Paralympics and conversion disorder

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Anyone who follows or participates in Paralympic sport will be in no doubt that it provides as much drama, excitement, elation and despair as its Olympic counterpart. In addition, it has undoubtedly contributed to reducing stigma against disabled people. However, an ongoing challenge for the Paralympic movement is to decide which impairments can compete in which sports and how to group athletes to ensure fair competition.

Understanding the effects of stigma around disability and dealing with them are part and parcel of work in medicine but especially the mental health field. Within the medical specialties there is a ‘race to the bottom’ for whose disorders are the most stigmatised. Psychiatry has a strong claim on this with mental illness generally regarded as among the most feared and least understood. And within psychiatry there is a similar hierarchy such that patients with ‘hysteria’ or conversion disorder (CD) are those found to be least satisfying to treat and are least liked by psychiatrists—the feeling is mutual of course.

Paralympics and CD (or functional neurological syndromes (FNS)) have recently come together over a number of well-publicised episodes. These are well-worth considering. First, and most simply, they might encourage a useful partnership between the organisers of such sport and the psychiatric profession, which might prevent individuals becoming targets of media speculation and reputational damage to the Paralympic Games. Second, they might tell us something about attitudes to disability and mental health which may not be evident in more measured discourse. Finally, these episodes may focus our minds on tightening up our concepts regarding the rights and obligations inherent in the sick role and the perennial debates around diagnostic criteria for CD.

What is the process for deciding whether an athlete is eligible to compete in Paralympic sport? First, it should be noted that each of the 22 Summer and 5 Winter Paralympic sports, has its own classification rules. Clearly, the impact of an athlete’s impairment varies from sport to sport but there are some broad principles which apply. The first stage is to secure a medical diagnosis (which for athletes with a physical impairment does not include psychiatric diagnosis). This diagnosis must be seen as leading to 1 of 10 ‘eligible impairments’ recognised by the International Paralympic Committee (IPC): impaired muscle power, impaired passive range of movement, limb deficiency, leg length difference, short stature, hypertonia, ataxia, athetosis, vision impairment, and finally, intellectual impairment. Chronic pain and epilepsy are not eligible impairments. Following that, the athlete undergoes a series of bench tests and skill assessments relating to the sport to measure how their impairment affects them on the field of play, the athlete may then also be observed during competition to ensure their performance in the previous skill assessment is replicated in the competitive environment.

In light of some recent cases, the IPC is looking to each of the International Federations of sport to increase their efforts to verify underlying impairment types, as well as reminding athletes and their support staff to disclose full medical diagnostic information prior to presenting for classification. There is no academic literature on the issue of FNS and Paralympic sport, only sporadic reports in the lay press and Wikipedia.

In 2005 the Scottish Daily Record (28 April 2005) described a case of a 43-year-old man, Frank Duffy, who had been ‘wheelchair user for 10 years after falling just 4 feet from a ladder at work’. He became captain of the Great Britain wheelchair curling team that won silver at the Turin Games in 2006. The story came to light following an out-of-court settlement for personal injuries where the diagnosis of CD was revealed, a condition ‘where the brain converts emotional trauma into physical symptoms’.

In 2012, the case of swimmer Victoria Arlen caused considerable controversy. According to the New York Times, she spent 3 years ‘in a vegetative state because of an autoimmune disorder and woke in 2010 with paralysed legs and other symptoms of the neurological condition transverse myelitis’. The IPC released a statement on 12 August 2013 saying that five independent medical experts reviewing her case agreed that there was insufficient evidence of an eligible impairment leading to permanent or verifiable activity limitation.

The most recent and significant case to reach the headlines was of Dutch para-cyclist Monique van der Vorst, a winner of two handcycling silver medals at the Beijing 2008 Paralympics. According to the IPC statement of 4 June 2013, van der Vorst experienced a ‘miraculous’ recovery following an accident in March 2010 and ‘started to feel tingling sensations in her paralysed limbs. By July of that year she was able to start walking again.’ It goes on to say that in late 2012, ‘the Head of the Spinal Cord Injury Unit at the Amsterdam Centre for Rheumatology and Rehabilitation diagnosed her with Conversion Disorder’.

According to her website http://www.moniquevandervorst.com/Monique, Ms van der Vorst, born in 1984, had been in a wheelchair since 1998, “when her left leg was paralysed and her right knee stopped working properly. During her rehabilitation period, she was introduced to handcycling.”

During training in the USA on 20 April (2008) “Monique and her training partner were hit by a car. Monique was unconscious and had to be transported to the hospital by helicopter. Monique had
a heavy concussion, a very severe injury of her back and a whip-lash …” She recovered enough to compete in the Beijing games in September 2008, and was successful through 2009 in triathlon and marathon events. In 2010

She felt some twinklings in her paralysed legs. It was so strange because she didn’t feel anything in her left leg for 12 years. Later she could move her legs a bit and from that moment she really tried everything to get her legs working again. She spent months in the hospital and rehab centre, but now she is walking again after being in a wheelchair for almost 13 years!

In 28 June 2012, it was reported in a cycling magazine that she had a ‘recurrence’ and was back in her wheelchair and that her agent had to defend her against accusations of being ‘a fake’.

The IPC was prompted to investigate the case because of media reports, to determine whether she had misrepresented her abilities when originally classified prior to her becoming European Champion in 2001. Following its investigation into this case, the IPC released a statement in June 2013 that said van der Vorst’s original classification was based on “the available medical documentation at the time, although post career a more conclusive diagnosis was made on the athlete. The IPC accepts therefore that Monique did not deliberately misrepresent her impairment when subject to classification evaluation on a number of occasions during her paracycling career.” As a result of that investigation, the IPC concluded that it would take no action against van der Vorst.

That statement also confirmed that the IPC would be looking for classification panels to increase their efforts to verify underlying impairment types, in particular when clinical manifestation is confounded by pain. Athletes and their support staff were also reminded to disclose full medical diagnostic information prior to presenting for classification.

It is unwise to speculate on psychiatric or even medical diagnoses on the basis of media reports but in two of the above cases the diagnosis of CD has entered the public domain. It has not been made in respect of the Arlen case in which there have been no suggestions of periods of normal functioning. In any event, what is significant is that the stories were, by definition newsworthy, and as is the trend nowadays, each sparked blogs and hostile responses on the internet and other media. Opinions have ranged from outrage towards the athletes whose behaviour was considered disrespectful of many disabled people whose conditions are permanent, to more generous attitudes such as: ‘as medical knowledge advances, it becomes almost impossible to predict just how permanent any disability might be’.

THE DIAGNOSIS OF CD/FNS

According to the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM5), the diagnosis of CD (FNS Disorder) rests on: ‘Clinical findings that demonstrate incompatibility between the symptom and recognized neurologic or general medical conditions (eg, Hoover’s sign)’. In other words, inconsistency and the presence of ability alongside professed inability are to be expected in CD—indeed it is part of the definition. However, the moral and ethical implication that their disability is (therefore) feigned or faked goes a step further. Also part of the DSM5 definition is the criterion that “The symptom or deficit causes significant distress, psychosocial impairment or warrants medical evaluation.” This would imply that unlike other (physical) causes of disability, the person with CD is barred from overcoming or compensating for their predicament, or coping with it positively (eg, taking up competitive sport), without distress. Paradoxically, la belle indifference has long been held up as a useful indicator of CD as distinct from neurological conditions—in fact it is found more or less equally in both.

The real dilemma is distinguishing CD from a factitious disorder or malingering. It is commonly stated that in factitious disorder (and malingering) the individual is deceiving his attendants while in CD he is deceiving himself. Or equally prosaic-ally, in factitious disorder and malingering the deception is conscious and in CD, it is unconscious. Across this unholy trinity one can apply the notion of ‘secondary gain’ which can be ranked from the sympathy afforded to the sufferer, through relief from responsibilities, to net financial gain. The ethical issue here is perhaps twofold: first, while any illness brings secondary gain as an entitlement of the sick role, a necessary condition for its legitimacy is that the illness is visited on the sufferer against his wishes. He is an innocent victim. The second is that such gain must be proportionate. So while we do not mind the sick surviving in modest comfort, they must not be better off than they would otherwise have been. In relation to sport, they must not seek an unfair advantage.

It is not appropriate for patients with CD to be considered eligible to compete in the Paralympic Games for two reasons. First, with the increasing status of each Games, a patient with CD could receive significant ‘secondary gain’ from associating themselves as a Paralympian, reinforcing the patient’s perception of the benefits of their condition and wishing it were permanent—reducing the possibility of making a recovery. Second, is the perception of injustice from athletes with a permanent impairment competing against athletes with CD—whose impairment may be variable and who may experience a significant recovery at any time.

No matter how we as clinicians may wish to acclaim CD as a disorder ‘like any other’, one which may be understood in terms of information processing and attentional biases, or drawing on the latest neuroscience technology, a reaction to stress, or the manifestation of a mental disturbance in the physical domain, it is hard if not impossible to separate it from a moral/volitional context. There are other lessons: moving away from ‘miraculous cures’, these cases might encourage clinicians to believe that patients with CD have the potential to recover even after years of functional impairment. The importance of secondary gain, regardless of the ethical dimension, is that we need to understand the interpersonal and social forces that might bear on the patient which work counter to recovery. Finally, with increasing prominence given to the Paralympics, we would hope and expect more disabled people to take up sport. This might bring to attention more people with CD. While sports-governing bodies may be content simply to find better ways of excluding such people, it is also an opportunity to make the proper and timely diagnosis with help from specialists across disciplines, including neuropsychiatry. That is not to say that individuals with CD should be discouraged from being physically active or taking part in non para-olympic sport—quite the opposite; as clinicians we should be looking to steer our patients towards a fulfilled, active and healthy life.

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