

*Common*Health

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TABLE OF CONTENTS

INTRODUCTION TO THE ISSUE

- i-iii** **The Way We
Communicate about
Public Health Matters**
Deborah A. Cai

CASE REPORT

- 1-10** **The "Our Words
Matter" Campaign to
Reduce Stigma and Bias
in Clinical
Communication: A Case
Report**
*Megan Healy, Meghan Snyryn,
Nicole Strand, Deirdre
Dingman*

OP-ED

- 11-12 **Gender-Inclusive
Language and Abortion
Protections**
*Amanada Elyse, Sarah J.
Keaton*
- 13-15 **The Challenge and
Responsibility of Public
Health Communication**
*David B. Sarwer, Sarah
Bauerle Bass, Maura O'Fallon*
- 16-20 **The Language
Advocated for by
Persons with Non-
Communicable
Diseases: Lessons from
Working with Persons
with Amyotrophic
Lateral Sclerosis (PALS)
and those with Obesity**
*David B. Sarwer, John C.
Furey*

The Way We Communicate about Public Health Matters

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In his 1963 book, *Stigma: Notes on the Management of a Spoiled Identity*, Erving Goffman proposed that individuals who were grouped by certain attributes could be stigmatized by society, whereby they may be stereotyped and dehumanized for those traits. Such attributes may be visible, such as disabilities or ethnicity, or not visible but still result in being publicly disparaged, such as having a disease. Goffman categorized stigmas into three types that can result in being treated as an outsider or ignored: tribal, such as ethnicity and religion; physical, such as disabilities or visible flaws or diseases; and character, such as sexual orientation and addiction. Now, 60 years later, we are still addressing how to prevent people from being discredited and ostracized. The collection of articles in this issue of *CommonHealth* each address how we can better understand and show compassion for various health concerns and how communication—especially language—can affect how patients are cared for and the type of care that they may seek—or avoid.

Stigmas are created within social contexts in which particular attributes are devalued within a society, such as obesity or addiction, so that anyone within that society perceived as having or exhibiting that attribute is also devalued (Yang et al., 2007). Bresnahan et al. (2020), for example, identified ways that stigma against breastfeeding in public is reinforced, such as “disapproving looks, insults, and name calling” (p. 395).

Communication is a central aspect of stigma. Bresnahan and Zhuang (2011) created a multidimensional measure to study stigma in

which they identified distinct behaviors that related to stigmatizing other people. *Labeling* is using harmful descriptions of those who display a stigmatized attribute, or how people are talked about. *Negative attributions* are when character flaws and poor judgment are attached to those who are stigmatized, and *status loss* is when people assign lower social status to others because of the stigmatized attribute. These two dimensions affect the way in which people are spoken to by other people. And *distancing* is when people remove themselves from stigmatized individuals, which reduces the amount of communication others will have with a person who has been stigmatized.

Each of the four articles in this current issue of *CommonHealth* addresses how the use of language medical and public health professionals affects the way individuals are viewed and the quality of the treatment they may receive. The first article is a case report by Healy, Swyrn, Strand, and Dingman. The importance of their work is captured in the title of their article, which says “our words matter.” This article describes an educational campaign to change how medical and public health professionals describe their patients. The campaign was developed by a multidisciplinary team, in consultation with people from the North Philadelphia community that is served by the Lewis Katz School of Medicine. The researchers sought feedback about the campaign from a wide range of stakeholders who would be affected by the change in language. The materials produced by the team provides examples of how to describe patients in ways

that supports rather than stigmatizes them. The core principles culminate in the following directive: “When in doubt, ask yourself: If I were the patient reading/hearing this, how would I feel?”

The opinion piece by Elyse and Keaton puts forth a compelling case for the importance of using gender-inclusive language when talking about pregnancy and abortion in order to protect every person who may become pregnant. Elyse and Keaton argue that gender-inclusive language is “a powerful tool that can be used to promote equality and end gender bias.” Yet only 11 states plus the District of Columbia have adopted gender-inclusive language related to protecting access to abortion. In response to the Supreme Court decision, states have the opportunity to protect the right to have an abortion; using gender-inclusive language is an opportunity to move further ahead by protecting and promoting the rights of all people who can become pregnant.

Along these lines of gender-inclusive language, Sarwer, Bass, and O’Fallon take the conversation in a different direction. They begin their op-ed by citing a 2022 congressional hearing on abortion rights in which Dr. Bridges, a law professor from University of California, Berkeley, described “people with the capacity for pregnancy.” Instead of providing the inclusivity—and accuracy—of language to describe people who may seek an abortion, the language itself became the focus of attention. Sarwer et al. use this example to challenge how academics, especially those in public health, communicate with the broader public outside of the academy. Instead of the internal echo chamber of ideas about public health, these authors argue that scholars need to think beyond traditional academic language and learn,

instead, to communicate more effectively so that the general public can understand and learn from the knowledge and practice of scholars who research and write within the academy.

Finally, in Sarwer and Furey’s op-ed, they argue that language needs to reflect respect for the whole person, rather than focusing attention on the disease the person may be experiencing. They describe two examples—Amyotrophic Lateral Sclerosis (ALS) and obesity—where changing how individuals are described can move away from stigmatizing individuals and toward recognizing the fuller experience that environmental and genetic factors have on the individuals experiencing these diseases. The authors write that, in the case of ALS, the acronym PALS has been “embraced by *persons living with ALS* to welcome a reality where they are no longer solely defined by their condition” (emphasis added). This type of person-first language is also recommended for people “living with the disease of obesity.”

Across these four articles—one case report and three op-eds—the language of public health is the primary concern. Use of person-first language, especially, is strongly advocated to reduce the stigmatization of individuals. Each of these articles shows the importance of how we talk about people and how language affects both the way patients are viewed and how they are subsequently treated by medical and public health professionals. Moreover, language can affect whether patients are willing to seek the medical treatment they need. In other words, this issue of *CommonHealth* addresses a key concern in health communication: That our words do matter.

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The “Our Words Matter” Campaign to Reduce Stigma and Bias in Clinical Communication: A Case Report

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Language choice in clinical communication has become increasingly important and timely given that patients now have access to their full medical record, as required by the 21st Century Cures Act. Students and faculty within Temple University Health System (TUHS) identified stigmatizing language as a significant issue impacting patient care. This case report describes the process of assembling a multidisciplinary team to create an educational campaign with the goal of reducing stigma and bias in the medical record. The campaign team leveraged a grassroots approach, a network of champions, iterative materials development and community engagement to design and implement this initiative within a complex academic health system. Changing language alone will not address all the disparities experienced by marginalized patients and communities but provides an important initial step for clinicians. Campaigns like this one can serve as models for medical and public health professionals who seek to advance health equity.

Keywords: open notes, stigma, medical training, bias

Background

With adoption of final rules from the 21st Century Cures Act in April 2021,¹ patients gained access to their full medical record, including notes written by their health care team. This change prompted discussion about language use within Temple University Health System (TUHS) and inspired the creation of the Our Words Matter (OWM) campaign, an educational initiative to decrease stigma and bias in clinical communication. Stigma is the social process of labeling, stereotyping, and rejecting

human difference as a form of social control.² Language is one way that stigma is operationalized on the individual, interpersonal and structural level.³ The developers of the OWM campaign recognize that stigmatizing language is often unintentional and can reflect implicit biases that are reinforced in medical practice and education. Language that reflects provider attitudes is common. For example, in a qualitative study of physician documentation, Park et al.⁴ described several themes of both

negative and positive language found in outpatient clinic notes that reflected clinician attitudes toward patients. The categories of negative language identified in the 600 notes were: questioning patient credibility, disapproval, racial or class stereotyping, references to the difficult patient and unilateral decision making.⁴ The language providers use may also impact patient care. Pejorative terms can deter patients from accessing medical treatment,⁵ and influence provider judgements. In a 2019 survey study, more than a third of people who use drugs reported that they chose not to seek medical care because of fear of mistreatment due to stigma around drug use.⁶ Adverse health outcomes attributable to stigma for other groups, such as gender minorities, have been well documented in prior literature.³ In a 2010 study,⁷ use of the term “substance abuser” in a patient vignette was more likely to

be associated with the belief that the patient was personally culpable for their problem. A 2018 vignette study of medical students and residents demonstrated that exposure to stigmatizing language was associated with choosing less aggressive management of the patient’s pain in the case of sickle cell disease.⁸ Two additional studies demonstrate that patients from historically marginalized groups are more likely to have stigmatizing language in their medical records.^{9,10} The first cross-sectional study identified stigmatizing language in 2.5% of all admission notes, with a greater frequency in the notes of non-Hispanic Black patients, those with diabetes, substance use disorder and chronic pain.⁹ The second identified negative patient descriptors using machine learning, and showed that Black patients had 2.54 times the odds of having a negative patient descriptor in their notes.¹⁰

A Grassroots Campaign

The OWM campaign was a grassroots effort originally spurred by student advocacy. In the summer of 2020, medical students at the Lewis Katz School of Medicine reported a disconnect between the language they were taught to use in the classroom and the written and spoken language they observed on clinical rotations in the Temple University Health System (TUHS). TUHS is an urban, academic medical center which serves a structurally vulnerable community in the neighborhoods collectively known as North Philadelphia. Philadelphia has no public hospital system. Temple cares for a population that is almost 70% Black or Latinx, with a 50% Medicaid and 30% Medicare payer mix, and at least 25% of patients are below the federal poverty line.¹¹ In the clinical skills didactic curriculum, students are taught to use person first language. The goal of person-first language is to humanize the medical record by placing the person before the disease. Instead of referring to a patient as a “diabetic,” someone using person-first language would say “a patient with diabetes.” However, students on clinical rotations reported this did not consistently happen in clinical practice. Students in the medical school’s Addiction

Medicine Interest Group (AMIG) were particularly concerned about the language used to describe patients who use drugs, people with whom greater stigma is targeted across medicine and society. When persons who use substances are referred to as addicts or substance abusers, they are more likely to be considered as having a moral failing by the public¹² and the medical field⁷ and are less likely to be included in treatment decisions or to be prescribed medications for substance use disorder e.g., buprenorphine.¹³ When medical records or experimental vignettes use the phrase ‘person with a substance use disorder’ or ‘person who uses drugs,’ the public and clinicians are more likely to treat the condition as a chronic illness for which medication management is accepted^{7,12}. The students were unsure how to best advocate for patients in real time, especially considering the hierarchical nature of medicine. Students and faculty together began brainstorming a potential educational campaign to improve the language used in clinical communication at TUHS. While the project initially focused on language about patients who use drugs, it was broadened to address stigmatizing language used to describe other

marginalized populations and disease conditions where stigma is prevalent (e.g., obesity, diabetes, mental illness).^{14,15,16}

Stakeholder Identification

Changing the patterns of clinical communication in a large academic health system requires input from a broad coalition of both clinical and non-clinical personnel. The initial campaign team, which convened in the summer of 2020, consisted of medical students and physician faculty across multiple specialties. Non-clinical faculty from the school's Center for Urban Bioethics were brought into the project over the next few months due to their previous success with a similar project centered on improving the experience for LGBTQ+ patients in the health system. The initial stakeholder group also included a representative from marketing who was interested in incorporating best practices for patient-centered language in advertising and communication. Representatives from nursing were also included, as well as content experts with addiction medicine and public health experience. Members of the Patient Experience Office, who interface regularly with patients and families, were consulted throughout the

development of the initiative. Ultimately, a core group of three students, three physicians, one nurse, two non-clinical faculty and one hospital administrator were identified. A flat leadership structure was employed. One physician organized the meetings, but the agenda and decision making were driven by group consensus. The group met biweekly and completed a needs assessment, by requesting ad hoc qualitative feedback and taking detailed notes over a series of four virtual meetings about the patterns of perceived stigmatizing language across a diverse array of healthcare settings, including medical and surgical, inpatient and outpatient, written and spoken language. The group categorized the feedback into broader themes, such as pejorative terms and patient labeling, to organize the input. The group also sought community member input during live presentations multiple times during the year and a half long planning effort.

Strategy for Institutional Culture Change

The core campaign team had several initial meetings to explore the most effective strategy for creating institutional culture change. Given the multidisciplinary approach, the project did not fall under the supervision of one office or committee within the health system or medical school. Executive champions advised that the campaign team should first compile sample educational materials and bring those to hospital leadership for approval.

To begin this process, the medical students and faculty on the campaign team completed a review of the academic literature regarding stigmatizing language. The team also searched the gray literature using conventional internet search engines to identify recommendations across diverse sources,

including other institutional campaigns, patient advocacy resources and public health agencies. For example, Boston Medical Center created a pledge campaign to improve language used in clinical communication.¹⁷ Michigan's state health department enacted a campaign called "End the Stigma."¹⁸ Many of the recommendations came from addiction-related sources, but other disease and population specific guides were also identified (e.g., obesity, diabetes, cancer).^{19, 20, 21} The team also compiled language recommendations specific to historically marginalized groups, such as LGBTQ+ patients and patients with disabilities. Common themes were extracted, and guidance was distilled into core principles for clinical care at TUHS based upon group consensus over a

series of six meetings. This literature search led to an initial draft of Core Principles (see Figure 1).

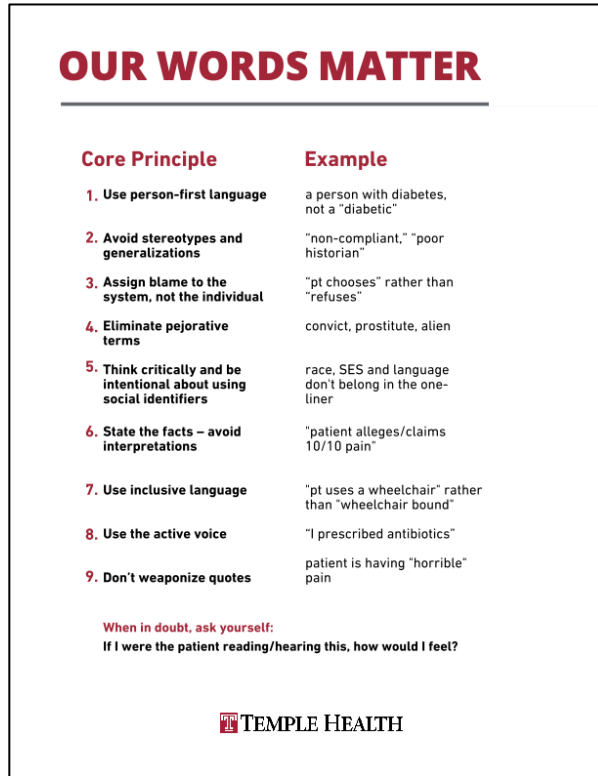


Figure 1: Core Principles of Our Words Matter Campaign

Iterative Materials Development

Next, under guidance of a team member with marketing expertise, sample educational materials were created including the Core Principles document, a Try This/Not That suggested language document (Figure 2), and sample posters to hang in clinical areas (Figure 3). Team members were especially mindful that the posters would be viewed by staff and the public and both perspectives were considered in the materials development phase. It was important for the team to bring sample campaign materials to community members for

input early. Temple Physicians, Inc., the main hospital's Patient and Family Advisory Council (PFAC), and members of the North Philadelphia Collective, a grassroots group of community leaders, were consulted early and the materials were updated as a result. For example, community representatives gave feedback on the poster headings, leading to the creation of the campaign title "Our Words Matter," meant to be inclusive of and directed toward both hospital staff and the public.

TRY THIS	NOT THAT
Person with a substance use disorder	Addict, druggie, IVDA, substance abuse/abuser
Positive/negative drug screen	Dirty/clean drug screen
Return to use, recurrence	Relapsed
Not tolerating treatment, declined treatment at this time	Refused treatment
Treatment failed the patient	Patient failed treatment
Patient with complex health issues	Frequent flyer
Patient with diabetes, sickle cell disease, schizophrenia, ESRD, PAD, asthma	Diabetic, sickler, schizophrenic, dialysis player, vasculopath, asthmatic
Difficulty taking meds due to...	Compliant/non-compliant
Person who has been incarcerated	Inmate, felon, convict
Opioid	Narcotic

Figure 2: Suggested Language Document: Try This/Not That

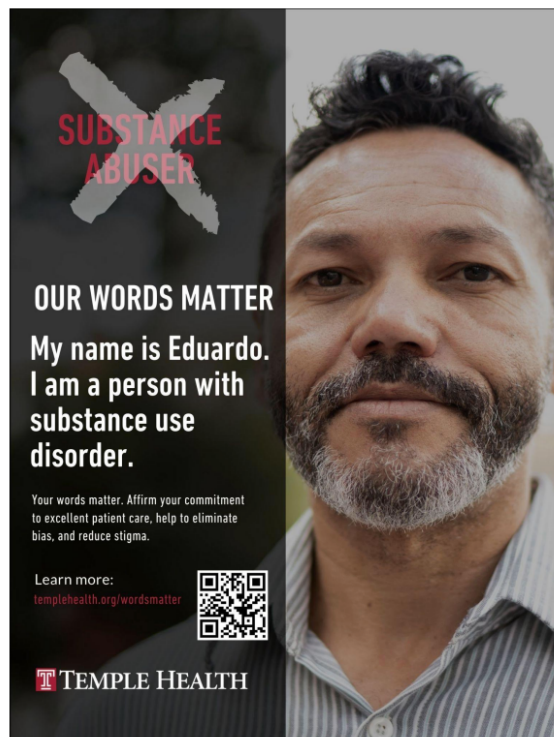


Figure 2: Sample Poster for Clinical Areas

A summary presentation of the recommendations was created and presented to the following groups over several months from summer 2021 through the winter of 2022: a large meeting of potential physician champions across specialties, faculty members, residents, medical students, and Patient Experience representatives. This occurred over a series of eight different presentations by core team members to more than 100 different staff members of all roles. Presenting the materials to multiple audiences allowed the team to adapt the mode of delivery, tone, and spokesperson to suit the group and venue. The presentations were structured with dedicated time for feedback and discussion. Open-ended written feedback was incorporated in an iterative process to improve the presentations for clarity and consistency. Peer-to-peer educational sessions were most well received, based on ad-hoc feedback. Final versions of both short (15 minute) and longer form (50 minute) presentations were completed by the early spring of 2022. Some sessions were presented in-person, and some were virtual sessions. From June 2021 to July 2022, the team

surveyed 113 audience members after educational sessions, of which 75% identified as residents, 16% as faculty and 9% as medical students or other roles. Most participants agreed or strongly agreed that they felt confident in their ability to identify (94%) stigmatizing language and use non-stigmatizing alternatives (92%) after the session. 96% saw value in using non-stigmatizing language. The majority reported being likely to suggest non-stigmatizing alternatives to peers (78%) and superiors (59%) upon hearing the use of stigmatizing language. For example, clearer examples were added to the Core Principles document and wording was simplified. An additional element of the strategy included coordinating with the medical school's diversity and inclusion office and aligning the campaign with a push for inclusive teaching and curricular review. This allowed stakeholders from a broader swath of the organization to be included in early training, and to act as champions for the work, and ensured synergy between faculty members' dual roles as clinicians and educators.

Navigating Pushback

Pushback to the campaign came in three varieties. First, some individuals wanted more evidence that language directly impacts patient outcomes. There is limited literature tying language to clinical outcomes. However, we assert that language reflects our stereotypes and by improving language choice we can challenge our own biases, encourage more compassionate care, improve the patient experience and, ideally, the utilization of healthcare services. The team stressed the inherent value of neutral, respectful, patient centered language, especially given patient access to medical records. This pushback created an important opportunity to educate providers about the importance of the patient experience and patient satisfaction, important standalone goals. Second, some individuals expressed initial resistance to changing their familiar language patterns. The team found that the best way to navigate this concern was by

discussing the dynamic nature of many aspects of medical practice that require continuing education, research, and quality improvement. It proved helpful to cite specific examples of language that is no longer used because it reflects a dated and inaccurate understanding of disease, such as "gay related immune deficiency (GRID)," a term used commonly during the initial emergence of the HIV/AIDS epidemic in the US. Finally, some providers expressed frustration with the number and evolving nature of recommendations. This feedback led to the creation of a guiding rule: "If I were a patient reading/hearing this, how would I feel?" The team also stressed that individual providers should use their best judgment and engage in ongoing dialogue with their patients about language choices, when possible. The team also normalized the experience of making errors

with language and the value of providing real time feedback to help one another.

Context and Limitations

There are many useful lessons from this campaign for those who want to affect culture change in medicine, however it is also important to consider the context and limitations of our setting. It is especially important to consider the impact of stigma and bias in language for communities that have been historically marginalized, given the recent studies demonstrating the higher likelihood of this language being found in the medical record of patients who are Black, patients with diabetes, and patients with a history of substance use disorder and chronic pain.⁹ Bias in clinical communication may be especially important to consider in settings where marginalized patients are less represented, as the impact of language may be compounded. There may also be issues of importance to other marginalized groups that were not adequately captured in our literature search, though we did make efforts to mitigate this by identifying the resources from the gray

literature. Ultimately, we believe that the principles of this campaign are applicable across a diverse array of practice settings and benefit all patients.

Language interventions cannot be implemented alone. Structural forces drive health disparities for marginalized patients. However, it is important to account for the lived experience of stigma and bias, and individual/interpersonal interventions like this one can be one piece of a larger strategy to address healthcare inequities. For instance, stigmatizing language is in many ways embedded in our technology. ICD-10 codes include medical terminology such as “substance abuse,” despite expert recommendation to use neutral alternatives. Federal governmental agencies that oversee substance use programming have called for an end to this terminology.²²

Strengths

Temple University has several strengths that were leveraged in the creation of this campaign. The Lewis Katz School of Medicine has a Center for Urban Bioethics (CUB), whose faculty teach and research health equity and social determinants of health. CUB faculty have worked closely with clinical faculty on other initiatives related to community engagement, medical education, and anti-racism. Experts from the Patient Experience Office and College of Public Health were readily accessible given the structure of a university-based health system

and were integral to the design and implementation of the campaign. Feedback from community members was another key component of campaign development, which was facilitated through the PFAC and the strong relationship between CUB and community partners, via the North Philadelphia Collective. A multidisciplinary approach and incorporation of iterative feedback were key to the success of the initiative.

Lessons Learned

The timing of the campaign coincided with new legislation requiring patient access to their medical records and helped build momentum and drive buy-in from various stakeholders, including hospital administration.

Some helpful lessons could be drawn from studies of healthcare workers who had piloted open notes before the law took effect in the spring of 2021.²³

Multidisciplinary input was essential to our success. For instance, the title of a campaign focused on language was an important consideration. The decision was the result of feedback from patients and community members, who identified that improving the language of the public was essential and that campaign materials in the clinical areas should be community-facing as well.

Primary concerns of many of the healthcare providers we spoke to were maintaining efficiency in charting and preserving information sharing. As a result, the campaign team focused on creating both overarching principles, as well as practical examples. Creating clear example language decreased perceived burdensomeness of the initiative. The team also sought to stimulate conversation amongst clinicians about best practices in clinical communication, and examples provided a helpful jumping off point for discussion in the education sessions.

A network of early adopters who acted as champions within their own spheres of influence was particularly helpful in spreading the message of the campaign and achieving later buy-in from hospital and medical school leadership. In early presentations to small groups of trainees, the team was able to

incorporate iterative feedback, build allyship and create awareness of the campaign. This led to invitations at larger venues, including departmental grand rounds, interdisciplinary committees, and ultimately hospital leadership meetings. Champions were then encouraged by hospital leaders to use the materials to initiate their own small group discussions in natural settings, such as didactics, staff meetings and teaching rounds.

Incorporating evidence from the academic and gray literature strengthened the campaign. Fortunately, there have been several recent quantitative and qualitative publications that describe stigmatizing language in the medical record. The team noted the lack of an overarching guideline for language best practices that extend across specialties and medical conditions. Much of the guidance comes from patient advocacy groups. A subgroup of the OWM team simultaneously worked to fill this gap with the creation of a guide to stigmatizing language for generalists that was published earlier this year.²⁴ Overall, the Temple Health OWM Campaign was unique, as it set out to create a broad and practical guideline that incorporated these various recommendations.

Future Directions

Campaigns like this one that are targeted to improve care at the individual and interpersonal level require ongoing education. We found physicians and physicians-in-training to be most accessible for education and training sessions. Standing series for continuing education provided opportunities for presentations. For instance, we requested training sessions for all incoming residents and fellows for the past two academic years, enabling the training of over 650 trainees at a time each year. Onboarding is a key time to reach new staff with important messages about language choice. Hospital leadership requested the creation of orientation materials for all staff who interface with patients, and that project is currently in process. It is important that

employees are consistently trained and that the principles are incorporated into their daily work. For example, the staff who do patient scheduling, those who work in nutrition services and social services, and those who create marketing materials can all benefit from education in best practices for communication that aligns with the health systems mission to serve all patients and provide respectful, quality care. The end goal is for uniform training before team members begin their work at the health system.

The topic of bias in language is dynamic and evolving over time and across contexts. Attention to this important mediator of the relationship between patients and healthcare providers will require both ongoing education

and assessment of efficacy. Both quantitative and qualitative research will be essential to describe the potential impact of a campaign like the one described here. By quantifying the use of negative language, such as pejorative terms, we can explore groups who might be at particular risk of this type of bias and determine which interventions are effective in creating behavior change. Some studies have already used natural language processing (NLP) to identify stigmatizing language in the medical record.⁶ Similarly, the OWM team has IRB

approval to examine the frequency of stigmatizing language use in the electronic health record before and after the educational campaign. Qualitative studies could further explore how this education might impact the beliefs, judgements, and behaviors of various members of the healthcare team. Such work could inform future interventions, such as a program to suggest neutral, patient centered alternatives in real time, using predictive text software.

Conclusion

In this case report, we have outlined how a multidisciplinary team convened to investigate an insidious issue that impacts patient care, compile best practices from the literature, create an educational intervention, and operationalize culture change across a complex institution with many stakeholders. The Our Words Matter campaign used grassroots energy, a flat leadership structure, passionate champions, and

community engagement to identify and disseminate best practices to reduce stigma and bias in clinical communication. Advocates across diverse disciplines can leverage these lessons and adapt this model to their own settings to strengthen the relationship between patients and providers and advance health justice.

Conflicts of Interest

We have no conflicts to declare.

Funding Sources

We have no funding source to declare.

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Gender-Inclusive Language and Abortion Protections

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In the wake of the overturning of *Roe v. Wade*, attention has turned to state-level protections for abortion rights. As state legislatures consider maintaining, revising, and creating laws to protect the right to choose to have an abortion, gender-inclusive language must be part of the consideration in order to offer protection to everyone who may become pregnant. When people are not covered by laws that protect abortion access, a pregnancy can lead to death from an unsafe abortion or pregnancy complications, negative and potentially long-lasting physical and mental health conditions, delays in obtaining healthcare due to having to travel, and the deprivation of one's ability to make choices about their life.

Gender-inclusive language is that which does not discriminate against a particular sex or gender identity; it is a powerful tool that can be used to promote equality and end gender bias (UN, n.d.). Reducing biases, stigmas, and disparities are of paramount importance in the healthcare profession, with its maxim of 'do no harm'; moreover, research suggests that inclusive healthcare improves outcomes (Chukwumerije, 2022). It follows, then, that our laws should reflect not only best, but most equitable, practices.

For example, in Maryland, "the State may not interfere with the decision of a *woman* to terminate a pregnancy before the fetus is viable" (Md. Health Gen. Code Ann. § 20-209, emphasis added). The language "woman" does not offer fully inclusive protection since people of gender identities such as transgender men, nonbinary, and agender may also become

pregnant, and thus need a clearly codified right to choose whether to access an abortion.

Until recently, Washington had the same issue as Maryland, with using the language of "every woman" in its reproductive privacy statute. But in the 2022 legislative session, its State Legislature changed the language to "every pregnant individual" has the right to choose to have an abortion (Wash. Rev. Code § 9.02.100). The Legislature noted that this change was to make the law gender-inclusive: "...[I]t is critical that we recognize that transgender, nonbinary, and gender expansive people also get pregnant and require abortion care. Washington's law should reflect the most inclusive understanding of who needs abortions and be updated with gender neutral language" (Wash. Rev. Code § 9.02.100, Legislative Affirmation 2022 c 65 § 1).

Twelve jurisdictions offer gender-inclusive language specifically in the context of explicitly protecting abortion access: California, Colorado, Connecticut, the District of Columbia, Illinois, Massachusetts, New Jersey, New York, Oregon, Rhode Island, Vermont, and Washington (PSP, 2022). For example, Vermont's code extends abortion rights to "every individual who becomes pregnant" (Vt. Stat. tit. 18 § 9493), New Jersey's code refers to "every individual present in the state" (N.J. Stat. § 10:7-2), and Oregon's code refers to a "consenting individual" (ORS § 659.880). These states should be applauded for their leadership, especially when antichoice policymaking is not reflective of the general population's beliefs, much less healthcare needs (Kitchener et al., 2022). The need for gender-inclusiveness is one

piece of a much larger post-*Roe* quagmire in which abortion access is increasingly difficult, if not impossible, in some states, particularly those which also have the least supportive healthcare and economic support systems for parents and children (Treisman, 2022). The legislative bodies of Maryland and many other states that do not yet have gender-inclusive abortion protection laws should look to the aforementioned states for examples of language to use in order to ensure that every person who may become pregnant has a clear legal right to choose to access an abortion.

Gender-inclusive abortion protection laws not only give every person who may become pregnant the ability to make choices about their circumstances, but also broadly

signal the values of the state. State legislators hold powerful positions, as the language in the laws they write impacts how our bodies are viewed, treated, and cared for, whether in doctor's offices, workplaces, or homes. We feel the impacts of laws in spaces far beyond legislative sessions or courthouses. And so legislators must use their power to make extraordinarily clear that laws regarding the right to have an abortion will not exclude people who are not of a particular gender identity. Rather, laws should signal that every person who may become pregnant deserves to have the right to choose because their life and health matter.

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The Challenge and Responsibility of Public Health Communication

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In the summer of 2022, Dr. Khiara Bridges, Professor of Law at University of California, Berkeley, was asked to testify at a congressional hearing on abortion rights. While congressional hearings are a regular occurrence, invitations for academic authorities to testify are less common. Too often, lawmakers coordinating these hearings do not invite testimony from members of the academic community, who are frequently some of the world's leading experts in specific content areas.

Dr. Bridges' testimony¹ made the national news. Unfortunately, it was not specifically for her depth of knowledge about abortion rights and the law. Rather, news outlets zeroed in on a heated exchange between Dr. Bridges and Congressman Josh Hawley, wherein the two sparred over terminology. Specifically, Mr. Hawley questioned Dr. Bridges' use of "people with the capacity for pregnancy," and questioned whether use of this term implied abortion was no longer a "women's rights" issue. While Dr. Bridges' justified her use of terminology by explaining that it accounts for individual differences in fertility and sex assigned at birth, Mr. Hawley's questioning highlighted the potential for such academic phrasing to be perceived as pedantic and potentially inaccessible to the broader population.

Maybe this was a trap by a savvy congressman who was hoping Dr. Bridges would walk into. Maybe it was an unforced error on her part. The unfortunate end result was that Dr. Bridges became known for this brief, wordy exchange over semantics rather than the reason why she was invited to testify: her expertise on abortion rights and the law.

This is not the first time that an academic expert has missed an opportunity to share their knowledge with the world. It certainly won't be the last. However, this example underscores the challenge and responsibility that academic professionals have when communicating their scholarship and its implications with the largest potential audience. In an age of 24-hour news cycles and social media, academics must change their thinking about how to communicate effectively with a broad audience.

Publishing papers in the peer review literature is the coin of the realm for many academic disciplines, including public health. For other disciplines, such as history, the coin is books. A tenure-track faculty member's productivity is primarily measured by the number of publications in peer reviewed journals. Disciplines have their own norms for evaluating "productivity." In some, adequate productivity translates to 2-4 publications per year, while in others the expected value may be two or three times higher.

While academics strive to publish their work in “high impact” journals, the relative impact of an academic journal is somewhat arbitrary. Journals like the Journal of the American Medical Association (JAMA) and the New England Journal of Medicine (NEJM) are internationally known; other specialty journals may have an impact factor dwarfed by those of JAMA or NEJM. In highly specialized areas of scholarship, publication in such lower-impact journals can be acceptable and may be seen as sufficiently productive for purposes of promotion or tenure review. But importantly, while acceptable for purposes of academic advancement, this endeavor usually only “impacts” a small number of people who read the literature or work in the specific field. Communicating with the public and changing discourse about public health events like COVID-19 or the opioid crisis is not going to happen through the peer-review process.

For some institutions, reliance on number of publications in academic journals is beginning to change. Some are now operationalizing productivity not only by the number of peer reviewed publications, but by the impact of the journals where those papers are published. Other institutions have begun to consider how well faculty members share their work with the world outside the ivory tower of academe, often in nontraditional venues. In this model, productivity would also be defined by the extent to which scholars share their work with the general public, via newspaper editorials or think-pieces, radio and television interviews, and perhaps even blogs and podcasts.

Public health is a discipline particularly well suited for this change. Much of our research and scholarship is (or at least should be) undertaken with the goal of promoting the health and wellbeing of individuals, neighborhoods, towns and cities. While some of this work impacts health policy, much has to be distilled down to the individual level. Sharing that work with the public via non-traditional venues might have a far greater impact compared to an obscure academic journal that may be behind an expensive paywall² and only read by a handful of people. This would also

elevate those with significant content expertise and the best interests of the public in mind to the role of credible public spokespeople, rather than politicians or “talking heads”.

In public health, we have lost the credibility narrative due to an inability to effectively navigate the new myriad of communication channels. In the past, a public health expert could be interviewed by one credible news organization, and their message would be repeated. Now, there are literally thousands of outlets for messages to be disseminated, many of which are pushing specific political or ideological beliefs while sharing “health” information.

Importantly, many of these new communication channels cater to their audiences far better than we do and traditional channels – such as newspapers – are falling short of their competition. Part of this problem may lie in readability. A recent report suggested that more than half of all American adults read below a sixth-grade level. However, newspaper articles are typically written at an 11th grade level³. Thus, the majority of Americans lack the literacy skills needed to understand the daily news through newspapers, and may turn to other, less credible channels for information. What chance does the public have to understand the writings of academics and international thought leaders, who often are writing for a small group of other highly educated peers⁴ if they cannot understand a typical newspaper article? Indeed, readability for many scientific papers is often above a college graduate reading level. Academics, particularly those in public health, have to start thinking differently about how to share our work with the broader public. That requires a seismic change in thinking.

If academic public health is to maximize its impact on addressing significant issues of both today and tomorrow, we need to move away from prioritizing the dissemination of findings to small groups of other academics and push ourselves to communicate effectively with the general public. Of course, for academics to move from the old to the new and shift their behavior, they will have to be incentivized. For

that to happen, more institutions must embrace the idea that academic productivity and scholarly impact extends beyond a number of peer reviewed publications. Importantly, one's productivity within nontraditional, public-facing dissemination avenues must be considered in promotion and tenure review.

This will also require a change from faculty members. We need to realize that communicating effectively with the general public is a skill, one that can be learned at any age if one's mind is open to doing so. That includes learning how to write for a public audience, as well as how to drill down research to its most understandable elements and

ultimate implications when communicating with the mass media. It also involves remembering at all times that your audience is everyone. So, while some may have appreciated the efforts that Dr. Bridges went to be as close to 100% accurate when describing "people with the capacity for pregnancy", her thoughts on the issue she was there to discuss—how the law impacts abortion rights for all—never reached the general public. Instead, news outlets focused on a clash that more illustrated a cultural and partisan divide over terminology, rather than the public health implications of eroding abortion rights

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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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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 expectancy¹.

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 health². 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 health³.

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 illnesses⁴. 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 today⁵.

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 technology⁵. 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 brains⁷. 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 months⁸. The disease affects between 5,000 to 6,000 Americans annually with an incidence of about 2 per 100,000⁹. 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 ALS¹⁰. 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 obesity¹¹. 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 obesity¹².

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 extent¹³.

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

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 many 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 biases¹⁴. This is certainly a step in the right direction and, hopefully, is one that leads to greater change over time.

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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