

**Measuring Quality of Life in Dystonia:
An Ethnography of Contested Representations**

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Preface

Measures of quality of life (QOL)² have become more numerous and prestigious over the past decade as they receive funding from national health services, pharmaceuticals and the US health insurance industry, and support from clinicians, social scientists, and patient support organisations. This expansion is linked to increasing cost consciousness in medicine and the need for more sensitive measures to compare (and position) treatments for chronic illness.

The three key questions of this thesis are:

1. If the disabling impact of dystonia cannot be fully represented by clinical measures, can it be captured by a measure of QOL?
2. Do measures of QOL give a voice to people with chronic conditions (as has often been claimed)? If so, “why can’t these natives speak for themselves?”
3. If QOL measures cannot represent complex conditions like dystonia or give a voice to people living with dystonia, why are they still so successful?

The thesis falls into three sections: the first (chapters 2 and 3) explores how people live with dystonia, looking particularly at dystonia’s representation within medical and popular discourses and how this affects their experience of the condition.

The second section (chapters 4-6) looks at people’s encounters with medical and social bureaucracy and how this is mediated at the micro and macro levels by the Dystonia Society and umbrella organisations like the European Federation for Neurological Advocacy. I look at the difficulties the Society has in representing dystonia in a way that is both true to the experiences of people living with dystonia and politically effective I also explore how problems with representation and the Society’s relationships with doctors and pharmaceuticals influence their support of studies of QOL. The detailed ethnography of the Society is valuable, as small voluntary organisations have been little studied by anthropologists of organisations, even though they share many of the concerns of larger structures. I also explore the appeal that QOL has to the different stakeholders identified in this thesis and demonstrate how this network drives the development of QOL measures.

The third section (chapters 7-9) explores how QOL is defined and measured, and how QOL measures are used in the UK and internationally, linking these practices to the classification

²These are typically questionnaires containing <50 questions about different areas of life (e.g. physical function) which ask the respondent to indicate their performance/satisfaction in that area using a 5-point scale (from very bad to very good). These scores are totalled (and often weighted) to produce an overall QOL score.

and hierarchisation of “audit culture” [Power 1994]. I describe how the expression of “the patient perspective” through measures of QOL³ can silence the voices of people with a limiting condition, explore who has the right to value the lives of people with disabilities, and address the problems with creating universal systems of classification and valuation.

In the conclusion, I discuss whether QOL has actually benefited people living with dystonia by creating a discursive space for the discussion of health in non-clinical terms and a language to make claims for resources and the acknowledgement of their experiences.

Structure of the thesis

Abstract

Contents

Preface

Chapter 1: Introduction

Describes my personal engagement with QOL measurement and disability. Situates research in a theoretical context by reviewing literature on the anthropologies of disability, audit, medicine, the body, and science and technology. Introduces dystonia and my field sites and briefly describes healthcare provision in the UK (including the role of the National Institute of Clinical Evidence).

Section 1: Experiences of people living with dystonia

Chapter 2 Living with dystonia

Briefly reviews anthropological and sociological literature on living with a chronic illness, before focusing on the themes that characterise the experience of dystonia (understanding and representing changes in the body, obtaining a diagnosis and maintaining relations of trust with doctors, communicating dystonia to others, responding to dystonia, and external responses to dystonia).

Chapter 3 Stories from people living with dystonia

Explores the themes identified in chapter 2, using six stories to give a sense of how dystonia is integrated into people’s lives. Looks at how people use narrative to make sense of illness and give it personal meaning and explores methodological problems with using narrative.

³The expressed aim of the designers of a disease-specific measure of QOL, described in chapter 8.

Section 2: Encounters with bureaucracy

Chapter 4 Encounters with medicine: Derek's story

Examines individual encounters with medical bureaucracy through the story of Derek, an intelligent and articulate man with generalised dystonia. His story is contextualised by other interviews and accounts from people living with dystonia, and sociological and anthropological literature on “doctor-patient relations”.

Chapter 5 Professional or bureaucratic?: The dilemma of the Dystonia Society

Examines the Dystonia Society (the main patient support organisation for people living with dystonia), which is an influential actor in the networks explored in chapter 6. Describes its history, culture, and relationship with members, and looks at how it constructs “the voice of people living with dystonia” in fundraising and media campaigns.

Chapter 6 “Partnerships for progress”?

Explores the relationships between pharmaceutical companies, patient support organisations, doctors, and the government, and their mediation through QOL, using ethnography from national and international meetings of neurologists, neurological patient support organisations, and QOL researchers. Treats QOL (and its related discourse on “the patients’ voice”) as a “boundary object” around which diverse alliances can form and explores these further in the context of submissions to the National Institute of Clinical Excellence.

Section 3: Quality of life

Chapter 7 Defining and measuring QOL

Examines how the discipline of QOL research has expanded and professionalised, and constructs a “genealogy” of QOL to explore the links between its psychometric ancestry and the expansion of statistics and eugenics in the nineteenth century. Looks at the implications of definitions of QOL and assumptions underlying different measures. Explores how they are used in the health economic analyses that are increasingly guiding resource allocation in the UK and addresses the ethical and methodological problems of asking “healthy” people and health professionals to value the lives of people with disabilities.

Chapter 8 An ethnography of QOL measurement

Describes how measures of QOL are created and used, using ethnography from fieldwork on a multiple sclerosis-specific QOL measure and a European survey of the QOL of people living with dystonia.

Chapter 9 Realising the potential of QOL: The World Health Organisation

Uses the example of the WHO to demonstrate the double-edged nature of QOL by examining three projects: a multilingual, multidimensional QOL measure to be used internationally with “healthy” and sick populations; a universal classification of health (the International Classification of Functioning, Disability and Health); and the Global Burden of Disease Project, which uses health economic analyses to set international priorities for health spending using the Disability Adjusted Life Year.

Conclusion

Addresses key questions explored in the thesis, specifically how the rhetorics of QOL and the “voice of the patient” are used as resources in the struggles of doctors, patient support organisations, and pharmaceuticals; how QOL measures can represent “invisible” conditions like dystonia and make them visible and accountable; whether QOL measurement is an example of medicalisation and/or the extension of audit culture into health, and, finally, whether the voices of patients are currently being heard and what can be done to facilitate this.

Chapter 1: Introduction

In November 1996 I started work as a part-time researcher on an epidemiological study to establish the prevalence of dystonia in Europe, which was based at the Institute of Neurology⁴ in central London. My role was to collect data on the number of people with dystonia in London and co-ordinate data collection in the other eleven centres. The organiser was a consultant neurologist specialising in “movement disorders” and medical advisor for the Dystonia Society. They had supported his grant application because they realised the value of numbers in establishing dystonia as a threat to public health⁵ and hoped that the new figures would be closer to their estimates (which were considerably larger than previous studies).

This was the first time I had heard of dystonia. I was given leaflets on dystonia to prepare myself and saw videos of people with dystonic movements made by neurologists. However, it was only when I met people living with dystonia while preparing the first draft of the epidemiological study’s QOL questionnaire that I began to appreciate its impact. What intrigued me was that while the condition did not seem disabling (in some cases the movements were little more than a tic) its impact was extremely severe. There was often no correlation between my perception of the intensity of the movements and the person’s assessment of their impact. Although my observations could be described as objective because I was external to the situation and had no interest in a particular outcome, I wondered how useful they were when they bore little relationship to the perception of the person living with the condition. Neurologists also wanted to quickly assess their patients’ well-being, but if frequency and severity of movements were not a good guide, what was?

The discipline of health-related QOL measurement developed to answer this type of question. Researchers experienced in psychological techniques for quantifying abstract qualities like intelligence applied themselves to defining and measuring well-being, QOL, health-related QOL, and health status, as the concept has variously been described. These measures are now incorporated into trials of drugs and surgery and their scores are treated with as much respect as clinical outcome measures like blood pressure. Funding bodies like the Medical Research Council insist on the incorporation of QOL measures into grant proposals as they are thought to represent the patient’s perspective. But can these measures do what they promise, namely

⁴A research institute attached to the National Hospital of Neurology and Neurosurgery.

⁵The role of statistics in creating “social problems” with social causes is described by Rose [1987].

to simply and accurately represent a person's QOL in a manner that enables comparison across conditions?

When I first encountered these measures, they seemed to bridge the gap between emic and etic perceptions of the severity of an illness. Although I frequently discovered examples of ambiguous or incomplete measures of QOL, I attributed this to "bad science". If measures that could be used with everyone were unsuccessful in capturing experiences of illness, the answer was obviously greater specificity. The exponential expansion of measures of QOL suggested that others agreed with me. In 1999 I participated in a proposal to develop a QOL measure specific to dystonia (proposed name "Dys-QoL"). Ironically, this wasn't funded because it wasn't considered to be specific enough. We had decided to cover focal dystonia, which includes dystonia of the eyes, limbs, hand, neck, jaw, and larynx. The referees of the grant felt that we should focus on cervical dystonia (the most common focal dystonia) even though this would make the measure applicable to less than 0.001% of the UK population. The change was made and on reapplication a year later, the measure was funded.

During the intervening year I was involved in two QOL projects: the development and administration of a postal questionnaire containing a "battery" of QOL measures to investigate QOL in dystonia, and the creation of a multiple sclerosis-specific QOL measure, both described in chapter 8. I also attended the International Society of QOL Research conference and became more involved with the Dystonia Society. Meeting people living with dystonia and hearing their stories made me doubt that their complex experiences could be represented and understood through these measures, even if they (or the Society) were consulted during the design process.

My thesis arose from this problematic – how can the experiences of people living with dystonia be represented, and more importantly, why do researchers and clinicians try to do so? In sections 1 and 2 I explore experiences of living with dystonia and individual and group encounters with medical and social bureaucracy, and in section 3, I examine the political economy of QOL measurement in dystonia. I bring the three sections together in the conclusion where I argue that even though the phrase "quality of life" promises an empowering and holistic vision of health, there are two main reasons why QOL measurement cannot fulfil this promise. Firstly, it is primarily a tool for audit, and secondly, measures reproduce the assumptions of existing measures or clinical models and exclude the elements that people consider most important in maintaining quality of life. Paradoxically, the

discourse can reduce people's QOL when it is used to justify rationing in the UK and redirection of resources internationally.

My two main fieldwork sites were the Society's central office in London and the coordinating centre for the questionnaire on QOL in dystonia. At the Society I worked predominantly with the Development Officer⁶, but also visited members and spoke to distressed callers. The projects I was involved in included drafting and analysing the membership survey (funded by a pharmaceutical company), coordinating the annual awareness week, writing leaflets for GPs and people living with dystonia, liaising with the 30 branches, and organising "living with dystonia" days. I was also a participant observer at Society events (local and nationally), analysed illness stories from a range of sources (the Society's Newsletter, collections of "patients' experiences", and dystonia-related "bulletin boards"), and carried out in-depth semi-structured interviews with people living with dystonia. I became involved with the European Dystonia Federation through the QOL questionnaire and attended national and international medical meetings on their behalf. I also presented a poster to neurologists at the Movement Disorders 2000 conference, which summarised the initial results from the questionnaire.

Doing "anthropology at home" involved melding personal and professional roles⁷ (a "messy, qualitative experience", according to Marcus and Fischer [1986:22]) and maintaining an "incoherent" persona of partial and shifting identities [Caputo in Amit et al 2000]. In this respect I resembled my subjects who were neurologists in one context and QOL experts in another, or simultaneously trustees, Chairs of European advocacy organisations, and dissatisfied patients. I could not sustain the illusion that my field was "out there" as I was aware I was constructing it through my research interests and personal relationships⁸, while experiencing moments of bizarre synchronicity⁹ (for example, hearing both a WHO neurologist and a Society branch organiser talk about "marketing" dystonia).

I found it difficult both to disconnect from my life to do fieldwork and maintain firm boundaries after my return, sharing the experience of Amit that subjects (and their computer problems) are "as likely to leave us when we don't want them to or follow us when we think

⁶Responsible for raising awareness through publications and the media, and communicating with the branches.

⁷c.f. Dyck's ethnography of children's sport which used his past involvement as a parent [in Amit et al 2000].

⁸c.f. Amit's role in the construction of the social group 'Cayman migrant workers' that she was studying [ibid].

⁹This also happened to Martin who, pursuing relationships between popular concepts of health and the "ideal worker", "practically fainted with astonishment when I discovered that [corporate] trainers elect to use the image of the immune system to convey the kind of flexible innovative change they desire" [1994:214].

we have left for good” [in Amit et al 2000]. My position at the Society was important as it gave me somewhere to “hang-out” (always a problem when the processes you are studying produce common social statuses rather than “coterminous collectivities” [Amit in Amit et al 2000:15]) and stopped me from “mystifying the commonplace” [Strathern 1987:17] as my colleagues were all too ready to provide a reality-check. Despite this base, however, my field was characterised by “absences” which required me to use a mix of methods to construct my ethnography, for example, reconstructing sequences of events using “grey literature” (like e-mails and minutes). I also drew on notes made before I was officially in the field, which made my research feel a little like “espionage” [Young 1991].

When I began looking at chronic illness and disability¹⁰, my history of good health was a significant disadvantage. My last visit to hospital was when I was hit on the head by a lacrosse ball, and I had escaped the usual childhood illnesses. However, my status as “temporarily able bodied” was brought home to me when midway through my fieldwork I was run over by a truck while cycling to work. Although I didn’t know it at the time, the truck broke most of the bones in my lower body (my hip, femur, pelvis, and ankle) and knocked a chunk out of the base of my spine, fortunately missing the nerves that control movement. I also had extensive scarring to my right leg after I was dragged for a few yards by the truck¹¹.

When I came round after nine days in intensive care I was very weak and found my lack of strength alarming. It took two nurses to roll me gently on to my side to change my bedding. My partner had to spoon-feed me as I couldn’t sit up while my pelvis was healing. I found it difficult to concentrate so the long hours in bed were frustrating and I felt dependent on my daily visitors to bring some interest into my life. While one leg felt stiff and numb, the other was exquisitely painfully and I dreaded being touched. Would my body respond appropriately? I was no longer confident that I knew what it would do.

Having gone through one rite of passage (getting married) a few days before the accident, I felt I had reverted to an infantile state. Although I didn’t talk about my fears, whether I could still be a “real woman” occupied my dreams. Suddenly my body didn’t feel like my body anymore. If it didn’t look like my body and didn’t respond to my commands, in what sense

¹⁰In this thesis I use impairment to refer to loss of function, and disability to activity limitations related to the impairment or society’s reaction to it. My definition of disability also incorporates any disadvantage arising from the activity limitations (what the WHO defines as “handicap”).

¹¹That I can describe the experience in this way shows the influence of the objectifying discourses of medicine!

was it still mine? I had a sense that I'd been absent from my life while I was in intensive care, like waking up after a particularly good party and having to ask your friends what you said and did, and how you got those marks on your hands. I now had an insight into what the onset of a disabling illness might feel like, and how it could affect your belief in a stable and knowable reality¹².

Fortunately I was very fit before the accident and made a speedy recovery. My problems started when I left hospital to stay with my parents in Cardiff. Outside the hospital it wasn't normal to be in a wheelchair or unable to use an upstairs loo. At least on the ward everyone was facing the same problems and were grimly humorous about them. At home I felt very isolated. Even speaking to friends was difficult as it reminded me of how much I missed my home in London and the life I'd had before the accident. Now all I did was read novels and watch day-time TV which didn't give me a lot to talk about. I tried to feel proud of my recovery and not feel guilty about the burden I was putting on my family and ashamed of how little I could do to ease it. I even felt guilty about insisting on cycling in London and not taking a honeymoon as these had "caused" the accident.

When the consultant told me my hip had healed and I could make plans to come back to London and return to work, I felt as though my life had started again. Now I could make a contribution to society, socially and financially, now I could feel tired in the evening because I had actually done something, and now I could enjoy the pleasures that you only allow yourself after a "hard day at work". Of course, here my story diverges from the pattern because many people with chronic illnesses and late-onset disabilities never return to work. Some find this satisfactory, even in our work obsessed society, but I suspect many feel disenfranchised, as though they no longer have a right to the things healthy people take for granted. National Health Service clerks are probably equally rude to the employed, and doctors as careless of your time, but it's hard not to interpret these experiences as a response to your inner worthlessness. Being labelled as a chronic rather than acute "case" impacts on self-esteem and access to resources, as I discovered when my physiotherapy was discontinued after x-rays revealed that part of my leg muscle had turned to bone. My range of movement was the same (i.e. limited), but I had now become one of "the chronics" that the physiotherapists had confided to me they found so unsatisfying to treat.

¹²While I don't pretend that I shared the experiences of my informants, my sensory knowledge was a shared resource for comprehension [Okeley 1992] and helped me develop a sense of "ethnographic relevance" [Scheper-Hughes 1988; Wikan 1990].

The division between chronic and acute medicine maps onto existing medical hierarchies, for example, general practice (which manages the majority of chronic illnesses) is less prestigious than surgery. Neurology is anomalous as its association with the brain makes it one of the most prestigious specialties (recommended to intellectual and research-oriented medical students) but the practice of neurology involves routine management of chronic illnesses, which requires a very different set of skills. Consequently, many people living with dystonia have poor relationships with their neurologists, something I explore in chapter 4.

In the next section I look at how disability is defined by people with disabilities as this relates to the debate among people living with dystonia about whether it is a chronic illness or a disability. The separation between writers on chronic illness and disability has been one of the most interesting aspects of reviewing the literature for this thesis, as this divide can seem artificial and counter productive, particularly for a condition like dystonia, which lacks clear boundaries.

Defining disability

Recent disability research has been dominated by the “social” model, which argues “disability has nothing to do with the body and everything to do with society” [Oliver 1996]. This is encapsulated by the definition of the Union of the Physically Impaired Against Segregation [1976], which distinguishes impairment (functional limitation) and disability (loss of opportunity to participate in normal life on an equal basis due to physical and social barriers), and regards the latter as something “imposed on the top” of the former by prejudice against people with disabilities. The Union goes to the opposite extreme to the medical model by downplaying the importance of “natural” or physically grounded aspects of disablement to avoid these being used to justify inequality¹³. This makes disability indistinguishable from the social constructs of gender or class and obscures the relationship between impairments and disabilities¹⁴. Health professionals have compared this model unfavourably with the International Classification of Impairment, Disability and Handicap, arguing that the fusion of disability and handicap makes it difficult to show how an aspect of the environment constitutes a barrier, or suggests a person-level intervention. However, this misses the point of the model, which is a tool for social action rather than research or management.

¹³The medical sociologist Bury calls it the “oversocialised model” [1996].

¹⁴For example, under this model it is impossible to examine impairments that do not cause limitation, or are disproportionately limiting.

Contemporary disability theorists maintain a fine balance between insisting, “impairment is not ‘natural’ but a historically changing category”, and recognising its materiality [Abberley 1996, p.61]. To describe impairments as biological phenomena risks suggesting that inequality is biologically inevitable, but viewing impairments as just another form of oppression could collapse the politically important distinction between disability and impairment. This is an example of the “dilemma of difference” [Goffman 1963] where demands to end inequality require the identification of people who have been disadvantaged by drawing attention to their difference. However, if difference is downplayed to support the claim of equality, then people’s different needs may be ignored. In the next section, I briefly describe the “minority group” and “universalist” approaches as the latter influenced the latest version of the WHO’s International Classification tool (discussed in chapter 9).

Disability activists use two main political strategies, which have been characterised as the “minority group” and “universalist” approaches [Bickenbach et al 1999]. The former arose from the civil rights movement in North America and uses “identity politics” to develop pride in “group identification”. The main product of this is the Americans with Disabilities Act 1991, which borrows from the Civil Rights Act to justify its anti-discrimination measures. However, this approach is based on an unsustainable analogy between racial minorities and disabled people, for example, there is no unifying culture, language, or set of experiences for people with disabilities (even between the movement’s leaders¹⁵ and their members) and many of the inequalities experienced by people with disabilities result from maldistribution of power and resources rather than discrimination¹⁶.

The universalist approach to disability was pioneered by Zola (an American sociologist with physical disabilities) who described the “special needs” approach as short-termist¹⁷ because everyone is at risk of chronic illness and disability and suggested that people with disabilities form alliances with the elderly [1989]. He maintained that “[b]y seeing people with a disability as ‘different’ with ‘special’ needs, wants, and rights in this currently perceived world of finite resources, they are pitted against the needs, wants, and rights of the rest of the population” [ibid]. This perspective is echoed by Finkelstein (a disability researcher and activist with physical disabilities) who notes that mobility aids for “people with abilities” (for example, shoes) are seen as “attractive personal possessions or desirable environmental

¹⁵With the exception of organisations of deaf and blind people, the leaders tend to be highly educated, white middleclass males with late onset disabilities and minimal medical needs (as in the Dystonia Society).

¹⁶For example, “economies of scale” mean that people with common impairments like myopia receive better provision than those with greater needs.

¹⁷It also risks reinforcing the medical conception of disability by representing it as dichotomous and fixed.

adaptations” [1999]. None are defined as “assistive devices”, described as meeting special needs, or prescribed by health professionals. A universal disability policy should expand the range of human normality to include the variations caused by disability, in the same way that “universal design” aims to produce environments and tools that can be used by everyone. Although this is the aim of the broad definitions used by the WHO International Classification tool, they seem to have the opposite effect of medicalising even larger areas of human life. This is not surprising since it was drafted by health and social care professionals who would presumably be unlikely to define themselves out of a job.

In the following section I contrast the writings of disability activists and researchers with the anthropology of disability, and also link the experiences of people living with dystonia to relevant literature within general anthropology, and the anthropologies of audit, science and technology, medicine, and the body/embodiment. The foregrounding of audit and “governmentality” is intentional as the thesis aims to combine this literature with medical anthropology to enable a fuller analysis of people’s experiences as they engage with bureaucracy (and bureaucratic classification) in an attempt to make their experiences “count”.

Anthropology of disability

The experience of impairment is rooted in a person’s sense of having multiple past, present and intended future selves. Having a disability can limit possibilities for self-realisation in the future, and is particularly difficult in countries like the UK and USA which regard disablement as “a punishment for a crime” and praise independence, control, and an upright stature [Murphy 1987]. For example, the contemporary emphasis on appearance, productivity, and bodily control and containment increases the disability experienced by people living with dystonia who often feel they have to counter prejudice by demonstrating their moral worth.

Some disability researchers emphasise the emancipatory potential of disability and illness when bodies “escape their former social shackles” [Turner 1992] and people are “left alone with their bodies” to reflect upon them [Shilling 1997]. But developing a new body in response to disability can be discouraged by the discourse of rehabilitation which invites people to deny the reality of their bodies and manage them to be “socially acceptable”¹⁸ [Oliver 1990; Albrecht 1992], for example, by not using a wheelchair [Zola 1982]. People with late-onset disabilities often choose maintaining “social connectedness and biographical

¹⁸“I think I was in denial [...] and wanted to conform and be normal” [Geoffrey: The Society Newsletter].

continuity” over remaking themselves [Savage 1998] and may present themselves more conservatively to “compensate” for their disability¹⁹. They are aware that, “within a culture that places a high value on power, control, productivity and mobility, disability is a failure to meet social standards” [Duval 1984].

Anthropologists have examined the practice of medicine, including the subordination of patients to the “voice of medicine” in consultations [Mishler 1981], the collective construction of medical records [Berg 1996], and the transmission of medical culture through medical education [Sinclair 1997] (I review this literature in chapter 4). But there are relatively few anthropological accounts of illness experience or disability. Notable exceptions include Ingstad and Whyte [1995] (edited collection of studies of disability internationally) and Frank [2000] (life of a North American woman born without limbs). This is partly due to the difficulty of participant observation, although the North American anthropologists Murphy (physical disabilities) [1987] and Greenhalgh (fibromyalgia) [2001] are exceptions. Anthropologists researching disability have been criticised for focusing on specific impairments, working within the biomedical model, concentrating on acquired impairments, and conflating disability and illness [Davis and Corker 2001]²⁰.

Nonetheless, general anthropology has much to offer disability researchers investigating the fluid interdependency of cultural, structural and individual issues in the lives of people with disabilities²¹. For example, Davis, a disability researcher who works with children with disabilities, attributes his anti-hegemonic approach to Clifford and Marcus [1990]. Anthropologists participated in extensive debate during the 1980s and 90s about doing and writing-up research and were encouraged to consider how their academic and personal lives affected the power relations of the research process [Callaway and Okeley 1992; Campbell 1995]. The subsequent attempt to create a paradigm that incorporates reflexivity²², sensitivity to power, and a commitment to participation provides a point of connection with disability research.

Ethnographers can make an important contribution to disability studies by breaking down the ‘them and us’ characterisation of oppressors and oppressed. [...] By

¹⁹“I make a point of appearing well groomed, particularly when I am speaking from a platform. This way I feel that people see me first and my dystonia second” [Petra: The Society newsletter].

²⁰Their review only identified one major anthropological collection [Ingstad and Whyte 1995], which they criticised for homogenising cultures, creating a construct of “Euro-American Disability” that ignored the “social model” of disability, and representing the experiences of people with disabilities as fixed and static.

²¹The stories in chapter 3 give a sense of this interdependency.

²²For example, acknowledging how one’s “personal thought line” develops [Fernandez 1995] and the interpretive consequences of one’s “standpoint” [Haraway 1988].

unpacking homogenised views of culture and recognising the fluid nature of identity, ethnographers can help to stimulate dialogue and mutual recognition between disabled people

[Davis 2000:203]

While few anthropological texts engage with disability directly, many deal with it allegorically by examining the relationship between disabling processes and local, national, and global issues. For example, Campbell explores the way different people in the Amazon respond to disabling political and economic forces [1995]. Anthropologists have also problematised the concept of identity in marginalized groups²³, which contributes to debates within disability studies on self-identification versus labelling and the complexity and fluidity of disabled identities. For example, some people living with dystonia describe themselves as disabled in particular situations²⁴ but are reluctant to be labelled as such, partly because of prejudice, partly because they are reluctant to abandon the possibility of a cure. Anthropological work on identity can help disability researchers take a “relational” view of disability that focuses on interaction between the individual and their social location, rather than their medical category [Bury 1996].

An anthropological approach also encourages attention to the way language shapes thought and action. For example, how the reality of living with a chronic illness or disability is obscured by euphemisms that “linguistically are brought in to replace the bed linen when a particular word feels too raw, too near a disturbing experience” [Mittler and Sinason 1996]²⁵, or the way the language of policy works to silence some groups and conceal the workings of power [Shore and Wright 1997]. Disability in particular can become “a metaphor for something else rather than a mundane part of life” [Hevey 1992].

When we make [disabled] people ‘Other’, we group them together as the objects of our experience instead of regarding them as subjects of experience with whom we might identify, and we see them primarily as symbolic of something else – usually, but not always, something we reject and fear and project onto them

[Wendell 1996:60]

People with disabilities are “socialised into the world of the ‘normal’ with all its values, prejudices and vocabulary” [Zola 1982], which makes expressing a positive identity difficult.

²³ Okeley on gypsies [1997]; James [1993] on children.

²⁴ c.f. Parents describing their “dwarf” child as handicapped to access resources [Ablon 1990].

²⁵ Sinason “disdainfully” changed the name of an “educationally subnormal” workshop to “mental handicap” only for this to be changed to “learning disability”, each change reflecting the process of euphemism rather than a change in underlying assumptions. She observes that no other human group has been asked to change its name so frequently (“the sick and the poor are always with us, in physical presence and verbal terms, but not the handicapped”) and suspects that the constant change of terms expresses a “manic desire to erase difference”.

Stating that you are more than a person with disabilities may come across as denial²⁶, but once someone has been labelled “sick”, all their activity and beliefs are related to and explained in terms of their condition [Zola 1993]. “States” such as weakness and dependency (traditionally linked with illness) become “traits” and the person is equated with their condition. Longmore describes this as a “spoiling process” where the condition comes to “obscure all other characteristics behind that one and swallow up the social identity of the individual within that restrictive category” [1985]. This “spread” was the target of “I am not dystonia”, a song accompanying a Dystonia Medical Research Foundation video.

Positive descriptions of people with disabilities can be unrealistic or sanitised or imply that the failure to integrate is an individual one²⁷. The stereotype of the “supercrip” (for example, the disabled mountaineer in a recent Schweppes advert) is equally damaging because it defines disabled people in the terms of the able-bodied and excuses discrimination; “if disabled people are viewed as ‘normal’ then there is little need of a society free from disablism” [Barnes 1992]. While it may reduce the “otherness” of some people with disabilities, it increases that of the majority by creating an impossible ideal.

Language realises its potential through metaphors, which are an essential part of “knowing about knowing”. For example, “open” and “closed” metaphors define the parameters of discussion [Latour and Woolgar 1979]. Metaphors enable communication by providing “new cultural forms” [Strathern 1992] and act as “conventionalising agents” by describing the unfamiliar in terms of the familiar [Fiske 1987]. They also obscure their own origin and can operate as “the ‘sonar’ of our minds, revealing deeply submerged but none-the-less fundamental realities that we cannot or will not consciously acknowledge”²⁸ [Hibbitts 1994].

The very specificity, familiarity and tangibility that may recommend a metaphor may incidentally enable it to obscure and distort. Calling chess a battle distracts from the cooperative aspects of the game

[ibid]

Consequently, metaphors merit careful study and this is an area where anthropology has much to contribute (for example, Shore’s study of the way metaphors are used to promote different visions of the future of the European Union [2000]). We need to ask not only “whose interests are served by metaphors”, but to what extent they work as “instruments of

²⁶Encouraged by a society where “I never think of you as handicapped” is “the supreme compliment” [ibid].

²⁷Auslander and Gold describe an article about a woman with cerebral palsy who wanted to end her life which omitted that her motivation was her inability to access support to live independently [1999].

²⁸For example, Elkind studies the suppressed contradictions of the NHS using contrasting metaphors of religion, machine, organism and marketplace [1998].

power” and “give authority to particular concepts [...] while implying silence and closure on others” [Shore 1997].

Although metaphors operate by “subjectification” [ibid] and shaping the “meta-discourse” (or “the argument about what the argument is about” [De Waal 1994]), we can disempower them by “waking up sleeping metaphors” [Martin 1987] and exposing their “covert categories” [Shore 1997]²⁹. For example, Haraway argues that the “metaphorical structures” of science determine what counts as an interesting question and an intelligent answer, something that is also true of QOL measurement. She demonstrated this by examining the relationship between primatology and theories of gender where primatologists anthropomorphised their objects of study, then used their findings to support conservative theories of human behaviour³⁰ [1989]. Her study of the organising metaphors of biology in the 1940s and 50s situated them in the widest possible context, linking them not only to developments in operational research and laboratory management, but also to the economic and cultural language of the self [1981-2].

Strathern similarly suggests that the “social and natural facts” studied by kinship theorists are “cultural facts” of recent origin³¹ [1992]. The disputes over kinship caused by “new reproductive technologies” highlight the contingency of these “certainties” and demonstrate that conceptual shifts affect social practice. This is also true of QOL where the development of measures have changed peoples’ ideas about what it consists of and transformed it from a personal evaluation to a property that can be measured and compared. I return to the anthropology of science later in this chapter when I explore the role of social context and alliances in determining which technologies are successful.

Anthropology of Audit

QOL measurement, in the form of Quality and Disability Adjusted Life Years, is fundamentally a tool for audit, a practice that has become increasingly common since the 1980s in response to political demands for accountability and control [Power 1994, 1997; Strathern 2000]. Audit fits Habermas’s definition of a science, as its goal is to expand the

²⁹For example, Martin explores how menstruation and menopause are presented as pathological in North American biomedicine but could be reclaimed through redescription [1989], Sontag describes how certain illnesses are used as metaphors for unrelated fears and fantasies [1988], and Frankenberg suggests that the emergence of AIDS as a new disease metaphor “reflects the feeling of the ruling class and associated elites that they have lost the power of rationally controlling both policy and economy” [1986:612].

³⁰This also applies to molecular biology where gendered metaphors and narratives of “male birthing” and “second birthing” are used as strategies of legitimation [Keller 1990].

³¹For example, distinguishing between relatives by nature and by law post-dates Darwin who was the first to use “genealogy” to describe life as organised through natural selection. When genealogy was “naturalised” his “loan” was “read back”, creating the “natural” family. The “biological” parent then became the “real” one, contrary to Victorian conceptions of parenthood as “moral guardianship” rather than “physical connection”.

human capacity to predict and control the world [1970]. It does this by creating common measures of value, like QOL scores, which act as synecdoches. According to Marx, common measures of value require everything to be thrown into “the great social retort” which boils out particular flavours and leaves only abstract qualities; a process that Martin observed with the gene:

The ability for the gene to stand in for the whole of the organism, to instantiate pure information, gives it a function much like other measures of value in highly rationalised capitalistic societies [...] this standard of value, it appears can be abstracted from its contingent and accidental form (persons) without loss of anything significant

[2000:187]

The idea of audit is difficult to criticise as it promotes valued concepts like responsibility and transparency and brings together economic efficiency and good practice. However, audit (in the form of WHO Global Burden of Disease tables) can be part of the machinery of “bureaucratic indifference”, which enables organisations to evade responsibility³² [Herzfeld 1992]. Strathern notes that in higher education (as in medicine) audits and league tables proliferate alongside of the language of ethics and QOL [2000].

Audit indicators, like the Disability Adjusted Life Year, are examples of “managerial rationality”, which centres on the belief that institutional behaviour can be changed if the right information is combined with the right reinforcement:

The assumption is that if those in charge know what’s going on, they can manage a social system better. ‘To know’ in this context means having information on the variation of certain indicators that are thought to capture the essence of the phenomenon at hand

[Tsoukas 1997:831]

The key assumption is that the indicators “capture the essence of the phenomenon” being measured³³, however, I argue that Disability Adjusted Life Years do not capture the burden of disability for either the individual or society. Although policy and audit appear to be opposite ends of a process, this distance is illusory as policy makers build auditing within their schema, while auditing provides policy with a basis for its claims of effectiveness. This exposes the fallacy of the designers of the Disability Adjusted Life Year’s belief that it could be an impartial resource for health decision makers as policy and audit are already embedded within the measure.

³²Bureaucratic indifference occurs when the bureaucracy mobilizes values or practices beyond the competence of any individual bureaucrat, prompting them to adopt a stance of indifference.

³³So unexpected variations are attributed to individual rather than systemic failure.

Audit is an example of “the view from nowhere” [Haraway 1997] as, like a ritual, it tries to persuade participants of the way the world is without acknowledging its particular perspective [Strathern 2000]. Harper uses the metaphor of ritual to describe the final meeting of an audit conducted by the International Monetary Fund [2000]. When the Fund’s figures were accepted by the audited country, they underwent a “moral transformation” from “mere numbers” to “resources for policy”.

Audit practices like QOL measurement cause individuals and organizations not only to see themselves through the eyes of the auditor, but to describe themselves and their activities in ways that alter their self-perception (making themselves “auditable”). The transformation of the progressive and socially democratic Open University during the late 1980s and early 90s is a good example of this phenomenon. Stuart Hall claims that while they “believe what they have always believed, what they do, how they write their mission statements, how they do appraisal forms [...] that’s what they are interested in now”, resulting in the transformation of the institution [Hall 1993 in Strathern 2000].

Kleinman and Kleinman have also observed this in medicine where patients are using the “language of efficiency and cost” (rather than the “language of caring”) to describe their problems, transforming illness from a “consequential moral experience into a merely technical inexpediency” [1996:15]. Statistics also operate as a strategy of “information and control” by “determining classifications within which people must think of themselves³⁴ and of the actions that are open to them” [Hacking 1986]. Through enumeration and classification, “memorable man” becomes “calculable man”, making him/her easier to “improve” and control [Armstrong 1983].

QOL measurement constitutes the individual as a set of norms and invites them to produce truths about themselves using techniques of self-surveillance and confession that complement the “clinical gaze” [Foucault 1994]. Shildrick and Price use Foucault to analyse applying for Disability Living Allowance where the move to self-certification requires the subject “[to] police her own body and report in intricate detail its failure to meet standards of normalcy; that she should render herself, in effect, transparent” [1996:49]. The subject therefore becomes responsible for obtaining the allowance as the reason for withholding it will be attributed to a failure of reporting rather than a denying external agency. The form focuses on

³⁴For example, Hacking argues that the reports of nineteenth century factory inspectors structured the class system by creating categories in which people came to recognize themselves.

individual behaviour and ignores social and environmental factors. It obliges people to place themselves within its definition of disability, turn a critical gaze on their bodies, and effectively produce themselves as disabled subjects: “it is in the very gestures of differentiation and individuation, as exemplified by the numerous subdivisions of the questions posed on the DLA form, that the claimant is inserted into patterns of normalization which grossly restrict individuality” [ibid:51].

Foucault and Bourdieu

The ideas of Foucault and Bourdieu were particularly useful in exploring key themes of this thesis, for example, how the voice of the patient is constructed and the effect of QOL measurement on the self. The two theorists work well together since Foucault’s emphasis on contextualisation highlights the way Bourdieu’s use of terms like “capital” and “linguistic market” form part of the prevailing economic rationality critiqued by later Foucauldians. Bourdieu’s concept of “symbolic violence” illuminates how, because the language of QOL has become a dominant speech practice in the field of health/medicine, subjugated groups need to use this language in order to be heard [1991]. Their strategy is not wholly successful, however, as “authority comes to language from outside” so the capital of the speaker in other “fields” (for example, educational, economic) determines whether/how they will be heard³⁵. QOL has become a tool in a continual struggle to push back the limits of “doxa” (the area of thought “beyond question”) and return to a state of “heterodoxy” which gives the experiences of people with limiting conditions “the right to be spoken publicly”. Bourdieu also recognises that classification is a “question of force” as it determines and supports relations of domination; for example, the WHO classifications of disability perpetuate the idea that disability (and people with disabilities) are a burden, which justifies not addressing the inequalities they experience.

The two concepts from Bourdieu I found most useful were “field” and “habitus”³⁶ as the former illuminates the networks explored in chapter 6, and the latter contributes to Foucauldian understandings of how discourses shift. Medicine in Britain can be seen as a “field of struggle” because doctors are attempting to maintain their definition of the field and defend/improve their position by drawing on different forms of “capital” (for example,

³⁵Bourdieu calls this the “law of price formation”.

³⁶Habitus was originally a phenomenological construct (experience and action are structured by sediments of previous experiences and actions and leave sediments that structure future experiences and actions) but was enlarged by Bourdieu to include the conditions that shape the agent’s and the social distribution of perceptual and linguistic schemes [1984]. It is therefore both a “structuring structure” and a “structured structure”, but the concept should not be used deterministically as under certain conditions an “oppositional habitus” (a “disposition of resistance and change”) can emerge.

educational and moral). Different symbols, concepts, and social strategies are used according to their perceived instrumental value, for example: “the appeal of evidence based medicine for the profession - and the administrative elite - is that it demonstrates unequivocally the commitment to high standards of care thereby justifying professional autonomy” [Armstrong 2002].

The medical field is also affected by the socio-economic context (or “field of power”), for example: the challenge to medical authority from new right ideology, new social movements, patient support organisations, and professional advocates, who all claim to speak with the voice of the patient; the long-term implications of demographic change and the growth of chronic illnesses; the increasing power and competitiveness of the pharmaceutical industry; and cost-cutting in the health services. These struggles may enable an inversion of values, which creates an opportunity for patients to speak and be heard. For example, if the doxa of medical paternalism is being contested by NHS managers, then patients can contest it on different grounds. The individual anger of people living with dystonia about their experiences with doctors may also be “shaped and focused by collective schemas of critique” into an “oppositional habitus” [Crossley and Crossley 2001:1485].

Crossley and Crossley also examine the construction of the “voice of the patient” by comparing two anthologies of people with mental health problems (published 40 years apart) that “illustrat[ed] the historically and socially constructed nature of voice” [ibid:1478]. For example, credibility in the first anthology came from formal qualifications and professional status, and in the second from personal experience and active membership of mental health groups. The constraint on what could be expressed in the first anthology was not just one of context but “an anticipation of context and the various assumptions and prejudgements which structure that anticipation [...] Agents have a pre-reflective sense or feel for what is acceptable to say and this structures what they will say” [ibid:1480]. Also, the therapeutic narrative underlying contributions to the second anthology had only recently developed, for example, “no contributor to the [first anthology] could have discovered a ‘hole’ in their ‘aura’ because to do so presupposes specific schemas of perception, imagination and speech which simply were not available at the time. The ‘child within’ is not a lost soul waiting to be found but rather the function of a specific manner of constructing distress” [ibid:1486]. Similarly, QOL is not a natural property like height or weight that merely awaits measurement, as one might imagine from using QOL measures.

Crossley's analysis is supported by Armstrong's comparison of texts on medical history-taking from the 1930s and 70s which demonstrate that the changes were "not simply the form of the incitement to speech but the very structure of perception; it was not what the patient said but what the doctor heard which established the reality (and accuracy) of the patient's view" [1984:737]. Interestingly, the requirement for an extended case history in medicine was paralleled by the growth in medical sociology and, later, QOL measurement, which used psychometric techniques to provide information about a condition without the unreliable filter of the patient.

Foucault analysed knowledge in so far as it furthered power relationships³⁷, arguing that science was not about "facts" but authority and legitimation through the process of "claims making". I found this approach useful as it directed my attention to how claims about QOL are made and the role of the "power-knowledge complex"³⁸; and led me to link my analyses to the growth of "surveillance medicine" (which extends the type, location and personnel of possible medical interventions) [Armstrong 1995].

QOL measurement is one of the "intellectual technologies" described by Rose that make aspects of life amenable to inscription, calculation, and ultimately regulation [Miller and Rose 1990]. Inscription enables "the pertinent features of the domain [...] to literally be represented in the place where decisions are to be made about them" [ibid:7], for example, medical records enable doctors to travel through their patient's body from behind their desks [Berg 1996]. Like the statistics collected by the early Victorians (see chapter 7), this information is "not the outcome of a neutral recording function" but "a way of acting upon the real" [Miller and Rose 1990:7]. Latour characterises this process as "action at a distance" [1987:219], using the example of 18th century French navigators who could only colonise the East Pacific because it was "mobilised" through maps, drawings, tide-tables, etc. which could be brought home to "centres of calculation". These "mobile traces" were stable enough to be moved back and forth without distortion so could be accumulated, combined, and calculated upon. Domination was thus enabled by the "intellectual mastery" of those at the centre who manipulated information about persons and events distant from them (a contemporary example of this is the WHO's Global Burden of Disease project).

³⁷For example, epidemiology was interesting because it extended the "clinical gaze" into the community [1976].

³⁸These are linked but separate; power is non-stratified, local, unstable and flexible, but knowledge is stratified, stable and segmented, so power needs to avoid the forms of knowledge to operate [Foucault 1982].

Another example of how statistics and a common language enable “problems” to be defined and acted upon is the government of the UK economy in the 1960s and 70s [Miller and Rose 1990]. The first step was harmonising different actors’ definitions of growth, a problem common to QOL where everyone agrees that it is “a good thing” but has different ideas about what it is, how to measure it, and how to achieve it. Next, calculation techniques were recommended to nationalised and private industries and taught in business schools so “the ideal of economic growth was rendered congruent with democratic freedom, social justice and a fair standard of living” [ibid:18].

The language of enterprise forms a kind of matrix for thought here, consumers being considered as, in a sense, entrepreneurs of themselves, *seeking to maximise their ‘quality of life’* through the artful assembly of a ‘life-style’ put together through the world of goods. Within this politico-ethical environment, the expertise of market research, of promotion and communication, provides the relays through which the aspirations of ministers, the ambitions of business and the dreams of consumers achieve mutual translatability

[Ibid:25, my italics]

A similar transformation is occurring with audit in anthropology [Strathern 2000], and QOL measurement which employs the “language of care” to conceal its concern with “efficiency and cost” [Kleinman and Kleinman 1996:15]. Finally, it was only possible to think about the economy in this way because systems of national accounting had turned it into a calculable and comparable entity, for example, the OECD tabular comparisons of different countries’ growth rates enabled the identification of Britain’s low growth rate and the development of programmes/technologies to address it, in the same way that the WHO Global burden of disease tables produce something called “the burden of disease” that can be compared internationally.

The case study of the UK economy demonstrates how in modern liberal democracies technologies “seek to act upon and instrumentalise the self-regulating propensities of individuals in order to ally them with socio-political objectives” [ibid:28] while apparently limiting the role of the state. The languages and techniques of “expertises of the enterprise” provide “both the necessary distance between political authorities and organisational life, and the translatability to establish an alliance between national economic health, increased organisational effectiveness, and progressive and humanistic values” [ibid:27].

QOL measurement can also be seen as an example of “pastoral power”³⁹ which makes people into both “objects” (of study) and “subjects” (“subject tied to his own identity by a conscience of self-knowledge”) [Foucault 1982]. This “subjectification” is accomplished in three ways: by academic disciplines; by “dividing practices” where subjects are divided from others, or within themselves (for example, self-assessment for benefits); and by making someone turn themselves into a subject (for example, by engaging in the reflexive self-monitoring required by QOL measures or managing their “risk factors”). Filling in QOL measures or responding to health economic questions about “preferences” helps develop economic rationality, as did “new regimes of the intellect” like numeracy, literacy, and calculation (first promulgated in the 19th century) which were designed “to install foresight, prudence and a planful relationship to the future” [Rose 1996:313]. QOL measurement is also connected to the injunction to “know yourself” which Foucault describes in the *History of Sexuality* [1978].

Reading Foucault’s writings on the archaeology and genealogy of knowledge [1972, 1973] encouraged me to contextualise my analyses. For example, approaching health technologies as emerging from (and creating) particular cultural conditions [Escobar 1994]⁴⁰, which reduces the tendency towards “technological determinism”. Health technologies cannot be treated as “given”, nor can researchers “stay in the lab”⁴¹ as changes occur in the context of global health-care reform, new professional models, and new groups of experts (for example, QOL researchers). Cultural assumptions are unconsciously embedded in new health technologies⁴²; for example, QOL measures prioritise performing activities of daily living and working and rarely take account of the effort involved [Hunt 1999].

Anthropology of science and technology

The anthropology of science provides a new model for anthropology, where anthropologists work across sites and disciplines, incorporate multiple perspectives, and handle the compression of space and time associated with post-modernity. Scientific work itself destabilises the boundaries between “pure” and “applied” science and science and society [Latour 1987]; for example, the hybrid nature of health technologies [Faulkner 1997], the information flows between sites of knowledge creation and application [Elston 1997], and the

³⁹Pastoral power “focuses on the development of knowledge of man around two roles: one globalising and quantitative, concerning the population, the other, analytical, concerning the individual”.

⁴⁰Escobar also argues that modernity caused a move from organic and mechanical models of life to ones linked to production and maximisation, for example, health economic models that maximise aggregate QOL.

⁴¹As Knorr Cetina advised on learning the multi-sited nature of Martin’s study of the immune system [1994].

⁴²For example, a database designed to empower people with migraines by giving them access to information about their condition only included the information their doctors wanted them to have [Forsythe 1996].

complex, transnational networks of medicine regulation [Davis 1997; Abraham 1995]. The culture of “Science” (characterised as detached, immutable, and dispassionate) has shifted to one of “research” which is more open and enquiring. Science is expected to acknowledge and increase the complexities of life rather than resolve them, so instead of subscribing to the myth of objectivity, “the more connected a scientific discipline [to society], the better” [Latour 1998]⁴³. Contemporary studies of science explore this connection by examining the “traffic between the establishing of knowledge and those cultural practices and formats which philosophers of science have regarded as external to knowledge” [Rouse 1992]. For example, acknowledging that disciplines are created and transformed by new instruments⁴⁴ as well as concepts, and that the former frequently precedes the latter. This is a useful approach to the history of QOL measurement as it demonstrates that alliances rather than technological superiority secure the adoption of a measure⁴⁵. Once a measure has been used in a number of studies it becomes an “obligatory point of passage” [Callon 1986] and researchers are expected to use it (even if it does not measure the aspects of health that they are interested in) and validate their measures against it.

I explore the contribution of “actor network theory”⁴⁶ [Law 1982; Latour 1987] to my thesis in greater detail in chapter 7 when I examine how QOL researchers (an example of “scientific entrepreneurs” [Latour 1987]) form complex networks to create measures of QOL. They also participate in the “battle” between proponents of “evidence-based” and “patient-centred” or “narrative” medicine as QOL measures claim to be simultaneously objective and patient-centred. Of course, this battle is more rhetorical than actual since both discourses conceal the usual government concern with efficiency and economy and power struggles within medicine (c.f. Armstrong who explores how the discourses are used by differently positioned doctors to achieve professional autonomy [2002]).

⁴³The pressure on researchers to be connected to commerce can cause bias, as I explore in chapter 6.

⁴⁴For example, the difference in instrument style between North American and Japanese high-energy physics laboratories affected both the types of questions asked and what counted as a “good result” [Traweek 1988].

⁴⁵The military and government institutions who provided sophisticated equipment for Bjerckness’s study of atmospheric geophysics also ensured the international acceptance of common instruments and temporalities [Friedman 1989]. Similarly, standardised mortality rates only became accepted forms for epidemiological data after they had been used in particular public health controversies [Bartley et al 1997].

⁴⁶It also highlighted the vital role of the technician in resolving “error” and “noise” (for example, interpreting ambiguous responses to the dystonia QOL questionnaire; coding causes of death [Prior 1997]).

Medical anthropology and the anthropology of the body

Young's review of medical anthropology [1982] usefully distinguishes between "clinically applied anthropologists"⁴⁷ like Kleinman who produce "anthropologies of illness", and "critical medical anthropologists"⁴⁸ like Scheper-Hughes, Taussig, and Young himself, who write "anthropologies of sickness". His main criticism of the former is that instead of questioning the premises of biomedicine, they argue for its expansion into social dimensions of illness. For example, the anthropologist Guarnaccia [in Spilker et al 1996] is an advocate for QOL measurement, which could be regarded as an extension of the "clinical gaze".

One thing I do not hear from my colleagues in medical anthropology [...] is an invitation to reduce rather than expand the parameters of medical efficacy, a call for a more humble model of doctoring as 'plumbing', simple 'body-work' that would leave social ills and social healing to political activists, and psychological/spiritual ills and other forms of existential malaise to ethnomedical healers

[Scheper-Hughes 1990:192]

Critical medical anthropology is the most useful theoretical approach for this thesis as it takes a deconstructive approach to illness and situates it in its political and economic context, exploring how every condition is a "culture bound syndrome"⁴⁹ because of the role of cultural factors in the construction and expression of illness⁵⁰ [Hahn 1995]. For example, Hacking's description of the "conditions of possibility" for new syndromes illuminates the diagnostic process for all conditions [1998]⁵¹. According to Singer, the key themes for critical medical anthropology are reification, privatisation, "healthism", displacement of social aetiology⁵², medical hegemony, medicalisation, medical social control, micropolitics of medicine and the class structure of medicine, somatisation, and the struggle for health; many of which are

⁴⁷Scheper-Hughes describes clinically applied anthropologists as "content to tinker (endlessly it would seem) with the doctor-patient relationship)" [1990:189] and likens them to colonial anthropologists who attempted to ameliorate the position of the indigenes without challenging the inevitability of colonial appropriation. She believes that the incongruity between anthropological and biomedical knowledge practices has been resolved by reducing anthropological knowledge to innocuous concepts like "lay explanatory models" (or the "biopsychosocial" model described in chapter 9).

⁴⁸Critical medical anthropology is more commonly used to describe writers who apply Marxist political economy to the social relations of sickness and healthcare delivery (for example, Waitzkin [1978] on coronary care units, Bates [1990] on coronary artery bypass grafts, and Navarro [1986] on the how distribution of biomedical roles mirrors existing stratifications of capitalist society) rather than those who criticise biomedicine.

⁴⁹Nervios [Low 1994], Koro [Cheng 1996] and Dhat [Bottero 1991] are classic examples of culture bound syndromes, but they are also found in contemporary western societies and may represent the disappearance of traditional cultural idioms for expressing distress so social problems are interpreted as symptoms (for example, parasuicide, agoraphobia, exhibitionism, and domestic sieges [Littlewood and Lipsedge 1982]; stress and post-traumatic stress disorder [Collins 1999; Young 1980, 1995]; hysteria [Showalter 1997]; mania [Martin 2000]; multiple personality disorder and fugue [Hacking 1995, 1998]).

⁵⁰Scheper-Hughes [1979] and Littlewood and Lipsedge [1982] observed the tendency of Afro-Caribbean and Irish psychiatric patients to structure their illnesses as religious experiences.

⁵¹Diagnosis requires "an ecological niche, with four principal vectors to be named medical taxonomy, cultural polarity, observability, and release" [Hacking 1998:80].

⁵²For example, the redescription of "delirium del fome" (madness from hunger) as psychosis [Scheper-Hughes 1988]; or the lack of medical interest in the "trigger events" for dystonia.

important parts of the experience of dystonia. His rallying cry is “comforting the afflicted while afflicting the comfortable” [1990:185] which expresses the interest in political engagement that characterises critical medical anthropology. Sickness becomes a focus for ideological practice because it disrupts people’s “uncritical acceptance of life”, turning them into “metaphysicians and philosophers” [Taussig 1980] and giving doctors “a powerful point of entry into the patient’s psyche”. Medicine is also criticised for presenting social conditions as natural and immutable “facts of life” and dismissing them from discussion as “not-medicine” [ibid]⁵³.

Where critical medical anthropology appears lacking is in its approach to the body, which often focuses on its representation and manipulation⁵⁴ rather than the experience of embodiment⁵⁵ (mirroring the privileging of object over subject in biomedicine). Etic accounts of the “meanings” of illness take precedence over emic ones, for example, the “ordinary” pains of the elderly are rarely examined, even though elderly people embed them in their lives and give them a meaning that challenges their “ordinariness” [Becker 1999]. Studying the body is difficult as it “tends to recede from our experience” [Leder 1990], only coming to our attention when it “dys-appears” at moments of crisis and transition [Backett-Milburn and Cunningham-Burley 1999]⁵⁶. There are also “socially structured barriers” that prevent people from speaking with the “voice of personal bodily experience” [Zola 1982] even though narrating illness can lead to “re-embodiment” [Williams 1984]. As I explore in chapter 3, representing experience is not a straightforward process, for example, temporal [Fabian 1983; Geertz 1973] or emotional experiences [Freund 1990; Abu Lughod 1987] often cannot be verbalised and there may be powerful taboos preventing their communication.

The multiplicity of bodies proposed as heuristic devices complicates things further⁵⁷. Fracturing the body into numerous “topical” bodies (e.g. “medical”, “consuming”, “labouring”) disguises their linkage at the macro and micro levels and mirrors the fragmentation that occurs within biomedicine. For some theorists the body is a more pliable replacement for the subject, “a more or less passive object of disciplines and representations”

⁵³Although Taussig’s description of the reification of the patient is persuasive, he doesn’t distinguish between objectification and reification and assumes that his viewpoint is free of the mystification he identifies in others.

⁵⁴For example, Douglas treats it as an instrument of the rational mind and subordinates it to the semantic [1970].

⁵⁵For example, until recently, studies of pain focused on cognitive mediation and interpretation, or the way doctors made sense of it, rather than the experience which was left to neurophysiologists like Melzack [1973].

⁵⁶The experience of illness and impairment is characterised by a continual awareness of the body, partly because of the pervasive “disablism” which “makes the world alien to impaired bodies [...] simultaneously produc[ing] impairment as an experience” [Paterson and Hughes 1999].

⁵⁷Leder suggested “ecstatic” (outfolding) and “recessive” (infolding) bodies [1990]; Douglas: social and physical bodies [1970]; and Scheper-Hughes and Lock: three bodies with three complementary epistemological approaches (individual - phenomenological, social - structural/symbolic, political - post structural) [1987].

imbued with unrepresentable psychodynamic and sexual desires [Turner 1984]. But using the body as a synonym for the self without a sense of its bodiliness objectifies it, missing the opportunity to add sentience and sensibility to ideas of self and make history and culture more material [Csordas 1994]. It fails to acknowledge that people experience themselves simultaneously in and as their bodies, which also shape interrelationships, modes of production, and reproduction [Turner 1984]⁵⁸. As Haraway observed “neither our personal bodies nor our social bodies may be seen as natural in the sense of existing outside the self-creating process called human labour” [1988]. Foucault [1978, 1994] and Bourdieu [1977 1984, 1992] have also demonstrated that the body is an important site of social differentiation and control. For example, Bourdieu’s concept of “hexis” (the body as a “mnemonic device” of cultural practice) suggested why the uncontrollability of the bodies of people living with dystonia is experienced as threatening. This means oppression is “not simply an abstract structure manifest, for example, in exclusion from the labour market – it is felt in the flesh and the bones” [Paterson and Hughes 1999].

Marginalised groups resist bodily oppression through a “politics of proprioception” which deconstructs aesthetic, political and economic tyrannies (for example, Black, gay, and disability “Pride” movements) [Hughes and Paterson 1997]. The Pride movements’ representations of the body are an empowering contrast to some post-structuralist views as they involve “an agent that produces discourses as well as receiving them” [Turner 1984]. Body image is pliable and social, demonstrating an “in-folding” and “out-folding” relationship with culture [Kleinman 1978]. Modes of embodiment are linked to ideas about personhood (for example, “individuality” and “dividuality” [Strathern 1988; Boddy 1998]), which are rarely predictable. For example, individuation does not necessarily imply individualism as it can be a way of becoming aware of our position within a larger whole [Obsekere 1981].

The subject/object dualism is not confined to doctors as it enables people to describe their experience in an “everyday” language that allows distanciation and control, precisely because the representation is not coterminous with the experience. It is even evident in psychoanalysis and psychosomatics where illnesses are treated as either organic or psychological: where psychopathology is diagnosed, the organic aspects of the illness are immediately forgotten. While the objectivist perspective on the body can be useful in the treatment of certain conditions, it makes chronic pain incomprehensible as it is impossible to distinguish between

⁵⁸This relationship is expressed by the German phenomenological concepts of “lieb” (“body-for-itself”) and “korper” (“body-in-itself”).

pain behaviour, experience of pain, and the accompanying emotional states [Good 1994; Jackson 1994]. Medical activities – including QOL measurement - attempt to objectify the pain⁵⁹ to produce a gap between self and experience and transform it into a symbol, which can support a healing narrative. This approach is rarely successful with chronic pain syndrome, nor with dystonia whose symptoms also resist organisation (as its medical definition suggests).

Dystonia

Dystonia is a “syndrome of multiple different disorders” involving “involuntary sustained muscle contraction” [Fahn 1987], which is classified with neurological “movement disorders” like Parkinson’s Disease. People living with dystonia experience visible twitching and jerking of the muscles (for example, involuntary closing of the eyes in blepharospasm), often accompanied by pain.

This definition gives a sense of how difficult dystonia⁶⁰ is to classify and position; it is usually described as a neurological condition as the symptoms are caused by a chemical imbalance in the area in the brain that controls movement. Similarly, it is chronic (or “long-term”) and is usually classified as an illness because the symptoms are potentially treatable and many people living with dystonia hope ultimately for a cure. Some define themselves as disabled (especially people with generalised dystonia), recognising that they may have more in common with other wheel-chair users or people with sight problems, than people with neurological illnesses. Others use the definitions pragmatically, for example, people with writer’s cramp (affecting the writing hand) in Canada petitioned for it be redefined as a “repetitive strain injury” so they could successfully argue for compensation from employers. This highlights not only the politics underlying medical classification but also the tactical use of these classifications. The use of “syndrome” in the definition also arouses suspicion among many GPs as it links dystonia to people with chronic fatigue and chronic pain syndromes who are often perceived as discontented and demanding patients. Like “essential tremor”, which is significantly over-diagnosed [Schrag et al 2000], it can also be used as a “garbage” diagnosis by neurologists who are uncertain about the cause of a set of symptoms, and often the deciding factor is whether it responds to the main treatment for dystonia, botulinum toxin⁶¹ (see Genevieve’s account, chapter 2).

⁵⁹For example, by quantifying it using a pain-specific measure.

⁶⁰Which literally means incorrect (dys-) muscle movements (tonia).

⁶¹This is not infallible as it works by freezing the muscles, so is equally effective with psychiatric conditions.

“Primary” dystonia is the most common form and is believed to be genetic in origin. “Secondary” dystonia appears similar (and may also be genetic) but is secondary to a precipitating event, for example, use of psychiatric medications, head injury, or another movement disorder. Generalised dystonia was identified by Oppenheim in 1911 and the less severe segmental and focal dystonias were included in the classification “dystonia” from 1944 [Oppenheim 1911; Herz 1944].

The most common type is focal dystonia, which affects one muscle group (for example, cervical dystonia affects the neck muscles) and is usually neither progressive nor fatal. It begins when people are in their mid-fifties⁶² and (with the exception of “writer’s cramp”) is more prevalent in women than men by a ratio of 3:2 [ESDE 1999]. Segmental dystonia (affects adjacent muscle groups) and multi-focal dystonia (affects unrelated muscle groups) are less common. Generalised dystonia, which onsets in childhood, is the rarest and most disabling form as it affects a number of muscle groups, progresses rapidly, and can be fatal. The main campaigning image of the Dystonia Society is a girl in a wheelchair who is literally doubled up with generalised dystonia.

When someone with focal dystonia of the limbs begins walking, the basal ganglia (the part of the brain which controls movement) brings more groups of muscles into action than is necessary and these groups of muscles work against each other [Rothwell and Obeso 1983; Calne and Lang 1988]. The struggle between the muscles is exacerbated by the tension of the walker who has come to associate this movement with difficulty and is tensing their muscles in anticipation. Bleton (a physiotherapist specialising in movement disorders) has demonstrated this in writer’s cramp by showing how the hand becomes so tense when holding a pen that the person is unable to write. People can make writing movements with a paintbrush, and even an inverted pen, but cannot do so when the pen is placed in the correct position. Even where surgery is successful, they may not be able to function “normally” as their bodies cannot approach certain movements “naively”.

Although dystonia has been recognised by neurologists since the beginning of the last century and dystonia advocates claim they can identify people living with dystonia in paintings by Bruegel, it has only been generally recognised in the past twenty years. People diagnosed more than ten years ago were often referred to a psychiatrist rather than a neurologist. Treating dystonia as a psychiatric condition exacerbated their feelings of guilt and shame and

⁶²There is variation between subtypes, for example, writer’s cramp begins when people are in their late forties and blepharospasm in the mid-sixties.

meant that physical experiences of pain and fatigue were often ignored (see especially chapter 4).

Dystonia research

There have been few epidemiological studies of dystonia, due to its rarity and low mortality rate⁶³ [Ben-Shlomo et al 2000]. I coordinated an epidemiological survey in eight European countries [ESDE 1999, 2000] to provide current prevalence figures as previous estimates were based on very small numbers⁶⁴. The study calculated a European prevalence rate of 152 per million for primary dystonia: 117 per million for focal dystonia, and 35 per million for dystonia affecting more than one body part [ESDE 2000]. This compares poorly with UK prevalence rates of 1,465 per million for multiple sclerosis and 2,067 per million for Parkinson's disease. However, measuring the prevalence of rare diseases is difficult as it is only possible to measure people who have been diagnosed. For a person to appear in the study they needed first to see a sympathetic GP, then be referred to a neurologist rather than a psychiatrist or specialist in the affected body part, and finally to have a type of dystonia that responds to treatment with Botulinum toxin. Since the average wait for diagnosis for participants from the London centre was eight years, we can assume that many eligible participants were missed. In fact, genetic studies of dystonia have demonstrated that over 50% of people living with dystonia have affected family members who have not been diagnosed. Although people living with dystonia frequently report a family history of movement disorders, dystonia is difficult to diagnose without examination⁶⁵. As the numbers are so small, prevalence rates can also be biased by clerical errors at the collecting or coordinating centre⁶⁶.

Previous research in dystonia focused on its aetiology (the role of the basal ganglia and the thalamus), and how messages are sent through neural pathways to the muscles. Genetics is a prestigious and well-funded area, but although gene loci have been identified in at least six forms of dystonia including focal, dopa-responsive⁶⁷, PDC⁶⁸ and two of the rare X-linked

⁶³ Hospital mortality rates are an important source of epidemiological data.

⁶⁴The most cited study [Nutt et al 1988] reported a prevalence rate for generalised dystonia of 36 cases per million population, but this was only based on three cases, two of which would now be classified as segmental.

⁶⁵Another component of the ESDE study demonstrated that someone living with dystonia could diagnose dystonia from a video as well as a neurologist and that confidence in diagnosis was inversely related to skill.

⁶⁶I later discovered that the French centre had 100 cases who were active at the time of the prevalence study but were not recorded which would have doubled their prevalence rate.

⁶⁷Dopa-responsive dystonia (DRD) onsets in childhood and responds dramatically to the drug Leva-dopa.

⁶⁸PDC presents as a focal dystonia but its severity varies during the day.

recessive syndromes, disease genes have only been identified in three⁶⁹. The test for the DYT1 gene has been used to confirm diagnoses of generalised dystonia in the USA and UK but the gene's predictive role is uncertain.

Health economic and QOL studies of dystonia are a new and expanding area of research [Butler et al 1998; Gudex et al 1997; Camfield et al 2000, 2002; Hilker et al 2001; Ben-Shlomo et al 2002], especially as centres develop dystonia-specific QOL measures⁷⁰ (Austria CDQ-24 [Mueller et al 2000], UK DysQol). This is anthropologically interesting because it is an example of both audit culture (linking efficiency and control to well-being) and the inculcation of economic rationality as part of "governmentality". It may also indicate more general concerns with the "taming of chance" [Hacking 1990] and "management of uncertainty" [Giddens 1991], which form part of what some theorists call a "risk society" [Beck 1992]. The psychological aspects of dystonia have been well researched [Jahanshahi 1991; Jahanshahi and Marsden 1990ab, 1998], partly because even in the mid-nineties articles were being published in psychological journals suggesting that focal dystonia was psychogenic.

Representations of dystonia

Public understanding of dystonia is not aided by the Dystonia Society publicity campaigns that represent it as a mysterious and horrible disorder, treated with a deadly poison. While this gets attention and money, it also increases the fear and isolation of people living with dystonia and reinforces popular prejudice⁷¹. The Society's position is contradictory because it wants to empower people living with dystonia (as far as it serves its interests) but needs to represent them as pitiable and in need of the Society's support in order to fundraise. In this context QOL scores offer little more than clinical measures as while most people understand the concept of QOL, the scores need to be supported by vignettes to make them meaningful⁷². QOL studies and articles about people living with dystonia are analogous in the sense that because dystonia is so little represented, even a partial or inaccurate representation is generally perceived as beneficial.

⁶⁹Generalised dystonia (DYT1), DRD (DYT5) and X-linked sensorineural deafness, dystonia and mental retardation (DDP).

⁷⁰While there are many clinical scales for dystonia (for example, the TWSTRS for cervical dystonia [Conskey and Lang 1994]), these cannot pick up small differences in the performance of different therapies, or give any sense of what a "10-degree improvement in angle of rotation" means to someone with cervical dystonia.

⁷¹c.f. Campaigns by the Neurofibromatosis [Ablon 1995] and MS Societies [Duval 1984].

⁷²c.f. the pharmaceutical company sponsoring the Society's membership survey's request for "strong quotes" to "drive" the publication, chapter 5.

In addition to interviewing people living with dystonia, I examined representations of dystonia in local and national media (analysing 36 articles published between 1997 and 2001) to see if the language used would give a sense of the prejudice that they experience. The main themes of the articles were the strange and horrible nature of dystonia, problems getting a diagnosis, uncertain futures, and the exotic nature of the treatment. 25% of the articles were about the same three people, all of who had made “miraculous” recoveries – an ex-dancer who had written a book about her experiences, a photogenic woman with laryngeal dystonia, and a girl with severe generalised dystonia. The articles about men (25%) were reported differently, for example, focusing on career rather than inability to fulfil domestic responsibilities, and not mentioning their families. The language used for people living with dystonia was the same in all articles: sufferer⁷³ was most common, also victim, unfortunates, patient, crippled, and if their mobility was affected, wheelchair-bound, bed-bound, and bed-ridden. These descriptors have been criticised by people with disabilities as etic projections that disempower the subject, present a sensationalist image of disability, and encourage pity rather than respect⁷⁴. For example, “patient” connotes passivity and refers to a specific role that people living with dystonia occupy infrequently.

The articles usually begin with the person’s struggle for diagnosis, involving either failure by their GP⁷⁵ to take their complaint seriously, or psychiatric referral when symptoms of dystonia are attributed to stress, depression, nervous disposition, “wear and tear”, postnatal depression, or phobic notions. The experience of not being able to describe what was happening to them was one of the most traumatic memories of the illness (“she knew that something must definitely be wrong with her, but no-one seemed able to say what it was”) and caused many people to doubt their sanity (“at times I thought I was going mad and other people think you are too”). Some were accused of imagining the condition or inventing it to escape their responsibilities (“one consultant thinking it might all be in the mind told her briskly ‘this won’t do Mrs Smith. You’ve got to get out of bed and go home to your family’”). The articles emphasise their relief at the diagnosis of a “real” (i.e. organic) condition (“believing it was a mental problem was worse because I blamed myself [...] when the consultant told me it was physical, I cried”) and show the stigma experienced by people with psychiatric conditions (characterised by one person as “psychological freaks”) and by extension people living with dystonia whose condition appears psychiatric in origin. They

⁷³Some people living with dystonia describe themselves as sufferers because they feel it represents their daily reality, but may not want to be labelled as that.

⁷⁴They also represent disability as individual tragedy rather than social responsibility [Oliver 1990].

⁷⁵While the GP is a legitimate target for anti-medical feeling, the neurologist is the hero who can diagnose at a glance (“he recognised what it was straight away”).

reiterate popular prejudices: that psychiatric illness is not genuine, can be controlled, and is a legitimate cause of guilt.

Lack of public awareness is another factor that increases feelings of isolation. Dystonia is characterised as “this forgotten disease” (referring also to resource allocation) and people living with dystonia emphasise that before diagnosis “even [they] hadn’t heard of it”. After diagnosis, many feel they should raise awareness and help diagnose others (“she has helped two other sufferers by spotting their condition before their GPs”).

Although the articles are written to evoke sympathy, the descriptions of dystonia (“rare nerve condition”, “mysterious disorder”, “devastating brain disorder”) cause the reader to step back, not wanting to encounter this horror at close hand. Not surprising then that people living with dystonia report feeling “like a total freak when it first started” and “[that] you are the only person in the world that has this”. It is described as “a horribly disfiguring, painful and debilitating illness” which even close relatives need to be protected from (“I locked myself in the bathroom when I got home so as not to frighten my wife”). The muscle spasms are described graphically (“my arms were bent up like this, she says, contorting hideously in her chair”), implying that people living with dystonia do not have any control over them (“my arms and legs started to shake uncontrollably, my face began to twitch and the corners of my mouth pulled downwards - I was terrified”). Dystonia is represented as a powerful and merciless invader that strikes without warning and cannot be resisted (“the muscles seem to have a will of their own [...] if you try and fight it, it only makes things worse”), appearing closer to spirit possession than chronic illness.

The ordinariness of people living with dystonia is contrasted with the strangeness of dystonia by looking at the person’s life before the onset of dystonia (“she was a vivacious 23 year old with a demanding job and a hectic social life”) and their family relationships (“I was a normal active mum”). Articles about women describe them in relation to their families (for example, “Preston grandmother”) while those about men focus on active and productive lives before onset to counter the equation of disability with weakness (“I was once extremely active but now my body can’t quite keep up”). Their strength is emphasised by hyperbolic descriptions of their pain (“seven years of pain and torment”) and testaments to their fortitude (“[my nerves] had become so sensitive that the mere touch of a bed sheet left me in agony”).

The articles construct an ideal person living with dystonia who is uncomplaining (“there was no good getting depressed. I just got on with it”), fulfils their responsibilities (“as a single mum I had to continue my job as a nurse despite the problems with my neck”), and may have coped with similar experiences in the past (“after a male partner had let her fall to the ground in a pas-de-deux she danced on with a fractured spine for seven months”).

Dystonia affects participation in valued and self-preserving activities such as work, socialising, and (in the case of women) domestic chores and many experience “existential fatigue” and withdrawal [Toombs 1992] (“everything was a struggle - doing the washing up, vacuuming or just putting on my makeup”⁷⁶). Fear of attracting attention reduces participation in social activities (“[he] now feels so ashamed of his shaking and twitching that he stays at home rather than risk being mocked at the pub or in shops”), contributing to a feeling of losing one’s humanity, which is exacerbated by the language used in these articles (“her balance was so bad she was led around like a dog”). Being dependent on others apparently removes your qualification as a full member of society (“bed ridden at home where she had to be dressed, washed and fed”).

Stress on partner and family relationships is a theme that only appears in the women’s articles, which vividly express a fear of being a burden (“I was worried how my boyfriend was going to feel [...] ‘I’ll understand if you don’t want to marry me’”) and highlight “disturbing” role reversals (“she has become dependent on her two sons”), particularly when the male partner is the carer. Their guilt extends to fears that they have “contaminated” their children with dystonia, even though the role of inheritance is not clear (“the worst thing is I know it is hereditary and I have passed it on”).

The main focus for the articles I analysed was treatment by Botulinum toxin as the paradox of a “lethal poison” being used therapeutically seems to have captured journalists’ imaginations (demonstrated by its appearance in the majority of headlines). Every article had a different account of how Botulinum toxin works, respectively “cutting”, “paralysing”, and “killing off” the nerve endings. The risks of the treatment were highlighted, underlining the “desperation” of people who undergo it (“she became poisoned by the Botulinum toxin used to treat the spasms and could no longer swallow”). This desperation was emphasised by two articles on rationing in Preston, where being “denied” treatment was tantamount to an exclusion from “normal life”.

⁷⁶This and other quotes tell a particular story about being female; obviously you are seriously ill when you no longer have the energy to wash up or apply make-up.

Other articles mentioned new surgical techniques, emphasising their novel, experimental, and risky nature (“radical new treatment [...] never before been performed on such a young child”). However “radical treatments” lead to “miraculous recoveries” that not only relieve people’s dystonia but give them their life back, possibly even a life better than they had before (“she can drive again, play tennis, sail, in fact do everything”). The only regret is for “lost” time (“I wish I’d had this treatment years ago”).

Where treatment was not effective, the articles implied a gloomy future that echoes negative stereotypes of disabled people (“I knew I’d have to give up ideas of being a teacher”). For people in this position, the articles advise using your experience to help others (“my determination to fight my own disability helps me to fight on their [her pupils] behalf [...] the motivation to help them progress is greater than my own pain”) and being positive (“positive thinking has helped her to get back behind the driving wheel again and give her the precious privilege of being able to hold her granddaughter”). The “super-crip” [Barnes 1992] can then reject the weakness associated with disability by rejecting the disabled “other” (“in the Dystonia Society newsletter they have photographs of people who are in a much worse state than me”). These narratives reflect the way that people living with dystonia “account” [Stimson and Webb 1975] for themselves and demonstrate how their embedding in a politics of representation obliges them to tell particular stories of overcoming and normalisation, which perpetuate negative stereotypes of people with disabilities and the myth of the “super-crip”.

Causes of dystonia

There is little research on the causes of primary dystonia and how different causes affect its aetiology. Even if the ultimate cause is genetic, there is usually a reason why a genetic predisposition “expresses” itself at a particular time and discovering the “provoking factor” [Hunt 1998] can enable the person to integrate it in their biography, experiment with alternative treatments, or reinforce their sense of themselves as knowledgeable actors. The interest in causation shown by people living with dystonia is reflected in the full responses to questions about causation in the Society’s membership survey [TDS 2001] and the pilot study for the dystonia QOL questionnaire [Camfield 1998]. In the survey, 55% of respondents thought their dystonia was triggered by an external factor⁷⁷ and 14% mentioned more than

⁷⁷These can be broken down into stress (41%), injury (26%), medication (19%), surgery (9%), virus (6%), not known/other (6%), repetitive strain (3%), stroke (2%), and exposure to chemicals (1%), which reflect

one factor. Even where only one was specified, it was possible to read others beneath it; for example, where “medication” was taken after the death of the respondent’s husband, or “accident” occurred after a lapse in concentration due to the repetitive nature of the respondent’s job. Despite the space restrictions respondents produced powerful and complex narratives that embedded dystonia in their life histories. In fact, much of their power derived from their terseness and omissions which let the events speak for themselves [Skultans 1998]. For example, one respondent simply recorded “blue baby/fractured skull/bombed out/injured spine” and another noted the “year of stress and no laughter” that followed her parents’ death aged 16. The accounts used medical vocabulary (“retinal blood clot to the r eye”, “myoclonal from sunstroke as a baby”) but wove in personal elements, often including a critique of the treating doctor. The majority attributed the onset to external factors (stress, illness, family or work problems, or childhood events) rather than personal weakness.

55% of respondents to the pilot study for the questionnaire also identified external triggers and had sufficient space to produce detailed and dense narratives that functioned as moral accounts, as they argued persuasively that the respondent had a right to have dystonia and that if you had been through those experiences, you would have it too. For example, one man recalled the death of his sister (aged 20), redundancy after “26 years of being in continuous service”, two car accidents, the lengthy illness and death of his father, and, as an afterthought “repossession of my house in 1991”. Another attributed his condition to his persecution by his colleagues after he “broke ranks to report a senior police officer for malpractice and an unhealthy association with a millionaire businessman”, culminating in early retirement “due to stress and injury” when he was “tripped deliberately in a running race”.

In the absence of a comprehensive medical explanation, individuals weave together disparate strands from personal experience to give coherence and meaning to their condition and “claim the capacity for living uniquely – seizing the point of one’s life – with illness” [Frank 1998:343]. I explore the role of causal narratives in greater detail in chapter 3.

Impact on people’s lives⁷⁸

During my fieldwork I organised a survey of Society members [“The true impact of dystonia”, 2001] to record dystonia’s surprisingly severe impact on people’s lives and

contemporary preoccupations with stress and environmental and medical risk. Since the organic nature of their condition had already been established, they did not risk being labelled psychosomatic by their choice of cause.⁷⁸The impact recorded by the membership survey (28% employed, more than half either part-time or self-employed) is more severe than that recorded by the QOL questionnaire [Camfield 1998] (38% employed, 25% full time and 14% part time, at least 25% retired on medical grounds, and another 11% “unemployed because of my dystonia”). Note that there is an age-effect as most people living with dystonia are in their early-mid fifties.

implicitly justify the money spent on pharmaceutical treatments (I provide more detail in chapter 5). The focus of the survey was its impact on employment which, even allowing for the age of the respondents, was much lower than in the general population and comparable to people with disabilities. There was also considerable “underemployment” as over a quarter of respondents had reduced their hours or taken a less demanding job. This may be due to the unsympathetic attitude of employers⁷⁹, for example, some people living with dystonia who worked in customer-service positions were transferred in case their twitching disturbed the customers⁸⁰ and one even experienced discrimination at a prominent centre for neurological research and treatment. Mina told me she originally worked as a typist but her unit closed when her typist’s cramp started and the other departments wouldn’t accept a ‘one handed typist’; “even though I was a member of staff and my neurologist recognised my problem as dystonia, I was sent to a psychiatrist”⁸¹. Although she found another job at a council Careers Service, ironically she experienced discrimination there as well; “I was eventually transferred to a job that was impossible for someone who couldn’t write fast and legibly - effectively ‘constructive dismissal’”. While some people had more sympathetic employers, few escaped the self-imposed pressure to “prove” yourself and not let “it” beat you. Like Anthony⁸² “at the end of every working day” they felt “it’s a little victory that I have got through another day”.

Family and friends can be unsympathetic and may not appreciate how disabling dystonia can be as it is very variable. Many people living with dystonia described feeling insecure in social situations and having a poor body image. “Social life” was also listed as the most affected area in the dystonia QOL questionnaire [Camfield 2000] but is poorly covered by QOL measures, which can only measure it by reducing it to numbers of friends or activities engaged in. This can affect other areas of life; one respondent described how “being excluded from social events [...] especially where there are opportunities to meet the opposite sex to form new friendships leads to poor social skills, ultimately leading to a very poor success rate with job interviews which has a dramatic impact on one’s ability to find paid work” [in Camfield 1998].

Half the respondents to the QOL questionnaire thought their condition was very visible and this appeared to correlate with their scores on the SF-36 QOL measure⁸³, for example, people

⁷⁹34% of employed people reported no or minimal support from their employers [Camfield 1998].

⁸⁰7% had taken a job involving less contact with the public [TDS 2001].

⁸¹When she copied her notes years later she found that he had “double circled ‘fear of flying’”.

⁸²A man with cervical dystonia writing in the Society newsletter.

⁸³Described in the first footnote of chapter 7.

with oromandibular dystonia which affects eating and saliva retention had particularly low scores. People's fear of being observed and judged affected every aspect of their lives (an issue explored further in the next chapter). One informant described to me how "people think I am strange when they see my head moving all the time and mickey taking is normal for them". He had even been banned from his local supermarket and felt self-conscious socialising as "girls in pubs jump a mile when they see my head moving" [in Camfield 1998].

Treatments

Part of dystonia's impact can be explained by the paucity of effective, non-invasive treatments. Drug treatments⁸⁴ are often ineffective and have considerable side effects. Focal dystonia is treated using injections of Botulinum toxin⁸⁵ [Jankovic 1994, Dressler 2000] that last for up to six weeks, however injections can only be given quarterly due to shortage of spaces in the clinics (and the possibility of developing resistance). Where these are immediately and sustainedly effective, they can transform people's mental health, as another informant explained to me:

I was depressed, crying a lot, feeling suicidal at times. I had my first Botulinum Toxin injection [...] and there has been steady improvement and I am very pleased with the way I am now [...] I don't pretend I can cope all the time and at times get rather down, but don't let it get a hold now

[in Camfield 1998]

However, injections are not available nationwide (some health authorities will not fund them and there is a shortage of places at clinics) and resistance is developing among long-term users. Five other strains have been developed but only types A and B have been approved by drugs agencies in the USA and UK⁸⁶.

Until recently, surgery for dystonia was out of fashion, partially because Botulinum toxin had become the main treatment for people with focal dystonia. Practices like cutting nerves in the neck to relieve cervical dystonia (surgical peripheral denervation), and creating lesions with electrodes in the area of the brain that controls movement were considered ineffective and barbaric. Surgery was still done for hemifacial spasm and blepharospasm (particularly in the USA) but UK neurologists only referred their patients as a last resort. The work of neurosurgeons in Canada and France with people with cervical and generalised dystonia, the success of neurosurgery in other neurological illnesses, and the development of resistance to

⁸⁴ Anticholinergics, antispasmodics, dopaminergic agents, benzodiazapines (e.g. Valium), and anticonvulsants.

⁸⁵ Botulinum toxin acts on the junctions between the nerves and the muscles reducing involuntary muscle contractions (twitching and jerking) while maintaining normal muscle function.

⁸⁶ Type B was launched in the UK during my fieldwork; I discuss the launch further in chapters 5 and 6.

Botulinum toxin combined to cause a paradigm shift. Deep brain stimulation (surgically inserting an electronic transmitter into the brain to stimulate the thalamus) and surgical peripheral denervation are now presented as the therapies of the future, even though they have only been tested on small numbers of people living with dystonia. For example, at the Movement Disorders conference in 2000 there were 12 abstracts on surgery for dystonia, admittedly only half the number for Botulinum toxin, but more than double those for all other therapies.

People living with dystonia use “gestes antagonistes” to control their muscle movements (for example, pulling the head down and to the left to prevent tremor), alternative therapies, and monitor their diets. But although they are encouraged to develop routines to manage their condition (especially where no treatment is available) they are not treated as knowledgeable actors. For example, many of those interviewed as part of the pilot study for the dystonia QOL questionnaire did not know what drugs they were taking and were not aware that the majority were to manage the side effects of the dystonia drugs. After diagnosis, some people are offered genetic counselling and testing at specialist neurogenetics clinics but this is usually linked to participation in research.

The Dystonia Society mediates encounters with medical and social services, for example, ensuring that people with severe dystonia claim Disability Living Allowance to employ carers and make modifications to their homes. However, the rarity and variability of the condition can be a problem with external assessors and consequently only 38% of respondents to the Society’s membership survey reported receiving one or more benefits⁸⁷ (ranging from 30% of people with blepharospasm to 73% of people with generalised dystonia), a lower figure than for other neurological conditions. In chapter 6 I explore the problems the Society had mediating medical encounters as doctors are more powerful, and (according to the Society’s staff) more credible allies than the members.

⁸⁷ Disability benefits received by anyone in the household	No.	% of total
Disability Living Allowance	153	25%
Incapacity Benefit	89	15%
Attendance Allowance	39	6%
Severe Disablement Allowance	38	6%
Income Support	33	5%
Housing Benefit	24	4%
Industrial Injuries Disablement Benefit	12	2%
Invalid Care Allowance	12	2%
Disabled Person’s Tax Credit	1	0%
Other	1	0%

Until 1999, the Society was the only UK organisation for people living with dystonia , until the North East branch broke away to form Action for Dystonia Diagnosis, Epidemiology and Research (ADDER⁸⁸) in 1999 following a row over who had the right to fundraise. They have both established websites and chat-rooms, and members also use ones provided by North American dystonia patient support organisations.

The healthcare system in the UK

The majority of healthcare in the UK is provided by the NHS, which is free at the point of delivery and financed from general taxation. Overall responsibility rests with the Secretary of State for Health who chairs the NHS Policy Board, which sets out the framework within which the NHS operates. Health Authorities were responsible for commissioning healthcare until 2002 when they were replaced by Primary Care Trusts, which bring together a number of local Primary Care Groups⁸⁹. Although most decisions about purchasing are made locally, the Department of Health has influenced the provision of specialist services and issued guidelines for new medicines (for example, Beta interferon), and local prescribing is monitored by regional health authority “prescribing advisers” who check that budgets are being used cost-effectively. Information about the relative effectiveness of interventions is disseminated through the NHS Research and Development strategy (established 1991), which receives 1.5% of the NHS budget. This money funds two centres in Oxford and York that conduct economic reviews and meta-analyses⁹⁰ and disseminate information through two journals and an on-line database.

Evidence-based medicine and the National Institute of Clinical Excellence

The current white paper on the NHS [1997] foregrounds evidence-based medicine, which uses clinical guidelines to limit prescribing to treatments of demonstrable efficacy to increase the efficiency and “customer-focus” of the health service (and control over medical staff). The “gold standard” for evidence is the randomised controlled trial but QOL measures are increasingly influential as they are thought to be an inexpensive way to include the “patient’s perspective”. Only treatments and technologies judged efficacious by the Institute will be included in clinical guidelines, and while doctors will not be prevented from prescribing treatments that the Institute consider to be of marginal efficacy, they will have to argue strongly for the resources to do so⁹¹. Two other bodies evaluate medical interventions (the

⁸⁸ ADDER, after the snake around Asclepius’s (the god of medicine) staff.

⁸⁹ Collectives of “fundholding” GPs who are both purchasers and providers as they manage their own budgets.

⁹⁰ Different studies are analysed together to increase the “power” of the numbers by increasing the sample size.

⁹¹ The health economist Maynard believes “inefficient prescribing” should be a disciplinary offence.

organisation for Health Technology Assessment and the Cochrane Collaboration Review), however these focus on treatment efficacy rather than NHS resource implications.

The National Institute of Clinical Excellence was established in 1999 as a coordinating centre for the evaluation of treatments, development of clinical guidelines for common conditions, and clinical audit⁹². It investigates treatments of marginal effectiveness (for example, Riluzole in motor neurone disease) or that represent a high proportion of NHS expenditure, either due to the individual cost (for example, combination therapies in HIV), or the volume required (for example, hip replacements). The institute has a budget of £10.5 million, employs 40 staff, and has a non-executive board of clinicians, economists, health service researchers, politicians and patient representatives.

The test case for the Institute was the flu drug Relenza, which the NHS wanted “rapidly appraised” before it advised health authorities to purchase it [NICE 2000]. The appraisal concluded that the main benefit of the drug (that it delays the onset of flu by 24 hours) would only be useful if it was given to the working population where it would produce considerable savings for industry. Since it would be primarily given to the elderly whose time was “less valuable”, it was not a worthwhile investment. This decision received considerable attention (the Institute handled 400 press enquiries during that week) despite their promise that the drug would be given a fuller appraisal later in the year⁹³. Glaxo Wellcome (Relenza’s manufacturers) were distressed by the adverse publicity and the Institute found it difficult to communicate that they were not rejecting the drug outright or suggesting it was harmful, just that it was not the best use of NHS funds. The need for them to balance efficacy and resource implications has proved the hardest aspect of its work for outsiders to grasp, largely because the move to evidence-based medicine was presented as a means to ensure that patients get the best treatment as quickly as possible. HIV patient support organisations in the US have successfully lobbied the Food and Drugs Agency for the early release of drugs and it will be interesting to see if UK organisations have the same success with the Institute where the main consideration is cost to the health service rather than product safety. I explore this further in chapters 6 and 7 when I look at submissions from the Alzheimer’s and Motor Neurone Disease societies and the case for Beta interferon.

⁹² In 2002 its website (www.nice.org.uk) recorded 39 treatment evaluations ongoing, 33 completed, 7 audits in progress, 8 completed, and 32 guidelines being developed and 5 completed. However, I noticed some double-counting as procedures were listed as ongoing *and* completed once they had been through their first appraisal.

⁹³ Relenza can now be prescribed to “at-risk adults” if they start treatment within 48 hours of onset of symptoms.

increase the NHS's interest; for example, the efficacy of existing drug treatments is being reviewed by the Cochrane Collaboration.

Conclusion

Within the context of wider anthropological debates, this thesis sets out to answer three questions which can be usefully approached using the insights of Foucault and his interpreters (e.g. Rose [1990, 1996, 1997], Armstrong [1984, 1995, 2002]), anthropological writers on "audit culture", Bourdieu [1977, 1992], and Latour [1987, 1992]:

1. If the disabling impact of dystonia cannot be fully represented by clinical measures, can it be captured by a measure of QOL?
2. Do measures of QOL give a voice to people with chronic conditions (as has often been claimed)? If so, "why can't these natives speak for themselves?"
3. If QOL measures cannot represent complex conditions like dystonia or give a voice to people living with dystonia, why are they still so successful?

In addressing these the thesis explores a number of related questions, including:

- How does the Society represent people living with dystonia? How might its interests as a self-sustaining bureaucracy conflict with those of its members?
- What are the origins of QOL and how do we explain its rapid expansion? How do the actors described in this thesis (especially the pharmaceuticals and patient support organisations) use QOL to enrol each other into networks?
- Can people without disabilities understand the experiences of people with limiting conditions and give them a value? Why it is currently necessary for them to do so?
- Why is the relationship between people living with dystonia and their doctors both important, and often unsatisfying?
- How do people use narratives to embed dystonia in their lives and give it a meaning that enables the construction of a new "self-story"? And how does the personal and holistic representation of dystonia in these narratives compare with the fragmentation, objectification, and aggregation performed by measures of QOL?

I begin to address the last question in the next section by exploring the experiences of people living with dystonia.

Chapter 2: Living with dystonia

This section consists of two chapters where I explore people's experiences of living with dystonia (set in the context of other chronic illnesses) and the stories they tell about them. The second chapter develops the themes raised in the first using six stories from people living with dystonia, while acknowledging the problems inherent in such narratives.

The experience of living with chronic illness has been widely studied by sociologists and anthropologists [Cornwell 1984; Blaxter 1976; Conrad 1990; Bury 1991; Strauss et al 1994], many focusing on a particular condition [Scambler 1989, Jacoby 1994: Epilepsy; Robinson 1988: Multiple sclerosis]. But starting from medical categories rather than people's experiences can ignore diversity within conditions and similarities between them. This is apparent in dystonia where someone whose eyes close compulsively (blepharospasm) may have little in common with someone who is inaudible due to muscle spasms in their voice box (laryngeal dystonia) or whose hand seizes up when they write (writer's cramp). What they share are problems representing and communicating their experiences, due to the diversity and variability of dystonia and the inadequacy of existing forms of representation. The problems of representation that are fundamental to the experience of dystonia are not captured by medical categories or measures of QOL based on these. This means that the experiences of people living with dystonia are not validated or responded to by "gatekeepers" of medical and social care and they are often not believed or taken seriously, which accounts for much of dystonia's impact on wellbeing⁹⁴. In the next section, I briefly review literature on living with a chronic illness, before focusing on the themes that distinguish living with dystonia.

Illness can cause "biographical disruption" [Bury 1982] as it reverses the cultural logics that people use to define themselves [Murphy 1987], putting personal meanings "at risk" and potentially causing "loss of self"⁹⁵ [Charmaz 1987]. Liminality has been used to describe how chronic illness disrupts the routine and structure of life⁹⁶ [Frankenberg 1986; Kleinman 1988]

⁹⁴This is common to other syndromes like chronic fatigue and pain, which I describe later in this chapter.

⁹⁵The neuropsychologist Sacks described how his image of the "ship of life" with himself as captain was disrupted by illness. This changed his status from "all-knowing specialist" to "know-nothing patient" [1984], an experience shared by Rabin, a neurologist with ALS (Motor Neurone Disease) [1982].

⁹⁶And to characterise people with disabilities [Murphy 1987], and cancer [Frank 1995, Little et al 1998].

and reduces people's "sense of coherence" and "potential" [Antonovsky 1979], entailing a cycle of adaption and re-adaption⁹⁷.

However, much of the literature on chronic illness ignores sick people's "multiple positionings" (gender⁹⁸, age, class⁹⁹, sexual orientation, race, ethnicity, and citizenship) and treats illness as a "master status" (hence the reluctance of patient support organisations to explore internal power differentials). Characterising illness as "biographical disruption" ignores the role of age and social class [Pound et al 1998; Williams 2000], as in certain contexts illness can also represent a "biographical continuation" or "reinforcement".

The term "stigma" [Goffman 1963] has been used to describe the social anxiety experienced by people with visibly different appearances or behaviour patterns (due to illness or disability). However, its utility is debatable as it implies deviancy and conflates identification and labelling. Stigma can be externally or "internally referential"¹⁰⁰ [Scambler and Hopkins 1990] and "spread" to intimates of the affected person¹⁰¹ ("courtesy stigma" [Goffman 1963]). It is managed through concealment, avoidance, "appearance checking", "reassurance seeking", compensation and pre-emptive disclosure [Facial injury: Clarke 1999 and Kent 2000; Diabetes: Ryan and Coates 1998; Rheumatoid arthritis: Weiner 1975; Ileostomies: Kelly 1991]. But these public strategies require considerable energy and can damage close relationships if the person privately "dumps" on their partner or family.

Chronic illness often has a transformative effect on close relationships¹⁰² [Corbin and Strauss 1988; Parker 1993; Kuyper and Wester 1998], especially where partners are carers [Orona 1990]. However, its impact on single people can be greater as future relationships may be inhibited by social isolation (exacerbated by the financial implications of chronic illness) or low self-esteem. Illness can also change people's relationship to time and space [Garro in Delvecchio-Good et al 1994a; Little et al 1998; Kleinman 1994; Lawton 2000; Davidson 2000]. For example, severe deterioration or disability can cause "existential fatigue" and "withdrawal" [Toombs 1992] and so dominate consciousness that it becomes difficult to

⁹⁷Adjustment to chronic illness [Golembieski 1976; Antonovsky 1979] was studied by psychologists focusing on coping [Felton and Revenson 1994], sense of coherence [Antonovsky 1993] and mastery [Pearlin 1989].

⁹⁸Women with disabilities are regarded as more disabled than men [Moss 1997; Fine and Asch 1988; Morris 1991] but studies of individual conditions present a more complex picture [neurofibromatosis: Ablon 1996].

⁹⁹Different class positions can produce different health beliefs [Blaxter 1983; D'Houtard and Field 1984].

¹⁰⁰Many suffer more from "felt" than "enacted" stigma [Jacoby 1994], for example, parents can act as "stigma coaches", limiting their children's activities and life expectations to protect them from discrimination.

¹⁰¹Who also engage in impression management to protect their own identities [Alzheimer's: MacRae 1999].

¹⁰²Not always negative, see [Radley 1989] (supported by Bella's story, chapter 3).

attend to the everyday, undermining the idea that we live in the same world as those around us [Garro in Delvecchio-Good et al 1994; Kugelmann 1999].

While these themes are also relevant to people living with dystonia (as the stories in chapter 3 suggest), their accounts tend to focus more on the following: firstly, on the onset of dystonia (understanding and representing changes in the body); secondly, on obtaining a diagnosis and maintaining relations of trust with doctors¹⁰³; thirdly, on communicating dystonia to others; fourthly, on responding to dystonia¹⁰⁴ (by integrating it or fighting it); and finally, on external responses to dystonia¹⁰⁵. These are the themes I have chosen to explore in the next section, using extracts from interviews and accounts from the Dystonia Society's newsletters¹⁰⁶, collections of "patients' experiences", and dystonia-related "bulletin boards".

1: Understanding and representing changes in the body

I could not describe what was happening to me, and no matter how much I tried could not help myself

The onset of dystonia can trigger an epistemological crisis if people cannot understand or describe what is happening to them. They may feel isolated because their experience feels uniquely horrible and their family or friends either cannot or will not share it. They may also feel frustrated that an apparently trivial problem can have such severe consequences. Tim¹⁰⁷ recounts how finding the winter sun "troublesome" and "blinking more than usual" soon progressed to his eyelids "closing firmly" if he walked more than a hundred yards, watched television, or went into a building with strip lighting. He was only able to read by holding his eyelid up with his fingers. Tim became "housebound" and has vivid memories of "feeling my way around my own house". But far worse than the "isolation" was the "frustration" at knowing that "everything else about my body was functioning as before and yet I could do virtually nothing".

Tim's first step was to present his symptoms to a GP in the hope that they could "organise" them into a condition [Balint 1968] and create a narrative about them that suggests a future

¹⁰³I explore this further in chapter 4.

¹⁰⁴I look at people's ways of making sense of dystonia in chapter 3.

¹⁰⁵The hostility they experience may be explained by dystonia's contravention of social ideals like self-control and containment and the equation of health with moral personhood [Crawford 1980].

¹⁰⁶The Society newsletter (published four times per year) is an important source as each issue has at least three pages of letters from members and another five pages of articles discussing their experiences in a more general manner. Although the editors prefer inspiring accounts, submissions are rarely edited and surprisingly frank, possibly because the newsletter has delegated the role of "public face" to Dystonia News, which is directed at donors (see chapter 5). Despite the gap between newsletters, there are often lively exchanges (for example, on whether positive accounts of living with dystonia are inspiring or demoralising).

¹⁰⁷One of the founder members of the Society, writing in its Newsletter.

direction (“therapeutic emplotment” [Mattingley 1998]). In his case this strategy was successful¹⁰⁸, however, many people find it difficult to describe their symptoms or convey their impact (even to a partner). Catherine¹⁰⁹ movingly describes her embarrassment at the way her head was jerking, which she managed to conceal “using certain muscles in my neck”. Not only could she “not describe what was happening to me” but “no matter how much I tried I could not help myself”. She recalls how she “even talked about separating” from her husband as (after the collapse of his business) she “knew he couldn’t bear to look at me”.

2: Obtaining a diagnosis and maintaining relations of trust with doctors

I asked whether I have got dystonia. He did not answer and neither did the hospital that diagnosed me when I telephoned them. I am now left in midair

The moment of diagnosis is a pivotal part of accounts of illness as it combines internal understanding and epistemological validation, with external recognition, and access to resources. But it can be one of mixed emotions. Anne¹¹⁰ describes experiencing not only “joy” on diagnosis as “it was a physical illness and I didn’t have to hide any more”, but “anger” because she “had lost so many of what should have been the happiest times of my life” and suspected that “had I not found out about my condition, my children may not have had a mother as they were growing up”.

People living with dystonia often have difficulty negotiating a diagnosis as many GPs believe it is psychosomatic¹¹¹ despite recent physiological studies that have established its organic causation. The persistence of this belief among doctors may be partly due to lack of knowledge or feelings of powerlessness, but its effect is to increase people’s feelings of guilt and isolation. Sontag observes “theories that diseases are caused by mental states and can be cured by will power are always an index of how much is not understood about the physical terrain of a disease” [1988]. This uncertainty increases disability, as do disagreements between people living with dystonia and their doctors (see also chronic pain [Greenhalgh 2001]).

Once its organic nature has been established (synonymous with its reality), people can explore psychological contributions (for example, the role of stress), but before diagnosis these are seen as competing with the physical, distracting doctors from the “real” cause, and

¹⁰⁸His condition was alleviated by surgery in the 1980s and has not recurred.

¹⁰⁹A woman with cervical dystonia writing in the Society’s Newsletter.

¹¹⁰A woman with torticollis writing in the Society’s Newsletter.

¹¹¹This also true of chronic fatigue [Cooper 1997], irritable bowel [Adamson 1997], and chronic pain syndromes [Kugelmann 1999], all of which occur mainly in women.

allowing them to conceal their lack of knowledge behind “it’s all in the mind”. After diagnosis, they can be used to shift responsibility back onto the person with the condition¹¹², what Crawford describes as “victim blaming” [1980]. Harriet¹¹³ vividly recalls how “so many of us have suffered through doctors thinking the condition was psychosomatic - one person even told me she was told for ten years that she was avoiding her marital problems by ‘looking away’!” She emphasises “how important it is that people don’t feel they are in any way responsible for their own illness - that if only they were ‘better’, happier, and more relaxed people, they wouldn’t be so disabled!”

People with conditions like dystonia that appear psychosomatic are vulnerable to doctors’ expectations that they will be “good patients” (for example, people with chronic fatigue advise each other to conceal independent research, interest in alternative therapies, or membership of a support society in order to receive good treatment¹¹⁴). Garro describes this process in Temporomandibular Joint disorder (TMJ) as “becoming a real sophisticated TMJ patient” [in Delvecchio-Good et al 1994]. People with these conditions tend to “idealise” and/or “demonise” their doctors [Greenhalgh 2001], but have not relinquished hope in conventional medicine and continue to search for a “good doctor” to validate their experiences. Their search for diagnosis is a search for a name with the power to control the pain, which is also the goal of treatment among the Dinka [Lienhardt 1961] as naming the spirit that causes sickness enables one to symbolically free oneself from the condition. According to Good, people with TMJ also look for “an image that will name its source and allow it to be separated off from the self, an image that will provide the symbolic structure for a remaking of the world” [in Delvecchio-Good et al 1994].

Dystonia has most in common with chronic pain, which is also diverse, difficult to represent, and could be described a “classificatory anomaly”¹¹⁵ [Douglas 1970]. Consequently, the approach to the experiences of people with chronic pain recommended by Kleinman [in Delvecchio-Good et al 1994] of situating them in their “local moral worlds” and life courses and recognising that pain narratives arise from interactions with positioned researchers, is just

¹¹²“Accounts that give a key role to ‘stress’ in the causation of IBS involve accepting that ‘psychological’ and ‘social’ factors are implicated in one’s illness. Such a position, though to varying degrees, raises the spectre of the assignation of some degree of responsibility to the patient for their illness” [Stenner et al 2000]

¹¹³A woman with cervical dystonia writing in the Society’s Newsletter.

¹¹⁴This caution is understandable when at one meeting a specialist in chronic fatigue spoke about “saving” his patients from the “charlatans” and criticised the “political” nature of their patient support organisations.

¹¹⁵By definition pain is an acute signal of bodily dysfunction so if it is not acute and does not represent anything beyond itself, can it even be described as pain?

as applicable to dystonia where impairment can seem slight but lead to considerable disability.

Like dystonia, there are hierarchies within chronic pain according to the nature and source of the pain¹¹⁶ and its responsiveness to medical intervention. At onset chronic pain is diagnosed as “real” but when treatment fails there is “emergence of doubt” and it is downgraded to “chronic pain syndrome”, forcing the person to turn to lay theories of causation and seek help in the chronic pain “subculture” [Kotarba 1983]. Genevieve¹¹⁷ provides a dystonic example of this as she recounts how her diagnosis was “taken away from her” when her spasms failed to respond to Botulinum toxin; “it was suggested that I have an EMG to find out exactly what muscles were affected. When I went for the next lot of Botulinum toxin injections in June, the doctor told me that the EMG was normal [...] so he wouldn’t give me any injections. His words were ‘it would be like smashing a walnut with a sledgehammer’. I asked whether I have got dystonia. He did not answer and neither did the hospital that diagnosed me when I telephoned them. I am now left in midair. My neck twists. I feel disfigured and discomforted, and I can get no help from anyone”.

The search for relief often becomes central to the lives of people with chronic pain, something that can also be seen in dystonia; for example, Beatrice¹¹⁸ manages her spasms by creating a “controlled environment” with “no carpet, no wall paper, filtered air and water” and no visitors (see chapter 3). Most people with chronic pain end up at pain management clinics (or “dumping grounds” [Bendelow and Williams 1996]), which aim to reduce “pain behaviour” rather than pain, despite the psychological damage caused when others do not acknowledge your reality [Jackson in Delvecchio-Good et al 1994].

Sociological research on illness is still influenced by Parson’s “sick role” [1951], which was intended for acute rather than chronic (or asymptomatic) illness. This characterised illness as undesirable, “deviant” and temporary and once the sick person’s condition had been certified by a doctor, they were allowed temporary relief from work¹¹⁹ and social responsibilities. Sick people were not responsible for getting well, but for seeking medical help, relinquishing their independence to a doctor, and segregating themselves from the healthy¹²⁰. The balance of

¹¹⁶Acute pain from a specific cause that can be visualised with medical technology or chronic pain with no origin or from a past injury [Bendelow and Williams 1996; Jackson in Delvecchio-Good et al 1994].

¹¹⁷A woman with dystonic spasms writing in the Society’s Newsletter.

¹¹⁸A woman with oromandibular dystonia writing in the Society’s Newsletter.

¹¹⁹Work can also be a source of distraction and validation [Delvecchio-Good et al 1994; Fifield et al 1991].

¹²⁰And from other sick people in case they sapped their will to recover.

power in the Parsonian relationship rests with the doctor¹²¹ who controls what is labelled as illness [Kelly and Field 1996], what is included within particular illnesses [Heijmans 1999], and what counts as recovery [Bendz 2000]. This model is undermined by the way uncertainty about diagnosis and prognosis, and limited therapeutic possibilities turn people with dystonia into “lay clinicians”¹²² [Robinson 1990]. For example, Beatrice hopes that now she is treating her allergies she will experience “spontaneous remission”. She wishes that “doctors would listen to us more and help us to get to the bottom of the cause of our own individual case”. Beatrice believes that “like headaches” dystonia is “a symptom not a disease”, the difference being that “most doctors try to find out the cause of severe headaches” and “don’t just call them ‘idiopathic’”. The process of becoming a lay clinician is currently being encouraged by the government who sees the “expert patient” as a key figure in reducing the demands of chronic illness on the NHS [Department of Health 2001].

3: Communicating dystonia to others

*Neither my husband nor my family could understand why I could not open my eyes:
‘such a simple thing to do’!*

People with all-encompassing conditions like severe forms of dystonia often experience “communicative alienation” due to the “unsharability” of their experience, which can cause the “collapse of language”¹²³ [Scarry 1985; Little et al 1998]. Hilary¹²⁴ vividly describes her fear after being diagnosed with laryngeal dystonia and her problems communicating with her children; “I had to repeat things over and over and over as if it wasn’t hard enough the first time. I sometimes would just stop talking. The kids would ask ‘Mummy, Mummy, why aren’t you talking to me?’ They couldn’t understand what was happening to me”. Hannah¹²⁵ reflects ironically on the difficulty of conveying the reality of torticollis (muscle spasms in the neck) to someone whose knowledge comes from text and two-dimensional images rather than experience; “for a sufferer [...] certain things are out of the question - being an astronaut, or a trapeze artist, or being a steeplejack. It’s obvious why these lifestyle options are unavailable. Obvious to us sufferers. But not to doctors, it seems”. Consequently, she has had to obtain a letter from a consultant Otolaryngologist explaining why “a tracheostomy [slit in the

¹²¹Parsons responded that this was inevitable and desirable [1972] as they were situated in a hierarchical social structure, and the doctor was also entrusted with the population’s health [Mascide 1991].

¹²²Similarly, one year after stroke most people realise that biomedicine has little to offer and the degree to which they adopt medical understandings varies with their doctors’ contribution to illness management [Becker and Kaufmann 1995]. They tend to select useful elements and discard what doesn’t help them make sense of their condition and get on with their lives, what Early calls the “customisation of illness” [1984].

¹²³The “strangeness” and “fuzziness” of dystonia is described by Alan in chapter 3.

¹²⁴A woman with laryngeal dystonia, contributing to an internet chat room for people living with dystonia.

¹²⁵A woman with torticollis, writing in the Society newsletter.

windpipe to aid breathing] and spasmodic torticollis would be a fatal combination” and offers to send a copy to anyone who needs it!

Representing dystonia is difficult as it is a diverse and incoherent condition¹²⁶ (“a higgledy-piggledy package” [Alan, chapter 3]) that resists classification. Mark¹²⁷ describes “we Dystonians” as “an odd lot” because of their refusal to “fit comfortably in any of the GP’s obligatory pigeonholes” (apart, of course from “one marked ‘miscellaneous’, being a non-offensive word for ‘all in the mind’”). Similarly Tim¹²⁸ feels that Blepharospasm “makes us ‘special’” because they exist in a liminal space between the categories of “sighted” and “unsighted” - “we are not optically blind but for most of our day we cannot see”.

Dystonia’s variability makes it difficult to convey its impact to others¹²⁹ (hence the problems people living with dystonia have had obtaining disability benefits). The invisibility of dystonias affecting writing and speech means that they must be “performed” to reveal the person’s suffering (even though to them it “is paradigmatic of what it is to have certainty” [Scarry 1985]), undermining their credibility and contravening social rules about displaying emotion or weakness¹³⁰. One of the reasons people living with dystonia are keen to embrace QOL research is that they feel they have been a “muted group” [Ardener 1975] and their experience is still not acknowledged in popular or medical discourses. Jane’s¹³¹ story provides an example of this as her “uncontrollable blinking” was misdiagnosed as “severe depression”, and after three years of anti-depressants, a year of therapy, and “constantly being told ‘no-one can help you except yourself’” she “stopped seeking medical advice”. The clinicians’ failure to respond to her experience had repercussions on the rest of her life as “neither my husband nor my family could understand why I could not open my eyes” and her friends avoided her “because they didn’t know how to cope with me”. She even missed out on the first three years of life of her first grandchild as she couldn’t see to take her out. Jane concludes “I felt stupid, I looked stupid and I thought my life as I knew it was finished. I had been reduced from a happy, confident, outgoing person to nothing”.

¹²⁶The accepted medical definition is hardly precise: “a syndrome of multiple disorders” involving “involuntary sustained muscle contractions” [Fahn et al 1987].

¹²⁷A man with laryngeal dystonia, writing in the Society’s newsletter.

¹²⁸A man with blepharospasm, writing in the Society’s newsletter.

¹²⁹“One day I could walk or get around fairly easily, another day I was struggling to get the leg down [...] the doctors thought, ‘this kid is just putting it on’” [David, chapter 4])

¹³⁰For example, the discourse of positive thinking treats pain as weakness because it stems from a failure to “master” one’s emotions [Kugelmann 1999].

¹³¹A woman with Blepharospasm, writing in the Society’s newsletter.

For Simon¹³², it is the “lack of awareness and ignorance” from his employers that causes him to feel “despair and a feeling of helplessness”, rather than the “painful and disabling nature of torticollis. Paradoxically, he is cheered by reading others’ comments about the effect of torticollis (like ‘my head feels like a lead balloon’ or ‘I find social gatherings a nightmare due to pain and embarrassment’) as although “this all sounds very negative [...] perhaps the reality is just that!” This confirmation of his perceptions enables him to ignore comments like ‘is your neck better?’ or ‘I heard that it was the draught from the car window’ and confront his employers’ belief that he is “skiving”.

In later chapters, I explore whether the discourse of QOL can give people a voice, either through QOL measures or by creating a discursive space where different voices can be heard. I also examine whether it can be used as an “oppositional habitus”, even though its expansion has been driven by QOL researchers, health economists, and pharmaceuticals, rather than people with limiting conditions.

4: Responding to dystonia

The point is I have dystonia, not I am dystonia

Paul powerfully describes the anger experienced by many people with dystonia - against God, society, our families, and “above all, against ourselves”. The “fear and loathing of our own bodies” fuses with “fear of helplessness and dependency” and of “leav[ing] the house because you feel like a freak and you think everybody is going to stare at you”. For him, and I suspect many others, “the most difficult thing is learning to love and accept my body, which is so often tense and helpless”. While accepting disability is an internal and individual process, accepting the label “disabled” can provide access to community support, resources [Ablon 1990] and opportunities to campaign. For example, Geoff¹³³ was motivated to take an MA in Disability Studies by his colleague’s refusal to take his condition seriously and acknowledge his identification as a disabled person:

I think I was in denial about my condition, and wanted to conform and be normal, especially as a young person (this was before disability was cool). I negatively internalised and absorbed the way I was told I should view myself, by others who did not share my experience of dystonia and did not understand disability. [...] I think the turn around came ten years ago, when a work colleague of mine - an experienced, qualified social worker (non disabled) - told me in no uncertain terms that I couldn’t define myself as a disabled person because I wasn’t ‘disabled enough’ - i.e. I didn’t use a wheelchair. I was infuriated, because I felt strongly by then that I had the right

¹³²A man with torticollis, writing in the Society’s newsletter.

¹³³A social worker and disabled activist with cervical dystonia, writing in the Dystonia Society’s Newsletter.

to acknowledge my impairment and ally myself with other disabled people. Imagine a white person telling a black person that they couldn't call themselves black, because their skin wasn't, in their view, a dark enough pigment! In some ways I am grateful to my irksome ex-colleague, because his discriminatory comments really cut me to the quick and forced me to think through my own views about disability and 'coming out' as a disabled person. And I am definitely the stronger for it. [...] In a strange way, I am now quite proud to have dystonia. I have accepted myself as a disabled person and everyone else can basically like it or lump it

However, this strategy has its costs as identification occurs through accepting a stigmatising and externally imposed label (which may "spread" to other areas of the person's life) and identifying with disvalued "others". Thomas¹³⁴ emphasises the importance of maintaining that "I have dystonia, not I am dystonia" so that others understand that "we are much more than the disorder that affects us" and "whilst it may limit us and confine us, it should not be allowed to define us".

Many people living with dystonia even feel conspicuous among others with the condition, which limits their ability to engage in collective action or support others. James¹³⁵ describes how "many people in this position do not have the emotional capacity to cope with their own problems, and cannot be expected to help themselves, let alone others with the disease", especially as "their instinct is to [...] completely avoid others in a similar position, lest they are forced to recognise their own degree of disability and how awkward they appear to others". Positive identification as a person with a disability may also require "demedicalisation", which involves rejecting fantasies of a return to "normality" through successful treatment.

Many people make sense of illness by embedding it in their personal histories¹³⁶ [Williams 2000]. For example, Maria¹³⁷ uses her dystonia to order and explain past experiences and guide the future; "I have grown accustomed to being laughed at for poor coordination, and people treating me as stupid when I am tired and my thinking/talking process slows down. [...] I know that I should not, even vicariously, experience passionate discussions, emotional scenes, aggression or violence. And I have lived with the fact that I simply cannot do anything quickly, nor two things at once. But nobody could tell me why. So it was such a relief to learn [...] that this is all part of dystonia". After what she now realises was "a lifetime of dystonia", she is able to "instinctively balance my life between the cerebral,

¹³⁴A man with cervical dystonia, writing in the Society's Newsletter.

¹³⁵Partner of someone living with dystonia writing in the Society's Newsletter.

¹³⁶In chapter 3 Sarah links it to childhood clumsiness and migraines ("different pockets of things happen and fit into place and I think 'I've been here before'") and Jane recalls her feet always turning inwards.

¹³⁷A woman with generalised dystonia, writing in the Society's newsletter.

physical and social”, and her new role as an “expert patient” was facilitated by her early retirement last year.

Maria’s story provides an example of how illness can provide a space for reflection and legitimise self-expression and role change [Heurtin-Roberts 1993]¹³⁸. Blepharospasm prompted Mike¹³⁹ to leave an “exhausting corporate job”, start his own business, and increase the amount of time he spent with his family (“this really changed my entire life and I’m so grateful for it”). Belinda¹⁴⁰ also redirected her finances from maintaining her “greedy” car to “regularly investing money” in her body through complementary treatments, which recovered her “sense of well-being and hope” and gave her an “increasing level of energy”. Catherine¹⁴¹ started going to art classes and learnt to ask for what she wanted, realising that “if you go about in life with the impression that it’s all due to you and your physical disability, people will let you”. She now maintains that she “couldn’t be any happier” without dystonia because “I probably would never have fought quite as hard to do something with my life as I have” and reckons she has “come out of this a better and more understanding person”. However, illness can also inhibit change by adding biological to social and financial constraints (suggesting that some “progressive” or “healing” stories may be following narrative conventions [Robinson 1990; Crossley 1999]) and can be ultimately limiting if it “naturalises” an intolerable situation¹⁴².

5: External responses to dystonia

A healthy body [is] the mark of distinction that differentiates those who deserve to succeed from those who fail

Dystonia can be described as a “social disability” [Nijhof 1995] as the problems associated with it are often more acute in particular situations and locations, for example, when acknowledging people in the street or ordering food in a restaurant. Martin¹⁴³ describes his uncomfortable awareness that “the twist of my head” can give the impression that he is either “staring” or “looking away from people as though I didn’t want to see them”, making negotiating public places an embarrassing experience. Similarly, Connie’s¹⁴⁴ problems

¹³⁸For Afro-American women in Heurtin-Roberts’s study, hypertension became a “milestone” that signalled the relaxation of external demands and acknowledgement of their needs.

¹³⁹A man with Blepharospasm, writing in a volume of “Patient’s stories” [BEBF 2000].

¹⁴⁰A woman with dystonia affecting the eyes and neck, writing in the Society’s Newsletter.

¹⁴¹A woman with cervical dystonia, writing in the Society’s Newsletter.

¹⁴²For example, in Kleinman’s study of depression in Chinese intellectuals during the cultural revolution [1986] and Brodwin’s of a woman who communicated through chronic pain [in Delvecchio-Good 1994].

¹⁴³A man with cervical dystonia, writing in the Society’s Newsletter.

¹⁴⁴A woman with oromandibular dystonia, writing in the Society’s Newsletter.

chewing and swallowing can be circumvented with “baby food” at home, but this proves difficult to explain “to the waiter at the ‘Angus Steak House’ or even the guy behind the counter at McDonalds!” The role of environment makes it difficult to predict the level of disability associated with dystonia¹⁴⁵; in fact much of this disability is not caused by the condition but by external reactions to it, as Nanette¹⁴⁶ explains:

I have had movement in my right hand and arm since I was about four years old [...] and (etiquette being so strict in 1920) I had to find ways of covering up my disability in my right hand. It was impossible to hold a cup of liquid or use a spoon in my mouth, and when I used my left hand, I was shouted at to use my right. I realised that if I asked for a glass of water instead of tea in a cup, I could get away with using my left hand. So for years I pretended not to like tea, cocoa, etc., and only drank water

Of course, all disabilities are context dependent to some extent (for example, high unemployment among people with disabilities has been linked to “Taylorisation” in manufacturing), but this is especially true of dystonia as it encapsulates the cultural and economic tension between “control” and “release” in contemporary society¹⁴⁷ [Crawford 1984]. A condition involving visible and uncontrollable muscle spasms is obviously more disabling in a society that emphasises appearance, bodily control and containment, and maps social values onto the body [Duval 1984; Bordo 1993]. In fact, Crawford argues that in modern Western society the pursuit of health has become the pursuit of moral personhood; “a healthy body has become a sign of individual achievement [...] the mark of distinction that differentiates those who deserve to succeed from those who fail” [1980].

Self-control is embodied as “self-containment” and the “open” or “untamed body” is feared in case it reverts to its pre-civilised nature¹⁴⁸ [Elias 1994; Bakhtin 1981]. Examples of this are the preservation of “firm bodily margins” by dieters and athletes [Bordo 1993] and the popular discomfort with “leaky bodies” [Grosz 1994; Lawton 2000], which extends to the “unproductive” bodies of menopausal women [Martin 1997]. The dystonic body also contrasts powerfully with the disciplined and productive bodies required by capitalism [Foucault 1980:55-62].

Bodily deterioration is also culturally significant as the Western concept of the self as unified, unitary and self-contained (a construct that underlies QOL measures) is challenged by

¹⁴⁵A disappointing conclusion for the creators of Disability Adjusted Life Years (discussed in chapter 9) who assume that it is possible to assign universal weights to disabilities.

¹⁴⁶A woman with dystonia affecting her right arm, writing in the Society’s Newsletter.

¹⁴⁷Capitalism needs both control in the workplace and release in the shopping mall in order to function.

¹⁴⁸Kleinman attributes this to the secularisation of modern society, which changed the body from “a vehicle to higher ends” to “the secularised, private domain of the individual person” [1988].

processes like “incorporation” (where prosthetic mobility devices become part of the self) and “intersubjectivity” (when carers experience the recipient of care as an extension of themselves because they have become the agent of their actions) [Savage 1998]. Bodily control is important as it produces a sense of efficacy and coherence, which can be projected into the future. Its loss “impairs the capacity to be counted as a competent adult” [Featherstone and Hepworth 1991]. The need for control often leads to objectification and fragmentation. Objectification has been observed in groups as diverse as young men [Watson 1998], the middle-aged [Backett-Milburn and Cunningham-Burley 1999], and people with TMJ¹⁴⁹ [Garro in Delvecchio-Good et al 1994]. Fragmentation can be seen when dystonic body parts are separated from the whole (“the wretched neck starts”) and assume terrifying agency (“my eyes can’t keep me in now”). This mirrors the objectification and fragmentation that occurs in biomedicine. The imperative of control is also extended to the emotions, which should be experienced and displayed according to dominant models [Foucault 1978; Hochschild 1983; Harre 1986].

The need for control often overstates people’s agency, for example, according to Farmer¹⁵⁰ recent models of patient compliance ignore the “radical differences in the ability of different populations to comply with demanding therapies, whether they be admonitions to move to ‘consumptive climes’, as in the past century, or exhortations to take a year’s worth of several drugs” [1997]. If treatment fails, the patient often takes responsibility for not following the doctor’s instructions (even if they were incompatible with their lives) or maintaining a positive attitude¹⁵¹.

The imperative to be positive is reinforced by “Courage” awards from organisations like the Dystonia Medical Research Foundation (celebrating people who have “overcome” disability) and “public accounts” [West 1990] like Leah’s description of her daughter Nia who was “not a disabled person and never would be”. Nia’s “incredible attitude” expressed itself in adopting a gruelling fitness regime, changing her diet, continuing with her “full time job in the bank”, and even going on an “outward-bound” honeymoon. Her life choices justified Leah’s attack on “all of you out there who think ‘Why me?’ and who lie back and feel sorry for yourselves” and the families who “sympathise” and fail to “push if necessary”. Nia resembles the “super cripp” who has been criticised by disability activists for presenting an

¹⁴⁹Whose bodies changed from “lived bodies” to “object bodies” (where body constrains or opposes self).

¹⁵⁰A tuberculosis physician and anthropologist working in Haiti.

¹⁵¹For example, people with stroke are told that motivation is the most important factor in their recovery even though neurological recovery is usually spontaneous and unpredictable [Becker and Kaufman 1995].

unattainable ideal that justifies discrimination against those who fail to attain it. Leah's account is an example of the way some people manage the threat of deterioration by creating a series of "others" (for example, people with cancer who don't want to "fight" it [Diamond 1998] or people living with HIV who don't have a positive attitude [Crossley 1997]), but this requires constant patrolling of boundaries, and can cause guilt, and self-hatred if the person's condition deteriorates.

Conclusion

The experiences of "communicative alienation", invalidation and discrimination described above are not captured by measures of QOL as these focus on the individual and are biased towards aspects of physical and psychological function that can be improved by medical intervention¹⁵². Consequently they provoke more questions than they answer because while the measures testify to the disabling impact of dystonia, they cannot explain its cause, prompting some doctors to hypothesise that dystonia affects moaners and malingerers¹⁵³. In the next chapter, I explore why dystonia is so disabling using six stories that represent the varied experiences of people living with dystonia. These embed dystonia in people's lives and explore its effect on the self. I also examine potential problems with using narrative in research.

¹⁵²Themes generated by people living with MS like "public response", "financial strain", "doctor-related statements", and "impact on significant others" were excluded from the measure described in chapter 8.

¹⁵³Comments like "it can't be that bad, walking around with your head on one side" are not uncommon.

Chapter 3: Stories from people living with dystonia

This chapter is an extended exploration of the themes raised in chapter 2, using six stories from Jane, Sarah, Bella, Iris, Paul, and Alan¹⁵⁴ to give a sense of how dystonia is integrated into people's lives. It looks at how people use narrative to make sense of illness (by linking past, present and future) and give it personal meaning. It explores the methodological problems with using narrative and warns that their lability and complexity (what Bakhtin calls their "cultural polyphony" [1981]) may be obscured if the research process emphasises fixity and homogeneity.

I have attempted to avoid or acknowledge these problems in my use of illness stories; for example, being aware that although the stories are personal, they are rarely individual as they are embedded in the "institutional structures" of narrator and audience [Saris 1995]¹⁵⁵. While it could be said that the stories that follow were created by the circumstances and structures of a research interview, I believe they came from genuine and relatively equal relationships, which were strengthened by my local knowledge of significant events and institutions in the lives of people living with dystonia. The stories have narrative qualities because they are free-flowing, unconstrained, and "about those aspects of life that matter most" [Mathieson and Stam 1995:284]. In some cases they convey more by what they leave out than what they say [Skultans 1998], in the same way that the "silences" of QOL measures reveal most about their culture. This supports Rosaldo's challenge to the assumption that the most important things are most thickly described; for example, Ilongot head-hunters give only "rage borne out of grief as the reason for their activities [1993:178].

Jane

If you have a short illness it's alright, but if you have a long one people get fed up with it

The first story is from Jane, a calm and gentle woman in her forties who has generalised dystonia and is partially sighted. She has had Bell's palsy for six months, which caused her to miss two appointments for Botulinum toxin injections¹⁵⁶ and left her weak on her right side. Her narrative explored the lack of support and understanding for people with chronic illnesses, and the shame attached to disability, which caused her parents to reject the

¹⁵⁴All were elicited during semi-structured interviews in the narrator's home; Bella, Iris and Paul spoke to me as a researcher on the dystonia QOL questionnaire, Sarah, Jane and Alan while I was working for the Society's Welfare Officer (which may account for these narratives' focus on benefits and social care).

¹⁵⁵E.g. a preference for "stories of hope" on the part of some newsletter editors.

¹⁵⁶Her neurologist won't inject until she recovers in case she becomes permanently paralysed.

educational support offered to her. It drew on epic themes of loss and retreat made more poignant by the fact that most people take the small victories she described for granted (for example, being able to use a knife and fork). She copes by humour, Christianity, and sharing experiences through the Society newsletter and an informal network of people living with dystonia.

Jane had to change her GP practice when her doctor died, as the practice manager threatened to strike her off. At her new surgery “there’s a few Christians in reception, it’s much better - you get ‘hello’”, but her new doctor won’t visit her at home and “argues” with her. One doctor at her last practice tried to send her to “a home”, but her own doctor arranged accommodation at a Christian hospital which she goes to once a month when there is someone to take her. Her carers cover her meal times but she is worried about losing her independence if she takes on more support. She would like a motorised scooter but can’t afford it.

There is no practical help for people with dystonia. If you have a short illness it’s alright, but if you have a long one people get fed up with it. I wish someone would ring me up or come down, people don’t look at your real needs

She recalls a carer’s day run by her local church where even though she was “spasming on the floor” people were still talking to her about their problems, “you can see I’m on the floor, you can see I’m in spasm, but...” She checks her irritation by recalling that, “we’re all special to God”.

Jane believes she was born with dystonia as her feet have always turned inwards and she had problems with her eyes and writing hand. Her headmistress recommended a special school but her parents didn’t want to send her because they were ashamed and told her there weren’t any places, something she now resents, “I never really knew what was wrong with me”. Consequently, Jane “got into bad company” and got married “for the sake of it”. She later left her husband and went to a battered wives’ home, “I thought, ‘I’ll never go out with anyone again, never have a boyfriend’”. A few years ago she met a man with Parkinson’s disease and mental health problems who wanted to marry her and regularly sent her roses and “friendly” Valentine’s day cards.

I hadn’t intended to become involved but found myself drawn in. He died in hospital a few months ago on a machine that was breathing for him. My father died when I was young so I hadn’t seen anybody dead before, I thought he’d be blue but he was white

Jane found it difficult to get paid work as employers wouldn't provide large print books and lamps. When her three children got jobs she thought "I'll have nothing now" so went to an occupational therapy centre for 10 days "to see what I could do". She enrolled in adult education to improve her literacy and numeracy and wanted to go to a special college in Yorkshire but was judged "too bright". Instead she studied in Birmingham for a year, gaining a merit. Jane prayed for a fellow student who had applied for a teaching job and he got her a position at the same college. She had the job for a year until her dystonia worsened, making it difficult for her to walk or sit down. She was shaking so badly that she couldn't pick up a fork and recalls her embarrassment at a friend's dinner party, "I didn't want anyone to know what it was like. I wanted to curl up in a corner". Her friend tried to bathe her to help with the spasms but it made them worse.

Jane was sent to hospital for investigations and was originally told she had Huntington's disease (a progressive neurological illness that affects the personality).

I had nine or ten blood tests a day and my spasms were so bad they pulled the curtains around me to avoid frightening the other patients. I overheard people saying, 'she's really sick'. The pain in my neck and shoulder was awful and I had to lie on my side to get relief. I couldn't sit on a seat or look in a mirror as this brought the spasms on. I'd apologise but people would say to me 'oh, just spasm on'. I watched people in the neurological ward and if the doctors couldn't find anything wrong with them they were sent to the psychologist. I thought, 'blow, what do they do to them?' But the psychologist only came to see me because he couldn't understand why I was so cheerful

She spent three weeks in hospital after diagnosis; there were only two patients in the ward and the nurses treated them well, "if I woke up at ten I had breakfast then". However, the physiotherapy she was offered ("balancing on a 'Swiss ball'") was not appropriate for someone with dystonia and she recalls that the physiotherapists used to get people to come an hour early so they wouldn't have to wait for latecomers. Jane believes this insensitivity to the problems of people living with dystonia is common, "I went on a holiday for disabled Christians in Torquay and met this doctor who knew about dystonia as a condition, but still parked halfway up a hill when he took me for a walk - he wasn't thinking".

She misses her "sea holidays" but now needs to sleep in the afternoon as she has insomnia, "I can't even walk to the shops now although I want to do things on my own". She feels "exhausted in her body" as her trunk muscles are pulling in opposite directions. On a recent church retreat she found it exciting that her dystonia had improved enough to eat with a knife

and fork but is now back to a spoon. Her dystonia is variable, “today my legs are behaving themselves a bit”.

Jane was prescribed Diazepam (although she hadn't complained of depression) and now describes herself as addicted, “there's no-one at home to support me if I wanted to give them up”. She would like to discuss her medication with her new GP as she feels her neurologist doesn't have time, “you're in, out, have your jab”.

I've noticed a change in the service at the National over the past two years; I often don't get back to south London until 9.30 pm as the transport is so bad. They used to have regular guys who lived locally but now they use car hires with people from Essex who don't know the area. I have to ask them to call out the signs to me so I can direct them

Her injections cause choking and difficulty drinking but her spasms are so bad that she perseveres. Before one injection she drank two glasses of water in succession, joking with the neurologist that she might not be able to drink afterwards, “he said that he'd never met anyone with my sense of humour”.

She has been on Christian radio talking about her dystonia and has people praying for her now her blepharospasm has worsened. She wanted to be a “life-liner” on their 24 hour help-line but her balance is so bad that she couldn't travel to London for the training; “people say to me ‘you have a lovely voice’ but I'm worried I wouldn't know what to say when people call, although I have helped other people with cervical dystonia - I talked to one person for two hours”. She recalled hearing Julie Shelton on the radio (a dancer with dystonia who believes she was miraculously healed and wrote *Danced off her feet* [Sheldon 1998]) and was able to trace her through the churches mentioned in her book. “When I spoke to her I heard tears in her voice but she said there was nothing wrong, ‘I often cry as it's healing’”.

Jane is currently having problems eating and drinking (she even chokes on the skin of baked beans) and had an x-ray while eating yoghurt that showed that only half had been swallowed. “I wrote an article for my local branch of the Dystonia Society about the advantages of the ‘yellow top’ over the ‘orange top’ Sunny Delight [still fruit drink] but now I can't even swallow that. I can only drink water”. She talked about a friend with generalised dystonia whose mother was recently sectioned. She was worried that he wasn't coping but he assured her that he was putting his meals in the microwave and walking to buy a newspaper from the local shop, “I said to him ‘you might be all over the place and everyone looking at you but you are doing it’”.

Sarah

It all adds up, eventually your body says 'enough, I'm going to rebel'

Sarah is an ex-geriatric nurse in her thirties who was diagnosed with generalised dystonia in 1997. She has a flat in sheltered accommodation, which has been adapted to her wheelchair, and receives the top rate of Disability Living Allowance to employ four carers. Her narrative explores her fear of deterioration and its effect on self-preserving activities like her craftwork, how her relationship with doctors is characterised by mutual distrust, and her problems with applying for the Disability Living Allowance (for example, the intrusiveness of the questions). She links her dystonia to her childhood and working life and attempts to capture (and control) it through vivid and precise description.

Sarah feels that her fear of future deterioration isn't acknowledged by her doctors, as in the last two months she has noticed a "change of direction", "I've got all these dilemmas running through my mind, different things in different ways". Previously she had spasms, migraine with "acid sickness" and dry retching, and problems with her jaw and right hand. The spasms have now spread to the whole of her right side and her hand "balls", "spreads", and "claws".

How can I think of a sensible way of putting it without sounding really strange? It's like something in a film where someone is trying to cling on to something while being frozen in a block of ice. It's like someone getting an electric shock as my fingers stiffen in different directions

Sarah showed me how her right foot rotates and inverts, shortening her Achilles tendon. Her left leg only "spasms" up to the knee, "it pulls up and down, a bit like I was rowing". Before she began using Baclofen (a common antispasmodic) her spasms were very violent, "I was like an American jumping bean".

She describes her oromandibular dystonia as "a yawn" or "a tic", accompanied by blinking. Last night she "tossed and turned" until 2 am as the grinding of her jaw caused her other muscles to go into spasm, "I tried to glue my jaw with a carrot rather than chomping at my cheeks"¹⁵⁷. She said she didn't want a gum shield as she doesn't like things in her mouth or near her face and recalled how during an asthma attack her ex-husband put pillow over her face during for a "joke". Her jaw sometimes locks when she speaks which she said made her sound "like a scratched record"; "I have to wait until the needle has jumped over the scratch before I can continue the sentence".

¹⁵⁷She has ulcers as her jaw grinding "takes chunks" out of her mouth.

Sarah explains her dystonia by situating it in a history of personal and work-related stress, for example, having dreadful migraines as a child (“I would come home from school, throw my bag in a corner, flop out on the kitchen floor and my mother would put a blanket over me and leave me there to sleep it off”). She also attributes her early clumsiness to her dystonia (“different pockets of things happen and fit into place and I think ‘I’ve been here before’”), which she uses as an explanatory device to make a coherent narrative from diverse and traumatic memories¹⁵⁸.

She is pleased that her GP is leaving the surgery in July as she has a good relationship with his female replacement who “takes her time and doesn’t make me feel like a pain in the bottom”. This contrasts with her other medical relationships (“I’ve not had it easy with doctors or specialists”), which demonstrate paternalism rather than mutual respect; “sometimes doctors are like ‘be a good girl, run off and get some more tablets’”. Before diagnosis she was frequently told, “it’s all in your head” and during one assessment heard a doctor say to the nurses that she should “get up. She could walk on hot coals if she wanted to” (“I thought ‘why would I want to walk on hot coals?’ What a thing to say!”) Her neurologist often tells she could “do anything if you put your mind to it”. “I feel like whopping her one. If they [the doctors] can’t find out anything, it’s easier to say ‘it’s all upstairs’”. She finds not being believed particularly painful as “when I was a child, no-one would believe me”.

Sarah was not told her diagnosis until she changed GP, she suspects because he didn’t want to admit that he had been wrong. She is taking antibiotics for her ulcers (and an infection of the saliva glands caused by Benhexol) and tablets for the acid reflux that cancel some of the antibiotics’ effect; “I’m on so many tablets it’s unreal - I’m like a baby’s rattle”. She was surprised to find that the side effects did not improve after a few months and felt it was “sinister” that her doctor hadn’t told her; “Eventually he did have to admit it. I thought ‘why didn’t you give me that ammunition and information in the beginning?’ Do you put it down to ignorance or the fact that they’re not really interested and don’t give a damn?” Sarah doesn’t want to challenge her neurologist in case she is labelled as a “troublemaker” and imagines the doctors “whispering behind my back”, “when do you shout ‘It’s not good enough?’” She continually experiments with her drugs to test their interactions but is

¹⁵⁸This sense of predestination is shared by people with Temporomandibular joint syndrome, “one person described herself as ‘a walking time bomb for TMJ’” [Garro 1994b:782].

reluctant to try Botulinum toxin as the Society welfare officer described it as “a funny road to go down” and advised her to “hold off” as long as possible¹⁵⁹.

Sarah has a curvature in her spine and sciatica, which can trigger spasms, especially when travelling long distances. She has to travel to central London for her injections on her back in an ambulance; “last time the ambulance got lost and the journey took four hours which cancelled out any benefit from the injections”. She has stress-incontinence and uses pads rather than self-catheterisation as “if I’m in spasm I’m going to end up sticking it up my nose instead of the other place”. Sarah also has problems with her eyes as blurred vision is a side effect of Benhexol (“it’s like a fog over my eyes”). Consequently the “senior” ophthalmologist needed her to visit five times to get her prescription right. She can still read but finds writing difficult as it involves hand-to-eye coordination, which often brings on a spasm; “I can only write a shopping list three lines at a time, taking regular breaks”. She worries about future deterioration in case it means the end of her “craftwork”, which is a “life saver” (c.f. Cassell’s definition of “suffering” [1982]).

My normal spasms are familiar and I can accept them. I’ve never been a person to sit and do nothing, even when watching the television I would be crocheting. I don’t sit back and dwell on it - I’m a pushy person to myself. I try to be too independent - I say, ‘sod it body, I want to this and I’m doing it’. I haven’t got the time to be bitter. I’ve been dealt that hand

[my emphasis]

She believes her dystonia was triggered by an injury to her back while working as a nurse for elderly people with mental health problems.

The home was on four levels and there were no hoists, so if someone wanted to go down for dinner, three people would carry them up and down the stairs in an ambulance chair. People often wanted to return after the first course and they could be obese or have psychological problems that made them struggle as they moved. We were always short staffed. It all adds up, eventually your body says ‘enough, I’m going to rebel’¹⁶⁰

Sarah got high rate Disability Living Allowance after six years of “struggle” and moved to adapted accommodation two years ago. She should have received it automatically when she moved but was told that as an ex-nurse she was “sensible” enough not fall out of bed retrieving her duvet so didn’t need night cover. “You have forms and forms and forms to fill

¹⁵⁹Untrained staff giving medical advice is a source of tension with neurologists, as I explore in chapter 6.

¹⁶⁰Here the body is represented as an independent agent with needs and goals of its own.

in¹⁶¹. I feel I'm having to apologise for my disability, to justify why I need the money". A friend who was a social worker helped her fill them in as "it would have taken me months to fill the forms in and make them legible". However, this increased her embarrassment at the "inappropriate" questions, for example, "how many times do you go to the toilet?" "I asked them about it but they said, 'it's just what's printed on the form'¹⁶². I imagine someone getting perverted pleasure putting my responses onto a computer".

Bella

No-one knows how I feel but me, there are days when I'm on top of the world and, like anyone else, there are days when I wake in a bad mood

Bella is a forceful Irish woman in her forties who has segmental dystonia and lives with her husband in North London. Her narrative explored her wish to be treated holistically while insisting on physical causation¹⁶³, communication problems with her doctors who didn't value her expertise as a patient, the role of technology in living with dystonia, adapting to and trusting a changed body, the invisibility of some forms of dystonia, and being physically confined by dystonia. She talked about receiving support from her partner when their roles reversed and acceptance from the local community, but not from her friends who found it difficult to adjust to the change in her.

When Bella's head started shaking her doctor told her it was "all in her head" and to "go home". Six months later her condition had not improved so she returned and "begged" for help. She was referred her to hospital but felt this was a dismissal: "it was as if they though they could give you medicine and forget about the rest of you. No-one who knew me seemed to want to help me". This was reinforced by her stay in hospital where she was treated as an "interesting case" and "talked over" by her doctors.

She has had difficulty getting injections of Botulinum toxin since her diagnosis because of the "laissez-faire" attitude of some neurologists who "miss clinics to go to foreign conferences". While she and her husband know more about the effect of the injections than her neurologist, she feels this expertise is not acknowledged, for example, she was told that missing her last injection wouldn't affect her even though she knows that missing injections

¹⁶¹The form comprises about four books with 70-80 questions (see Shildrick and Price's Foucauldian analysis of the specificity of social security forms [1997]).

¹⁶²An example of the "bureaucratic indifference" described by Herzfeld [1992]?

¹⁶³She referred to a history of "nerves" and repressing emotion that may have contributed to her dystonia.

affects her voice. Bella doesn't think her neurologist is an experienced injector, as last time she was injected the area was not anaesthetised properly.

Her husband notices the change after her injection as the tension in the injected areas vanishes. "He's learned to look at my face and my eyes and not just listen to what I say - 'I'm fine' [she mimes a forced smile]. I joke about it, that's how I get through, I laugh first and everybody follows on, all the jokes are done then". She is diabetic and asthmatic which affects her speech and breathing, particularly when she is upset. Her dystonia gets worse in tense situations "because I can't let it out, scream and shout". For example, when she argues with her husband, by the time she stops feeling distressed and starts feeling angry he is "smiling again" so she never gets to speak about what upset her.

Bella has two adult daughters living in Ireland and is estranged from the eldest who won't let her see her grandson. She believes her dystonia provoked the argument that caused the estrangement. She can't see her other daughter at the moment as her brother-in-law is decorating the house where she normally stays. Bella was adopted and has a poor relationship with her birth mother. She described how helpful she found "relaxation therapies" as she tends to "take on other people's feelings" and finds it difficult to distance herself from her family. She used to go swimming every day and is now slowly learning it again, "there used to be three things I could do - walk, swing my legs and breathe, but then my brain stopped. I've had to learn again to do what I can do now". She is also controlling the spasms in her leg with weight training.

Bella describes herself as forgetful (for example, leaving the oven on) but wants to take responsibility for her mistakes, even though her husband treats her dystonia as a shared enterprise. "The forgetfulness upsets me more than anything else because I feel it isn't me". She enjoys baking diabetic cakes and calls her husband when it's time to take them out of the oven; "we do it, the two of us". Her husband has asked her how she feels about the change in her but she analogises it to his being bald, she has to accept him the way he is now; "I will never be the person I was".

Her best friend (who used to go shopping for clothes and out to lunch with her) died recently, followed by her friend's partner who "lost the will to live": "the cancer didn't kill him - he just stopped, he didn't want to be here anymore". She says that the local people know her well and accept her, but she becomes frustrated when they ask over her head "how is she?"

“No-one knows how I feel but me, there are days when I’m on top of the world and, like anyone else, there are days when I wake in a bad mood”. Bella can’t use her left hand (it doesn’t grip) but can type one-handedly on her computer. She uses the Internet and has pen friends in Spain and Russia.

Her husband first noticed the shake in her hands but her GP thought she was imagining it as she was on anti-depressants due to her husband’s addiction to alcohol and painkillers. She has experienced considerable pain, especially in her arm, which often wakes her up at night. Bella says this has never been acknowledged by her doctors. She was given Benhexol to control the spasms but had to stop it as she was becoming very confused; “I nearly walked under a bus! They used to give it to Parkinson’s patients but stopped because the side effects were so bad”. She says that she wasn’t warned that she was taking a high dose and was prescribed other anti-depressants to counter the side effect of confusion; “I always needed to ask questions. I was never given any explanations by the doctors”. Doctors have suggested her dystonia is caused by stress and depression but she doesn’t agree, although she acknowledges that she represses emotion - “tell no-one nothing and no-one can hurt you”. When she recalls painful experiences in the past she remembers having the same shaking symptoms that characterise her dystonia; “I was always told I was nervous”.

She gets frustrated when she feels that people are not listening to her; “if I don’t pick anything up with my right hand, no-one knows I have a problem until I open my mouth”. Bella has lost touch with most of her old friends as she believes they found it hard to accept the way she had changed and were pitying her and comparing her to how she was before. She doesn’t think that her dystonia is hereditary but still feels worried and guilty in case she has given it to her daughters; “I would only have had one child had I known”.

Her life feels confined as she doesn’t go out alone or beyond the local shops and sports centre; “before I used to love walking the dog for miles”. Bella can’t drive because of her medication so feels very dependent on her husband who looks after her “24 hours a day”. He has become very sensitive to her moods and when he sees her “getting stuck” will help without comment.

He gets very frustrated. He got the brunt of it when my younger daughter walked out two years ago. My husband always said I was the strong one and suddenly his strong woman was slumped at his feet. It’s been hard for him

Iris

If I feel less attractive it is because of my age rather than my dystonia

Iris is an elegant woman in her seventies with laryngeal dystonia who lives in retirement flats in South-east England. She described herself as an “old hand with dystonia” who was now able to support others and act as an ambassador. Her narrative explored work-related discrimination and flexible working, people’s insensitivity and rudeness (giving examples of “communicative alienation”), the “miracle” of Botulinum toxin injections (and being the first person in the UK to receive them), poor communication by doctors (including problems securing a diagnosis), managing her condition (for example, taking care over the scheduling and location of social events), integrating dystonia-related changes into the experience of aging, the invisibility of laryngeal dystonia, and her rejection of psychological interpretations.

Iris decided to work from home after the start of her laryngeal dystonia as although she was doing the same work on a lower salary, the extra time enabled her to travel. “I had an epiphany on a beautiful day and converted my room into an office”. She said she would have continued working but her “funny boss [...] felt disabled people should be put down”.

Her first injections of Botulinum toxin were like “magic” and she can now speak “easily”. She is conscious of her voice “quavering” before and immediately after her injections but doesn’t let what others think bother her; “before the treatment I had no voice for five years”. Iris said this didn’t bother her immediately but later she became determined to speak and wouldn’t give up, despite her “strangled and whispery voice”. She tries to avoid places with background noise (like restaurants) so she can be heard more easily and arranges outings when her voice is at its best; “I manage it”. However she sometimes has difficulties with deaf friends, “I often get very funny answers to my questions!”

I needed great perseverance in the beginning as it was very difficult when I had no voice and couldn’t look after my grandchildren properly or read them a story - I feel I missed out on their growing up

She recalls her bank manager shouting at her when he couldn’t hear her, but believes that people are generally sympathetic, if uncomprehending. A common reaction is “oh dear, have you lost your voice?” Iris finds speaking on the telephone easier than talking face to face,

although people at the National Spasmodic Dysphonia Association¹⁶⁴ conference said they hated it.

She describes laryngeal dystonia as the “least mentioned dystonia” and maintains that “you become invisible”. Iris, however, has been very visible as she was the first person in the UK to have Botulinum toxin injections; “when my neurologist presented my case at a conference in Switzerland it turned it from being a killer into a healer”. She worked for the Society for 12 years doing publicity with national media to facilitate diagnosis and was interviewed by Sky and Radio 4’s “Today” programme. She recalls going to her GP on the day of the programme to give him information and a video but these were rejected as “we get so much stuff sent to us”. Iris thinks the public are becoming more aware of the problems of people living with dystonia, particularly children. Twelve years ago she suggested a poster campaign using a child with generalised dystonia but the then medical advisor rejected this as he said it would be too upsetting for parents whose children had just been diagnosed. It is now one of the Society’s most popular fundraising images.

Iris waited three years for a diagnosis and was seen by more than four neurologists and “no end of ear, nose and throat consultants, some of whom were dreadful. I was sent from one to another”. One suggested a psychiatrist “which really annoyed me. It’s a physical thing that happens over which I have no control”. She asked the doctor who referred her “how do you think that makes me feel?” and adds “people suffered dreadfully under that kind of treatment that was totally wrong for them. Being told it is psychological is the most depressing thing of all”. After three years of inconclusive tests, she rang the hospital to tell them they were wasting her time:

Another doctor came to the phone, almost pleading with me to come back in. He was so nice I couldn’t refuse. He was ninety percent sure it was dysphonia [laryngeal dystonia] and would like me to see Professor Munday. The Professor said dysphonia was a very mysterious thing and we didn’t know what caused it so there wasn’t a cure. He asked me ‘how do you feel?’ It was an enormous relief to know what it was

Although Professor Munday mentioned a “pioneering” treatment available in North America, he said it would be another two years before it reached Britain, so instead prescribed drugs “which did nothing except give me dreadful side effects - confusion, weight loss, nausea, bowel problems”. She also developed a tremor in her arms and was “terrified” that she had Parkinson’s disease like her mother. The doctor told her that if she stopped taking the drugs

¹⁶⁴The North American organisation for people with laryngeal dystonia.

the side effects would stop within 48 hours; “I was so angry that I hadn’t been warned about them beforehand”. At the National Professor Munday and three other doctors discussed the new treatment with her:

I decided to take a chance on the injections as I felt I had to, even though my family said ‘it’s a dreadful thing, don’t do it’. I had the treatment late one afternoon and the next morning I could speak, it was amazing. When I found I could swallow a cup of tea I thought, ‘shall I ring my doctor? But it’s six in the morning!’ It was quite emotional

The effect lasted a few weeks then Iris found she had problems saying words beginning with vowels; “there was considerable experimentation to get the right site [for the injections] and the right amount”. It was also difficult to distinguish between the spasms and tremor caused by her dystonia and those by the drugs. Now, four to five weeks after treatment her voice becomes whispery and difficult to control and after 12 weeks the spasms restart in her larynx. Her tongue and jaw are sometimes affected by the injections and she used to get stiffness from her jaw to the top of her head and problems swallowing immediately after treatment.

Iris told me proudly that she lives in retirement flats without a warden. She has family living locally but her son (initially very supportive) has moved away. Her dystonia hasn’t made her cut back on social activities as friends and family make allowances for her. When her voice quavers she has seen people turn around and look, “but if I feel less attractive it is because of my age rather than my dystonia”.

The doctors refer newly diagnosed people to her and she has had “a lot of contact with them” particularly reassuring people about the “throat injections”. She notes the “anger” among people living with dystonia when they are told things like “open your eyes” when they can’t physically do it. Iris also observed that people have very different approaches to illness:

Children enjoy being better and spring into health but older people hang on to illness. You’ve got to be careful because there are advantages to being in the sick role. Sometimes you need a break just to recharge during working life

Paul

I’m someone who has this, without it being my identifying feature

Paul is an open and friendly man in his thirties with cervical dystonia who works in north London as a teacher of English as a foreign language among “supportive” colleagues. He describes himself as someone who has integrated dystonia into his life and no longer finds it disruptive or constraining. His narrative recounted his speedy integration of dystonia into his

life (for example, he wasn't threatened by people's curiosity), his interest in its psychological effects, the support he received from colleagues and friends, ideas about causation stimulated by guilt, and how as a young person living with dystonia he didn't find the Society helpful.

If I'd been in a tough comprehensive, having dystonia would have been a more uncomfortable experience. Actually my pupils were very nice and seemed genuinely concerned when my neck started to jerk. I don't have any pain and sleep well so I can continue to work. If you have those, that's important

He finds walking difficult (particularly carrying shopping) and hopes the second course of injections will improve this. He can now cycle and dance but feels slightly self-conscious.

Normally I'm not conscious that I'm not doing this or that. It's funny how quickly it becomes part of you, supporting my neck has just become a mannerism. Strangers come up and ask you if you're okay but you just explain it. It's difficult because it is a strange condition and not very well known

Paul lived in Spain for five years and wonders if his dystonia was triggered by the stress of his return, or by taking recreational drugs; "I think these theories probably came from my shock and guilt when I was diagnosed. I now think things happen and you can't go back; I try to put it to the side as much as possible".

The improvement since his injections has helped him keep his dystonia in perspective; "I'm someone who has this, without it being my identifying feature". Before the injections his dystonia was noticeable when eating (especially in restaurants) but Paul is glad he has maintained his social life. He doesn't feel "too bad" (compared with other people living with dystonia) as "when your friends know and are comfortable with it, you feel more comfortable too". Paul found the Society useful for information but not meeting people as most of the members were older than him and he was "wary of getting involved". He has also researched dystonia through the medical database at the hospital

It took three months to get a diagnosis during which time he went from his GP to an acupuncturist, then back to Spain, then back to the surgery (his condition was worsening) where he saw another GP who referred him to a physiotherapist. The physiotherapist suggested he might have "torticollis" and a friend's wife told him what it was. He then obtained a referral to a neurologist and was diagnosed. He initially felt isolated and uncomfortable with strangers but "once I had broached it with friends, it wasn't a big thing". Paul believes that your personality mediates the effect of dystonia, but acknowledges that the diagnosis takes a while to sink in and his attitude could change over time.

I was happy, angry, I've confronted all those things and come through - you have to live with this. I find the psychological aspects of living with dystonia very interesting, the gradual and long term effects, how you change in personality and character, possibly in ways that you aren't aware of¹⁶⁵

Alan

I'm trying to cope, but it's everyone else not doing it. I'm left in the lurch

Alan is a middle-aged man with generalised dystonia and diabetes who lives with his mother in his childhood home. His narrative explored his self-consciousness in public, life before the start of his dystonia, problems getting support or acknowledgement (even from his social worker), use of medications, and his determination not to be labelled as "mentally ill".

He told me his doctor had promised he would go into remission, but three years later there has been no improvement. He is conscious of people looking at him when he goes out:

When I go to Tesco's I feel there's a whole load of trumpets around me, 'oh, he's making a big arrival' they'll say. They stare at me all the time but I stare back, a cat can look at a king I say. Why should I be worried what they think? Who's normal these days?

Alan is also very aware of people's thoughtless or prejudiced reactions to his condition and feels he is "always trying to educate people that are ignorant"; "someone once asked me where my dystonia came from. I told her I was from the second planet next to Mars - ask me a silly question and you'll get a silly answer. Dystonia's not where you come from. It's what you've got".

His Disability Living Allowance was reduced from medium to low care last year with no prior warning or explanation. The appeal process was tiring and took a whole year. His mother helped him fill in the 200 pages of forms as his hands are affected by dystonia but she didn't understand the wording; "before the hearing she said, 'If anyone's going to win it'll be you because you've really worked on those forms'". Although Alan was supported at the tribunal by his social worker, he felt she had a different agenda as she was trying to establish the minimum he would need to live:

I once saw her writing down 'he does very well on his wheel-walker'; well that's what it's for. Then she wrote a silly thing like "he can get a cigarette and grip it", what the hell's that got to do with being disabled I don't know. You have to keep fighting those things. The social worker says, 'you can cope', I say, 'no, everything

¹⁶⁵Here Paul appears to be treating himself as the subject of an experiment, making me wonder at what point detachment and reflection become objectification.

takes six times as long. You're trying to make me lose my benefits saying that I'm capable. I'm coping, I'm not capable'

His brother also describes him as "independent" but Alan (interpreting this in relation to benefit) argues, "even if I'm independent I can still get medium care allowance". Currently he gets £161 per week in invalidity benefit, income support for his mortgage, and Disability Living Allowance at medium rate for care and high rate for mobility, but these were hard won; "at one point I wondered if the appeal office were shredding my forms to cause trouble".

Alan felt ill on the day of his appeal, which was exacerbated by waiting in the cold outside "a Nissan hut with a falling down chimney". "It was no place for a disabled person" he recalled, apparently without irony. His social worker complained about their treatment but the staff were reluctant to let them in; he maintains "they hadn't heard of dystonia and didn't respect me because I'm disabled". After the hearing he was so exhausted that "my knees went down till they were almost touching the floor". Fortunately the tribunal ruled that the Department of Social Security had acted illegally by not informing him before stopping the benefit.

His dystonia came on suddenly ("before I was able bodied but I've been rocking and rolling ever since") and, as he tells the story, comically "the bedclothes were moving so vigorously that my mother thought I had a woman under there". They called the GP who didn't come until the following evening; on seeing him she said, "oh my God, why didn't you tell me?" They had described his condition to the "grumpy" woman in the surgery reception but she hadn't told the GP. He recalls how the same receptionist sent him upstairs to get a prescription, despite protests from other people in the waiting room. "I was goose-stepping down the stairs; I was nearly on the floor when I got down". The GP got him a specialist's appointment the next day but the neurologist didn't tell him what was wrong for six months saying, "I'll just see how you go". His mother would tell people who didn't know about his dystonia that "he had come over all peculiar" but he would dryly correct her, "I haven't changed my sex or anything".

Alan's writing is "erratic" as he can't control his hand or stop his eyes rolling ("it's large one minute, small the next - you'd need a magnifying glass to read it) and he misses no longer being able to write "normally". He is taking Co-comadol for his "aches and pains" ("they love to give me these ones, hundreds at a time") but worries that they will "lodge in his kidneys" as his lifestyle is sedentary. Three fingers on his left hand are permanently bent over

and the other two are extended which makes it difficult to test his blood sugar, although he can use them to make rude gestures as people assume he can't help it!

He hasn't been to the local town for three years and gets deliveries from two supermarkets and meals-on-wheels. On his last visit to the supermarket a woman hit him with her trolley because she was trying not to look at him; "she apologised but it didn't make it better. I hate it when people apologise". His social worker told him to "throw the wheel walker away - you can walk" but she doesn't understand his fear of falling as he has a "pigeon-toed and Donald Duck type walk". Alan is aggrieved that Social Services are "dumping" him next month as they feel he would be better with the mental health team; "I'm physically disabled, not mentally ill". He also wants a higher level of care so someone can check on him in the morning and while showering.

Alan worries about his mother as she was sectioned eight weeks ago and is refusing to speak to visitors saying she is "filthy, dirty". He told me "we've always been close; occasionally we would share a bedroom to support each other". Alan is also part of a supportive telephone network of people living with dystonia:

We try to back each other up, we're people with the same problem sharing it. A friend called me who had built a wall that was wobbly. I said, 'you did it, that's the main thing'. My brother complains about the high telephone bills but I can't communicate with tom-toms

He feels dystonia is difficult to explain to people who don't have it as "you could sit there for hours, days, telling people about your movements". For example, he experiences "episodes" of rigidity where he lies on the floor or sits frozen "like a statue" in his chair. "People originally thought it was a put on job but then realised no one could continue simulating these movements. The problem with dystonia is that different things happen and there's nothing I can do about it"¹⁶⁶. Alan describes how his speech goes "childish" and mimes putting a finger to his lips and speaking in a babyish voice. He also jokes about forming a "Dystonia Society orchestra" of members with speech disorders; "you've heard of the gay men's choir? I still do a lot of quacking and I grunt sometimes". He even felt embarrassed by this in hospital and put on a NHS questionnaire that there should be special units for people living with dystonia.

Last year he became depressed and took an overdose; "I had to drink seven pints of liquid charcoal in casualty to absorb drugs; the charcoal gets all round your face and everything".

¹⁶⁶The assimilation of diverse symptoms within one condition is also occurs in TMJ [Garro 1994b].

He complained that even though he was admitted as suicidal the staff put his bed by the fifth floor window. Alan was subsequently prescribed Prozac, which put him “on edge” (“I was terrified of the postman pushing letters through the door”) and then Seroxin¹⁶⁷, which he stopped because of the side effects. Baclofen “revved” him up (“I used to hit my chest but now I was pounding it. I had to put a cushion against my chest and there were clouds of dust coming from it”) and he was also given anti-epileptics to stop the spasms. He is now taking Co-comadol, Zipofen and Glucophage for his diabetes and imagines “all the tablets looking at me and saying, ‘we’re going to give you another side effect’”. His neurologist recently told him “there’s nothing I can do for you. There isn’t a magic bullet”¹⁶⁸. Consequently his next appointment is in two years.

Alan was sent to a psychologist after diagnosis where he filled in a “thick” form and was “interrogated”, “they have you in there for one and a half hours and if they had the anglepoise lamp in your face you’d think they were the Gestapo. I thought I was a secret agent”. He found their questions irrelevant and offensive (“what the hell has your sex life and your sexuality got to do with dystonia?”) and resented being asked about his childhood and whether he was happy at school. His mother was present during the interview because he couldn’t fill the form in on his own but “she wasn’t much help as she’s deaf with tinnitus”. The psychologist took a break at the moment Alan wanted to walk out but when the psychologist left the room, he was sure there was a hidden camera. He recalled “crying because I couldn’t do what they asked” and being “literally on my knees when I left” as the stress brought on spasms in his legs. “[On the way home] I was below the axles on the taxi. I thought I’d jump out on the M40”. Alan didn’t feel the psychologist understood his condition although he reassured him it wasn’t “all in his mind”. He currently has “hallucinations” of spiders and pink and blue clouds; “it’s not in my mentality, it’s real, I see it. You try telling them and they think you’re cuckoo”.

Alan believes “doctors don’t like me because I talk back to them”.

They think, ‘If he can do that then he can fake all these movements’. They don’t like you to be one up on them. They think I’ve looked up what dystonia is and now I’m playing it out. The doctors say, ‘he’s a very nice man’. They don’t know nothing. What I want is what I get

To support this forceful image of himself he tells me how he set up a radio station with no prior experience; “I was disappointed when it was taken over but that was a sign that I’d

¹⁶⁷An antidepressant that, like Prozac, increases serotonin levels.

¹⁶⁸Rabin observed that the absence of a “magic bullet” shouldn’t make doctors impotent [1982].

developed an original and popular format. Middle of the road and modern contemporary you'd call it, it hadn't been done in the UK before, people like Fox FM were frightened of us".

Alan was a kitchen porter for 22 years. His mother used to nag him about getting a job where he could use his mind but he felt "if you're happy in your job, what's the point of moving?" His favourite subject is history and he would like to do an Open University degree but can't afford it. He went to boarding school, where he may have been sexually abused, but maintains a "stiff upper lip" about the experience. "It was good, you got your rough with your smooth, it does bring you out to grow up there because you can't go crying to mother".

He has cut his smoking from 120 to 60 cigarettes a day so says that scratch cards are now "my only vice. Wine, women and song, they're all out. You've got to have one treat in your life". He recently ate at Tesco's with a friend but could only have a sandwich as he was afraid he would splash the food over the people nearby; "I mean me with baked beans, there were at least two people in firing range". Alan describes his life as "just coping and filling forms in".

People say, 'why do I complain?' but I believe in rights. I'm trying to cope, but it's everyone else not doing it. I'm left in the lurch. Having dystonia isn't clear-cut, it's a higgledy-piggledy package. I wouldn't mind if it was 'you've got this, you've got that', but there are seven to eight versions and you might have two versions at once. I'm still learning every day about my dystonia, I get another tic and wonder if it's part of it. Another thing with dystonia is I have trouble speaking and remembering words but with a disability, if you can't do it one way, you find another. There are different ways of coping, some people don't want to admit they've got it but I try to have a sense of humour. I'm someone who's got something no one else has got; I have to stick with society in general

Illness stories

Many illness stories from people living with dystonia use ideas about causation to account for and master dystonia¹⁶⁹. The biomedical explanation of "a chemical imbalance in the basal ganglia" may not provide satisfaction or resolution as it ignores the "why me?" "Why now?" questions that are an important part of making sense of illness. For example, people with diabetes in Mexico use "provoking factors" (which link biomedical and personal understandings and enable the attribution of responsibility) to explain its onset [Hunt 1998]. These enable them to "bring meaning to the arbitrariness of illness" by "weaving the cause of their diabetes into their own life history" and "making it part of the fabric of their life" [ibid].

¹⁶⁹ For example, Sarah attributed it to a back injury while working as a nurse for exploitative employers.

Some theories fade into the background once a diagnosis is obtained, particularly if the person obtains relief from conventional medicine. For example, Thomas¹⁷⁰ advises “selectivity in choosing help” as “it is of little help spending a fortune rummaging around with such notions as the Oedipus complex to explain one’s condition when true causation lies in a chemical imbalance in the basal ganglia”. But other theories remain to organise the experience of illness and guide action. Beatrice’s¹⁷¹ allergic response to 55 of the 58 substances she tested prompted her to create a “controlled [home] environment” with “no carpet, no wall paper, filtered air and water and no cleaning chemicals”. Regretfully, this ideal of purity and control is occasionally disrupted by visitors “because of the chemicals that are still hanging around their persons from the environment outside”.

The interest in causation has been observed in other chronic conditions (for example, multiple sclerosis) where medical uncertainty about cause or aetiology provides space for alternative explanations. According to Robinson, “the problematic initial search for a diagnosis through the formal health care system, the often contentious and transient relationships with medical staff, and the frequently continuous experimentation with a wide range of medically unorthodox therapies are a corollary of personal attempts to create or maintain a progressive narrative of life in the face of the disease” [1990:1185]¹⁷². For example, Paula¹⁷³ makes discovering why she has dystonia central to a review of the effects of her life on her body, deciding “if only I could discover why I had this disease I would be able to put it right”. She attributes her condition to three “sets of reasons”: “physical defects or damage I have collected in the course of my life” (for example, “a nervous tick in my right hand when I was young” and “lower back pain after a pregnancy”), “mental, centring around stress”, and “age”, and likens her body to “an aging house with a lot of weaknesses in its fabric” which has experienced “collapse and major damage” after “a sudden shock or continuous stress”.

A similar process occurs among people with arthritis who reconstruct the past through narrative to create an impression of continuity and purpose [Williams 1984], and people with cancer (and their doctors) who “deny the arbitrariness of suffering by associating it with antecedent events and thereby sustaining the idea that the world is essentially orderly and controllable” [Hunt 1999]. Narratives often move from personal experience of suffering to generalised reflections about illness [Monks and Frankenberg in Ingstad and Whyte 1995],

¹⁷⁰ A man living with cervical dystonia, writing in the Society newsletter.

¹⁷¹ A woman with oromandibular dystonia, writing in the Society newsletter.

¹⁷² c.f. People with motor neurone disease’s desire to take Riluzole so they weren’t just waiting to die (chapter 6).

¹⁷³ A woman with cervical dystonia, writing in the Society newsletter.

motivated by a desire to help others understand and accept the condition. They have a moral tone (drawing on local constructs about “what constitutes a virtuous life”¹⁷⁴), attribute responsibility and blame¹⁷⁵, and are a way of positioning yourself and becoming accountable¹⁷⁶.

An illness narrative is a new “map” (or guide to living) that counters the “biographical disruption” of illness, which may have turned the person into a “narrative wreck”. By constructing a narrative they become the editor of their life and assume responsibility for it [Kierkegaard 1941]; an almost political act if the alternatives are to write or be written upon [Charmaz 1987; Spivak 1996]. Although Frank [1998] fears that encouraging “confessions” of illness may be “panopticism in benign disguise”¹⁷⁷, I believe that the problem for most people living with dystonia is not that their stories are recorded and used against them, but (aside from the Society newsletter) there is no discursive space in which those stories could be heard. Frank later notes the irony that “first-person stories are told to express what cannot be expressed in the clinic where people ostensibly go to talk about illness” as “the point of medical history taking is not to provide the person with a hearing of his or her suffering” [1998:340]. Stories can be a “technology of the self”¹⁷⁸ because relating them becomes a “moral imperative” and “involves a profound assumption of personal responsibility”, including a willingness to “re-shape that self story if the wrong self is being shaped”¹⁷⁹ [Crossley 1999]. But they can also be “care of the self” if they involve “reclaiming a voice that bodily trauma and institutional treatment have caused to be silenced” [Frank 1998]. Self-actualisation thus becomes a balance between opportunity (care of self) and risk (truth games and power).

“Narrative medicine” [Greenhalgh 1999] has been suggested as an epistemological corrective to evidence-based medicine and a new way of relating to patients [Brody 1994; Frank 1991]. However, anthropologists have identified a number of problems with narratives, not least that what people say is a poor guide to what they actually do [Malinowski 1925]. Informants’ intentions can be subverted by “narrative slippage” and intertextuality; large areas of culture cannot be expressed in “discursive statements” [Fabian 1983]; there is a discrepancy between

¹⁷⁴See Early 1982 on childhood illnesses in Cairo; Good 1994b; Price 1987 illness narratives in Ecuador.

¹⁷⁵See Baruch 1981 and Comaroff and Maguire 1981 on how parents establishing “moral adequacy”; Brock and Kleiber 1994 on career-ending athletic injuries; Garro 1995 on diabetes in Obijway Indians.

¹⁷⁶Radley and Billig 1996; Blaxter and Paterson 1982.

¹⁷⁷Or “pastoral power” [Armstrong 1995].

¹⁷⁸Where power operates by convincing people to transform themselves using practices like diet and therapy [Foucault 1978].

¹⁷⁹Crossley’s analysis of “healing” stories from sexual abuse survivors and HIV-positive men [1997] questioned whether they were “empowering” as they could lead to “narcissistic withdrawal” [Lasch 1978].

the “richness” of experience and the “paucity” of language [Bruner 1986]; and many informants cannot produce linear monologues [Okeley 1992] or do not want to share knowledge in this way [Holding 1999]. The experience of pain and suffering can also “derange” people’s lives so that they become unnarratable [Scarry 1985]. For example, the “chaos narratives” produced by people with chronic pain lack coherence, completeness, or any element of reflexivity, but are an accurate representation of suffering where sensation is too intense and immediate to enable reflection. Like all accounts of chronic illness, they remain ambiguous and negotiable as there is no ending to give them meaning [Good 1994b]. Chronic pain also “shatters” language and shapes the experiencer’s world to itself [Bendelow and Williams 1995]. Consequently it becomes a dimension of perception rather than an experience and can only be represented through metaphor. For example, the cliché “seeing stars” captures the consciousness-altering aspect of pain¹⁸⁰ [Jackson in Delvecchio Good 1994].

Although narratives are personal, they are rarely individual as they are “products of complex interactive social processes [that] constitute powerful and dynamic means of communication” [Steffen 1997:110]¹⁸¹. They are embedded in the “institutional structures” of narrator and audience [Saris 1995], which “filter [their] discursive potentials” [Lyotard 1984:17]¹⁸². For example, Mathieson and Stam acknowledged that their “narratives” from people with cancer [1995] were actually forms of “joint action” as they were created by the circumstances and structures of a research interview. They argued, however, that the conversations recorded in the article had narrative qualities as they were “about those aspects of life that matter most” [284] like “the quest for personal identity”¹⁸³.

Researchers can also affect narratives by creating homogeneity (emphasising theme over variation), assuming fixed meanings, and imposing concepts like stigma [Faircloth 1999; Nijhof 1998]. This conceals their “cultural polyphony” [Bakhtin 1981] where neither we, nor the informant, know which story we will hear due to “narrative slippage” and the subversion of intended stories by “master narratives”¹⁸⁴. For example, narratives of multiple sclerosis use

¹⁸⁰Sarah also uses vivid metaphors to describe her dystonia (“like something in a film where someone is trying to cling on to something while being frozen in a block of ice”).

¹⁸¹c.f. the “collectivisation” of experiences of HIV-positive men [Carricabu and Pierret 1995], Ojibway Indians with diabetes [Hunt 1998] and North American Indians [Spicer 1998].

¹⁸²Having to learn a “cancer vocabulary” [Mathieson and Stam 1995:298] to articulate your experiences is an example of what Bourdieu calls “symbolic violence”.

¹⁸³The concept of “radical empiricism” [James 1958] is a useful way to conceptualise research interactions as it acknowledges that we are continually changing and being changed by the experience of others.

¹⁸⁴For example, illness narratives draw on older narrative genres like stories of religious conversions (“pathographies”) where spiritual experiences stimulate reflection and rebirth [Hawkins 1990].

contrasting perspectives to represent it as both an intrusive problem and an integral quality of personal relationships [Monks and Frankenberg in Ingstad and Whyte 1995]. People with traumatic brain injury also manage multiple self-narratives to redescribe themselves as intact “in spite of” their injury or worthwhile “because of” [Nochi 2000].

Conclusion

In this chapter I suggest that a qualitative approach to illness is worthwhile, not only because telling stories can be therapeutic and enhance doctor-patient relationships, but because they are a useful research tool, if handled carefully (for example, acknowledging that stories are creative interpretations rather than transcriptions of experience and are highly context dependent). Illness stories offer more than other forms of representation because they “claim a unique way of being ill” against the “standardisation of disease”, refer to and develop “we” relationships (in contrast to the individualisation of QOL measures), and depend on and extend a “shared horizon of moral significance” [Frank 1998]. The division between “narrative medicine” and evidence-based medicine is an artificial one, however, as it fails to acknowledge that these fascinating and fallible stories also form the basis and justification for QOL measures. In chapter eight I demonstrate how these stories are selected and reinterpreted in particular ways, with particular consequences, during the creation of measures of QOL.

Section 2: Encounters with bureaucracy

Chapter 4: Encounters with medicine: Derek's story

He turned to me and said 'do you want to do the operation as well, then?' then he turned to the anaesthetist and said, 'Put him out'

This is the first chapter in a section that explores individual and group encounters with medical and social bureaucracy and their mediation by patient support organisations. The organisations use the discourse of QOL in their negotiations with doctors, pharmaceuticals, and the government (described in chapters 5 and 6) to strengthen their claim to speak in the “patient’s voice”. This chapter examines individual encounters with medical bureaucracy through the story of Derek, an intelligent and articulate man with generalised dystonia whom I interviewed on a number of occasions at his parent’s home in north London. The extracts describe his relationship with health professionals from the start of his symptoms as a child and are contextualised with other stories from people living with dystonia, and sociological and anthropological literature on “doctor-patient relations”. His story examines important themes neglected by the literature, much of which investigates problems defined by doctors. For example, the rivalry between psychiatry and neurology and the difficulty of convincing psychiatrists you don’t have a psychiatric problem once you have been referred to them; the effect of age on doctor-patient relationships; and participation in research. Through his story, Derek creates a comprehensive critique of modern medicine that most people living with dystonia (or any chronic condition) would recognise. Although he acknowledges that there are doctors with a “human touch”, many appear arrogant, defensive, paternalistic, exaggeratedly respectful of authority and expertise (though not of their patients’), and unable to admit the limits of their knowledge, or communicate concern for their patients.

Derek’s story begins as child in the 1960s when he entered Great Ormond Street for assessment because he was having difficulty walking:

I went into Great Ormond Street when I was 7 and was seen by various doctors there, I was there for 10 days, came out with my feet in plaster because there was a lot of tension in my feet so they thought the thing to do was hold them down, in and round, get the feet straight, put them into plaster, and leave them for a couple of weeks. So that’s how I was discharged and I had a night of hell with those things because the feet were fighting, the tension was so bad, it was just hell for a few days.

They hadn’t come across anything like this before and they had a suspicion that it may be psychological and attention seeking and so on. And they did certain things, which in retrospect I think were totally out of order, and these days’ accusations of child abuse would be hurled. I was very anxious, anxious about having visits and seeing my

parents, and visiting hours were a bit strange and because I was also in a ward with just young babies there was no one to talk to so they did things around the visiting times. They would arrange for me to have x-rays, the times of which coincided with visiting hours so I was down in the x-ray department knowing that my mother was sitting upstairs waiting and they made sure that I had to hang around for ages, eating up the whole visiting time and didn't return to the ward until the end to see how I reacted. And that was the least of their little stunts. Which I thought was kind of cruel when I heard about it afterwards [...] That was Great Ormond Street - great place.

His problems persisted ("one day I could walk or get around fairly easily, another day I was struggling to get the leg down") so his parents arranged a referral to a prestigious neurological hospital where he was seen by "a long list" of "world names" in the field.

The majority decision, I'm not sure if it was six to four or something like that, was that it was psychological. That was at a time when I think if neurology says this condition doesn't exist you straight away go into the psychiatric bag. I was good material for the psychiatrists because of the nightmares and because I was a bit too bright for my own good. This I'm sure upset the doctors. At the best of times they don't like answering questions from patients [...] and they definitely don't like questions from children.

[...] Three of the things that bothered them was that – first of all, one evening my parents came to visit and I said to them, 'I feel a lot more relaxed' and I got off the bed and walked perfectly normally all around the ward and this was something that I hadn't done or been able to do for several days and I was saying 'oh look at me, isn't this great'. Now the doctors got to hear of this and they were pretty pissed off and they thought, 'this kid is just putting it on'. As far as I was concerned I was just pleased that I could do it. They were very disturbed that I seemed curiously unconcerned about what was happening to me, the tension was progressing upwards yet I wasn't panic stricken and constantly in tears and asking 'what's happening to me?' and all the rest of it. And this added to their 'it's got to be psychological, attention seeking'. Now as I recall it I tended to have a very practical approach to things. If something happened to me I tried to deal with it. And okay these things were happening to me, I didn't know why but as each thing happened I had to adapt very quickly – if the leg wouldn't go down I had to press on the knee to keep it down if this didn't work, I had to try something else. It was like there were new problems happening and each time I had to quickly adapt to it. I didn't just sit back and think, 'Oh what's happening, am I going to die'? I just didn't feel like that. And they saw this as a curious unconcern.

In an attempt to test the genuineness of his condition (or the firmness of his resolve) he was given extensive physiotherapy under observation.

I call it physio but it was more like torture therapy. They gave you treatments which I've since found out weren't designed to do anything at all except inflict pain to see how I reacted because they still weren't getting anywhere. The test results had all shown nothing, nothing wrong with anything they could find and there had to be something wrong and if it is psychiatric then perhaps they can make it so unpleasant for me that I'll stop. I found out years later that I was being watched the whole time in this ward; either by nurses or by doctors when they came in, to see if I secretly walked

around or how I behaved. I didn't know any of this at the time. So I had these physio sessions, walking, running. There were two things they did: they attached electrodes to my toes and sent unpleasant shocks to see if I would twitch [...] Very painful, it reduced me to tears, had no therapeutic value whatsoever. The other thing they did regularly was they had this gadget which emitted mauve sparks that ran up and down the calves of my legs, I don't think it had any purpose at all [...] in terms of the condition, the sole idea I gather was to give me a very painful time.

There was still doubt as to whether his condition was neurological so over the next ten years he was sent to a psychologist who characterised him as a 'classic case' and was very reluctant to surrender him to a rival discipline when his diagnosis was confirmed¹⁸⁵.

She was sincere, not a charlatan, but if you turned up with your arm in two pieces she would say it was psychological [...] While I was in hospital [for surgery on his foot], the surgeon recommended I see a GP friend who was interested in neurology. The GP convinced the surgeon that it wasn't psychological. When my psychologist heard about this she went crazy with anger, even though doctors don't usually slag each other off. Her final verdict on me was 'it's quite clear that you've decided to stay like this'. In every version they win. I was reassessed in the seventies as by then psychology had gone out of fashion and was diagnosed with dystonia. When I had a definite diagnosis I told the psychologist and she said 'oh well, if that's what you want to believe'.

Despite his earlier experiences Derek found a later referral to a psychiatrist "very helpful", so long as it was "just to talk about problems at home and my personal life and not with a view to analysing dreams and all that stuff". However he had a couple of bad experiences, first, when he was referred for a second opinion, and second, on his psychiatrist's retirement.

On one occasion Prof. Munday¹⁸⁶ said 'I just want you to see someone upstairs who was a Freudian psychiatrist with Winnicott'. I think I saw him once - I heard he's written a book with Dr Smith and was highly regarded - weirdo! [...] I saw this guy and I don't think he said a single word or maybe one sentence throughout the whole time. Dr Lang said, 'these Freudians have an easy time of it, their excuse is that they don't say anything because they don't want to miss anything'. They just sit back and don't say a word. I saw this guy and he confirmed Dr Lang's view that there was nothing psychiatrically wrong, nothing that he could help more than Dr Lang was doing, I thought 'thank god for that!'

One bad experience I had was when Dr Lang was retiring and he said 'look there's somebody I can refer you to, go and see this chap' and he'd heard that he was okay. I went along to this chap, again with a view just to discuss problems now and then. I got into the room there, there was no couch that I could lie down on comfortably, and all he had was two wooden chairs together to lie down on. I couldn't stay in a chair like now in a relaxed way, I needed to lie down. So I got these two chairs together and I was moving around because it wasn't comfortable. He had a woman sitting in, another psychiatrist, he asked 'do you mind if she sits in?' but he gave me the

¹⁸⁵Collette recounted a similar experience in the Society newsletter when she was told by a psychiatrist that "if I took the "right" anti-depressant, the dystonia would go away".

¹⁸⁶Prof. Munday was his neurologist and Dr Lang was his psychiatrist.

impression I didn't have much choice. So instead of saying 'what's your view of what we want to do?' or 'why have you come to see me?' and being friendly, his opening gambit was, he was looking me up and down and I can tell when someone gives me that kind of look as if you're some kind of mutated object, and he was doing that and then said 'how does it feel to know that people are looking at you thinking that you are physically deformed?' or 'it's difficult for people to look at you', some really unpleasant thing, a real bastard. I thought anything I say to him he's going to throw it back to me, turn it into paranoia, I was completely thrown. I was trying to think up all these devastating replies and he said, 'Well how do you think I can help you? What would you want me to do?' This guy is not just a bastard, I think he's a sadistic loony and I feel sorry for anyone that he treats. He's probably still there. That the place has got such a reputation indicates there's something severely wrong with psychiatry

Derek also recounted bad experiences "participating" in medical research, which seemed to exemplify the worse aspects of the therapeutic encounter – typification ("I've seen hundreds of dystonics"), bad faith ("In the morning did he [the surgeon] come? Did he hell"), lack of reciprocity ("researchers tell you you'll receive the results but it's a pack of lies"), and misuse of power ("He [the surgeon] didn't like it. So I had six sleepless nights with pain from the stitches").

[Medical] researchers tell you you'll receive the results but it's a pack of lies. You do your part of the deal and then you never hear from them again. I'd agreed to have a muscle biopsy for a research project but when I was trying to discuss my particular problems with the surgeon he said, 'I've worked with Dr Johnson and I've seen hundreds of dystonics, I know all about it'. I thought 'do you hell, you've never seen me'. I'd offered to give them a sample from my left arm which was most affected, even though this would be more painful, so he said 'look, I'll come and see you in the morning and we'll decide which arm to do. I'll ask the staff to shave both arms but I'll come and see you and we'll discuss it'. 'Fine'. In the morning did he come? Did he hell and when I asked to see him it was 'oh he's busy, he's a very busy man'. There was no way he was going to come and see me. And then someone said, 'he's already decided'. I nearly went ballistic. I thought, 'okay, I can discharge myself'. I tried unsuccessfully to get hold of Prof. Munday to complain bitterly about the consultant and his cronies and his surgeon. I didn't manage to get hold of him but I thought 'for the greater good of medical science' and all that, I'll go ahead with it. But I am going to stay conscious until I get to the operating theatre, which is not the best thing to do. So they gave me this pre-med and I thought 'okay, stay awake, stay awake' and I got wheeled down, struggling with this and there was the surgeon so I gave him a telling off in front of everyone, just before I was put under - 'why didn't you come and see me and discuss this, I want to know exactly where you're going to do this incision, how many stitches, how you're going to do it, and so on'. I made it very clear that I was very angry with him, not the wisest thing to do when you're just going to be put under. He didn't like it. So I had six sleepless nights with pain from the stitches.

Gina describes a similar experience in the Society newsletter where her doctor's initial enthusiasm ("[he] asked if he could come and see me which he did the very same day") disappears after he has solved the riddle of her diagnosis and failed to get a photo to

accompany her “case history” for publication (“I was so upset at the thought of anyone seeing my screwed up face and eyes that I refused point blank. He never came to see me after that”).

Derek’s story provokes the question “how are these “weirdos”, “sadistic loonies” and de facto child abusers created? In the next part of the chapter I will suggest some answers by looking at medical training, language, practices and environment, and weaving together literature and accounts from people living with dystonia. The goal of medical training appears to be the production of the “socially neutral physician”. For example, studies of medical education in the late eighties suggest students’ values become homogenous and conservative (regardless of their background) as isolation and lack of time reduce their commitment to external activities [Shapiro 1987; Beagan 2000]. But although difference is thought to reside in the “other” (the patient), it persists in the gendered and racialised bodies of students and may affect them in ways they cannot control. For example, sick doctors report a sense of failure, inadequacy and guilt (“illness doesn’t belong to us. It belongs to them, the patients” [McKevitt and Morgan 1997a]), exacerbated by the responses of colleagues and patients who collude in their denial of illness. Doctors delay seeking help, informally consult colleagues, self-treat and self-refer to specialists. Their attitude to their bodies may reflect the competitiveness and machismo inculcated during training, which Derek illustrates by describing his cousin (a surgeon) who “made the decision about when he should go back to work [after a varicose vein operation] by finding out how long nurses took and taking half that, regardless of whether he’s in agony or not, just to show them”.

Doctors’ initial reluctance to enter the role of patient means that they often receive poor care as they are expected to be their own doctor [Ingelfinger 1980]. However, their subsequent desire to be treated as an “ordinary patient” reveals a lack of understanding of what patients experience; “[it is] a desire to receive the best routinised care [...] but probably not to be subjected to hospital waiting lists, lengthy waiting in the GP’s surgery or the routinised rudeness of health care workers” [McKevitt and Morgan 1997b]. “Doctor-patients” are “classificatory anomalies” [Douglas 1970] that challenge the biomedical paradigm of separation between subject and object (“being both doctor and patient threatens the integrity of the club” [Rabin 1982]). Consequently, they are circumscribed with a powerful taboo, which affected both Rabin (a neurologist with motor neurone disease) who noted that “becoming ill is tantamount to treachery”, and Ingelfinger (a doctor with stomach cancer) who described his frustration with colleagues who expected him to be a medical authority to the end [1980].

Medical language has penetrated popular culture to an extraordinary degree (what Habermas calls “technocratic consciousness” [1970]). However, there can be confusion between terms with popular and medical meanings (for example, hypertension and “hyper-tension” [Blumhagen 1980]). This occurred when Derek’s neurologist told his parents he had dystonia; “once they heard the brain was affected, they didn’t hear anything else; he instantly became the villain of the piece and they didn’t want to hear what he had to say”. Doctors use “lay” models to explain conditions because they are a shared cultural resource, undermining Mishler’s distinction between the “voice of medicine” (“affectively neutral, functionally specific, context stripping questions and responses by doctors”) and that of the “life-world” [1984]. The distinction also ignores the plurality of voices within medicine [Kleinman 1995] as the voice used depends on the doctor’s position in the hierarchy. For example, “the voice of science” is most frequently used by younger doctors [Aronsson et al 1994] who cannot use personal experience as a “warrant for action” [Freidson 1971].

The voice of medicine is also accessible to patients, for example, Aronsson et al [1994] describes how a woman with obesity fights to keep the problem within the voice of medicine to protect her life-world from the “clinical gaze” [Armstrong 1984]. Similarly, narrative is not confined to patients’ accounts of illness as the presence of “history”, “episodes” and “presentation” in medical vocabularies indicates [Atkinson 1995]. Hunter maintains that medicine is primarily an interpretive activity as knowledge is constructed and transmitted through narrative [1991]. The “diagnostic circle” is analogous to the “hermeneutic circle”, effectively making doctors into literary critics. Occupational therapists also use “clinical story telling” to examine social relations, emotions, cultural difference and morality (areas traditionally excluded from medical discourse) and collectively think through a course of action [Mattingley 1998].

Conceptualising medicine as an art rather than a science redirects attention to the “therapeutic relationship”, which is often neglected by medical training that focuses on “the centrality of diseases and medical science, learned decision-making, automatic behaviours, and rules of thumb” [Cassell 1997]. This implies “that the physician is secondary in care of patients: same science, different physician, same care” [ibid]. It also directs our attention to the language used in case presentations¹⁸⁷, which may reveal how doctors think about their patients. For example, the use of devices like “depersonalisation”¹⁸⁸, “omission of the agent”, “making

¹⁸⁷These occur during weekly ward rounds and are opportunities for junior presenters to exhibit “roundsmanship” (bluffing through hostile questions) rather than share information [Anspach 1988].

¹⁸⁸Calling a baby the “product of gestation” implies it was produced by the gestation rather than the parents.

technology the agent”, and “account markers”¹⁸⁹ [Anspach 1988]. Anspach claims “many of the values and assumptions of case presentation contradict the explicit tenets of medical education” (for example, devaluing patients’ accounts). Using this language inculcates “a scale of values which emphasise science, technology, teaching and learning at the expense of interaction with patients”.

Ironically, literary representations tend to focus on the scientific and technological aspects of medicine, for example, in *Martin Arrowsmith* the hero abandons medical practice to follow “the religion of a scientist”, praying “the prayer of the scientist” [Lewis 1925]. However, scientific medicine was attacked 50 years later in *The House of God* [Shem 1978] where doctors at a New York hospital “do everything always for everyone forever to keep the patient alive”, even where this results in lives without dignity and painfully prolonged deaths¹⁹⁰. More recent scepticism is linked to a growing awareness of the role science plays in creating risk [Beck 1992]. For example, the enthusiasm for neuroleptics (one of the therapeutic “advances” of the last century) was reduced when their dystonic side effects became public knowledge¹⁹¹ [Brown and Funk 1986].

Scientific medicine only became possible when the location for treatment moved from the bedside to the hospital or clinic and the main source of clinical data changed from the person with the condition to the doctor’s observations (what Armstrong calls “hospital medicine” [1995]). An increased reliance on diagnostic technology (“laboratory medicine” [ibid]), caused even more damage to the doctor-patient relationship as while a positive test result can create a “collegiate feeling” between doctor and patient, a negative one forces them either to deny their experience or reject medicine [Rhodes et al 1999]¹⁹². This is because tests offer “more than a relief from pain - they promise an escape from a stigmatising logic of causation that makes what is not clearly ‘body’ into only ‘mind’” [Rhodes et al 1999]. They also require a suspension of disbelief as the discourse of testing assumes firstly, that the inside of the body corresponds to visual images of it, and secondly, that variation can be measured against norms (producing guilt when the body fails even to conform to the norm of deviance!). The allure of these images have made actual bodies elusive, replaced by “multiple images and codings” where the body is doubled and redoubled” and risks disappearing in a

¹⁸⁹Used to emphasise the subjectivity of accounts from patients or other health care workers (indicating the “ecology of knowledge” within the hospital) [Atkinson 1995].

¹⁹⁰The doctor-hero is only able to save himself by leaving internal medicine and going into psychiatry!

¹⁹¹The slow recognition of drug-induced dystonia and dyskinesia was attributed to differences in the way doctors and patients define effective medications.

¹⁹²This can be postponed by arguing that insufficient or inappropriate tests have been done.

chain of simulacra [Frank 1995]. Consequently, the modern hospital has become an alien environment, pervaded by “screens” which exteriorise the body’s interior, display bodily processes, and entertain patients and visitors.

Everyday management in medical environments occurs through “methods of typification” [Douglas 1986] and “practices of division” [Foucault 1979] that classify people within a moral framework. On the ward the dual identities of “person” and “patient” are kept in play, each informing the other, and providing a means of deciding whether the person has a moral claim on the staff’s attention [Latimer 1997]. People’s problems are made “doable” in the consultation where the type of questions the doctor asks, the manner of asking (for example, leading questions), and the way the answer is interpreted limits the possible responses [Berg 1992]. However, diagnosis may not be “a passport to helpful forms of treatment”¹⁹³ and may close doctors’ minds to symptoms that fall outside the classification or within other disciplines. This happened to Fred who was told that the sudden deterioration in his sight was “all in the mind” because “people with dystonia aren’t supposed to lose their sight”. The problem (optic atrophy) was finally rectified “after a tour of teaching hospitals in London” when he was re-diagnosed with Leigh’s disease. His story is an example of how “the organisational routines of doctors transmute the unique, biographically constituted troubles of the person into the appropriate classes of diagnosis and management”, fixing the individual in “a domain of typified actors, actions, and outcomes” [Atkinson 1995]. The notion of “typified actors” (or “ideal types”) underlies the allocation of universal disability weights¹⁹⁴, which assume that everyone with a particular condition experiences the same level of disability (regardless of their personal or social context) and will be treated in a similar way, producing predictable, measurable outcomes.

The medical anthropologist Greenhalgh provides a detailed description of the mechanisms that turn people into patients, drawing on her experience of being wrongly diagnosed with fibromyalgia [2001]. First people are medicalised and turned into a “doable” problem for that speciality by stripping away their social context [Berg 1996]. Lily (the partner of someone living with dystonia) would endorse this as she maintains that doctors are “not really aware” of people’s problems” because they do not see them “trying to cut up food, shave, walk etc”. Consequently they deal with the “physical symptoms” but neglect the less visible problems, which “only those who suffer or care know about”.

¹⁹³ As Bob, a man with cervical dystonia, explained in the Society newsletter.

¹⁹⁴ Described in the section on Disability Adjusted Life Years in chapter 9.

Secondly, the clinical data is woven into a story about what is wrong and how to cure it, which even manages to incorporate epistemologically damaging treatment failures. For example, Edith¹⁹⁵ recalls how because the doctors “could find nothing wrong with me” she was admitted to a “mental hospital” to be treated for psychological problems including “attention seeking” (jealousy of her two elder brothers), “resentment”, “selfishness”, “over-confidence” and “a guilt complex”. As she ironically observes, “most 17 year olds would fit into this description”, although “perhaps not the guilt complex!” She wasn’t allowed to have a stick or any other walking aids (“this would have been giving in to me, and would only make me worse”) but her continual falls were dismissed as attention seeking by the hospital staff. This resonates with Derek’s account of the child psychiatrists who “were always searching for the ‘real’ reason for my dystonia [...] every time a reason was disproved they were convinced the real reason was just out of reach”.

Finally, any conflicting evidence is overcome by rhetorical devices like “domination”, “biomedical infallibility” (supported by the “white coat”), and “patient benefit”, which persuade the person of the truth of “their” story. This rarely worked with Derek as his description of meeting the ‘pioneer of stereotactic surgery’ on a rare visit to England demonstrates. The guru began with fake friendliness (“hello Derek, I think I can do a lot for you [...] get rid of 90% of your symptoms”) but when Derek challenged him (“can I just ask you why it is that in your book these figures... etc”) there was “a terrible silence” and his attitude “instantly changed from initially being friendly [...] to ‘well I don’t think I can help’ he got up, everyone looked acutely embarrassed, and he walked out”.

Greenhalgh characterises the four discourses used to turn people into patients as objectification (splitting mind and body and focusing on the body), quantification (turning symptoms into numbers and treating these as the most important measures), pathologisation (making the disease the object of interest), and amelioration (bracketing the question of cause and focusing on treatment). This transformation also takes place through the medical record, which conceals its provisional and human origin through self-reification, in the same way that QOL measures do [Berg 1996]. Berg reminds us that historical and examination data are not “givens which unidirectionally lead a doctor towards a disposal” but are mutually constitutive; “the data [...] are selected, interpreted, remoulded and, when necessary modified in view of other data and social factors such as time and the image of the person” [Berg 1992]. For example, a doctor who has decided not to operate on a 70-year-old man with

¹⁹⁵An elderly woman with generalised dystonia, writing in the Society newsletter.

stomach cancer orders new procedures to suggest the presence of metastases, which would support his decision.

Data underwent a similar transformation in two pain clinics in Puerto Rico and New England [Bates et al 1997] where the North American centre chose to focus on providing assistive devices as these both reflected their mechanical view of biomedicine and generated income. The care provided to people living with dystonia is also influenced more by what the system can offer than what the person needs, and many described brief and unsatisfying encounters. For example, Anne sees a neurologist “ maybe once a year - and then only as long as it takes to receive an injection [...] there is no time for chitchat, and there is no one else to talk to. And that’s it till I ask for another appointment”.

The impersonality of clinics could be balanced by a more intimate and long-term relationship with a GP or “family doctor”, however GPs received the harshest criticism from people living with dystonia (c.f. the “public accounts” given in chapter 1) who endorsed their characterisation by hospital doctors as “superficial”¹⁹⁶. Derek’s GP appears egotistical, authoritarian, and reluctant to accept that Derek wasn’t “just wasting his time” with “insignificant” problems. On one occasion he had a severe knee infection, caused by crawling around with bare legs when he wasn’t able to walk; “it was infected and I knew it but he thought I was just wasting his time [...] as he looked at it I could see his face fall, he prescribed 2g of antibiotic a day, anti-inflammatories, stuff like that. Then I made the mistake of saying to him ‘how will quickly should these begin to work?’ and he started shouting ‘I don’t know’ and quoting things from the Bible [...] I thought ‘he’s nuts’”. Less dramatically, Henry recounts how his GP “convinced me there was nothing wrong” although “deep down I knew that there was” and at one stage even syringed his ears in case the reason for his neck twisting was that he was going deaf in one ear and turning his head to compensate for it.

GPs’ low status may come from their symbolic role as the bridge between “pure” and “folk” medicine, or the fact that they work primarily with women, children and the elderly. This has enabled them to extend the “clinical gaze” into the personal, reducing the person’s ability to control its penetration. For example, the “patient-centred” techniques advocated in the 1970s (arguably the forerunners of QOL measurement) were a way of accessing information that would not otherwise have been available, particularly as the social worlds of doctors and

¹⁹⁶This tension is reflected in consultants’ reluctance to release patients back to their GP and the brevity of GPs’ letters of referral and follow-up [Somerset et al 1999]. Many GPs complain that their patients will not accept a diagnosis without “the laying on of hands by a consultant”!

patients became more separate. However, as with QOL ‘seeing through the patient’s eyes’ actually meant “adopting a new official language, which sought professionally to redefine what it was that patients were supposed to be seeing” [Gothill and Armstrong 1999].

Understandings of the doctor-patient relationship were enriched by the surprising results of a recent study that found the greatest degree of paternalism among newly qualified doctors as they didn’t have sufficient confidence to debate treatment options¹⁹⁷ [Falkum and Forde 2000]. Their reluctance to share information justified the power imbalance by sustaining the “competence gap” between doctor and patient [Maseide 1991]¹⁹⁸. Attempts to sustain this gap have not escaped the critical notice of people living with dystonia; Bea recalled “the word ‘dystonia’ has never been spoken to me by anyone in the medical profession”. The first time she heard it was from another patient who also told her about the Dystonia Society. Similarly, David thought for twenty years he had ‘non-essential tremor’ (“the doctor who diagnosed it said just that, then added, as an afterthought ‘it’s not life threatening’”) until he was offered injections of Botulinum toxin, “but still with no mention of dystonia”.

Although people resented not being given information about their condition, many preferred to delegate responsibility for their health or pursue both “consumerist” and “passive” strategies [Maseide 1991; Lupton 1997]. For this reason Lupton questions the applicability of consumerist models¹⁹⁹ in health care as the patient-consumer often has insufficient information and their “consumer rationality” may be impaired by their condition. There is a link between QOL and consumerist discourses as the latter encourages people to think in terms of rights and entitlements, for example, the right to a treatment that claims to enhance QOL. The “right to QOL” has been used to challenge the rationing of treatments under the European Human Rights act, and was cited in the Alzheimer’s and motor neurone disease societies’ submissions to NICE (partly because the presumed poor QOL of people with motor neurone disease had been used as an ethical justification for withholding treatment). Surprisingly, this discursive shift can have a positive effect on the therapeutic alliance if doctors see patients as a valuable resource or ally in their “field of struggle”. For example, patients can support demands for independent prescribing, as happened in examples from the Alzheimer’s disease society [2000:38] and the Neurological Alliance conference in chapter 6.

¹⁹⁷With this notable exception, the three attitudes to patient care identified by the study (paternalistic, autonomistic, and deliberative) were distributed according to age, gender and specialism [ibid].

¹⁹⁸Some argue that it is necessary because the doctor needs to balance the needs of the individual and the community and ensure their behaviour is institutionally defensible [ibid; Parson 1972].

¹⁹⁹Assuming health care can be treated as a commodity, a rational choice model may not be appropriate as all consuming takes place at subconscious and unconscious levels and involves emotional investment.

Medical abuses of power are challenged through “atrocious stories”, which also establish the author’s moral adequacy [Baruch 1981; Stimson and Webb 1975]. Their “thick description” contrasts richly with sociological studies that focus on disputes resulting in formal complaints and ignore their emotional impact [Annandale and Hunt 1998]. For example, Derek recounts his humiliation by a sadistic junior doctor as an 8-year-old child; “I had to strip off in front of the students, which had no purpose whatsoever [and] was forced to walk the length of the ward naked”. This left such a powerful impression that “I actually swore that one day I’d come back and blow up the hospital and all the doctors in it and I would get my revenge”, although he is careful to emphasise that “I wasn’t the kind of kid who had violent fantasies, far from it, and yet this was the effect the treatment had on me”.

Having explored the factors within the field of medicine that influence medical encounters, I will now look more widely to the contemporary preoccupation with surveillance and risk management (expressed through medicalisation and bureaucratisation) and the reaction to this in the form of doubt and scepticism. The emergence of what Foucault called the “clinical gaze” at the end of the eighteenth century should be seen as part of a “panoptic system of surveillance” (incorporating schools, asylums and prisons) to create a labour force of “docile bodies” [1994]. By the twentieth century, medical institutions were less important as the gaze had been internalised and controlled behaviour [Armstrong 1984] and the focus of medicine had moved to the community [Armstrong 1995]. For example, people with diabetes are encouraged to cultivate an “ideal self” whose techniques of self-care mimic the capitalist logic that links self-discipline, productivity and health²⁰⁰ [Ferzacca 2000]. Similarly, North American patients at a pain clinic are made responsible for “eliminat[ing] ‘deviant behaviours’” and adopting “Anglo-American middleclass values related to the importance of ‘working on a problem’, taking responsibility for one’s actions and problems, and remaining stoic and non expressive in the face of pain” [Bates et al 1997]. The gaze has even been turned on doctors through techniques like “encounter groups” [Balint 1968] that encourage them to express emotion, but exclude feelings that prevent them from being rational and altruistic, threatening the integrity of their personalities.

“Surveillance medicine” [Armstrong 1995] may be an example of the “medicalisation” of contemporary life [Freidson 1970; Zola 1972] as it replaces the binary separation of health and illness with a classification of bodies on a continuum that enables healthy and sick people

²⁰⁰The treatment attempts to generate a “habitus” [Bourdieu 1977, 1992] that mimics the rhythms of capitalist production (for example, eating three meals a day).

to be studied simultaneously²⁰¹. But it could also be related to the concept of “risk” which forms the basis of many analyses of modernity²⁰² as the “symptoms” and “signs” focused on by the predecessors to surveillance medicine have been replaced by “risk factors” inhabiting extra-corporeal spaces like lifestyles. Contemporary theories about risk suggest an alternative to the concept of “medicalisation”, which has been comprehensively critiqued²⁰³ as they suggest that people have become more sceptical about the expert systems on which they increasingly depend [Elston 1991; Lowenberg and Davis 1994]. This was illustrated by another of Derek’s anecdotes about being offered deep brain stimulation by his doctor; “he said it gets rid of 90% of symptoms and is particularly good for children. I then asked what happens with people who have had the condition longer. He appeared not to understand and turned to me and said, ‘what do you mean?’ [Derek imitates an imperious drawl]. I had to repeat the thing and after a couple of attempts he admitted that for adults the success rate goes down to 50%”.

Doubt has become characteristic of high modernity through the pluralisation of knowledge claims and systems of expertise. Trust needs to be “won” and “retained” (“active trust”) in a context of “lay reskilling” and the adoption of “life-political agendas” [Giddens 1991]. The Internet, patient support organisations and the media have increased the flow of information and shaped its reception by playing a “mystificatory” and “demystificatory” role [Karpf 1988; Fox 2001]. They have helped dissolve boundaries between orthodox and complementary medicine, and provide space for people to share experiences and compare treatments [Hardey 1999]. But scepticism is not a new phenomenon as medicalisation did not affect everyone in the same way. For example, older working-class people who could not form a “biomedical alliance” with their doctors by “playing the authority game” (playing the role of “ideal patient” in the ritual of the consultation) were more likely to be sceptical and oppositional [Cornwell 1984; Balshem 1991]. Paradoxically, disillusionment with medicine is accompanied by an increasing dependence on it to solve social problems [Lupton 1997]. Although the growth of conditions like multiple personality disorder is said to demonstrate a decline in the authority of doctors²⁰⁴, the “fringe of physician advocates” who promote them have considerable power [Hacking 1995; Greenhalgh 2001]. Similarly, the popularity of complementary therapies has not decreased dependence on biomedicine [Cant and Sharma 1998] and may support it by expanding the pathological sphere and encouraging people to

²⁰¹For example, the WHO’s International Classification of Functioning, Disability and Health (see chapter 9).

²⁰²Beck [1992]; Giddens [1991] (“manufactured uncertainty”).

²⁰³Fox described it as “overdrawn” [1977] and Williams and Calnan attributed it to “empire building” by medical sociologists [1996].

²⁰⁴From a time when the “ritual of the consultation was therapeutic in itself” [Shorter 1995].

accept their diagnoses [Williams and Calnan 1996]. There may not even be that much difference between the two since some complementary therapies also overstate individual contribution to illness (ignoring structural causes), focus on treatment, perpetuate the mind-body dualism [Sontag 1988; Greenhalgh 2001], and lose their distinctiveness when they are delivered in a busy NHS clinic [Bendelow and Williams 1996].

Conclusion

In this chapter I have looked at the way medical training attempts to produce “socially neutral physicians”, and linked this to the turning of patients into “typified actors” by making their problems “doable” and encouraging them to become “ideal patients”. I also examined how processes of classification (which have a moral and allocative role) are used in hospitals to manage medical work. I explore these further in section 3 on quality of life, which supports my contention that we are not experiencing the medicalisation but the “bureaucratisation” of human existence, using sickness and health as its entry point. To combat any determinism I have used the experiences of Derek to show how people become real “expert patients” as they strategise and play “the game” to get what they want from medical encounters and protect themselves from “bureaucratic indifference” (far more common than abuses of power).

Paradoxically, the voice of medicine can be a useful tool in this (for example, Kleinman and Kleinman describe the way patients have shifted from a language of caring to one of efficiency and cost to remain audible to their doctors [1996]) and in the following chapters I will investigate whether QOL can be used in the same way. I have also tried to deconstruct the homogenised picture of doctors presented in the accounts from people living with dystonia; for example, by looking at the way different positions and specialities provide access to different voices of medicine. Ironically, the dissatisfaction with scientific medicine expressed by people living with dystonia is shared by doctors like Cassell who recognise that dependence on technology may undermine doctors’ claims to particular expertise rather than support them.

In the first chapter of this section I have looked at individual encounters with medical and social bureaucracy; in the next two I look at group encounters, and their mediation by the Dystonia Society and other organisations that claim to speak with the “patient’s voice”.

Chapter 5: Professional or Bureaucratic?: The dilemma of the Dystonia Society

The Dystonia Society is fractured by fundamental tensions – firstly, it knows there is no common experience of dystonia but needs to create one so that it can gain strength through numbers. Secondly, its symbiotic relationship with doctors stops it working effectively for its members but the only thing that holds its membership together is a label given by the medical profession. Thirdly, it wants to simultaneously represent dystonia as a viable way of life and a disabling condition that deserves compensation. Finally, it feels the need to professionalise in order to work (and compete) with other voluntary organisations, while recognising that the consequent increase in bureaucracy distances it from its members. At the same time concepts like “empowerment”, “regionalisation” and “expert patient” are appearing in its policy documents (as in the NHS’s) and it is using the discourse of marketing to strengthen its relationship with the private sector.

This chapter is the story of the Society’s attempt to work out what its purpose is and whom it represents. It is drawn from a year’s fieldwork in the Society’s central office, embedded in a much longer relationship. In this chapter, I outline the history of the Society and explore its relationship with local branches and members using ethnography from the branch organisers’ conference and the membership survey. I describe the culture of the central office and the way the “professional” and voluntary management structures interact. Finally, I look at its future as it moves towards regionalisation.

The history of the Society exemplifies many of the changes in the health and voluntary sectors during the past two decades. Formed as a “self-help Charity” in 1982, it then became a “medical charity” (under the influence of its influential medical advisory panel), underwent professionalisation, and is now reinventing itself as a “self-help group”²⁰⁵ and using the Internet to engage directly with its members²⁰⁶. The Society’s original focus was blepharospasm (using the template of the Benign Essential Blepharospasm Foundation in the USA) but Professor Munday²⁰⁷ persuaded the founders to include all dystonias, more because of the small number of people living with dystonia than any similarities in experience. Goldie Benjamin (the wife of one of the founders) recalls the Society’s first meeting, which was

²⁰⁵Hevey describes the difference in approach between conservative and top-down medical charities and more radical grass-roots organisations [1992].

²⁰⁶A recent survey of UK neurological patient support organisations found that 71% had a website and also used the net for research, advertising, fundraising, and hosting discussion forums [Fox 2001].

²⁰⁷A prominent specialist in movement disorders who introduced the founders.

chaired by “Lord Young of Dartington” (greatly enhancing its prestige, in her view) in the “now famous ‘front parlour’” of another of the founders. She decided not to attend because she felt “*sufferers* might be embarrassed by the presence of strangers who were not similarly *afflicted*” (my italics), but noted that when her husband returned “he positively bubbled with enthusiasm” and was “greatly encouraged” by meeting others with focal dystonia who wanted “to build a self-help Charity and call it THE DYSTONIA SOCIETY” [the Society newsletter 1993]. This was facilitated by a donation of £500 from the Parkinson’s Disease Society (solicited by Professor Munday), which enabled them to form a management committee and register as a charity. To establish their credibility, they held a public meeting in the House of Lords with Professor Munday as the main speaker, which “was attended by many eminent medical people” [ibid]. They also received support from the North American Dystonia Medical Research Foundation who funded their first mailing to neurologists, psychiatrists and ophthalmologists in the UK²⁰⁸. Raising medical awareness of dystonia increased the rate of diagnosis, which also increased the membership and profile of the society.

During the first four years many of the founder members were replaced by members elected at the annual general meetings, but the Society still lacked an administrative base so they “borrowed” a manager from an insurance company for one year²⁰⁹. She developed local branches, organised a “travelling publicity stand” at shopping centres, produced literature, coordinated approaches to the media, and rented the Society’s first office. After her departure, the Society decided to appoint a full-time director (on the advice of the medical panel) who “tirelessly travelled all over the country, meeting members, consolidating existing groups, encouraging new groups, organising speakers and fundraising far and wide” [ibid]. Funding medical research was a priority because members still believed that a cure would be found and the Society needed to reward the doctors who had supported it and attract new medical supporters.

Ten years later, the first director was replaced by a “charity professional” who had not previously worked on health or disability. He outlined his priorities for the Society in their newsletter [1993]: “building awareness, not least within the medical profession, improving information support and welfare services which the Society can offer, and stimulating and funding more research into dystonia, so that more effective treatments - and a

²⁰⁸The fact that two of the founders had Blepharospasm clearly influenced their choice of specialist.

²⁰⁹She was allocated space in Harringay council’s Social Services offices - perhaps an early sign of the importance of the “administrative model” of support [Oliver 1996].

possible cure - can be found". These continue, although finding a cure has been downplayed, except in appeals to the public²¹⁰ and the Society spends more time fending off applications for research funding than "stimulating" them. But his omissions may be more significant than his inclusions: support to people living with dystonia is placed within a welfare model²¹¹, there is no mention of moving towards sustainability by developing branches or branch officers, and the discrimination experienced by people living with dystonia is attributed to lack of information.

Only one of the original founders remains as a contrary voice on what is now called the "Management Committee of Trustees" indicating its distance from the professional executive. This distance is reflected in the fact that the staff do not have dystonia while trustees and volunteers generally do. Although one of the Society's goals is to increase the employment of people living with dystonia, when they have applied for posts staff members have expressed doubt as to whether they could cope physically or present a "professional" image²¹². This attitude extends to trustees, for example, the request from the Yorkshire-based Treasurer to standardise the financial software (enabling work to be carried out by e-mail rather than through gruelling journeys to London) was described as "making trouble". While staff complained that members did not understand their work or appreciate the limits to resources, they were often dismissive of the work of branches²¹³. In the next section I shift into the first person to more fully evoke the branch organisers' conference, which illustrates the ongoing tensions between the Society's ambitions and resources, and the rhetoric of empowerment and reality of control.

"We're talking to ourselves here" (but who are "we"?)

The conference took place over a weekend at a York hotel that had recently started providing conference facilities and only had a vague idea of what was required. The main room was set out for 40 delegates but there were nearly 70 so the conference started slowly while the organisers negotiated another 30 chairs and attempted to fit them in. Would-be speakers had to struggle to the front of the room (with the staff and the majority of the trustees) or shout from their seats. The spatial segregation of staff and members became an issue²¹⁴ and was

²¹⁰Hence resistance to changing "fighting dystonia" to "supporting people with dystonia", even though the warlike overtones of the former reinforce the common confusion between Estonia and Dystonia.

²¹¹One of their first acts was to establish a "Welfare Service" run by a committee of neurologists and "retired social workers".

²¹²For example, they expressed surprise that the newsletter used to be edited by "dystonia sufferers" even though in most groups it would be more surprising for it to be edited by people who weren't disabled.

²¹³For example, a new staff member was told that there was "nothing going on" in London outside the Office.

²¹⁴When staff spoke among themselves there were cries of "are you having a meeting on your own down there?"

echoed in the language people used: “you’re doing a good job down there”; “come up and speak”. Although delegates were often told, “this is your conference” the programme did not offer many opportunities for active participation. There were sessions for delegate feedback, but these were cut back when the speakers (mainly staff) overran. There were also a couple of working groups, which were facilitated by staff. The Director and Development Officer set the agenda at the beginning of the conference, summarised the discussions, and outlined the plan for the future at the end.

The Development Officer introduced the conference by explaining that her focus was on our communication strategy and how we could work together. Her role involved “representing the society to outsiders” (members were included in this designation), “liaison and encouragement”, and “development and promotion”. A senior trustee then reviewed the history of the Society and concluded with an optimistic picture of its current position: income of “£400,000+” per annum (actually £313,000) and “3,500 members” (2,900). He emphasised that the Society only worked because of input from people living with dystonia; “like you, I am a member and I have dystonia”.

Delegates then discussed the need to “sell” dystonia to doctors, preferably using the tactics of the pharmaceuticals (“we’ve got a product - it’s a problem”). One delegate identified dystonia’s lack of “focus” as a problem in raising awareness. In comparison the brand “MS” “immediately conveys a disability and evokes understanding and support”, even though most people wouldn’t recognize a person with multiple sclerosis. Another noted that 3,500 members out of a potential 38,000²¹⁵ did not seem like a great success, especially as the Dystonia Medical Research Foundation has 20,000²¹⁶.

The relationship between staff and branches was addressed after some trustees criticised the Director’s use of “you” and “us” as “we’re talking to ourselves here”. Although the Chair of the trustees described the staff’s role as “doing what you, the members, want”, other delegates felt that “branch and central activities were very separate” and should be combined. One delegate from a strong northern branch felt there should be more communication over fundraising, “I’m not sure why we’re raising money and sending it to the central office”. He added that that lack of communication had “nearly caused a split”, a potent warning after the secession of the North East group to form a rival organisation (ADDER). The Director apologised for this, saying the communication problems resulted from the Society’s focus on

²¹⁵The Society’s estimate of the number of people living with dystonia in the UK.

²¹⁶One of many references to “the American way of doing things”.

research and lobbying which he believed were the members' priorities. He justified funding welfare and research (the Dystonia Medical Research Foundation concentrates on the latter) in terms of having a good portfolio for fundraising. He also explained that the Society wasn't necessarily about recruiting new members. In fact, the "loss" of 500 members each year from the database was a "good sign" as we were "giving them what they want". Instead, the Society aimed to "help people understand their condition, obtain the best treatment, and build awareness of dystonia", which did not require an ongoing membership²¹⁷. He felt that supporting people living with dystonia involved acknowledging that many people want to deal with dystonia in isolation and "don't want to meet other people who look as bad as they feel"²¹⁸. Not only do "some individuals need more support than others" (diverting the Society's resources from the more glamorous activities of "research and lobbying"), but also "it is difficult to see where support for dystonia ends and becomes support for individuals with complex problems".

The Director described the "ideal" person living with dystonia as "someone who can support and help others", which seemed a heavy burden for people who may only just be managing their own condition. However, it was difficult to encourage people who have "gone through the system" to remain with the Society, and there was a problem of burnout for long-term members as the management structure is "dense" and volunteer dependent. He acknowledged that the Society needs to develop "bottom-up as well as top-down" but said it still needed centralised business planning and fundraising.

The first working groups discussed ideas for raising awareness and money, some of which were becoming very familiar, for example, identifying celebrities with dystonia, and getting articles into general medical journals (which I know from experience is not easy). The staff member who was moderating emphasised that "we want your ideas" (reiterating the branch/central office split) but when branches discussed what they would like to do he seemed to think that they wanted the central office to do it for them. My group felt that that there was a limit to what could be done centrally, and that we needed to develop the capacities of branch officials and new ways of working together. One branch that had recently organised a "living with dystonia" day complained that the fundraiser at the central office had not asked them who he should approach for funding, suggesting that he didn't value "local knowledge" and connections. A delegate from the same branch added "we want

²¹⁷The annual membership fees are only £10 waged, £5 unwaged so are unlikely to be a deterrent.

²¹⁸I recalled one branch organiser who found it "frightening and depressing" when people in wheelchairs came to her meetings.

to use money raised locally locally. Our money just seems to disappear to the central office and we don't know anything about it". When the fundraiser pointed out that the money had been used for their living with dystonia day, the delegate said dismissively "oh that's the Development Officer's thing". This suggested that while organising the days centrally and limiting the branches' involvement to hosting them might be more efficient, it did not generate a sense of ownership.

One delegate observed that the East and West Midlands branches covered a huge area, "they obviously don't know their geography in the central office" and another riposted, "down south they think that the country stops at the Watford gap". A Welsh delegate was excited about the Society's website as "it will enable us to take ownership of our regions", but his suggestion that branches could contribute to it directly without going through the central office appeared to unnerve the Director. Some delegates worried that the Society's administrative structure was turning it into "a self-perpetuating bureaucracy" and wondered how it could be sustained. There was also a tension between the internal and external goals of the Society, for example, confining submissions to the newsletter to the "positive and upbeat" removes a space for the voices of people living with dystonia.

The next session explored the relationship between the central office and the branches, which, according to the Director, involved "swapping money" to make members "feel good about contributing to a wider unit"²¹⁹ and provide "local branch success stories" for the national donors. A Scottish delegate added supportively, "Scottish members say 'We don't want to send our money to London, it'll all disappear then'. I tell them 'No, it's going to the Society nationally and that's all of us'". The fundraiser then dryly observed that we weren't addressing the difficulty of raising money²²⁰, "the debate is all about who spends it". The Development Officer added, "I know the desperation but we mustn't try to run before we can walk. It's important to get the right message". This was poorly received by the delegates who muttered about "negativity" and "poor attitudes" at the central office.

On a few occasions the staff drew back so the delegates could direct the discussion but some delegates appear to resent this saying "I think it's the professionals who should tell us how to do it [fundraising]". One trustee told me, "There's an expectation at this meeting that at some point you're going to be told what to do". But I didn't think the situation was as simple as

²¹⁹The Society's branches contribute less than five percent of its income.

²²⁰The main problem is the low profile of dystonia ("it's difficult when you need to explain what dystonia is and why people should care" [Development Officer]).

that. What the delegates resented was the central office's apparent lack of understanding of the situation "in the field"²²¹ (as the staff described it). One delegate said that the central office must have a different conception of resources since they were offering "virtual" resources like links with other organisations, rather than "concrete" resources like stationery.

When I reviewed my notes that evening I saw a number of overlapping tensions: between the central office and the branches, north and south, London and the rest, staff and volunteers, and people living with dystonia and those without. These were expressed through "jokes" about geography, identity, and who was sitting with whom. Each group resented the other's high expectations and lack of empathy - "they don't know what it's like to be a person living with dystonia" versus "they don't know what it's like to manage a voluntary organisation". The discourses of "marketing" dystonia and being "professional" seemed oppressive and may contribute to volunteer and staff "burnout". There was also an assumption of passivity among the membership but no recognition that not getting involved is also a choice.

In fact, the central office has little contact with the bulk of its membership²²², which undermines its claim to be the voice of people living with dystonia. Last year it decided to survey them to find out if this was a bad sign. I drafted the survey with the Director and a PR firm representing the pharmaceutical that was funding it. The Society wanted to get basic demographic information and explore members' relationship with the central office and the branches, while the PR firm wanted quotes and statistics to support their company's entry into the Botulinum toxin market. The partnership worked fairly well, although we were alarmed when they withdrew their offer to fund a publication from the survey as they didn't feel that it would add anything to the marketing strategy, and they didn't appreciate our refusal to ask members to distinguish between the two existing brands of Botulinum toxin. The publication (*The true impact of dystonia* [TDS 2001]) generated a large response from members, many questioning the motives behind the way the lives of people living with dystonia were represented. One advised the Society not to become "drawn into the scenario of appealing to funders or potential allies through pity", despite the "financial pressures". He warned "statements like 'since having dystonia it is like I have given up on life' send profound messages to non-disabled people", including "medical professionals." He also questioned the ethics of "exploiting" the author of that statement's "genuine distress" for "tacit fundraising purposes". The Director's disingenuous response was that it would be

²²¹e.g. They couldn't limit calls from members to 15 minutes as they were "a lifeline for some people in need".

²²²Members order publications, renew memberships, register for the AGM and other events, write to the newsletter, and occasionally write to complain or phone for advice on problems with the NHS or DHSS.

wrong for the Society to “make its own judgement on what can and cannot be published” but this was exactly what happened in production meetings when the Society helped the PR firm select “strong quotes” and agreed that the quotes rather than the statistics should “drive” the publication.

The survey also addressed the role of the branches: sixty three percent of members had had contact with their local branch but only forty six percent had attended a branch meeting. Although fifteen percent were regular attendees only three percent wanted to be involved in running or supporting the society. This suggested that the image of the branches as “bands of dedicated enthusiasts competing for the opportunity to serve the cause”²²³ bore little resemblance to reality and it would be a mistake to depend on them to regenerate the Society. One of the trustees drew a more realistic picture when he observed that most of the branches are dependent “on the efforts of two or three people”, and not only has the Society never recruited any members from the branches but “many members of local branches are not, in fact, paid up members of the Society”²²⁴.

Survey respondents were positive about the services offered by the central office but few had used them²²⁵. In fact the results suggested a warm but distant relationship between the Society and its members²²⁶. At the end of the survey there was a question about satisfaction with the Society, phrased in terms of “value for money”. People could indicate their level of satisfaction and explain why they felt like this in an inch of “free text”. Interestingly, the most critical comments came from people who describe themselves as “satisfied” or “very satisfied”. They criticised the London bias, the proportions of income spent on research and administration, the role of pharmaceuticals (“[the publications are] always about Botulinum toxin”; “please do not get trapped by drug companies”), the bias against alternative therapies, the demands placed on members to raise awareness and money (“I feel you need to be looking at a celebrity to help this”), and lack of contact from the central office (“all we get is four newsletters a year”).

Ten percent of respondents had attended the annual patient’s conference, however, in many ways this event exemplifies the criticisms noted in the first part of this chapter as it was

²²³Extract from an open letter to the trustees from one of the founder members (sent in 2001).

²²⁴Additionally, some branch organisers have not been diagnosed, or diagnosed with other movement disorders.

²²⁵50% had read their publications but only 19% had phoned the office. 29% had attended an event but only 10% attended an Annual General Meeting or Patient’s Conference, key events in the Society’s calendar.

²²⁶The high response rate (60%) probably reflects their age and sense of duty, as did the polite but not particularly informative responses to the questions.

dominated by medical representations of dystonia and didn't provide a space where people's experiences could be heard and valued. I will move back into the first person to describe the conference, as it was the first Society event I intended and made a powerful impression on me. The conference was held at York university and although the venue was fully accessible, the accommodation, restaurant, bar, and meeting rooms were situated some distance from each other and linked by an open-air walkway. The main event took place in a large lecture hall, which increased the feeling that we were being lectured at by the people who knew about dystonia²²⁷. The presentations were oriented to a medical audience and participants admitted they found it difficult to relate the diagrams of neural pathways to anything that was occurring in their body. Although the conference was glossed as an opportunity to see "our" researchers working towards a cure, the inscription of people's knowledge about their bodies in biomedical language had an alienating and disempowering effect. While presenters admitted gaps in their knowledge of treatment efficacy and long-term effects, the audience were not invited to fill these with their experiences. The conference was chaired by the Director who filtered the questions after each presentation, often "translating" them for the speakers. Speakers were required to identify themselves (and implicitly justify their intervention) and I observed that the majority of questions came from other neurologists and the Society staff.

On the first day, there were presentations on surgical treatments, Botulinum toxin, and physiotherapy, although the latter was treated as light relief with volunteers summoned from the audience to make tai-chi like movements with their writing hands. The two surgical presenters (on Surgical Peripheral Denervation for cervical dystonia and Deep Brain Stimulation for generalised dystonia) were in competition to recruit trial participants and have their technique accepted as the future for dystonia treatment. The first speaker acknowledged that surgery had had a bad press in the past (due to the high morbidity and mortality rates) but said the first trial participants had shown an improvement of 88 percent using clinical measures (e.g. angle of neck rotation). However, the measures did not show an improvement in disability, which he attributed to "slow psychological adaptation" after "successful [sic] surgery" as the participants continued in their "bad habits". Cervical dystonia also recurred in many patients, which he admitted was due to poor technique in the first phase of operations²²⁸. The results appeared less impressive when he acknowledged that 30 of the 70

²²⁷The presentations were videoed for sale to members and were surprisingly popular, considering the cost (£30 for the set of 4).

²²⁸In the second phase he had reduced surgery time from 8.5 to 2.5 hours, hospital stay from 10 to 3 days, and reduced scarring, a warning to anyone who would be first in the queue for a new treatment.

applicants for surgery had been excluded as unsuitable. The second presenter had more impressive statistics but a much less imposing manner. Instead of striding about the stage declaiming his results, he appeared to be trying to hide behind his lectern. People's responses to the two presentations suggested that the doctor's charisma is influential in treatment as they were much more enthusiastic about the first procedure than the second, despite its comparatively poor outcome.

This was followed by a presentation and video from the Chair and Director of the Dystonia Medical Research Foundation. This was designed to impress - the professional video, the prestigious partnerships (including an "industry council" of pharmaceuticals), the range of activities - and provoked debate over coffee about whether the American model of self-help was superior to the British. There were also presentations on the classification, brain mechanism, and genetics of dystonia, which were pitched at undergraduate level, causing blank faces and notably fewer questions. One presentation provoked occasional snores! Nonetheless, participants described them as "very impressive" (apparently in inverse proportion to their comprehensibility) and were grateful that these important people had given up their time to talk to them²²⁹.

The conference seemed like a relic from the age of the grand medical charities (and their royal patrons). Not surprising then that this was its final year as it was put on hold due to shortage of money and new research findings. A new way of making contact with the members was through "living with dystonia" days²³⁰, which appeared to put them at the centre of the event, enabling them to meet other people living with dystonia and learn (I assumed from them) how to manage their condition²³¹. I attended the North West event, but was disappointed to see that the programme resembled the conference with speakers from medical and social services and no space for people to share their experiences.

This was the only day organised by the branch that hosted it and they were keen to demonstrate their organisational skills and connections²³² to guests from the central office who were treated like visiting royalty. After a town crier opened the event, there was then a welcome speech from the chair, and acknowledgements from the Development Officer to the male organisers (although I only saw female faces behind the desks on the day). These were

²²⁹"While most of the terminology used by the speakers sailed gently over the head of this little old lady, it seemed to be of little importance beyond the fact that there are people out there who care about us and are fighting to overcome the problems of dystonia" [Society Newsletter 1997].

²³⁰An idea imported from Diabetes UK by the Development Officer.

²³¹A goal of the Government's "expert patient" project to reduce the burden of chronic illnesses on the NHS.

²³²There were letters of support from MPs on display and one MP attending (from a marginal constituency).

followed by presentations from a representative of the benefits agency²³³, the Society's medical advisor, and a nurse practitioner. After lunch, the delegates attended workshops in the Alexander and Bowen techniques and reflexology. While these may have been an attempt to address the biomedical dominance of the Society events, they were non-compulsory and timetabled in the "recreation slot" in the afternoon²³⁴. I attended the workshop on Bowen technique, expecting a truly alternative approach, but although the workshop leader said "we treat you" not your diagnosis, she undermined this by referring to "my neurological clients". She was visibly irritated by frequent references to the Society's medical advisor (who was called by his first name) and seemed to retaliate by calling him "*Mr Brown*", rejecting any claim to superior expertise by virtue of his training.

The early start and intense interaction exhausted me and I felt uncomfortable with exchanges like "this is Laura, she's our new volunteer, doing research to help people with dystonia with our Medical Advisor". "Oh that's so good of you. We're so grateful that you're helping us, and as a volunteer too. You don't even have dystonia!" The paean to the benefits of medical research that followed was not halted by my attempts to explain the nature of my research and after a few exchanges I just smiled and took credit for everything from the discovery of the dystonia gene to deep brain stimulation.

The Society's central office

Most of my fieldwork was done at the central office, which was on the second floor of a smart street in Clerkenwell²³⁵. It was not accessible to people with disabilities as there was a step up to the ground floor entrance and no lift. The Director and Welfare Officers' offices were on the right as you entered through two sets of heavy and narrow double doors. The remainder of the office was open plan with two screens separating the kitchen and the tables where the volunteers prepared mailings from the rest of the staff. Despite the Clerkenwell location, it felt as though we were running the society from someone's front room. The computers were unreliable and infested with viruses (second-hand from an insurance company upgrade), the e-mail server rarely functioned, and I spent much of my fieldwork inside the ancient photocopier.

²³³Her authority was undermined by her admission that she had not dealt with any applications from people living with dystonia.

²³⁴To save the workshop leaders the inconvenience of changing rooms, the participants, complete with mobility aids, had to slowly move to the next room while new participants attempted to push their way in. This took over twenty minutes and many would-be participants gave up and sat outside.

²³⁵The Society had fixed the rent before the area became gentrified but it was due for review in June 2002 and they had been warned that it could rise by 150%.

When I began my fieldwork the staff consisted of the Director, Development Officer, Welfare Officer, an accountant, two fundraisers and a fundraising secretary, an office administrator and two general secretaries. The Director prepared reports for the management committees, liaised with other organisations (including pharmaceuticals), edited the newsletter, read all the incoming mail, and closely supervised the staff. He worked from home or attended meetings outside the office on two or three days a week. The Director had a genial and paternal manner but found it difficult to delegate or give staff freedom to innovate, as he liked to feel in control. Consequently he was overworked (often working at weekends or late into the night) and felt his time was absorbed in administrative trivia²³⁶.

The Development Officer was a new post that combined at least two jobs in one. The incumbent was responsible for raising public and medical awareness, developing branches, and organising many of the activities for members. She was in her second professional position, keen to use what she had learnt at her last employers (a large medical charity) and slow to recognise the difference between the two organisations, and between how the Society wanted to be perceived and the reality. The Development Officer became increasingly disheartened during my fieldwork as she attempted to reconcile the expectations of the members (people with dystonia in Coronation Street) with what she could achieve without a specific budget, and was frequently accused of “negativity”.

Fundraisers accounted for a third of the staff; there were two full-time fundraisers (one of whom was commencing her second period of maternity leave to ribald comment from the trustees²³⁷) and a part-time fundraising secretary who worked from home. The main fundraiser made applications to companies, trusts, foundations, and governmental departments. These received standard appeal letters (see below), accompanied by a poster of a person with dystonia, and a copy of *Dystonia News*²³⁸.

[Dystonia] can affect the whole body or, still debilitating and painful, can be a focal dystonia *attacking* one particular part of the body: the jaw, tongue and mouth, head and neck, arms and hands, or the muscles around the eye. Dystonia in children can be particularly *cruel*, generally being progressive. It can leave the child with *an able mind in a seriously disabled and contorted body*, sometimes even unable to communicate. [...] In some cases, *patient's bodies* are severely twisted and they can

²³⁶Exacerbated by the elaborate reporting formats of the different committees.

²³⁷One of the reasons the trustees gave for making the male Fundraiser's contract permanent was that he was unlikely to become pregnant.

²³⁸A quarterly newsletter for donors that showed proud donors ceremonially handing over cheques and grateful (and photogenic) members receiving motorised wheelchairs. Headlines from the last issue included “pioneering surgery for brave Louise!”, “charter mark recognition for the Glasgow Nurse Practitioner”, and “lottery gold for the golden mile” (successful application to the National Lottery by the Blackpool branch).

remain *prisoners in their own homes*, refusing to step outside to face *the cruel and inquisitive stares of others* [my italics]

Supplement for charities funding children's projects:

[...] To meet the special needs of young people, the Society developed a family support network known as 'Young Dystonia'. [...] This] is particularly helpful for children who use the support network to share their fears, anxieties and thoughts with others. Their friends are finding out about life, as they face the complexities of adolescence but children with dystonia have additional concerns: 'Will I be able to walk when I get older?' 'Will I be able to go to college?' 'Will I ever get a boyfriend/girlfriend?' 'How bad will my dystonia get?' All these are questions that may go through a youngster's head

In 2000 the main fundraiser sent 1,022 appeals and received donations from 13.2% of the organisations contacted. He was also responsible for individual giving, coordinating flag days and the distribution of collection boxes, although this represents a small proportion of the Society's total income. The Society's amateur fundraising indicates the demographic of its organisers as its focus is the "Great British tea party"²³⁹ and it relies heavily on Masonic, Rotary club and church events.

During my fieldwork one of my tasks was to design posters for a "symptoms awareness" campaign, similar to one carried out by Diabetes UK, which listed a series of symptoms beneath a picture of a urinating cherub. Dystonia proved equally difficult to represent and I resorted to images from a medical teaching aid that showed dull eyed subjects in neutral environments with screwed up eyes (blepharospasm) or a bent neck (cervical dystonia). These were in the worst tradition of charity advertising as the subjects were decontextualised, medicalised, and not engaging with the camera/viewer [Hevey 1992]²⁴⁰. Nonetheless, the fundraiser described them as insufficiently graphic and sympathetic, as the subjects were middle aged (representing the usual age of onset). He continued to use his favourite poster of a downwards shot of a doe-eyed girl in a wheelchair, despite the fact that dystonia is comparatively rare in children and the "girl" was now 25 years old and had recently applied for the post of Development Officer.

There were two other posters that were occasionally used: the first showed a cheerful looking middle-aged man with his head bent to one side by torticollis. This was considered to have less impact as the subject "looked drunk". The second showed a series of shots of an elderly

²³⁹An example of "the tea party route to the disability issue"? [Hevey 1992].

²⁴⁰Hevey compares the "marketing" strategies of charities with the "branding" of commercial organisations, for example, using a stark image of disability in black and white on posters, which acts as "the visual flagship for the myth of the tragedy of impairment". He likens it to pornography, which also focuses on a particular body part (breast/impairment) to provoke a response (desire/fear).

man with generalised dystonia in a wheelchair, demonstrating the continual and compulsive nature of his movements. This was an effective representation of a movement disorder, but the subject was staring into space rather than engaging with the viewer and the accompanying text (quoted below) completed the process of alienation:

[Heading]: With most forms of paralysis you can't move. With dystonia you can't stop. [Text]: Dystonia is a purely neurological disorder that causes its *victims* to constantly twist and *writhe* involuntarily. The results, as you can see, are distressing in the extreme. Yet despite affecting more than one in every two thousand, dystonia receives precious little in way of research and support. Please help us *to put matters straight* by sending a donation to the Dystonia Society
[my italics]

Perhaps understandably, fundraising activities were kept separate from welfare. The Welfare Officer handled enquiries about medical or social support, liaised with other disability organisations, organised the “young dystonia” group (targeted at parents rather than children), and provided support to individuals. This was the most time consuming part of her job as, in addition to enquiries from members, four or five people with complex problems would telephone her at least twice a week to talk about what was going on in their lives. Although the Welfare Officer attempted to restrict these calls to dystonia-related problems, every problem could be presented in this light (for example, whether the member should take a lodger if it might aggravate their dystonia)²⁴¹. She felt a genuine responsibility to “my” members and would encourage me to pursue pointless crusades on their behalf²⁴², believing (possibly because she had only worked with people living with dystonia) that dystonia was the worst thing that could happen to anyone. The Welfare Officer was also responsible for health and safety and “office cleanliness” which she extended to taking the tea towels home every week and washing them.

There were three female volunteers, all white, middle class, and over 65 who would not have looked out of place collecting for a cats' home or doing the flowers for their local church. Although they tirelessly photocopied and stuffed envelopes, their main task was managing the complex drinks rota that provided specified drinks and biscuits (e.g. “morning: white coffee, afternoon: tea, two sugars”) to every staff member at 8.30, 10.30, 1.00 and 3.30. While it was possible to make yourself a drink when you wanted one, this was strongly discouraged for reasons of efficiency! The volunteers' time was treated as though it had no

²⁴¹Her secretiveness about what she actually did may be due to an awareness that this would not be regarded as a productive use of her time. For example, her reports listed “meetings attended” but gave no sense of their length or importance - one was “meeting with Laura Camfield” which I recall as a chat over a cup of tea.

²⁴²For example, requesting a refund of travel expenses from a London hospital for a wealthy Scottish couple.

financial value and they were frequently given tasks that were unnecessary or could be performed more efficiently another way.

The office opening hours were from 8.30 to 4.30²⁴³, but the fundraiser and Development Officer had negotiated a later start time and were rarely in the office before the Director's arrival at 10.45. This caused resentment among the other staff²⁴⁴ as they were also allowed to work more flexibly and paid considerably more. The new professional posts were part of the Society's attempt to align itself with larger neurological charities, but this backfired because the incumbents exposed the Society's ways of working to uncomfortable scrutiny. For example, they both came from charities with a large administrative infrastructure and were not used to writing their own press releases or using a photocopier. The divide between old and new was also spatial as the fundraiser, accountant, and Development Officer were located in the left hand corner of the office (enabling them to chat together and make subversive comments sotto voce), while the Welfare Officer and Director were in separate rooms on the right hand side. The Welfare Officer and Director's secretary was situated between the two and complained bitterly that he found the "perpetual chatter" distracting²⁴⁵. The other secretary appeared to enjoy the office banter (despite its slightly sexist nature²⁴⁶) and said she would otherwise have found working in an office of older people depressing. She wasn't happy in her job, which was repetitive and poorly paid and left without warning halfway through my fieldwork.

The Society's day began at 8.30 when the office administrator checked the answer phone, made the first round of drinks, and collected the post. All post was opened (even if marked "private and confidential") and although you would be told when mail had arrived for you, you could not collect it until it had been read by the Director who would mark on the correspondence who it should be circulated to²⁴⁷. The strategy for circulation appeared to be more about creating a "paper trail" than imparting information since many interesting letters that were only addressed to the Director were never circulated on the grounds of "sensitivity". Only the Director could throw incoming mail away, even if it was obviously junk mail. The Society had e-mail but this was rarely used as the server was often down and staff rarely

²⁴³Designed for the convenience of the Welfare Officer and administrator (who were the longest serving staff members and had recently married) rather than the members.

²⁴⁴Concealed behind a discourse of health and safety and security: keeping regular hours was "healthier".

²⁴⁵His eventual resignation (and breakdown) was partially attributed to a stressful working environment.

²⁴⁶The Director once compared me favourably to the Development Officer because "Laura's got a nice figure but you couldn't say she was skinny. There's plenty of meat on those bones".

²⁴⁷The main problem with the system (designed so the Director could control the information flow in the office) was that the Director was not in every day so letters needing immediate action were often delayed.

checked their accounts. The trustees debated having a “mail-to” facility from the Society’s website but the Director was convinced that we would be “flooded” with enquiries as the discipline of writing a letter and purchasing a stamp deterred less serious correspondents. Memos (copied to the whole office) were the usual form of communication, even where a less formal approach would have been preferable²⁴⁸. In other respects, the office was very friendly, for example, people brought in food to share after holidays and cards were bought from petty cash to say thank you and mark significant events. But although I appreciated the warmth of my welcome as an “unpaid staff member” (a subtle yet important difference from a volunteer), I found the family atmosphere of the office oppressive and felt the emphasis on preserving good relations stifled debate²⁴⁹.

The volunteers and administrative staff answered the phone and logged all calls and the action taken in a red notebook, later adding the information to the member’s record. Maintaining the membership database was time consuming, as information was stored in a DOS-based application called “Logiscript” that the Director had brought with him from his previous position. Despite my computer literacy I failed to master it and was irritated by its incompatibility with external systems²⁵⁰. For example, information for the auditors had to be surreptitiously retyped into an Excel spreadsheet as it would otherwise have required eight sheets of A4 paper, sellotaped together. The “computer software issue” acquired symbolic importance during a row with the trustees in 2001 where it represented outsiders with “lofty consultancy hats on” attempting to impose their priorities without understanding how the society worked.

The trustees play an important role in managing the Society and provide a tangible link to its origins as a self-help group. They are elected at the annual general meeting but voting is a formality as there is never more than one applicant per position²⁵¹. Currently there are ten men and three women, 11 of whom regularly attend the quarterly meetings. The trustees appoint a Chair, Vice-Chair, Treasurer and Secretary and elect two or three trustees to join them on the “Finance and General Purposes” committee that administers and manages the Society. The Director sets the agenda for trustees’ meetings and takes minutes, which enables him to retrospectively shape the meeting and present his perspective in a studiedly neutral

²⁴⁸I made a off-the-cuff remark in a tele-conference about the “hair raising” language used in fundraising letters to describe the experience of people living with dystonia and received a formal memo rebuking me.

²⁴⁹Expressions of discontent, particularly from female staff, were interpreted as “depression” or “problems at home” and the person was invited into the Welfare Officer’s office for a “little chat”.

²⁵⁰For example, it wasn’t possible to e-mail the copious meeting papers to the trustees as attachments.

²⁵¹The manifestos give their marital status, number of children, profession, and previous “good works”.

manner²⁵². There are three sub-committees, each containing five to six trustees and a member of staff (“Staff and Management Structure”, “Welfare”, and “Research”) and two working groups (“Awareness” and “Regional Development”). Each of the six groups meet at least quarterly, which imposes a considerable burden on the 11 active trustees, all of whom have dystonia or support a partner with the condition (three also run local branches).

The quarterly trustees meetings were the main opportunity for staff to share concerns with the trustees who rarely came to the office uninvited. Having a “good geographical spread” of trustees also meant that most lived too far away to see each other outside meetings. The female trustees were younger and less conservative than the men. They were all still working (in health or social care) and aware of issues like equal opportunities and inclusive language²⁵³. One female trustee wanted to introduce the others to the social model of disability but strangely her presentation was always pushed to the next meeting. The female trustees sat together at the trustees meeting and supported each other, but were less vocal in subcommittee meetings where they were usually the only women.

I felt equally conspicuous (particularly after I had been introduced as a “medical expert”) and for the first few meetings was treated like the new in-law who can provide a fresh perspective on family quarrels²⁵⁴. I attended a number of meetings to present items that I was working on and (like most of the staff) found them a bit of a chore but recognised their importance. I didn’t agree that the trustees “disappeared” between meetings but did think their expectations were unrealistically high. Purely by chance I was present at a pivotal meeting in March (or “March 17th” as it has been grandiosely named) and record my impressions below.

It was my first trustees meeting after a serious accident in Autumn 2000 and I worried that I would become tired or uncomfortable if I sat for a long period of time. Bizarrely (considering I would be among other people with limiting conditions) I also worried about appearing awkward because I had just come off crutches. I had arranged to arrive 40 minutes late to make it a shorter day but was surprised to see that the meeting had already dispersed. Many of the staff had disappeared (including the Director) and the trustees were milling round in an agitated way. I checked my agenda nervously. All I should have missed was the Chair’s

²⁵²At “March 17th” (described later in the chapter) they were redrafted three times before they were agreed.

²⁵³This was a running joke among some of the male trustees who pretended not to understand why “girl” was offensive and refused to call the male Chairman “Chair” (“He’s not a piece of furniture”).

²⁵⁴I was asked my opinion on the seating arrangements at the branch organisers’ conference and cautiously said that although there were divides, I didn’t think the spatial one was important. This fuelled an argument about whether the staff should have sat together on the first night because of a shortage of seating.

reconfirmation for another term after an unsuccessful challenge from a trustee who ran a large branch in the North. I took my place as the others filtered back into the room, sure that I would find out the reason for the interruption when we broke for lunch.

We slowly progressed through the agenda, giving information and postponing the majority of items for discussion at some future date. There was a brief skirmish between the trustee who stood as Chair and the fundraiser about whether a letter had been sent to acknowledge a masonic donation of £1,500 that had been raised by his branch. The Director intervened to support the fundraiser and the issue suddenly became the way in which the trustee asked the question, and whether it was the Director's role to correct people's manners. We moved swiftly on to regional fundraising while the two combatants were held in check by their neighbours. Even this had the potential for conflict as two trustees questioned the central office's use of funds restricted to their geographical area to fund the branch organisers' conference. They asked why branches weren't told that this money was available and given the chance to spend it on their own projects; "shouldn't branches be driving this?" The Director assured them that branches were given a year to come up with a "feasible" project²⁵⁵ and only if they couldn't would the money be put into the general fund. Another observed that while branches had to inform the central office of any fundraising they were undertaking (and often ask permission), the reverse did not apply so regional and national fundraisers continually trod on each other's toes.

The next item was the financial report, an eight-page document that could only be read with a magnifying glass and great patience. The Treasurer described the current format as "largely worthless" as once "restricted funds"²⁵⁶ were removed from the report, the Society's income was only £257,708, against an anticipated £352,167. The Director felt he was being accused of deceiving the committee and retaliated strongly. The issue of local versus central control surfaced again after the Welfare Officer's presentation when some trustees said requests for welfare grants should be made directly to the local branch who knew the member and their needs rather than through the central office. Papers on "activity priorities" and "regional development" were discussed and it was agreed that a "Branch and Regional Development working party" should be formed to discuss the issue of control in more detail²⁵⁷.

²⁵⁵I racked my brains to think of an occasion when a branch had proposed a project.

²⁵⁶Money that can only be used for research or specific projects.

²⁵⁷This is a common way of smothering a controversy and I confess I didn't expect to hear any more, but the report was to shape the future of the society (examined in the section on regionalisation).

The atmosphere remained tense as trustees discussed the Society's relationship with its members. Some felt people living with dystonia weren't interested in "the medical side" as their main problem was "social phobia". They argued that the Society needed to help people empower themselves as it wasn't in the doctors' interests to do so. The concept of empowerment is a slippery one (as I explore later); firstly because the point of empowerment is that you can't do it for someone else. Secondly, because although the Society would like people to be empowered to fundraise and run local branches, they don't want them to campaign politically, alienate medical or pharmaceutical supporters, or argue with the central office.

We then looked at how staff used their time; an item tabled by trustees that was resented by staff who argued that writing reports about how little time they had was not a productive use of it²⁵⁸ (a common complaint of the audited). The reports did not support the Society's claim to efficiency as they created a surreally trivial picture of its activities ("even after some weeks no-one had been found who could put up a blind in [the Welfare Officer's] office, and trying to resolve this issue had been very time consuming"). The action taken by the meeting was naturally the reconstitution of another committee (the "Staff and Management Structure Sub-Committee") to examine this in more detail.

As the meeting was about to conclude, the trustee who had challenged the Director earlier asked whether the Section 64 application to the Department of Health had been circulated to trustees. The Director replied that it hadn't but the trustee remembered being told that it had. My notes give no sense of the drama of this moment. It was as though we were on the factory floor watching the northern union rep confront the southern supervisor. In an angry voice the trustee told him "I can't believe a word you say" and stormed out of the room. The Director responded heatedly ("Never in my career have I been accused of being a liar [...]") and in a later letter accused him of a "premeditated attack" in "conspiracy" with the Treasurer ("the two individuals could be seen smiling broadly and plainly enjoying their 'triumph' during the lunch break"). In the same letter he expressed his belief that trustees did not acknowledge the stress on the staff; "do you really understand how much we are being called on to do each day *dealing with* [my italics] and helping people with dystonia?" He also accused the Treasurer of "adopting the role of a lofty consultant, imposing on us a culture which is alien to the Society and demonstrating his own inability to recognise and work within the culture, which we have

²⁵⁸The professional staff already submitted quarterly reports to the trustees, kept diaries, and filled out weekly time sheets for the annual report to the Charity Commission.

adopted and cherish”. This meeting contributed to the Director and Chair’s resignations and a move towards regionalisation later that year²⁵⁹.

Debating regionalisation

Regionalisation was first discussed in the mid 1990s when the Glasgow nurse practitioner was made a regional coordinator to bring together the geographically dispersed Scottish groups after the formation of ADDER²⁶⁰. The lack of regional organisation (and in some areas local branches) contributed to the “generally apathetic attitude” among members towards the Society’s activities [“A blueprint for regional development” January 2001]. Local activists created a regional structure for Eastern England to “bring the Society closer to its members” and after a successful launch prepared a proposal for the whole of England, which was submitted for Section 64 funding²⁶¹. I describe the proposal below as an example of the Society’s attempt to reinvent itself using discourses of participation and empowerment.

The proposal was entitled “Independent living with dystonia” and aimed to fit with the Department of Health priorities of “more information for patients” and “independent living/self-management of illness”. The four regional coordinators would be responsible for raising general and medical awareness, increasing diagnosis rates, and creating “greater independence of patients through understanding, involvement and empowerment”. This would be achieved through “improved dialogue and coordination of resources”, including liaison with GPs, social care agencies, local branches, and members. According to the proposal “access to a local resource” providing “information and support” would “empower people with dystonia and their carers” as “greater knowledge of their condition” would enable them to “manage their dystonia and its impact on their lives, enabling them to live more independently”. Local volunteers would be involved in this, “facilitating the process of self-help and voluntary involvement”.

The proposal uses “patient” and “person with dystonia” interchangeably and seems linked to medical priorities (for example, increasing diagnosis rates and improving the quality of medical information). Having a regional coordinator who is also a nurse practitioner and part-funded by her health authority is not seen as a problem, as the priorities of the two roles are assumed to be the same. “Self-help or self-management” and “independence” are used

²⁵⁹As did the exclusion of all staff from subsequent trustees’ meetings.

²⁶⁰It was recently suggested that the organisations share functions with ADDER providing local support and the Society information, education, and literature, but this was rejected as ADDER wanted to work nationally and fundraise and the Society were reluctant to relinquish their few members in the North East.

²⁶¹Unsuccessfully, though it was finally funded in April 2002, along with a similar one for Wales.

frequently but never defined. For example, the introduction “encourages” people to “improve their quality of life by “self-management of their own condition” and “developing a more independent way of life”. It also discusses “empowering volunteers” to “giv[e] better support to people with dystonia. I asked myself what does it mean to “self-manage” your condition when your neurologist is the gatekeeper to services? Would the Society be campaigning to change the paternalistic attitudes of some neurologists and encourage them to value the knowledge of people with dystonia? People’s options are also constrained by NHS resources; I might want more frequent Botulinum toxin injections, but if my health authority only funds them once every four months, then that’s what I will get. Similarly, what is a more “independent way of life”? It seemed to me that most people living with dystonia are physically independent, and if this wasn’t the case it was due to their age or other conditions. Perhaps the Society meant financial independence, but how would they enable this? By targeting prejudiced employers? Perhaps in this context independence just means being less troublesome to your doctor²⁶² or the central office staff.

I was also interested in the use of “empower”. In the context of the proposal “empowering volunteers” appeared to mean training them, but might also mean increasing productivity through tighter management structures. I doubt that this would be experienced as empowering. Nor do I think that voluntary work is inherently empowering, though this belief also appears in *The Expert Patient: A new approach to chronic disease management for the 21st century* [Department of Health 2001]. The proposal appeared to define empowerment when it listed the key indicators for evaluation, namely “ability to remain in paid employment, to regain self-esteem, and to cope with everyday living despite a chronic neurological condition”. I thought it was significant that paid employment was the most important indicator, even though most dystonias begin when people are close to retirement. The focus seemed to be on the individual who had to address their “self-esteem problem” (presumably by getting a job) rather than on social problems like discrimination (or equating productivity with paid employment). Another contradiction was that although the project was designed to increase regional control, the timetabling and appointment of personnel was done centrally and it maintained “central reporting responsibilities”.

²⁶²c.f. The British Medical Association’s “think before you call your GP” advertising campaigns.

The tension between regional and central control within the Society continued through an exchange of proposals²⁶³, all suggesting that strategising, fundraising, and supporting local branches should take place on a regional level and be closely linked to the membership. The Director was initially enthusiastic as regionalisation seemed to be a cost effective way of reviving local branches, provided another arena for fundraising, reduced the risk of defections, and could paradoxically increase central control by standardising local practices. But it soon became a counter in the dispute between the Director and trustees who proposed returning to the Society's "grassroots" by disbanding the central office and turning the Director into a peripatetic "National Coordinator" [May 2001]. The proposal from the March trustees' meeting suggested that the Society had become "more control orientated than is necessary for what is a relatively small charity" and identified the following problems:

- Professional skills and capabilities are almost entirely perceived to be in the central office [...] there seems to be little attempt to transfer skills in awareness raising, support, fundraising, or welfare counselling to branch members
- Members are not empowered by the lines of reporting which are in place. Whilst there is a fair geographic spread of trustees there is no formal process for them to report back to the members or bring members concerns to management meeting
- Management values are very control-oriented [...] and] priority is not given to management tasks, which would empower and nurture branches, but rather to constrain
- The culture of the Society has become essentially introspective in nature

When I first read this I felt like punching the air with excitement. The Society (or at least some of the staff) were control orientated and didn't respect the knowledge of trustees or branches, members had no influence on the management of the Society, the information flow to the branches was limited, and the software was certainly antiquated. But it seemed that the "cure" was more debilitating than the disease. Perhaps after a year in the field I too "cherished" the Society's "unique culture". Or perhaps working in the office had made me more sympathetic to what staff members were trying to achieve in a hostile economic environment. I couldn't resist a smile, however, as I imagined the Director's reaction to his revised job description, "a pro-active role involving very little office work [...] line-managed by the Chair of the Society". This was not the post for a senior executive in his late fifties who was used to managing his workload without supervision.

After my fieldwork finished in August 2001, the Welfare Officer and office administrator left²⁶⁴. This was ostensibly to move outside London, but they said that lack of support from

²⁶³"A blueprint for regional development" January 2001; "Development of the Society in the North of England", January 2001; "Activity priorities working party report" January 2001; "A policy for the regional structure of the Society" May 2001; "Discussion Paper re: Strategy for Awareness and Fundraising" June 2001

²⁶⁴Her post was covered part-time by the niece of a trustee (or "Uncle Fred", as she ironically refers to him).

trustees was the main factor in their decision. The Director resigned shortly afterwards and left before his notice period was completed, refusing the trustees' offer of a farewell lunch. The Chair and one of the female trustees also resigned, but the remainder (who represent regional interests in East Anglia, Essex, Yorkshire and Wales) were eagerly anticipating the changes they will make, including switching all the software to MS Office. From December 2001 the Society was managed by the accountant and the fundraiser (who left in February 2002), with the help of a part time bookkeeper. Many of the central office functions were to be taken over by the six Regional Offices that should be established during 2002/3.

Conclusion

Although the Society began as a self-help group, during the process of "professionalisation" it became bureaucratic and lost touch with its membership, identifying itself with larger neurological charities and focusing on its external networks. Maintaining good relationships with neurologists, other patient support organisations and pharmaceuticals may initially have been for the benefit of people living with dystonia, but became an end in itself and impaired the Society's ability to represent the interests of its members.

Its construction of the ideal person living with dystonia (for example, in the Section 64 proposal) feeds into health service discourses about self-management of long-term illness and becoming an expert patient, and into more diffuse ideas about "rights and responsibility" and the development of "civil society". It also reflects QOL researchers attempts to create a typified "dystonia patient" from the diverse and inchoate experiences of people living with dystonia and express "their" perspective in a dystonia-specific QOL measure²⁶⁵. The Society's representation of people living with dystonia is alienating and potentially disempowering (possibly reflecting the discomfort of the able-bodied staff with disability) and was one of the main causes of conflict with its membership. There is obviously a fine balance between representing how disabling dystonia can be while not "wreak[ing] havoc among recently diagnosed people"²⁶⁶ [Duval 1984]. Ironically, the relationship of the staff with the "body" of the organisation (characterised as unpredictable, disparate, and diverse) mirrors the struggles of some people living with dystonia to gain control over their bodies.

²⁶⁵This process is described in chapter 8.

²⁶⁶The effect of a US Multiple Sclerosis Society campaign that described it as a "crippler of young adults".

Chapter 6: “Partnerships for progress”?

In chapters 4 and 5 I described people’s encounters with medical and social bureaucracy and the mediating role of the Dystonia Society (itself torn between pleasing its members and its peer group of medical researchers and neurological organisations). In this chapter I set these encounters in context by exploring relationships between pharmaceutical companies, patient support organisations, doctors, and the government, and their mediation through the discourse of QOL, using ethnography from national and international meetings of neurologists and neurological patient support organisations. I treat QOL (and its related discourse on “the patient’s voice”) as a “boundary object” around which diverse alliances can form. These alliances are explored these further in the context of submissions to the National Institute of Clinical Excellence.

The traditional model of science as the “pit of the peach” with society as its “soft flesh” has been discarded as authors recognise that society does more than merely slow or speed up the inexorable advance of science [Latour 1998]. Latour uses the example of the French Association for the treatment of muscular dystrophy, a hybrid research organisation that has funded more research on the human genome than the French government after raising £80 million in a telethon. Their headquarters “illustrates the limits of a metaphor that would separate science from society” as it contains a “jumble” of patients, lab workers, administrators and curious donors. This prompts Latour to ask, “Where is the science? Where is the society? They are now entangled to the point where they cannot be separated any longer”²⁶⁷ [ibid]. He is impressed by the way people with muscular dystrophy “turned genetic determinism (which, in many domains, is used as a way to render nature even more deterministic) into an instrument of unexpected freedom” by using it to generate their own science policy, a potential noted by Novas and Rose [2000]²⁶⁸. QOL measures can also be used as an oppositional habitus despite the biomedical understandings inscribed within them. For example, Alan’s response to his social worker’s refusal to request an adapted shower was “washing yourself with a sponge in your pants - I don’t call that quality of life” (chapter 3).

In the next section I take an ecological perspective on QOL and track the flow of QOL measures and concepts through a network of allies and social worlds. My analysis is mainly based on “actor network theory” [Law 1982; Latour 1987], but also looks at QOL as a

²⁶⁷c.f. Studies of CJD involving a “complex web of meat, ministers, bones, proteins, virus, and beef eaters”.

²⁶⁸c.f. Heath’s study of interaction between scientists and people with Marfan’s syndrome [1997].

“boundary object”²⁶⁹ [Starr and Griesmer 1989] and its networks as an example of the “string figure”²⁷⁰ described by Haraway [in Martin 1997].

QOL measurement is an example of “interessement” where scientific entrepreneurs (QOL researchers) recruit allies from a range of locations (doctors, pharmaceuticals, patient support organisations) and reinterpret their allies’ concerns to fit their programmatic goals (for example, QOL data enable pharmaceuticals to differentiate similar products). They then use their methodological authority to establish themselves as gatekeepers or “obligatory points of passage” [Law 1982; Callon 1986]. A second example was the use of “methods standardisation”²⁷¹ and boundary objects during the establishment of Berkley’s museum of Zoology, which were crucial factors in its success [Star and Griesmer 1989]. Standardised methods provided a common language for collectors and biologists, enabled amateurs to contribute on an equal basis, and created a broad “mesh” through which objects must pass to gain scientific recognition or money. Boundary objects were “immutable mobiles” that could be transported over long distances, convey unchanging information, and act as “anchors and bridges”. They were not “the imposition of one world’s vision on the rest” [ibid:413] but required their users to be “marginals” as well. For example, one QOL researcher is also a clinician, geneticist, and member of the Society’s medical advisory committee.

Although boundary objects are an important part of Actor Network Theory, it depends on three other concepts. These are: “punctualisation” (behind each entity is a complex network that orders other people and things and only becomes visible when the entity breaks down). “Delegation” (entities package networks and extend them through time and space, standing in for them in times and places remote from their origins). “Translation” (entities mutually enrol each other by interpreting, configuring and reconfiguring each other). Actors are treated as multi-faceted “entrepreneurs” who engage in political, social and economic activities as well as those commonly called scientific. Knowledge, organisations and technologies are produced by networks of human and non-human actors²⁷². For example, the metered dose inhaler delegates the biomedical work of controlling the dose, but doctors remain the obligatory “passage point” for people with asthma [Prout 1996]. The device “configures the user” [Latour 1991] as its use requires competencies that are not innate (something that is also

²⁶⁹ Boundary objects have “different meanings in different social worlds but their structure is common enough to more than one world to make them recognisable, a means of translation” [Star and Griesmer 1989].

²⁷⁰ A complex network (like a cat’s cradle) that simultaneously embodies discontinuity and connection.

²⁷¹ Analogous to the attempt by the developers’ of the MS-specific measure described in chapter 8 to create a “scientific” template for future measures.

²⁷² For example, networks built by cancer researchers to “make findings into fact” [Fujimura 1996]; the interaction between genetic “pedigrees” and understandings of kinship [Nukaga and Cambrosio?].

true of QOL measures [Barofsky 1996]), leading to the creation of self-help groups and educational packages to “reprogramme” users. While users can subvert these requirements by engaging in “anti-programmes”, they can also be controlled if the device is reprogrammed to reduce the need for human input.

Changes in the medical field, like the establishment of specialised structures to treat diseases, often arise from social movements in other fields. For example, Pinell and Brossat studied how the use of radiology to treat cancer in France at the beginning of the twentieth century led to the establishment of new medical institutions by diverse groups of actors (like the “French-Anglo-American Cancer League” of bankers, merchants, industrialists and “society ladies”) [1988]. The institutions were expensive but “paid” for themselves as they saved “socially valuable individuals”:

[A person with cancer is] usually a fully active person [...] a family man or woman, an able worker, a still solid farmer, or a woman just after her menopause, etc [...] Obviously this social value may be greater when the cancer patient belongs to the well-to-do classes; but in whichever he be [...] he is not a social waste
[Bergonie 1923 in Pinell and Brossat 1988]

The social cost of cancer was part of the spectre of “cancer peril” conjured up by the League to create a sympathetic climate for their work and differentiate cancer from competing conditions²⁷³. Utilitarian appeals are presumably less effective now or the Society would use middle-aged “bread winners” (preferably bank managers) in their advertising rather than children.

The image of the “string figure” (for example, the “cat’s cradle”) is also useful in examining the complex international networks of healthcare as it simultaneously embodies discontinuity and connection [Haraway in Martin 1997]. For Martin, it represents the anthropological ideal of participant fieldwork embedded in the widest possible context. This enables us to trace the connections between ideas and their “looping” trajectories, and examine heterogeneous knots²⁷⁴. Her study of the immune system demonstrated that the model of the “scientific avant-garde” was prefigured by popular ideas of the “mind-body relationship” and the effect of the environment on the body through diet, stress, and pollutants [1994, 1997]. This transforms our image of science by suggesting that it is participating in broader cultural

²⁷³For example, cancer was presented as a greater threat to young men than tuberculosis or syphilis.

²⁷⁴For example, the emphasis on “evidence-based medicine” within the NHS brings together QOL researchers, NHS managers, and clinicians [Faulkner 1997].

developments rather than leading them, something that is also true of the spread of QOL discourse.

“Health Technology Assessment”²⁷⁵ (a large and well-funded part of the NHS Research and Development strategy) is a good example of a string figure. The institution defines technology as “anything that might have an observable effect on someone’s life” (for example, a questionnaire or a conversation with a health promotion specialist). Its key features are multi-disciplinarity and a focus on cost effectiveness. However, this focus is camouflaged by a discourse of the social implications of new technologies, in the same way that the language of ethics conceals the implications of audit.

The elasticity of HTA’s metaphors enables uneasy partnerships to exist between disciplines and methodologies, such as qualitative and experimental methods, and clinical science and sociology

[Faulkner 1997]

The institution’s alliances have formed around “outcome measurement” and “cost-effectiveness”. However, although it brings together the “strange bedfellows” of clinicians, epidemiologists, health economists and sociologists, it marks out professional territory by defining appropriate concepts, methods and agendas. Its scientific agenda focuses on generalisability and elimination of bias, and attempts to represent “a form of aggregated public interest”. This limits opportunities for social and ethical enquiry and ensures that “projects which do incorporate users’ voices contain them within the design of the project” [ibid]. Paradoxically, although health technology assessment arises from a distrust of common medical techniques and authority, it draws on scientific rhetoric to legitimate itself by using a vocabulary of experiments (randomised control trials) and instruments (QOL measures)²⁷⁶. Faulkner claims that the institution has turned the NHS into a “massive lab” for the construction of knowledge.

In the next section I look at how networks and alliances are formed in the context of my thesis, using ethnography from the “partnerships for progress” meeting as an example of interessement. The meeting took place at the 2001 World Congress of Neurology conference and was organised by the European Federation for Neurological Advocacy (a campaigning association of neurological patient support organisations). Like the Dystonia Society, the

²⁷⁵It primarily reviews technologies associated with particular conditions but is also developing an inventory of health technologies with briefings on their efficacy and cost effectiveness.

²⁷⁶Similarly, new QOL measures claim to replace clinical outcomes and “gold standard” measures while using them as a source of validation (an example of “experimenters’ regress” [Collins 1999]).

Federation was initiated by a doctor (the president of an association of European neurologists) who wanted neurologists to work in partnership with patient support organisations²⁷⁷. Although the Federation's primary objective is "improving the QOL of people with neurological disorders", the majority of the others have clinical resource implications, implying that improving QOL is a job for doctors. It claims it will focus on the needs of people with neurological illness who are "not being listened to", but has already decided to do this by addressing "equity of service" and "treatment gaps". According to the Federation's president²⁷⁸, patient support organisations need to work with the "powerful" (the media, insurance and pharmaceutical companies, MEPs, doctors, and scientists) to get the "voice of the patient" heard in the European parliament. I was intrigued by the notion of the "voice of the patient" since I know that even within dystonia there are many contradictory and competing voices. I also wondered whose voice would be heard in a situation where there is a substantial imbalance of power. However, as the meeting progressed it seemed that, like QOL, this was an "empty signifier" [Strathern 1992] that anyone could use to support their interests.

The next speaker was the president of the European neurologists' association who apologised for the lack of partnership between neurologists and patient support organisations in the past. This had only occurred because they were so busy "serving" people with neurological illnesses that they weren't able to "attend to the wider picture". Unsurprisingly, he linked quality of care for people with neurological illnesses directly to the number of neurologists²⁷⁹. Other speakers recommended partnerships with industry, the pharmaceuticals, and the WHO, whose new neurological Director prioritises partnerships with patient support organisations. A WHO neurologist even suggested partnership between psychiatry and neurology, but comments like "schizophrenia is much too serious a disease to leave to psychiatrists" made it clear who would be the junior partner.

The theme of partnership was taken up by a speaker from a pharmaceutical who presented the development of new medicines as an altruistic act, a way of "giving back to the people [with genetic disorders] who have contributed so much" by producing "niche" products rather than

²⁷⁷The split between the association and the Federation is replicated by the International bureau for epilepsy (medical care and science) and the International league against epilepsy (people with epilepsy, carers and non-medical professionals). Similar alliances have been formed in the UK, e.g. the Association of British Neurologists with the Multiple Sclerosis Society over Beta interferon, and with the Neurological Alliance (association of neurological patient organisations) over National Service Frameworks for neurological care.

²⁷⁸Also president of the European Parkinson's Disease Association (the largest and richest neurological patient support organisation).

²⁷⁹"The UK has the best neurologists in Europe and patients get the worst treatment because they never see them as there are only 300".

“one-size-fits-all medications”. He lamented the development of a schism between industry, academia and government since the mass production of antibiotics in the 1940s, although (as another speaker observed) this collaboration did not benefit patients as it enabled the government to keep antibiotics secret during the Second World War to maintain its strategic advantage.

The enthusiastic involvement of Ford and AOK insurance with the Federation was explained firstly, by their need to appear as good “corporate citizens” (“good social values equal good business. It really is as simple as that” [Ford]) and secondly, to manage risk within the workforce (“to an insurance company neurology costs money, money, money” [AOK]). The language of risk in AOK’s presentation was supported by unattributed “scare” statistics²⁸⁰ and confident (and I suspect unsupported) assertions from the WHO. Do 80% of people in developing countries really have “brain disorders”? Only if malnutrition has become a neurological complaint. The parade of statistics reminded me of the president of the Federation’s description of the response of a neurologist on the panel at their press launch to the question “what is needed to make service better?” “He immediately said ‘600 more neurologists’ but if anyone had asked him ‘where is the evidence?’ he’d have been wrong footed”.

All participants recommended European collaboration and preferably centralisation (“we don’t want everyone having to do everything”). I heard catchphrases like “international centres of excellence” and “patient treatment without frontiers” but whether this was the best model of care for patients was not discussed²⁸¹. There was an implicit assumption that what was good for neurologists was good for patients. This was supported by examples like a survey conducted by a Canadian neurologist that found while people wanted better care and communication, they wanted these from “a balanced doctor, not a burnt out one”. The Federation was encouraged to use its power as a representative of patients to “empower, represent, and access resources for disease”. For example, by supporting people with neurological illnesses who wanted to sue for the right to better care (as has happened in Holland) and reviewing trial protocols to make sure they address patients’ needs.

The message of the meeting seemed to be that patient support organisations have untapped potential as they control access to people with neurological illnesses and offer legitimacy to

²⁸⁰For example, “in 30 years there will be 50% more sufferers of mental illness”.

²⁸¹This issue has been debated for HIV care in the UK where people living with HIV expressed resentment at having to travel to London or Cambridge for optimal care.

projects by enabling them to claim that they include the “voice of the patients” (in its least challenging form). However, this power could only be realised in partnership with other organisations, particularly commercial ones, who provide the resources and marketing expertise to sustain these “actor networks”. In the next section I look at pharmaceuticals in more detail, focusing on their marketing strategies (specifically how they use QOL), and relationships with patient support organisations, doctors, and the government. These relationships are summed up in a table in the appendix that outlines what the different partnerships have to offer.

How pharmaceuticals use QOL

Drugs are marketed like any branded product where most of the value is contained in the “informational envelope” surrounding the product, rather than the product itself. However, the context of pharmaceutical marketing²⁸² has changed since the halcyon days of the 1970s and 80s when “physicians looked forward to the latest offerings of pharmaceutical companies and eagerly prescribed new products [... they] paid little heed to the price of these new innovations and purchasers [...] paid the asking price” [Morris et al in Spilker 1996:541]. QOL data offers a clear advantage in a context of knowledgeable and sophisticated customers, increased product competition (and need for product differentiation), price sensitivity, (leading to lower introductory product prices and smaller price increases), competition among physicians (making them responsive to claims that pharmaceuticals increase patient satisfaction)²⁸³, and higher research and development costs. QOL data can also be used to support regulatory or formulary applications²⁸⁴, or for marketing. It is particularly useful for medicines in intense competition, “me-too” medicines²⁸⁵, medicines in areas like cancer or cardiology where QOL data may speed up the regulatory process, medicines that are applying to a regulatory body for an “expanded indication” to enable them to be used more widely, and palliative medicines [Spilker and Garbus in Spilker 1996]. However, QOL data is not regarded as inherently valuable as studies are not recommended

²⁸²Standard practices include “mail and journal advertising, video and broadcast television advertising, and desktop media (anatomic models, calendars, pens, notepads, etc.) [...] communications intended to inform and influence consumers and family caregivers such as print and television paid advertising, video news releases, talk show appearances, and grants to patient support groups in areas of marketing interest to the pharmaceutical company [and] forms of informational communication such as sponsored symposia and conferences, publication of clinical evaluations in the peer-reviewed medical press, discussion panels, and other forms of sponsored peer-to-peer communication” [Beckett in Spilker 1996:549].

²⁸³“The marketer [of Zofran] capitalised on the prescriber’s initial interest in quality of life by translating demonstrated clinical effects into language that used the “quality of life” buzzword to reflect benefits that might be derived by patients” [Morris et al in Spilker 1996:545].

²⁸⁴Hospitals, health maintenance organisations, government programmes, and some insurance programmes have established restricted formularies to control prescribing patterns.

²⁸⁵Copies of an existing product, slightly modified to evade copyright restrictions.

for medicines with no competitors or that are not expected to make a profit. Broad QOL claims, like claiming that a drug “improves” QOL when studies only show that the side-effects are less disruptive, have become less acceptable to customers and regulators²⁸⁶. They now need to be substantiated with data from QOL measures, and there is a trend towards making claims based on individual domain scores to enable subtler product positioning²⁸⁷. Examples include the hypertension drugs Hytrin (promises to maintain physical, mental and sexual performance), Prinivil (lets patients stay active), Trandate (preserves vitality and exercise tolerance), and Capoten (contributes to the patient’s feeling of well-being).

Historically, pharmaceuticals, doctors, and patient support organisations have worked together to create a climate where particular disorders can flourish. Healy explored how pharmaceuticals “groomed” new conditions like “social phobia”²⁸⁸ (dubbed “the panic disorder of the 90s”) after they were shown to respond to a previously under utilised category of drug [1997]. “Social phobia” had the advantage that it did not respond to behavioural therapy, was massively under-diagnosed (less than 3% of cases), and caught the imagination of the WHO and patient support organisations who were supported by Roche pharmaceuticals (the manufacturer of the main component). Potential patients were wooed through self-help books, magazine articles, television programmes, and adverts for therapy. “Prescribers” were invited to meetings in “expensive venues” to discuss trial results, sponsored seminars at the Royal College of Psychiatrists, and symposia organised by distinguished psychiatrists. Although grooming can be seen most clearly with new disorders, pharmaceuticals also “make views of illness” by investing in awareness campaigns for established conditions like dystonia. For example, a European study of the prevalence of dystonia and two surveys of QOL in North America and Britain were funded by pharmaceuticals.

How pharmaceuticals work with patient support organisations

You have a significant power because you have access to patients and without patients there are no drugs trials

Pharmaceuticals and patient support organisations can both benefit from partnership. For example, direct-to-consumer advertising can stimulate people to visit the doctor to request a therapy or a diagnosis, and “point of purchase” displays in chemists often contain a post-paid

²⁸⁶In 1997 Glaxo Wellcome had to apply to the US Food and Drugs Administration for permission to make an asthma-specific QOL promotional claim for Salmeterol Xinaforte.

²⁸⁷For example, “promotional materials could be geared to emphasize cognitive functioning (e.g. a theme of ‘when alertness counts’ might be used) and pictures of patients in tasks requiring alertness can be shown (e.g. an air traffic controller)” [Morris et al in Spilker 1996:546].

²⁸⁸Includes people who would previously have been diagnosed as depressive or anxious-depressive.

reply card offering the person a newsletter for people with the condition. However, as the author of the Alzheimer's Disease society submission to NICE observed, their relationship is not an equal one.

My experience of partnership with a pharmaceutical began at the Movement Disorders 2000 conference when I met with a pharmaceutical product manager who was planning the UK launch of a new strain of Botulinum toxin. He wanted to discuss conducting a "patient survey" of people living with dystonia (similar to one they had done for multiple sclerosis) and producing a "living with dystonia" booklet. After looking disdainfully at the leaflets stuck on the wall behind the European Dystonia Federation stall, he asked how much we would need for a professional "shell" for the stall ("£3,000? That's nothing!"), and assured me "we're here to help you do what you do better"²⁸⁹. This project came to fruition a year later when I helped the Society draft a membership survey (described in the previous chapter), which provided information about members' use of Botulinum toxin. It also generated quotes and statistics to support the UK product launch in May, timed to coincide with the Society's 2001 Dystonia Awareness week. The product manager gave us examples of quotes used in *Living with spasticity* like "the pain is awful [...] as if its actually in your bones" and asked if we could pull anything similarly graphic from the membership survey. Although the final quotes were apparently chosen to "balance positive and more 'hard-hitting' ones", many members felt the balance had tipped towards the "tragedy" narrative of disability²⁹⁰ which could disempower newly diagnosed people living with dystonia.

The partnership was not a complete success for the Society because the pharmaceutical's commercial interests dictated its terms. For example, the pharmaceutical later withdrew their offer to fund a publication from the survey, as it would not add anything to their marketing strategy. We also needed to make last minute corrections to *Living with dystonia* to reduce its bias against other therapies, including a rival strain of Botulinum toxin. More successful was a national and regional press campaign their PR firm conducted on the Society's behalf (using statistics targeted to particular regions) that generated twenty or more press articles. This was certainly an improvement on the Society's previous publicity strategies, which they unkindly characterised as "Botulinum toxin - the deadliest poison", "shock, horror - my doctor didn't know what it was", and "weep, weep, it took me 14 years to be diagnosed".

²⁸⁹I met him again while I was standing by my poster on QOL in dystonia, but the aspect of the research he seemed most interested in was whether there had been any "adverse events" with a rival strain of Botulinum toxin. We didn't receive a cheque for a new display stand.

²⁹⁰"Statements like 'since having dystonia it is like I have given up on life' send profound messages to non-disabled people" [extract from a critical letter from a member].

I discovered how common partnerships between patient support organisations and pharmaceuticals were at an international meeting of dystonia societies held before the Movement Disorders conference in Barcelona. The meeting was organised jointly by the European Dystonia Federation and the Dystonia Medical Research Foundation and funded by two manufacturers of Botulinum toxin and one that makes devices for deep brain stimulation. Partnerships with pharmaceuticals were presented as part of a discourse of acting “professionally”: “we [patient support organisations] are not ‘lay organisations’”. It was implied that as knowledgeable actors we could pick and choose what we wanted from these relationships: “obviously they will come in and push their product, but that’s okay as long as we know what’s going on”. However, despite the implication that we were participating in a purely rational producer-consumer relationship, the pharmaceuticals were presented in a very positive light: “Lex [the international director for one of the pharmaceuticals] is such a good friend to all of us”. All the organisations attending had received support from pharmaceuticals, and some had also arranged corporate sponsorship²⁹¹.

Representatives attended the meeting from the sponsoring companies, WE MOVE²⁹², and dystonia patient support organisations from Europe, North America, and Chile. The patient support organisations gave presentations about their work, while WE MOVE attempted to position its website (www.wemove.org) as the “portal” to dystonia²⁹³. “Gatekeeper” is obviously a useful position to compete for funding from and I watched them attempt to consolidate this at a Movement Disorders meeting I attended later in the week (described later in the chapter). The organisers told us that the themes of the meeting were “friendship, sharing, opportunities, learning, understanding and collaboration” (or “cooperation” as one delegate sceptically suggested). However, real partnerships were inhibited by differences of power, resources, and philosophy between the organisations. For example, the Dystonia Medical Research Foundation is able to offer a “total community” to its members²⁹⁴ and fund \$700,000 of medical research, much of which they have commissioned (“the researchers out there would not be interested in dystonia unless we were there to support them”²⁹⁵). The

²⁹¹For example, the Dystonia Medical Research Foundation has secured McDonalds who, according to the president, “love to be associated with something they can shine with”.

²⁹²North American “umbrella group” of neurological organisations, like the Neurological Alliance in the UK.

²⁹³“When people come to the web they only look at the first ten pages so it’s important that they come to us and are linked to you”.

²⁹⁴Its website, www.dmf.com, contains information for people living with dystonia, doctors and researchers, “patient referrals”, legal advocacy, “planned giving”, a bulletin board for people living with dystonia, “courage awards” (instituted after they were criticised as “too scientific”), and even on-line shopping.

²⁹⁵This independence is undermined by their worshipful attitude towards biomedicine: the president described her experience of one symposium as “so exciting to sit there and listen to these brilliant minds”.

Foundation was presented as a model for the other patient support organisations, for example, the Chileans (patronisingly described as a “fledgling group”) were advised to follow their example and allow “one strong person to emerge as the leader”. This ignored the experiences of other countries where different models had been successful. For example, in Sweden “loose” local networks worked better as, according to the head of Svensk Dystonie, “patients are scared of high ambitions”. Underlying the meeting was a power struggle between the European Dystonia Federation and the Foundation as the latter wanted to develop a “World Federation” of dystonia patient support organisations (run by the US) and had already produced an enrolment form. As an anthropologist, I was particularly aware that there was little understanding or respect for cultural differences. It was assumed that the North American organisational style was not only the best but could be transferred to any country without modification, an attitude shared by most international medical organisations.

The benefits of collaborating with pharmaceuticals appeared to be the key message of the meeting. For example, one delegate described pharmaceuticals and patient support organisations as “travelling on the same train to understanding the condition” and suggested we could “use research to our common benefit”. For me, this suggestion was undermined by an example of joint research presented later in the meeting (*The Dystonia Patient perspective*, a survey of 15,000 people living with dystonia [DMRF 2000]), which seemed to have been a wasted opportunity. The main finding of the survey was a high incidence of depression among people living with dystonia. While this may be true, the information was obtained by asking “Have you and/or your family or friends ever been treated for depression?” Considering the extreme generality of the question (basically “have you ever known anyone with depression?”) it is surprising that only 47% of people responded positively. The pharmaceutical sponsoring the survey was planning to launch a new strain of Botulinum toxin in North America when the FDA approved it²⁹⁶ and the findings of the survey were presented with this in mind (e.g. “85% [of people treated with Botulinum toxin] would be willing to consider trying a different Botulinum toxin if it became available”). Although the president attempted to distance herself from the survey by attributing it to an external PR company (“well they [the pharmaceutical] funded it, you know how it is”), the pharmaceutical involved, which also manufactures antidepressants, thought it was a great success and offered the Society funding to do a similar survey in the UK.

²⁹⁶The president presented support organisations as their allies against the regulators: “patients are so eager to get this drug, you will raise their hope again. What can we do to help?”

The message of “productive partnerships” was also coming from the pharmaceutical representatives. One asked the delegates “how do we build on what you’ve already got?” and suggested “we should empower every one of you and our [local] rep to get together and have face-to-face strategy sessions”. He gave examples of past cooperation, including providing an organisation with a directory of doctors so they could do a “waiting-room literature hit”, and distributing material jointly to doctors who “like to have something to give their patients [but] they don’t take manufacturers’ propaganda”. In the last example, the support organisation was opening doors for the pharmaceutical. However, this works both ways: the Chilean group was invited to accompany pharmaceutical representatives on their visits to doctors outside the capital. The Chilean group was of considerable interest to the international director of one of the pharmaceuticals who planned to “work on developing Latin America”²⁹⁷ and needed a “patient champion”. He later said thoughtfully “There’s no support group in Argentina and yet they have 50 million people. How can there not be?” This caused one delegate to remark “you could see the dollar signs in his eyes”.

Patient support organisations can be important allies for pharmaceuticals and medical organisations in applications to regulatory bodies like NICE. While NICE is not “patient led”²⁹⁸, patient support organisations have been moderately successful in getting their voices heard. In the next section I look at submissions from the Motor Neurone Disease Association and the Alzheimer’s Disease Society to see how they represent people with these conditions and what use they make of QOL.

The impact of the submission from the Alzheimer’s Disease Society in favour of Aricept (a drug that slows the progress of Alzheimer’s) [2000] can be seen by the “resonance” between their submission and NICE’s guidance [2001]. I was excited to hear the voices of people with Alzheimer’s (albeit mediated by the Alzheimer’s Society) as they are a stigmatised group and until recently were treated as though they had no history or future. The Society emphasised that the contribution from people with Alzheimer’s would not have been possible before Aricept improved their “social function”, an outcome ignored by the clinical trials, which focused on memory. Nor could the submission have used QOL data as people with Alzheimer’s were previously thought to be unreliable witnesses. Three quarters of the people questioned felt the drugs had helped, although this was difficult to measure as success basically meant that the person’s condition stayed the same. However, they also reported less

²⁹⁷ An area the International Society for QOL Research was also planning to expand into.

²⁹⁸ One neurologist claimed “anyone who believes that NICE is listening to the views of patients has been on Mars too long” (Neurological Alliance meeting 2001).

quantifiable outcomes like “new enthusiasm for life”, improvements in mood and behaviour, reduced anxiety and distress, restored confidence, maintenance of social relations, and improved QOL for carers, and focused on “small everyday improvements”²⁹⁹. The study’s focus on “user-defined outcomes” led to debates on the difference between anecdote and evidence. For example, a powerful illustration of the drug’s effect was a sample of handwriting before taking the drug and three months after. Consequently, although the submission was “peppered with quotes from people with Alzheimer’s and their carers”, the Society were told they had no “evidence” which may be a sign that you now need to use the language of QOL in order to be heard. As the author of the submission observed, “what is evidence of improvement? Two points on the cognitive function scale or people who can play snooker again or knit” [Neurological Alliance Meeting 2001].

I also read the Motor Neurone Disease Association’s submission in support of Riluzole³⁰⁰, which used the language of QOL to counter the argument that the lives of people with motor neurone disease should not be extended because their quality was so poor. Ninety one percent of respondents disputed this and described leading fulfilling and enjoyable lives despite their condition: “10 days before my husband died he was in a Cessna, then on a gondola lift in the South Island of New Zealand” [MND Association 2001:12]. However, the positive outcomes were difficult to represent quantitatively. For example, for people with advanced motor neurone disease side-effects were irrelevant, and any extra time was precious, especially if they had a family³⁰¹: “I am sure that if my five year old son was given the option of my life prolonged - even for a day [...] he would leave the NICE people in doubt that it should be available to all” [ibid:11]. They felt better able to cope because they were doing something “instead of waiting for events to take their natural course” [ibid:8]. Relationships with doctors had also improved, and doctors felt more comfortable delivering a diagnosis because they could offer some hope alongside it. Unusually, the Motor Neurone Disease association included a “declaration of interests” at the end of the submission, which recorded receipt of £31,500 from the manufacturers of Riluzole in 1999/00 (1% of their annual income). The chair of their trustees had also received funding for research and travel (filtered through European neurological associations), and was a member of the European Motor Neurone Disease study group, which was entirely funded by the company.

²⁹⁹ c.f. Outcomes for spasticity where changes in movement are less valuable than an overall increase in stamina, which could increase the time spent at school, leading to a better education and job.

³⁰⁰ Currently the only treatment for 3,000 people with motor neurone disease costing ~£10 per person per day.

³⁰¹ This suggests that taking an exclusively individual focus when defining QOL omits important aspects.

How pharmaceuticals influence doctors

People say you can't change doctors' behaviour but the pharmaceuticals make them dance on the head of a pin

The extent to which pharmaceutical funding influences the topics and conduct of research has been hotly debated. Since the career structure of clinical academics rewards them for publications, there is an institutional incentive for them to work cooperatively with an industry that can provide them with funding for research, and conformity to industrial interests can be a criterion for publication [Abraham 1995]. There was a notorious case in the 1980s when the editors of the Archives of General Psychiatry (the most prestigious journal in the field) were accused of succumbing to pharmaceutical influence in foregrounding the favourable results for a trial of Alprazolam [Healy 1997]. The case was difficult to adjudicate since the majority of senior clinicians held pharmaceutical consultancies, often using them to fund independent research.

I know from experience that this is true in neurology; in fact the possession of a large number of consultancies is thought to enhance the prestige of the research institute the person is affiliated to and demonstrate the “relevance” of their work. A few personal examples of these debates spring to mind: one neurological epidemiologist who does not accept money from pharmaceuticals described a “positive paper” (one containing trial results that favoured a drug) as an example of “money talking” and suggested clinicians who took “conditional funding” risked “peddling a lie”. The reputation of another neurologist who runs a clinical trial centre was “tarnished” by receiving “drugs money”. It was even suggested that the diagnoses of his trial participants were “suspect” and he had to be barred from his own data in case he attempted retrospective falsification. An internationally renowned research centre that also performs analyses for clinical trials was shocked to be accused by an anonymous peer reviewer³⁰² of “serving the interests of Big Pharma”.

These anecdotes are common currency among neurologists and reflect a profound unease about accepting research funding from pharmaceuticals. For example, the ethically dubious activity of building up an extensive private practice is excused because it makes doctors less vulnerable to financial inducements and enables them to fund their own research.

Nonetheless, many younger doctors attend quarterly meals organised by pharmaceuticals, and few refuse hospitality at conferences and seminars. I collected a handful of conference

³⁰²Papers are anonymously peer-reviewed, but even if your reviewer doesn't congratulate you afterwards (as happened to me), it isn't difficult to work out who it would have been, and reviewers' frankness is usually checked by the knowledge that as authors they may soon face the people they are reviewing.

announcements at the last medical meeting I attended, all presented like glossy holiday brochures³⁰³ and offering plenty of opportunities between scientific sessions to see the sites, sample the local cuisine, or play golf at the luxury hotel.

Once at the conference, the opportunities for advertising exposure are considerable, as I discovered when I was accidentally sent the 2002 Movement Disorders conference's "sponsorship opportunities and exhibitor prospectus". This promised "comprehensive scientific and educational programming, and *tremendous marketing opportunities* will, once again, be the hallmarks of our international congress" [my italics]. Every event or meal was available for sponsorship (even coffee breaks at \$20,000 each), as were the website, conference literature and bags, and even the cards held by "meeters and greeters" at the airport. If the format for the 2002 meeting remains the same as that for 2000, I calculated that they would make at least \$3 million from sponsorship, not including revenue from selling advertising or exhibition space (30 or so pharmaceuticals exhibited in 2000).

I had a memorable experience of pharmaceutical largesse at the Movement Disorders 2000 conference in Barcelona. I had originally put my name down for a gala dinner organised at a national monument to celebrate "10 years of Neurobloc [Botulinum toxin A]" but was persuaded by a colleague to join him at a less formal gathering organised by a rival company at the Andar Azucar (a restaurant in an eighteenth century palazzo, renowned for its Castilian cuisine). I was introduced as my colleague's PhD student and spent the meal worrying about being exposed if I failed to memorise the pre-meal lecture on the product or mispronounced its name³⁰⁴. The dinner conversation among the neurologists and pharmaceutical reps was mainly about money: who was getting NHS merit awards, who had a large private practice, and who had received pharmaceutical funding. One of the neurologists told me that this year three different companies had funded him for conferences in Barcelona, New York and Israel. The company funding his current trip picked him up at the airport and arranged his accommodation and dinner every night. In return, he was expected to attend their sponsored "satellite" seminars (to increase the seminars' credibility), and a 45-minute product presentation on his return to the UK, presented as an opportunity to "feedback" on the conference arrangements. He presumed it was worth it to them since even a single prescription for Beta interferon guaranteed an income of £10,000 per annum. I found myself giving advice on using QOL measures to a neurologist who assured me that "*they* say every

³⁰³The European Headache Federation announcement overlaid a picture of Istanbul harbour at sunset where the name of the conference was half the size of the tagline "Istanbul - where the continents meet".

³⁰⁴I had been told that the company (renowned for its lavish hospitality) only invited prescribers.

trial must have one now” [my emphasis]³⁰⁵. This comment represents the attitude of many clinicians that QOL measures are ubiquitous, mysterious, and imposed from outside, if a useful rhetorical resource when arguing for clinical freedom or increased funding.

One of the representatives estimated that their hospitality bill from this conference would be £3,500 per doctor, but said that it was worth it to “build relationships” and “make them feel comfortable with us”. Their strategy involves forming personal relationships by covering small areas (for example, two of the London hospitals). She felt this aim had been achieved because all the neurologists in her group went out with her last night, even though it was scheduled as a “free” evening. She told me that representatives need to be gregarious and well organised (“like holiday reps”) and usually had a biological or biochemical background, although ex-medics were particularly prized. Sometimes, despite the planning, the pharmaceuticals don’t get it right: another neurologist recounted attending a sponsored event in New York where they arrived at 10.30 pm after a three hour delay and still had to listen to a one and a half hour presentation before they could have dinner. These stories underlined the fact that most of the information on drugs that doctors receive comes from pharmaceuticals, either directly, or through adverts and funded research in medical journals. A recent review of the use of economic evaluations in the UK found that prescribers were most likely to have received information on evaluations from pharmaceuticals and that these influenced their prescribing in more than a quarter of cases [Drummond et al 1997]. Maynard³⁰⁶ has noted an alliance between cancer doctors and pharmaceuticals. For example, over Taxanes (an expensive group of anti-cancer drugs of limited efficacy) “the industry’s smiling happily and filling its wallets” (Neurological Alliance meeting, 2001).

How pharmaceuticals relate to the government

The pharmaceutical industry and the British government have an uneasy relationship, since the government is both its main client and its patron as a major employer and contributor to the economy. “Maintaining industry buoyancy” is a political choice: the government’s policy of “industry protection” means that it won’t drive down the price of drugs in the UK as this would reduce European prices and affect the “balance of payments”. In 1993 the government obstructed a Private Members bill on Medicines Information to “protect trade secrets [...] if the pharmaceutical industry is to continue to invest here” [White paper on open government 1993]. The British pharmaceutical industry has also applied pressure on the government to

³⁰⁵He had begun the conversation by describing his prescribing patterns in great detail, suggesting that he was confusing me with one of the reps.

³⁰⁶A controversial health economist and advocate for QALYs.

relax regulations perceived as detrimental to its commercial interests³⁰⁷. Their close relationship is enhanced by the number of pharmaceutical consultancies held by members of governmental regulatory committees. It forms part of a general policy of making science “more responsive” to industrial interests³⁰⁸, which are assumed never to conflict with or diverge from public interests. For example, in 1989 it was decided that the Medicines Control Agency would be funded entirely from fees for licensing applications paid by pharmaceuticals, making it “essentially a business selling its regulatory services to the industry and promoting itself as one of the fastest licensing authorities in the world for new drugs” [Abraham 1995:257].

The National Institute for Clinical Excellence (NICE) is an important mediator in this relationship, although its importance has been reduced by its unpopularity. It has not even gained support from health economists who are one of the disciplines most likely to benefit from its activities. Maynard describes it as “a mess” and says it has become like the Scott Intercollegiate Guideline Network which only looks at clinical effectiveness, and has “yet to say no to any drug” (Neurological Alliance meeting, 2001). He believes that clinical guidelines have had an unexpected and “deadly” effect as doctors use them to advocate for funding in their speciality “driving out other treatments that might be more effective”.

Maynard’s hostility towards the medical profession is not surprising as in the past health economists and doctors were not natural allies³⁰⁹, although this may change with their collaboration on preference-based measures of QOL (described in chapter 7). Economists claimed doctors did not consider cost when prescribing, put individual before population health, practiced covert rationing³¹⁰, and served sectional interests. For example, Maynard accused Sackett (the founder of evidence-based medicine) of “not accepting the social ethic associated with the pursuit of the maximum gains in terms of population health from a finite budget” and leaving efficiency and population health to “evidence-based purchasers” [1997]. He also suggested that evidence-based medicine was an example of “the medical empire striking back” after the market reforms to the NHS and subsequent deprofessionalisation (a conclusion broadly shared by Armstrong [2002]). While this may be so, Maynard’s solution (that doctors be made to account for deviations from “equitable and efficient practice”) would

³⁰⁷In the 1950s regarding the categorisation of brand name products using the Cohen Committee drug standards, and during the 1970s over the scientific standards required for a clinical trial certificate [Abraham 1995].

³⁰⁸c.f. recent white papers on science, technology, and education (“Realising our potential” [1993]).

³⁰⁹Loewy and Sackett (proponents of evidence based medicine) both likened health economists to Nazis.

³¹⁰Acceptance for haemodialysis in the 1970’s reflected availability of places, rather than clinical indications although this was not even acknowledged by the doctors who made the decision.

further increase government control over their activities³¹¹. This explains their suspicion of NICE, which has at least brought some transparency to rationing decisions and provided a common enemy for doctors, patients, patient support organisations and pharmaceuticals to unite against.

As a speaker from CMC Research Institute³¹² explained, NICE's methodology is deeply flawed. Firstly, pharmaceuticals are the main source of clinical data, which comes from trials "designed according to the evidence they want". Secondly, NICE's weighting of evidence puts randomised controlled trials at the top and clinical opinion at the bottom, even though the trials are "fantasy science" because "small, focused groups are treated in particular ways"³¹³. Finally, the trials are not designed for health economic evaluations, as the costs associated with chronic illness are diverse³¹⁴, only valid for a short time, and specific to particular settings. Despite these problems, NICE's expectations are high. For example, submissions should use raw data (rarely available as pharmaceuticals buy in drugs licences from other pharmaceuticals), and incorporate all costs, even if they can't be calculated in a short timescale. It rarely provides well-defined questions for the submissions and expects robust results in a very short time. Pharmaceuticals increase the confusion by encouraging "reanalysis of data for every conceivable subgroup" to get good results, even though the studies were designed to answer particular questions and the results may not be applicable to other patients. They also occasionally conceal unexpected deaths, or "adverse events" as they are more usually described. PBAC (the Australian version of NICE) had to reject 661 submissions for methodological reasons, including "suspect amalgamations of data", during its first few years of operation [Hill 2000].

Pharmaceuticals also negotiate directly with health authorities as potential customers for their "disease management packages". Between 1997 and 1999 one London health authority was offered an asthma care service for primary care, an epilepsy service for primary and secondary care, and a prevention programme for coronary heart disease in primary care [Greenhalgh et al 2000]. While recognising that "the spirit of 'new Labour' strongly supports efforts to align commercial and NHS interests" (for example, Private Finance Initiatives for hospitals), Greenhalgh felt these new developments should be carefully monitored. Potential

³¹¹This is consonant with NHS reforms, which simultaneously give greater autonomy to doctors through primary care trusts, and reduce traditional freedoms like the "right" to practice privately after becoming a consultant.

³¹²CMC analyse trial data, advise pharmaceutical clients on the value or validity of their product claims, and "groom" submissions to NICE.

³¹³RCT populations are self-selecting, compliant, well monitored, and likely to benefit from the treatment.

³¹⁴Comprising direct (drug costs), indirect (loss of productivity), and intangible (pain and suffering).

risks include special relationships developing for purchasing (involving agreements that restrict prescribing), breaches of patient confidentiality, failure to obtain informed consent, bias against less lucrative interventions (for example, counselling for depression), and escalation of costs.

Partnerships between doctors and patient support organisations

Let's get the user in front of the man [sic] with the purse strings

This is a finely balanced alliance, for example, the Society's close relationship with doctors has been criticised by members who do not see it as an impartial advocate. One member, who had been barred from the National Hospital after threatening the staff, left an abusive message on the Society's answer-phone accusing them of "lick[ing] up to the National [...] you sold your soul to the National for funding to keep the organisation open". This hostility was reflected at the branch organisers' conference where people described their relationships with their consultants as superficial ("you see the consultant and he's like a little god [...] The rest of us wait for hours and hours") and expressed frustration at Health Authority bureaucracy³¹⁵. However, when it represents the views of members, the Society is criticised by neurologists for misrepresenting the quality of services for political purposes. One letter from a specialist clinic blamed them for "damaging public perception" of their services, "demoralising" staff, and threatening a "programme of improvement [from] which patients will stand to derive clear benefits". Others feel that their voluntary work for the Society is not recognised: one correspondent was especially piqued that no mention was made of the talk for which he "gave up a Saturday [...] while other speakers have been mentioned". He also drew attention to his centre's "valuable, regional and consistent service to sufferers over the last 12 years" which had never received the appreciation he felt it deserved.

The relationship between neurologists and patient support organisations was the subject of a Neurological Alliance meeting I attended at the 2001 World Congress of Neurology. The first speaker (a general neurologist) perceived the barriers to partnership as mutual indifference, mistrust, professional jealousy, and fears about confidentiality (for example, discussing someone's case with a patient support organisation's welfare officer). "Problem areas" in the relationship were "wacky treatments", somatoform disorders ("there are people active in local branches who insist they have multiple sclerosis but have never been diagnosed"), angry

³¹⁵One recounted the problems he had had ordering a table for the physiotherapy department; "eventually I had to buy it myself. £20 - that's just a doctor's lunchtime drinks bill".

patients³¹⁶ (“support groups should hold ‘getting to grips’ sessions that enable people to overcome their post-diagnosis anger”), factionalism, disorganised patient support groups (“some are run as luncheon clubs for the branch officers”), denial, collusion, and low quality healthcare. Note that only the last of these could be attributed to the neurologist. He observed that the diseases neurologists diagnosed were not represented by the spread of support groups³¹⁷ where currently “the multiple sclerosis tail wags the migraine dog”. However, partnerships with “*upmarket* support groups” (my emphasis) could improve neurological services by focusing criticism on the NHS, particularly in the light of the expectations raised by the NHS plan³¹⁸: “under the NHS and GMC [General Medical Committee] rules health authorities have to listen to patients. Let’s get the user in front of the man [sic] with the purse strings³¹⁹. The speaker felt patient support organisations should argue for neurological care to be as great a government priority as heart disease and cancer as “when doctors do they are accused of empire building”.

Collaboration between doctors and patient support organisations was also encouraged in international settings. The aforementioned meeting of dystonia societies highlighted the importance of participating in international medical networks as “we [patient support organisations] influence just by being there”. For example, dystonia was originally excluded from the International Classification of Impairment, Disability and Handicap but the President of the European Dystonia Federation used his connections to “get something in at the last minute” (described in chapter 9). Similarly, the President of the Movement Disorders Society emphasised their intention to involve patient support organisations by “critically discuss[ing]” not just clinical trials, but “public health issues” and “quality of life”³²⁰. The new emphasis on partnership was signalled by the presence on the conference rostrum of the President of the European Parkinson’s Disease Association (and the Federation for Neurological Advocacy) who was introduced as someone who could “speak on behalf of the

³¹⁶And patient support groups, ME organisations were “too political and have alienated doctors”.

³¹⁷>50% of new referrals are “medically unexplained” and so don’t have a support organisation (or at least, not with a medical advisory board or pharmaceutical funding), even though “these are disabled people too”.

³¹⁸This promises patient information, choice, protection, advocacy, right of redress, scrutiny of the NHS, patient representation throughout the NHS, and expression of patients’ views through NICE.

³¹⁹He recounted having someone with primary-progressive multiple sclerosis in his office who wanted a prescription for Beta interferon (then restricted to relapsing-remitting multiple sclerosis as it is not as effective in other forms). He phoned up a public health official at the man’s health authority and asked them to explain to the man why he couldn’t have the prescription. The official authorised the speaker to write the prescription. While this can be seen as a victory for “patient power”, I felt the speaker had acted unethically by using the patient in this way since they were unlikely to obtain clinical benefit from the prescription.

³²⁰This was only covered by three research presentations at the Movement Disorders 2000 conference and none of the plenary sessions, confirming my belief that QOL is more evident in clinical rhetoric than practice.

US National Institutes of Health for the quality of their web site. The Huntington's Disease Association then asked about the involvement of pharmaceuticals with support groups. They were particularly concerned that patients were being used as "lobby fodder", for example, to influence EC directives on prescribing in favour of pharmaceuticals. This issue was only discussed after an attempt had been made to undermine the credibility of the questioner by suggesting that the issue of dependence was specific to Huntington's Disease Association because they only had one pharmaceutical working in their area³²⁴. WE MOVE cited unconditional "educational grants" as a good example of "co-operation" between patient support organisations and pharmaceuticals without "undue influence". But other participants gave examples of educational grants for surveys that specified which PR company should be used, or grants for publications that failed to mention subtypes of the disorder which did not respond to the drug that the sponsoring pharmaceutical produced.

It seemed to me that the message coming from the meeting was that collaboration with the Movement Disorders Society would be on its terms. For example, it would meet with "leaders" but not patients, and preferred patient support organisations to be filtered through WE MOVE. One organisation suggested that their events should be listed in the Society journal so that doctors could participate, but was told that this was a "scientific journal" and that the WE MOVE web site (which is mainly used by other patient support organisations) would be more appropriate. The Society president also asked for feedback on the "booths" that had been made available to patient support organisations at the back of the main hall. It was pointed out that these were actually "little tables", which looked "shabby" alongside the pharmaceuticals' stands, many of which incorporated espresso bars and club-style seating ("we voluntaries always get stuck with the smallest, least desirable space"). According to National Organisation for Rare Disorders, the solution to the problem was to get WE MOVE (which had the largest stall and, unlike the other patient support organisations, was allowed to hire professional-looking furniture) to distribute literature for the patient support organisations, thus "saving" them the trip to the conference!

Conclusion

The discourses of QOL and the "voice of the patient" bring together a diverse range of actors in international networks³²⁵, supported by financial and institutional interests in chronic illness. But the rhetoric of "partnership" conceals imbalances of power and resources, even within groups of actors (for example, the Dystonia Medical Research Foundation and Chilean

³²⁴Unlike the US Parkinson's Disease Association with twelve.

³²⁵These relationships are summarised in a table in the appendix.

dystonia society). The concept of QOL is difficult to stabilise and define, which may explain its utility as an “empty signifier” that can contain a range of meanings [Strathern 1992]. Characterising it as a boundary object risks reifying it and disguising the fact that it operates in a similar, capillary way to Foucault’s description of power. The concept of the “voice of the patient” can also be used as a form of ventriloquism to justify everything from faster drugs regulation to better conference furniture for patient support organisations. However, its “celebration” may enable future opportunities for subversion, as when real “patients” speak, it will be less easy to silence or contain them.

Although measures of QOL do not do what they claim, namely measuring what people say gives quality to their lives and representing the “patient’s perspective”, they are widely used and have become politically important because different groups of actors feel they have to engage with them to accomplish their goals. For example: doctors bidding for funding, patient support organisations raising awareness of their condition, and pharmaceuticals marketing new products. As with audit, once a procedure has been established, everything needs to be represented in that manner, making the procedure seem natural and inevitable. While it is then difficult to return to the beginning and ask how we ended up here, this is undoubtedly a role for anthropology, and is something I attempt to do in the first chapter of the next section on QOL.

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Section 3: Quality of Life

Chapter 7: Defining and measuring Quality of Life

In the first six chapters I described people's experiences of living with dystonia and attempted to understand why it has such a severe effect on some people's quality of life. I began to explore the problems with representing dystonia and separating the experience of dystonia from the fabric of people's lives in order to measure its impact. I hypothesised that what is distinctive about dystonia is the way it is interpreted and responded to by people living with dystonia and the rest of society, rather than its physical symptoms. In the next three chapters, I investigate whether this distinctiveness can be represented by QOL measures and ask if they offer much more than the clinical measures they resemble, using participant observation on a multiple sclerosis-specific measure to illustrate my points. I argue that the range of health states covered by QOL measures at the International Society for Quality of Life Research conference and the inclusiveness of the WHO's International Classification tool are evidence of an increasing "medicalisation of disability" and extension of the "clinical gaze". I also argue that although QOL is represented in terms of "caring", it is actually about "efficiency and cost" [Kleinman 1996]. The language of QOL therefore operates analogously to the current concern with "ethics" in anthropology, which is used to present audit in a positive light (c.f. [Strathern 2000]). Finally, I continue to explore the ways in which the discourse of QOL has become an important rhetorical resource.

The first chapter in this section examines how QOL is defined, measured, and "transformed" by health economists into a tool for resource allocation. I review the history of QOL research in medicine and explore how it continues to be influenced by its anthropometric origins, despite the discipline's expansion and professionalisation. The second chapter is an ethnographic study of QOL that explores the "unscience" at the heart of Science, using participant observation during the creation of a multiple sclerosis-specific measure, and a European survey of the QOL of people living with dystonia. The final chapter looks at the use of QOL scores internationally (in the form of the "Disability Adjusted Life Year") to compare the quality and value of people's lives. It describes the efforts of organisations like the Dystonia Society to ensure their condition's inclusion in the WHO's Global Burden of Disease rankings, which affects the proportion of resources allocated to alleviating it. It also explores how changing attitudes to health and disability (connected to discourses of QOL and the "patient's voice") have affected the WHO's attempts to create a universal classification of health.

QOL

There are two types of QOL measure: “generic”, which can be used in sick and “healthy” populations, cover all diseases, and are brief and easier to translate; and “disease-specific”, which are generated from interviews with clinicians and people with particular conditions and are only appropriate to that condition. Although disease-specific measures are popular with patients and clinicians because the items are obviously relevant³²⁶, generic measures are widely used as they express outcomes in a standard numerical format that enables comparison. They have grown exponentially over the past decade, funded by national health services, pharmaceuticals and the US health insurance industry. For example, the RAND Corporation funded the SF-36³²⁷ (the most commonly used generic measure). Medline, the main index for medical papers, first used the phrase “quality of life” as a heading in 1975. Since then tens of thousands of papers have been published (12,329 in the past 3 years alone [1999-2001]), and there has been a proliferation of study groups, conferences and special journal issues³²⁸.

This remarkable growth can be linked to increasing cost consciousness in medicine, risk management by health care providers, and the need for more sensitive measures to compare treatments for chronic illness. Consequently, many studies have an element of advocacy as well as evaluation [Najam and Levine 1981], which is particularly true for expensive therapies like transplantation [Joralmen and Fujinaga 1994]. Their scientific basis is now so established that the PD MED trial of drugs for Parkinson’s disease uses the Parkinson’s Disease 39-item Questionnaire [Peto et al 1995] as its main outcome measure.

What is QOL?

QOL is used to describe what a person feels about their life when they evaluate it as a whole. However, this is not necessarily what QOL measures assess as they are biased towards “physical function” [Leplege and Hunt 1997]. Although this is the easiest aspect to measure

³²⁶There are nearly 20 disease-specific measures for Multiple Sclerosis.

³²⁷The SF-36 contains two domains, physical and mental, divided into eight sections: physical function, role limitation physical, pain (all physical), and health perception, and vitality, social function, role limitation emotional and mental health (all mental). In theory the domains do not overlap, though “vitality” includes physical tiredness, “health perceptions” usually reflect mental rather than physical health, and the role limitation variables conflate different sources of limitation [Rose et al 1999]. It is not a sensitive measure as strong “floor” and “ceiling” effects have been observed (where the majority of respondents are grouped at one end of the scale) [Ruta et al 1998; O’Mahony et al 1998]). The wide “confidence intervals” (the range of scores that the actual score is most likely to be within) [McHorney et al 1996] limit its use to large studies where the volume of data cancels out individual irregularities. Studies using the SF-36 experience missing data [O’Mahony et al 1998] and low response rates [Parker et al 1998], possibly due to ambiguities in the phrasing of the items [Jenkinson 1995]. It also focuses on ability to work, rather than be a parent, family member, or citizen [Wiersma 1988].

³²⁸The discipline had its own journal in 1991 (Quality of Life Research) and its first conference in 1994.

and crosscheck (replicating the privileging of the tangible that has distorted recent Higher Education reforms), population and patient surveys suggest it is not the most important determinant of QOL³²⁹ [McDowell and Newell 1987; Bowling 1995; Rothwell 1997; Karlsen et al 1999]. A comparison of how people living with HIV and their doctors determined health change found the assessment of both groups was influenced by their interests rather than disease severity variables³³⁰, undermining the conventional association of doctor/objective and patient/subjective [Ruocco and Holmes 1998].

Researchers use QOL loosely: one popular edited collection entitled *Quality of life after open-heart surgery* [Walter 1992] focused on common medical outcomes like clinical measures and survival times. Descriptions of the measures (QOL, health status, well-being) are used interchangeably, even though they have different implications and problems. For example, “health-related QOL” implies that QOL can be separated into health and non-health related components. The proliferation of measures also prevents them from becoming a framework for comparison: one review found 159 different measures cited in 75 articles, 136 of which had been used only once [Gill and Feinstein 1994]. In the absence of a “gold standard” some researchers simply multiply the number of measures used: in one study pancreatic transplant recipients were sent 11 different measures [Milde et al 1992].

Representing QOL as a measurable property or “commodity” is part of a move towards models of life that are linked to the production and maximisation of human resources [Escobar 1994]. For example, the WHO’s definition of health prioritises an “economically productive life”. If the main determinants of QOL are social and environmental [Bowling 1995; Bullinger et al 1998], it can be improved by action at the level of society, but this is obscured when it is located in the “natural” body of the individual [Taussig 1980]. This reinforces the “decomposability” of society by reducing “social processes and structures” to individual attributes and “detach[ing] knowledge, action and events from their social settings”³³¹ [Young 1980].

QOL measurement is a classic example of an “explanatory science”, which:

³²⁹People with multiple sclerosis and Parkinson’s disease in studies by Rothwell [1997] and Karlsen et al [1999] were more concerned about mental health and vitality. Similarly, epilepsy-specific measures focus on the frequency and severity of seizures, physical function and paid employment, while people with epilepsy worry about being labelled epileptic and feeling stigmatised [Scambler and Hopkins 1990].

³³⁰People living with HIV were influenced by depression, overall function, financial worries, life satisfaction, and medication concerns, while doctors were most influenced by patients’ health worries, presumably because this affected their use of services.

³³¹A study exploring the hospitalisation of people with Alzheimer’s demonstrated that their carers’ QOL scores were a better predictor than their own [de Froidment et al 1999].

Aim[s] to cover a wide range of different phenomena with a small number of principles. [Its] explanatory power [...] comes from its ability to deploy a small number of well-understood expressions to cover a wide variety of cases. But this explanatory power has its price [which is] to constrict our ability to represent situations accurately

[Cartwright 1983]

The abstraction that takes place during the development of measures of QOL has methodological as well as political consequences as the context in which measures are created and used is important. For example, measures created with people in hospital are less sensitive in other environments [Jenkinson 1994]. Similarly, the counterintuitive conclusion that the health of transplant recipients is as good as the general population's (for example, Caine et al [1990]) may be explained by strong feelings of gratitude towards their doctors (the "saviour effect") and the socialisation process prior to donation [Joralmen and Fujinaga 1996]. Ignoring context may also cause resources to be targeted to the wrong areas: in the late 1980s the National Epilepsy Centre in Japan aimed to improve the QOL of people with epilepsy through surgery but although they reported a general improvement, this did not include areas like employment [Mihara 1994 in Yeh 1996]. The lack of improvement in this area was explained as behavioural problems from living with a chronic illness, which could be cured by offering surgery earlier. This conclusion ignores the high unemployment rate for people with epilepsy (10 to 20 times that of the general population³³²) and demonstrates how "progressive" discourses like QOL can be used to shift social responsibility. Yeh concludes "blame for lack of social integration is placed on personal characteristics, thus shadowing the blatant reality that few spaces in a 'socially integrated' Japan exist for individuals with disabilities" [1996].

QOL measurement is part of the "medicalisation of human distress" [Heath 1999] where common experiences like grief are pathologised and placed within a normative framework, and doctors are invited to become "moral philosophers, counsellors, or social reformers" [Leplege and Hunt 1997]. For example, the range of health states represented by disease-specific measures at the 1999 International Society for Quality of Life Research conference, many rare, previously untreatable, or not defined as a condition, may be an example of "creeping medicalisation" where "well" people become the target of medical interventions focusing on the "subjective individual" rather than the physical case [Illich 1976]. On the other hand, many clinicians and patient representatives are clamouring for disease-specific

³³²In Germany, where people with disabilities must compose 6% of adults working in the private sector, the employment rate of people with disabilities is 5%, in Japan where the equivalent requirement is 1.6%, the rate is 1.41% [Yeh 1996].

measures to “validate” their condition [Hacking 1995] and enable it to compete for treatment resources. For example, the project to develop a measure for dystonia was initiated by the Dystonia Society who used the scores from generic measures of QOL to demonstrate that the impact of dystonia is equivalent to epilepsy, depression and multiple sclerosis [Camfield et al 2000].

In the next section, instead of merely recording the history of QOL measurement, I aim to provide a genealogy that exposes its “disreputable origins and unpalatable functions” [Foucault 1973]. For example, to enhance QOL’s scientific respectability, many researchers claim descent from “psychometrics” presumably unaware of the discipline’s link with the eugenics movement, which gives credence to suggestions by Pfeiffer et al of the eugenic potential of Disability Adjusted Life Years and the WHO’s International Classification tool. I also explore the historical role of statistics in surveying and controlling the population³³³.

Interestingly, statistics did not originate from within the discipline of mathematics. The Victorian statisticians were social reformers rather than mathematicians producing “facts” to advance their programmes. The development of statistics at the beginning of the last century as a scientific specialty, as well as a form of intervention, was largely due to the work of Galton, Pearson (his collaborator and successor), and Fisher. All of these men were eugenicists: Fisher gave his first scientific paper to the Cambridge Eugenics Society, and Pearson was a “Professor of Eugenics”, in addition to heading the first university statistics department. Like the WHO, the early statisticians collected (or created) facts in order to intervene. According to Pearson’s biography of Galton, his goal was to exert the same control over human evolution that man exerted over other creatures. Galton also popularised “anthropometry” as a way to discover “all that [a man] ever has been, and all that he will be” as he believed that physical and mental measures provided the key to human nature. Influenced by the work of Lombroso (and other criminal anthropologists) he developed a technique to uncover a “criminal type” by fusing photographs of individual criminals on a photographic plate³³⁴.

Mackenzie traces the eugenicists’ view of human nature (“the person as largely the sum of a number of potentially measurable abilities and personality traits”) and human populations (“manipulable aggregates of such abilities and traits”) to its origin in a society where the

³³³Drawing on MacKenzie’s critical account of statistics in Britain 1865 -1930 [1981].

³³⁴This technique was replicated in 2000 using images of women considered beautiful in different societies to create the “beauty of the Millenium”. Unsurprisingly, the result was a European with a heavy tan.

ultimate criterion of a person's worth was quantitative [1981:34]. The reduction of people to their wage rates or to "marks" in a "eugenic examination" is an example of reification [Lukacs 1971] where people, or more precisely their abstract labour power, are treated as things. A similar process occurs with Disability Adjusted Life Years where people with disabilities are made synonymous with fixed diagnoses, assessed using scales that are biased towards economic functioning, and valued according to their "social utility".

Galton was also the first to argue that intelligence was an individual, inherited characteristic and developed methodologies like "twin studies" (with Pearson) to demonstrate this. He believed that every individual possessed a fixed amount of the characteristics that make up "civic worth"³³⁵, which was distributed according to a "Gaussian curve" (or normal distribution) in the same way as physical characteristics. He used Booth's social survey of London [1903] to map a social structure over this curve so criminals and middle-class professionals ("the brains of the nation") were at opposite ends of the curve, while the "respectable working classes" formed the majority in the centre.

Since civic worth was hereditary, the only way to increase the amount in society was promote the fertility of the "better classes" and reduce that of the "inferior". Galton believed that money spent on environmental reforms would be wasted since you couldn't improve "the human raw material", a belief that resonates with the Disability Adjusted Life Year's bias against non-curative interventions for people with disabilities. In both cases the logic displaces responsibility for success or survival onto the individual and removes the need for social intervention to address inequalities. He advocated both "negative" and "positive" eugenics: negative eugenics involved preventing criminals and the insane from reproducing by segregation and sterilization. He also wanted to discourage reproduction by people with low IQs or incomes³³⁶, possibly by stopping their unemployment benefit if they had more than two children. Positive eugenics was a more subtle strategy of introducing family allowances and tax breaks to encourage the middle classes to have larger families. Interestingly these still form part of new-right policy on the family.

Eugenic proposals gained a surprising amount of popular support. The Eugenics Society was founded in 1907 and had over one thousand members by 1914, mainly doctors, academics,

³³⁵Civic worth was never defined, and was later interpreted as "intelligence quotient" or IQ. Psychologists attempted to give his model an empirical basis by testing the intelligence of people in different classes.

³³⁶His disciple Darwin regretfully commented that correlation techniques needed to improve before income could be reliably used as a variable.

and other professionals. Keynes and Beveridge were members, as were the majority of the Fabian socialists (including the Webbs, HG Wells, and George Bernard Shaw) who saw it as the logical extension to their commitment to a planned society. Support for eugenics fitted well with a belief in the meritocracy, and the insistence on the individual and cognitive determinants of success reflected the experience of the professional middle classes. This individualizing approach is reflected in the disability weightings for the Disability Adjusted Life Year, which ignores the effect of social support and the environment on the experiences of people with disabilities.

Despite widespread support for eugenics from those frightened by the “urban residuum”³³⁷ (now called the “underclass”), there were dissenting voices. Chesterton claimed that “the eugenicist was the employer” and objected to the idea of “herding and breeding the workers like cattle” [1922:147]. The eugenicists attempted to increase their control over the working classes through the IQ test whose validity was apparently proved by its correlation with the father’s occupation. This enabled the professional middle classes to define the terms under which working class children achieved social mobility.

The respectability of eugenics was diminished by the actions of the Nazis in the 1930s who passed bills for the sterilization of criminals (including political “criminals”), “the feeble minded”³³⁸, people with disabilities and the “insane”. The eugenicists were also attacked by their core constituency who realised that a eugenic utopia would have little need for social workers, family doctors, and public health officers. Their legacy was the IQ test, which crystallized the assumption that “ability is an individually possessed ‘thing’ that can at least potentially be measured, and that the results of this process ought to bear an important relation to an individual’s social position” [Mackenzie 1981:49]. Rose describes the IQ test as a paramount example of all tests, which codify, mathematise and normalise difference” [1990:140]. Tests are an indispensable tool for governance as they can quickly and economically differentiate individuals within any schema. They make individuals “knowable, calculable and administrable” and enable them to be differentiated from others and evaluated in relation to them, and to the “norm”. The IQ test, for example, was soon transformed from a device for diagnosing the pathological to one for hierarchising the normal. Both the IQ test and QOL measurement enable “a calculation to be made about personal fortunes in terms of an assessment of individual capacities” [ibid].

³³⁷This was described as a “natural” category (a degenerate form of Homo Sapiens) however the majority were “reclaimed” when they were able to get jobs in the labour shortage after the Second World War.

³³⁸Britain debated a “Feeble-minded persons (control)” bill in 1912.

There are obvious similarities between the IQ test and QOL measures, not least because the IQ test was the first time an “abstract” (and undefined) quality had been measured with the same apparent accuracy as height or weight. Another link is that Spearman, Burt and Thomson, psychologist disciples of Galton and Pearson, developed “psychometrics”, which is one of the “disreputable” ancestors of QOL. This enabled psychology to establish itself as the appropriate authority to adjudicate on the lives of individuals and manage them to maximise their “social utility” and minimize the “social danger” their difference might create [Rose 1990]. Measures of IQ and QOL are implicitly linked to interventions, enable the exertion of control over individuals, lead to the creation of types, assume that the ultimate measure of a person’s “life quality” (or quality of life) is stable and quantitative, and ignore the role of the environment.

Despite their methodological flaws, their usefulness to a range of groups ensures their continued use as a way of creating classifications and hierarchies. For example, the International Society of QOL Research furthers its “mission” to promote the study of health-related quality of life internationally by making alliances with non-scientists who share their discourse (a process of “translation” first observed by Star and Griesmer in Berkeley’s museum of Zoology [1989])³³⁹.

The International Society is the main disciplinary body for QOL researchers, which organises satellite conferences at medical events, conferences on specific conditions or methodological issues, and liases with other societies like the Society of Clinical Trials. Its official language is English and two-thirds of the membership is from the UK and USA. The two main disciplines represented are clinicians and economists, and a third of its members are from pharmaceutical companies or consultancies. The society’s close links with pharmaceutical companies (who comprised seven of the eleven conference sponsors³⁴⁰) enhance its credibility and the perceived usefulness of its programme. One of the “Six good reasons to attend” given in the promotional literature for its annual conference was to “know the directives on QOL information that regulatory agencies will use for drugs approval”. There was also a satellite meeting preceding it (chaired by pharmaceutical representatives) that looked at QOL and regulatory issues in Europe and the USA. The assumed consonance between the interests of QOL researchers and pharmaceuticals was emphasised by the style of

³³⁹For example, the Mayor of Barcelona, who claimed at their 1999 conference in Barcelona that they had “common aims and goals” as they were both “insisting on quality of life” and “giving voice to the people”.

³⁴⁰The other sponsors were the Spanish Ministry of Education and Culture, Barcelona Council, a medical publisher and a QOL research consultancy that worked for pharmaceuticals.

the event (lavish hospitality, sponsored social events, omnipresent pharmaceutical logos), which resembled an international medical conference.

The most important areas covered by the presentations are summarised in the table below. These seemed to be the growth of disease-specific measures (usually sponsored by a patient support organisation), reduction in the length of measures to facilitate their use in health economic analyses, translation of measures for use internationally, use of QOL outcomes in clinical trials (still a new area as only ~5% of trials use them), and submissions from patient organisations, pharmaceuticals, and clinicians to regulatory bodies like the National Institute for Clinical Excellence.

Growth area	Example
Patient satisfaction	Measuring the QOL of patients while attending clinics
Population survey	Incorporating QOL measures in censuses; comparing the health of migrants with the indigenous population
Disease-specific measures for new or rare conditions, states that were not previously considered health problems, and new groups of people	Grave's disease "Planning to undergo IVF treatment" Parents of children with asthma, caregivers for people with dementia
Patient-centred measures	My Medical Outcomes Profile [Paterson 1996, Paterson and Britten 1999]
Measures for specific groups	Children and adolescents
More comprehensive measures	The Good Life Questionnaire [Mozes and Maor 1999]
Examining equity	Los Angeles Latino Eye Study examined the association of QOL and access to healthcare
Shorter measures or shorter versions of existing measures, either for stylistic reasons or health economic analyses	EuroQol 5-item questionnaire [Kind 1996]
International measures and translation and validation of North American and British measures	WHOQOL [1995] Spanish version of the International Index of Erectile Function, Hong Kong Chinese version of SF-36
More "scientific" methodologies	Rasch analysis
Exploring methodological problems	Using proxies for people with physical and cognitive impairments; aggregating QOL scores to produce single figures for health economic analyses
Using QOL in clinical trials and submissions to regulatory bodies	European Regulatory Issues in QOL assessment project
Using qualitative methods to generate material for measures and understand people's models of health	Living a "good life" in MS [Satinovic 1999]

Although the discipline of QOL measurement seemed able to withstand a high level of internal criticism, for example, Hunt (the designer of the first "patient self-report" measure, the Nottingham Health Profile [Hunt and McEwen 1980]) made a keynote conference speech called "A philosophical attack on QOL" and expressed doubts as to whether "all this [QOL] activity had ever benefited a patient", the conference did not address some fundamental problems with measuring QOL. These can be summarised as follows: firstly, the clinical context in which measures are designed and used means that even individualised measures

don't represent what is important to people with limiting conditions. They also cannot use a more inclusive definition of health as clinical measures are used as the template and source of validation.

Secondly, QOL is a complex, holistic, and personal concept, which cannot easily be measured. For example, how do you weight the scores of different aspects of QOL to produce a total score, or compare conditions? The challenges of measurement are exacerbated by poor measure design and concealed by the apparent simplicity of "global" questions of QOL and visual representations like the EUROQOL thermometer. Thirdly, QOL is hard to predict as there is no direct relationship between impairment, disability, and lowered QOL, and people's perceptions often change as their health deteriorates. Consequently, assessments of future QOL are usually based on negative stereotypes of people with disabilities. Reduced QOL, like disability, often results from lack of support and hostile external responses to the condition, rather than the condition itself.

Fourthly, different measures express different conceptions of QOL. However, these are rarely stated explicitly, making it difficult to tell what they are actually measuring. QOL measures naturalise assumptions about health and performance (for example, the importance of independence in "activities of daily living") and draw the boundaries of normality even tighter. Finally, QOL measures assume not only that Western conceptions of QOL and measurement practices are applicable across cultures, but also that internally homogenous cultures still exist

Some of these criticisms have been acknowledged within the discipline. For example, Hunt argues that the "emphasis on psychometric harmony not individual meaning" leads to the removal of items that are relevant to individuals. She also observes that the aggregation of scores from different domains creates a false homogeneity, and the "rush" to develop measures before developing their underlying conceptual models means that we cannot be sure what they are measuring [1999]. More fundamentally, Hunt believes QOL does not fit within positivism as it is "vital and unique" to the individual: "we cannot measure what we cannot define". She also criticises the ethics of QOL research, citing the implication that "there is a normative level of function to which we should all aspire" [Leplege and Hunt 1997], and the "false promises" of doctors and pharmaceuticals that a product will enhance QOL rather than merely alleviate symptoms [1999]³⁴¹. However, for the reasons I address in the following

³⁴¹The Good Life Questionnaire [Mozes and Maor 1999], which is described as "an attempt to define the essence of human existence", is an example of this hubris. It demonstrates the developers' role in defining what

chapters, these reservations have not checked the growth of QOL measurement. In the next section I explore the conceptual and methodological issues with QOL in greater detail.

Historically, there has been little consensus over what constitutes a “good life” and how it should be measured, and this is also true of QOL measurement today³⁴². For example, Downie identifies four models of QOL (“significant toil”, “choice”, “happiness or well-being”, and “social factors”), which are individually plausible, but incommensurable and unquantifiable [1999]. He suggests that it be measured using a combination of subjective and objective approaches as the latter enables external measurement of activities, endowments, and resources³⁴³. But which approach (or whose judgement) should take priority? If someone with an illness or disability expresses satisfaction with their life, it is insulting to assume, like one of the designers of the Disability Adjusted Life Year, that this is “false consciousness” [Murray in Murray and Lopez 1996]. The lack of correlation between subjective and “objective”/external judgements of QOL may suggest that different things are being measured [Wu et al 1997; Brown and Gordon 1999], for example, predictors of QOL, adjustment to disability, the presence of psychiatric disorders, or personality traits such as hypochondriasis³⁴⁴.

Contrary to common assumption, there is no direct relationship between functional limitations, disability, and loss of QOL [Wilson and Cleary 1995] as the relationship is mediated by cognitive [Barofsky 1996] and sociocultural factors [Guarnaccia in Spilker et al 1996]. To imply that there is, risks reinforcing disablist stereotypes [Leplege and Hunt 1997]. Low quality of life is actually related to “impairments that produce fatigue, constant or unpredictable pain, and to physical and social environments that discourage them from becoming empowered and acting as agents in their own lives” [Albrecht and Devlieger 1999].

The long-term effects of a condition depend on individual resources and social context³⁴⁵. In fact, the only constant is the variety of conditions in which people flourish if they are grounded in autonomy and self-determination [Hodge 1990]. The process of adaptation to a

counts at QOL, for example, scoring is weighted in favour of “life plans” (60:40) rather than “pleasures”. Although respondents can define their own pleasures and plans, the list of suggestions indicates what would be appropriate. For example, two of the six suggested life plans relate to fulfilment in your career.

³⁴²Evidenced by the low level of agreement between different raters on many measures of QOL [Aaronson 1990; Sprangers and Aaronson 1992].

³⁴³Thus avoiding a doctor prescribing antidepressants for “a single mother living in damp housing in an area of multiple deprivation” to improve her QOL “even though the life lived remains exactly as it was before” [ibid].

³⁴⁴Muldoon’s population study found all SF-36 domains correlated significantly with neuroticism [1998].

³⁴⁵Whether a person can substitute other valued activities for the ones they are cannot perform [Ormel et al 1997]. For example, Murphy described “retreating” into his mind when his body became paralysed [1987].

condition is described as “response shift” [Sprangers and Schwartz 1999] and may account for the “disability paradox” [Albrecht and Devlieger 1999] where some people with disabilities report a higher QOL than the general population. Of course, this is only a paradox if we assume that diminished QOL and satisfaction necessarily result from physical difference and that the only significant criteria to consider are medical [Koch 2000]. Many people living with dystonia (quoted in the first three chapters) testified to the positive life changes and raised self-esteem that developed from their condition, suggesting that “the view that illness in some personally significant way leads to a reduction in self-worth need not be true” [Drummond 2000].

Health economic measures (examined later in the chapter) demonstrate the difficulty of predicting QOL [Koch 2000, 2001], particularly as people’s perceptions often change: over a four-month period a quarter of people living with AIDS revised their “advance directives” which had rejected life-sustaining treatment [Weissman et al 1999]. Too often these measures are more about “the way ‘they’ [able-bodied] think ‘we’ [disabled] live, than the way ‘we’ actually live”³⁴⁶ [Darke 2002]. For example, Amyotrophic Lateral Sclerosis (or Motor Neurone Disease) is a chronic, progressive, neurological condition that has been used as the paradigm of low QOL in debates over euthanasia³⁴⁷. But some people with the condition present a different picture, describing the physical restriction as “life enhancing” [Goldblatt 1993], and “an adventure in life” and tool for spiritual exploration [Young and McNicoll 1998]. The technological and social support offered to Steven Hawking (a famous physicist with Motor Neurone Disease, c.f. [Hawking 1993]) enables him to describe his current life as “certainly happier” than his life pre-diagnosis. Reduced QOL after disablement often results from isolation, stigma, and fear of being a burden on the community. It may be this, rather than the disability itself, that precipitates requests for euthanasia [Miller 1993; Auslander and Gold 1999]. Existing measures of disability “create” low QOL scores by only asking about problems, incorporating a tacit model of disqualification [Ziebland et al 1993], and recording “underlying disability” which is what would be experienced if people could not adapt or seek help [Agree 1999].

Neglecting the “individual meaning of illness” has created the false impression that “the measurement of QOL is simple and feasible” [Parmentier 1994]. Drummond suggests that, “the process of attributing value to a subjective condition is best conceived of as an aesthetic

³⁴⁶For example, only 18% of Accident and Emergency staff believed people with traumatic spinal cord injuries could achieve an acceptable life quality, compared to 92% of people with these injuries [Gerhart et al 1994].

³⁴⁷Dr Jack Kevorkian (a North American advocate for euthanasia) consciously chose a person with motor neurone disease as his first client after Michigan passed a ban on “assisted suicide”.

one, involving an emotional engagement with (rather than rational evaluation of) everyday experience” [2000]. For example, one study of older people found they focused on “being, belonging and becoming” rather than health [Raphael et al 1997], while people living with multiple sclerosis defined “living a good life with MS” as being an “active and constructive participant” [Satinovic 1999].

Providing a robust assessment of your QOL involves introspection, reflection and judgment [Barofsky 1996], essentially becoming the contemporary role model of the “reflective self” [Giddens 1991]. This is particularly true for conditions like focal dystonia and epilepsy where relatively good physical function needs to be reconciled with poor psychological well-being: “many patients with epilepsy are unable to express numerically the constant anxiety due to the unpredictability of the next seizure or occasional difficulties with finding words” [Selai and Rosser 1995]. The rubric of some measures exacerbates the problem, for example, the Functional Limitations Profile requires people to complete it with reference to how they are feeling today and to make this judgement only on the basis of their health [Patrick and Peach 1989]. This requires the person to make two judgements for each response: “I am not driving today” should only be affirmed if they are not driving today for health reasons, rather than because they never learnt to drive. Jenkinson gives the following example of the cognitive contortions required to respond to “I have attempted suicide”:

Respondents must not tick ‘Yes’ if they have attempted suicide today, but did so because their spouse has been killed in a car accident (this is, after all, not a problem with their health). Maybe it would be legitimate to tick “Yes” if the respondent reasoned that their mental health had been adversely affected by a relative’s death, and they had attempted suicide today (just before filling in the questionnaire in fact)
[Jenkinson 1995]

He observes that, “questions such as these must make researchers sit back and take stock of how such questionnaires are interpreted (or re-interpreted) by respondents if results from such measures are to be of any meaningful use whatsoever”. An example from my own research was an interviewee who asked a friend to fill in the QOL in dystonia questionnaire because she found the retrospective questions too distressing, but suspected that he had done so “sarcastically” as “he felt some of the things were so obvious they didn’t need to be asked”.

A single QOL score (a requirement of health economic analysis³⁴⁸) can be obtained through global QOL questions that invite the subject to weigh different areas of their life in making

³⁴⁸The single figure is combined with data on health preferences [e.g. Rosser and Kind 1978] to produce Quality/Disability Adjusted Life Years, which can be used to guide resource allocation.

their assessment. For example, “on this thermometer [marked 0-100] [...] indicate how good or bad your own health is today” [EUROQOL 1990]. However, it is difficult to know what these questions measure³⁴⁹, something that is concealed by their apparent simplicity [Selai and Trimble 1997]. For example, the response “yes, I am better” could refer to resolution of the disorder, readjustment, or redefinition³⁵⁰ [Beaton et al 1999]. The questions are most likely to record psychological well-being, or “health perceptions”, which correlate strongly with future deterioration (this is not surprising as believing that you are going to deteriorate probably causes deterioration). This suggests QOL is actually “a reflection of the way that patients perceive and react to their health status and to other non-medical aspects of their lives” [Gill and Feinstein 1994].

QOL measures assume that “human life consists of a series of essentially discrete components or dimensions, each of which is amenable to independent measurement” [Joralmen and Fujinaga 1994]. However, the concept is holistic, not “reductivist” and cannot be measured by breaking it down into specific characteristics. Attempts have been made to define common domains of QOL (for example, [WHOQOL 1998]) but the links between the domains and their relative significance has been little explored. The need for a more holistic measure of QOL links to debates over whether it can be expressed in a single figure for health economic analysis [Kaplan and Anderson 1997]. Some researchers describe combining different domains in a single score as “adding apples and oranges” [Stewart and Ware 1992], especially when questions about levels of functioning are aggregated with how the person feels about the situation [Muldoon et al 1998]. Others (responding in the same metaphor) claim that it’s “the overall evaluation of the basket of fruit that’s important” [Hays et al 1993]. Some researchers also question whether we can compare QOL scores from different conditions (for example, eating disorders, angina, and heart transplants [Keilen et al 1994]) as the researcher is invited to “play God” in assigning relative weights to very different experiences.

While the differences in results from QOL measures probably arise from their different models of QOL³⁵¹, developers are more likely to describe their “psychometric properties”

³⁴⁹A population survey in Israel found that only 48% of the global rating could be explained by the domains of the SF-36 (refer note 1) [Mozes et al 1997], although this could also be a criticism of the SF-36.

³⁵⁰Patient satisfaction studies also fail to explore how people transform experiences into evaluations of a service as a whole [Williams et al 1998], for example, being satisfied with a treatment can encompass feelings of resignation and helplessness and a belief that the treatment is useless [Kilian et al 1999].

³⁵¹Ziebland [1993] distinguishes four models of disability underlying measures used for rheumatoid arthritis: functional, subjective distress, comparative, and dependence. All of these contain questionable assumptions, for example, the second assumes that dependence is pathological (the Stanford Arthritis Healthy Activities

than their philosophical underpinning [Keedwell and Snaith 1996; Ziebland et al 1993]. This, combined with the “pragmatism of clinical practice”, means that “many measures make no reference to the concepts that they are trying to measure [...] It is rather like possessing a thermometer and knowing that it is intended to identify patients with a fever but not knowing that what it actually measures is temperature” [Wilkin et al 1992:18]. Measures contain (and naturalise) normative assumptions about what constitutes health, posing the central question for QOL, which is whose values are being measured? This is often difficult to discern, as many researchers do not indicate how the items were generated. Using interviews with people living with the condition makes it more likely that their concerns will be included, but this is not certain (as I demonstrate in the next chapter) because of the way people’s responses are homogenised and made “quantifiable” during the development process. Some researchers argue that if the measure incorporates values that differ from or conflict with the subject’s (for example, defining QOL as a function of income level and education), it is measuring something other than QOL [Minaire 1993; Brown and Gordon 1999].

Where surveys and questionnaires begin with the assumption of ‘disease burden’ and a medical model of life quality, the assumptions of those positions – not the individual’s health state – is often what is typically measured. The questions asked and the tenor of their presentation defines the parameters of the data while limiting the potential for survey population response. It is a dialogue with only one speaker
[Koch 2000]

For example, although the correlation of measures with clinical variables is taken as a sign that they tap areas of interest to the patient, it is more likely to mean they tap areas of interest to the clinician. Seedhouse criticises the privileging of sickness as an obstacle to social function over unemployment, poor education, etc. but warns that this was inevitable considering the relative power of clinicians and academic social scientists: “opting to tackle a more powerful political opponent on his own terms is not a particularly intelligent tactic” [1996]. This problem was previously identified by Ardener in his description of “muted” groups who fail to “modify dominant structures by their own ‘rules’” because of the “totally reality-defining nature of such structures” [1989:130]. This should be a cautionary note to patient support organisations who fail to realise that the “neutral” technology of QOL is using them as much as they are using it.

One response to suggestions that QOL measures don’t address the changes that are important to patients has been to produce individualised measures where patients identify the areas that

Questionnaire score is increased to “much difficulty” if the person received assistance from a person or aid, regardless of their assessment of the degree of difficulty [Fries et al 1982]).

are important to them and rate their treatment according to its effect on those areas [Guyatt 1993]³⁵². The “Measure Your Medical Outcome Profile” [Paterson 1996] is an unusual example as it was validated against interviews with people with asthma, rather than another QOL measure. However, although it picked up treatment effects, it didn’t observe medication avoidance and reduction, which were key themes in people’s accounts [Paterson and Britten 1999]. This suggests their ability to represent what is important to the patient is limited by the influence of the context in which they are designed and used. While these measures have been used in a few aggregated studies (despite obvious problems of data interpretation), they are still something of a curiosity since they cannot be used comparatively or for health economic analyses.

Health economics: QOL’s “evil twin”?

Health economic analysis demonstrates the double-edged nature of QOL measurement and the way it simultaneously constructs what it records. While organisations like the Dystonia Society can use QOL to demonstrate the severe impact of dystonia and the cost-effectiveness of treatments, they are ultimately vulnerable to its being used against them (as happened to the Motor Neurone Disease Association) to argue that the lives of people living with dystonia are literally not worth living and no money should be diverted from other conditions in order to prolong them. This logic reaches its extremity with Disability Adjusted Life Years where QOL scores are used to estimate just how much of a “burden” on society the continued existence of people living with dystonia or other limiting conditions represents (this process is described in chapter 9).

The main unit of comparison for British decisions on the availability of treatments is the Quality Adjusted Life Year (QALY). This is based on two dubious assumptions: that is possible for external observers to value QOL in different health states from 0 (worst possible state) to 1 (best possible state), and that we can be fairly certain of the number of years a person would live in a particular state. QALYs are calculated in three stages: firstly, valuations of different health states are obtained (obtaining “preferences”); secondly, preferences and QOL scores are combined in “preference-based measures”; and, finally, QALYs are calculated using the scores from these measures and information about costs. They are inherently discriminative as a person with “perfect” health (i.e. a score of 1) who

³⁵²For example, the Patient Generated Index [Ruta et al 1994] defines QOL as “the extent to which our hopes and ambitions are matched by our experiences” [Calnan 1984] and explores this gap by asking people to list the five most important areas affected by their condition, and the Schedule for the Evaluation of Individual Quality of Life asks people to nominate the five most important areas of their life and assess the impact of their condition on these (taking the risk that it may have little or no impact) [O’Boyle et al 1992].

was going to live ten years would gain ten QALYs (i.e. 1 x 10) from an intervention, but a person with only half-perfect health (0.5) would only gain five (i.e. 0.5 x 10), making them less worthy of treatment [Jenkinson and McGee 1998].

In the remainder of this chapter I examine in more detail how QALYs are calculated and used. I also critique the assumption that external observers can provide accurate, numerical valuations of QOL in different health states. I argue that health economic analyses can sustain a vicious circle where anticipated QOL is low, so interventions are not funded because they appear poor value, reducing the QOL of people with the condition. In fact, Koch argues persuasively that the process turns “eugenic assumptions” into “social science fact” by assuming “that an individual or group’s life quality can be described in a rigorous manner based solely on the presence or absence of physical conditions deviating from those of the normal population [...]; that future life quality can be accurately predicted solely on the basis of current physical condition irrespective of social values or context [... and] that positive life quality cannot be achieved in the presence of physical defects” [2000].

How QALYs are used?

QALYs provide an apparently neutral and scientific justification for politically sensitive decisions on resource allocation.

Once complex administrative decisions have been reduced to simple, and usually quantified, comparisons of cost and benefit, it comes to seem irrational (or improper...) not to act in accordance with the numbers

[Ashmore et al 1989]

However, despite the rhetoric, they are rarely the decisive factor in decision-making as they are difficult to defend to the general public and can be criticised on ethical and methodological grounds. The provocative suggestion by Maynard³⁵³ that hospitals shut their intensive care units and divert the money to hip replacements exposes the limitations of an approach based solely on cost per QALY³⁵⁴. In the following examples QALYs are used to

³⁵³Speaking at an MS Society conference 2001.

³⁵⁴For example, the following table for NHS purchasers shows how comparisons of various interventions are made using QALYs [Mason et al 1993]. However, this does not help decision-making as the ethical and political issues (for example, the relative power of the specialities) are so enormous.

Treatment	Cost per QALY (UK, 1990)
Cholesterol testing and treatment by diet (adults aged 40-69)	£220
Neurosurgical intervention for head injury	£240
Advice to stop smoking from GP	£270
Hypertensive treatment to prevent stroke (aged 45-64)	£940
Pacemaker implantation	£1,100
Hip replacement	£1,180
Heart transplantation	£7,840
Hospital haemodialysis	£21,970
Erythropoietin for anaemia in patient receiving dialysis (assuming no increase in survival)	£126,290

identify the most cost effective treatment for a condition (which is then compared with interventions in other specialities³⁵⁵), to argue for or against funding for new treatments (Botulinum toxin for dystonia and Beta interferon for MS), to decide which treatments to fund (the Oregon experiment), and to prioritise waiting lists.

Treatment options for people with angina [Williams 1985]

The health economist Williams asked three cardiologists to judge the life expectancy and health of people with angina, including some who had had coronary artery bypass grafting³⁵⁶. He used the patient profiles to calculate an average gain from surgery of 1.5 QALYs for people with mild angina and 3.5 for people with severe. He also calculated that only 67% people would benefit from surgery (gaining six years of life), 30% would stay the same (life expectancy five years), and 3% would die (losing their life expectancy of five years), so the overall measure of QALYs gained would be $11 \text{ years}/67\% - \text{five years}/3\% = 7.22 \text{ QALYs}$.

67%	People who benefited from surgery	Gained an extra 6 years of life (11 years)
30%	People who didn't benefit from surgery	Didn't gain any years so life expectancy still 5 years
3%	Died	Lost 5 years of life

He concluded that bypass grafting compared favourably with valve replacement for aortic stenosis and the implantation of pacemakers for heart block, and was better than heart transplantation and treatment of renal failure. However, it was less cost effective than a hip replacement (the author's favourite measure of value), though possibly more useful for individuals with angina! This study provoked popular debate about using QALYs to allocate resources [Ashmore et al 1989].

Use of Beta Interferon in Secondary Progressive Multiple Sclerosis [Forbes et al 1999]

QALYs were famously used to justify the Department of Health's decision not to fund Beta interferon for people with secondary progressive MS. The study reported that 18 people needed to be treated for 30 months to delay one person's deterioration to wheelchair-dependence by nine months³⁵⁷ [Forbes et al 1999]. Even when the social costs of wheelchair-dependence were included (estimated as 15-20% of the costs of the disease), the cost per QALY gained was £1,024,667. This compared poorly with similar studies between 1995-98 where the median cost per QALY was £15,625. The response to the high profile campaign against the decision, orchestrated jointly by the MS Society and the Association of British

³⁵⁵The choice of a cardiac treatment for review is significant as Cardiology is a prestigious speciality, practicing expensive "high technology" medicine that historically has shielded its practices from scrutiny or comparison.

³⁵⁶For an anthropological critique of this technique, see Bates [1990].

³⁵⁷The equation used was $\text{cost per QALY gained} = \text{net cost of treatment}/\text{number of QALYs gained}$ (where this = $\text{total cost of treatment} - \text{costs averted}$ [from reduced relapses and wheelchair dependence]) [ibid].

Neurologists³⁵⁸, suggests that treatments for very disabling conditions (particularly affecting young adults) have a stronger claim on resources that may outweigh their relative inefficiency.

Treatment options for people with dystonia [Gudex et al 1997]

Gudex generated QALYs to assess the benefit of Botulinum toxin as a treatment for focal dystonia. However, the type of dystonia, duration of treatment, method of obtaining preferences for health states, and the characteristics of the participants caused considerable variation in the number of QALYs gained from the treatment. Despite these methodological problems, the study was used by the Dystonia Society to lobby successfully for health authority funding for Botulinum toxin, and an increase in the number of clinics giving injections.

The “Oregon experiment” [Oregon Health Services Commission 1991]

This was the most comprehensive attempt to derive a set of priorities using a preference-based measure (the Quality of Wellbeing scale [Kaplan and Anderson 1987]). The context to the experiment was that in 1988 Oregon ran out of money for its Medicaid programme³⁵⁹. It decided to deny coverage to organ transplantation (including a seven year old boy requiring a bone marrow transplant) to fund maternity care for 1,500 women. There was a public outcry and so the following year, when Oregon wanted to cut services to extend Medicaid to cover 100% of costs instead of 67%, it decided to involve the public in the decision making process, even though ultimately they had little influence on the final outcome.

It carried out a telephone survey of 1001 people who were asked to rate a certain number of health states between 0 (death) and 1 (perfect health). 709 health states were rated in total and the ratings were combined with information from health professionals about treatment cost and efficacy to create “condition-treatment” pairs, put in order of priority. These pairs were substantially reordered by the Oregon health commissioners before the proposal was submitted to the Federal Government. It was rejected because the Government thought that the results of the telephone survey were irrelevant and might contravene the Americans with Disabilities act by underestimating the QOL of people with disabilities. The proposal was resubmitted with treatments evaluated on the basis of three “objective” criteria: probability of death, probability of a complete cure, and cost of avoiding death. It was rejected again for

³⁵⁸The relationship between the MS Society and the ABN is strengthened by the funding provided by the MS Society to research units run by ABN Officers.

³⁵⁹ Medicaid provides poor Americans with free healthcare.

contravening the act by expressing preference for treatments that cured conditions completely as this discriminated against people with chronic conditions and disabilities. Oregon eventually limited its prioritisation process to the probability of preventing death as this would not be covered by the act. If any pairs tied on that basis, the cost of treatment was the tie-breaker. If the pairs still tied, they were ordered alphabetically by diagnosis – a sad conclusion to the Oregon experiment³⁶⁰. The main problems with the experiment were that treating the decision as a unitary one (the “people’s perspective”) ignored differences in preference (for example, elderly people did not want to fund obstetric care), having to contravene the “life saving imperative” in prioritising treatments demoralised participants, and the range of costs to be avoided or benefits sought were not clearly identified. Ultimately, participants were suspicious about the genuineness of the consultation and felt they were being given responsibility without power [Blumstein 1997].

Prioritising waiting lists

“Priority scoring systems” which attempt to equitably allocate positions on hospital waiting lists have been used successfully in Australasia, Canada, and Sweden³⁶¹. The main arguments in favour are that they make the management of waiting lists “transparent” (another audit buzz-word), they lead to patients being treated in order of need, and they make it possible to set minimum thresholds of need for referral onto waiting lists. In the UK scoring systems have been used at hospitals in Salisbury [Lack and Armand Smith 1997], London [Gudex et al 1990], and Carmarthen, sparking debates over what clinical and social criteria should be used to decide the relative priority of patients, and who should decide on the criteria and their relative weight. The systems have also caused “clustering” of conditions, which makes it difficult to prepare balanced theatre list: ten hours of hip replacements are not satisfying for experienced surgeons or educational for trainees.

³⁶⁰The top five ailments were severe/moderate head injury, haematoma (blood clot) or oedema (fluid accumulation) with loss of consciousness; insulin dependent diabetes; peritonitis (inflammation of the lining of the abdominal cavity); acute glomerulonephritis (kidney disease); and pneumothorax (air between lung and chest wall) and haemothorax (blood in chest). The bottom five were mental disorders with no effective treatments; infertility; hepatorenal syndrome (liver failure leading to renal failure); spastic syndrome (voice disorder); and disorders of refraction (affecting cornea and lens) and accommodation (eye muscles).

³⁶¹Studies of cataract surgery in Sweden found that centres using formal scoring systems were more successful at adhering to waiting times than those without [Lundstrom et al 1996] and in Australia the fears about “gaming” by doctors and patients (exaggerating the case for priority to secure treatment earlier) were not realised [Street and Duckett 1996]. However, an evaluation of surgical priority criteria in New Zealand showed wide variation between surgeons’ judgements and the score patients obtained on the scoring system, suggesting that different definitions of priority were being used [Dennett and Parry 1998].

How are QALYs calculated?

The three stages in the process (described below) are obtaining people's preferences for different health states, combining these with QOL scores to create preference-based measures of health, and calculating QALYs using scores from these measures and information about costs.

1. Obtaining preferences

Single scores from QOL measures are combined with "preferences" for different health states (revealingly called "utilities") obtained from samples of "healthy" volunteers and health professionals by asking them to make judgements about QOL in hypothetical situations. The techniques for obtaining preferences can be divided into "comparative methods", where individuals compare the imagined experiences of people with health conditions, and "choice-based methods", where individuals imagine what their QOL would be with a particular condition. Although the latter are considered more reliable as respondents are required to make a sacrifice to return full health³⁶², their complexity often produces bizarre outcomes. For example, participants from a study using the Rosser Scale described "feeling a lack of ambition" as 45% worse than "complete bowel incontinence" [Rosser et al 1992].

The main problem with these techniques is their assumption that individuals with little or no experience of illness or disability can estimate QOL in different conditions, and predict what their reaction to them would be. This was not the case in a study of people with late-onset disabilities, as the majority had never imagined having a limiting condition in the future, even if they had acted as a carer to a family member [Koch 2001]. However, all noted unexpected benefits from being disabled in social, family, spiritual, and even professional areas. Individual evaluations of health states differ according to the person's background and previous experience of illness [Froberg and Kane 1989]. For example, older respondents to the time trade-off technique were less prepared to live 10 years with diminished health [Robinson et al 1997].

People's responses to health valuation questions are artefacts of an artificial research process. The difference between the perspective of a health economist and a lay person is illustrated by the creator of the Rosser scale's observation that subjects who evaluated states of health using their interview procedure "experienced the interview as traumatic and felt that it changed their perception of illness" [Kind et al 1982]. People do not usually make good

³⁶²“Economists are wary of approaches that don't involve people sacrificing one thing they value to get another” [Williams 1999].

judgements when asked to assess the experience of hypothetical illness states [Kahneman and Varey 1991; Nord 2001] and find it hard to imagine the transition from one health state to another after treatment. People tend to prefer low risk interventions that spread the benefits, even if the expected value is lower, and score them more favourably if they are likely to benefit [Richardson and Nord 1997]. Different experimental tasks (for example, gambling life expectancy on a cure, or rating conditions from 0-100) produce different valuations of health states. This is also the case with preference-based measures as they encapsulate the designer's perspective on resource allocation (for example, favouring curative interventions or targeting the worst-off). The following table demonstrates this by using the Health Utilities Index [Furlong et al 2001] and 'person trade-off' scores [Murray 1994] to estimate the benefits of two interventions, the first to cure 100 people with condition A, and the second, to take 30 people with condition B to a functional level corresponding with condition A.

Name of measure	Intervention 1	Intervention 2
Health Utilities Index	400 QALYs	240 QALYs
Person trade-off	80 QALYs	126 QALYs

[Nord 2001]

Another core assumption for health economic analysis is that preference techniques produce equal-interval level scales³⁶³, so we can be sure what different valuations mean (for example, a valuation of 0.5 means that a health state is half as valuable as full health, but twice as valuable as one valued 0.25). However, this was challenged by a recent study, asking people with prostate cancer to use different methods to value prostate cancer-related health states, where none of the methods produced equal-interval level scales [Cook et al 2001]. This suggests that it would be unwise to use health economic measures as a basis for decision-making, a conclusion that surprisingly has not affected the NHS's enthusiasm for the technology.

2. Combining preferences and QOL scores in preference-based measures of health

Although it is possible to combine a single score from a QOL measure (for example, the total score for the SF-36) with preferences elicited by the techniques described above, preference-based measures that combine the two in the same measure are considered to be more accurate³⁶⁴. However, there is considerable variation in preference scores between the

³⁶³Where data is ordered and the distances between values on one part are equal to those on another part so it can be used like a thermometer [Jenkinson and McGee 1998].

³⁶⁴This may change with the move to shorter QOL measures, for example, creating a single score for the SF-36 and reducing its items to 12 (the SF-12).

measures³⁶⁵, suggesting that what you are trying to prove is a big factor in your choice of measure (as with QOL measures). This was surreally demonstrated by a researcher with physical disabilities who rated himself using three different measures:

In the Health Utilities Index (Mark I) the author scored 0.53, which means he is halfway between being healthy and being dead. In the Health Utilities Index (Mark II) he scored 0.13 for the multi-attribute value function and 0.63 for the multi-attribute utility function. The 0.13 score indicates that his quality of life is low, but the 0.63 score that he is not as bad off as one might suppose. On the Quality of Wellbeing Scale he scored 0.48, again not a very healthy result. He lost most of the points on the measures because he uses a wheelchair reflecting the 'experts' stereotypes of wheelchair users

[Pfeiffer 1998]

I provide further detail on the five established preference based measures³⁶⁶ in the appendix.

3. Calculating QALYs from preference-based measures and data on costs

In this section I use a hypothetical example from Spiegelhalter of four programmes bidding for funding [1992] to show how QALYs might be used in health resource allocation and highlight the role of "discount rates"³⁶⁷ in shaping the data in particular directions.

1. To provide 100 middle-aged women with short-term treatment to relieve anxiety or depression ($q=0.75$ [assigned a preference score of 0.75]) estimated to remove symptoms for on average seven months.
2. To try out a new neurosurgical treatment on 100 middle aged patients with the same symptoms in (1). If successful, it will relieve symptoms for life, but it carries a 24% risk of death during operation.
3. To provide 10 patients with advanced cancer with treatment that will give them two extra years of reasonable quality life ($q=0.75$).
4. To carry out one heart transplant on a 5 year old child, who without the operation is expected to live two years with poor quality ($q=0.50$); if the child survives the post operative period (there is 20% initial mortality) he or she will return to healthy life [ibid]

Assuming a 5% discount rate for future years, all four options provide about 15 QALYs, but two different aspects of equity are involved. The first is that while in 1 and 2 the patients are similar to start with, 1 guarantees a small benefit for all while 2 envisages large variation among patients (and also trades off mortality and QOL). The second concerns the numbers

³⁶⁵ A comparison of the preference scores for moderate, considerable, and severe levels of disability found ranges of 0.70-0.995, 0.40-0.94, and 0.10-0.85 respectively [Nord 2001].

³⁶⁶ The North American Quality of Wellbeing scale [Kaplan and Anderson 1987], Rosser Disability/distress scale [Rosser and Kind 1978], Health Utilities Index 1 to 3 [Furlong et al 2001] and the European 15D [Sintonen 2001] and EQ-5D or EUROQOL [Kind 1996].

³⁶⁷ Discount rates assume that years in the distant future are worth less than years in the immediate future. They are usually set at inflation to reflect depreciation of capital, but this can be used to justify postponing investment.

and initial health of patients in each option: if resources should be concentrated on the people who can benefit most (a Rawlsian rather than a Utilitarian perspective) then option 4 should be funded.

Changing the discount rate (an apparently “technical” decision) changes the situation entirely, as the table below shows:

	0% discount rate	5% discount rate	10% discount rate
Option 1 (in QALYs gained)	15	15	15
Option 2 (in QALYs gained)	30	15	10
Option 3 (in QALYs gained)	15	15	15
Option 4 (in QALYs gained)	57	15	8
Implications of discount rates	Favours interventions with long-term consequences	Standard rate	Favours immediate benefit; averse to risk of early death

[Spiegelhalter et al 1992]

Spiegelhalter wonders if those who rated anxiety or depression at 0.75 realised this could be used to justify the high operative mortality in option 2, and observes, “If the means of assessing values from individuals does not reflect the use to which they will be put [... it] could give rise to dubious conclusions” [ibid].

Conclusion

There are two main reasons why QALYs are not a sound basis for health economic analyses. Firstly, they place a low value on health states with a high degree of discomfort and distress, and do not acknowledge that people not only cope with these states (“It’s funny how quickly it becomes part of you”, Philip chapter 3), but place greater value on them as time passes (“In a strange way, I am now quite proud to have dystonia”, Geoff chapter 2). They are also underpinned by a utilitarian philosophy, which causes them to be weighted against the elderly³⁶⁸ [Grimley Evans 1992] and people with disabilities as “full” recovery from a life-threatening condition will always be worth more QALYs for the young and healthy³⁶⁹. Secondly, the poor quality of data available for most interventions makes it difficult to calculate QALYs. Accurate cost estimates are hard to obtain, especially for private costs like family care, and life expectancy has to be estimated from a very small group for each condition-treatment combination. However, this complexity and fragility is disguised by the way the analyses are presented, for example, as summarised tables that suggest quick and easy solutions and don’t acknowledge that cost per QALY figures are only “best estimates of averages” [Petrou and Renton 1993]

³⁶⁸Proponents of the “fair innings” approach [e.g. Williams 1997] argue that this bias is insufficient as young people should *always* be treated ahead of old, even where the old person would benefit more.

³⁶⁹What Nord calls “utilitarian ageism” [Nord et al 1996].

Health economic analysis in general has limited explanatory power as it is rooted in individual consumer theory³⁷⁰ and looks at activities solely in terms of health benefit. This makes it difficult to explain why a person continues to smoke since they are irrationally trading a “current negative” (reduced health and life expectancy) for a “future positive” at zero or negative cost. While economists emphasise that “cost” should not be interpreted as “money required in exchange for a particular commodity” (the common use of the word), but as “opportunities foregone by employing scarce resources” (or “opportunity cost”), they often find themselves using money to make comparisons as it is a familiar, if skeletal, measure of value. But basing valuations on “the total amount that individuals are willing to pay for health improvement” is problematic because it assumes that they are the rational and well-informed “ideal consumer” of economic theory, and is obviously affected by their income level [Drummond 1986].

The assumptions underlying QOL measurement and health economic analysis of aggregate representation, correspondence to reality, stability of preferences, and neutrality of quantification do not stand up to further investigation. For example, “correspondence to reality” assumes that the categories used by the analyst correspond with everyday evaluations. In fact, they are abstract, artificial, and bear little resemblance to the judgements people make in real situations where the choice is not between “carefully defined categories” but “ill-defined courses of action [...] which are complex, diffuse, and subject to change” [Mulkay et al 1989]. The assumption of “stability of preferences” ignores that fact that the process of measurement changes respondents’ evaluations. Consequently, Mulkay recommends “we treat participants’ expectations as variable social phenomena and their evaluative responses, not as expressions of stable underlying preferences, but as reactions to socially defined situations [1989:105]. While the analyst assumes that preference values have a real meaning to the respondent and express quantifications that are already implicit in the way they think about health states, the smooth distribution of preferences is more likely to be “the respondent’s recognition of a quantification already implicit in the analyst’s prearranged categories”. In fact, “[QALYs are] the interpretative outcome of a special, and indeed rather peculiar, form of social interaction between economists and ordinary people” [ibid:106].

Although QALYs are presented as “an accurate reflection of [ordinary people’s] preference”, they are only able to express this through a measurement procedure “constructed in terms of

³⁷⁰Critiqued by economic anthropologists like Polanyi [1958].

social scientists' preconceptions" [ibid:106]. The same criticism could be made of QOL measures that claim to represent "the patient's voice" but actually "mute" it [Ardener 1975] by only including utterances that fit with the developers' preconceptions and goals, a situation I explore in the next chapter.

Chapter 8: An ethnography of QOL measurement

In this chapter, I describe how measures of QOL are created, using ethnography from participant observation during the creation of a disease-specific measure for multiple sclerosis (the 29-item Multiple Sclerosis Impact Scale or MSIS-29). This supports my claim that QOL measures do not speak in the “voice of the patient” as it shows how the items identified by people living with multiple sclerosis are systematically removed from the measure to enhance its “scientific” properties. I then examine the use of QOL measures in survey research, drawing on my experience coordinating a European survey of the QOL of people living with dystonia [Camfield et al 2000, 2002; Ben-Shlomo et al 2002]).

Designing measures of QOL: the MSIS-29

When measures are created, as on other occasions where Science is practiced, the rules set out in handbooks like Streiner and Norman [1989] are used flexibly, mainly as resources in disputes between different actors. This was even true of the MSIS-29 project whose explicit aim was to create a “scientifically sound patient-based measure” which would be a “gold standard” for future measures and “combine patient perspective with rigorous psychometric methods” [Hobart et al 2001]. The singular (“patient perspective”) is significant since the aim was to take the different perspectives of people living with multiple sclerosis and aggregate them into one person who, by representing no one (no item should be recognisable to its contributor) could represent everyone.

My field notes from the project contest the measure’s claim to represent the “patient perspective”, but what may be more interesting is that this is the new justification for and way of judging measures of QOL. This is reminiscent of the primatologists studied by Haraway who claim that their enterprise is not about “power and control” but “translates the active voice of their subjects” [1989:8]. However, while there are people who are patients at different times and contexts, “the patient” is as artificial a construct as “the third world woman” [Mohanty et al 1991] and created for the same reason, as an object of intervention. Kane exposes the futility of this sort of reification in her description of working on an AIDS prevention project which not only assumed a culture of intravenous drug users but “a culture of the non-drug injecting, non-HIV-positive spouses or sex partners of drug-injecting, HIV-infected persons” [Kane and Mason 1992]. While people with limiting conditions are “natives who can speak for themselves”³⁷¹, can they be heard? (c.f. [Armstrong 1984; Spivak 1996,

³⁷¹A gay slogan born of frustration with the anthropological response to AIDS/HIV [Frankenberg 1995].

Crossley and Crossley 2001]). Or do current discursive conditions ensure that they remain a “muted group”, unless they are prepared to speak either as a consumer or in the language of QOL (a process Bourdieu calls symbolic violence [1991]). Perhaps we should be suspicious of the motivations of researchers and advocates who want to “give patients a voice” as “no activist wants to keep the subaltern in the space of difference [...] You don’t give the bloody subaltern voice, you work against subalternity” [Spivak 1996].

I worked for six months as temporary coordinator on this project so I could observe how the measure was created and “validated” against existing measures, and the organiser³⁷² could participate in an unsuccessful funding application for a dystonia-specific measure. This period covered the reduction of the scale from 129 to 29 items after the first and second field tests, but I have also used “grey literature” and informal interviews to follow the measure from its inception. The project, supported by the MS Society, aimed to produce a self-report measure to evaluate expensive new treatments like Beta interferon “using outcomes that are important to patients” [Hobart et al 2001].

The first phase of the project involved 30 semi-structured interviews with a representative sample of people living with multiple sclerosis. The interviews were transcribed and the coordinator and another investigator separately extracted statements about the impact of multiple sclerosis. Although the two sets of statements were fairly similar, the project team described the coordinator’s set as “over-inclusive”. They attributed this to her inexperience with outcome measures, implying that a more experienced person would have automatically excluded statements that would not fit in a measure³⁷³. The statements were reviewed to exclude areas that the team did not think related to QOL (for example, reactions to diagnosis), even where they were key parts of the person’s narrative. They were then organised into symptoms, activities of daily living, emotional impact of multiple sclerosis, doctor-related statements, drug side-effects, financial strain, required planning, public response, relapses, impact on and responses of significant others, and wheelchair-related statements. Items related to “coping with multiple sclerosis” and the “positive impact of multiple sclerosis” were excluded as “irrelevant”, although they were obviously relevant to the people who generated them. This may be an example of the way measures of disability “create” low QOL by focusing on the negative [Ziebland et al 1993].

³⁷²The team members were a clinical neurologist and “psychometrician” (organiser), another neurologist, a social scientist experienced in measure design, a psychologist, a statistician, and a QOL expert.

³⁷³Subsequently, I read a set of interviews for a different measure where the interviewer kept the focus on symptoms and treatments, probing these areas aggressively and cutting the interviewee short when they attempted to change the topic or give “irrelevant” detail.

The initial questionnaire was divided into two sections on “subjective distress” (mixing physical symptoms and “psychosocial” problems), and limitations to activities of daily living. The items were made more specific; for example, splitting “fatigue” into “physical” and “mental” (a slightly superfluous division since mental fatigue is experienced in the body). 38 new items were added, some suggested by focus groups of health professionals. Other new items came from a review of existing measures, making the validation process seem tautologous since the new measure would be validated against measures that had served as its source and template (as was the case for diagnostic measures for Multiple Personality Disorder [Hacking 1995]).

The second draft was tested in two groups of people living with multiple sclerosis³⁷⁴ and four more items were added (body image, tinnitus, limitations in walking, and feelings of loss related to your multiple sclerosis), none of which made it to the final measure. The team were concerned that the large number of items might tire respondents and distort the data, and that the MS Society database (the source of addresses for the field test) contained an unknown proportion of people without multiple sclerosis³⁷⁵. A quarter of the participants received two questionnaires: one to be completed immediately, the other 10 days later to check that the responses to the measure were reproducible. This was not wholly successful, as many respondents didn't complete the second questionnaire at all. Others returned it with the first questionnaire, or returned it late, or returned the first questionnaire late because they had used that to “check their answers”!

The next phase used psychometric methods to reduce the questionnaire to 35-40 items (considered to be the optimum size), taking it even further from the original interviews. When two items correlated highly with each other (>0.7), the one with worse psychometric properties would be eliminated³⁷⁶, unless it was thought to be “clinically important”. The three items on sex and body image were cut because of missing data, even though excluding these aspects as difficult to measure increases the artificial and disembodied appearance of measures of QOL. This reduced the items to 42 (there is a table of correlations between the

³⁷⁴Half of who had participated in the original interviews; it would have been fascinating to have observed their reaction to this alchemical transformation of their narratives.

³⁷⁵This is also true of the Dystonia Society where even some of the branch organisers have not been diagnosed with dystonia. We conducted a pilot study to estimate how many members needed to be mailed to get a sufficient sample of people living with MS, but we still had to trust that people without the condition wouldn't bother to fill in the form since we had no way of excluding their responses.

³⁷⁶These were items that were most or least frequently ticked (indicating that they were either very common or rare), had high floor/ceiling effects (indicating that they weren't sensitive measures), or missing data ($>5\%$).

original items in the appendix) and these were then “factor-analysed” to produce models showing how many factors underlay the items. The factor analysis produced six possible models containing between two and seven factors, three of which were equally plausible. The choice of the two-factor model (physical and psychological) appeared to be made because it felt most “natural” and mirrored other successful measures, even though it explained the smallest amount of variance in scores (only 47%). This shows how the culture of QOL measures makes them actors in their own right (c.f. Callon and the electric fridge) as they are saturated with collective memories and expectations that direct future interactions. It also poses the question “who is using who?”

The final phase of item reduction involved deleting another 10 items from the 39-item³⁷⁷ scale to make it more “economical”. I reconstruct the motivation for the deletions below. Complex items were obvious candidates for deletion, as were ones that correlated with more than one factor (despite the pervasive influence of Cartesian mind-body dualism, this would be true of most statements that people make about their health). An item on long-term work plans was removed as it correlated with two items on use of transport. To me this represented a waste of data as under a social model of disablement the strong correlation between the ability to continue working and the availability of accessible transport would merit further research. After extensive debate an item on the effect on partner or family was removed, giving the measure an exclusively individual focus. Two symptoms-related items were also removed, I suspect because they are common symptoms that are unlikely to respond to treatment and so would not be useful when evaluating treatments.

Deleted items from the 39-item two-factor solution

Item	Possible reason for cut
1.30 MS has limited ability to walk indoors	Similar to item 5 in the final measure “difficulties moving about indoors”
1.84 Bothered by difficulties planning things on an everyday basis	Loaded on physical and psychological factors
1.94 Bothered by feeling you had missed out on things through your MS	Loaded on physical and psychological factors
1.60 Bothered by the effect of MS on your spouse/partner or family	Insufficiently focused on the individual?
1.4 Bothered by hot or cold temperatures making your MS worse	Common symptom of MS that would be unlikely to respond to treatment?
1.79 Bothered by having to change long term work plans	Correlated with 1.80 Bothered by the effect of MS on your driving, and 1.81 Bothered by problems using transport (item 17, MSIS-29).
1.51 Bothered by feeling frustrated	Loaded on physical and psychological factors
1.41 Bothered by getting tired when you do things	Similar to item 23 in MSIS-29 “feeling mentally fatigued”
1.2 Bothered by pins and needles,	Common symptom of MS that would be

³⁷⁷Three were deleted because they didn’t belong strongly to either factor (“bothered by numbness or lack of sensation”, “bothered by problems in vision when reading”, “bothered by problems with constipation”).

<i>tingling or burning sensations</i>	unlikely to respond to treatment?
1.5 <i>Bothered by pain</i>	Explained the lowest amount of variance, possibly because it was in the wrong factor?

Italics = part of “psychological well-being” factor

The final 29-item measure (20 physical, 9 psychological) is in the appendix.

In the next section, I look at how the final items correlated with the deleted ones to gain an insight into the reduction process. I also examine why, of the eleven themes drawn from interviews with people with multiple sclerosis, only symptoms, activities of daily living, “emotional impact of multiple sclerosis”, and “required planning” were included³⁷⁸, despite the importance of the others to people living with multiple sclerosis (and anyone who wants to understand life with multiple sclerosis). Finally, I discuss other representations of life with multiple sclerosis that could have been created from the same data by analysing six of the original interviews.

When I looked more closely at the final scale, I was interested to see that many of the items correlated, for example, 2 and 3 (gripping and carrying), and 11 and 21 (body not doing what you want and feeling unwell), even though this seemed to contravene the rules of the psychometric methodology. The item on “feeling unwell” was particularly interesting as its correlations with the deleted items “having to limit what you do because of tiredness” and “your body not doing what you want it to do” suggested distinct components of “unwellness”: alienation, constraint, tiredness, and frustration, any of which could be affirmed when someone ticked that item. Similarly, although problems maintaining attention during tasks, organising things, thinking clearly, and learning new ways of doing things are all aspects of concentration³⁷⁹ (item 27), I felt these were qualitatively different experiences that could have different impacts, depending on your lifestyle. These correlations underline the fact that people’s experiences are not neatly compartmentalised in preparation for their measurement.

Most of the correlations made sense on some level³⁸⁰ except the one between gripping/carrying and swallowing food. The mystery was solved when I looked at the original

³⁷⁸Public response, financial strain, drug side-effects, doctor-related statements, relapses, impact on and responses of significant others (mentioned indirectly in item 12 “having to depend on others to do things for you”), and wheelchair-related statements were excluded.

³⁷⁹Problems with vision also correlated with concentration but I think this was an example of an external factor affecting concentration rather than a part of concentration; however, the decision had already been made to exclude the item on vision as it didn’t belong clearly to either factor.

³⁸⁰I presume tinnitus, which correlated with ability to do physically demanding tasks, is a “third variable” as it occurs when someone has severe MS.

scale where the item on swallowing is preceded by ones about fine hand movements, suggesting that people filling the measure in quickly (or tiredly) had ticked it by accident. I was intrigued by the link between employment goals and problems using transport, and also between wheelchair use and uncertainty about what the future holds³⁸¹. I had no difficulty understanding the correlation between wheelchair use and reduced spontaneity. The most interesting aspect for me was that many of the deleted items were significant, but this criterion wasn't sufficient. They also needed to be good indices to the area of life beneath the sightline of the measure, enabling the measure to see more while simultaneously seeing less.

Correlations between the MSIS-29³⁸² and deleted items

1.	Do physically demanding tasks?	Tinnitus (ringing in the ear) Limited your ability to run Limited your ability to sit
2.	Grip things tightly (e.g. turning on taps)?	Made it difficult for you to swallow some foods Limited your ability to use both hands doing things Made it difficult for you to hold things Made it difficult for you to carry things
3.	Carry things?	Difficulties achieving as much as you would like at work or during your regular daily activities Made it difficult for you to swallow some foods Made it difficult for you to grip things tightly
4.	Problems with your balance?	Difficulties moving about outdoors
5.	Difficulties moving about indoors?	Difficulties moving about outdoors Limited your ability to walk
6.	Being clumsy?	No correlations
7.	Stiffness?	No correlations
8.	Heavy arms and/or legs?	Weakness anywhere in your body
9.	Tremor of your arms or legs?	No correlations
10.	Spasms in your limbs?	No correlations
11.	Your body not doing what you want it to do?	Having to limit what you do because of tiredness Feeling unwell
12.	Having to depend on others to do things for you?	No correlations
13.	Limitations in your social and leisure activities at home	No correlations
14.	Being stuck at home more than you would like to be?	Difficulties with self-care activities
15.	Difficulties using your hands in everyday tasks?	No correlations
16.	Having to cut down the amount of time you spent on work or other daily activities?	No correlations
17.	Problems using transport?	Having to change your goals concerning employment
18.	Taking longer to do things?	No correlations
19.	Difficulty doing things spontaneously?	Having to use a wheelchair Uncertainty about what the future holds for you
20.	Needing to go to the toilet urgently?	No correlations
21.	Feeling unwell?	Having to limit what you do because of tiredness Your body not doing what you want it to do
22.	Problems sleeping?	
23.	Feeling mentally fatigued?	

³⁸¹This supports other studies [e.g. Duval 1984] where the wheelchair is a symbol of dependence and despair.

³⁸²The rubric to the items was either "in the past two weeks, how much have you been bothered by..." or (for items 1-3) "[...], has your MS limited your ability to..." and there were five possible responses.

24.	<i>Worries related to your MS?</i>	No correlations
25.	<i>Feeling anxious or tense?</i>	
26.	<i>Feeling irritable, impatient, or short tempered?</i>	
27.	<i>Problems concentrating?</i>	Problems with your vision when reading Problems maintaining your attention during tasks Difficulties organizing things Difficulties thinking clearly Difficulties learning new ways of doing things
28.	<i>Lack of confidence?</i>	No correlations
29.	<i>Feeling depressed?</i>	

Italics = part of "psychological well-being" factor

The final stage was the validation of the MSIS-29 against six commonly used measures (two multiple sclerosis-specific), which were sent alongside it in batches of three. This is standard practice, although I wonder how plowing through four similar measures, one after the other, affects responses. On the basis of these somewhat tautologous comparisons the MSIS-29 was judged valid (for example, the physical domain of the scale correlated with the main clinical measure). The measure was not affected by the age of the respondent or how long they had had multiple sclerosis (which seems a little suspicious), but it wasn't possible to calculate the effect of class as there was so much missing demographic data³⁸³.

Although I believe that within the context of QOL measurement the MSIS-29 is a relatively good measure (and probably superior to many of its contemporaries), it is interesting to return to the original interviews and note how few of the themes made it to the final measure. I summarise how the themes were covered in the table below.

Theme	How covered
Developing coping strategies, adapting, not dwelling on the past	Excluded as "irrelevant"
Effect on sex, e.g. erectile dysfunction	Excluded as too much missing data
Frustration at inability to do basic tasks, unreliability, slowness, alienation from body	Included - items 11, 15, 18
Confinement, loss of independence (e.g. ability to drive), lack of spontaneity	Included – items 14, 17, 19
Anger, resentment, lack of sympathy towards others' physical problems	Not adequately covered – item 26 mentions "feeling irritable, impatient or short tempered"
Public reactions ("I fell over on the platform and it was about 4 o'clock in the afternoon and everybody was looking at me like 'you must be drunk' and I sort of resented that I was just on my way home from work or something and there was nothing I could do"), embarrassment – particularly around walking and toilet use, secrecy ("I'm afraid that my friends are going to have the same [negative] reaction that I did"), guilt and shame	Not included
Refocusing on self as a useful effect of diagnosis, increased assertiveness ("if somebody was really rude to me I would just take it. Now I really stand up for myself"), becoming a "nicer	Excluded as "irrelevant"

³⁸³ At least five female respondents had refused to fill the employment section in as the standard classification from the Office of Population and Census classifies women on their partner's employment. Another had filled in her female partner's occupation and suggested we calculate it on this!

person”	
Work as central to life and self-definition (“it’s stopped me doing the work that I love”)	Not adequately covered – item 16 mentions “having to cut down the amount of time you spend on work or other daily activities”
Changed relation to quotidian time, and to past and future (“it’s preventing me from getting involved in a very serious relationship [...] I don’t want to be a burden to somebody ten years from now”)	Not included
Role reversal in primary relationships (“it does feel a bit strange that she is doing all the heavy lifting and not me [...] you have to sit there like a lemon and do nothing”), discomfort with dependency, support from your family or pressure to deny your condition, importance of self-control and resisting others’ attempts to control you	Not adequately covered – item 12 mentions “having to depend on others to do things for you”
Uncertainty, problems planning ahead, others’ perception of illness and health as dichotomous (“either you have to be hobbling along and they realize you’re ill or you have to be completely well”)	Not included

During this section I have documented the process where, for many sound and scientific reasons, the patient’s voice seems to get smaller as the measure develops. I suspect that if people living with multiple sclerosis had been as influential in the development process as the other stakeholders³⁸⁴, the measure would not look like a clinical measure (even down to its individual focus), and the positive aspects of living with multiple sclerosis, which are less visible to an outsider, would not have been dismissed as irrelevant. The final measure follows the conventions of audit by privileging experiences that are individual, pre-packaged and quantifiable, and neglecting those that are diffuse or ambiguous. In the next section I look at one of the main uses for QOL measures, drawing on fieldwork from a European survey of the QOL of people living with dystonia.

Using QOL measures in survey research: The dystonia QOL questionnaire

The dystonia QOL questionnaire arose from a vague desire to “do something for people living with dystonia” (whose experiences were not acknowledged in popular and medical discourses) using the database from the epidemiological study, and a more pragmatic one of holding the participating centres together while a strategy for future collaboration was developed. The European Dystonia Federation (who had part-funded the epidemiological study³⁸⁵ to generate figures for lobbying) wanted to create a team of researchers equal in eminence to the group who worked with the Dystonia Medical Research Foundation in the US to bolster their authority and create a more equal relationship with the Foundation.

³⁸⁴The director of the MS Society (an able-bodied, middle-aged, male “charity professional”) attended few project meetings so could not balance “expert opinion” with the equally reified “patient perspective”.

³⁸⁵The remainder came from two British pharmaceuticals who market rival brands of Botulinum toxin.

This was the first postal questionnaire my collaborators and I had drafted so our first attempt looked like a written version of a semi-structured interview. This was rejected because of the problem of translating responses into English and coding them for statistical analysis. The next draft was produced with the help of a psychologist (known for disproving theories about the psychological causation of dystonia) and a neurologist turned “psychometrician”. It contained a brief biographical section, and a range of QOL measures covering depression, anxiety, social support, leisure activities, self-esteem, stigma, acceptance of illness, and general QOL (SF-36). Although these were either the most commonly used or the only measures of each concept, they had a number of problems. For example: many of the physical symptoms of anxiety in the Beck Anxiety Index overlapped with those of dystonia [Beck 1981]; the choice of activities like hunting and fishing suggested that the leisure activities scale was locale (if not class) specific [Kelly et al 1987]; and the ambiguous wording of the acceptance of illness measure [Felton and Revenson 1984] meant that we had to exclude it from the final analysis as we had no idea what the person who filled it in had intended. The only measure we could find for stigma was originally designed for people with colostomies after bowel cancer [Macdonald and Anderson 1984], an experience I now suspect has little in common with dystonia. This suggests that the designers envisaged a continuum of stigma where the differences between ratings are ones of quantity rather than quality.

After discussing the questionnaire with people living with dystonia, staff from the Dystonia Society, and other neurologists, we piloted it with members of the Society, receiving 80 completed questionnaires. The pilot was successful in the sense that there was little missing data and the feedback in the “free-text” section was generally positive. But my interviews with six of the respondents gave me a completely different perspective on the value of survey research. Basically, once a questionnaire leaves the research office anything can happen to it. Even if you have constructed it to “configure” the ideal user [Woolgar 1991], it can be “destabilised” by their not behaving in the expected manner or engaging in “anti-programmes” [Latour 1992] like using a proxy respondent, missing out questions, answering “sarcastically”, or responding on the basis of age or other conditions³⁸⁶.

Before we mailed out the questionnaire researchers from each centre³⁸⁷ met in London to discuss its content and the quality of the translation. Translating the measures brought some of the problems with QOL measurement into sharp focus, for example, the implicit

³⁸⁶Destabilisation has been explored by sociologists of technology who have studied designers’ attempts to restrict the way their products are used (for example, Prout’s study of the metered dose inhaler [1996]).

³⁸⁷London, Innsbruck, Turku, Bordeaux, Barcelona, Rome, and Munich.

assumption that a measure of QOL is as culturally neutral and reproducible as a thermometer and that northern European and American conceptions of health are grounded in human biology and represent the norm from which other societies deviate. Hunt observes ironically that “the ethnocentricity of assuming that a measure developed in, say, the USA, or England, will be applicable (after adaptation) in pretty much any country or language in the world [...] is highlighted if one imagines the chances of a health questionnaire developed in Bali, Nigeria, or Hong Kong, being deemed suitable for use in Newcastle, Newark, or Nice” [1999]. For translation to be possible there needs to be a similar concept of health in both cultures, used in the same way, with the same relationship to other values, and a comparable system of health care and medical education, an assumption that doesn’t even seem plausible in Europe, let alone internationally [Leplege and Verdier 1995; Anderson 1996].

Currently, there are two styles of translation: “source oriented” (produces a measure that compares well with the original but contains items that are irrelevant in the new culture), and “target oriented” (aims for conceptual rather than semantic equivalence, often producing a measure with a different structure to the original). We adopted the first approach, which is preferred by QOL researchers because the second produces a measure that is not comparable in the formal sense. However, if the new measure is meaningless to the respondents and does not measure the same concepts as the original, the results cannot be compared anyway. This point was made by a participant at a workshop I attended on “cross-cultural issues in instrument development” but was dismissed by the organiser who “didn’t want to get into that sort of philosophical thing”. While involving the author of the original measure is supposed to ensure that the same concepts are conveyed in translation, this assumes that the measure is derived from a conceptual model of QOL, something I have suggested is rarely the case.

Although translation issues are theoretically less acute in Europe [Aaronson et al 1992], problems have arisen translating items related to psychological and emotional states, social function and daily activities. For example, in the US “social activities” (items 6 and 10 of the SF-36) means different activities with different people, while in Russia it means, “to participate in political meetings or act like a trade union leader” [International Quality of Life Assessment, unpublished report]. Items that are translatable but “culture-linked” (for example, many of the items in the Leisure Activities scale), or do not have an equivalent in

the target language are usually excluded³⁸⁸, which can present a problem where there are large differences between cultures³⁸⁹ (the existence of internally homogenous “cultures” is assumed). We asked the lead researcher from each centre to “back-translate” the new measures for comprehensibility and were pleased with the results of this, although arguably we had only demonstrated that it was comprehensible to multi-lingual, university-educated health professionals, many of whom had worked with the original measures.

On the same occasion we mentioned our plan to produce a dystonia-specific QOL measure, only to discover that the Austrian centre was already producing a measure for focal dystonias affecting the eyes and neck (the 24 item Cranio-cervical Dystonia Questionnaire [Mueller 2000]). I was unsure about the utility of this combination since cervical dystonia, which can be painful and exhausting, is very different from blepharospasm. Although blepharospasm is less painful, it is potentially more disabling (if people’s eyes close unexpectedly or “lock” closed) and affects people who are at least 10 years older. It might, therefore, be difficult to represent both experiences in a single measure, particularly one with only 24 items.

When the first questionnaires came back we realised that many of the questions designed to establish the social class of the respondent (for example, by educational level) were insufficiently detailed. We sent out a supplementary sheet asking about vocational qualifications, father’s job, and whether the respondent’s first job was manual or non-manual. However, we were not able to use it in the analysis as only half of the participating centres returned them. We did have complete data on whether people had continued education after 16 or obtained a degree, but although we found significant differences between their QOL scores these results were excluded from the papers after the referees advised us that they were “not interesting to neurologists”.

The pace of the project was often frustratingly slow as I could only spend one day per week on it, and much of my work (for example, classifying the different forms of dystonia³⁹⁰) required endorsement from the consultant neurologist who was responsible for the epidemiological study. My collaborator was also the grant holder for five other research

³⁸⁸This occurred with the QUALIOST measure and meant that the most important item for French groups (to find it difficult to manage but have to continue anyway) was excluded, an example of “the common compromise between meaningful content and common structure of the tool” [Leplege and Marquis 1999].

³⁸⁹For example, the majority of functional items in French blindness scales were inapplicable to Francophone Mali (e.g. Can you drive a car? Can you see street lamps?) [Leplege et al 1999].

³⁹⁰This did not require medical training since it was mainly about working out what the respondent wanted to convey (e.g. whether a mild movement in the eye was blepharospasm or a nervous tick; whether they really had movement everywhere in their body or just wanted to emphasise how ill they felt).

projects employing four staff, did undergraduate and postgraduate teaching, had NHS and private patients in two different hospitals, and was the Society's medical adviser so could spare me little time. I usually worked alone, entering the data into SPSS, removing errors, and carrying out routine analyses to compare the mean scores for different instruments and establish whether the differences were significant. I presented the initial results in the Society and European Dystonia Federation newsletters, at the World Dystonia Leadership meeting, and at the Movement Disorders conference in Barcelona, where there were a small but growing number of QOL studies³⁹¹. The statistics were also used in press releases for the 2001 Dystonia Awareness week to support the *True Impact of Dystonia* booklet [TDS 2001].

Despite the methodological problems described earlier, which reduced my confidence in the results, the survey produced some interesting and unexpected findings that provoked as many questions as they answered. Although we found significant differences between QOL scores from people living with dystonia, the general population, and people living with other neurological illnesses (drawn from other studies using the SF-36), we found few between the different types of focal dystonia, once the results were adjusted to acknowledge different ages of onset. There are a number of possible explanations, which involve hypotheses about where the “real” experience of dystonia resides (the body, the person, or the social context) and how it should be measured (for example, brain scans, personality tests or studies exploring the prejudice of the population towards people living with dystonia). Is dystonia not (as is generally supposed) an arbitrary categorisation for conditions caused by the basal ganglia, but a coherent experience that is qualitatively different from others? Or is it the similar problems people have communicating their experience and getting it acknowledged and taken seriously by medical gatekeepers that create the experience of dystonia? Is it in the experience of muscle spasms, wherever they are located (so having spasms in your hand when you sign a cheque would be no different to your eyes locking shut while crossing a busy road)? Is it about individual reactions? (“fighting it” or “giving in”). Or is it just that existing measures of QOL are not sensitive to the experiences of people living with dystonia?

The explanation you choose may depend on your position. For example, the Chair of the European Dystonia Federation believes your experience of dystonia depends on your “moral fibre”, while my collaborators prefer the insensitivity of general measures since they are currently designing a dystonia-specific measure. My experience of working with and listening to people living with dystonia suggest that while the demands it places on your body

³⁹¹Although we placed papers from the study in neurological journals, we were rejected from the *British Medical Journal* (the main general medicine journal in the UK) as “not of general interest”.

are an important part of having dystonia (as is your ability to adjust to them), the frustration caused trying to communicate your experience to others (“at times I thought I was going mad and other people think you are too”), the isolation arising from their refusal to acknowledge it (“neither my husband nor my family could understand why I could not open my eyes: ‘such a simple thing to do!’”), and the discrimination from their inability to understand it (“the lack of awareness and ignorance from my employers are devastating and exasperating”) are the most important parts of the experience.

I found two aspects of the survey particularly interesting: firstly, the process supported Latour’s characterisation of research as increasing rather than decreasing the complexities of life and adding “new ingredients to the collective process” [1998]. Secondly, it confirmed my suspicion that QOL measures did not offer more information than clinical or psychological tests since the elements that make the experience of one condition different from another cannot always be quantified or represented in an individually-focused measure.

Conclusion

These examples illustrate some fundamental problems with QOL measurement. Firstly, it supposes that every individual has a certain amount of QOL that can be measured and compared by separating it into conceptual domains and devising indicators to represent them. It is assumed that these indicators measure what is important and relevant to people living with a chronic illness (rather than to doctors or pharmaceuticals) and that studies using these measures are really listening to the patient. Secondly, it assumes that what people say about their level of function corresponds to actual behaviour. For example, while someone may be physically capable of “walking 1 km” [Ware and Sherbourne 1992], there may be other, non-individual factors that prevent them from doing so, which is why scores from physiotherapy assessments cannot predict performance outside that environment. And finally it maintains that QOL measurement is Scientific, even when adjustments represent the developer’s “common sense”. For example, setting higher cut-off scores on the Beck Depression Inventory to diagnose depression in women [Beck et al 1961]. Paradoxically, the further QOL measurement moves from Science, the more scientific its vocabulary becomes.

Chapter 9: Realising the potential of QOL: The World Health Organisation

In chapters 7 and 8 I examined how QOL measures are developed and used, especially in health economic analyses. I argued that the “feel-good” language of QOL obscures the way “facts” created by QOL measures about the lives of people with limiting conditions are used to direct resource allocation. I reinforce the point in this chapter by an exploration of the WHO’s use of QOL which shows how the discourse can move from the relatively benign goal of representing a broader range of life experiences, to classifying and managing those experiences, and finally, to valuing and controlling the lives of the experiencers in the interests of projective risk management. I examine the WHO’s use of QOL through three related projects: firstly, the development of a multilingual, multidimensional QOL measure to be used internationally with “healthy” and sick populations (the WHOQOL-100 [WHOQOL 1995] and WHOQOL-BREF [1996]). Secondly, the creation and revision of a universal classification of health (the International Classification of Impairment, Disease and Handicap); and finally, the Global Burden of Disease Project, which uses health economic analyses to set international priorities for health spending using the Disability Adjusted Life Year.

The WHOQOL-100

Internationally, the WHO has been one of the keenest advocates of QOL, which is consonant with its holistic definition of health as “a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity [...] whose realisation requires the action of many other social and economic sectors”³⁹². In 1991 the WHO formed the WHOQOL group to develop a measure that would assess QOL³⁹³, rather than merely the impact of disease and impairment, perceived health, or functional status, as existing “QOL” measures did (c.f. chapter 7). This measure would combat “the increasingly mechanistic model of medicine” and use QOL assessments to introduce a “humanistic element into healthcare”, supporting the WHO’s “continued promotion of an holistic approach to health and healthcare” [WHO 1996]. QOL was defined as an “individual’s perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”. The definition reflects the

³⁹²First set out in the Alma Ata declaration of 1978

³⁹³Described by Fallowfield [1990] as “the missing measurement in health”.

WHOQOL group's view that it refers to a subjective evaluation embedded in a cultural, social and environmental context.

This is inspiring rhetoric, but does the WHOQOL-100 measure successfully address the problems outlined in chapter 7? The short answer is only at the cost of its ability to provide meaningful measurement: by covering everything it effectively tells us nothing³⁹⁴. For example, many domains cannot distinguish between respondents on the key variables of country of origin or health status. The association between the importance and quality of domains in people's lives is generally low (except in the case of spirituality, one of the few attributes that people can control). Finally, curves plotted with data from different countries showed that responses to the items were concentrated in the centre of the scale. While this could mean that the WHOQOL represents dimensions that are common to all humans, it could also mean that it represents nothing more than the human tendency to circle the middle number in a questionnaire, particularly when you are uncertain what is being asked [Bourdieu 1984]. However, despite its methodological shortcomings the WHOQOL's development process (it was developed simultaneously in 15 countries and includes a domain of country-specific items [Skevington 1999]³⁹⁵) provides much of anthropological interest, which I do not have space to address in this thesis. While it has not yet challenged the ascendancy of the SF-36, the WHOQOL group's development of a brief version of the scale (WHOQOL-BREF, 26 questions) suggests this may be its next ambition.

In the next section I look at the creation and revision of a universal classification of health (the International Classification of Impairment, Disease and Handicap [ICIDH] and its successor the International Classification of Functioning, Disability and Health [ICF]) by the WHO. I investigate what the transition from ICIDH to ICF over the past two decades tells us about attitudes to health and disability, and why the ICF fails to "challenge mainstream ideas on how we understand health and disability" [WHO 2001].

³⁹⁴It has 100 questions, divided between 24 universal and one country-specific section, which cover physical, cognitive/psychological, level of independence, social relations, environmental and spiritual, for example, "how available to you is the information that you need in everyday life?"

³⁹⁵For example, the composition of the focus group that produces the items was not always considered by the national research centres - in Turkey the country-specific domain is "social pressure" which includes an item on the pressure city dwellers experience from rural relatives who expect them to arrange jobs and accommodation [Fidaner et al 1999]. Of course, a focus group of rural Turks might experience these networks as sustaining rather than constraining.

International Classification of Impairment, Disability and Handicap (subtitle: “a manual of classification relating to the consequences of disease”) [WHO 1980]

The ICIDH has been used for QOL research, population surveys, vocational assessment, and as a basis for social policy since 1980³⁹⁶. It represents disablement as a linear and unidirectional path: firstly, from “Disease” to “Impairment” (“any loss or abnormality of psychological, physical, or anatomical structure or function”). Secondly, from Impairment to “Disability” (“any restriction or lack (resulting from an impairment) of ability to perform an activity³⁹⁷ in the manner or within the range considered normal for a human being”). Finally, from Disability to “Handicap” (“a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual”). Handicap occurs when an individual cannot fulfil seven “survival” roles (orientation, physical independence, mobility, occupation, social integration, and economic self-sufficiency, and “other”³⁹⁸), chosen to ensure universal applicability.

Disease → Impairment → Disability → Handicap

The classificatory role and biomedical focus of the ICIDH is obvious from the elaborate codes in the impairment section³⁹⁹, which are more extensive and detailed than those of either disability or handicap [Ingstad and Whyte 1995]. Although it claims to have been influenced by both medical and social models, its representation of disablement follows medical convention. While the text acknowledges the complexity of the relationship between Impairment, Disability and Handicap, the diagram shows them linked by arrows going in one direction. It also implies that the problems of people with disabilities are best solved by person-level, medical interventions rather than social ones. This is why Bickenbach characterises it as “at best [...] a tool for research, administrative and planning uses by medical professionals and physiotherapists who, for their purposes, focus entirely on the individual impairments and treat the environment as unchangeable” [1999].

³⁹⁶In Italy and Belgium, it has been used to determine people’s eligibility for residential care and assistive devices, and in the Netherlands, Germany and Scotland, their ability to work. American insurance companies have used it to make decisions about funding treatment and it was also used in the 1988 UK OPCS survey (leading to the “discovery” of 3 million more people with disabilities since the 1971 survey [Abberley 1992]).

³⁹⁷Impairment tries to be universal by using “basic” activities like “grasping”, but these are more difficult to conceptualise as they are abstractions from the concrete and actual activity of grasping an object.

³⁹⁸These survival roles are drawn from Maslow’s five-level “hierarchy of human needs” [1970].

³⁹⁹For example, “language impairments” is 3 but a second digit can be added to indicate “impairment of voice production” and a third for people who use a “substitute voice” or have “indistinct speech” [Pfeiffer 1998].

This perspective is reinforced by the language used to describe Handicap, which suggests that people are disadvantaged by their disabilities rather than the environment, and that handicaps are caused by impairments and disabilities⁴⁰⁰ Although Handicap is described as a classification of “circumstances in which disabled people are likely to find themselves”, because it does not mention the social and environmental factors that create these circumstances it gives the impression that handicaps are merely complex disabilities⁴⁰¹, making it difficult to record or address environmental problems [Bickenbach et al 1999; Chapiro and Colvez 1998]. Stating that Handicap is influenced by values also implies that Disability and Impairment are neutral and universal categories.

The model also represents disability as an illness or disease [Chamie 1995]. For example, its reference to the sick role (“the sick person is unable to sustain his [sic] accustomed social role and cannot maintain his customary relationships with others”) is not applicable to people with disabilities (or living with dystonia) who may have minimal contact with healthcare systems and will never “recover” in the sense that Parsons intended. The ICDH can therefore be seen as part of the “medicalisation of disability” [Friedson 1970], which gives control over the lives of people with disabilities to health professionals who may have little idea of people’s performance in their home environment or QOL. The broadness of its definitions suggests it represents an extension of the “clinical gaze”. For example, it could be used to label the behaviour of political dissidents and homosexuals as “abnormal”, and further medicalise pregnancy and menstruation [Dickson 1996; Shakespeare 1995]. It could also strengthen the normative role of medicine: “the ICDH is based on Western, able-bodied, male, middle class ideas of normal which are viewed as desirable and praise worthy” [Pfeiffer 2000]. For example, deviations from the norm listed in Disability include “cultural shock (such as immigrants), moving in different identities (e.g. transvestism and passing, such as black passing for white), pseudo-feeble-mindedness, and breaking taboos” [Wood 1980:149].

International Classification of Functioning, Disability and Health [WHO 1997]

The WHO noted these problems with the ICDH and in 2001 it replaced it with the ICF (after seven years of consultation and redrafting) as a more accurate representation of its approach to health. The ICF is based on the “biopsychosocial” model, which supposedly synthesises the medical and social approaches to disablement⁴⁰² (note that this is the biopsychosocial rather than the “sociobiopsych” or “psychosocialbio” model). It aims to be universally

⁴⁰⁰ e.g. People have handicaps of mobility because “their disabilities interfere with their ability to get around”.

⁴⁰¹ Reinforced by the domain’s explicit reference to the individual’s competence and abilities.

⁴⁰² c.f. Armstrong [1987].

applicable and provides detailed definitions of the items so users can make them intelligible in local languages and cultures. The ICF's classifications of disablement are intended to be linguistically and etiologically neutral to enable its use as a common tool for policy. For example, there should be no predictable correlations between health conditions and aspects of disablement. However, its use of neutral language often slides into euphemism, reducing clarity and obscuring "the very real consequences of disablement" [Bury 2000] (c.f. the section on language in chapter 1).

The ICF's three dimensions are "Impairments", "Activity limitations" (previously Disability), and "Participation restrictions" (previously Handicap⁴⁰³) which are intended to be multidirectional, equal in significance, and represent different facets of disablement.

Impairments ↔ Activity limitations ↔ Participation restrictions
 Corresponds with Body Person Society

Its press release claims it will "challenge mainstream ideas on how we understand health and disability" by putting physical and mental health conditions on an "equal footing" ("a person may not be able to attend work because of a cold or angina, but also because of depression"), focusing on how people live with their health conditions, and recording social and environmental barriers to "achieving a *productive* and fulfilling life" [WHO 2001, my italics]. The ICF does this by collapsing different models of disability into "medical" and "social" models, which are both concerned with "managing" "problems". Consequently, interventions are prescribed for each dimension (for example, rehabilitation or provision of assistive devices for "Activity limitations"). Its version of the social model bears so little resemblance to what is commonly meant by the term (see chapter 1) that disability activists have dubbed it the "social (services)" model⁴⁰⁴. The two models are actually rhetorical devices, which were only created so they could be "synthesised" in the biopsychosocial model ("[an] incorporation [...] that otherwise would be quite impossible" [Finkelstein 1999]). Although ICF has also attempted to replace the disabled/non-disabled dichotomy with a continuum⁴⁰⁵, this is undercut by the detailed classification codes, which provide an insight into its concept of health:

⁴⁰³It claims to extend Handicap from "survival roles" to all areas of life by using a list of environmental factors to identify person-level determinants of disablement (note the ICF is still operating at the level of the person rather than society), however, critics suggest it only represents one dimension of Handicap [Bury 2000].

⁴⁰⁴It is in fact the "administrative" model, which is a subsidiary of the medical model [Oliver 1996].

⁴⁰⁵c.f. Foucault [1979] and Martin [2000] on the replacement of the normality/abnormality dichotomy with a classification of bodies on a continuum where differences are positional rather than essential.

Developing a language concerned with disablement which is to serve as a frame of reference for the ‘consequences of health conditions’ surely already presumes that disability is a health condition! In which case [the ICF] cannot be anything else than a rewording of the ‘medical’ model of disability in order to include some words from the social model and thereby placate the criticism of disabled people

[Finkelstein 1999]

The ICF continues the ICIDH’s functional definition of health, which devalues people who cannot do “wealth producing labour” [Pfeiffer 2000]. It also disenfranchises people with disabilities by continuing to construct disability in terms of the sick role where social rights are linked to “getting well” by following the doctor’s orders. In fact, the effect of taking a “universalist” approach to disability (described in chapter 1) while maintaining a biomedical perspective is to continue the work of the ICIDH in extending the clinical gaze as widely as possible. Despite the inspiring rhetoric, disability is still conceptualised as “a ‘complex collection of conditions’ (i.e. problems) to be managed in the well-established manner by PWAs rather than as unique lifestyles that require unprecedented, original, and creative support systems” [Finkelstein 1999]. The continued representation of disability as a burden paves the way for the Global Burden of Disease project, which is described in the last part of this chapter. Finkelstein also notes the supreme irony that “the highly political demand for a continually expanding health and medical service consistent with the medical model” has been attributed to the social model and “projected into the ideological aims of disabled people trying to create their own natural services and professions” [ibid].

The WHO’s Global Burden of Disease Project

In contrast to the first two initiatives described in this chapter, the Global Burden project is explicitly biomedical, most obviously in its assumption that disease is the main cause of ill health (thoroughly critiqued in Williams [2000]) and medicine its only cure. This conceals the way many health sector interventions have non-health sector returns (and vice versa⁴⁰⁶) and imposes closure on other ways of discussing causation and cure⁴⁰⁷ [Taussig 1980]. For example, its main tool, the DALY, represents health as an individual rather than community-level problem, and implies that health intervention alone can raise life expectancies to the standard level, even though in many countries the burden measured by DALYs is of disease and underdevelopment, not disease alone⁴⁰⁸.

⁴⁰⁶For example, female education also reduces infant mortality and increases contraceptive use.

⁴⁰⁷For example, the position of road traffic “accidents” at number nine in the table may relate to the World Bank’s encouragement of car use to stimulate economic development. The World Bank also put the cost of mental health problems in a “discretionary” category so the state is not held responsible [Kleinman 1996].

⁴⁰⁸For example, 15.9% of DALYs lost worldwide are attributable to childhood malnutrition, and 6.8% to poor water and sanitation [Global Burden of Disease results 1990, in Murray and Lopez 1997].

Like QOL, the Global Burden of Disease project has been very successful in publicising its endeavours and recruiting new participants, particularly among neurologists and neurological patient support organisations who were previously neglected in favour of more glamorous specialties.

There is no doubt that as a marketing or ‘attention-seeking’ activity, the Global Burden of Disease enterprise currently has no rivals in the health policy field
[Williams 2000]

I first encountered the Global Burden Project in 1999 when an enthusiastic Italian neurologist who was then working for the WHO asked me to join a team putting together a “position paper” on the social and economic impact of dystonia. The head of the European Dystonia Federation, an Italian professor of neurology and a junior colleague, the neurologist from the ESDE study, and I assembled at a London club with our laptops for a day of brainstorming. What we were doing, the neurologist from the WHO told us, was “marketing” dystonia; in fact she defined herself as a “neurological account manager”. We were making it into a “product” (by constructing it as a coherent condition) and selling it to the WHO. She told us that although this might seem like a strange activity, we were lucky to have this opportunity (through her connections to the European Dystonia Federation) as many conditions who had not submitted a paper would be unrepresented when the WHO calculated the Global Burden and their impact would not be acknowledged⁴⁰⁹.

Our task was aided by her production of a similar paper on headache that she was happy for us to use as a template. In fact the most difficult part of the process was making sure that all references to headache had been deleted from the final document. The exercise reminded me both of the Dystonia Society’s struggles to get dystonia included in the Disability Living Allowance handbook of conditions as “if we [dystonia] are not in the book, we don’t exist”, and the comments made to the Branch Officers conference about the need to market dystonia using the strategies of the pharmaceuticals. Submitting “identikit” position papers seemed a pointless exercise since the WHO committee would still need to use their professional (and personal) experience to assess them, as they would all say the same thing. I suspect this may also be true of disease-specific measures whose individual and biomedical focus often causes them to omit what is most distinctive about a condition in order to make it more visible by “concretising” it in a measure. However, as the example of league tables demonstrates, once a

⁴⁰⁹She felt this was especially true because the head of the WHO’s neurological division was not a neurologist but “a Russian expert on substance abuse”.

form of audit has been agreed, people are compelled to participate and to represent their experience in those terms to be sure of it “counting”.

The Global Burden Project theoretically enables the identification and prioritisation of the main international health problems internationally so resources can be allocated more effectively. For example, one consequence of the publication of the first results in 1990 [Murray and Lopez 1997] was increased interest in pharmaceutical interventions to relieve depression in low and middle-income countries as it was ranked as the fourth main cause of DALYs lost worldwide⁴¹⁰ [Murray and Lopez 2000]. This was capitalised on by pharmaceuticals who changed their strategy to market directly to health officials in these countries and included the results in their marketing materials. However, the utility of the rankings has been disputed as they assume an implausibly high level of accuracy for statistics on the cause of death⁴¹¹, decontextualise diseases, and compare the incomparable⁴¹². The Global Burden results resemble the QOL rankings undertaken in US counties and cities in the 1970s (reviewed by Flax [1978]). Although the data on the individual indicators of QOL was interesting, if surreal (one indicator was number of scooters per head of population), the aggregation of scores to produce a ranking was implausible, especially considering the variable quality of the data. The problem of data quality applies to a greater extent here as the indicators are difficult to interpret, there are variations in the data collected in different countries, regional variations may not be picked up by a countrywide measure (for example, differences in female health and life expectancy between northern and southern India), and there is little local consultation to determine what diseases people find most burdensome (for example, in some parts of Mexico a particular skin disease is so common that it would be considered pathological not to have it [Helman 2000]).

This approach also disguises striking differences in the pattern of disease and expenditure in rich and poor countries. Worldwide, non-communicable diseases are responsible for 56% of death and communicable diseases 34%. Among the richest 20% of countries the ratio is 85% to 8%, but among the poorest, it is 34% to 56% [Gwatkin 1997]. Rich countries only account for 11.6% of the Global Burden, but 90.2% of recorded health expenditure.

⁴¹⁰The top ten causes were lower respiratory infections, diarrhoeal diseases, perinatal disorders, unipolar major depression, ischaemic heart disease, cerebrovascular disease, tuberculosis, measles, road-traffic accidents, and congenital abnormalities.

⁴¹¹These only give the proximal causes of death so HIV-related pneumonia would be a “lower respiratory infection” [Prior 1997].

⁴¹²For example, HIV and heart disease have different epidemiologies and effects [Schwartlander 1997]: HIV is preventable, mainly affects young adults and families, and in poor countries mortality increased by 500% between 1990-6. Heart disease is prevalent in rich countries, affects older adults, and mortality has plateaued.

The Global Burden Project has been accused of discriminating against people with disabilities as it uses “disability” interchangeably with “ill-health” (contrary to WHO policy) and represents them as a drain on society: “[it] assumes that individuals with a disability lie somewhere between life and premature death” [Groce et al 1999]. The DALY table of disability weightings confirms this as it states with frightening precision that the value (presumably to society rather than the person) of one year for 1,000 people without disabilities is equivalent to one year for 9,254 people with quadriplegia, 4,202 with dementia, 2,660 blind people, 1,686 with Down’s syndrome without cardiac malformation, 1,499 deaf people, 1,236 infertile people, and 1,025 underweight or overweight people⁴¹³ [Murray in Murray and Lopez 1996a].

Disability Adjusted Life Years

The DALY was ostensibly developed for three reasons; to enable the inclusion of non-fatal health outcomes in debates on international health policy; to provide neutral figures on population health for policy decisions; and to facilitate cost effectiveness analysis [Murray 1996]. The latter aim may be why the World Bank sponsored the development of the measure. The DALY’s designers aimed to open “the black box of the decision-maker’s relative values” to “public scrutiny and influence” by making the value choices incorporated in them explicit (the discourse of transparency, critiqued by observers of audit culture) [ibid]. They also believed that tackling disease would promote global equality [Murray 1996], although DALYs focus on cost-effectiveness rather than equity⁴¹⁴.

DALYs are created by combining preferences for health states (or “disability weights”) with the numbers of years lived with a condition and any reduction in life expectancy due to that condition. This figure is then modified by “age weights” that attribute different values to the lives of people at different ages and a “discount rate” that favours different types of intervention (for example, acute over preventative). I describe this in detail later in the chapter.

The creation of universal disability weights is arguably the most important part of the process as if these do not represent the common experience of people living with a condition they cannot be used to calculate the condition’s “global burden”. I have two problems with this part of the process: Firstly, I don’t believe there is a common experience of any condition

⁴¹³People whose weight differs from the norm by two standard deviations in either direction are “disabled”.

⁴¹⁴For example, “age weighting” implies a focus on the societal usefulness of people’s life years rather than individual quality of life [Arneson and Nord 1999].

even within one society (this is certainly true of dystonia). Secondly, if this common experience existed it could not be accessed by asking healthy people what they imagined life would be like with a particular condition (which is what the methodology involves), nor could it be represented quantitatively. In the next section, I support these assertions by looking at how the disability weights were derived.

Stage 1: Deriving disability weights

Twenty two “indicator conditions” were assessed for their impact on QOL by a panel of “experts” during a two-day meeting at WHO’s Geneva headquarters in 1989. None of the experts represented an organisation of people with disabilities, or had a disability, which may have reduced their estimate of QOL in each condition⁴¹⁵. The panel’s task was to give a numerical value to “the average individual with the condition described, taking into account the average social response or milieu” [Murray and Lopez 1996a]. This construct of the “average individual” in an “average society” is an example of the way that the process of measurement (quantification) “makes up” classes of people [Hacking 1986].

The disability weights were assigned using two different “person trade-off”⁴¹⁶ questions. The first one, which invites the respondent to compare the value of disabled and non-disabled lives, is reproduced below:

PTO1: You are a decision maker who has enough money to buy only one of two mutually exclusive health interventions. If you purchase intervention A, you will extend the life of 1,000 healthy (non disabled) individuals for exactly one year, at which point they will all die. If you do not purchase intervention A, they will all die today. The alternative use of your scarce resources is intervention B, with which you can extend the life of n individuals with a particular disabling condition for one year. If you do not buy intervention B they will all die today; if you do purchase intervention B, they will die at the end of exactly one year

[Murray and Lopez 1996a]

The sample response given in the manual is that “if the participant judges that 1,000 healthy people would have an equal claim on the resources as 8,000 people with some severe disability, the weight assigned to that particular disability is equal to 1 minus 1,000 divided by 8,000, or 0.875” [Murray and Lopez 1996b].

⁴¹⁵Able-bodied health professionals are prone to seeing people’s lives in terms of their medical needs (or “using [a] specific medical diagnosis as a proxy for the entire life experience” [Groce et al 1999]), rather than seeing healthcare as one component of a full life [Makas 1993].

⁴¹⁶Person trade-off is a grotesque but literal description of what the methodology requires.

In the second question, subjects are asked to value cures for chronic conditions relative to interventions that extend life, for example, “how many people cured of blindness would be equal to prolonging the lives of 1,000 people?” Although participants who do not wish to discriminate between people with and without disabilities in the first question could answer $n=1,000$, this would prevent them from recording the condition’s impact on QOL in the second question (which is phrased in a slightly less discriminatory manner) as participants are not allowed to give two different weightings. Arnesen and Nord describe how this scenario occurred at a meeting of European researchers working with DALYs:

In PTO1, the response that extended life for disabled people is as valuable as extended life for 1,000 people without disabilities was regarded as unreasonable. Anyone who chose this option was told that he or she was implying that being disabled is as good as being non-disabled and that there is no need to spend resources on disabled people. It was suggested that he or she should therefore indicate a number higher than 1,000 [1999]

The weightings are then averaged, and the indicator conditions ranked in order of seriousness, and grouped in threes (each group has a defined range of average scores). Seven groups of conditions were identified and labelled with a “disability level” from 1 to 7. The midpoint of each group was taken as the score for that level of disability, producing a 7-point scale⁴¹⁷ that was used to assess the treated and untreated impact of hundreds of conditions. The methodology relies on the quality of evaluations made by a small group of presumably “all-knowing” experts who needed to know not only “the lifetime sequelae of each condition”, but the valuations people would attach to them at each stage and the effectiveness of typical treatments [Williams 1999b].

Ustun (a WHO researcher who coordinated the revision of the International Classification of Impairment, Disability and Handicap) repeated the method for producing disability weights with a different set of “experts” (healthcare professionals, policy makers, people with disabilities and their carers) from 14 countries to assess the robustness of the weightings produced by the original study [Ustun et al 1999]. Although the order of the ranking was similar, he found significant differences between countries on 13 of the 17 health conditions,

417 Disability class	Severity weight	Indicator condition	[Murray and Lopez 1996b:11]
1	0.00-0.02	Vitiligo on face; weight for height less than 2 standard deviations	
2	0.02-0.12	Watery diarrhoea; severe sore throat; severe anaemia	
3	0.12-0.24	Radius fracture in stiff cast; infertility; erectile dysfunction; rheumatoid arthritis; angina	
4	0.24-0.36	Below-the-knee amputation; deafness	
5	0.36-0.50	Rectovaginal fistula; mild mental retardation; Down’s syndrome	
6	0.50-0.70	Unipolar major depression; blindness; paraplegia	
7	0.70-1.00	Active psychosis, dementia, severe migraine, quadriplegia	

and between groups of informants on 5 health conditions. The differences suggest that the assumptions that universal weights are possible⁴¹⁸, and that health professionals represent the preferences of the societies they come from were both incorrect. This was reinforced by a study in Zimbabwe that found high levels of agreement between the original weightings and those of Zimbabwean health professionals ($p=0.91$), but low ones between health professionals and the public ($p=0.15$), and the public and the original weightings ($p=0.12$), suggesting that “GBD values represent those of an international elite of healthcare workers”⁴¹⁹ [Jeisma et al 1999]. They caution that “the greater the divergence of the local culture from the individualist western world view, the less likely that GBD weights will be applicable” [ibid]⁴²⁰. Universal weightings would only be useful if resources were to be reallocated internationally to produce more DALYs, for example, from Alzheimer’s disease in the US to cerebral malaria in Africa, but this is very unlikely to occur [James and Foster 1999].

Stage 2: Calculating DALYs

The disability weighting for a condition is multiplied by the number of years lived with the condition, and added to the reduction in life expectancy caused by the condition. For example, for a person with Down’s syndrome the calculation would be 0.43 (disability weight for Down’s syndrome) x 40 (average life expectancy with Down’s syndrome) + 42.5 (number of years lost from the “standard” life expectancy [the greatest recorded life expectancy of 80-82.5 years] due to Down’s syndrome) = 59.7. When years with a condition and years lost to a condition have been calculated, these are modified by “age weights” that attribute different values to the lives of people at different ages and a “discount rate” that favours different types of intervention.

1. Calculating years lost to a condition

There are two points to note about this methodology: Firstly, in deciding to use a Japanese figure as the standard life expectancy (82.5 years for women and an estimated 80 years for men, although the actual male figure was 76.5) the authors effectively applies an age weight of greater than one in countries where the life expectancy is less than this. For example, if life

⁴¹⁸For example, HIV was ranked low in Japan, Spain, Turkey, Luxembourg and the UK, but first in Egypt and Tunisia, reflecting the fact that it is usually fatal in poorer countries.

⁴¹⁹Differences were greatest for reproductive disabilities, and cognitive and sensory disorders. Jeisma et al suggest that this is because the former are a threat to the collective, while the latter are an individual problem that can be accommodated within the community [1999].

⁴²⁰Hacking notes that statistical laws for social data were found in the West where libertarian, individualistic and atomistic concepts of person and state were popular, rather than the East where collectivist and holistic attitudes were more common [1990].

expectancy were 40 years (as in some African countries), then each year of life would carry an age weight of 2. In poorer countries this has the bizarre effect of biasing interventions towards older adults, as years of life gained by those who have survived into old age have higher weights than those gained by younger adults⁴²¹ [Williams 1999b]. Ironically the justification for this is equity as otherwise interventions to help people in richer countries who have longer life expectancies would appear to be better value as they would save more years of life.

Secondly, the assumed difference in life expectancy between men and women of 2.5 years is considerably smaller than the observed difference in low mortality populations. This discriminates against women by reducing the female contribution to the global burden relative to the male, therefore reducing the proportion of resources that will be allocated to “female” problems like breast cancer.

2. Age weighting

Lives lived at different ages have been valued using instrumental rather than intrinsic criteria⁴²². For example, the lifetime is weighted so it is most valuable in the twenties and thirties when people are supporting others rather than receiving support, and least valuable in childhood and old age (there is less “social value” in preventing a baby from dying as they may not survive to adulthood, or prolonging the life of an older adult) [Murray 1996]. This is an example of the “human capital” approach which the designers claim to have rejected. Anand and Hanson suggest ironically that the instrumental perspective be taken to its logical conclusion by extending it to include occupation and ability to pay tax [1997].

3. Discount rates

Future health problems are “discounted” at a rate of 3% per year (chosen because it is the rate of inflation in many Western countries), which favours future-oriented interventions⁴²³. While preventative and child-oriented interventions are obviously important in the long-term, the discount rate currently discriminates against poor countries whose problems are more immediate (if the current generation doesn’t survive there won’t be any future ones).

⁴²¹This is also true with international comparisons where old people in richer countries have higher equity weights than young adults in poorer ones.

⁴²²Anand and Sen argue instead for a “universalism of life claims” where there is a common intrinsic value to life, regardless of the age at which it is lived [1994].

⁴²³This point is more obvious in the Spiegelhalter table in chapter 7 which compares different interventions.

Criticisms of the DALY

DALYs have been criticised for being universalising, inequitable, unparticipatory (and potentially discriminatory), and representing an exclusively biomedical world view.

The main example of their universalising approach is the assumption of the disability weightings that impairment will always result in a certain level of disability, even though the influence of context means that the range of any weighting must be so large as to make it “dangerously imprecise and arguably meaningless”⁴²⁴ [Metts 2001]. The value attached to any disability state varies markedly between cultural groups and even impairment may not be measurable cross-culturally⁴²⁵ [Groce and Zola 1993; Whyte and Ingstad 1995; Groce et al 1999]. An absolute disability weight implies that the lives of people with disabilities will not be affected by healthcare and social and economic support as their level of disability is solely determined by their diagnosis (a justification for not funding these interventions). The weightings also fail to distinguish between functional limitations associated with illness and age⁴²⁶, and cannot measure the presence of more than one condition since this is currently calculated using an additive model (for example, the disability weight for someone who was blind and depressed would be $0.60 + 0.60 = 1.20$, considerably worse than death).

The inequity of DALYs arises from their failure to acknowledge people’s circumstances. For example, the Global Burden project’s definition of the “burden” of disease appears to be closer to the “aggregate quantity of disease”, rather than the actual burden of disease. Researching the actual burden would require information about the circumstances of people with limiting health conditions (for example, availability of family support networks, access to public services), particularly if resource allocation was designed to reduce it [Anand and Hanson 1997]. The designers argue for “treating like health outcomes as like” [Murray 1994:431] but this can lead to inequity depending on how “likeness” is characterised (for example, whether it includes wealth or access to public services [Anand and Hanson 1997]). The DALY is ethnocentric as although it is mainly used in developing countries, the indicator conditions used in its creation reflect the preoccupations of a western industrialised society with an advanced medical system [James and Foster 1999] (as does the choice of discount

⁴²⁴For example, paraplegia (assumed to result in a 50-70% decrease in QOL) would result in a much greater decrease if the person were a member of a nomadic tribe that prized physical prowess, or a lesser one if they were a Professor with an endowed chair at a prestigious university [ibid].

⁴²⁵For example, the North American DSM-IV psychiatric criteria were redrafted to enable the diagnosis of “mania” within Amish and Mennonite communities (e.g. “excessive involvement in pleasurable activity” became “racing one’s horse and carriage too fast”) [Martin 2000].

⁴²⁶For example, the most severe level of disability includes states where the person needs assistance with eating or toilet use, which seems to imply that infants are disabled.

rate). For example, quadriplegia is rare in the developing world because people would not survive such severe injuries.

The unparticipatory nature of DALYs arises from their use of a “disease scenario” approach to create disability weights, which limited participation to health professionals. Wider participation, especially of people with disabilities, might also have avoided the assumption that impairment is always a negative experience. Accounts from people with severe disabilities (for example, Motor Neurone Disease [Hawking 1993; Goldblatt 1993; Young and McNicoll 1998]) suggest that disability can improve people’s QOL and may be economically beneficial by creating jobs as support-workers, manufacturers of assistive devices, etc.

The designers decided not to measure “handicap” as they believed this would discriminate against people with disabilities by measuring their “adaptation” rather than their real condition (which presumably exists outside their experience of it)⁴²⁷. However, this decision excludes interventions like workplace support for people with disabilities from funding as they are not rehabilitative or life-extending. The DALY approach assumes that the lives of people with disabilities have less value than those of people without disabilities, and consequently that they are less entitled to scarce health resources for interventions that would extend their lives [Anand and Hanson 1997; Arneson and Nord 1999].

According to the weighting scheme used in the production of DALYs, the years that Franklin Delano Roosevelt spent as president of the United States, were years of ‘life lost’ to disability, as are the many years that the astrophysicist Stephen Hawking has spent teaching and writing. This is because the only calculation possible is of the deficits that are incurred by the very existence of the disability itself. Although DALYs may help economists and ethicists distribute health care to the masses, we fear that it may also allow them to more easily justify the disenfranchisement of an entire segment of humanity

[Groce et al 1999]

One researcher with disabilities provocatively linked DALYs and the Latimer case in Canada (the prosecution of a father who killed his disabled daughter to “end her suffering”) as they both support the claim that “a life lived with disabilities has less value than a life lived without disabilities, based on evidence of ‘suffering’ derived from biomedical expertise” [Rock 2000]⁴²⁸.

⁴²⁷One designer even suggested that people with disabilities who reported health and happiness were experiencing “false consciousness” [Murray in Murray and Lopez 1996a].

⁴²⁸Many Canadian disability activities believe that the trial and subsequent appeals put Tracey Latimer’s QOL on trial rather than her father’s actions.

Pfeiffer suggests that this could lead to eugenic policies as if countries are asked to reduce their number of DALYs to receive funding from the World Bank, the quickest way to do this would be to reduce the number of people with disabilities.

To conclude, the DALY's configuration of suffering as an economic indicator makes it a "thin' and abstract representation" of people's experience of disease and disability, which nonetheless influences the responses of those offering social and medical support.

The moral and political issues [...] cannot be made to fit into this econometric index. Likewise, the index is unable to map cultural, ethnic, and gender differences [and] focuses on the individual sufferer, denying that suffering is a social experience. [...] This] may in time also thin out the social experience of suffering [...] by becoming part of the apparatus of cultural suffering that creates societal norms, which in turn shapes the social role and social behaviour of the ill, and what should be the practices of families and health-care providers

[Kleinman and Kleinman 1996:14]

Conclusion

The examples I have examined in this chapter demonstrate that, despite the apparently benevolent nature of QOL, like other expert knowledges it can be used in ways its originators could never have imagined. In common with other measures, it constructs what it appears only to be observing, and these constructions merit our attention because they affect how people with limiting conditions are thought about and responded to. QOL measurement can therefore become a Scientific justification for not addressing inequality, as the statistical instruments of the eugenicists did during the previous century.

Conclusion

In this thesis I address five main questions. Firstly, how the twin rhetorics of QOL and the “voice of the patient” are used as resources in the struggles of doctors, patient support organisations, and pharmaceuticals, each trying to position themselves within a crowded “field” and welcoming the “moral capital” they provide. I explore the dynamics of these struggles using the concepts of field and capital from Bourdieu and the “power-knowledge complex” from Foucault. Secondly, how QOL measures can represent “invisible” conditions like dystonia that lack even an adequate clinical definition, making them visible and accountable. Thirdly, whether QOL measurement, which is clearly an extension of the clinical gaze, is an example of medicalisation? I suggest instead that it is “bureaucratisation” through the medium of health, which affects both doctors and patients (evidenced by their shared dissatisfaction with clinical encounters). Fourthly, whether QOL measurement represents an extension of audit culture into the previously sacred space of health? I argue that no area of contemporary life is safe from this particular technology. The idea that everyone has a quantity of QOL that can be measured and maximised is an example of a contemporary mode of thought (“economic rationality”) which the measures crystallise and sustain by implicitly training those who use them in this way of thinking⁴²⁹. The exponential growth of QOL arises from the way the QOL industry has “enrolled” a range of actors in its project who use the technology, and in turn are used by it⁴³⁰. Finally, whether the voices of patients are being heard and what can be done to facilitate this. I argue that even though narratives of illness are limited by the conventions of their genre, they currently offer the best approach to understanding the experiences of people with limiting conditions. However, there are few places where these stories can be heard, and this is particularly true of medical environments, due to pressure of resources, procedures, and gaps in the training of doctors⁴³¹. While patients can speak through the language of QOL, it transforms their concerns in a way that can only be described as “symbolic violence” [Bourdieu 1991], effectively “muting” them [Ardener 1975]. This is also true of patient support organisations who have seized upon the discourse of QOL without considering that it might ultimately be used against their members.

⁴²⁹c.f. Rose and Miller’s description of the reform of the UK economy in the 1970s [1990].

⁴³⁰c.f. Latour [1987, 1992] et al on “actor network theory” and the “social life” of technologies.

⁴³¹According to Frank [1998], the role of illness stories is “to express what cannot be expressed in the clinic where people ostensibly go to talk about illness”.

In the next section I will enlarge on these points and make some suggestions for future research. As this thesis has illustrated, dystonia is extremely difficult to define and represent, even within medical discourses. This affects people with dystonia who need to understand their condition, integrate in their lives, and represent it to others so they can have their experiences acknowledged and gain access to social and economic resources. The latter goal is shared by dystonia patient support organisations who recognise the marketing potential of QOL measurement. For example, how it might contribute to dystonia's "branding" as a coherent and mainstream neurological condition.

Studies using QOL measures have made the negative aspects of the impact of dystonia visible and comparable, and have provoked some interesting questions. For example, drug-induced dystonia is a common side effect of Parkinson's disease and yet people with Parkinson's disease and dystonia report better health than people with dystonia alone [Camfield 2000, Camfield et al 2002]. This question can only be answered through a qualitative approach, which explores the social construction of dystonia by engaging with and contextualising the experiences of people living with dystonia. As I describe in chapter 8, the Scientific methodology for creating measures of QOL ensures they are no more representative of the experiences of people with limiting conditions than clinical measures. What does it mean to say someone with cervical dystonia has a worse score on a QOL measure than someone with Parkinson's disease? While it may mean that they have less of whatever it is that QOL measures measure, it does not necessarily tell us anything about their quality of life, nor can it explain why cervical dystonia might have this effect.

QOL scores become meaningful when you need to compare the impact of different conditions to allocate resources, compete against other patient support organisations for grant or donor money, or convince your doctor or family that you have a serious condition. For example, the credibility of the Alzheimer's disease society's submission to NICE was questioned because their evidence of improvement was "anecdotal" rather than from measures of QOL. The words of people with Alzheimer's are thus only audible if they are translated into the scientific and quantitative language of QOL; in the same way that the voice of the patient is most likely to be heard if they are speaking as a consumer. This has important implications for understanding how patients' narratives are heard and valued in contemporary Britain⁴³².

⁴³²As Arizpe said of Mexico, "everyone seems preoccupied with the Campesinos, but very few people are interested in them" [Mohanty et al 1991].

I believe that measures of QOL are particularly poor at representing the experiences of people living with dystonia because much of its impact is due to people's inability to represent their experiences and have them acknowledged and validated by medical and social gatekeepers. However, precisely because dystonia is so rarely represented in popular and medical discourses, any representation (no matter how thin) is welcomed as it enhances the condition's credibility and means that people living with dystonia are less likely to be dismissed as malingerers or somatisers⁴³³. The fact that QOL has become an issue within medicine may indicate a change in the structure of medical perception and create a discursive space where the voices of people with limiting conditions can be "heard". Even though QOL has been put on the agenda by doctors and pharmaceuticals, it could become an "oppositional habitus" [Crossley and Crossley 2001] which generates resistance and change, and has potential as a rhetorical resource for people living with dystonia⁴³⁴.

The focus on physical function in QOL measurement is not necessarily a bad thing. However, QOL measures need to be clear about their aims, and their limitations, thus avoiding the "false promises" of doctors and pharmaceuticals that a product will enhance quality of life rather than merely alleviate symptoms⁴³⁵ [Hunt 1999]. In fact, I think anthropologists should encourage modesty not only in QOL researchers, but also in doctors who could return to "a more humble model of doctoring as 'plumbing', 'simple body work'" [Scheper-Hughes 1990:192]. Paradoxically, as research becomes more "patient-centred", many people find it "intrusive and unacceptable" [Greenhalgh 1998], recognising it as the latest extension of the clinical gaze.

While you do not need to "be" a person with a disability to understand the experiences of people with disabilities (participant observation thrives on the tension between sharing and reflecting on others' experiences without becoming the other), people's understanding of what life would be like with a chronic condition are not aided by the valuation methods I describe in the thesis and this can lead to bizarre and discriminatory evaluations. People's experiences might be better approached through narratives that embed their conditions in their lives and give them a meaning that is not wholly negative. For example, the positive outcomes of motor neurone disease are difficult to represent quantitatively, and might even be dismissed as irrelevant by the designers of a motor neurone disease-specific measure, as

⁴³³This was clearly the case in past, see especially chapter 4.

⁴³⁴People with neurological illnesses in the Netherlands have successfully used the Human Rights Act to argue for access to treatment since denying them treatment infringed their right to a good quality of life.

⁴³⁵These claims have been checked by the scepticism of consumers who demand statistical evidence from measures of QOL before they will accept them, cementing QOL researchers' relationship with pharmaceuticals.

happened with the multiple sclerosis-specific measure described in chapter 8. I concur with Kleinman that “economic measures need to be complemented by narratives, ethnographies, and social histories that speak to the complex, even contradictory, human side of suffering” [1996:14].

QOL measures continue to be successful because their plasticity and inoffensiveness makes them ideal “boundary objects” [Starr and Griesmer 1989]. Although they are not successful in their own terms (i.e. they don’t represent the “patient’s perspective”), they generate publicity, provide employment (even for anthropologists), sustain QOL-related organisations, journals and conferences, stimulate the sales of pharmaceutical interventions, and occasionally provoke interesting research questions (for example, from a clinical perspective dystonia appears trivial but its impact can be very severe). In one sense, therefore, QOL measures have become an industry, which explains the variety of actors who now have a major stake in their success and development. They are a further illustration of the growth of audit culture as observed by Strathern et al, indicating that even health is no longer a sacred space. I believe that QOL measurement is a fascinating area, which merits greater academic attention, however, the moments of surreal comedy it provides would take on a darker hue if it was used as the WHO intends to make decisions affecting people’s lives on an international scale.

Although people with limiting conditions have historically been a muted group, I suspect the reason why these natives are not now speaking for themselves relates to the growth in social care professionals and patient support organisations. No matter how “grass-roots” their origins, patient support organisations tend to become large, self sustaining bureaucracies⁴³⁶ who have an interest in perpetuating relationships of dependency. Illness and disability can be taboo subjects, even sources of fear, and this lack of engagement enables “healthy” people to sustain negative stereotypes and believe that illness, disability, and old age will never happen to them. Engaging with a wider range of needs (for example, the elderly, parents, people with learning difficulties) would require fundamental changes in the way society is organised, an imperative that is concealed by the “feel-good” language of quality of life.

My thesis highlights several issues that deserve further study: how people construct and use narratives of causality, the “boundary maintenance” between chronic illness and disability and what prompts someone to identify as disabled, and whether charities can develop ways of representing people with disabilities that are “experience-near”, politically aware, and

⁴³⁶The sumptuous new offices of the MS Society (different coloured carpets for each department) spring to mind.

effective for fundraising. It would be interesting to monitor the Dystonia Society over the next few years as it moves to a regionalised structure and the development of the Dys-Qol and WHOQOL measures. Two important themes highlighted by this thesis are the rise of the “expert patient”⁴³⁷ and the relationships between clinical research institutions, pharmaceuticals and patient support organisations, both of which merit exploration. I would also like to follow the “career” of QOL within medicine and see if it realises its subversive potential.

⁴³⁷Expert patients are at the centre of a six year NHS project to “address the challenge of chronic disease”.

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The Short Form 36 Health Survey Questionnaire (SF-36)

The following questions ask for your views about your health, how you feel and how well you are able to do your usual activities. If you are unsure about how to answer any questions, please give the best answer you can and make any of your own comments if you like.

(Please tick one)

1. In general, would you say your health is:
- Excellent
- Very good
- Good
- Fair
- Poor
-
2. Compared to one year ago, how would you rate your health in general now?
- Much better now than one year ago
- Somewhat better now than one year ago
- About the same
- Somewhat worse now than one year ago
- Much worse now than one year ago

3. **HEALTH AND DAILY ACTIVITIES**

The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much?

(Please tick one box on each line)

		Yes, limited a lot	Yes, limited a little	No, not limited at all
a)	Vigorous activities , such as running, lifting heavy objects, participating in strenuous sports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b)	Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling or playing golf	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c)	Lifting or carrying groceries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d)	Climbing several flights of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e)	Climbing one flight of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f)	Bending, kneeling or stooping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g)	Walking more than a mile	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h)	Walking half a mile	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i)	Walking 100 yards	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j)	Bathing and dressing yourself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**?

(Answer Yes or No to each question)

		Yes	No
a)	Cut down on the amount of time you spent on work or other activities	<input type="checkbox"/>	<input type="checkbox"/>
b)	Accomplished less than you would like	<input type="checkbox"/>	<input type="checkbox"/>
c)	Were limited in the kind of work or other activities	<input type="checkbox"/>	<input type="checkbox"/>
d)	Had difficulty performing the work or other activities (eg. it took extra effort)	<input type="checkbox"/>	<input type="checkbox"/>

5. During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

(Answer Yes or No to each question)

- | | Yes | No |
|--|--------------------------|--------------------------|
| a) Cut down on the amount of time you spent on work or other activities | <input type="checkbox"/> | <input type="checkbox"/> |
| b) Accomplished less than you would like | <input type="checkbox"/> | <input type="checkbox"/> |
| c) Didn't do work or other activities as carefully as usual | <input type="checkbox"/> | <input type="checkbox"/> |

(Please tick one)

- | | | |
|---|--------------|--------------------------|
| 6. During the past 4 weeks , to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups? | Not at all | <input type="checkbox"/> |
| | Slightly | <input type="checkbox"/> |
| | Moderately | <input type="checkbox"/> |
| | Quite a bit | <input type="checkbox"/> |
| | Extremely | <input type="checkbox"/> |
| 7. How much bodily pain have you had during the past 4 weeks ? | None | <input type="checkbox"/> |
| | Very mild | <input type="checkbox"/> |
| | Mild | <input type="checkbox"/> |
| | Moderate | <input type="checkbox"/> |
| | Severe | <input type="checkbox"/> |
| | Very severe | <input type="checkbox"/> |
| 8. During the past 4 weeks , how much did pain interfere with your normal work (including work both outside the home and housework)? | Not at all | <input type="checkbox"/> |
| | A little bit | <input type="checkbox"/> |
| | Moderately | <input type="checkbox"/> |
| | Quite a bit | <input type="checkbox"/> |
| | Extremely | <input type="checkbox"/> |

These questions are about how you feel and how things have been with you **during the past month**. (For each question, please indicate the one answer that comes closest to the way you have been feeling).

(Please tick one box on each line)

9. How much time during the past month:	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a) Did you feel full of life?	<input type="checkbox"/>					
b) Have you been a very nervous person?	<input type="checkbox"/>					
c) Have you felt so down in the dumps that nothing could cheer you up?	<input type="checkbox"/>					
d) Have you felt calm and peaceful?	<input type="checkbox"/>					
e) Did you have a lot of energy?	<input type="checkbox"/>					
f) Have you felt downhearted and low?	<input type="checkbox"/>					
g) Did you feel worn out?	<input type="checkbox"/>					
h) Have you been a happy person?	<input type="checkbox"/>					
i) Did you feel tired?	<input type="checkbox"/>					
j) Has your health limited your social activities (like visiting friends or close relatives)?	<input type="checkbox"/>					

10. Please choose the answer that best describes how true or false each of the following statements is for you.

(Please tick one box on each line)

	Definitely true	Mostly true	Not sure	Mostly false	Definitely false
a) I seem to get ill more easily than other people	<input type="checkbox"/>				
b) I am as healthy as anybody I know	<input type="checkbox"/>				
c) I expect my health to get worse	<input type="checkbox"/>				
d) My health is excellent	<input type="checkbox"/>				

Appendix 2

Preference-based measures

Rosser disability/distress scale [Rosser and Kind 1978]

The Rosser scale was created from a survey of 60 doctors from different specialties who proposed that the best criteria to assess the severity of health states were disability (defined as “objectively assessed loss of physical and social functioning”), and distress (defined as “subjective evaluation of factors such as pain and psychological condition”). The classification of disability was refined into eight states (from unconsciousness to no disability) and distress into four groups (severe to no distress). Six of the most representative health states were rated by 70 subjects (mainly health professionals) who were told that the people in these states were young adults who would only be cured if they were treated. Median values for the scores were transformed so that 1 was attributed to perfect health with no distress, 0 to death, and negative values to conditions regarded as worse than death.

Disability rating	Distress rating			
	A (None)	B (Mild)	C (Moderate)	D (Severe)
I No disability	1.000	0.995	0.990	0.967
II Slight social disability	0.990	0.986	0.973	0.932
III Severe social disability and/or slight impairment at work. Able to do all housework ¹ except very heavy tasks	0.980	0.972	0.956	0.912
IV Choice of work or performance at work very limited. Housewives and old people able to do light housework only, but able to go out shopping	0.964	0.956	0.942	0.870
V Unable to undertake any paid employment. Unable to continue any education. Old people confined to home except for escorted outings and short walks and unable to do shopping. Housewives only able to perform a few simple tasks	0.946	0.935	0.900	0.700
VI Confined to chair or to wheelchair or able to move around in the home only with support from an assistant	0.875	0.845	0.680	0
VII Confined to bed	0.677	0.564	0	-1.486
VIII Unconscious	-1.028	NA	NA	NA

[Rosser and Kind 1978]

EQ-5D (EUROQOL) [Kind 1996]

The European EQ-5D was derived from the Nottingham Health Profile, the Sickness Impact Profile and two existing preference-based measures (the Rosser scale and the Quality of Wellbeing scale). Five dimensions were defined (mobility, self care, usual activity, pain, and mood) and divided into three levels, according to whether the

dimension represented no problem, a moderate problem, or a severe problem. This generated 243 health states (or 245 when death and unconsciousness were included), which were valued using the time trade-off to indicate what proportion of perfect health they represented¹. Although the measure has become one of the most widely used in Europe, it has a number of methodological problems, which I summarise in the table below:

Summary	Problem
Influence of typographical factors on responses	The values for some states were influenced by changes in the number of boxes representing the various conditions and the length of the EUROQOL thermometer.
Response consistency	Inconsistent responses occurred frequently, especially on the pain dimension, or with elderly or poorly educated respondents [Kind 1996; Carr-Hill 1992]. The difference in responses from different demographic groups suggests that it may not be valid cross-culturally either.
Influence of external factors on responses	Respondents tended to record higher scores for more severe conditions if they were told that the index would be used for resource allocation [Kind 1996].
Sensitivity	The measure is not sensitive to many of the health changes that are important to patients (e.g. fatigue) [Jenkinson et al 1997].
Use of composite health states	The use of composite health states has been criticised as while subjects are unlikely to regard all dimensions as equally influential on health, their weighting is concealed if valuations are made on composite conditions [Carr-Hill 1992]. Subjects also find it difficult to relate composite conditions to real ones, which may increase the variance in individual valuations.

15D [Sintonen 2001]

The Finnish 15D is a profile and single index measure that is available in 14 languages and has been used in clinical studies and Finnish and Danish national population surveys since 1986. It was devised in 1981 from the WHO definition of health and revised in 1986 after feedback from doctors. Two other versions have been developed for children aged 8-11 and 12-15 years.

The 15 dimensions (breathing, mental function, speech (communication), vision, mobility, usual activities, vitality, hearing, eating, elimination, sleeping, distress, discomfort and symptoms, sexual activity, and depression) are measured across seven levels of impairment (for example, for the “depression” dimension, level 1 would be “I do not feel at all sad, melancholic or depressed” and level 5 “I feel extremely sad, melancholic or depressed”; levels 6 and 7 are unconsciousness and death). The “importance weights” for each dimension, and values for impairment levels were elicited

¹ Respondents were also asked to rate their current health status on the EUROQOL thermometer to gain a

from population samples who were asked to indicate the relative importance and desirability of each aspect on a visual analogue scale.

Health Utility Index (HUI; versions 1 to 3) [Furlong et al 2001]

The Canadian HUI is a profile and single index measure that has been used in clinical studies and Canadian national population surveys since 1989. It has been used in over 25 countries and translated into more than 15 languages. The first version is now obsolete, but the second and third are used as complementary systems that measure different aspects of disability, for example, the “emotion” attribute in HUI 2 focuses on worry and anxiety, while HUI 3 focuses on happiness versus depression. Generally, the HUI 2 is recommended for clinical studies and HUI 3 for long-term follow-up and population health surveys.

The HUI covers eight “attributes” (vision, hearing, speech, emotion, self-care, pain or discomfort, learning and school ability, and physical activity ability), measured across six levels of impairment (for example, in HUI3 level 1 of the “emotion” attribute is happy and interested in life”, level 6 is “so unhappy that life is not worthwhile”). Preferences were derived from a combination of visual analogue scale (a 100 point “feeling thermometer”) and “standard gamble” methods. Assessing the value of the HUI system is difficult as the literature validates it exclusively in terms of existing preference-based measures, which provided the content for the measure.

Appendix 3

Multiple Sclerosis Impact Scale (MSIS-29)

- The following questions ask for your views about the impact of MS on your day-to-day life **during the past two weeks**
- For each statement, please **circle the one number that best describes your situation**
- Please answer **all** questions

In the <u>past two weeks</u> , how much has your MS limited your ability to...	Not at all	A little	Moderately	Quite a bit	Extremely
1 Do physically demanding tasks?	1	2	3	4	5
2 Grip things tightly (e.g. turning on taps)?	1	2	3	4	5
3 Carry things?	1	2	3	4	5

In the <u>past two weeks</u> , how much have you been bothered by...	Not at all	A little	Moderately	Quite a bit	Extremely
4 Problems with your balance?	1	2	3	4	5
5 Difficulties moving about indoors?	1	2	3	4	5
6 Being clumsy?	1	2	3	4	5
7 Stiffness?	1	2	3	4	5
8 Heavy arms and/or legs?	1	2	3	4	5
9 Tremor of your arms or legs?	1	2	3	4	5
10 Spasms in your limbs?	1	2	3	4	5
11 Your body not doing what you want it to do?	1	2	3	4	5
12 Having to depend on others to do things for you?	1	2	3	4	5

Please check that you have answered all the questions before going on to the next page

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In the <u>past two weeks</u> , how much have you been bothered by...	Not at all	A little	Moderately	Quite a bit	Extremely
13 Limitations in your social and leisure activities at home?	1	2	3	4	5
14 Being stuck at home more than you would like to be?	1	2	3	4	5
15 Difficulties using your hands in everyday tasks?	1	2	3	4	5

16	Having to cut down the amount of time you spent on work or other daily activities?	1	2	3	4	5
17	Problems using transport (e.g. car, bus, train, taxi, etc.)?	1	2	3	4	5
18	Taking longer to do things?	1	2	3	4	5
19	Difficulty doing things spontaneously (e.g. going out on the spur of the moment)?	1	2	3	4	5
20	Needing to go to the toilet urgently?	1	2	3	4	5
21	<i>Feeling unwell?</i>	1	2	3	4	5
22	<i>Problems sleeping?</i>	1	2	3	4	5
23	<i>Feeling mentally fatigued?</i>	1	2	3	4	5
24	<i>Worries related to your MS?</i>	1	2	3	4	5
25	<i>Feeling anxious or tense?</i>	1	2	3	4	5
26	<i>Feeling irritable, impatient, or short tempered?</i>	1	2	3	4	5
27	<i>Problems concentrating?</i>	1	2	3	4	5
28	<i>Lack of confidence?</i>	1	2	3	4	5
29	<i>Feeling depressed?</i>	1	2	3	4	5

Italics = part of "psychological well-being" factor

Appendix 4

MSIS-29 Significant Intercorrelations (>0.695)

(n) = correlated with (n) >0.695

1.6 (1.7) Weakness anywhere in your body	1.7 (1.6) Heavy arms and/or legs?		
1.10 (1.11) Problems with your balance	1.11 (1.10,1.12,2.3) Difficulties moving about outdoors	1.12 (1.11,2.2,2.3,2.5,2.6,2.11,2.14) Difficulties moving about indoors	
1.18 (1.21,2.24) Problems with your vision when reading	1.19 (1.20) Problems with your vision when doing things other than reading	1.20 (1.19) Memory problems	
1.22 (1.21,1.23,1.24,1.25) Problems maintaining your attention during tasks	1.21 (1.18,1.22,1.23,1.24,1.25) Problems concentrating	1.23 (1.21,1.22,1.24,1.25) Difficulties thinking clearly	1.24 (1.21,1.22,1.23,1.25) Difficulties organizing things
1.25 (1.21,1.22,1.23,1.24,1.26) Difficulties learning new ways of doing things	1.26 (1.25) The effect of MS on your interest in sex		
1.32(1.33) Needing to go to the toilet frequently	1.33 (1.32) Problems with constipation		
1.42 (1.43,1.44) Having to limit what you do because of tiredness	1.43 (1.42,1.44) Feeling unwell	1.44 (1.42,1.43) Your body not doing what you want it to do	
1.64 (1.65) A lack of emotional support from people close to you	1.65 (1.64) A lack of practical support from people close to you		
1.67 (1.68) Difficulties forming new relationships	1.68 (1.67) Difficulties keeping close relationships		
1.74 (1.75) Being confined to your home more than you would like to be	1.75 (1.74) Difficulties with self-care activities (e.g. washing, dressing, etc)		
1.77 (1.78,2.16,2.17,2.30,2.31) Difficulties achieving as much as you would like at work or during your regular daily activities	1.78 (1.77,2.8,2.9,2.13,2.15,2.16,2.20,2.23,2.24,2.25) Limitations in the type of work or other daily activities you can do	2.25 (1.78) Affected your bladder function	
1.79 (1.80,1.18) Having to change your goals concerning employment	1.80 (1.79,1.81) The effect of MS on your driving	1.81(1.79) Problems using transport (e.g. car, bus, train, taxi etc)	

1.85 (1.86) Difficulties planning things in the future (e.g. going away for weekends or holidays)	1.86 (1.85,1.87,1.88) Uncertainty about what the future holds for you	1.87 (1.86,1.88) Difficulty going out spontaneously (e.g. going out on the spur of the moment)	1.88 (1.86,1.87,1.90) Having to use a wheelchair
1.90 (1.88) Unpleasant side effects of MS drugs	1.91 (1.92) Financial difficulties because of your MS	1.92 (1.91) Difficulties getting answers from doctors about your MS	
1.96 (2.1) Tinnitus (ringing in the ear)	2.1 (1.96,2.3,2.6) Limited your ability to do physically demanding tasks		2.2 (1.12,2.3,2.5,2.6,2.8,2.9,2.10,2.11,2.12,2.13,2.14,2.15,2.25) Limited your ability to walk
2.3 (1.11,1.12,2.1,2.2,2.4,2.5,2.6,2.8,2.9,2.10,2.11,2.13,2.14,2.15,2.25) Limited your ability to run	2.4 (2.3) Limited your ability to climb up and down stairs	2.5 (2.2,2.6,2.8,2.10,2.11,2.12,2.13,2.14,2.15) Made standing while doing things more difficult	2.6 (1.12,2.1,2.2,2.3,2.5,2.8,2.9,2.10,2.12,2.11,2.14,2.15) Limited your ability to sit
2.7 (2.8) Made it difficult for you to get up from sitting	2.8 (1.78,2.2,2.3,2.5,2.6,2.9,2.11,12,2.13,2.14,2.15,2.23,2.24,2.25) Made it difficult for you to sit up from lying	2.9 (1.78,2.2,2.3,2.5,2.6,2.8,2.10,2.11,2.12,2.13,2.14,2.15,2.16,2.23,2.25) Made it difficult to transfer into and out of a chair or wheelchair	2.10 (2.2,2.3,2.5,2.8,2.9,2.11,2.12,2.13,2.14,2.15,2.17,2.22,2.23,2.24,2.25) Limited your balance when standing or walking
2.11 (1.12,2.2,2.3,2.5,2.6,2.8,2.9,2.10,2.12,2.13,2.14,2.15,2.22) Made it difficult for you to move or turnover in bed	2.12 (2.2,2.5,2.6,2.8,2.9,2.10,2.11,2.13,2.14,2.15,2.23,2.25) Made it difficult to get in and out of a car or other similar vehicle	2.13 (1.78,2.2,2.3,2.5,2.6,2.8,2.9,2.10,2.11,2.12,2.14,2.15,2.16,2.17,2.20,2.23,2.24,2.25) Made it difficult for you to bend down	2.14 (1.12,2.2,2.3,2.5,2.6,2.8,2.9,2.10,2.11,2.13,2.15,2.23,2.25) Made it difficult for you to get out of the bath or the shower, whichever you use most frequently
2.15 (1.78,2.3,2.5,2.6,2.8,2.9,2.10,2.11,2.12,2.13,2.14,2.20,2.23,2.25) Made it difficult for you to do up buttons	2.16 (1.78,2.9,2.17,2.22,2.23,2.24,2.25,2.30) Made it difficult for you to cut up food	2.17 (1.77,2.10,2.13,2.16,2.20,2.21,2.22,2.24,2.25,2.28,2.29,2.30,2.31) Makes it difficult for you to swallow some types of food	2.18 (2.19)
2.19 (2.18) Limited your ability to wash your hair	2.20 (1.78,2.13,2.15,2.17,2.21,2.22,2.23,2.24,2.25) Limited your ability to brush your teeth, put on make-up, shave		

<p>2.21 (2.17,2.20,2.22,2.23,2.24,2.29,2.30) Limited your ability to wash the top half of your body</p>	<p>2.25 (2.2,2.6,2.8,2.9,2.10,2.12,2.13,2.14,2.15,2.16,2.17,2.20,2.22,2.23) Affected your bladder function</p>	<p>2.29 (2.17,2.21,2.22,2.24,2.28,2.31) Limited your ability to use both hands together when doing things</p>	<p>2.22 (2.10,2.16,2.17,2.20,2.21,2.24,2.25,2.29,2.30) Limited your ability to wash the bottom half of your body</p>	<p>2.26 (2.27) Affected your bowel function</p>	<p>2.30 (1.77,2.16,2.17,2.21,2.22,2.28,2.31,2.32) Made it difficult for you to hold things</p>	<p>2.23 (1.78,2.9,2.10,2.12,2.13,2.14,2.15,2.16,2.20,2.21,2.23,2.24,2.25) Limited your ability to dress the top half of your body</p>	<p>2.27 (2.26) Limited your ability to write</p>	<p>2.31 (1.77,2.17,2.28,2.29,2.30,2.32) Made it difficult for you to carry things</p>	<p>2.24 (1.18,1.78,2.8,2.10,2.13,2.16,2.17,2.20,2.21,2.22,2.23,2.25,2.29,2.30) Limited your ability to wash the bottom half of your body</p>	<p>2.28 (2.17,2.29,2.30,2.31) Made it difficult for you to grip things tightly (e.g. turning on taps)</p>	<p>2.32 (2.30,2.31) Limited how far you are able to walk</p>
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Appendix 5

	People living with dystonia	Patient support organisations	Doctors	QOL researchers	Pharmaceutical companies	Government
People living with dystonia	<p>↔ Through local groups and the Society newsletter: Support, advice, reduced sense of isolation, shared sense of struggle (anti-medical subculture)</p>	<p>→ Reason for existence, political credibility, direct funding and justification for fundraising, trustees and other volunteers</p>	<p>→ Support for expansion of clinical services and medical control over prescribing, participants in clinical trials, objects of study</p>	<p>→ Interviews for /validation of DysQoL measure, survey respondents for the dystonia QOL questionnaire</p>	<p>→ Customers (accessible through direct marketing or the Society), allies for submissions to NHS or NICE</p>	<p>→ Political credibility and support where interests coincide, consultancy, reduced burden on NHS from "expert patients"</p>
Patient support organisations	<p>→ Opportunities to meet people living with dystonia and doctors, reduced sense of isolation, validation, advice, information, support, occasional grants/events, volunteer opportunities</p>	<p>↔ National and international organisations like the Neurological Alliance, European Federation for Neurological Advocacy, and European Dystonia Federation provide training, share information, opportunities to find partners for campaigns, joint approaches to supranational governments and funding bodies</p>	<p>→ Provide access to people living with dystonia, funding for research, clinical services and training, support for expansion of clinical services, credibility for grant applications, information ("diagnosing dystonia" leaflet) and training (GP seminars), and manage the demands of people living with dystonia</p>	<p>→ Provide access to people living with dystonia, funding, credibility for grant applications, market for research (e.g. awareness campaigns)</p>	<p>→ Connections give them credibility with patients, doctors and regulatory bodies</p>	<p>→ Political credibility and support where interests coincide, consultancy, reduced burden on govt. by supporting people living with dystonia and encouraging "self-help" philosophy</p>
Doctors	<p>→ GPs provide access to neurologists and ongoing support, neurologists diagnose (personal and social validation and access to support services)</p>	<p>→ Speak at the Society meetings, write articles/publications, members of medical advisory committee, increase knowledge about dystonia and raise</p>	<p>↔ National and international organisations like the Association of British Neurologists and Movement Disorders Society provide</p>	<p>→ Important customers, collaborators and intellectual influence (through primacy of the biomedical model in QOL), provide access to people living with dystonia, new sources for grants and fora for research</p>	<p>→ Important customers and collaborators in research and submission to regulatory bodies, access to people living with dystonia</p>	<p>→ Run the NHS and affect the cost of the health service, can provide support for govt. initiatives or challenge them (in the name of the</p>

	and treat with drugs or injections	awareness through research publications	training, authorise and disseminate research through journals and conferences, and find partners for research	dissemination		patient)
QOL researchers	→ Raise awareness of dystonia and its severity increasing popular sympathy and understanding and increasing rates of diagnosis and social and medical provision	→ Provide data for campaigning and submissions to NICE, raise awareness of dystonia and its severity (raising the Society's profile)	→ Research collaborators, provide ethical credibility (especially on grant applications), inexpensive outcome measure for clinical trials	↔ National and international organisations like Oxford Centre for Research and Dissemination and ISOQOL provide training, share information, opportunities to authorise and disseminate research through journals and conferences, find partners for research and funding from pharmaceuticals	→ Provide measures for clinical trials and submissions to regulatory bodies, credibility from using patient-based measures	→ Provide data that supports govt. initiatives, inexpensive method of assessing new interventions and allocating resources, using discourse of QOL and the "voice of the patient" politically advantageous
Pharmaceutical companies	→ Sponsor the Society's events and literature, develop new products for people living with dystonia	→ Sponsor the Society's events and literature (the Society survey, "living with dystonia" booklet), and international events, develop new products for people living with dystonia	→ Fund research, clinical services, patient information, medical organisations, conferences, seminars, govt. accredited training, and events (involving lavish hospitality)	→ Fund research and dissemination, QOL organisations and events, major client for QOL research (in clinical trials, regulatory submissions and advertising)	↔ Joint submissions to regulatory bodies (medicine controls agency and NICE) and funding for medical conferences	→ Major UK employer and exporter
Government	→ Healthcare, social security benefits and assistive devices, control access to injections and new treatments like deep brain stimulation	→ Economic advantages of charitable status, funding for joint projects like the "Expert patient" scheme, enables the Society to demonstrate political power which enhances their credibility	→ Employment, professional status through initial training, General Medical Council registration, and accreditation for "continuing medical education", funding for clinical services	→ Funds research through Health Technology Association and Medical Research Council, NHS major client for QOL research, directly and indirectly (through NICE)	→ Main customer through NHS, approves new drugs, supports expansion of the industry in the UK and overseas for economic reasons	↔ Collaborates on international projects with EU and WHO, benefits from international funding, research, and tools for health policy like the Disability Adjusted Life Year

Key:
→ what they give to the body at the head of the column
↔ what they share

1.85 (1.86) Difficulties planning things in the future (e.g. going away for weekends or holidays)	1.86 (1.85, 1.87, 1.88) Uncertainty about what the future holds for you	1.87 (1.86, 1.88) Difficulty going out spontaneously (e.g. going out on the spur of the moment)	1.88 (1.86, 1.87, 1.90) Having to use a wheelchair
1.90 (1.88) Unpleasant side effects of MS drugs	1.91 (1.92) Financial difficulties because of your MS	1.92 (1.91) Difficulties getting answers from doctors about your MS	
1.96 (2.1) Tinnitus (ringing in the ear)	2.1 (1.96, 2.3, 2.6) Limited your ability to do physically demanding tasks		2.2 (1.12, 2.3, 2.5, 2.6, 2.8, 2.9, 2.10, 2.11, 2.12, 2.13, 2.14, 2.15, 2.23, 2.25) Limited your ability to walk
2.3 (1.11, 1.12, 2.1, 2.2, 2.4, 2.5, 2.6, 2.8, 2.9, 2.10, 2.11, 2.13, 2.14, 2.15, 2.25) Limited your ability to run	2.4 (2.3) Limited your ability to climb up and down stairs	2.5 (2.2, 2.6, 2.8, 2.10, 2.11, 2.12, 2.13, 2.14, 2.15) Made standing while doing things more difficult	2.6 (1.12, 2.1, 2.2, 2.3, 2.5, 2.8, 2.9, 2.10, 2.12, 2.11, 2.14, 2.15) Limited your ability to sit
2.7 (2.8) Made it difficult for you to get up from sitting	2.8 (1.78, 2.2, 2.3, 2.5, 2.6, 2.9, 2.11, 12, 2.13, 2.14, 2.15, 2.23, 2.24, 2.25) Made it difficult for you to sit up from lying	2.9 (1.78, 2.2, 2.3, 2.5, 2.6, 2.8, 2.10, 2.11, 2.12, 2.13, 2.14, 2.15, 2.16, 2.23, 2.25) Made it difficult to transfer into and out of a chair or wheelchair	2.10 (2.2, 2.3, 2.5, 2.8, 2.9, 2.11, 2.12, 2.13, 2.14, 2.15, 2.17, 2.22, 2.23, 2.24, 2.25) Limited your balance when standing or walking
2.11 (1.12, 2.2, 2.3, 2.5, 2.6, 2.8, 2.9, 2.10, 2.12, 2.13, 2.14, 2.15, 2.22) Made it difficult for you to move or turnover in bed	2.12 (2.2, 2.5, 2.6, 2.8, 2.9, 2.10, 2.11, 2.13, 2.14, 2.15, 2.23, 2.25) Made it difficult to get in and out of a car or other similar vehicle	2.13 (1.78, 2.2, 2.3, 2.5, 2.6, 2.8, 2.9, 2.10, 2.11, 2.12, 2.14, 2.15, 2.16, 2.17, 2.20, 2.23, 2.24, 2.25) Made it difficult for you to bend down	2.14 (1.12, 2.2, 2.3, 2.5, 2.6, 2.8, 2.9, 2.10, 2.11, 2.13, 2.15, 2.23, 2.25) Made it difficult for you to get out of the bath or the shower, whichever you use most frequently
2.15 (1.78, 2.3, 2.5, 2.6, 2.8, 2.9, 2.10, 2.11, 2.12, 2.13, 2.14, 2.20, 2.23, 2.25) Made it difficult for you to do up buttons	2.16 (1.78, 2.9, 2.17, 2.22, 2.23, 2.24, 2.25, 2.30) Made it difficult for you to cut up food	2.17 (1.77, 2.10, 2.13, 2.16, 2.20, 2.21, 2.22, 2.24, 2.25, 2.28, 2.29, 2.30, 2.31) Makes it difficult for you to swallow some types of food	2.18 (2.19)
2.19 (2.18) Limited your ability to wash your hair	2.20 (1.78, 2.13, 2.15, 2.17, 2.21, 2.22, 2.23, 2.24, 2.25) Limited your ability to brush your teeth, put on make-up, shave		