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The Language Advocated for by Persons with Non-Communicable Diseases: Lessons from Working with Persons with Amyotrophic Lateral Sclerosis (PALS) and those with Obesity

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DAVID B. SARWER, PHD[1], & JOHN C. FUREY, BS[2]
[1]Department of Social and Behavioral Sciences, College of Public Health, Temple University
[2]Clinical Research Coordinator, Department of Neurology, Lewis Katz School of Medicine, Temple University, Adjunct Instructor, Department of Bioengineering, College of Engineering, Temple University

Correspondence: David.sarwer@temple.edu (David B. Sarwer)

Understanding of health and well-being is continuously changing. Scientific study and clinical experience leaves every generation of health professionals, those who work in health care settings and those who work in public health, with a more sophisticated understanding of the course of illness and treatment. Approaches to disease prevention evolve. Just as disease treatment and prevention evolve to meet the clinical needs of the patient so too must our language evolve to meet the desire of the patients to no longer be identified by their medical conditions.

A brief tour of the history of human understanding of the processes of disease and treatment can leave one bemused at the naïve understanding of illness and treatment held by many who came before us. Yet, we owe those individuals a tremendous debt of gratitude. Without those original beliefs about what makes us ill and what makes us better, we would not have experienced the unquantifiable advances of even the past 100 years that have almost doubled human life expectancy[1].

Currently, many professionals who have dedicated their life's work to improving the health and well-being of others use major tenants of the biopsychosocial model of health[2]. This model posits that health sits at the intersection of biological (genetic and physiological), psychological, and social factors. Thus, health is not all about what is happening at the cellular level in the body. It's not all between the ears. It's also impacted by our environment—our families, friends, and neighbors as well as the quality (or lack of quality) of the resources in our neighborhoods, cities, and countries. Using the language of public health, these resources are part of our social determinants of health[3].

We also are at a time in history where our understanding of what it means to have a disease has begun to change. Language plays a significant role in this changing discourse. Historically, far too many individuals have been defined by their physical condition with the meaning of these words has transformed into nondiagnostic stigmatizing and derogatory descriptors. The "People First" movement was initiated in the early 1970s and made initial progress to change how we talk about persons and their illnesses[4]. Subsequently, the American

Psychological Association strongly advocated for the move toward the use of person first language, which has been the likely catalyst for where we are today[5].

Nevertheless, there is still an apparent difference between what is taught in the classroom, practiced in clinical settings, and required by the peer reviewed literature. For instance, those who use wheelchairs or other devices to ambulate are frequently and unfortunately not viewed as a complete human, but one that is merged with their technology[5]. Those with visible disfigurement are often seen through the lens of "what is anomalous is bad"[6], their facial disfigurement defines them as "other". While it may be tempting to blame this particular bias on the mass media's fascination with physical perfection, some evidence suggests that this bias against those who look different may be hard wired into our brains[7]. While there is some evidence to suggest that psychoeducation and cognitive interventions can reduce biased beliefs about those with certain illnesses, including obesity, it is currently unclear if those biases that appear to be hardwired are ultimately malleable.

Below, we use two diseases—Amyotrophic Lateral Sclerosis and obesity—as examples of how the language advocated for use by those with these conditions has changed over time. While these conditions are intuitively quite different, we believe that the visible nature of both place the diseases on some shared ground and illustrate that a patients and providers working on the widest range of non-communicable diseases can find paths to the use of non-stigmatizing language.

Amyotrophic Lateral Sclerosis

Persons with the disease of Amyotrophic Lateral Sclerosis (ALS), during the course of their disease, often have to rely on wheelchairs to ambulate. Their facial and physical appearance also frequently reveals their deteriorating condition to others. ALS is a devastatingly progressive neurodegenerative disease characterized by progressive decline in motor function affecting limbs, speech, and swallowing. Deterioration in these abilities leads to malnutrition and respiratory failure over time. Individuals with ALS have a median life span after diagnosis of 34 months[8]. The disease affects between 5,000 to 6,000 Americans annually with an incidence of about 2 per 100,000[9]. However, there is significant variability in the clinical characteristics of the disease with 20% of persons with ALS (PALS) living more than 5 years and 10% living more than 10 years.

The acronym PALS was embraced by persons living with ALS to welcome a reality where they are no longer solely defined by their condition. Those living with ALS often lose their ability to walk, speak, and/or breath on their own, necessitating the use of devices to assist with ambulation, augmentative and alternative communication (AAC) devices, and non-invasive ventilation (NIV). As a result, many experience stigma, be it 'felt' or 'enacted', associated with the use of this equipment and ultimately their disease progression. PALS should not be dismissed and minimized to their disabilities, but be heard and empowered by their surrounding community. Recognition as a person rather than a terminal diagnosis is just one of many battles PALS continue to fight.

PALS also are challenged collectively, as they often are unable to enduringly advocate for themselves due to severity and progression of their disease. A few years ago, patients called for action to be taken to fully fund ALS research. PALS want to finally have a voice and identity beyond a patient dying of ALS. They wish to unlock the mysteries of ALS. This call by PALS was answered when President Biden signed into law ACT for ALS[10]. ACT for ALS established an expanded access grant program that funds research on and provides access to investigational drugs for ALS who may not be eligible for clinical trials. Additionally, it facilitated the first federal effort distinctly charged with expediting the development and approval of therapies for ALS.

Obesity

The disease of obesity is another example of a medical condition that is readily visible to others. Presently in the United States, 42% of adults have a body mass index (BMI) > 30 kg/m², the clinical criteria for obesity[11]. Approximately 30% of American's are in the category of being overweight and at risk of crossing that threshold with further weight gain as they age. It is estimated that by 2030, more than one billion individuals around the world, one in five women and one in seven men, will be living with the disease of obesity[12].

Obesity has only been recognized as a disease by the American Medical Association since 2013. Prior to that, many mistakenly believed that obesity was a psychiatric diagnosis, although it has never been characterized as such. Yet, individuals erroneously believe that obesity results from moral failings, a lack of will power, or a depressed mood. If the individual was just of stronger character, they could control their eating and their weight. This approach not only ignores the genetic and numerous physiological contributions to obesity, it also discounts the potent impact of a wide range of environmental factors that have likely driven the dramatically increasing rates of obesity seen around the Western world in the past 50 years.

It's not just the general public that struggles to appreciate the current obesity crisis; state and federal government agencies have been slow to proactively respond as well. Policies addressing the obesity driving elements of our food systems are lacking. Prevention efforts for children, adolescents, and families are underfunded, contributing to their limited success. Obesity treatments are often not covered by health insurance and, as a result, even the most effective ones are not utilized to their fullest extent[13].

Despite these challenges, the approach to the management of the individual patient with obesity has changed. In the past 10-15 years, the field has moved to using "person-first" language—using phrases such as "person with obesity" no differently than describing an individual as "having ALS". In clinical interactions, patients are described as "Mr. Smith has obesity" rather than the pejorative "Mr. Smith is obese." The former phrasing reminds all that Mr. Smith has characteristics, talents, and abilities independent of his body weight and should be seen for being more than just his body habitus.

Use of "person-first" language is now required by most, if not all, of the major obesity journals. Many also have moved away from using the term "morbid obesity" which also has a highly negative connotation. These changes are encouraging, but more universal adoption still awaits. Many manuscripts are still submitted without use of the preferred language, some are still published. International conferences still include far too may presenters who have not adopted these changes when sharing their scientific findings or clinical experience with others. To aid in this universal adoption, more robust efforts are needed to educate trainees, researchers, and health professionals on the use of person-first language. There has been a recent call for the inclusion of person first language in healthcare simulation training promote inclusivity and prevent dialogue that contributes to unconscious or implicit biases[14]. This is certainly a step in the right direction and, hopefully, is one that leads to greater change over time.

Conclusion

As our understanding of disease and health continue to rapidly evolve, it is important that we remember to slow down and focus on the individual, treating them with the respect and compassion we all deserve. How we treat individuals with disabilities begins with how we speak about them. How we use words and how others perceive the use of those words matter. In the continuous pursuit for more inclusive practices, it is crucial that we understand and acknowledge the power of our chosen words because they are a symbol of respect and identity.

Conflicts of Interest

Dr. Sarwer currently has grant funding from the National Institute of Diabetes, Digestive, and Kidney Disease, National Institute of Dental and Craniofacial Research, and Department of Defense. He has consulting relationships with Ethicon and Novo Nordisk.

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