

Person-first language: are we practicing what we preach?

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Abstract: Person-first language is taught in most health professions programs and mandated by scholarly journals but is often not practiced by health care practitioners. The disconnection between academia and clinical practice is significant. Students and new practitioners are often faced with the challenge of holding to their training or falling in line with the status quo. While the use of person-first language should be the norm in all health care settings, unfortunately, often the opposite is true. The person-first language movement began in 1974. Since that time, the culture of disability has drastically changed. There is greater integration of individuals with a disability and with that integration has come greater understanding and acceptance. Increased community integration has allowed for greater opportunities for advocacy and has also forced a shift in how the community at large views people with a disability. This shift in how individuals with a disability are viewed has resulted in a change in language. A change in semantics is not enough. Health professions educators need to ensure that students understand why this change has taken place and why it is essential. The power language can have not only on patient care but also on patient outcomes is profound and should be understood by both educators and practitioners alike. The purpose of this paper is to discuss the factors surrounding person-first language and its integration into health care, including the difference between what is taught and mandated, and what is practiced.

Keywords: inclusive language, disability language, identity-first language, patient-centered care, person-centered care, health professions education

Introduction

During our graduate health professions education, significant emphasis was placed on the importance of using person-first language. Our instructors were not shy about correcting us when we did not use person-first language. It was the cultural norm of the program and school. Once we became health care practitioners, it was blatantly obvious that while the use of person-first language was the norm at our school, it was not the norm in most practice settings. We were burdened with the internal struggle of sticking to what we had been taught or conforming to what seemed to be the prevailing culture of health care, which did not embrace person-first language. We made the decision to stick with what felt right to us and aligned with our values and beliefs. Using person-first language is our norm.

Since transitioning from clinical practice into academia, we have seen how our students embrace person-first language while in the classroom setting and struggle with how to integrate the use of person-first language into practice when their peers and

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superiors do not. We teach in a program that sends students for a clinical experience after their third semester. Prior to their first clinical experience, students are immersed in a culture where the use of person-first language is an expectation. Surveys conducted after the students have completed their first clinical experience reveal that students are consistently surprised to see how rarely person-first language is used in clinical practice and often feel they cannot affect change. While we encourage our students to become change agents, we know that they are facing an uphill battle. The path of least resistance is to fall in line with what is happening around them. Until there is a cultural shift in health care at large, it will continue to be a struggle, both for novice and experienced clinicians, to consistently use person-first language, not only in their patient/client interactions but also during interprofessional communication.

Background

Nearly one in five people, 19% of the population of the USA, has a disability.^{1,2} Disability does not discriminate, as it affects individuals within all ethnic, socioeconomic, and religious groups. How we treat individuals with disabilities begins with how we speak about them. The very words that were initially intended to describe medical conditions, over time, morphed into nondiagnostic stigmatizing and derogatory descriptors.³

In 1974, the first self-advocacy conference was held in the USA. The “People First” movement began during that conference, advocating for people to be placed before their disabilities.³ The movement sought to empower individuals with a disability by placing emphasis on their individuality and personhood rather than their impairments. One year later, the Education for All Handicapped Children Act mandated that all children should receive a “free and appropriate public education” in the “least restrictive setting.”⁴ That same year, the Federal Developmentally Disabled Assistance and Bill of Rights Act required that states develop protection and advocacy programs in order to receive federal funding.⁴ Since that time, the number of individuals with disabilities who are institutionalized has significantly decreased, and efforts have been made for greater community integration. Increased community integration has allowed for greater opportunities for advocacy and also forced a shift in how the community at large views people with a disability. This shift in how individuals with a disability are viewed has resulted in a change in language, as language reflects how members of society view each other.⁵

The most visible changes surrounding the disability community center around cultural shifts. These shifts have occurred due to grassroots efforts by both individuals with a disability or injury, and their families and friends. The Spread the Word to End the Word campaign was started in 2009 by two college students as an effort to “inspire respect and acceptance through raising the consciousness of society about the R-word and how hurtful words and disrespect can be toward people with intellectual disabilities.”⁶ The campaign supports a yearly event that encourages participants to sign a pledge to not use the R-word (retarded) in a demeaning way, but rather to advocate for inclusion. The Spread the Word to End the Word campaign is supported by Special Olympics Best Buddies and over 200 organizations who have banded together to take a stance on the terminology used by both medical professionals and the public.⁶

In 2010, Congress passed Rosa’s Law, removing the terms “mental retardation” and “mentally retarded” from all federal documents and inserting “having intellectual disabilities” in their place.⁷ The initiative for Rosa’s Law began when Rosa’s mother learned that she had been labeled as “retarded” at school. She did not want her child to be referred to as “retarded” and petitioned for the change in terminology which ultimately led to Rosa’s Law. The language that is used when referring to disability continues to evolve. Choices concerning language use shape how individuals think, feel, and behave toward others, including individuals with disabilities.⁸ “What you call people is how you treat them [...] what you call my sister is how you will treat her. If you believe she’s ‘retarded’ it invites taunting, stigma. It invites bullying and it also invites the slammed doors of being treated with respect and dignity.”⁹

Language has the ability to change how we think and how we view the world.^{5,10} Despite the shift away from a paternalistic medical model toward the concept of a partnership, where the patient is seen as an individual and a member of the health care team, there continues to be debate concerning the words or labels used when referring to individuals who are engaging in the health care system, including the use of the word patient or client.¹¹ How health care practitioners communicate can both positively and negatively affect their patients’ health outcomes in a way that is not directly linked to the medical treatment they provide.¹² Language and communication are at the heart of patient care, and the words practitioners choose to use may influence the effectiveness of their care.¹³ While there is limited evidence about the impact this language has on practice or outcomes, health care practitioners should be

cognizant of their word choices and understand the power that communication plays in patient care.¹⁴

A shift in language can be found most notably in scholarly journals. Most scholarly journals now require that articles submitted for publication use person-first language.^{15,16} This change is not as noticeable in practice. Health care practitioners may not consistently use person-first language, especially when communicating with other health care professionals. There seems to be a chasm between what is expected in an academic setting vs clinical practice. Why is there a disconnection between what is taught in health professions education and expected in scholarly journals, and what is typically practiced in health care settings?

Purpose

Emphasizing the use of person-first language within health professions education, including the clinical components, and empowering students to choose to utilize this language, even when their professors or clinical instructors do not, will be integral to the widespread adoption of person-first language. The purpose of this paper is to discuss the factors surrounding person-first language and its integration into health care, including the difference between what is taught and mandated, and what is practiced.

Person-first language

What is person-first language?

In 1992, the American Psychological Association led the movement toward the use of person-first language.¹⁰ Referring to people first was thought of as an alternative to labeling individuals, which may have led to promotion of biases, devaluing of individuals, and expressing negative attitudes.¹⁰ The use of person-first language may provide a means to separate the individual from their diagnosis or impairments. Referring to a group of children as “children with Down syndrome” rather than “Down syndrome children” is one example of person-first language. The intention is to decrease the focus that is placed upon the diagnosis and increase the focus on the person with the diagnosis. By decreasing the stigma of disability, there is hope that greater equality will exist. The use of person-first language has been widely adopted and is considered standard in government documents, scientific journals, various organizations’ publications, and by the United Nations.^{10,17} When person-first language is used in a plural sense, using the phrase “patients with chronic pain” instead of “chronic pain patients,” it fights the notion of the “one size fits all” mentality.¹⁵

Person-first versus identity-first language

While the concept behind person-first language is clear, what is not clear are the preferences of individuals with disabilities.¹⁰ One group that has made their preferences known are members of the Deaf community. Notably, the Deaf community has chosen not to embrace the notion of person-first language but has embraced identity-first language. This approach views the individual’s disability as an integral part of the individual’s identity.⁸ The Deaf community contends that deafness is not a disability but rather a medical condition and that being deaf means that you are a member of a community of individuals who happen to have hearing impairments, but should not carry a negative connotation. The Deaf community has been very emphatic in their opposition of the use of person-first language in regard to deafness. Their stance is a perfect example of ensuring that the verbiage used is in line with the desires of the individual or community being referred.¹⁸ The importance of this statement is that the decision was made by the individuals themselves, not society, scholars, or editorial boards. The extent to which individuals with disabilities identify with disability culture is affected by the development of their own identity in relation to their disability, and the choice of whether to use identity-first or person-first language may be impacted by the stage of the individual’s disability identity development and whether or not the disability is congenital or acquired, and whether the condition is temporary or one with long-term or lasting effects.⁸ While use of person-first language is a step in the right direction, it is by no means a perfect solution and should be practiced with the full understanding that it may not be accepted by all individuals.

Integration into health care

A person-centered approach to care should be the goal of all health care practitioners. The Institute of Medicine (IOM), in its landmark report in 2001, defined patient-centered care as “care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (p. 6).¹⁹ The word “patient” implies that one is sick or being cared for due to an injury or illness.²⁰ While both patient-centered and person-centered concepts acknowledge the values, needs, and preferences of individuals, person-centered care focuses on the person as an individual in a holistic manner.²⁰ The object of care is the distinction between patient-centered care and person-centered care. When person-first language is not used, the patient’s preferences, needs, and values may not be honored,

they may not be respected, and the goal of person-centered care may not be met. Patients are frequently referred to by their medical diagnosis (eg, the stroke patient, the amputee, or the quadriplegic) in casual conversations and patient education materials. While many health professions education programs teach students to use person-first terminology, this language is often not mirrored in clinical practice. In health care, the disuse of person-first language has become the cultural norm, in part, due to habit. Using person-first terminology involves intentionality. Some terminology may reflect the clinicians' own biases regarding disability.²¹ It is imperative that health care professionals examine their own biases and take actions to ensure that they do not contribute to the stigmatization of disability.^{8,22,23}

When practitioners do not use person-first language, they may place a barrier between themselves and the person in their care. This barrier enables the practitioner to view the diagnosis or injury independently from the individual, distancing them from the person and shielding them from having to consider the person as a whole and all the complexities that entails.¹⁵ The goal of health care should not be to create barriers between patients and their care providers but rather to ensure that practitioners provide person-centered care, taking into account all aspects of the patients' lives. The International Classification of Functioning, Disability, and Health (ICF) was created, in part, to encourage practitioners to look at all aspects of a patient's life to fully understand how their lives are affected by their disability or injury.²⁴ The ICF was first established in 2001; however, 17 years later the principles of the ICF, while acknowledged, are often not considered or practiced. While person-first and identity-first language are contained within the ICF model, there continues to be challenges with language surrounding disability that affect individuals with disabilities and health care practitioners.⁸ When examining an individual through the lens of the ICF, health care providers are prompted to consider the medical and physical components of disability along with the personal and environmental factors that affect the individual's life.⁸

Position and rationale

Health professions educators, including clinical educators, are perfectly positioned to assist with incorporation of person-first language within health care. Person-first language should become the cultural norm in health care and educators need to not only have an awareness of person-first language but also model its use. Health professions programs need to empower students to be change agents who lead by example,

as educators are in a prime position to impact future health care professionals' views and behaviors.

A change in semantics is not enough. Health professions educators need to ensure that students understand why this change has taken place and why it is essential. Members of the disability community are making their wishes known, and we, as health care providers, need to acknowledge that. Our behaviors need to reflect an awareness and acceptance of their preferences and values.

Discussion

Language matters; however, the extent to which language affects patient care, health care providers, and the recipients of their care is currently unknown. Some disability groups have made their wishes known regarding the use of person-first language and the empowerment that results from it, and health professions educators have noted the importance of person-first language by continuing to include it in their curricula. While there are many possible reasons why person-first language has not been adopted into practice by all health care providers, the possibility that some providers may need the psychological distance that is provided by the disuse of person-first language is the most intriguing. The notion that providers may not be able to take on the burden of treating every patient as a person and may need to solely focus on the impairment or disease warrants further investigation and could provide greater insight into both provider burnout and the role language plays in patient care. While anecdotally we believe that person-first language has not been adopted into practice, more research is needed to assess how often it truly is used and to determine in which settings its use is most prevalent. Health professions students are often immersed in the practice of person-first language while in school yet find it difficult to maintain this practice while performing patient care. Is the influence of more seasoned health care providers too great for novice clinicians to overcome or have they only adopted its use in school but not achieved a true understanding of the role language plays in patient care? Gaining a greater understanding of how language is being used in current practice will enable educators to better prepare future health care professionals to provide person-centered care.

Conclusion

There is an undeniable difference between what is taught and expected in health professions education and mandated in scholarly journals and demonstrated in health care practice. Research that examines the attitudes and beliefs of practicing health care professionals surrounding person-first language

would provide greater insight into why this difference in practice occurs. Further research into the preferences of individuals with disabilities and the impact of language on practice and outcomes would not only clarify the prevailing desire of individuals with disabilities in regard to person-first language but also guide future use or disuse. The ultimate change agents should be the individuals with disabilities who are ready to insist that their voices be heard.

Disclosure

The authors report no conflicts of interest in this work.

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