yeah] I'm just saying that I'm too busy to come really and I'm to sort of er (pause) I don't know […] I think that sort of- part of the

reason I don't like that sort of thing is because I find socialising quite an effort, I find parties incredibly difficult [Matt: Oh yeah] for instance so because- because of standing, so if I'm going to meet someone and I've just (murmurs from the group) well yeah I need to sit down, I'll be- I'll be talking to someone really interesting that I want to talk to and after three minutes all I'm thinking about the conversation is that my legs hurt and I need to sit down [Matt: Yeah] and it's really difficult to say- to sort of stop them mid flow and say 'come and sit [Matt: Yeah] next to me and talk about this.' Or-
Matt: If you're- if you're at the support meeting people understand that.
Oscar: Oh I'm sure they do, yeah I'm just saying that I think I've got a sort of inbuilt fear of (laughs) that sort of interaction. [Support Group 1 members, group interview 3]

Werner et al (2004) found that some women in pain preferred not to meet other people with the same problem because of concerns that they might be perceived as 'moaning' about their 'private' experiences of suffering rather than taking an active role in getting better. This view links to wider discourses surrounding gender and coping, whereby women are deemed to be 'whingers' and 'hysterics' (*ibid.*). In order to present a more socially acceptable identity, they might choose to repress their feelings of pain and suffering in public (Werner et al 2004; Broom et al 2015). Related to these gendered ideas about coping, studies have also shown that men often view illness as an affront to their sense of masculinity and control (Charmaz 1994; Evangelista et al 2001; Nordgren et al 2008). Specifically, Charmaz (1994) has noted that male patients attempt to ignore the physical and psychological impact of their

illness on their everyday lives to perform an independent and responsible self. Furthering this viewpoint, Oscar's perceptions of lay-led provision were discordant with the overall aims of the group (i.e. to discuss common difficulties and offer support) because he preferred to evade conversations about his own corporeal restrictions and carry on with life as best he could. Consequently, he decided to present a stoical attitude that conformed to hegemonic notions of the sick role, despite the fact that he regularly suffered from carnal disruptions and flare-ups.

Another reason that Oscar's sense of identification was significantly less than other participants' was because he found socialising difficult both within and outside of the support group site. While other participants felt able to put aside their concerns about appearing different and derive immense value from sharing their experiences (e.g. Nicola), Oscar's reluctance to ask for help made him feel anxious that his needs would not be fully accommodated at the meetings. This also impeded his ability to assemble a shared identity and emotionally connect with other people with dystonia. While Matt challenged Oscar's worries in order to emphasise the supportive nature of the group, Oscar continued to justify his decision to repress his experiences by blaming himself for being frightened of social situations and not telling other people when he was in pain (I examined Oscar's reported difficulties with going out with friends in chapter 6).

Whereas Oscar did not feel completely part of the group because of fears that the effects of his impairment might prevent polite forms of conduct, how accessible this space was to other participants also influenced their sense of belonging. Agatha is

aged 62 years old or over and lives with laryngeal dystonia. She first joined Support

Group 2 in 2000 but currently finds participating in meetings problematic because of

communication difficulties:

> Celia: (Louder and looking over to Agatha because she is hard of hearing)
> What types of things do you talk about at your support group?
>
> Agatha: Urm well this is the first group I've been to for quite a while and it's
> nice to hear what the others say and what events that are forthcoming and
> things that will help us which is a help urm but I do find it difficult to talk for
> very long urm I just run – ah ha! Out of puff –
>
> Charlotte: Sure.
>
> Agatha: And my throat then is - I ache after –
>
> Miranda: Aww, poor thing. [Members and representative, group interview 2]

Since individuals' sense of embodiments co-exist with prescribed methods of social

interaction, those who are unable to follow established norms and rules as a result of

their carnal differences are more likely to notice the effects of their condition

(chapter 6) (Hughes and Paterson 1997; Paterson and Hughes 1999; Paterson, K

2001). Similarly, Agatha's vocal impairment became increasingly more perceptible

in relation to the group's preferred style of communication i.e. talking (as well as

during the interview itself). These taken-for-granted norms and customs not only

caused her to feel physical pain but also excluded Agatha from participating in the

exchange of knowledge, giving her a disadvantage in forming relationships with

others in the group. While Agatha found it helpful to listen to other members discuss

their condition-specific experiences, the structure of the group constrained how she

could perform a shared identity. Even though The Dystonia Society prides itself on representing, and campaigning on behalf of, people with dystonia, the range of symptoms associated with the condition restricts a truly inclusive space (Camfield 2002). Supporting this viewpoint, Shakespeare (2006; 2014) has noted that the needs of impairment groups are sometimes incompatible due to individuals' varying levels of capabilities and limitations. Further, laryngeal dystonia is relatively uncommon with a low prevalence rate (11 – 59 per million people) compared to other focal types such as cervical dystonia (23 – 130 per million people) and blepharospasm (17 – 133 per million people) (Defazio et al 2007). Thus, support group members may not have been familiar with Agatha's particular needs and simply assumed that she would be able to fit in with group norms and communicate verbally. Despite the fact that Agatha identified with the aims of the group, she could not mobilise her knowledge in the way expected by other members and hence occupied a liminal status in which she wanted to form a shared identity but could not physically adhere to pre-existing requirements. Consequently, the support groups sometimes found it difficult to create accessible spaces that made everybody feel relaxed.

Constructing impairment hierarchies

Many of the participants generated a range of social comparisons about the perceived relevance of lay knowledge, with varying implications for wellbeing and the development of an 'epistemologically meaningful' identity (Mazanderani et al 2012: 546). Finkelstein (1993: 13-14) and Deal (2003) have argued that disabled people often assign particular values to other impairment groups in order to normalise and differentiate their experiences from less socially desirable individuals. These

comparisons may lead to a 'hierarchy of impairments' in which some health problems are considered more preferential and acceptable than others (Deal 2003). For example, as has been noted throughout this thesis, psychiatric problems are usually at the bottom of the impairment hierarchy since these particular illnesses are associated with culturally deplorable traits such as personal irresponsibility and weakness (e.g. Corrigan and Watson 2002). Furthermore, individuals with an impairment may view other people with the same or different medical condition as lower in the hierarchy based on the perceived severity of their symptoms (Finkelstein 1993; Deal 2003). Arguably, eliciting comparisons and distinguishing themselves from those perceived as less acceptable can help disabled people to make sense of who they are and where they fit within the social order, providing them with a degree of certainty over their lives (e.g. Festinger 1954; Taylor 1983; Austin 2015).

Related to the term hierarchies of impairment (Deal 2003), Mazanderani et al (2012: 551 emphasis original) have noted that 'people's *bodies* serve as important vehicles for the articulation of experience, which means that the *visibility* of patients' bodies plays a significant role in the sharing of experiences.' Similarly, a large part of participants' sense of identification depended on the way they perceived other people's physicality. Roberta, for example, is aged between 51-61 years old and has been diagnosed with cervical dystonia. At the time of the pre-intervention interview, she reported that she had never attended a dystonia support group or met other people with the condition. Participating in WADSS had been an enriching experience and enabled Roberta to talk with other individuals diagnosed with similar focal dystonia types. However, while largely positive, Roberta also found meeting other

people with dystonia challenging. More specifically, the presence of one particular WADSS participant, William, meant that Roberta had to negotiate a range of felt emotions in response to seeing his noticeably disordered movements:

> Roberta: Urm when I first seen him (William) urm my heart started to thump urm my heart went out to him because obviously his head tremor was *a lot* worse than my own urm and I-I-I did er I just said 'thank you Lord, you know, I'm not that bad' urm and my heart went out to him because his tremor was very defined urm whereas I can urm I've learned little tricks to cover mine up, I think it would be very difficult to cover up such a urm significant head tremor urm and I did I felt for him. But it did make me *very* grateful that yes, I've got dystonia but I haven't got dystonia to that degree. [Post-intervention interview, 1 month after initial interview]

Social psychologists argue that there is a propensity for individuals who notice undesirable similarities between other group members to perceive the latter's experiences completely differently from their own (Festinger 1954; Wills 1981; Meeres and Grant 1999; Carmack Taylor et al 2007; Locock and Brown 2010). This process is commonly referred to as a 'downward social comparison' (Festinger 1954; Wills 1981) and, in some cases, can perform a significant role in enhancing stigmatised individuals' emotional wellbeing and sense of social worth (Wills 1981; Taylor 1983; Carmack Taylor et al 2007: 266; Percy et al 2009; Holbrey and Coulson 2013; Heaton 2015). While meeting somebody with a more pronounced tremor than herself caused Roberta some initial distress, negatively evaluating William's symptoms meant that she could retain a positive self-identity. Indeed, in the pre-

intervention interview, Roberta reported that she had felt upset by the onset of her noticeable symptoms ('*I didn't want to go out, I didn't want people looking at me […] it was constant tremor […] it affected all aspects of my life.*'). Goffman (1963) has maintained that individuals with perceptible impairments are less accepted than those affected by socially invisible problems since the former often struggle to conceal their condition and 'pass' for 'normal' successfully, particularly within Western societies that value a specific kind of bodily aesthetic (chapter 6) (Glassner 1992; Hughes 1999; Zitzelsberger 2005). Yet, favourably comparing the relatively less visible effects of her impairment to William's more noticeable ones enabled Roberta to utilise this evaluation as evidence that she had overcome previous experiences of physical and emotional suffering. Shakespeare (2006; 2014) has noted that disabled people's relationship to their own impairment influences their understandings of their illness experiences. Given that her dystonia had started later in life and threatened her previously taken-for-granted identity, Roberta may have felt that she needed to compare in order to preserve her pre-illness self and recreate a sense of normality. In fact, Boardman (2010) and Heaton (2015) have observed that people with chronic conditions often positively distinguish themselves from others with the same or different long-term medical problem to emphasise their relatively less troublesome experiences in comparison to these reference groups. Similarly, Roberta's evaluation of William's 'abnormal' bodily behaviours permitted her to reconcile 'identity tensions' (Locock and Brown 2010) between her former and current self, as well as allay any fears surrounding her present sense of embodiment.

Thus far, I have examined the extent to which the construction of a downward social

comparison enabled participants to normalise and positively assess their own embodied experiences. Despite viewing some WADSS participants as worse off than herself, Roberta still managed to forge strong emotional and social alliances with other members due to perceived resemblances surrounding bodily comportment ('*I felt quite pleased that there was somebody else in the group with exactly the symptoms that I've got.*' [Post-intervention interview, 1 month after initial interview]). However, the literature has also noted that downward social comparisons can be negatively interpreted 'as a sign of how things might get worse', even though the person using such evaluations perceives themselves more favourably than the reference group (Heaton 2015: 337; Carmack Taylor et al 2007; Boardman 2010; Locock and Brown 2010; Mazanderani et al 2012; Holbrey and Coulson 2013). For a minority of participants, the prospect of meeting other people with dystonia, especially those with more severe symptoms and/or poor adjustment strategies, incited palpable fears about their future prognosis (William: '*I'm not sure whether reading about the problem that other people have got is goin' to help me much [...] I mean most of them ended up not going out of the house [...] and I don't want to end up in that situation.*' [WADSS participant, pre-intervention interview]). In an exploration of the impact of online peer support for women affected by polycystic ovarian syndrome, Holbrey and Coulson (2013) found that these services could heighten users' anxieties by exposing them to negative stories about the other (e.g. infertility, unwanted hair growth). To deal with the prospect of worsening impairment effects, the women refused to engage with other individuals with the condition or experienced ambivalent feelings as to whether they could (*ibid.*). Indeed, meeting individuals regarded as worse off can highlight the limits of

experiential knowledge since the person may become starkly aware of the fact that they do not know how their condition may progress for them in the future (Boardman 2010; 2014a; 2014b). For example, Beth is aged 62 years old or over, lives with cervical dystonia, and, at the time of interview, said that she had never attended a Dystonia Society support group meeting and had no intention of doing so in the future. Ruby was the only other participant who expressed similar sentiments about peer support services. Specifically, Beth claimed that as her dystonia is currently manageable, going along to group meetings would be futile:

> Celia: Have you ever say attended a dystonia support group?
>
> Beth: (Abruptly) No I'm not that sort of person (laughs).
>
> Celia: Okay. Could you go into some detail about what you mean by that?
>
> Beth: Well (sighs) I've got dystonia, I've got to live with it and I've learned to live with it and I don't want to go to these support groups particularly, I'm not a very gregarious social person and I don't want to have to sit and listen to people that are far far worse than me. […] I mean initially when (name) my husband got Parkinson's he was urm referred to a very good (support) group […] and I saw the other people that had got Parkinson's that were far far more advanced than (husband) and I just switched off, I didn't want to know because everyone is different and if I've got to cope with that in the future, well I will cope but not until it arrives (laughs slightly) if it arrives, and it's the same with dystonia, I think it's very individual to each person, and I've got my own way of coping with it urm and I'm living quite happily with it and I just thank my lucky stars it's not worse than it is and that's me (laughs).

Celia: So when you say that there could be worse people [Beth: Oh yeah] what do you mean?

Beth: I saw a girl on television some time ago, she was having treatment at the (hospital name) and this one leg was up underneath her chin she was in a wheelchair and her arms were all distorted she was in a *terrible* state and they were saying that they were going to try and operate on her to help her and I thought 'oh she's got the same as me thank *goodness* I'm not like that' you know I thought 'poor girl (quieter) I hope they can help her' urm and she was much much younger than me, I think she was only in her 20's. [NHS Hospital 1 patient]

The information that Beth obtained from watching a television documentary about a young woman with highly visible dystonic symptoms contributed to her decision not to engage with other individuals with dystonia. In particular, seeing televised images of this young person had caused her to become upset. This may have been because Beth wanted to be viewed as displaying a caring and empathetic attitude towards the woman who '*was in a terrible state.*' Supporting this viewpoint, Holbrey and Coulson (2013) have argued that a potential drawback of downward social comparisons can be the way these invoke 'sadness on behalf of the perceived suffering of others' (see also Werner et al 2004; Ussher et al 2008). Yet, Beth's concerned outlook also conformed to hegemonic ideas about the alleged 'tragedy' of disability and the ways in which individuals with impairments are automatically considered vulnerable and helpless (e.g. Oliver 1990). Related to this point, it is an enduring belief in Western societies that youth is associated with desirable

experiences such as health and vitality and hence, is afforded a higher social status than those who are considered old (Lupton 2012). Consequently, having an impairment as a young adult is doubly stigmatised as it contravenes the assumption that this group are more physically attractive and economically productive (*ibid.*), and that further, should be morally exempt from experiencing any kind of misfortune often associated with illness (Asch 1999).

In addition to sustaining cultural perceptions of age and disability, the media also produced a significant impact on Beth's perceptions of peer support. Etchegary et al (2008: 8) have argued that embodied and empathetic forms of experiential knowledge can co-exist simultaneously throughout an individual's lived trajectory and be a crucial factor 'in shaping meanings about' healthcare and/or lay identification (Mazanderani et al 2012). Similarly, Beth not only drew on previously upsetting experiences of attending a Parkinson's support group in order to refrain from visiting dystonia meetings, but also used her embodied sense of the condition to reject a shared identity and present a stoical outlook. This was because the possibility of coming across other people with more severe symptoms misaligned with how she currently experiences and understands her condition. In fact, the shock of seeing a young person living with the same impairment as her but in a far more critical way (empathetic knowledge) caused Beth to temporarily assimilate with and later disassociate from the woman's bodily behaviours *('I thought "oh she's got the same as me thank goodness I'm not like that."')*.

Etchegary et al (2008) have also applied the terms 'vivid' and 'vague' empathetic

knowledge to describe the types of sources that individuals use to gather information about other people's realities. Empathetic knowledge generated through personal contact with those living with a specific condition represents a 'vivid' experiential dimension, while 'vague' forms are typically obtained from the media or distant acquaintances (*ibid.*). Arguably, the vague empathetic experiential knowledge source that Beth acquired through witnessing a televised documentary about a person with dystonia was made vividly meaningful because she already knew what living in a dystonic body was like. Research on disabled people's experiences of peer support has shown that individuals may be more likely to negotiate a support group identity successfully by mediating their experiential knowledge in different ways (e.g. at the support group, using online forums) to minimise their risk of coming across others with poor adjustment strategies or more severe symptoms (Mazanderani et al 2012). Beth, however, rejected any type of medium that could lead to knowledge sharing, experiencing this as an emotionally distressing downward social comparison. Deal (2003) has noted that distancing and differentiating themselves from others' adverse experiences enables disabled people to construct highly specialised groups that seek to protect their fragile identities (Meeres and Grant 1999; Locock and Brown 2010; Mazanderani et al 2012). Given that her involvement in peer support services would have contributed to a frightening prospect, namely, that she could become like those she perceived as 'socially inferior', Beth used the medical gaze on herself and other people to emphasise the acceptability of her bodily behaviours in comparison to their troublesome and 'abnormal' comportments. By evaluating bodies and impairments according to ocularcentric versions of normality, Beth assertively refused to associate with, and recognise herself in the experiences of, other people with dystonia. In

doing so, she attempted to protect herself from thinking about her future prognosis and own sense of differentness.

While the majority of participants generated downward social comparisons by distancing themselves from other people's more severe symptoms (n=24), none invoked positive upward social evaluations (i.e. viewing those with a similar experience as relatively more fortunate than oneself (Festinger 1954)). However, as was noted in chapter 6, one Support Group 2 participant, Jasmine, said that she no longer experiences the physical effects of her dystonia. Carmack Taylor et al (2007) have suggested that patients with cancer may derive psychological benefit from liaising with better off individuals and asking for their advice about coping. On the other hand, those living with a potentially life-limiting condition may choose not to create upward comparisons with favourable implications for wellbeing because of the relative lack of motivating accounts surrounding improvement (Taylor 1983; Bellizzi et al 2006: 783; Locock and Brown 2010). Affiliating with non-distressed or mildly affected individuals may also produce a negative impact on the self-esteem of poorly functioning social actors (Carmack Taylor et al 2007: 268). Similarly, it can be argued that taking inspiration from somebody with dystonia may have seemed inconceivable given that many participants simply preferred not to have the condition at all. It can also be argued that the other Support Group 2 members may have wanted to overlook Jasmine's 'success story' in order to view her as part of the patient group and/or because they thought that they would never recover from their illness completely, thereby considering this dimension of her experience too divergent from their own.

Ironically, another way participants' sense of identification could become fractured was through the *acceptance* of embodied resemblances. This is known as a 'lateral' or 'parallel social comparison' and occurs when individuals do not distinguish themselves from other people that they consider similar or part of the in-group (Goffman 1963; Crocker and Major 1989; Bellizzi et al 2006; Locock and Brown 2010; Mazanderani et al 2012; Heaton 2015). While the 'mobilising lay knowledge' section demonstrated that many participants *favourably* identified with other individuals' analogous experiences, some felt unable to do this due to negatively held beliefs about their own bodies. Malcolm, for example, is aged 62 years old or over and has been diagnosed with cervical dystonia. He regularly attends Support Group 1 meetings and feels that he receives a substantial amount of social and emotional support. However, his experiences of meeting other dystonia group members for the first time had not been particularly pleasant:

> Malcolm: […] you might be reluctant to come along to meetings. Like the first one I went to I thought, 'oh I don't want to go along to this. I don't want to be in a room with a lot of other people with dodgy necks like me' (some group members laugh) you see? *But* it wasn't like that at all. [Group interview 1]

It has been argued that lateral social comparisons can enable stigmatised individuals to form shared identities and unite against prejudice and discrimination (Goffman 1963; Crocker and Major 1989; Bellizzi et al 2006; Locock and Brown 2010: 1503; Mazanderani et al 2012; Heaton 2015). Yet, for Malcolm, witnessing other individuals display similarly undesirable bodily behaviours vividly reminded him of

the embodied adversities he experiences as a result of living with a '*dodgy neck.*' Consequently, Malcolm drew on occularcentric observations to identify with people showing similar bodily movements to him, without considering other potentially salient experiential characteristics (e.g. social exclusion). By passing unfavourable judgements about the perceived fallibilities of certain aspects of members' experiences, Malcolm reinforced widespread stigmatising beliefs about those with visible conditions (Goffman 1963). He also created a hierarchy of impairment (Deal 2003) in which he assigned himself and other people like him a low social value. In contrast to other participants (e.g. Roberta) who felt part of the in-group (i.e. individuals with milder or easier to manage symptoms), Malcolm initially refused to forge a group identity because he wanted to belong to the out-group (i.e. the non-disabled). Heaton (2015) has observed that individuals with chronic conditions sometimes portray themselves as 'analogues' of other people with the same or another health problem by likening certain features of their illness experiences to the reference group in order to feel they are not suffering alone. Though many participants forged positive alliances with other people with dystonia by drawing on a range of experiential similarities, the interviews also revealed that participants sometimes used lateral comparisons to reproduce exclusionary ideas about non-conformist types of carnalities (Paterson and Hughes 1999; Paterson, K 2001). In doing so, they not only became more aware of their own bodily limitations but also negatively identified with other individuals living with analogously undesirable bodily behaviours.

A minority of participants reported that the ways in which they experienced their condition directly corresponded with their diagnostic type (n=3). In fact, the only similarity unifying these participants was that they wanted to meet other people with the same diagnosis in order to form a shared identity around their particular experiences. Dawn, for example, is aged 62 years old or over and lives with oromandibular dystonia. Unlike Malcolm who negatively experienced seeing other people with similar dystonic symptoms, Dawn drew on established medical categories in the hope of meeting other individuals with comparable impairment effects:

> Celia: Can you tell me something about your experiences of attending the dystonia support group? (Pause)
>
> Dawn: Urm (pause) well I've met quite a few other people, obviously they all have got dystonia in some way or another urm I haven't met anyone who's got oromandibular dystonia which I have er and I joined particular- well in the hope that I would meet other people with the same problem […]
>
> Celia: Would that be something you would like to do (go on days out with the dystonia support group)?
>
> Dawn: I don't know really because once again it would be mixing with the people from the group but it wouldn't be any help to me you know because they've all got it in different parts of the body. [Support Group 1 member, semi-structured interview]

When individuals with an impairment are in a group of non-disabled people they are more likely to perceive themselves as disabled, with varying consequences for mood, than when they meet groups with a medical condition (Deal 2003: 902). Indeed, it

has been argued that the more specialised a group is the more likely members will differentiate themselves from other similarly affected individuals (the out-group) by selecting and evaluating particular experiential dimensions that align with their perspectives (the in-group) (Taylor 1983; Meeres and Grant 1999; Deal 2003). Similarly, Dawn disassociated herself from those undiagnosed with her specific type of dystonia in order to search for people with her diagnosis, who she assumed would be able to understand and authenticate the reality of her unique bodily experiences. Yet, applying medical classificatory frameworks to approach decisions about identification prevented her from regularly attending Dystonia Society events, primarily because there were few people with her type that she felt had intimate knowledge of her particular sense of embodiment. This demonstrates the pervasive influence of expert epistemologies on Dawn's understandings of other people's experiential knowledge, as well as her abilities to form a shared identity. Related to this issue, she made a series of judgements about individuals' experiences based only on her perceptions of their specific diagnosis. Thus, in a similar way to Malcolm, overlooking other potentially salient aspects of members' embodied knowledge diminished Dawn's sense of identification and sustained reductionist beliefs about individuals' personal experiences of dystonia.

Conclusions

Drawing on the wider social scientific literature on lay identification, this chapter has examined the extent to which participants felt able and willing to use their subjective experiences to connect with other people with dystonia. The process of 'experiential information sharing' (Mazanderani et al 2012: 549) relates to a wider emphasis on

patient choice, empowerment, and expertise within contemporary, Western societies (Ziebland and Herxheimer 2008; Blume 2016). Indeed, by viewing members' personal experiences as useful and credible 'sources of knowledge and support', the recent increase in patient advocacy groups arguably challenges older paternalistic models of healthcare, which assumed that the doctor possessed the authority and knowledge to provide expert skill and judgment (Mazanderani et al 2012: 551; Ziebland and Herxheimer 2008).

The first part of this chapter demonstrated that participants developed a sense of identification as a result of coming together to offer support and share their expertise about individually focused, biomedical strategies. Although the emphasis placed on the practical self-management of dystonia enabled participants to repair uncomfortable tensions between experiential and expert knowledge, it significantly undermined any explicit attempts for them to mobilise against disablism. This was because its focus on symptom management and control reinforced participants' view that dystonia was primarily the problem and not social barriers. While dystonia charities and groups do not dismiss individuals' non-medical concerns (e.g. welfare officers sometimes attend meetings to provide general advice about benefits), in the context of participants' understandings of belonging, overt challenges to disablist ideologies were noticeably missing from their accounts.

The second section examined the various ways in which participants negotiated their sense of unification, primarily in accordance with the personal tragedy and medical models of disability (Oliver 1990). Whether this was enacted through, for example,

the presentation of a stoical attitude (e.g. Oscar) or the groups' inability to accommodate all of its members' embodied difficulties (e.g. Agatha), participants' conceptualisations produced personal knowledge of suffering that predominantly conformed to dominant notions of coping and carnal acceptability. This also occurred in relation to participants' constructions of downward and lateral social comparisons. Finkelstein (1993) and Deal (2003) have argued that people with chronic conditions use cultural perceptions of normality in order to generate impairment hierarchies surrounding the degree to which an individual believes they are 'really' disabled. Shakespeare (2014) has maintained that disabled people form social comparisons because of the embodied variability associated with illness and not necessarily because they are reproducing hegemonic ideas about the social worth of other people with impairments. Yet, the interviews revealed that participants re-appropriated the medical gaze and drew on exclusionary ideologies concerning the low social status afforded to unorthodox carnalities (Paterson and Hughes 1999; Paterson, K 2001) to make sense of the range of physical symptoms associated with dystonia. In doing so, participants' views of other people affected by the condition shaped their perceptions of identification and generated different constellations of impairment hierarchies, with varying consequences for wellbeing.

Chapter 8

Discussion

I utilised a broad and exploratory qualitative research design in order to investigate participants' subjective experiences and understandings of the hyperkinetic movement disorder dystonia. As such, I have obtained an intricate insight into the ways in which individuals attempt to manage dystonia successfully within their everyday lives. I have done this in two ways. Firstly, I explored the nature and relevance of experiential knowledge to healthcare decision-making. Secondly, I investigated how people use, and ascribe meaning to, this episteme within a disablist society. Through these two strands of investigation, I have demonstrated the political implications of experiential knowledge for promoting, modifying, and challenging the proliferation of medicalised and stigmatising ideologies surrounding disability, as well as for highlighting moments when support structures can create moments of inclusivity.

My research contributes to a range of sociological and political debates in which theorists have struggled to explain the intersection of disabled people's experiences of various intrinsic (e.g. impairment severity, personal abilities and attitudes) and extrinsic factors (e.g. attitudes of others, dis/enabling systems and environments) (chapter 3) (Shakespeare 2014). Indeed, the findings from this study contribute to the nascent sociology of impairment and disability corpus by using dystonia as an example through which to investigate experiential knowledge. I have also considered four exploratory research questions to frame the project and address the gap in the literature (chapter 4):

1) What are individuals' views and experiences of dystonia?

2) What role do medicalised understandings and practices perform in individuals' experiences of living with and managing dystonia?

3) How do social constructions of (ab)normality and (dis)ability within (quasi)medical establishments and wider society influence individuals' experiences of dystonia?

4) Does a shared patient identity exist among individuals with dystonia? Why(not)?

In the following sections, I summarise the key points from the previous results chapters, which attend to the aforementioned questions, as well as present a detailed analysis of the empirical findings. Consequently, I note the contribution of my research to pre-existing sociological theory on the role of experiential knowledge in medical decision-making and also move beyond previous insights. Finally, I examine the strengths and limitations of this study and document areas for further investigation.

The interrelationship between experiential and expert medical knowledge is characterised by two permeable synergies: 1) dissonance and 2) resonance
Chapter 3 demonstrated the ways in which sociological research has, firstly, explored the dynamic between experiential and medical knowledge and, secondly, noted the significant impact that these two epistemologies produce on patients' understandings of disease and illness. While some theorists have suggested that these epistemic structures exist separately in order to conceptualise lay notions of health as a

challenge to dominant expert sources (e.g. Whelan 2007), further work into this area has focused on the synergistic and mutually co-constitutive nature of these bodies of knowledge (e.g. Boardman 2010; Markens et al 2010; France et al 2011a). Arguably, viewing the interplay between experiential and medical knowledge sources as intrinsically oppositional and disparate overlooks the possibility for multiple voices, arguments, and ideas to exist dialogically both within and outside of therapeutic encounters (Gwyn 2001; Boardman 2010). Supporting this vein of scholarship, my own research confirms that participants interpreted the credibility and usefulness of medicalised discourses and practices in relation to the particularities of their experiential knowledge across their lived trajectories. In fact, as I demonstrate in this chapter, participants' embodied desires to obtain suitable forms of healthcare provision meant that they never completely rejected medicine, despite frequently hitting the boundary of what it could feasibly and reliably provide. Consequently, their experiential accounts were fundamentally altered by, and thoroughly grounded in, medical model ideas about disease and the body.

The experientially complex nature of dystonia has led to shifts in the way it is medically understood and treated. As was reported in chapter 2, clinical explanations of this condition, including its emergence from a profoundly psychiatric to a predominately neurological disorder, continue to evolve and shape patient care (Munts and Koehler 2010; Stamelou et al 2012; Albanese et al 2013; Jinnah 2015). More recently, researchers have begun to recognise the importance of 'holistic' care pathways for improving dystonia patients' quality of life (Jinnah 2015; Bernstein et al 2016; Sandhu et al 2016). Within the clinical field of health psychology, for

example, research has tentatively suggested that individuals with idiopathic, adult-onset dystonia could benefit from reflecting on their experiential knowledge through the application of behavioural therapy and mindfulness practice (Sandhu et al 2016). However, echoing lay-led and consumerist models of healthcare, these types of interventions often overlook the wider socio-political conditions that situate and frame lived experience (Camfield 2002; Newbould et al 2006; Taylor and Bury 2007; Wilson et al 2007; Greenhalgh 2009; Bury 2010; MacGregor and Wathen 2014). Nevertheless, developments in the medical and health sciences literature on dystonia indicate that attempts are being made to foreground and incorporate the dual impact of the non-motor and motor symptoms with a more integrated, albeit apolitical, understanding of patient experience.

In addition to the mutually co-constitutive nature of experiential and medical knowledge, the interviews also revealed the various ways in which participants responded to this relationship. Most reported that their trust in expert epistemologies fluctuated over different temporalities because of difficulties with getting clinicians to address their embodied concerns successfully. This variability prompted a range of emotional reactions that influenced how participants constructed and evaluated their past, present, and (anticipated) future healthcare decisions and understandings (see 'dissonance' and 'resonance' sections). It also affected the way they could attribute meaning to, and reflect on, continually evolving expert opinions and practices. Researchers have used thematic descriptors to emphasise, for example, how far patients and doctors negotiate and cooperate as two equal partners, closely working together towards a shared therapeutic goal ('concordance' and 'discordance') (Mead

and Bower 2000; Bissell et al 2004; Ong and Hooper 2006; Latter et al 2007; Sulik and Eich-Krohm 2008). Others have examined the relative degree of 'fit' between experiential and medical models during consultations ('(in)congruence') (May et al 2004) and health research project meetings ('epistemological dissonance') (Ward et al 2009). The focus has, thus, been practically oriented, contingent on the ability for laities and doctors/medical scientists to adhere to the widespread rhetoric of patient involvement and engagement in medical research or healthcare systems. However, within my own research, the nature of the lay-expert interplay depended on how far these two knowledges harmonised and complemented each other. In particular, it relied on participants' abilities to obtain and absorb expert explanations that tallied with their own sense of embodiments and not merely because of whether they regarded their consultations as 'patient-led' or 'equal' (although this could be a factor in shaping their responses to medicine). Furthermore, whereas the previous corpus has explored the character of the relationship between experiential and medical knowledge largely in reference to the therapeutic encounter, the findings demonstrate that this association shifted in intensity both within and without the clinical consultation due to the pervasiveness and permeability of medicalised discourses and practices. Consequently, I examine the significance of two particular types of synergistic interplays or strategies, which, although are porous and collapsible, frame the lay-expert association. These categories are: '*dissonance*' and '*resonance*' and reflect the extent to which participants believed that biomedical agendas provided accurate and authentic accounts of what was going on in their bodies that also supported how they were intuitively experiencing and understanding it from the inside. By specifically drawing attention to the dimensional aspects of the synergistic

lay-medical relationship, I illuminate its contours, outline its temporal components,

and most crucially, provide some definition to the ways in which it changed

throughout the lived and living experience of dystonia.

Dissonance

This term describes the synergy between experiential and medical knowledge as

discordant, whereby scientific ideas and practices do not (suitably) capture or align

with the richness of one's sense of embodiment. Despite the fact that a dissonant

association could happen throughout participants' lived trajectories (as discussed

later in this section), it was particularly dramatic during the negotiation of a

diagnosis. Researchers argue that the patient's subjective experience of illness can

often conflict and collide with the doctor's evaluative judgement, causing them to

become frustrated and distressed with the medical services that they receive (e.g.

Åsbring and Närvänen 2002; Lillrank 2003; Nettleton et al 2004; 2005; Jackson

2005; 2011; Dumit 2006; Nettleton 2006). Indeed, many participants reported

multiple difficulties with obtaining an (acceptable) explanation of their bodily

symptoms, which in turn caused a breakdown of trust and communication with

health professionals (notably GPs). In addition to this, they felt unable to explain and

attribute meaning to their troublesome carnalities partly due to the limited

information available to them. Nettleton (2006) has referred to this phenomenon as

'embodied doubt' in order to highlight the feelings of disorder and confusion that

usually occur during the process of diagnosis. The absence of suitable forms of

expert knowledge may also generate a liminal existence in which individuals with a

contested condition lack the medical vocabulary to make sense of their embodied

discomforts but, nevertheless, perceive a change in their bodies (e.g. Lillrank 2003; Nettleton 2006). The elusive and idiosyncratic nature of dystonia further intensifies these problems; the disorder is relatively unknown within both lay and medical domains, making it difficult for people with dystonia to describe their enigmatic embodiments to social (un)familiars. Dystonia may present with a divergent range of complex, unpredictable, and 'unusual' symptoms (e.g. patients may be able to run but find it difficult to walk, disrupting taken-for-granted assumptions about the 'normal' chronology of bodily action) (Marsden and Harrison 1974: 805; Fahn 1988: 2-3). Moreover, many health professionals, particularly GPs and general neurologists, do not often come across the disorder enough to know how to make informed clinical decisions (Logroscino et al 2003; Tiderington et al 2013; Jinnah 2015). Several participants spoke of their frustration at the length of time it took to be referred to a specialist neurologist and receive a definitive diagnosis of dystonia. In fact, the combined effects of these aforementioned issues often contribute to adverse experiences of healthcare and lead individuals with dystonia to believe that doctors have denied the truthfulness of their accounts of their everyday experiences (Camfield 2002).

Thus far, I have illuminated the emotional turmoil that can result from the negotiation of a suitable explanation for a person living with dystonic symptoms. I now move on to discuss in further detail participants' specific responses to the arduous process of diagnosis and the ways in which these affected their abilities to cope with their complaints. Firstly, the interviews revealed that some participants felt distressed when physicians were unable to provide any explanation of their

symptoms. Scholars note that clinical diagnoses enable the medical profession to classify and treat patients' problems within an authoritative bioscientific framework and so, not receiving one can produce a profound impact on wellbeing (e.g. Werner and Malterud 2003). In fact, participants felt that the medical profession had viewed them as a malingerer or fraud, which misaligned with their embodied sense of illness. Moreover, the lack of validation from health professionals permeated beyond the remit of the clinic and into everyday life, whereby participants found it difficult to convince relatives and friends of their experiential challenges (e.g. Miranda). Yet, participants tried desperately to 'prove' the materiality of their symptoms. For example, they repeatedly visited their GP and/or attended patient-led support groups in order to contest claims from family members, who had misused psychosocial explanations (e.g. 'it's all in your mind') (e.g. see Dumit 2006). These efforts were important for participants to be seen as performing a 'credible' patient identity in which they took an active role in conforming to socially acceptable ideas about coping and recovery (Lillrank 2003; Werner and Malterud 2003). Related to this issue, research has emphasised the way patients with enigmatic symptoms or contested illnesses often have 'their right to define their bodily condition' denied (Lillrank 2003: 1051). This form of medical and social delegitimation is often justified in the absence of any visible pathological marker (discussed in more detail later) (e.g. Rhodes et al 1999; Dumit 2006). As a result of not receiving a diagnosis, many participants lacked emotional support from their colleagues and families and also perceived a stigma associated with the need to have their ongoing embodied discomforts authenticated.

In a similar way to those who had not been given any explanation, the arrival of a psychological diagnosis also left many participants feeling upset and insulted. Researchers argue that society views the label of mental illness unfavourably, particularly when compared to physical health problems (Dear et al 1997; Deal 2003). Those who are perceived to have a psychiatric diagnosis are often chided and reduced 'from a whole and usual person [actual identity] to a tainted, discounted one' (virtual identity) (Goffman 1963: 12). Commonly held beliefs about mental illness relate predominately to the way it is attributed to a lack of morality, emotional strength, and personal responsibility in which anybody (deemed to be) experiencing this condition is considered to possess defective and reckless personalities (Goffman 1963; Pollock 1993; Bendelow 1996; Camfield 2002: 38-39; Mulvany 2000; Rose 2003; Jackson 2005; 2011; Corrigan 2007; Garand et al 2009; Jutel 2010; Fein 2012; Lupton 2012). Getting this label may be particularly devastating in Western societies that strongly focus on the perceived virtues of self-help and autonomy (Ayo 2012; Murdoch et al 2013; Broom et al 2015). As such, patients with inexplicable or socially difficult to read symptoms may view the arrival of a psychiatric diagnosis as a deliberate attempt to undermine their experiences (Robinson 1988; Nettleton et al 2004; 2005; Nettleton 2006; Daker-White et al 2011), despite the fact that clinicians might genuinely believe patients are psychologically disturbed and require medical treatment in order to get better (Barker 2010). While a minority of participants reluctantly accepted a psychological explanation because of the legitimating role of medicine, having this label still produced a negative impact on wellbeing (e.g. Kim). Overall, taking offense to the insinuation that they could be mentally ill and preferring not to be associated with its aforementioned attributions meant that

participants reinforced these particular perspectives and, in doing so, sustained stigmatising ideas about psychiatric disorders.

Additionally, many participants reflected on their subjective feelings and experiences of living in a body affected by dystonia to avoid having these defined as a mental health condition. Though participants reported fluctuating corporeal *and* emotional symptoms, they emphasised the physiological and unintentional aspects of their experiences (e.g. muscular spasms) in medical contexts to attract a diagnosis more aligned with their perceptions of the condition, which would also absolve them of responsibility for their involuntary movements. Consequently, participants activated prevailing ideologies surrounding the (il)legitimacy of (psychiatric) disease (Jackson 2005) in order to provide a believable and credible account of their experiential knowledge. In fact, such an approach enabled them to challenge the claims of clinicians and relatives who, they believed, had given an inaccurate reading of their dynamic embodiments.

While the medical profession may not be directly responsible for creating exclusionary discourses surrounding mental illness, especially since this condition is diffusively bound within the perimeters of biomedicine (Barker 2010: 153), Rhodes et al (1999) have, nonetheless, argued that it sustains these ideologies through 'the cultural model of the visible body.' This framework refers to the way expert bodies of knowledge determine the nature of one's illness experience through the identification of an observable pathology (Rhodes et al 1999). As a consequence of objectifying the body through visual mediums (e.g. MRI machines), scientific

discourses and practices inadvertently maintain the idea that clinically unverifiable symptoms (e.g. unexplained pain) ought to be incontrovertibly managed in the subjective and socially inferior domain of private experience (Rhodes et al 1999; Jackson 2005; 2011). However, this may produce a negative impact on wellbeing and undermine patients' trust in the certainty of their embodied knowledge (Lillrank 2003; Broom et al 2015). Medicine's emphasis on the identification of visible bio- or neurological markers leads to the production of dualistic and moralising conceptions (e.g. 'crazy' or 'lazy' vs. 'ill') concerning the locatable and fixed body/brain (representing disease) and the fluid, rectifiable mind (signifying fraudulence) (Åsbring and Närvänen 2002; Camfield 2002; Lillrank 2003; Jackson 2005; 2011; Fein 2012; Lupton 2012). These meanings also have an impact on clinicians' perceptions of certain patients, whereby health professionals often regard those with contested illnesses or syndromes as 'discontented and demanding' compared to individuals with less effusively defined disorders (Camfield 2002: 34). Individuals with these problems often occupy a liminal status in which society views them as not 'quite well enough' to be 'normal' but not quite 'ill enough' to be deserving of support (Jackson 2005; Lightman et al 2009; Fein 2012; Lupton 2012). Furthermore, using observable indicators to locate disease is no longer confined to physical illness. Recent research has reported that, within psychiatry, mind-based, psychodynamic theories are being overshadowed by materialistic, neurological explanations (e.g. abnormal brain wiring) (Rapp 2012; Gardner 2014: 222). Consequently, the medical profession's uncritical acceptance of the materiality of physical and, to a lesser extent, psychiatric disease inevitably creates *aetiological* hierarchies and divisions between soma and psyche in which pathologies that are identifiable are afforded

more legitimacy and authenticity than those that are not (Hadler 1996; Rhodes et al 1999; Lillrank 2003; Nettleton et al 2004; Jackson 2005; Dumit 2006: 583; Anspach 2011; Pickersgill and Van Keulen 2012: xiii; Broom et al 2015). This issue is particularly salient in the context of the dystonia disorders since most cannot be confirmed with biological markers (Albanese et al 2013; Charlesworth et al 2013). Yet, in spite of the difficulties with getting an (accurate) diagnostic label, individuals with contested illnesses continue to search for answers and solutions within the authoritative medical system because they want to get better and believe that this particular institution will be able to help (Robinson 1988). This demonstrates the ways in which the epistemological influence of medicine continues to increase and expand within social life (May et al 2004).

Though clinicians often examine the body to locate pathologies and identify the existence of disease (e.g. Rhodes et al 1999), some of its physical processes and functions (e.g. digestion, breathing) are viewed as 'primitive', 'unruly', and contrary to the rhetoric of corporeal boundedness and containment (e.g. Williams and Bendelow 1996; 1998; 2000). Further, the body is conceptualised as a superficial and unintellectual object due to its metaphorical separation from the 'rational' and cognisant self (Williams and Bendelow 1996; 1998; 2000). While psychological conditions are more stigmatised than physical illnesses often because they are seen as controllable whereas certain bodily factors are not (Williams and Bendelow 2000), explaining the cause of one's complaint in relation to this socially inferior and unbounded object may still be problematic (Williams and Bendelow 1996). Indeed, despite the fact that wider cultural perceptions refer to the body as a 'disordered' and

'transgressive' entity that threatens 'to "overspill" the boundaries which currently seek to "contain" it' (Williams and Bendelow 2000: 65), a minority of participants (e.g. Eric) viewed the arrival of a diagnosis of strained muscles as an affront to the claim that their symptoms were involuntary and uncontrollable. In other words, these participants believed that getting this particular diagnosis wrongly implied that not only would they recover quickly, but that they were in some way personally responsible for having caused the problem in the first place. In contrast, the brain is considered a fixed and predictable material system that is 'governed by physical laws' and emblematic of Western values such as reason, autonomy, and impartiality (Fein 2012: 29; Camfield 2002: 16; Rose 2003; Jackson 2005; 2011; Vidal 2009). Consequently, physical illnesses that are attributed to the inner workings of this particular organ are accorded a higher social status than problems accredited to the mind or other parts of the body that are associated with control and personal responsibility (*ibid.*). Whereas Cassidy (2012) has argued that people with ataxia have to cope with the troublesome effects of their condition during the process of diagnosis, the findings from this study reveal that many participants' concerted efforts to adjust to their symptoms at this time were made further difficult by the meanings they ascribed to particular medical labels.

By rejecting certain physical and psychiatric diagnoses due to the perceived illegitimacy of these labels, many participants prevented themselves from fully entering into the socially acceptable 'sick role' (for a definition of this term see chapters 3 and 5). Unlike participants who had initially not received any explanation of their problem, those with a ('wrong') diagnosis had technically been allowed

admittance into it by virtue of their medical label. However, even though participants and the diagnosing physicians recognised that they had a medical complaint, since participants had violated a key component of the sick role – to accept clinical explanations and submit to the authority of the doctor (Turner 1987) – they had averted their responsibility to get better. On one level, this conflicted with their efforts to obtain optimal healthcare but participants justified their non-compliance (to themselves and the medical profession) by using the doctor's inability to diagnose them appropriately as evidence of professional ineptitude. My own research supports some of the findings from Murdoch et al's (2013) study on patients' (in)adherence to treatment. In particular, the authors found that one individual vindicated her decision not to use asthma therapy by making 'moral connections […] between those who provide healthcare, how that care should be delivered, and the motivations and characteristics of those doing the caring' (Murdoch et al 2013: 458). Since she wanted her clinicians to attend to the specificity of her experiential knowledge rather than simply being prescribed potentially unsafe and ineffective substances, she used their perceived failures to undermine the credibility of their decisions (*ibid.*). Arguably, she was able to do this because the sick role discourse allows individuals not only to absolve themselves (temporarily) of personal responsibility for performing day-to-day tasks but also enables them to draw on culturally informed ideologies about how they believe this role ought to be performed (Murdoch et al 2013: 457-458). Similarly, given that the sick role enables patients to combat potential criticism from society and the medical profession (*ibid.*), participants carefully modified it in order to blame incompetent doctors for their alleged failure to comply with the rules around coping and adjustment.

A minority of participants experienced the arrival of a diagnosis of dystonia adversely, as it threatened their previously upheld understandings of normality (Bury 1982). In particular, they worried about whether they would be given a poor prognosis or find it difficult to manage the continually disruptive effects of their condition, although many participants variously reflected on their abilities to cope with corporeal change and deterioration throughout their lived trajectories (Larsson and Grassman 2012). Nevertheless, the disruption that three participants specifically reported as a result of having their embodied experiences defined in authoritative medical terms confirmed the reality of their condition and sparked a range of concerns that needed to be dealt with beyond the point of their neurology consultation. The fact that Megan also obtained a diagnosis of dystonia relatively quickly may have contributed to her negative evaluations of it. Supporting this finding, Ashtiani et al (2014) found that parents who had spent comparatively less time getting a genetic diagnosis of their child's illness were not as ready to receive the 'bad news' as those who had experienced a longer 'diagnostic odyssey.' These factors demonstrate the ways in which receiving an explanation that is acceptable to the patient may not entirely ameliorate existential concerns and may even generate new ones (Pinder 1992; Tobin and Begley 2008; Cassidy 2012). Consequently, participants alleviated their harrowing experiences through the use of creative strategies such as attending a Dystonia Society event or positively re-evaluating the benefits of their diagnosis in order to restore a sense of continuity to their otherwise disrupted biographies (Bury 1982).

While I have argued that the lay – professional relationship could be described as dissonant during the process of diagnosis, variations of this synergistic dimension also occurred sometime afterwards. For example, participants reported that when they had attempted to access healthcare or discuss their views of treatment, clinicians had not taken their embodied concerns as seriously as they would have liked (e.g. Irene). Thus, the accounts of those espousing negative experiences of medicine partly transpired as a result of the dynamic confluence of medicalisation and the rhetoric of health self-management. Similarly, the literature has noted that the underlying principles of patient-centred and consumerist healthcare (e.g. shared decision-making, personal responsibility and autonomy) can conflict with established forms of medical and bureaucratic authority, and by proxy, increase tensions between experiential and expert knowledge (e.g. Bury 1997; 2010; Henwood et al 2003). These patient-led models may ironically reinforce medical power since the caring profession determines the choices (usually individualistic ones) experiential experts can make about their healthcare needs (e.g. Sulik and Eich-Krohm 2008; Lupton 2012). In this way, health consumerism undermines patients' agency at the same time as it proclaims to provide it (Opie 1998; Paterson, B 2001). For many participants who had turned to medicine as a legitimate way of ameliorating their symptoms, their hopes were soon abated by the fact that their physical and emotional needs had been dismissed or not sufficiently met. Though some found it useful to make decisions on their own or search for information online, other participants found this an isolating and frightening experience due to concerns that their searches might bring up fearful material (e.g. Liam). Supporting this finding, Leydon et al (2000) have argued that individuals with cancer sometimes choose to opt out of information-

seeking in order to avoid coming across contradictory and distressing advice. As a result of the problems associated with consumerist and patient-centred models of care (Dahlberg et al 2009), participants had to consider how they would mobilise appropriate forms of support in order to manage their symptoms and avoid further emotional upheavals.

Within the literature, there is consensus that the limitations and uncertainties of medicine are widely dispersed throughout its discipline and practice (e.g. Davis 1960; Mechanic 1998: 663; Fox 2002; Griffiths et al 2005; Baillergeau and Duyvendak 2016). At the same time, however, it continues to be represented in the media and other outlets (e.g. support groups) 'as a science of certainty' (Griffiths et al 2005: 6), which can be trusted to deliver beneficial treatment to those who need it (Collins and Pinch 2005; Novas 2007). Yet, as some participants perceived that few effective therapeutic options existed, they conceded to the view that a cure would never be found and chose to self-manage their condition as best they could with the limited (medical) help available (e.g. William). Budych et al (2012) found that the low prevalence of patients' diseases coupled with the insufficient knowledge and expertise of their treating clinicians created major tensions and problems during consultations. To mitigate some of these difficulties and assist their physicians in the treatment process, individuals developed an expert patient health identity in which they became highly knowledgeable about their disease (*ibid.*). Related to this issue, research has suggested that the personal responsibility and informed expert patient discourse reifies moral sensibilities about coping (Murdoch et al 2013; Broom et al 2015), encouraging individuals to adopt a stoical or resilient attitude towards their

illness (Williams, G 1993; Charmaz 1994; Evangelista et al 2001; King et al 2002; Werner et al 2004; Nordgren et al 2008; Boardman et al 2011). Consequently, participants' decision to self-monitor their symptoms and look after their own healthcare needs with the (limited) assistance of professional practitioners was a socially acceptable way for them to manage the perpetual challenges that they faced, even if doing so meant their concerns were unlikely to be resolved.

Aside from participants' negative experiences of healthcare, medico-popular representations surrounding carnal normalcy (Davis 1995) and perfection (Glassner 1992) also contributed to the generation of hostile interactions in everyday situations (Hughes 1999). This is because the ways in which the medical gaze demarcates bodies as 'normal' or 'abnormal' (e.g. Rhodes et al 1999) also informs how Western societies universally privilege and value particular types of bodily aesthetics (Hughes 1999; Reeve 2002). The interviews revealed that all participants had at some point felt self-conscious and/or experienced an unwelcoming stare or insensitive comment in response to their perceived corporeal differentness. Indeed, experiencing a body that noticeably spasms and shakes unpredictably and without warning violates normative standards of corporeal desirability (Zitzelsberger 2005) and containment (Battersby 1993; Williams and Bendelow 1996; 1998; 2000; Hallam et al 1999: 11). These acts of 'deviancy' may lead affected individuals to suffer stigmatisation (Goffman 1963) and profound feelings of embarrassment and shame (Camfield 2002; Reeve 2002). By echoing the principles of biomedicine and prioritising the visual as an authoritative source of knowledge, it has been argued that the 'medical' or 'non-disabled gaze' annihilates the subjectivities of those living with socially

undesirable forms of embodiment (Hughes 1999; Paterson and Hughes 1999; Paterson, K 2001; Zitzelsberger 2005). Some participants' experiences of the gaze were further compounded by the fact that they had not previously been conscious of their 'incompetent' bodily movements until others had made a flippant remark about their physicality. Watson (2002) has contended that individuals with impairments may choose not to identify with the disabled label because of its connotations with personal deficiency. As such, they may become distressed when they are (unexpectedly) confronted with their 'peculiar' carnalities (*ibid.*). Since participants felt that they were personally responsible for managing other individuals' negative perceptions of their bodies, they used a range of strategies to lessen the emotionally harmful effects of stigmatisation (e.g. retreating into the private sphere), even though these could cause them to become further isolated and alone.

Yet, participants experiencing less 'visible' symptoms (from time-to-time) also sensed a stigma in certain situations. For example, while many participants with these particular embodied states enjoyed the benefits of 'passing' for 'normal', they often worried that the unpredictable and varied nature of their impairment effects would unintentionally reveal their 'spoiled identities' (Goffman 1963). Some participants also said that when they (temporarily) experienced socially imperceptible symptoms, others would question the authenticity of their claims to enter into a modified version of the sick role. This finding confirms previous research on the way some young adults with chronic illness experience various difficulties with adhering to social expectations and use upward comparisons, with negative consequences for emotional wellbeing, to describe their distress (Austin

2015; Heaton 2015: 341-342). Indeed, by contrasting their embodied knowledge (e.g. fatigue) with normative beliefs about how they ought to behave (e.g. socialise all day with friends), participants felt excluded from their social networks and unable to access the support that they required. It can, thus, be argued that participants distinguished themselves from their non-disabled peers (what Heaton (2015) has referred to as a 'foil') to emphasise the challenges they faced with attempting to comply with established definitions of disability and difference (Hughes 1999; Mitchell 2001; Reeve 2002; Olney and Brockelman 2003; Stone 2005; Zitzelsberger 2005). Whereas Goffman (1963) has argued that discredited and discreditable identities are distinct and dependent on the social perceptibility of one's differences, participants sometimes felt dismissed or powerless to vocalise their own embodied struggles and arguably became as discredited as when their symptoms were visible (e.g. see Stone 2005; Lightman et al 2009). This is not to imply that participants never generated a discreditable identity when deciding whether to disclose their socially invisible symptoms (Goffman 1963). Rather, the boundaries surrounding the formation of a discredited or discreditable identity were collapsible and not merely dependent on the (im)perceptibility of participants' impairment effects or their desire to 'pass' for 'normal' (Wendell 1996; Stone 2005). Instead, these identities were formed depending on the way the non-disabled gaze perceived and responded to participants' dynamic carnalities in particular situations and socio-spatial contexts, as well as how far they internalised this particular technology of power (Reeve 2002; Lightman 2009). Overall, participants' stories illuminated the extent to which the fluctuating nature of their dystonia coupled with culturally informed understandings of (ab)normality led to moments of invalidation and isolation, whereby the perceived

'peculiarity' of their physical movements or lack thereof attracted (degrees of) scrutiny and had to be self-managed, albeit with varying outcomes for health and wellbeing.

That individuals with impairments like dystonia often occupy a paradoxical position in which their bodies, irrespective of whether they actually appear different to others, are highly visible, while their desires and needs remain confined firmly to the 'private' – viz. invisible – domain, exposes an emotionally 'felt' tension between their complex lives and the way medico-cultural understandings of disability and difference represent them (Zitzelsberger 2005). Yet, participants sometimes reproduced ocularcentric ideologies by emphasising the visible aspects of their embodied experiences to health professionals and/or by attempting to appear less impaired in public. The way many participants assigned values to other people's more severe dystonic symptoms also sustained 'the power of the visible' (Rhodes et al 1999). Re-appropriating the clinical gaze caused some participants to invoke a lateral or downward social comparison, with adverse consequences for identification and wellbeing. In particular, looking at other individuals' bodies had reminded them of their own carnal differences or raised the frightening possibility that their symptoms could deteriorate in the future (Carmack Taylor et al 2007; Locock and Brown 2010; Mazanderani et al 2012; Holbrey and Coulson 2013; Heaton 2015: 337). These negative perceptions subsequently affected their abilities to assemble a shared identity. Since participants' stories of, and emotional responses to, stigmatisation illuminated the interrelationship between soma and society, identity and culture, embodiment and medicine, these personal experiences should be

examined in confluence with social model thinking to highlight the damaging effects of disablism across the life-course of those with dystonia.

Even though many participants' accounts of healthcare were less striking compared to when they negotiated and, for a minority, initially arrived at a dystonia diagnosis, which at the time had created extreme feelings of alienation and disruption, the possibility of contestation was always present. This outcome was due to the ways in which intersecting medicalised and stigmatising discourses often misrepresented participants' subjectivities and caused a profound sense of misery during therapeutic encounters and/or everyday situations. Yet, participants drew on individualistic (medical) ideas about coping to self-manage their physical movements and/or internalise their 'private' experiences in order to perform a socially acceptable version of personhood. As such, the findings from this thesis extend previous theorising into the way distress is felt and managed merely within the experiential confines of individuals living with ambivalent explanations and associated prognoses (e.g. Rhodes et al 1999; Lillrank 2003; Nettleton et al 2005). Although I have drawn on the sociology of MUS and contested conditions literature in order to elucidate some of my analysis, like other chronic problems (e.g. ataxia in Daker-white et al 2011: 121, 131), dystonia does not neatly fit into either of these categories. Rather, it is medically defined as a heterogeneous group of movement disorders or syndromes that can present multifariously (e.g. as a symptom of another condition or an isolated disease caused by genetic, acquired [psychiatric/functional, viruses, drugs], idiopathic, or nervous system-related factors) (e.g. Steeves et al 2012; Albanese et al 2013; Albanese 2017; Mezaki 2017). The diverse and somewhat confusing ways in

which dystonia has been clinically and aetiologically classified (Albanese et al 2013) may also explain why (the prospect of) disputation reoccurred throughout participants' narratives. To this end, I maintain that a dissonant synergy produces a profound impact on the lives of those with a highly complex condition like dystonia, often encumbering their abilities to access (appropriate) support and healthcare in a way that tallies with their embodied needs.

Resonance

This type of interplay occurs when the association between embodied and expert knowledge comes to be harmoniously aligned. Specifically, medical accounts are compatible with agents' visceral experiences and present them with an insightful and authentic understanding of their life contexts, particularly at the point of diagnosis. Indeed, many participants believed that getting a definitive dystonia explanation meant the medical profession had (finally) taken their concerns seriously and would be able to prescribe effective treatment to help them manage their condition. Even those participants who had originally evaluated a diagnosis of dystonia adversely still appreciated its relevance for legitimate entry into the sick role. Participants may have also viewed this label positively because of its connections with the prestigious discipline of neuroscience (only neurologists had diagnosed them). Researchers argue that neurology has produced a significant impact on the way people conceptualise their health identities (Pickersgill and Van Keulen 2012: xiii; Fein 2012; Gardner 2014). In particular, Gardner (2014: 222) has used the term 'neurosociality' in order to document the influence of brain-based perspectives on individuals' understandings of disease and the body. The complexity of lived

experience has gradually been 'colonised' by the neurologisation of the self, whereby contemporaneous notions of personhood are normatively classified in relation to the functioning of the immutable and physical brain (Fein 2012; Singh 2012: 813, 814). In fact, The Dystonia Society emphasises the cerebral origin of the condition by, for example, reproducing brain-based viewpoints online[41] (Camfield 2002). As such, adopting neurological jargon to define and legitimate the suffering of dystonia illuminates the influential nature of, and authority invested in, this particular branch of medicine.

That participants felt a diagnosis of dystonia verified and confirmed the realities of their experiential knowledge demonstrates the embodied character of this label. Related to this point, those who had initially been tested for, or given an explanation of, a 'wrong' neurological disorder did not react negatively to it, partly because the meanings ascribed to this particular problem (e.g. blamelessness, permanence, materiality) aligned with the visceral day-to-day experience of living in an uncontrollable and disrupted body. These findings move beyond previous theories that have conceptualised medical explanations as mere discursive constructs (e.g. Hughes 1999) and instead, supports the phenomenological perspective put forward by Csordas (1994) regarding the relationship between embodiment and language. In particular, the author has argued that discourse does not represent or precede the materiality of experience but rather, is 'brought to' it and meaningfully

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[41] The Dystonia Society (2014: 4) defines dystonia as 'a neurological condition causing involuntary and sometimes painful muscle spasms resulting in abnormal movements or postures […] in most cases, it affects the motor pathways in the brain that control recruitment and movement of muscles.' The Society also has links with The Neurological Alliance and British Neurotoxin Network (Dystonia Society 2014).

communicated at particular times and contexts (Csordas 1994: 11). Conceptualising language in this way demonstrates how it can be regarded as an 'embodied modality', which closely aligns with, and is animated through, experiential knowledge (Csordas 1994; Hallam et al 1999; Todres 2004). Applied to obtaining a diagnosis, Csordas' (1994: 11) theory arguably illuminates the extent to which medical explanations can provide 'access to a world of experience' (see also Csordas et al 2008). For individuals with dystonia, who require a credible account of their strikingly dynamic and stigmatising symptoms (Lim 2007), diagnostic labels are both tools with which health professionals classify enigmatic appearances (Garand et al 2009: 3, 10; Jutel 2009) and apparatuses patients utilise to evaluate their existential concerns (Csordas et al 2008). In view of that, many participants felt able to repair fraught relations with the medical profession following a neurological (organic) diagnosis, although some reported that this was more difficult to achieve when neurologists dismissed their emotional experiences. Nevertheless, many participants believed that the dystonia label and the information they obtained surrounding it appropriately explained the realities of their complex and confusing symptoms. In doing so, it helped to bolster their faith in expert knowledge in a more amicable way than before their bodies had been defined and classified in neurological terms.

Though it was apparent that cerebral explanations held embodied significance, one participant, Oscar, who arrived at a dystonia diagnosis relatively smoothly but still reported some problems with getting doctors to confirm his type, questioned the relevance of neuroimaging. As patients construct their versions of personhood in relation to an assembly of knowledges about the mind, body, and society, they may

use their understandings to interpret the experiential importance of brain-based perspectives (Pickersgill et al 2011). That is, 'neuroscientific concepts [may] compete with, integrate into, and only occasionally fully supplant pre-existing notions of subjectivity' (Pickersgill et al 2011: 346). Supporting this viewpoint, Gardner (2014) found that dystonia clinicians did not rely solely on neurocentric discourses to make sense of the brains of paediatric patients because they considered these too reductive. As an alternative, the team highlighted the importance of understanding the patient's neurological abnormalities in confluence with their experiences and social ecology (*ibid*). Similarly, the discipline of neurology was not completely inconsequential to Oscar since he willingly acknowledged that his condition had been diagnosed by a neurologist and attributed to a lack of oxygen to his brain at birth. Rather, this embodied resource was one of many that he could (positively) select in order to interpret the nature of his dynamic subjectivity.

As well as receiving a socially legitimated explanation of their symptoms, the arrival of a dystonia diagnosis meant that participants could begin another arduous but, at the same time, potentially rewarding journey of negotiating suitable treatment. Though individuals may utilise their subjectivities to (de)select (in)appropriate forms of healthcare provision (e.g. Markens et al 2010), doing so arguably reproduces widespread ideas about corporeal containment and atomistic versions of the self (e.g. Battersby 1993; Williams and Bendelow 1998; Hallam et al 1999: 11; Broom et al 2015). Indeed, my own research confirms that participants used their experiential knowledge within and without medical systems to expand their health-related choices and obtain treatments that could effectively control their 'unruly' and

'transgressive' bodies (Williams and Bendelow 2000). Moreover, lay identification closely related to medicalised ideas about dystonia in which participants re-appropriated expert terminology with each other at group meetings to learn about useful management strategies (Rapp 1999; Rapp et al 2001). In many ways, drawing on their experiential knowledge to seek appropriate treatments enabled them to feel more in control of their bodies and manufacture a sense of certainty around medicine in spite of limited effective therapeutic options (see 'dissonance' section). Nevertheless, these consumer health behaviours sustained normative expectations surrounding the private management of illness: the same set of ideas that had repeatedly prevented participants from vocalising and authenticating their experiences of suffering during the negotiation of a diagnosis and beyond.

While ideological and organisational shifts in the way healthcare is practiced have bolstered laities' awareness of medicine's shortcomings (Kelleher et al 1994; Bury 1997; Mechanic 1998: 663), researchers argue that patients continue to invest faith in its perceived authority (Abel and Browner 1998; d'Agincourt-Canning 2003). Many participants hoped that the medical profession would provide an effective treatment or cure to alleviate their visceral experiences of suffering. However, their focus on these types of interventions arguably reduced their embodied needs to the language of medicine (Novas 2007) and, in doing so, reinforced normative ideas about carnal behaviour (Davis 1995). Indeed, participants' prioritisation of biomedical approaches undermined the influence of the politico-cultural context (Shakespeare 2014: 139), which is notable considering that their subjective experiences intersected with it throughout their lived trajectories.

In addition to negotiating an appropriate diagnosis and treatment plan, participants spoke fervently about the benefits of accessing humanistic forms of healthcare and having the medical profession authenticate their experiences. While theorists adopting a Foucauldian perspective argue that the medicalisation of embodied knowledge has extended the power of the medical gaze into the intimate fibres of everyday life (Armstrong 1983; 1984; 1995; Arney and Bergen 1983; Silverman 1987), my own research demonstrates that participants preferred health experts to enquire about their physical, emotional, *and* social wellbeing whether this was from an orthodox and/or alternative professional (e.g. Malcolm). Broom and Woodward (1996) have maintained that a categorical distinction ought to be made between 'medical dominance' and 'medicalisation', whereby the latter can facilitate the enactment of suitable healthcare if patients are listened to and respected (see also Maseide 1991; Massé et al 2001; Prior 2003; Busfield 2017). Furthermore, since properly applied medical interventions can enhance the lives of disabled people (Prior 2003), Shakespeare (2014: 83) has suggested that a 'failure to meet general or impairment-related health needs is itself a disabling barrier.' I would also add that, in spite of some of the problems participants reported with medical knowledge and the caring profession, it could sometimes perform an active role in pushing against stigmatising notions of disability and difference. In fact, though participants searched for medical solutions, they still preferred to discuss the emotional impact of dystonia on their everyday lives and wanted clinicians to attend to those aspects of their experiences that had repeatedly been silenced by society.

Researchers note that both laities and clinicians view concordant therapeutic relationships positively since these often lead to favourable outcomes and effective styles of communication (Mead and Bower 2000; Bissell et al 2004; Ong and Hooper 2006; Latter et al 2007). Yet, while those participants who tended towards a resonant synergy during consultations viewed it as beneficial to wellbeing, there were several drawbacks of this particular interplay. For example, some participants had used private healthcare insurance during the process of diagnosis and/or treatment in order to expedite the delivery of suitable support. Further, through their attempts to obtain an authentic reading of their enigmatic symptoms, many participants sought a second opinion and demanded referrals to secondary care. These examples reflect the play of power within medical systems since individuals unable to afford private healthcare and/or take an active role (e.g. due to the severity of their illness) may unfairly be disadvantaged (e.g. Ong and Hooper 2006). Lastly, as clinical priority setting means that some patients 'are diagnosed or treated before others' based on their medical needs (Norheim 2008: 337), those with less clinically severe focal forms of dystonia may have different levels of access to treatment resources compared to individuals with generalised types (Jinnah 2015). Thus, even though Shakespeare (2014) has (rightly) maintained that a failure to provide disabled people with (better) access to healthcare is itself disablist, my research demonstrates that this alone does not automatically ensure all individuals with impairments will be positioned equally within the caring profession.

Aside from their positive experiences of healthcare, many participants willingly mobilised medical knowledge alongside their own in order to generate body-centric

evaluations of other individuals' experiences of dystonia, even though these could sometimes lead to feelings of distress (see 'dissonance' section). As a matter of course, participants lived with a number of uncomfortable embodied markers such as fatigue and shaking in varying degrees throughout their trajectories. Shakespeare (2014: 140) has noted that 'the diversity of impairment experiences among disabled people' makes the formation of hierarchies almost inevitable. This issue may further be compounded through the way such individuals relate to their own medical problem (*ibid.*). In particular, those with a fixed congenital condition may be 'well adjusted to their situation, partly because they have known no other state', while people who develop a disorder in mid- to late life may (initially) feel distressed by the sudden change to their biographies (Shakespeare 2014: 140-141). Given that many participants' dystonic symptoms had begun in adulthood, they had already obtained some experience of enjoying the benefits and privileges associated with living as a non-disabled person. Consequently, they may have needed to compare to feel part of a community of sufferers experiencing similar problems or more secure and 'normal' in contrast to those perceived as worse off.

Since the findings from this study illuminate the dynamism of experiential and expert knowledge both within and without the medical profession, resonant synergies could also point to inequalities operating beyond the traditional therapeutic encounter. While the results support previous research on the way downward and lateral social comparisons can provide a number of psychological benefits (e.g. Wills 1981; Crocker and Major 1989), it would be misguided to overlook the impact of structural forces on the formation of these evaluations. Indeed, writers such as Finkelstein

(1993) and Deal (2003) have argued that one of the reasons individuals with impairments construct hierarchies is due to their own sense of embodiments intersecting with cultural definitions of normality. That is, individualistic conceptions of disability inform how those with medical conditions circumscribe who is different ('the out-group') and who is similar ('the in-group') (*ibid.*). Many participants positively (and sometimes negatively) formed downward or lateral social comparisons by using bodily decrement and shared diagnostic labels as salient dimensions to document the perceived abnormalities and struggles of individuals with dystonia. In fact, participants strategically privileged symptom severity and distribution to differentiate or assimilate at the expense of other equally relevant experiences (e.g. social oppression).

As participants also used other people's physical characteristics to make particular assumptions about them, they framed and interpreted their evaluations firmly in confluence with the non-disabled gaze and medico-popular attitudes surrounding carnal (un)desirability (Hughes 1999; Reeve 2002; Zitzelsberger 2005). Shakespeare (2014: 81) has maintained that 'differences in the significance of impairment are not of moral or political relevance.' However, using the findings from this study, the ways in which participants reduced the particularities and complexities of others' varied experiences to their physiological components not only imbued their comparisons with moral sensibilities concerning the wider social standing of disabled people but also generated a profoundly politicised reading of these embodied differences. For example, conceptualising dystonic bodies as aberrant and tragic could leave participants feeling both fortunate and alarmed by the perceived severity

of the condition (e.g. Beth) or less different and isolated when in the presence of other similarly stigmatised individuals (e.g. Cassie). Consequently, participants' 'impairment hierarchies' (Deal 2003) could assist them in approaching decisions about peer support, but these perceptions were continually structured in accordance with the ethos of the medical and personal tragedy models of disability.

A minority of participants also made a series of temporal self-contrasts between their formerly distressed selves and 'the positive ways in which their life had changed since' coming to terms with their illness (Heaton 2015: 343). This method of communication echoes Frank's (2013) notion of the 'quest narrative', whereby individuals believe 'that something is to be gained from the experience' of suffering (e.g. empathy) (Smith and Sparkes 2004: 607). As is mostly typical of these kinds of stories, participants described the way journeying from a place of incoherence to one of relative calm and acceptance developed in relation to the personal management of recurrent embodied problems such as corporeal deterioration (e.g. Ollie) or fluctuating therapeutic outcomes (e.g. Roberta) (Smith and Sparkes 2004: 608-610). Moreover, using their former experiences of healthcare (and dystonia) as evidence that they had successfully surmounted adversity enhanced participants' self-esteem. Arguably, this demonstrates the ways in which their retrospective evaluations of dissonant synergies could favourably contribute to a present sense of progress and achievement.

However, none questioned the operation of power situating their resilience or the potential ways in which these moral-focused strategies, related to the hegemonic

notion of individual responsibility (Broom et al 2015), could exclude those struggling to manage the disabling nature of their condition and commit to a socially acceptable version of personhood. For example, Liam evoked negative temporal self-comparisons to emphasise the difficulties that he had faced since the onset of his symptoms. A minority of participants also drew on the framework of the medical gaze and personal tragedy model of disability to suggest that all individuals with long-term conditions like dystonia experience distress, particularly as a result of their noticeably disordered carnalities. Thus, using medico-popular notions of normality to inform their positive self-reflections permitted participants to sustain disablist assumptions about the alleged suffering of disabled people.

The politics and status of different knowledges

A key issue to emerge from my detailed exploration of the experiential knowledge of people affected by dystonia is the nature, use, and status of different epistemic claims across multiple contexts and temporal junctures. In fact, it has been argued that classifying different types of lay knowledge sources (embodied and empathetic) according to their perceived familiarity is 'a means by which' individuals can 'check the authenticity of each other's accounts […] and affirm the validity of their own' (Boardman 2010: 299; 2014a; Doan et al 2018). That is, experiential experts often claim 'epistemic privilege' on the grounds that they possess 'better' and more 'valid' forms of knowledge than those without their particular understanding (Boardman 2010; 2014a; Casey and McGregor 2012; Doan et al 2018). Boardman (2010; 2014a) has observed that agents affected by inheritable disease generate a hierarchy of epistemic claims by privileging certain types of experiential knowledge as more or

less credible. In particular, embodied experiential knowledge was strategically accorded higher status than 'those family members who came to know SMA empathetically' (Boardman 2014a: 147). In doing so, individuals were able to justify their views and/or actual uses of reproductive procedures to themselves and other people deemed to be less knowledgeable (Boardman 2010; 2014a). Similarly, I found that participants considered their experiential notions of dystonia authentic because these enabled them to challenge and reject other perspectives and accounts (lay and medical) that denied or misrepresented the truthfulness of their interpretations of their embodied subjectivities. Indeed, the findings demonstrate that participants' perceived proximity to medical and experiential bodies of knowledge depended on how far these fully encapsulated their visceral sensations, and that further, provided credible and acceptable explanations of their realities. Participants, thus, arranged different types of epistemic resources hierarchically and ascribed them a particular status at various timeframes. Yet, while their abilities to decipher medical and experiential ideas were assessed and weighed up intuitively through their ongoing carnal and/or emotional experiences, these privileged standpoints were still malleable and subject to numerous modifications and revisions (Abel and Browner 1998; d'Agincourt-Canning 2003; 2005; Boardman 2010; 2014a; 2014b; Doan et al 2018).

The idea that different knowledge sources can strategically be systematised according to their perceived authenticity relates to the literature on feminist epistemologies (Hekman 1997). More specifically, standpoint feminist scholars maintain that discriminating between different epistemic sources is both possible and politically necessary for the emancipation of oppressed groups (Hartstock 1997; Hill-

Collins 1997). Nancy Hartstock (1997: 372-373), for example, has advocated the view that some standpoints or epistemes can be considered 'better' if the applied criteria are grounded in and through an emancipatory framework that practically seeks to lessen the damaging effects of social oppression. Since individuals' experiences develop from real embodied struggles and conflicts intersecting with broader hierarchical relations of power (e.g. patriarchy, racism, disablism), these can be used to illuminate and dismantle hegemonic knowledge constructs (Hartstock 1997; Hill-Collins 1997). Similarly, participants made concerted efforts to modify limited or uncertain medical perspectives through the mobilisation of health-informed ideologies like autonomy and personal responsibility. As participants perceived that some claims dismissed or distorted the realities of their dynamic subjectivities, their everyday experiences permitted them to make strong evaluative judgments about the usefulness of experiential and medical bodies of knowledge. While participants sometimes used medico-cultural understandings to invoke disablist, body-oriented comparisons about other people with dystonia, assessing medical ideas enabled them to adjust to their condition as best they could and minimise further suffering, with varying implications for identification and the lay – professional interplay. Consequently, the cultural character of embodied knowledge acquired a distinctly political dimension in the context of healthcare decision-making. Participants viewed their experiential knowledge as authentic and used it to adapt, select, challenge, as well as (gladly) accept those aspects of medicine (related to its practice and wider representation) that they viewed as meaningful and instrumental to their enjoyment of life.

Overall, though the strategic privileging of ideas and knowledge claims could facilitate better access to more suitable forms of support and healthcare provision, as well as enhance self-confidence, it also became apparent that resonant synergies could sustain financial inequalities and/or discriminatory attitudes about disabled people. Conversely, dissonant synergies could be assessed retrospectively, and by proxy, transformed into resonant ones through the adoption of individualistic (medical) ideologies that focused predominately on self-help and health self-management practices. In view of that, the relative (dis)advantages of dissonant and resonant synergistic relationships for individuals with long-term health conditions should not be taken at face value. Rather, these ought to be situated within a broad social context that recognises the political consequences of agents' uses of 'epistemic privilege' (Casey and McGregor 2012) across the life-course.

Strengths and limitations

The main limitation of my research is the relative lack of (demographic) diversity with respect to gender, age, ethnicity, and dystonia type, particularly as I recruited the majority of participants through The Dystonia Society. Indeed, the relatively high number of women in the sample might be explained by the fact that the majority of participants came from local dystonia support groups (64.3%). Obtaining samples from patient organisations can be problematic given that these are self-selecting and often reflect the demographics of white, middle-class women who mainly attend meetings (Rapp 1999; Rapp et al 2001; Stockdale and Terry 2002; Blume 2016: 8). In addition, 31% of my sample comprised patients who had originally been invited to participate in WADSS, a residential group-based intervention that was somewhat

similar in style and approach to local dystonia collectivities (69.2% of the WADSS sample were women) (Sandhu et al 2016). Lastly, given that stoical attitudes towards illness management (e.g. 'just get on with it') are linked to notions of 'rationality' and 'masculinity' (Murray et al 2008; Moore et al 2013: 165-166), some men may have considered talking about their condition in the context of a support group and/or research study a sign of weakness.

One of the limitations of this study are the low numbers of black and ethnic minority participants with dystonia. However, this under-representation is broadly reflective of the prevalence of dystonia across ethnic groups. Indeed, the incidence of cervical dystonia has been estimated to be significantly higher among white North Americans (1.23 per 100,000 person-years) than individuals from Hispanic, black, and Asian communities (0.15 per 100,000 person-years) (Marras et al 2007). While childhood-onset generalised dystonia is most prevalent among European Jewish people (chapter 2) (Defazio et al 2004), recent estimates have indicated that this remains a rare condition with an overall range of 2 – 50 people affected per million in the population (Defazio 2010). In contrast, the adult-onset focal dystonias are significantly more common (30 – 7320 per million people) and tend to affect non-Jewish groups (*ibid.*).

None of the participants explicitly reflected on their ethnicity or spoke about the ways in which it shaped their experiences and perceptions of dystonia. This may have been because most identified as belonging to the ethnic majority (e.g. white British) (chapter 4; appendix 6). It is possible that participants from black and ethnic

minority backgrounds may not have discussed their ethnic identities with me and/or my colleague from WADSS because they were speaking to white interviewer(s) and/or white group interview participants, although this cannot be confirmed. Moreover, using The Dystonia Society to recruit the majority of participants may have further compounded the under-representation of individuals from black and ethnic minority backgrounds in my study. Research has demonstrated that people from black and ethnic minority groups are less likely than those of other ethnic backgrounds to access patient support organisations (e.g. The Dystonia Society), relying instead on community and familial based support systems (Avis et al 2008). Consequently, further research could fruitfully explore how ethnic minority communities respond to complex health problems like dystonia where stigma and social exclusion play an important role in everyday experiences.

My sample was most likely limited to those people who supported the beliefs and practices of The Dystonia Society. Support group attendees are often highly knowledgeable about their condition and have enough skills to mobilise the required resources in order to navigate support and care services successfully (Rapp 1999; Rapp et al 2001; Kroll et al 2007: 692). This may have meant that my sample primarily reached those individuals who felt they had something interesting to say or wanted to raise a controversial or overly positive point about their experiences of healthcare. The Dystonia Society largely represents dystonia as a neurological condition but people who identify as disabled and not a person affected by dystonia or who live with the disorder as a symptom of another condition, as a cause of mental illness, or as a side effect from treatment may not readily identify with the

charity's depiction. Consequently, these groups of individuals may have inadvertently been excluded from taking part in my research.

In order to address limitations on my sampling strategy and reduce the risk of self-selection bias, I recruited patients with dystonia from an NHS hospital. I also asked The Dystonia Society to distribute the study documents for the group and semi-structured interviews to everybody registered on the mailing lists of two separate support groups to give (non)regular attendees an equal chance of participating. Furthermore, I conducted secondary qualitative analysis on data that had originally been collected from another group of patients with dystonia, who had agreed to participate in WADSS. This helped to enlarge my sample and obtain enough information on the phenomenon under exploration.

However, my sample remained somewhat limited with regards to types of treatment and dystonia. Indeed, all patient participants had initially been recruited through two different BoNT clinics, meaning that the chances of approaching those with a focal dystonia like cervical dystonia were high. This is an important point to consider since cervical dystonia tends to be treated with BoNT and is often idiopathic with neurologic (organic) consequences (Albanese et al 2013). Moreover, unlike the primary study that included all forms of dystonia, members of the WADSS research team intentionally excluded patients with combined or acquired types from participating in the study. These variations demonstrate the potential challenges of conducting a secondary analysis, most notably, under-representative samples and data incompatibility (Heaton 2008). Overall, my recruitment methods resulted in a

lack of diversity in dystonia type and severity in my sample, leading to the over-representation of older people with idiopathic focal dystonia. Since patients with this type often have to wait a considerable amount of time to get diagnosed and treated because their symptoms are considered to be clinically less severe than those of people with generalised dystonia (Jinnah 2015), the findings could be reflective of the particular demographic details of my sample of participants.

Other perspectives are also missing from the study, including, health professionals, carers/family members, and individuals under the age of 18 years old. Furthermore, though the primary study did not explicitly exclude those individuals who had additional care needs, my criteria may have inadvertently done this by requiring potential participants to approach me directly rather than through somebody else (e.g. their carer). In counterargument, some of the aforementioned populations are particularly hard to reach given the relatively rare and unknown nature of dystonia. Yet, the data that I did obtain was enough to develop an original theoretical framework. Cassidy (2012: 263) also experienced difficulties with recruiting participants with ataxia (an uncommon neurological disorder) but tried to mitigate some of these through the adoption of a fairly broad recruitment strategy. Similarly, I developed a wide-ranging purposive approach to sampling with the intention of recruiting as many individuals as possible into the study. Consequently, I was able to recruit from two separate support groups, a hospital site, as well as undertake a secondary analysis of a qualitative dataset that was relevant to the overall aims of the primary research.

While qualitative interviewing methodologies can help to solicit the perspectives of marginalised groups like disabled people, providing a 'voice' is rarely a simple matter because it is linked to a range of ethical and political dilemmas (e.g. Kroll et al 2007). More specifically, interviews may not be entirely suitable for individuals with chronic health problems since these techniques may cause them to experience a plethora of different impairment effects such as fatigue and/or pain (*ibid.*). In this way, the interview situation may prevent such groups from experiencing qualitative research as 'empowering' (*ibid.*). Two participants affected by dystonia in their vocal chords both experienced difficulties speaking during group interview 2 (Agatha and Miranda), potentially limiting how much they were able to contribute to this discussion. Despite these problems, however, Miranda did say that she felt comfortable to talk about her experiences of dystonia and healthcare provision in the presence of her friends and fellow support group members, who understood the challenges she faced.

Though I had initially intended to recruit equal numbers of group interview and non-group interview participants to reduce the risk of bias, in practice, only one person (Dawn) who had not previously taken part in a group discussion agreed to participate. This meant that I, therefore, re-interviewed the majority of people from the group interviews. The individual who only participated in a semi-structured interview did not regularly attend meetings because she had not found anybody with her particular type of dystonia (chapter 7). In contrast, nearly all the people who took part in both interviews were regular attendees, suggesting that they may have had a particular understanding of the groups. Re-interviewing a large number of support

group participants and having some prior knowledge of their illness trajectories beforehand may have also (un)wittingly informed what I asked them about their understandings, and by proxy, shaped the findings from this study. Yet, it enabled participants to further elucidate upon their own viewpoints and experiences, as well as permitted an exploration of other ideas that may not have been fully developed during the group interviews (Madill et al 2000: 10).

The identified themes could have been an artefact of the research, based on the samples that I obtained and questions asked, rather than these emerging 'naturally' from the data (Braun and Clarke 2006). For example, since The Dystonia Society representatives, Paige and Charlotte, participated in group interviews 1 and 2, respectively, their presence during these discussions may have persuaded other participants to proffer a certain view of the groups and the quality of the support that they receive. In addition, as I made personal involvement with dystonia a key inclusion criterion, as well as used data obtained from support group attendees and patients (including those taking part in a treatment-based intervention), my research decisions may have affected the overall content and structure of the analysis chapters (i.e. medicalisation, day-to-day life with dystonia, and patient collectivities). However, I kept a series of highly detailed reflexive notes throughout the research process, which enabled me to consider and refine my developing insights and ideas. This was also important in order to remain open to alternative viewpoints that may have diverged from my initial preconceptions and everyday experiences of dystonia (chapters 1 and 4). Due to my prior engagement with disability politics, for example, I had expected participants to talk about their shared struggles with social oppression

rather than situate their suffering resolutely within an individualistic (medical) paradigm. Thus, through my reflexive stance and awareness of my own personal involvement with dystonia, I was able to record any potential biases that could have substantially narrowed or distorted my focus and prevented me from generating 'data-driven' codes within the three master categories (Gibbs 2007).

Implications for future research

The present study obtained original data on the dystonia syndromes to contribute to the evidence-base and generate novel empirical insights surrounding the lived and living experience of long-term health problems. In fact, a compelling justification for doing my research on dystonia was because it has important dimensions related to stigma and social exclusion that can be broadly applied to theory and other similar situations. As such, this thesis makes a timely contribution to the evolving social scientific literature on the relationship of experiential knowledge to biomedicine in the context of healthcare decision-making.

My research expands and moves beyond recent theoretical developments in the field by carefully detailing the ways in which the synergistic nature of the experiential – professional dynamic moves backwards and forwards across various times and contexts. Future research could be done to identify the range of factors that influence this oscillation. Whereas patient involvement in medicine is often regarded as a useful way of dismantling paternalistic styles of healthcare and developing concordant therapeutic relationships (chapter 3) (e.g. Quill 1983; Bissell et al 2004), through my novel theoretical constructs, I have demonstrated that this process is by

no means a straightforward or static one. Instead, the creation of a resonant synergy depends on how far one type of episteme enters into and influences the other, which can change at different temporal locations throughout a person's lived trajectory. Further studies could consider the way individuals affected by complex illnesses approach decisions about healthcare and subjectively assess the relevance of medical knowledge across various contexts.

Another key finding to emerge from my research was the ways in which medicalised agendas caused difficulties not merely within the confines of the clinic but also within the everyday inflections of social life. More specifically, I have demonstrated the way (modified) biomedical constructs and the operation of social power shaped participants' understandings of their dystonia *throughout* their lived trajectories, with varying implications for wellbeing. Consequently, it is suggested that further research explores how far the cultural domain of medicine intricately plays out in lived experience for other socially (im)perceptible conditions and informs the character of the experiential – expert relationship across the life-course.

This thesis makes several political contributions to the literature. Firstly, the findings from the study could be used to understand the politics of the patient – clinician relationship, and in particular, highlight the experiences of those who have little negotiating power within medical consultations. Secondly, though the findings note that challenges to certain aspects of medicine did not entail a complete rejection of its orthodoxy, whether choosing to opt out of treatment completely for a particular condition might lead to the radical disruption of medical hegemony could be

considered. For example, proponents of the neurodiversity movement around autism have called into question the scientific validity of a medical model understanding of 'normal' cognitive function (Neurocosmopolitanism 2016). Instead, Autist campaigners endorse an anti-pathology philosophy in which they view autism as a neurological difference that should be accommodated by social model thinking (e.g. removal of barriers to inclusion, wider social acceptance of autistic traits) and not medical intervention (*ibid.*). In contrast, this study highlighted the relevance of medical notions of health to treatment decision-making and personal understandings of embodiment. Future research is suggested that would offer a comparison of a range of disease groups and ask questions around why certain communities become more politically active than others, as well as what impact these different health identities may have on the nature of the relationship between lay and medical knowledge.

In terms of policy and practice implications, my research draws attention to the range of challenges that individuals with rare and contested conditions experience within the medical encounter (e.g. being regarded as a 'psychiatric problem', having limited effective therapeutic options). Despite the fact that (degrees of) dissonance may be unavoidable and expected due to, for example, the uncertainties and limitations inherent within medicine (e.g. Griffiths et al 2005), the findings indicate that it may, nevertheless, be beneficial for health professionals to try to resonate their expertise with that of their patients'. Indeed, although many participants welcomed the arrival of a definitive diagnosis of dystonia, having to live with the ongoing effects of their condition raised anxieties about prognosis and the possibility of corporeal

deterioration. This meant that participants required their doctors (GPs and neurologists) not only to have sufficient expertise of their problem but also to act empathically towards them during consultations. With this in mind, future work is suggested to inform primary and secondary clinical practice, and in particular, draw attention to the importance of providing sensitive and emotional forms of support to patients displaying dystonic symptoms during the negotiation of a medical label and thereafter. By noting the ways in which dissonant *and* resonant synergies interweave throughout a person's disease trajectory and shape their therapeutic decisions, clinicians and patient support organisations may be able to identify times when the lay – medical interplay is likely to become (mis)aligned. Consequently, my theoretical insights suggest that it may be beneficial for those who care for people with complex and contested conditions to provide personalised forms of support, which resonate with the dynamism of patients' embodied subjectivities. In fact, through a consideration of experiential knowledge, clinicians may not only be more likely to meet the unique support needs of individuals but also be reflexive and transparent about the limitations of medical practice when diagnosing and treating patients living with rare diseases.

Finally, while some participants' sense of identification was less than others' or completely absent, my research indicates that most found peer support beneficial. Yet, the findings also demonstrate that among dystonia support groups there is a reliance on biological notions of disability and difference to denote individuals' subjectivities and shared identities (Camfield 2002). This is an important point to consider given that, firstly, the findings from this thesis reveal participants' varied

embodied states tightly interweaved with disablist contexts and, secondly, The Dystonia Society aims to support those with the condition. Though Hughes (2009: 683) has noted that patient collectivities focus on corporeal malfunction and not overtly political agendas (unlike disability rights groups), The Society is ideally positioned to provide the impetus to consider the role of disablism in the daily experiences of people with dystonia because of the profound impact of unequal power relations on their mood and sense of self. Therefore, the findings from this study indicate that it may be beneficial for patient group organisations that help individuals with rare and complex diseases like dystonia to engage in disability politics and social model thinking.

Conclusions

My research provides a holistic and novel understanding of the ways in which people experience dystonia and make important decisions about their healthcare. From a detailed exploration of the accounts of 42 individuals living with some form of dystonia, it was evident that experiential knowledge performed a salient role in justifying their support choices and preferences alongside helping them to navigate asymmetrical power relations. Indeed, participants invariably formed this knowledge through their physical, emotional, and social responses to living in and managing a predictably unpredictable body that closely intersected with expert and medico-popular ideologies and practices. Since participants' experiential knowledge changed in confluence with various contexts, the ways in which they understood and evaluated their personal experiences of healthcare also fluctuated at different times. In situations where medical knowledge cohered with participants' real embodied

needs and requirements, it could offer valuable clinical and emotional forms of support. At the same time, however, experiential and medical knowledge could both become uncertain and limited, necessitating the use of creative negotiation strategies in order to manage these epistemic instabilities and build a more optimistic future (e.g. by making positive temporal self-contrasts). Though previous studies have subsumed the psychological implications of medical and social (de)legitimation within individuals' illness accounts (e.g. Rhodes et al 1999; Lillrank 2003), my research has used these reactions and feelings (e.g. alienation, uncertainty, relief) to process and interpret the dynamic, synergistic relationship between experiential and expert knowledge. In particular, this study has drawn attention to the ways in which ideas about lay and medical sources are currently framed as dichotomous *or* interwoven conceptual categories. I have, however, demonstrated that these knowledges can mutually constitute each other *and* be hierarchically ordered in relation to each epistemic source's acceptability to the person. This original contribution indicates that it may be beneficial for health professionals and support groups to be reflexive about their own limitations and sensitive to the complexities of the lived and living experience of dystonia. Agencies and institutions that support individuals with this complex and contested condition may be able to attend empathetically to their moments of vulnerability, apathy, and joy, as well as relate these personal experiences to a wider social context. Consequently, the caring profession may be able to honour a fundamental principle of human intentionality: to be listened to and respected as a creative individual with something credible to say in spite of the difficulties that they may face.

Appendices

Appendix 1: Dystonia Treatment Options

Biomedical interventions are currently the mainstay of treatment for dystonia and typically include medication, neurosurgery, and neurotoxic injections (Termsarasab et al 2016). As part of the process of diagnosis, clinicians sometimes look for treatable causes first before excluding particular types of dystonia (Cloud and Jinnah 2010: 11-12). For example, in cases where dopamine-responsive dystonia cannot be definitively excluded then the synthetic dopamine drug levodopa is trialled (Morishita et al 2009: 7; Termsarasab et al 2016). This is because it is highly effective in the treatment of dopamine-responsive dystonia (*ibid.*). Paediatric and adult patients with generalised or focal limb isolated dystonia are usually prescribed this pharmacological agent since these cases are more likely to reflect atypical characteristics of the condition (Termsarasab et al 2016). Dopamine-responsive dystonia can be ruled out if symptoms do not improve with levodopa treatment (Morishita et al 2009: 7). Following its exclusion, clinicians may prescribe a neurotransmitter blocker like an anticholinergic (e.g. trihexyphenidyl, benztropine) in order to see whether this helps to alleviate spasms (*ibid.*). If this intervention does not work then the muscle relaxant baclofen may be offered as a 'second-line agent', although its effectiveness in generalised and focal dystonia has been disputed (Termsarasab et al 2016: 30; Morishita et al 2009: 8; Cloud and Jinnah 2010: 7). Benzodiazepine (e.g. diazepam, clonazepam) may also be prescribed in cases where baclofen is deemed to be unsuitable or ineffective (*ibid.*). Alternatively, 'when monotherapy achieves a "good" dose but symptom control is incomplete, or dosage is impeded by side effects', clinicians may offer a 'cocktail' of different medications

(Termsarasab et al 2016: 24). However, empirical data on the usefulness of this strategy are scarce (Morishita et al 2009: 9).

Botulinum toxin injection therapy (BoNT) is a denervation agent that is derived from the Clostridium botulinum bacterium and is usually administered to patients with focal or segmental dystonia because of its relative success at targeting specific groups of muscles (Haussermann et al 2003; Pappert and Germanson 2008; Costa et al 2009; Cloud and Jinnah 2010: 9; Delnooz and van de Warrenburg 2012; Jankovic 2013: 1008; Termsarasab et al 2016). The chemical inhibits the release of the neurotransmitter, acetylcholine, which subsequently weakens the affected muscle(s) (Cloud and Jinnah 2010: 9). To relieve tension and cramping in focal regions in clinically severe forms of dystonia, BoNT may be used in conjunction with some of the aforementioned pharmacological agents (Termsarasab et al 2016). Despite the effectiveness of the toxin, however, patients may develop neutralising antibodies and subsequently, become resistant to its effects over time (Jankovic 2013: 1008). The diffusion of the toxin to local areas may also cause muscle weakness in affected or nearby regions (Cloud and Jinnah 2010: 9). Practically speaking, individuals may find it difficult to make regular trips to the hospital in order to obtain treatment (usually, a neurologist administers BoNT once every 2 – 4 months (Fleming et al 2012: 7)) (Haussermann et al 2003: 306). Overall, research on BoNT has found that it is a generally safe and effective treatment to apply in the management of dystonia, particularly for focal types like cervical dystonia (Haussermann et al 2003; Pappert and Germanson 2008) and blepharospasm (Costa et al 2009). Nevertheless, this

therapy might not work as well for more severe types of these particular dystonias as it might for milder ones (Comella and Bhatia 2015).

More complex procedures like Deep Brain Stimulation (DBS) surgery are usually offered to patients with medically severe types of dystonia (e.g. generalised or myoclonus dystonia) (Albanese et al 2006; Termsarasab et al 2016). However, individuals diagnosed with a focal dystonia may also be recommended for surgery if previous treatments have failed to work (Krauss and Loher 2007: 215; Cloud and Jinnah 2010: 10; Termsarasab et al 2016). DBS involves inserting battery-powered electrodes into a particular region of the brain (usually the globus pallidus internus) in order to block incorrect signals and decrease spasticity (Albanese et al 2006; Krauss and Loher 2007; Termsarasab et al 2016). Even though the mechanism through which stimulation takes place is still unknown, DBS has been found to benefit patients with generalised, segmental, or cervical dystonia (Albanese et al 2006; Cloud and Jinnah 2010: 10). The Burke–Fahn–Marsden Dystonia Rating Scale is used to assess movement and functional disability in DBS patients with generalised dystonia (Cloud and Jinnah 2010: 10). Vidailhet et al (2005), for example, found a mean improvement of 54% in the movement score and 44% in the disability score 12 months after surgery (Cloud and Jinnah 2010: 10). Despite its benefits, however, DBS may cause a range of adverse effects such as hardware failure, battery depletion, infections, and/or intracranial haemorrhage (Balash and Giladi 2004: 361). On the other hand, the degree and frequency to which these occur in DBS patients remains unknown due to the fact that not many controlled trials have been conducted (*ibid.*). Moreover, since some types of acquired dystonia respond

better than others to DBS, researchers have been unable to determine its clinical

effectiveness (Cloud and Jinnah 2010: 10). Arguably, this ambiguity reflects the

phenotypic and aetiologic heterogeneity of the dystonia syndromes (*ibid.*).

Appendix 2: Group Interview Schedule (support group representatives and members)

1) Can you tell me about your overall experiences of attending the dystonia support group?

2) What do you typically discuss at the support groups? Why?

3) What are people's concerns/needs? How are these addressed by the support group?

4) What advice and/or support have each of you had since attending the support group? Has the advice and/or support been effective for helping you live with dystonia? How has the advice and/or support you receive been effective?

5) How did you cope with dystonia before you visited the support group? How have your coping strategies changed, if at all, since attending?

6) Can you tell me how you currently cope with your dystonia on a daily basis?

7) How is the support group organised? Who tends to organise the support group? How often do you meet?

8) How does attending a dystonia support group help you live with your condition?

9) Can you tell me which roles/activities each of you perform at the support group? Why do you perform these roles/activities?

10) How do your experiences of healthcare compare to the advice provided at the dystonia support group?

11) Is there anything else you would like to add?

Thank you for taking the time to participate in this group interview.

Appendix 3: Semi-structured Interview Schedule (support group representatives)

1) Can you tell me about your role as a dystonia support group representative at the support group?

2) Can you tell me why your role is important for assisting members at the support group?

3) What is usually discussed at the support group?

   - How useful are the discussions for helping support group members live with dystonia?

   - Would you like to see other topics or areas related to dystonia being discussed?

   - Who typically decides the discussion topic(s) at each support group meeting?

4) What have been some of your past and/or current experiences of assisting members at the support group?

5) How would you describe dystonia to somebody who is not familiar with the condition?

6) How do you think people living with dystonia experience their condition? Feel free to talk about your own experiences when answering this question.

7) What kinds of advice and/or support are typically provided to support group members? This may include any advice and/or support provided to members outside of the support group setting.

   - How effective do you think the advice and/or support provided to members is for helping them live with dystonia?

   - Who typically provides this advice and/or support?

8) What issues/concerns/queries/needs do support group members typically ask you and/or share with the rest of the group?

- How are these issues/concerns/queries/needs typically addressed by yourself and/or the rest of the group?

9) Name something positive about the support group?

– What are your reasons for thinking this?

10) Do you think the support group could be improved in anyway?

- *If participant answers yes:* in what way do you think the support group could be improved?

- What are your reasons for thinking this?

11) Is there anything else you would like to add?

Thank you for taking the time to participate in this interview.

1) Can you tell me what you typically do at your support group? Feel free to talk about your relationships and encounters with other members in the group, including your support group representative.

2) What is usually discussed at your support group?

   - How useful are these discussions for helping you live with dystonia?

   - Would you like to see other topics or areas related to dystonia being discussed?

   - Who typically decides the discussion topic(s) at each support group meeting?

3) Do you perform any roles and/or activities at your support group? E.g. raising public awareness of dystonia, organising charity events, trips away, taking part in dystonia-related conferences, leading support group discussions, being involved in support group discussions, etc?

   - Can you talk about your experiences of any past and/or current roles and/or activities you perform at the support group?

   - How effective are the roles and/or activities you perform in the group for achieving your aim(s) and/or the aim(s) of the support group? What are these aims?

4) Can you tell me how attending a dystonia support group helps you live with your condition?

5) What needs related to your dystonia would you say you have?

6) Do you think your dystonia support group meets your needs sufficiently?

   - Please give reasons for your answer.

7) How does your support group compare to other forms of support you may receive? E.g. from healthcare professionals at your movement disorder clinic.

8) Name something positive about your support group?

   – What are your reasons for thinking this?

9) Do you think your support group could be improved in anyway?

   - *If participant answers yes:* in what way do you think your support group could be improved?

   - What are your reasons for thinking this?

10) Is there anything else you would like to add?

Thank you for taking the time to participate in this interview.

Appendix 5: Semi-structured Interview Schedule (National Health Service [NHS]

Hospital 1 patients)

1) Can you tell me something about yourself, including what you are currently
   doing in life?

2) Can you tell me the story of how you came to be diagnosed with dystonia?

   - What were your initial experiences of being diagnosed?

   - How do you feel about your diagnosis now?

   - Can you tell me what your life was like before you were diagnosed with
     dystonia?

3) Can you tell me how dystonia has impacted on your life since your
   diagnosis?

4) Can you tell me (in some more detail) about the physical impact of your
   dystonia?

   - Does the physical impact of your dystonia vary?

   - *If participant answers yes:* How? When? Where? Why?

   - *If participant answers no:* Has the physical impact of your dystonia ever
     varied?

   - *If participant answers yes:* How? When? Where? Why?

5) In your own words, how would you describe (living with) dystonia to
   somebody who has never heard of it before? Feel free to draw on any
   metaphors or allegories you think may be helpful to illustrate your answer.

6) How do you manage your dystonia on a daily basis?

- Why?

- Does your dystonia differ according to where you are? How? Why?

- Has the way you manage your dystonia changed since you were first diagnosed with dystonia? How? Why?

7) Have you ever felt embarrassed as a result of living with dystonia?

- *If the participant answers yes:* Can you tell me more about your embarrassing experience? This experience can include your time at university, at school, at the workplace, interactions with friends and/or strangers, etc.

- Why did you feel embarrassed?

- How did you manage this embarrassing situation? Why?

8) What medical treatment(s) have you received for your dystonia since your diagnosis?

- What are the circumstances in which these treatment(s) came to be prescribed?

- How effective were they/are they for treating your dystonia?

- Do you still engage with some or all of these treatment(s)? Why(not)?

9) *Participants who have undergone DBS surgery*: Can you describe the process of how you came to undergo DBS surgery?

- How effective would you say the surgery has been for you? Why do you say this?

10) Are you treated by more than one kind of health professional?

- *If participant answers yes:* Which types of medical professionals treat your dystonia?

- Have you always had the same kinds of health professionals treat your dystonia?

- *If participant answers no:* In what way, if any, has your healthcare changed?

11) What are your experiences of the medical professionals who currently treat your dystonia?

- Why?

- Do you feel they have been effective for managing your dystonia so far? How? Why?

- How does your current experience of healthcare provision compare to past experiences of service provision? Feel free to talk about as many past experiences as you think are relevant. This can include your experiences of changing hospitals, encountering new healthcare professionals, changing from children's services to adult services, etc.

12) What information has your consultant neurologist told you about your dystonia since your diagnosis?

13) What information has your dystonia nurse told you about your dystonia since your diagnosis?

14) How effective has this information been for you to understand and manage your condition?

15) Has there ever been a time since your diagnosis when you were dissatisfied with the service you received?

- Why?

- What happened?

16) Has there ever been a time since your diagnosis when you were satisfied with the service you received?

- Why?

- What happened?

17) Do you currently attend, or have you ever visited, a dystonia support group?

- *If participant answers yes:* What was your experience of visiting a dystonia support group?

- *If only visited a dystonia support group once or twice:* Would you consider visiting again?

- *If participant answers no:* What are your reasons for not visiting a dystonia support group?

- Do you think you would like to attend a dystonia support group in the future?

18) What role do you think dystonia support groups perform (if any) for people with the condition?

- Why do you think this?

19) As a person affected by dystonia, how do you feel about living with it? (E.g. do you harbour any positive or negative feelings towards your condition? Why(not)?)

20) Is there anything else you would like to add?

Thank you for taking the time to participate in this interview.

Appendix 6: Table 1: Participant Demographics

Pseudonym (place name and role)	Age Group (years) and Gender	Ethnicity	Work Status and/or Occupation*	Type of Dystonia	Type of Interview and Setting
Jason (Support Group 1 SGm)	40 - 50, male	White British	Part-time	Cervical dystonia, blepharospasm, generalised dystonia, laryngeal dystonia	Group 1 Support group
Malcolm (Support Group 1 SGm)	62+, male	White British	Retired	Cervical dystonia	Group 1 Support group
Sheila (Support Group 1 SGm)	62+, female	White British	Retired	Blepharospasm, oromandibular dystonia, laryngeal dystonia	Group 1 and Semi-structured Support group
Keith (Support Group 1 SGm)	62+, male	White Irish	Retired, car company employee	Focal hand dystonia, cervical dystonia, oromandibular dystonia, facial muscles	Group 1 Support group
Paige (Support Group 1 SGr)	62 +, female	White British	Part-time, secretary	Cervical dystonia	Group 1 and Semi-structured Support group
Whitney (Support Group 1 SGm)	51 - 61, female	White British	Unemployed, used to work in a hospice	Cervical dystonia, laryngeal dystonia, other (unknown)	Group 1 and Semi-structured Support group
Tristan (Support Group 1 SGm)	40 - 50, male	White British	Retired	Generalised dystonia	Group 1 and Semi-structured Support group
Charlotte (Support Group 2 SGr)	51 - 61, female	Black other	Unemployed, used to work as a teacher	Oromandibular dystonia, paroxysmal dystonia	Group 2 and Semi-structured Support group
Agatha (Support Group 2 SGm)	62+, female	White British	Retired	Laryngeal dystonia	Group 2 Support group

Xavier (Support Group 2 SGm)	62+, male	White British	Retired	Focal hand dystonia, cervical dystonia, oromandibular dystonia, segmental or multifocal dystonia	Group 2 Support group
Agnes (Support Group 2 SGm)	62+, female	White British	Retired	Dystonia (type unknown)	Group 2 Support group
Allen (Support Group 2 SGm)	62+, male	White British	Retired, Royal Air Force/armed forces employee	Focal hand dystonia, oromandibular dystonia	Group 2 and Semi-structured Support group
Jasmine (Support Group 2 SGm)	62+, female	White British	Retired, teacher	Blepharospasm (in remission)	Group 2 Support group
Nicola (Support Group 2 SGm)	51 - 61, female	White British	Full-time	Cervical dystonia	Group 2 Support group
Rachael (Support Group 2 SGm)	62+, female	White British, Mixed other	Retired	Oromandibular dystonia	Group 2 Support group
Cassie (Support Group 2 SGm)	62+, female	White British	Retired	Focal hand dystonia	Group 2 Support group
Miranda (Support Group 2 SGm)	62+, female	White British	Retired	Cranial dystonia and slight anterior cervical dystonia	Group 2 Support group
Matt (Support Group 1 SGm)	51 - 61, male	White British	Retired, shop worker, office worker	Cervical dystonia	Group 3 and Semi-structured Support group
Ollie (Support Group 1 SGm)	51 - 61, male	White British	Full-time, office worker	Generalised dystonia	Group 3 Support group
Kim (Support Group 1 SGm)	62+, female	White British	Retired	Dopamine-responsive dystonia	Group 3 and Semi-structured Support group
Oscar (Support Group 1 SGm)	29 - 39, male	White British	Full-time, academic	Generalised dystonia	Group 3 Support group

Mandy (Support Group 1 SGm)	62+, female	White British	Retired	Cervical dystonia	Group 4 Support group
Faye (Support Group 1 SGm)	62+, female	White British	Retired	Blepharospasm	Group 4 Support group
Irene (Support Group 1 SGm)	62+, female	White British	Retired	Cervical dystonia	Group 4 and Semi-structured Support group
Amber (Support Group 1 SGm)	62+, female	White Irish	Retired, school lunchtime supervisor	Cervical dystonia, myoclonus dystonia	Group 4 Support group
Britta (Support Group 1 SGm)	62+, female	White British	Unemployed	Blepharospasm	Group 4 Support group
Dawn (Support Group 1 SGm)**	62+, female	White British	Unknown	Oromandibular dystonia	Semi-structured Support group
Ruby (NHS Hospital 1 patient)**	Unknown, female	White British	Retired, data entry clerk	Cervical dystonia	Semi-structured Home
Beth (NHS Hospital 1 patient)**	62+, female	White British	Retired, estate agent	Cervical dystonia	Semi-structured Home
Roberta (WADSS participant)	51 - 61, female	White Irish	Part-time, social worker	Cervical dystonia	Pre- and post-intervention Home and telephone
Bella (WADSS participant)	40 - 50, female	White British	Full-time, social worker	Cervical dystonia	Post-intervention Home
Megan (WADSS participant)	51- 61, female	White British	Part-time	Cervical dystonia	Pre- and post-intervention Office and home
Eric (WADSS participant)	51 - 61, male	White British	Full-time, manual work	Cervical dystonia	Pre-intervention Home
Aileen (WADSS participant)	62+, female	White British	Retired, game keeper's assistant	Cervical dystonia	Pre- and post-intervention Home
William (WADSS participant)	62+, male	White British	Retired, company director	Tremors (head and hand)	Pre-intervention Home

Ava (WADSS participant)	40 - 50, female	Mauritius/South America	Full-time, office worker, part-time, hair stylist	Cervical dystonia	Pre- and post-intervention Home and telephone
Liam (WADSS participant)	40 - 50, male	White British	Full-time, software developer	Cervical dystonia	Pre- and post-intervention Home and telephone
Zara (WADSS participant) **	Unknown, female	White Irish	Pub owner/pub chef	Head tremor and shakes/neck pains/dystonia (reported variously in the interview)	Pre-intervention Home
Eve (WADSS participant)	62+, female	White British	Retired, café waitress	Cervical dystonia	Pre-intervention Telephone
Edna (WADSS participant)	62+, female	White British	Retired, carer	Cervical dystonia	Pre- and post-intervention Home
Olivia (WADSS participant)	62+, female	White British	Full-time, carer	Participant had not been aware that she was diagnosed with dystonia prior to the conduct of the research	Pre- and post-intervention Home and telephone
Larry (WADSS participant)	62+, male	White British	Retired, car manager	Cervical dystonia	Pre- and post-intervention Home and telephone

*The data on occupation were obtained from the interviews.
**The demographics of these participants were obtained exclusively during a semi-structured interview.
SGm – Support group member;
SGr – Support group representative;
WADSS – The Warwick Dystonia Self-Management Study.

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22 May 2014

Ms Celia Janine Bernstein

Dear Ms Bernstein

Study title:	**Investigating the role of healthcare in the construction of patients' experience of physical disability: A case study of dystonia patients and healthcare practitioners** .
REC reference:	**14/LO/0305**
IRAS project ID:	**147697**

The Research Ethics Committee reviewed the above application at the meeting held on 03 March 2014.   Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager nrescommittee.london-riverside@nhs.net.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on question 2 of the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact ▋▋▋▋▋▋ ▋▋▋▋▋▋▋▋▋▋▋▋▋▋▋▋▋▋▋▋, the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

[CTIMPs only]
Clinical trial authorisation must be obtained from the Medicines and Healthcare products Regulatory Agency (MHRA).

The sponsor is asked to provide the Committee with a copy of the notice from the MHRA, either confirming clinical trial authorisation or giving grounds for non-acceptance, as soon as this is available.

[Clinical investigations of medical devices only]
Notice of no objection must be obtained from the Medicines and Healthcare products Regulatory Agency (MHRA).

The sponsor is asked to provide the Committee with a copy of the notice from the MHRA, either confirming no objection or giving grounds for objection, as soon as this is available.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Summary of discussion at the meeting

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Copies of advertisement materials for research participants	Poster for NHS Movement Disorder Clinics v.1	03 September 2013
Covering letter on headed paper	Covering Letter regarding new ethics form re-submission	03 February 2014
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		06 August 2013
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		26 July 2013
Interview schedules or topic guides for participants	Observation Schedule for Support Group Meetings with Members and Representatives v.1	03 September 2013
Interview schedules or topic guides for participants	Interview Schedule for Support Group Members v.1	03 September 2013
Interview schedules or topic guides for participants	Interview Schedule for Group Interview with Support Group Members and Representatives v.1	03 September 2013
Interview schedules or topic guides for participants	Observation Schedule for Consultation Meetings	30 January 2014

	with Patients and Health Professionals v.2	
Interview schedules or topic guides for participants	Interview Schedule for Health Professionals v.1	03 September 2013
Interview schedules or topic guides for participants	Interview Schedule for Support Group Representatives v.1	03 September 2013
Interview schedules or topic guides for participants	Interview Schedule for people living with dystonia v.1	03 September 2013
Letter from sponsor		30 January 2014
Letter from statistician	DELETE	
Letters of invitation to participant	Reminder Letters for Interviews with Health Professionals v.2	06 January 2014
Letters of invitation to participant	Reminder Letters for Observations with Support Group Members v.2	06 January 2014
Letters of invitation to participant	Reminder Letters for Consultation Observations with Health Professionals v.2	06 January 2014
Letters of invitation to participant	Reminder Letters for Observations with Support Group Representatives v.2	06 January 2014
Letters of invitation to participant	Reminder Letters for Interviews with people living with dystonia v.2	06 January 2014
Letters of invitation to participant	Reminder Letters for Interviews with Support	06 January 2014

		Group Members v.2	
Letters of invitation to participant	Reminder Letters for Consultation Observations with Patients v.2	06 January 2014	
Letters of invitation to participant	Reminder Letters for Interviews with Support Group Representatives v.2	06 January 2014	
Other [Unfavourable Ethical Opinion of Research Letter]		02 January 2014	
Other [ESRC Confirmation Letter]		06 September 2013	
Other [Covering letter]		25 March 2014	
Participant consent form [Consent Form for Home Interviews]	3	06 January 2014	
Participant consent form	3	06 January 2014	
Participant information sheet (PIS) [Participant information sheet for observations and group interview with dystonia support group members]	4.0	24 March 2014	
Participant information sheet (PIS) [Participant information sheet for observations during consultation meetings with healthcare professionals]	4.0	24 March 2014	
Participant information sheet (PIS) [Participant information sheet for observations and group interview with dystonia support group representatives]	4.0	24 March 2014	
Participant information sheet (PIS) [Participant information sheet for in-depth interviews with people living with dystonia]	4.0	24 March 2014	
Participant information sheet (PIS) [Participant information sheet for individual interviews with dystonia support group members]	4.0	24 March 2014	
Participant information sheet (PIS) [Participant information sheet for consultation observations with patients living with dystonia]	4.0	24 March 2014	
Participant information sheet (PIS) [Information Sheet for Observations with Support Group Members]	3	06 January 2014	
Participant information sheet (PIS) [Participant information sheet for interviews with healthcare professionals]	4.0	24 March 2014	
Participant information sheet (PIS) [Participant information sheet for individual interviews with dystonia support group representatives]	4.0	24 March 2014	
REC Application Form	2	07 February 2014	
Referee's report or other scientific critique report	Report from Upgrade Panel	13 June 2013	
Research protocol or project proposal	3	09 January 2014	
Summary CV for Chief Investigator (CI)	(Academic Supervisor - Prof Gillian Lewando Hundt)	30 January 2014	
Summary CV for Chief Investigator (CI)	(Academic Supervisor - Dr Felicity Boardman)	17 July 2013	
Summary CV for Chief Investigator (CI)	(Chief	30 January 2014	

	Investigator/ Student - Celia Bernstein)	

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

▆▆▆▆▆▆▆▆ declared an interest in knowing the Chief Investigator. The Committee agreed that the ▆▆▆▆▆ could remain in the room and take part in the discussions.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

<u>*Reporting requirements*</u>

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- *Notifying substantial amendments*
- *Adding new sites and investigators*
- *Notification of serious breaches of the protocol*
- *Progress and safety reports*
- *Notifying the end of the study*

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

<u>*Feedback*</u>

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

14/LO/0305	**Please quote this number on all correspondence**

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

Dr ▨▨▨▨▨▨▨
Chair

E-mail: nrescommittee.london-riverside@nhs.net

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

"After ethical review – guidance for researchers"

Copy to:

NRES Committee London - Riverside

Attendance at Committee meeting on 03 March 2014

Committee Members:

Name	Profession	Present	Notes
▓▓▓▓▓▓	Microbiologist	Yes	
▓▓▓▓▓▓	Pharmacist	Yes	
▓▓▓▓▓▓	Lawyer	Yes	
▓▓▓▓▓▓	Consultant Cardiologist	Yes	
▓▓▓▓▓▓	Former Civil Servant	Yes	
▓▓▓▓▓▓	Research Scientist	Yes	
▓▓▓▓▓▓	General Practitioner	Yes	
▓▓▓▓▓▓	Modern Matron	Yes	
▓▓▓▓▓▓	Retired	Yes	
▓▓▓▓▓▓	Lawyer	Yes	
▓▓▓▓▓▓	Advocacy and Mediation Consultant	Yes	
▓▓▓▓▓▓	Head Teacher	Yes	
▓▓▓▓▓▓	Consultant Neonatologist	No	
▓▓▓▓▓▓	Senior Producer	Yes	
▓▓▓▓▓▓	Clinical Psychologist	Yes	

Also in attendance:

Name	Position (or reason for attending)
▓▓▓▓▓▓	REC Manager

Chapter 3 documented the different ways in which social scientists have referred to people directly or indirectly experiencing an illness. For example, some scholars have used terms such as 'lay knowledge' (e.g. Prior 2003), 'experiential knowledges' (Faulkner 2017), and 'cultural expert knowledge' (Rubel et al 2017). However, I have predominately applied the neologism 'experiential knowledge' because it is the most well-known and recognised within the literature. Sometimes I have referred to participants' unique understandings as 'embodied knowledge' and/or 'empathetic knowledge' in order to demonstrate the diverse ways in which one comes to comprehend illness and approach decisions about healthcare provision.

While participants recruited from local dystonia support groups variously described themselves as a 'volunteer', 'chairperson', and/or 'patient', for clarity, I have referred to individuals leading the meetings as 'support group representatives' and individuals attending the groups and/or belonging to The Dystonia Society as 'support group members.' The term 'member' does not automatically imply that participants (regularly) attended the groups but rather, that they belonged to The Dystonia Society (and/or went along to meetings). In addition to this, the notion of 'support group attendees' has sometimes been applied to describe both representatives and members. Yet, where they referred to themselves as, for example, a patient, I have considered the significance of this term in my analysis. I have also defined those participants who were recruited from a hospital as 'NHS Hospital 1 patients' and those participants who came from another research project known as The Warwick Dystonia Self-Management Study (WADSS) as 'WADSS

participants.' In other words, I have referred to participants from the source of each of their interviews to avoid confusion.

Finally, following medical convention, I have referred to botulinum injection toxin therapy as 'BoNT.' However, I have used participants' abbreviated version, 'Botox', when presenting the data extracts to reflect what they said during the interviews.

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