

Dystonia: Where Now?

**Strategic utilisation of sport and the media to increase
the awareness of dystonia in the United Kingdom**

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Introduction

Spectacular accomplishments have been witnessed in recent decades into the pathophysiology and treatments for the conditions comprehensively described as dystonia.¹ Such is the pace of discovery that even amongst the rarer monogenic dystonias, over twenty separate genetic loci have been elucidated in less than two decades.^{2,3} Rather than the acceptance of dystonia as an untreatable psychiatric condition⁴, research has challenged beliefs to recognise the condition in the current form as an organic neurological disorder⁵. Equally relentless pursuit by dedicated researchers has explored numerous validated therapeutic strategies, with novel methods uncovered ranging from Botulinum Toxin utilization to Deep Brain Stimulation (DBS) and even the selective surgical intervention rhizotomy.⁶⁻¹²

Statistically the third most common movement disorder¹³ – or put another way; with five times more people in the UK with the condition than all 2012 Olympic and Paralympic athletes combined, understanding amongst the general population is unacceptably poor.^{14,15}

Consider Paralympic champion Anne Dunham's description of her diagnosis,

“My symptoms started when I was in my twenties, more than thirty years ago. They started with a dropped foot and the muscle spasms have since progressed to my leg, shoulder, right arm, hands, face and jaw. At the time, I received a diagnosis of Multiple Sclerosis.”¹⁶

Low levels of awareness are understandable – evidence highlights that uncontrolled physical movements exert a large effect on interpersonal communication and social acceptability,¹⁷⁻¹⁹ with the resultant sequelae of increased social phobia reported by patients with dystonia²⁰. Additionally, authors have exposed the prevalence of

depression amongst those living with dystonia to be significantly increased in comparison to the general population.²¹⁻²⁴ Poor awareness of the condition amongst primary care physicians requires attention, with average delays of four years occurring between presentation and correct diagnosis.^{25,26} Knowledge and diagnostic expertise are inadequate throughout all echelons of healthcare structures, requiring involvement of movement disorder specialists to regularly establish correct diagnoses^{27,28}.

Thus whilst such social stigmatization^{15,19} and mental health disability²¹⁻²⁴ effects our patients, it must no longer persist unchallenged. This essay expounds strategies for implementation across the two broad domains of sport and the media, aimed at tackling social stigmatization and depression experienced by patients with dystonia. Fundamentally these approaches leverage the spectacular accomplishments into the scientific understanding of dystonia, and ensure the translation of these breakthroughs into tangible benefits for those living with dystonia.

Utilising sport for the integration of dystonia into society

Since the inauguration of the Paralympic movement in the 1940s to the finale of London 2012 and the most successful Paralympic games in human history, disabled sport and social integration of those with disabilities has continually broken new territories.³⁰⁻³² Much is owed to the tenacious Sir Ludwig Guttmann at Stoke Mandeville Hospital, who heralded a new era of strategic thinking by implementing participation in disabled sport into the accepted culture of the United Kingdom.³³ The Paralympic movement is now the most powerful international body to continue improving disability rights, increasing accessibility, and forming new paths of social inclusion into mainstream society for those living with disabilities.³⁴

However, whilst reduced psychological wellbeing²¹⁻²⁴ and social stigmatization^{15,29} are still experienced by those living with dystonia, it is imperative that the excellent work initiated by Sir Guttmann is completed, eradicating any inequalities or reduced self-worth experienced by those living with disabilities – in particular dystonia. Let us consider how three well defined levels of sporting ability – from the inexorable pursuit of Olympic glory to grassroots participation each represent an important sphere for the implementation of strategies for increasing social inclusiveness and the psychological well being of our patients.

Olympic sport

Following the magnificent accomplishments of Paralympic athletes Anne Dunham,³⁵ Monique Kalkman³⁶ and Ross MacDonald,³⁷ one briefly shares the euphoria these exceptional figures experience, conquering all on the highest stage in spite of the well studied limitations imposed by dystonia.³⁸ Data evidences the monetary value assigned to Paralympic champions now equates that of Olympic champions, enabling medal winners to demand sums of £10 000 per public appearance.³⁹ But considering the affection of spectators and monetary reward as the biggest accolade for these athletes would be fatalistic. Anne Dunham and colleagues represent the new breed of athletic superstar and for those living with dystonia their gift is that far greater – it is that of role models.

For decades sports sociologists have theorized over the influence of role models on the exceptional over representation of certain groups in particular sporting spheres. Consider crews in Olympic rowing finals – do we truly believe that white athletes from prosperous families are the most physically gifted rowers in the world? Or the track and field sprint finals – do we accept that black athletes from lower social classes are predisposed to just run faster than any other demographic? Gold medal winning South African rower Sizwe Ndlovu and European sprint king Christophe Lemaitre are

just two examples of the flawed logic. Acknowledge is given to those who advance the debate reasoning that genetics and social class really are the decisive factors,^{40,41} but defining evidence from the leading minds in sports sociology expound the reason for such gross misrepresentation as simple – the self fulfilling prophecy of role models.⁴²⁻⁴⁶

Thus the triumphs of athletes at London 2012 who also live with dystonia represent a new paradigm of possibilities and opportunities never before deemed plausible. Newly diagnosed patients are presented with an opportunity – rather than their condition limiting progress, it becomes the determinant creating chances never before in existence. It is crucial that influential bodies such as Dystonia Medical Research Foundation⁴⁷ and The Dystonia Society⁴⁸ lobby the International Olympic Committee to increase the inclusion of athletes with dystonia into all 20 sports at the 2016 games in Brazil. Doing this would build upon the exceptional achievements of our athletes at London 2012, and concomitantly secure a bright future for the next generation of sporting stars living with dystonia.

Mass participation

Olympic and Paralympics legacies provide rich opportunities for those even considering engaging with a sport to get involved.⁴⁹⁻⁵¹ Ben-Shlomo and colleagues²⁴ uncover the marked effect dystonia has self-esteem, self-depreciation, mental health and perceptions of stigma compared to the general population,⁵² which are interpreted as a direct result of the condition. Mass participation sport provides the ideal medium through which these negative entities can be addressed and eradicated from the lives of those living with dystonia.

The benefits of physical activity in reducing depression and anxiety have long been studied with great interest. Such is the powerful effect on combating mental health

illnesses that exercise represents a real alternative to pharmacological intervention,^{53,54} with these findings also applicable to older adults.⁵⁵ Thus the recent increase in opportunities to participate in sport and physical activity creates an ideal avenue for those with dystonia to confront norms dictating that a life with the condition increases the risk of depression and perceived stigmatization. Positive engagement with physical activity and sport permits a gain of the well-known benefits, whilst also creating new links and increasing awareness of the condition amongst the general public through interpersonal communication.

Notable studies link development of stigma to lack of knowledge.^{56,57} As a result of the relatively low profile of dystonia in the UK, enacting change in recent times has proven laborious, due to interaction between those with dystonia and the rest of the population tending to be one of passive observation on the part of the population. By increasing the numbers of our patients who publicly engage in sport, many more opportunities for education exist, enabling discussions regarding the condition and thus education to be provided, debunking the myths surrounding dystonia and providing an accurate representation of the condition to those with a knowledge gap to fill. By increasing the numbers of our patients actively participating in sport the factors of depression and social stigmatization as reported by dystonia patients²¹⁻²⁴ can be addressed and conclusively altered. This would permit our patients to experience the world in a new way, eradicating stigma and combating depression, ensuring that those with dystonia experience a world cleansed of inequalities.

Grass roots

Utilising sport as a method for the installation of principals, challenging beliefs and traversing boundaries has been recognized for centuries. Since the 1800s when Thomas Arnold advocated “Muscular Christianity” as a principal for raising young

men^{58,59} to the national curriculum of today,⁶⁰ incorporating sport into the process of education has long been regarded as a vital measure.

Policies for tackling behaviour incorrectly enshrined in popular culture include the Let's Kick Racism out of Football campaign.⁶¹ In tandem with adult level initiatives, the football community recognised that targeting the grass root⁶² level where the next generation of footballers and supporters existed was the most efficacious method of implementing long term change. Thus rather than forcing someone change, they provided circumstantial change, thereby shifting the norms of those developing incorrectly into a predefined role.

Application of this principal is warranted when combating the social stigmatization and exclusion reported by those living with dystonia. It is our duty to bring together those with dystonia and able bodied children to engage in sport together, giving our future generations the opportunity to perceive dystonia no longer as a condition that makes someone different, but as a positive personal attribute. Enablement of tomorrow's adult society to interact comfortably with those living with dystonia secures a platform upon which future generations of people experiencing the condition are treated as equal to their peers.

Education, education, education

*"Though it cost all you have, get understanding."*⁶³

Throughout history the fruits of knowledge and understanding have long been espoused, with civilizations as early as the ancient Greeks understanding the value of widespread education irrespective of social divide.⁶⁴ Development and expansion of the Roman Empire was impossible without the thorough education of it's citizens,⁶⁵

with little change to the theoretical approach between then and recent installations of British Government delineating their three priorities whilst in power as, “Education, education, education.”⁶⁶

Early models of child development evidence social learning as the most useful tool to challenge behavioural norms accepted by a peer group, and modify understanding to incorporate a new belief model.⁶⁷ Thus it is clear – a core strategy in tackling the lack of awareness and social exclusion experienced by dystonia patients must be education, education, education. This secures the transmission of knowledge, challenges currently held societal norms and lay beliefs, and equips those with no background in the area with sufficient information to engage with people living with dystonia. Fifteen years ago New Labour recognised the necessity of internet communication, including in their manifesto a proposition for a National Grid for Learning online.⁶⁸ We must move swiftly to harness the immense power of social media presence and leverage it our advantage, educating and informing society regarding dystonia. The use of three free social communication tools as methods to disseminate knowledge regarding dystonia will be explore.

Facebook

$$E_A = \frac{1}{1 + 10^{\frac{R_B - R_A}{400}}}$$

Ever since a Harvard sophomore scrawled the formula above on his dormitory wall to develop facemash.com, social communication has never been the same. The sophomore is better know as Mark Zuckerberg, and his more famous invention is that of Facebook.⁶⁹ 584 million daily active users and over a billion members from every country on earth⁷⁰ make Facebook presence a 21st century necessity. The concomitant rise of Twitter with 500 million users and growing, determines social

media as representative of a new frontier in global information transmission. Most notably utilized for human empowerment and education during the Arab Spring,^{71,72,80} the power and presence of social media must no longer be underestimated. A recent study points to 87% of doctors interacting via social media in their personal lives,⁸¹ but a mere 26% using more than two sites to connect professionally.⁷³

My proposition is to build upon the exemplary work initiated by the Dystonia Medical Research Council by establishing an active Facebook community, daily connecting those living with dystonia to the wider population. The simplest and most effective methodology is for creation of a Facebook resource from a highly credible resource such as The Dystonia Society, followed by invitation of all in the UK with the disease and access to the internet to join and enjoy free membership. This occurrence would concentrate up to 70 000⁴⁸ users together, forming an alliance to discuss their condition and share experiences. US data delineates that healthcare groups possess the ability to grow user numbers by a mean of 23.2% per quarter.⁷⁴ Thus successful replication of this growth strategy into the education of the public regarding dystonia enables the potential for a Facebook based web resource that in one year *of average growth* would engage over 160 000 users researching and understanding about living with dystonia.

Twitter

A further avenue for development is an expansion upon the “Hello Health” system of healthcare communication available in the United States. This Brooklyn based primary care practice is responsible for the implementation of software permitting interaction with their patients out of work hours, enabling fast, free and effective dissemination of expert advice for simple problems via social media.⁷⁵ A proposition for the integration of this framework to raise awareness amongst the general public

about dystonia is the creation of a “Sunday Surgery” conducted via Twitter. Realisation of this concept is elementary – someone living with dystonia and access to a freely created Twitter account endorsed by the dystonia community is all that is required for success. Dystonia.co.uk, the Dystonia Facebook group and other linked members would advertise that a discussion is scheduled for 7pm each Sunday under the hashtag #dystonia.

If this initiative was conducted correctly and engaged sufficient users appropriately, this surgery would provide the fastest, most engaging method for those with questions to connect with dystonia sufferers. This is certain to debunk the myths and uncertainty that surrounds much of the lay beliefs and informs the stigma held by many people unaware of dystonia. As an example of the simplicity, the power of twitter and speed of realising this proposition, contact me now @ferg1986 to explore the requirements to make this concept a reality.

YouTube

Platforms on Web 2.0 such as YouTube provide an unrivalled educative tool for disseminating vast amounts of information in ways never before possible. Research highlights the efficacy of using mediums such a YouTube in the advancement of understanding amongst the next generation of doctors – 58% currently use YouTube to inform their professional studies⁷⁶. As a forward thinking community we should chose to build upon the evidence and resources freely available and utilize the power of YouTube as medium for educating about dystonia. Some users have already engaged with YouTube to share their experiences and stories about living with dystonia⁷⁷⁻⁷⁹ with a current combined figure for the three most popular videos of 170 803 views evidencing the power of this resource.

Part of our future direction could include a weekly diary from a person with dystonia, sharing the experiences they have and informing the viewers on the reality of existence with the condition. Creation, verification and explanation of these videos by the dystonia community would herald a new era of education on the condition, concomitantly stimulating debate and thus incorporating awareness of the dystonia into the public domain. Successful completion would serve to benefit not only those educated by the measures, but also support those with the condition to feel no barriers to entering into society, thus abolishing any differences between those with dystonia and those without.

Conclusion

In spite of the brilliant scientific advances into the pathophysiology¹⁻³ and novel therapies available to us as clinicians,⁶⁻¹² translation of these advances into the reality experienced by our patients is only partially complete. Whilst the condition continues to result in social stigmatisation^{15,29} and compromises the mental health²¹⁻²⁴ of our patients, it is our duty to do more. In domains of both sport and the media, three novel strategies have been discussed to combat the inequalities currently encountered by those living with dystonia. It is vital that we coalesce as a medical community and leverage the power of social media whilst building upon present successes found across all three sporting domains. Achieving this uncovers a new paradigm of social equality for all living with dystonia, and enables fulfilment of our duty as medical professionals.

Word count: 2698

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