

HOPE:
VALUING LIVES AND PERSONS WITH DEGENERATIVE CONDITIONS –
DUCHENNE MUSCULAR DYSTROPHY

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ABSTRACT

Duchenne muscular dystrophy (DMD) is a life-shortening genetic condition involving progressive muscular wasting for which there is no hope of recovery at present. The lives of people with DMD, cherished by their families, are systematically marginalised and undervalued by healthcare bureaucracies while enrolment in clinical trials of new treatments offers possibilities of longer-term biomedical solutions. How is hope preserved under such circumstances and what activities can promote a full and meaningful life for those with DMD? Ethnographic research within the DMD community in Aotearoa New Zealand provided a basis for addressing these questions and for understanding different concepts of hope and social suffering, the value of life in DMD and disability studies, and how these are shaped by regimes of governmentality.

Keywords: Aotearoa New Zealand, disability, hope, governmentality, muscular dystrophy

INTRODUCTION

Inside Auckland's Spinal Rehabilitation Unit, team members with various neuromuscular conditions and their supporters gathered for powerchair soccer. When this research began, the Auckland team was one of only two New Zealand teams. The sport was often a family affair with players arriving in their soccer uniforms with parents, partners, and other family members who set up goals on the court inside the rehab unit and attached large metal footguards to the footplates of the powerchairs. The playing area was clearly designed for basketball and was edged by physiotherapy machines and equipment.

Both players and supporters were often fans of other, more traditional, New Zealand sports, such as rugby, netball and basketball, and brought those eagle fan eyes to this game. Detailed discussions of chair and footguard capabilities ensued on the sidelines as the players – adults, teens, and children – rolled onto the court. Each week a parent filled the position of coach/referee. Practice began with passing, marking, blocking and shooting drills as the players honed their skills, spinning the chairs around the court and avoiding contact with other players. Powerchair soccer involves speed; players race around the court using their chair controls to intercept and pass the ball, but contact with other chairs is not allowed. The ball is large, 330 mm in circumference, and especially designed to be hit at high speed by heavy chairs.

After practising, the players divided into two teams of four, the coach balancing experienced and less experienced players. When more than eight turned up for a game, some players would substitute on and off during the match. Powerchair soccer is fast and competitive, requiring good hand-eye coordination. Players follow rules that require keeping distance from other players while darting towards the ball and using the chair controls to swing the footguard so the ball rolls in the correct direction. Like other Saturday morning sports games, the matches are exciting, with players determined to win, and supporters encouraging from the sidelines. Despite such competition, the spirit remained sportsmanlike. ‘Good shot!’ exclamations were called out from all sides when players scored.

‘Perhaps’, commented Kerry (a watching staff member of the Muscular Dystrophy Association) on the soccer-playing boys, ‘they too will be able to tell the class they have been awarded “Player of the Day”’. Kerry also lived with a neuromuscular disorder and loved playing powerchair soccer, volunteering for administrative tasks to enable any youngster with muscular dystrophy to play. He wanted to ensure that the children could go to school and share conversations about weekend team sports. From his own childhood, he knew how important this was.

One family described the enormous change in their son’s life when he became involved with powerchair soccer. They recalled how he was becoming isolated, wanting only to play on his computer and losing touch with friends who had developed new interests that he could not participate in. Playing powerchair soccer gave him something to anticipate each week. It increased his social networks and gave him pleasure and enjoyment. Other parents noted how finding a sport their boys could play helped enormously with their confidence. For these boys, sport was one way of providing a meaningful, purposeful life in

the present and near future. This was hope in action, allowing the boys to live what was for others an ordinary life. As a young Australian powerchair soccer player in the same league, Taylor (2019) wrote:

It is a fun, fast-paced game that gets you out of the house. [...] We have developed so many amazing friendships and connections that I know will last forever. [...] I'm so close now with my teammates. Another reason why powerchair soccer is so incredible is the support that you get from and give to each other. We all have struggles, and we lean on each other's backs when we need additional support.

This statement echoes similar off-the-cuff comments from the young players in Aotearoa New Zealand: for example, one young player used his eligibility for Make-A-Wish⁶ to get a top-of-the-range sporting powerchair for international competition.

Not all participants in this research project played soccer. One composed electronic music. Others designed websites. Another used a 3-D printer and was experimenting with creating devices that would enhance his and others' independence. Others took pride in their academic achievements. Still others found meaning in their spiritual development and participation in their churches or other community groups. Whatever they engaged with, these boys and the people who supported them were intent on living meaningful and valued lives in a variety of contexts, as our article explores.

APPROACHES – METHODOLOGICAL

As part of her doctoral research in Anthropology, the first author adopted a multistranded methodology (Gupta and Ferguson 1997, 37), which involved three interconnected fieldwork sites. Over the course of a two-year research process, she volunteered with the New Zealand Muscular Dystrophy Association (MDA) (Fieldwork Site 1), participated in community events (Fieldwork Site 2), and conducted interviews with people in the community, both families and professionals (Fieldwork Site 3). The MDA agreed to all of this involvement, understanding that it was part of her doctoral research and that members' privacy would be protected. For this anthropological fieldwork, in accord with our ethics agreement, no children under the age of 16 were interviewed, but the parents of those under 16 years were. As the DMD community in Aotearoa is small, a decision was made not to identify families by ethnicity. In some cases, there was only a single family of a particular ethnic group and thus their anonymity would be compromised by ethnic identification. In line with the

condition, a random cross section of Aotearoa New Zealand ethnicities was involved, including a proportion of Māori, Pākehā and Pacific Island families. There were distinctive ethical considerations involved in this research because of the emotional intensity of the field and its inevitable spiral of grief (Longmuir 2016, 44). The research was based on an Anthropological field that followed the families but went beyond them to include advocacy and support agencies. The research was primarily New Zealand-based but had tendrils that extended to international networks. Due to the fieldwork and analysis being conducted by a Pākehā group of researchers, it was deemed inappropriate (Heaton, 2018) to pursue a Kaupapa Māori research analytic.

DMD is a mutation of the dystrophin gene on the X chromosome and has an incidence of 1 in 3600 males in Aotearoa New Zealand. It is a severe form of muscular dystrophy in which not enough dystrophin is produced to maintain muscle function. Just over 100 people live with DMD in the country. There are an estimated 1800 mutations in this gene, which is the largest gene in humans (Nowak and Davies 2004). Boys with the mutation usually start showing symptoms before age six, and by age 12 most will be in wheelchairs. Breathing difficulties, heart problems, and many other issues must be contended with. Seldom do these young men live beyond 30 years.

The first author's research included 41 semi-structured conversations with young men aged 16 years and over, parents of younger children (aged from one to 15 years), parents of deceased men, health professionals, and others involved with the DMD community. Besides the young men themselves, key participants included family members, grandparents, parents, siblings and other support people, and some of the MDA staff and members. Their experiences provide the grounds for this article. Research participants chose whether to be named in publications or to have pseudonyms. Fieldwork was nationwide, involved extensive travel, and extended into Australian and world neuromuscular organisations. The first author completed this fieldwork in 2016, but her engagement with the community continued. She and the second author drafted the article. All authors contributed ideas and information according to their expertise as the project and the article progressed and reviewed and commented on several drafts.

APPROACHES – CONCEPTUAL

Ethnographic data about those living with DMD and trying to live good, meaningful lives in the face of their diagnosis challenged us theoretically. Our conceptual framework was guided by considerations of how to preserve the posi-

tive, worthy lives encountered during fieldwork. Without downplaying the pain of DMD, we wanted to contribute to an anthropology of hope rather than solely to studies of the ‘suffering subject’ (Robbins 2013). We worked with the key concepts of hope, moral laboratories, social suffering, governmentality and value to achieve this goal.

Everyday activities, such as powerchair soccer, can be best understood through the lens of hope: the type of hope that Good and colleagues (1990) discovered working with oncologists – a broad idea about making life better. It is not about prolonging life as a goal itself but about hope for positive and rich experiences, a life well-lived, and good relationships. In the context of a team sport or shared activity such as making music, religious observance, or designing websites, hope is about the capacity to trust in mutual support and to overcome barriers (Mattingly 2010).

Hope is a complex moral concept, fundamental to human existence, but requiring delicate and practised work to navigate the local normative contradictions of embracing too much or too little of it when living with chronic conditions (Eaves, Nichter, and Ritenbaugh 2016). Like Hage (2003), we acknowledge its contingent nature and the role of the state in providing the conditions for hope. Hope also underpins the struggles of marginalised communities for recognition and inclusion (Mattingly 2014) and for rebuilding lives harmed by historical trauma (George *et al.* 2014). Novas (2006) developed a similar concept in relation to patient organisations, noting their lobbying and support of scientific research were often based on hope: hope that such efforts would facilitate effective treatments and reduce suffering. As he argued, ‘the hope invested in science is not only an aspiration, but can also be thought of as having a political and economic materiality’ (Novas 2006, 289). This form of collective hope in relation to biomedical developments that relieve physical limitations and prolong valued lives was also evident in the MDA. As we discuss below, hope can also be dashed and circumscribed by the harsh realities of DMD, technological timeframes or failures, and by ‘bureaucratic indifference’ (Herzfeld 1992).

Mattingly’s (2014) concept of ‘moral laboratories’ proved helpful for interrogating the paradoxes of hope. This concept highlights the moral decision-making families undertake in creating a good life when facing the predicaments that arise when children have a progressively worsening health condition. Beset with uncertainty, these families must experiment with ways to make fulfilling lives.

What informed the moral reasoning of families and caregivers supporting sons, brothers and clients/patients with DMD was the value they placed on the lives of the boys and young men. Their aims were to enable good days and meaningful lives, often encapsulated in the concept of hope, understood as both orientation and moral practice (Good *et al.* 1990; Hage 2003; Mattingly 2010). Bringing Hage's state-level work on hope in conversation with 'care' as conceptualised in Mattingly's family-level work on moral laboratories offers a powerful analytical framework that also highlights how spaces of hope can be created that challenge the tendency to devalue certain lives.

Powerchair soccer works as a site that exemplifies what Mattingly highlighted as a moral laboratory. Through participating in a team that was part of a wider league, including Australia, boys, their parents, and community workers partake in the process of becoming moral, acting in ways they considered ethical, of benefit to themselves and to the wider community. They were defining lives with DMD in terms of what the boys could *do*, rather than what they were no longer capable of – all the while aware of the morality of their decisions. Hope here emerges not only as affect and orientation but also as hard work.

For the DMD community, hope is entwined with pain and grief. The progressive nature of DMD causes physical and psychological pain. This is a constant feature of life. Yet, as Tom Shakespeare (2012, 2013) cogently argues, the impacts of such pain are intertwined with social suffering (Kleinman, Das, and Lock 1997) caused by those societal features which are disabling and devalue the lives of people with conditions like DMD. Just as a caring society can nurture hope (Hage 2003), social suffering increases where care is absent.

Buch (2015, 280), reviewing the concept of care in anthropology and aging, finds that despite the diversity of approaches to care, they all involve a concern with the social constitution of personhood, of social relationality: they are about looking after 'the space between', relevant to many cultures within the DMD community in Aotearoa New Zealand. As Mol explains (2008, 53), the logic of care is about living and about making living bearable, or as bearable as possible. While acknowledging the realities of DMD, including failures of care, we follow Robbins (2013, 457) in examining how people 'strive to create the good in their lives'.

Social suffering among these young men, their families, and caregivers centred around the effects of dealing with Aotearoa New Zealand's health and disability systems. These institutions can either alleviate or increase suffering and are visible manifestations of how societies value different lives. Social suffering

enabled us to conceptualise the specificities of DMD as inseparable from the systems created to deal with disabilities. Here, theories of governmentality help explain the disconnect between the declared intention of policies and service providers and the experience of families.

Foucault (1991) used governmentality to describe how modern states exercise disciplinary control over individuals and populations. Governmentality also refers to the ways that subjects are mobilised to govern themselves; power is not only imposed from above but also enacted through daily routines and norms of conduct. Governmentality can ‘concern one’s relation to oneself, interpersonal relations that involve some form of control or guidance, and relations within social institutions and communities, as well as relations concerned with the exercise of political sovereignty’ (Tremain 2005, 8). It includes meticulous attention to economic detail, often seen in careful allocations of capped budgets. Bureaucrats demand comprehensive documentation to ensure eligibility criteria are met and prioritisation of service can be ensured. Value is central to such calculation. The state requires that painstaking reporting and auditing processes are followed. This system of organising society is a complex form of power governed by the principles of political economy and efficiency (Foucault 1991, 102).

Governmentality helps explain the lack of fit between the needs of people with DMD and healthcare provided under a neoliberal system of government. This is an anomalous group within the population, and government systems are not designed to meet exceptional or unusual needs. Their equipment and support needs are costly and often not adequately met. Families had to deal with complex and contradictory regulations, multiple agencies, and cost-constrained technologies. As Fitzgerald (2004) demonstrated in a New Zealand hospital system, many financial and behavioural requirements work to discipline health agencies themselves by constraining or enabling their work.

Foucault’s governmentality provides a useful way of understanding the rationality that shapes health and disability policies and services. It also reminds us that while the state provides health assistance and ensures a general level of security, these are not tailored to specific individual needs. Commenting on Foucault, Shore and Wright (1997, 10) note that while state policies are typically presented as ‘pragmatic, functional and geared to efficiency’ and couched in the technical and neutral language of economics, they are usually morally loaded and conceal or obscure political and ideological agendas. A key aspect of neoliberal governmentality is its emphasis on inculcating dispositions that lead people to take responsibility for themselves, which is problematic for those with

DMD. As Trnka and Trundle (2017) have critiqued, neoliberal responsabilisation obscures the competing responsibilities that people have to themselves, to one another, and to various collectivities. In the case of people with DMD, their predicaments prevent them from participating in the workforce, and their lack of income prohibits them from providing services autonomously, or acting as the responsible, self-governing individuals that Foucault identified in lectures on technologies of self (Foucault *et al.* 1988).

The differential valuing of lives (Fassin 2012) that disabled people and their families experience (Scully 2008) afforded ways to understand how people made their decisions in the face of competing responsibilities and paradoxes in how biopower is exercised through policy and practice (Shore and Wright 1997). Fassin's distinction between the value placed on the biological preservation of an individual life and the lesser political valuing of meaningful lives is key in our analysis. Millions may be spent on biomedical-pharmaceutical developments to prolong or save biological life, but every dollar that enhances quality of daily life and social participation of persons with disabilities is hard won. Yet it is the value accorded to the quality of everyday life for people with DMD that is key for them and their families and motivates their struggles with agencies and regulations. This interrelationship between competing concepts of hope and value, social suffering, bureaucratic indifference and governmentality provided the framework through which we came to understand how our participants crafted their lives.

Our area of analysis included not only people involved with DMD but also the health systems, administrators, manufacturers, and purchasers and distributors of equipment and pharmaceuticals, and the equipment itself, such as powerchairs, cough-assist machines, and ventilators. Our approach was to study the assemblage of actors and networks (Latour 2005) created around people living with DMD. This enabled us to follow the interactions between key stakeholders and technologies, and the strategies and tactics that participants in the network pursued. Our field was thus not a geographical location but a conceptual one and an epistemic community that existed both within and beyond Aotearoa New Zealand.

THE HOPE OF BIOMEDICINE

As our opening account of powerchair soccer shows, hope for a good game, a good day, meaningful activity, and quality relationships are key to living with DMD. Hope came in many guises. For our participants, biomedicine also provided hope for medical advances that might reduce pain and prolong life.

Miriam was a key professional in relation to biomedical developments. With a background in genetic counselling, she had developed specialist expertise in biomedical science relating to neuromuscular conditions. In the past she was employed by the MDA as a Programmes and Service Advisor. When this article was submitted, she managed the Neuromuscular Disease Registry and was employed as the Neurogenetic Research Lead at Te Whatu Ora Auckland. She prizes research, participates in it, and was an advocate in the 2011 establishment of the New Zealand Neuromuscular Disease Registry. Miriam said that for a long time there had been little hope for Duchenne patients from biomedicine, but now hope was on the horizon. This was why she worked so hard to enable New Zealanders to participate in trials.

At just over five million, Aotearoa New Zealand's population is too small to sustain clinical trials for any of its less common disease groups, but through national registries, individuals may be enrolled in international trials for treatments that may prolong life and reduce pain. The international work involved went well beyond a register and entailed everything that would help translate research into therapies, including databases of clinical trials and their geographical reach, efforts to reduce duplication of research effort, and a commitment to publishing negative as well as positive results of trials. Involvement by New Zealand health professionals and members of MDA in research, conferences and international communication about neuromuscular conditions both created and enacted hope for the future, including treatment and developments in genetics.

During our research, three boys from Aotearoa New Zealand were enrolled in such trials. One example was with Translarna (Ataluren) designed by the company, PTC Therapeutics, to bypass the stop signal DMD caused in the dystrophin gene (Muscular Dystrophy News 2022). This type of mutation is responsible for about 13 per cent of DMD. The drug may increase the production of dystrophin, delaying the deterioration of muscle function and enhancing the boys' quality of life. Recent long-term, community-based research (Mercuri *et al.* 2020) suggests that it is effective, for example, in preserving the boys' ability to walk for a few more years and delaying the onset of lung and heart disease.

In 2017, the United States drug approval agency (FDA) rejected PTC Therapeutics' application for approval on the grounds that there was not enough information on effectiveness. The company continues to pursue pathways to FDA approval. Since 2014, the European equivalent drug regulator, EMA, has issued annual conditional marketing authorisation for its use by walking patients over two years of age. PTC continues to conduct trials to seek full approval from the

EMA (PTC Therapeutics 2019). Translarna was approved for use by Britain's NHS in 2016. At the time of writing, it has not been approved for use in Aotearoa New Zealand or Australia, but additional New Zealand boys were enrolled in various Australian trials.

The three boys and their families involved in this trial during our research had to travel to Sydney, Australia, every two months to participate. This entailed over three hours' flight time. The drugs themselves (Translarna or a placebo) could be taken daily, but assessing the boys' walking, response times, and general health and any side effects had to be done in Sydney by the clinical trial team. This travel and the monitoring were major logistical feats even in pre-COVID times. Although all the direct costs associated with participation in the trial were covered by the drug company, the incidental costs associated with an adult having to leave the family, such as time off work, paying for childcare for the other siblings, *etc.*, had to be borne by the family. It was part of the work of hope for the boys and those who would come after them with the same mutation. Their other treatments and care, such as their steroids, were ongoing. Pollock, M'charek, and others (2001) discuss biomedicine outside the laboratory, where laboratory-generated knowledge, for example, on genetics, comes to play important and often paradoxical roles in the wider society. They introduce the idea of mobilising (Pollock *et al.* 2001, 436): in their case, of race, but in the context of this article, we suggest that lab-based knowledge, clinical trials and biomedical community research can mobilise hope – or grief – in the DMD community.

When Kunkel first identified the Duchenne gene in 1987 (Schmeck 1988), a wave of hope spread through the community that a cure or effective treatment was on the horizon. However, as Ron, the father of a boy who died in 2009, said, 'they all died away, and [our son] was the only one left'. His wife, Judith, added, 'We did have a lot of hope back then'. Since that time, scientific research has detailed the complexities of how protein synthesis occurs, and how mutations that result in the lack of dystrophin work (Emery and Emery 2011). Community members have learnt how slowly advances are made and how hope often ends in grief. When drugs like Translarna provide a more effective treatment, there is renewed hope. The difficulties of medical research still temper hope, but now that therapeutics are available, regulation and cost create more barriers, providing new examples of how hope can be both created and trammled through institutional means.

In Aotearoa New Zealand, Medsafe approves the use of any new drug, and all approved drugs can be funded only if Pharmac, the national purchasing agency,

agrees (Pharmac, n.d.). Expensive drugs like Translarna, which help just a small fraction of the people with a relatively rare condition, are weighed against drugs for other comparable groups. The largest obstacle to approval is the comparison with drugs that can improve the health of large groups of people at low cost. Since 2016, Pharmac has ring-fenced part of its budget for drugs that treat rare disorders while continuing to fund them from its usual funding streams, and the government has increased Pharmac's general budget. Pharmac's policy exemplifies Hage's (2003) argument about the way governments may distribute hope and demonstrate care, engendering a sense of belonging for some citizens but limiting hope and care for others. That boys in the United Kingdom, any country in Europe, South Korea, and Brazil can obtain Translarna while boys in Australia, Aotearoa New Zealand, and the United States cannot, highlights the global unevenness of access and increases the sense of injustice felt by those to whom it is denied. Within some of those countries where the drug is approved, only the wealthy can access it, but in others with state-funded access, such as Britain, access is based on need.

THE POWERCHAIR – HOPE AND SOCIAL SUFFERING

Similarly, while powerchairs enabled mobility and belonging, paradoxically, for parents of a newly diagnosed boy, they were a focus of grief, signalling what their DMD diagnosis meant. Arriving at a local MDA Christmas function, the first author saw several mobility vans in the carpark and a boy in a power wheelchair being hoisted onto the rear lift of one of them. In a nearby car, a woman sat weeping with a distressed man and two children in the back. The wheelchair boy's mother went to talk to the family. Later, at mealtime, the first author found herself near the mother – Anita – who had been crying. Anita recounted her complete shock at their young son's recent diagnosis as they had no known family history. This Christmas social was their first MDA event, and seeing the mobility vans and boys in powerchairs vividly illustrated their future.

Later, during a conversation in her home, Anita acknowledged how challenging this had been: 'I got in and out of the car three times, just bursting into tears, but once we got in there, it was good.' The woman in the carpark had guessed that their son's diagnosis was recent, and she completely understood what that meant. She said that everyone goes through it. In every interview, parents talked about the grief and despair that they felt as the diagnosis became real.

Once boys grow and begin to find walking difficult, having a powerchair makes a very positive difference to their lives. A chair with good suspension helps reduce daily pain and allows boys to take part in a wider range of

meaningful activities, enabling good days, social participation, and better mental health. For some, a chair capable of outdoor use can relieve the feeling of being trapped inside and enable the benefits of fresh air, work and social independence. As an assistive technology the powerchair is highly desirable and emancipating.

In the process of being prescribed a wheelchair, families with DMD interacted intensely with the state and its agents. Families and boys were concerned to enable hope and create meaningful lives through having good days and rewarding relationships and activities. This is where the moral values of the family rub up against the practices of governmentality through the regulations that enable the provision of services. For example, Harry wanted a chair with better suspension to reduce his back pain. Unfortunately, his quest to avoid pain took him through an intricate bureaucratic maze. Liyanagunawardena (2023) has aptly labelled this struggle to obtain resources ‘wrangling’.

The first step for Harry was a wheelchair assessment undertaken by an occupational therapist or specially trained physiotherapist. This person was employed by Mobility Solutions, which was part of the [then] Auckland District Health Board, one of 20 such boards funded by the government health budget. Although the arrangements differed somewhat in the different Board areas, they followed the national protocols for provision, constituting a national system.

The wheelchair assessor must be familiar with Ministry of Health eligibility criteria and the fiscal constraints of equipment providers. If the assessor concluded that a wheelchair or modification was needed, then an application was made to the private company, Accessible Ltd, which had the contract to provide disability equipment and modification services. This company followed the Ministry of Health’s eligibility criteria and Prioritisation Tool to decide whether it would support the application. The company also researched available chairs to select preferred options that offered the best value for money. About 20 per cent of people would need something more specialised than the preferred ones, and this could be negotiated. Accessible Ltd reported regularly to the Ministry of Health and employed equipment and modification advisors who worked with the wheelchair assessors to ensure that the solutions the assessors designed could be met through the funding and equipment available. The equipment was bought from one of the two private companies that sold wheelchairs and other mobility aids in Aotearoa New Zealand. These companies also employed specialists to provide more sophisticated equipment.

Harry's quest to secure a more suitable chair began when the wheelchair assessor was on six month's leave and was not replaced. Harry's pain was so bad that he approached one of the companies that sold wheelchairs to see if they could give him some ideas about how his pain could be ameliorated. When the assessor finally returned from leave, Harry and his support person offered some possible solutions. However, their initiative was not well received. The assessor dismissed his suggestions, was unconcerned about his pain, and acted like a gatekeeper to the government finances. Harry remarked, 'I felt like I was asking her to spend her own money'. In addition, Harry thought that the only chair the assessor would recommend was solely for indoor use, otherwise he had to keep his current chair which contributed to his pain.

Pain is a difficult phenomenon in disability studies. Not all people with disabilities experience physical pain, but most assuredly, boys and men with DMD do, and their pain is progressive. Disability worlds are plural, as Ginsburg and Rapp (2020) eloquently describe. Siebers (2008) argues that a challenge for theorists and activists is to find ways to represent pain and resist models of the body that blunt the political effectiveness of these representations.

Pain is not a friend to humanity. It is not a secret resource for political change [...] Theories that encourage these interpretations are not only unrealistic about pain; they contribute to the ideology of ability, marginalizing people with disabilities and making their stories of suffering and victimization both politically impotent and difficult to believe. (Siebers 2008, 64)

Siebers cites Wendell who, acknowledging the philosophical limitations of the social model of disability, 'calls for an approach capable of recognizing the "hard physical realities" of disabled bodies' (81). What drove Harry to wrangle solutions was the exacerbation of his physical pain by a chair with poor suspension and it was the indifference of the state agencies and their proxies that compounded the pain. This combined pain and social suffering is part of the disability world of DMD.

When we sought clarification of the wheelchair issue at MDA, we were told that this was not a unique case. Yet Mobility Solutions, who employed the assessor, insisted that the preferred chairs could be used outside, and that 'no-one should be confined inside because of their chair'. The arcane complexities of the allocation system confused all who had to use it. The *Equipment Manual* (New Zealand Ministry of Health 2014) generated divergent understandings. For example, Section 2.3 states:

Funding for equipment can be considered where it has been identified as being the most cost-effective intervention and is essential for the person (independently or with assistance from support people) to do one or more of the following:

The first item on the list, 'get around, remain or return to their home,' appeared to refer to home-based mobility. This interpretation is reinforced by item 2.3.1, which states:

Equipment can be considered to support the person, and/or their primary carer, to manage one or more of the following everyday tasks:

- eating and drinking
- personal hygiene (washing and toileting)
- getting dressed
- transferring from their bed or chair
- getting in and out of and around their home
- preparation of food and drinks, if they live alone or are by themselves for much of the day.

Mobility equipment such as a walking frame or wheelchair may be provided when a person is unable to manage getting around in their home.

Funding is not available for mobility equipment if the person has difficulty getting out and about in their community but can manage getting around in the home, including access to where a vehicle can reasonably be parked.

The manual's eligibility criteria referred to another funding stream, and possibly the specialist needs of young men with DMD might be met by a similar assessment process but funded through a different stream called 'Long Term Supports – Chronic Health Conditions funding' (LTS-CHC, item 7.1.2). The Needs Assessment and Service Coordination (NASC), which was funded by the District Health Board, determined eligibility. In Auckland this was devolved to Taikura Trust, which worked with people under 65 years.

Given this complexity and the numerous organisations involved, it is no wonder that Harry and other members of MDA were confused. Their endless wrangling added to their daily stressors. These specifications created additional constraints for clients as they appeared to assume that people whose disability required a wheelchair to enable them to get around would be confined to the domestic sphere and not participate in the community. Other specifications of eligibility also pertained to how lives of people with disabilities were val-

ued. These were: study full-time or do vocational training; work in full-time employment; work as a volunteer; be the main carer of a dependent person; communicate effectively.

Studying full-time included tertiary enrolment. Full-time work was defined as at least 30 hours a week, and volunteer work as 20 hours a week. Young men with DMD are rarely able to study or work at the rate required. None could be the main caregiver of a dependent. 'Communicate effectively' translates to making 'needs and feelings' known to support their safety and interact more effectively (2.3.6). This precludes wheelchairs.

Under these provisions, a neoliberal workfare rather than a well-being approach to the value of life is clear. Enabling a young man to get around his neighbourhood independently in his self-propelled wheelchair, pursue an interest, engage in part-time work, or play a sport are not considered appropriate criteria. Under Section 7 for chronic health conditions, no such criteria are provided. Instead, the following is required:

An assessment by an EMS [Equipment Modification Service] Assessor who has identified that the person has an essential need for, and an ability to benefit from the equipment, and the outcome of the Prioritisation Tool has indicated that funding is available, and [they have] been identified by their local DHB NASC as being eligible for LTS-CHC funding. (7.1.2)

Whether 'essential need' acknowledges quality of life or well-being features as a priority is unclear.

The Prioritisation Tool was developed 'to prioritise access to EMS services based on client need, risk and ability to benefit' (New Zealand Ministry of Health 2015). The tool renders its assessments scientific while concealing the values the prioritisation is based on. As a replacement for a 'first in, first served' approach, it was evaluated as desirable (New Zealand Ministry of Health 2012, 5). This tool added another dimension to the way this population has been subjected to ever more precise disciplinary measurements and to the assemblage of governmentality techniques that determine how people with DMD are valued in practice (Foucault *et al.* 1988; Foucault 1991). Wrangling with the complexities of the bureaucratic processes, time, stress, exhaustion, and anxieties over whether a young man would qualify for needed equipment were part of the social suffering of the families and their sons. For them, this was living with DMD.

Olivia and her husband Dean were talking about the challenges of having four children, one with DMD. Olivia: 'I find it frustrating [...] getting them to understand what daily living is like. You are giving [Stan, their son with DMD] daily medicine and ringing people and filling in forms and trying to stay on top of things as well as managing family life. [...] Dean: 'So Dad might pop round after work and the house will be a mess. [...] And she will have sat at the computer all day. [...] We had to get a computer because Olivia needs it to run Stan's life.'

Similar social suffering was evident when trying to obtain better equipment to assist breathing and coughing, hoists for wheelchairs to get into vans, vans capable of accommodating hoists, bridging the gap between care in the community and care in the hospital, and receiving high-quality hospital care in a crisis (Longmuir 2016). One young man disclosed that one reason why he hated being admitted to hospital was because some staff did not think his life was worth living: they could not see past his disability, his wheelchair, his ventilator, his carers, and the fact that he needed help with eating and toileting: 'They just look at us and think we are not really living.'

Scully (2008) usefully distinguishes between a more conventional ethics of disability and disability ethics. The former is the philosophical consideration of the way disabled people should be treated. Common metaphors based on a 'normal' body carry embedded moral meanings, such as being 'upright' or 'standing on your own two feet' (p.100). One can surmise, therefore, that different bodies embed different moral meanings. The alternative disability ethics that Scully (p. 11) advocates entail

Look[ing] at the embodied effects of impairment [...] working from people's experience of disability to see if and how it colors their perceptions, interpretations, and judgements of what is going on in moral issues that have direct relevance to disability and where differences in the experience of disability might be expected to have weight. (Scully 2008, 11)

For boys like Harry and powerchair soccer players, powerchairs are both symbols *of* hope and technologies *for* hope. Their provision is a moral act of love and care. Yet, for those outside this community, wheelchairs evoke loss and grief. Even for people with a physical impairment, wheelchair use may signify giving in or surrendering independence, because of the symbolism that surrounds them (Scully 2008). This was the case for a New Zealand man with haemophilia, described by Park and colleagues (2019, 83), who delayed mov-

ing into a wheelchair long after it would have assisted him. Once used to his chair, he found he could be more helpful to others, such as by taking a cup of tea to his wife. The meaning of a wheelchair changed for him too, over his lifetime, as did the moral salience of ‘standing on your own two feet’. A high value on uprightness is by no means confined to Aotearoa New Zealand and Australia. Kohrman (2005), for example, discusses this value for post-polio men described as *canji* who speed around on motor trikes in China, reminding us of the powerchair users.

VALUES

The subject of having children affords a poignant way to bring together several themes in this article and demonstrates the dilemmas and dynamism of family moral laboratories given the contrasting contexts we have described. It reveals different views and tensions within the DMD community, more so than any other topic canvassed.

Both Scully’s (2008) disability ethics and ethics of disability were evident in this moral reasoning. People living with the daily cares of DMD develop in their moral laboratories experiential ethics, especially in the context of reproductive technologies. A mother and grandmother exclaimed: ‘I mean all those people that talk about ethics, [...] they have absolutely no clue and never will have until they have been in exactly the same situation.’ They show the wide range of values and moral reasonings that can be found in the general Aotearoa New Zealand community (Fitzgerald, Legge, and Park 2015), but, unlike the general population, they have to confront and sometimes change their views in the context of a severe genetic condition. Despite these differences, parents and siblings shared how valuable the lives of their beloved sons and brothers were with DMD, and how important it was to respect the experience-based decisions of others.

Preimplantation genetic diagnosis (PGD) and pregnancy termination for conditions including DMD are available in Aotearoa New Zealand – if a family history of DMD is known. Family stories about reproductive decisions varied greatly. Some individuals’ views remained constant: because of their personal experience they ‘would not knowingly bring a child with DMD into the world’ and would always use prenatal tests or PGD. Others would always avoid prenatal technologies: ‘He is a dude. I know how beautiful my two children are now. I wouldn’t not want to meet one of them’, or ‘He is a gift, no different to any other child’.

Some couples discussed how their responses to DMD and selective reproduction might or did change over time as they experienced parenting a boy with DMD; some who declined testing initially moved towards accepting it for a subsequent pregnancy. Mark and Brenda's boy with DMD was born when they were 'so young and you know, "Nah, it's not going to happen to us"'. They felt marked disapproval and pressure from their parents that they did not use testing then. They anticipated worse parental disapproval if they had another baby with DMD. They had a prenatal test in their next pregnancy and were delighted to have an unaffected girl: 'I just thank God that we didn't have to make that decision [to terminate if a positive boy]'.

In contrast:

If we hadn't experienced Evan and we were about to have a child for the first time and someone said they might have muscular dystrophy, I might have said 'Yes' (to testing). But the reality is that we have lived with a terrific kid. And no matter what the future holds, you would not undo him, so I would say 'No [to testing]'.

The situated nature of this decision-making is notable. Evan's parents imagined a changing moral position on prenatal testing. But the way they grew to value Evan's life prompted them to decline offers of a prenatal test in a subsequent pregnancy. But as many parents explained, like Mark and Brenda, they had to contend with sentiments of anxiety, concern and judgement when they announced the birth of a baby with DMD, eclipsing more usual expressions of joy and hope.

A determination not to have a child with DMD was not a reflection on the value of lives with DMD but was based on an assessment of a couple's ability to bear the grief. In this situation, couples may turn to PGD which, as Franklin and Roberts (2006) describe, is a technology of hope and a treatment for grief. That was the case for one woman, Emma, supported by her husband and her mother, Sarah. Sarah had lost her brother and then her son to DMD, and had supported her carrier daughter, Emma, through three traumatic terminations of wanted pregnancies where the foetuses were affected boys, and then the loss of her brother. Emma's brother supported her decision, but he died before Emma's daughter was born. Emma said that she could not face any more terminations: 'It used to really annoy me. People were like, "Would you not just try again yourself?" I was like, "NO! I will not try again myself". We have been through enough'. Their subsequent PGD-assisted pregnancy which gave them an unaffected daughter was an exercise of hope.

Megan had also grown up with a brother with DMD but had erroneously been told that she was not a carrier. Her first child had DMD. Several years later she became pregnant again but decided against a prenatal test: ‘It just doesn’t agree with me, no it’s not my thing at all. [...] I’ve already done this, dealt with my brother, doing it with Frankie [her son]. To me it wasn’t a big deal, easier said than done though’. Her relief when her second son was born unaffected was enormous. This decision not to test prenatally was difficult. She could not believe her good luck: ‘So I redid the test when he was three months’. For every couple who made one decision, another apparently made the opposite.

Lock and Nguyen (2010, 319) sum up the researcher’s predicament well: ‘People interpret what fate has dealt them in the form of genes in numerous ways. [...] An outsider who tries to generalize about such responses is, it seems, doomed to failure’. Nonetheless, all endorsed the ‘cultural ideal of choice as a symbol of a decent society’ (Fitzgerald *et al.* 2015, 414).

What was common to these families was the love and ties between close family members and the boys and young men with DMD. Sometimes the requirements of care overwhelmed a family member, but their devotion remained. A boy with DMD was not experienced as a burden but as a family member who was sometimes happy, upbeat, funny; sometimes cross, angry, fed up; sometimes focused and busy: an ordinary person. This devotion was the primary motivating factor in the fraught moral laboratory of decision-making about reproduction. Decisions always centred around the experience of a much-loved family member (brother, son, or both) and might change over time as those experiences changed: a highly charged instance of how people create the good in their lives. This way of valuing life, based on caring for a beloved family member, is, we suggest, a fundamental contribution to a comprehensive understanding of how lives lived with DMD are valued within that disability world.

REFLECTIONS

This article addresses contradictions in the way the lives of people with DMD are valued in Aotearoa New Zealand. Within the immediate community of family and friends, these lives are cherished. We discuss this through an anthropological discourse of hope. Considering hope also facilitated an analysis of the advances in care and treatment, including pharmaceutical developments. Immediate family and friends love and cherish the child with DMD with special attentiveness as people with DMD are in need of highly responsive care: each individual life is valued. As the network widens to include those whose relationships are professional, other ideas about the way lives are valued become appar-

ent. Fassin's (2012) insights about the value of life apply: while each individual life is still considered important, the ability to live a meaningful life is often no longer an important part of the calculation. However, as Novas (2006) shows, the involvement of biomedicine and pharmaceuticals also involves a political economy of hope. The desire of members of the community for effective treatments to reduce pain and increase mobility is in tension with economic considerations associated with drug development. However, hope is embedded in both drug development and a desire to reduce suffering.

Those with DMD often fall outside the state's capacity to care: they are a marginal, anomalous group whose needs do not align with the majority population. People with DMD are situated outside the economic rationale that justifies resource allocations in the healthcare system, and their care reflects this bureaucratic indifference. These unmet needs and the challenges people with DMD experience in attempting to access services create further social suffering for lives already imbued with pain and difficulty. Neoliberal policies and the discourses that legitimate bureaucratic interventions effectively authorise forms of social exclusion (Shore and Wright 1997, 11). By creating categories of deserving and undeserving based on utilitarian calculations of costs and benefits, policies governing disability become 'actants' that produce further exclusionary effects (Shore and Wright 2011, 3). The technologies which structure the health system – diverse types of organisations managed by fixed budgets, service specifications, reporting schedules, and policies that determine eligibility and funding streams – remove care from the moral sphere and recast it in technical and financial terms. Hence the technology of the wheelchair and those eligible to be granted one renders compassion a utilitarian concern about budgetary provision.

The moral value of each life lived with DMD should be about enabling people's lives to have purpose and meaning, to be included in society, and to be able to participate in, and contribute to, their communities. However, these values are often replaced by discourses about the pecuniary value of lives (Fassin 2012). Technical considerations about service delivery and what level of provision is affordable supersede moral decisions about how to improve the quality of life. Engaging with theories of governmentality, hope and value enables us to explain the dominance of a technical concern for a utilitarian application of budgets in which services provide the greatest benefit for the greatest number. This rationale for providing services reinforces social exclusion for people with DMD and increases social suffering. The message that the community receives in constantly advocating for barely adequate service provision is that their lives are not fully valued and deemed inconsequential. This contrasts starkly with the way the boys' lives are cherished within the DMD community itself.

As we were readying our article for publication, the government announced major changes in Aotearoa New Zealand's health, disabilities and Pharmac institutions which took effect from late 2022. These changes created a national health system, Te Whatu Ora, a Māori Health Authority, a Ministry for Disabled People, and increased funding for Pharmac, with the aim of achieving equity. For the DMD community, these initiatives offer further hope that the gulf between care and bureaucratic indifference can be bridged and that boys with DMD will no longer think, 'they just look at us and think we are not really living'. Instead, they can be 'player of the day'.

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- 6 Make-A-Wish is a charity whose mission is to ‘create life changing wishes for children with critical illnesses’ (2021, <https://makeawish.org.nz>).

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