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Accessibility, Acceptance, and Equity: Examining Disability-Linked Health Disparities as Nursing and Communication Scholars

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Abstract

People with disabilities (PWD) experience health disparities, often related to contextual factors beyond the physical differences in body structure and function. The purpose of this article was to develop a research agenda for nursing and communication scholars that explores how developing accessible and empowering communication environments in healthcare contexts might mitigate disability-linked health disparities. We focused on two broad research objectives: developing both accessible communication environments and empowering communication environments in healthcare settings. Elements proposed as comprising accessible communication environments were: making health literacy accessible, addressing complex communication needs, and communicating the embodied experience of disability. Empowering communication environments were explored in light of various models of disability and their resultant effects on stigma and on promoting empowerment or disempowerment. Finally, an agenda for future research was proposed that considers: barriers to developing accessible communication environments, how communicative patterns in the patient-provider encounter create (dis)empowering communication environments, the ways in which providers draw upon models of disability in their actions with PWD, and the role that providers can play as allies for PWD.

Keywords: disability, health disparities, health inequity, stigma, accessibility

Introduction

According to the World Health Organization (WHO, n.d.), over one billion people in the world experience disabilities. Disabilities can be mental, physical, or sensory and can include chronic illness. Specifically, disability is often defined from a medical perspective, where variations from a "normal" body merit professional diagnosis and, if possible, treatment. However, the term "disability" is increasingly being conceptualized more broadly to incorporate social justice, identity, and quality of life (QOL) elements. For instance, the Americans with Disabilities Act (ADA) defines a disability as "(a) a physical or mental impairment that substantially limits one or more of the major life activities of such individuals; (b) a record of such an impairment; or (c) being regarded as having such an impairment" (Ameri-cans with Disabilities Act, 1990, para. 1). Similarly, the WHO's (n.d.) International Classification of Function, Disability, and Health (ICF) defines disability as "an umbrella term, covering impairments, activity limitations, and participation restrictions" (n.d., para 1). Both definitions move beyond recognizing physical differences in body functioning and structure, termed "impairment," toward considering if and how those impairments affect a person's capacity to complete desired activities and to participate in social life. More than this, these definitions recognize that contextual factors related to both the individual person and their environment shape the experience of disability (Roush & Sharby, 2011).

Individuals with the same physical impairments experience themselves as more or less disabled depending on the ways in which contextual factors (i.e., physical spaces, social attitudes, local and national policies) support or constrain them. Further, both body and context interact in ways that shape a person's self-concept and his/her psychological well-being. In thinking about health challenges for people with disabilities (PWD), then, researchers must consider challenges situated both in individual bodies and in the settings those bodies inhabit.

PWD experience health disparities, defined as adverse differences that face a group that encounters greater obstacles to health (Healthy People 2020, n.d.). Health disparities among PWD, which are evident globally, can result from various factors. In some cases, the physical impairments associated with a condition put an individual at risk for secondary conditions, resulting in increased health disparities (Rimmer, Chen, & Hsieh, 2011). However, many health disparities experienced by PWD are not caused by the condition itself, but by institutional, political, and social realities that preclude both equal participation in society and equitable access to quality healthcare. As such, the purpose of this article is to develop a research agenda for nursing and communication scholars that explores

how developing accessible and empowering communication environments in healthcare contexts might mitigate disability-linked health disparities.

Many health disparities experienced by PWD reflect oppressive discourses and practices that pervade society. Stigmatizing discourses marginalize PWD by framing them as "undervalued, undesirable, asexual, naïve, and dependent" (Foster & Sandel, 2010, p. 181), in turn, increasing the likelihood that they will be mistreated. PWD are at higher risk for intimate partner violence and violence perpetrated by caregivers (Foster & Sandel, 2010). Basile, Breiding, and Smith (2016) found that men and women with disabilities experienced increased sexual violence compared to their non-disabled counterparts; 39% of US women who had been raped in the past year had a disability. Strand, Benzein, and Saveman (2004) found that 35% of respondents in their survey of 122 staff members in Swedish group homes for people with developmental disabilities have been involved in or witnessed violence against PWD. In addition, PWD face more insidious forms of violence like those present in blatant discrimination and microaggressions, and in policies and norms that make it more difficult for PWD to get an education, remain consistently employed, establish romantic partnerships, live independently, and secure other resources that contribute to a person's QOL.

Scholars who research the relationship between nursing and communication should attend to the ways in which aspects of the current healthcare system exacerbate or ameliorate these sources of health disparity. Indeed, healthcare providers (HCP) and the institutional structures in which they participate can contribute to the negative health outcomes PWD experience. PWD contend with (a) inaccessible healthcare services (i.e., hospitals or clinics that do not accommodate alternative physical, communication, and sensory needs and/or are cost prohibitive); (b) inadequate communication between PWD, their HCP, and/or potential support persons (family members, professional caregivers, interpreters, etc.); and (c) stereotypes about people with disabilities that encourage stigmatizing, infantilizing, and paternalistic approaches to providing healthcare. Such approaches limit patient self-determination and perpetuate ableism, defined by Roush and Sharby (2011) as systematic discrimination against, and oppression of, people with mental, emotional, and physical disabilities. Further, disability-related stereotypes may cause HCP to overlook health needs not directly linked to a person's disability. For instance, symptoms presented by people with intellectual disabilities are often wrongfully attributed to their disability, a process known as "diagnostic overshadowing" (Ouellette-Kuntz, et al., 2005; Turnbull & Chapman, 2010).

Perceptions of PWD as physically inactive lead HCP to be less likely to counsel them to engage in exercise regimens, despite higher levels of obesity in this population (Palsbo & Kailes, 2006). Similarly, assumptions that PWD are asexual, prejudices that suggest that PWD are sexually undesirable or should be prevented from having sex, and beliefs that their sexuality and sexual behaviors are symptoms of pathology contribute to inadequate access to both opportunities for empowering sexual experiences and to sexual health services— particularly for individuals who identify with alternative gender and/or sexual identities (Brodwin & Frederick, 2010; Friedman, Arnold, Owen, & Sandman, 2014; Noonan & Taylor Gomez, 2010; Vaughn, Schoen, McEntee, & McGrady, 2015). Among adolescents with physical or mental disabilities, nurses have reported providing sexual healthcare as being very difficult due to time and resource constraints and privacy concerns (McCabe & Holmes, 2013), resulting in a potential unmet needs. HCP in the Philippines have reported that their ability to provide sexual and reproductive healthcare to adults with disabilities was undermined by their own prejudiced attitudes and lack of knowledge on the topic (Lee et al., 2015).

Stereotypes and prejudices, as well as limited understanding of both individuals' condition-specific needs and broader norms of disability culture, negatively affect the ways in which HCP communicate with PWD. People with psychiatric disabilities have identified ineffective patient-provider communication as leading to substandard care (Ali et al., 2013; O'Day, Killeen, Sutton, & Lezzoni, 2005). Similar dissatisfaction with patient-provider communication was articulated by pregnant or lactating Ghanaian women with physical, visual, speech, or hearing disabilities, leading to challenges accessing healthcare (Ganle et al., 2016). Adults with autism/autistic adults[1] have reported more unmet healthcare needs and lower satisfaction with patient-provider communication than neurotypical adults (Nicolaidis et al., 2012).[2]

While some communication challenges stem from the unique communication needs associated with a particular condition/individual, dissatisfaction with HCP communication also stems from providers' unwillingness to approach their patient as an empowered collaborator in the healthcare encounter. For example, mothers with disabilities have reported that prenatal education was negatively affected when HCP failed to provide sufficient materials or encourage full participation (Blackford, Richardson, & Grieve, 2000). Similarly, Witham, Haig, and Foy (2014) found that HCP, when caring for patients with mental or intellectual disabilities undergoing cancer care, performed problem solving without the patients' input.

These communication challenges, in addition to challenges linked to inaccessible healthcare services, compound the condition-specific risk factors PWD face in ways that magnify poor health outcomes. For

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[1] While some in the autism community prefer people first language to differentiate themselves from their diagnosis, others prefer to be called "autistic" because they view autism as an important, positive aspect of their identity.

[2] "Neurotypical" is a term developed by the autism community to refer to people who are not on the autism spectrum.

instance, people with intellectual disabilities have higher morbidity and mortality than the general population (Fisher, 2004; Goddard, Davidson, Daly, & Mackey, 2008), are six times more likely than their able-bodied peers to be hospitalized (Hemsley, Balandin, & Worrall, 2011a), and are three times more likely to experience preventable adverse events when hospitalized (Hemsley, Balandin, & Worrall, 2011b). Likewise, people with communication disorders are at increased risk of experiencing medical errors (Burns, Baylor, Dudgeon, Starks, & Yorkston, 2015). These outcomes may be partially explained by the prevalence of diagnostic overshadowing (Ouellette-Kuntz et al., 2005), as well as delayed diagnosis, inadequate treatment, and neglect (Greenstock & Wickham, 2011). Other health disparities may be tied to the presence of particular stereotypes, such as stereotypes about sexuality and PWD. For instance, when exploring components of reproductive health, researchers have found that women in South India with disabilities are less likely to successfully become pregnant, and more likely to experience negative conditions during pregnancy, than women without disabilities (Murthy, John, & Sagar, 2014). Further, "professionals' negative attitudes lead to exaggeration of normal behavior, feeling guilty, group stereotype behavior, rage and denial behavior amongst disabled people" (Sahin & Akyol, 2010, p. 2272), potentially contributing to increased mental health challenges.

Despite mounting evidence that PWD face unique challenges in the healthcare system, researchers in nursing, public health, and other allied health fields have only recently begun to address disability as a minority group similar to race, ethnicity, and socioeconomic status. (Hayward, 2004; McDonald & Raymaker, 2013). To some extent, this paucity of research exists because disability has long been framed as an individual physical pathology, rather than as a distinct identity and cultural category. Indeed, because health researchers often use the language of biomedicine, they alienate potential research participants who identify positively with their disability, and who are wary of historic abuses PWD have experienced at the hands of researchers (i.e., eugenics movements; McDonald & Raymaker, 2013). Further, researchers are discouraged by overprotective stances taken by Institutional Review Boards, often avoiding working with this population rather than considering how the informed consent process can be reconfigured in ways that are both accessible and empowering for PWD (McDonald & Raymaker, 2013).

Even when researchers attend to health disparities faced by PWD, they often overlook or ignore intersecting sources of inequity, where PWD who are also people of color, members of the LGBT community, and/or belong to another minority group experience "double jeopardy" stigmatization (Block, Balcazar, & Keys, 2001; Noonan, & Taylor Gomez, 2010; Vaughn et al., 2015). Worse, as Vaughn et al. (2015) noted, "there are few communities where an individual who belongs to multiple minority groups is fully accepted into each cultural sub-group due to internalized oppression among in-group members" (p. 50). This means that black lesbians with disabilities, for example, contend with manifold sources of social isolation that threaten their QOL.

Researchers who are interested in nursing and communication, as well as in disability studies, are particularly well-positioned to consider how both physical impairments and social realities intersect and contribute to health disparities for PWD. In addition, researchers in these fields can consider how communicative practices might be reimagined in ways that contribute to better health outcomes for this population. In the following discussion, we draw on literature from nursing, public health and allied health fields, disabilities studies, and communication studies to develop an agenda for future research. We focus attention on two broad research objectives that we believe are particularly vital: (a) developing accessible communication environments in healthcare settings and (b) developing empowering communication environments in healthcare settings.

Developing Accessible Communication Environments in Healthcare Settings

For PWD who experience physical impairments, or who are highly sensitive to stimuli like light, sound, and smell, healthcare facilities are inaccessible when they do not adequately accommodate the ways in which different bodies navigate spaces and process sensory input (i.e., by providing quiet spaces and by designing accessible bathrooms, weight scales, adjustable-height exam tables, exam chairs, etc.; Palsbo & Kailes, 2006). More than being inaccessible *physical* environments, however, healthcare facilities are often inaccessible *communication* environments. This is particularly true for people who have complex communication needs (CCN; i.e., people who are Deaf/deaf or hard of hearing, blind or who have low vision, nonverbal or who have aphasia, apraxia, or another communication disorder, and people who have developmental disabilities and require assistance to process complex medical information). These individuals may have trouble accessing health information, making their needs and desires known to healthcare providers, and communicating the complexities of their embodied experience of disability. For example, people who are nonvocal and ventilated reported that lack of reciprocal communication makes them feel incomplete, frustrated, and powerless (Carroll, 2007).

Accessible Communication and Health Literacy

Communication researchers have considered how challenges accessing health information constrains

health literacy for PWD, particularly in the context of internet-based health information. For example, HCP are increasingly utilizing vision-based materials (Harrison & Lazard, 2015) such as infographics, especially online. However, these forms of information may remain inaccessible to users with visual differences, particularly when they are not accompanied by text and image descriptions. Similarly, people who are culturally Deaf and communicate via sign language often learned English as a second language and read at aand communicate via sign language often learned English as a second language and read at a third to fourth grade level, on average (Jones, Renger, & Kang, 2007). Consequently, health content included in online videos may remain inaccessible to Deaf individuals, even when captioning is included.

Indeed, health communication scholars have researched the ways in which inaccessible or poorly designed health websites might make it more difficult for people with disabilities to obtain and understand health information (Davis, 2002; Kushalnagar et al., 2015). Increasing interest in universal design and the development of web accessibility guidelines and tools have helped to address this form of the digital divide, but accessibility errors remain on most health sites (Geiger, Evans, Cellitti, Smith, O'Neal, & Firsing, 2011). Legislators have sought to address this issue. For instance, Section 508 of the Rehabilitation Act requires that "all federal public web sites including those developed under contract must be fully available to individuals with disabilities" (Geiger et al., 2011, para. 15), while the ADA and the Individuals with Disabilities Education Act (IDEA) also provide similar mandates to make public resources accessible to people with disabilities. In fact, healthcare companies are increasingly facing lawsuits over ADA website compliance (Bulgaru, 2019), placing pressure on healthcare organizations to consider how they might eliminate digital barriers that contribute to lower levels of health literacy in PWD.

Accessible Communication and Complex Communication Needs

People with CCN also encounter challenges communicating with their HCP during medical interactions. For example, misunderstandings and negative outcomes resulted when patients who were nonvocal and ventilated were not understood by others, as demonstrated by a metasynthesis of studies on this population and experience (Carroll, 2004). While people with CCN often utilize augmentative and alternative communication (AAC) systems (i.e., communication boards, gestures, or signing), they typically do not bring these systems to a hospital setting and rarely make use of them with HCP (Greenstock & Wickham, 2011; Hemsley et al., 2011a). Instead, they rely on family members and other support persons who may not always be present when a need arises, or who may not be comfortable

taking that role (Hemsley et al., 2011b).

Nurses have reported learning to communicate with patients more effectively over time, especially if they used humor to diffuse tension, approached the work of communication as a collaborative process, and recognized patients' rights to autonomy (Hemsley et al., 2011a). However, HCP tend to use "close-ended questions, limited turn-taking, and other conversational devices" that discourage patients with disabilities from taking an active role in the conversation (Burns et al., 2015). Additionally, time limitations in the healthcare context, as well as HCP limited knowledge of a patient's specific needs, can cause frustration on the part of both parties, sometimes leading HCP to resort to guessing or walking away before a communication challenge can be resolved (Burns et al., 2015; Hemsley et al., 2011a). Hemsley et al. (2011a) noted that patients with CCN are less likely to be afforded adequate time to communicate when nurses,

(a) expect that it might be a waste of time, (b) lack
(b) access to adaptive communication strategies,
(c) assume that the patient would not understand,
(d) lack confidence or competence in communicating with the patient, or (e) doubt that such communication would be successful. (pp. 119-120)

When HCP are unable and/or unwilling to communicate effectively with patients with CCN, these individuals feel dehumanized and socially isolated. These communication challenges also lead to very real health concerns—limited capacity to communicate pain; feelings of being "unsafe" because of body positioning (i.e., needing to be secured in a wheelchair); inability to advise HCP of dietary preferences/restrictions or concerns about aspiration, potentially causing patients to refuse to eat; and challenges in making hygiene-related requests (i.e., needing to visit the bathroom; Hemsley et al., 2011b).

Even when HCP do make use of AAC systems, they usually only address the "Big 5" topics: (a) pain, (b) hunger/thirst, (c) comfort, (d) hygiene, and (e) nausea (Hemsley et al., 2011b). This standard communication structure ignores important needs identified by patients, including the need to communicate about what is medically wrong and what procedures will be done to address the issue, the need to communicate about post-discharge care plans (often solely discussed with caregivers), the need to demonstrate personal intelligence, and the need to establish social connections during extensive hospital stays (Hemsley at al., 2011b). These inaccessible communication environments prevent PWD from telling, controlling, altering, and claiming their stories (verbally or in alternative formats), limiting their ability to engage in self-healing and to claim their personhood (Cameron, 2015).

Using interpreters in healthcare settings can create more accessible communication environments. Patients

with aphasia benefit from using family members as interpreters when they successfully develop communication teams. Patients and their family members co-construct messages; patients attempt to communicate their experiences, signal their need for help, and monitor support persons' messages to correct and clarify, while support persons' messages to correct and clarify, while family members "jump in" to interpret for the patient as needed, translate medical jargon, and communicate to make sure that the patient was correctly understood (Burns et al., 2015). However, issues arise when the HCP directs their communication to the family member rather than to the patient, or when family members "jump in" too soon or push an agenda that does not correspond to the patient's desires (Burns et al., 2015).

Professional interpreters can be useful, but requesting one places an extensive burden on patients. For instance, DeVault, Garden, and Schwartz (2011) note that, unlike hearing patients, Deaf/deaf patients must engage in the communicative labor of making their requirements understood, the logistical work of requesting and arranging for an interpreter, and the emotional labor of advocating for their needs and managing annoyed nonverbal responses or outright rejections from HCP. Indeed, Deaf/deaf patients may delay asserting their right to an interpreter, despite its protection by the ADA, because they fear being perceived as a nuisance (DeVault et al., 2011). Devault et al. (2011) emphasized reframing these requests for HCP so that they recognize that their patients are burdened by additional labor expectations and aren't just being "difficult." In addition, HCP should acknowledge that the benefit of interpreters applies to them as well, by allowing them to build rapport with their patient. Moreover, policies for providing interpreters may remain ineffective if they failed to consider patients' individual needs (i.e., recognizing that some Deaf/deaf individuals may speak a different dialect of sign language, or may have always utilized spoken language and never learned sign language), or consider additional contextual concerns like patient privacy (i.e., hiring a man to serve as an interpreter for a woman's mammography appointment).

Communicating the Embodied Experience of Disability

Finally, even when PWD do not have CCN, they may experience communication challenges in explaining the embodied experience of having a disability. For instance, Yorkston, Johnson, Boesflug, Skala, and Amtmann (2009) explored the challenges patients with a variety of physical disabilities faced in communicating about their chronic pain and chronic fatigue. Reporting pain using the typical 1-10 pain scale prevented patients from conveying dimensions of pain, including type of pain, location, pain experience or intensity, and time-related aspects; did

not acknowledge that their pain baseline is not typically zero; and did not capture the ways in which pain affected their ability to complete desired life activities. Similarly, questions about fatigue did not allow patients to differentiate between physical fatigue and cognitive fatigue. Most worryingly, patients often felt that these invisible components of their experience were dismissed by HCP because they could not be measured empirically. Such communication challenges highlight the link between developing an accessible communication environment and developing an empowering communication environment in healthcare settings.

Developing Empowering Communication Environments in Healthcare Settings

While physical impairments can pose very real, embodied challenges for PWD, of equal and sometimes greater concern is the ways in which discriminatory attitudes and ableist practices impede their QOL. For this reason, the ways in which disability is framed, and resulting policies and patterns of patient-provider communication, can produce either oppressive or empowering communication environments in healthcare settings.

The Medical Model of Disability

Historically, disabilities have been conceptualized via the medical model. This model activates the metaphor of disability as a medical problem (Coopman, 2003) and frames the disabled body as pathology—a deviation from a "normal" body that must be treated and cured (DeVault et al., 2011; Hubbard, 2004; Palsbo & Kailes, 2006; Roush & Sharby, 2011; Sahin & Akyol, 2010). From this perspective, disability is conceived of as an *individual* issue, caused by disease, genetic deformity, or injury and affecting a particular person's ability to function "correctly." The medical model remains the primary way in which HCP are trained to conceive of disability; their job is to rehabilitate PWD so that become as able-bodied as possible. This model is not applied just to people with physical disabilities. Temple and Mordoch (2012) found that nursing students tended to conceptualize intellectual disabilities using a medical model orientation. Similarly, invoking the medical model when describing mental health conditions, by referring to them as "brain diseases," is a common strategy used for combatting stigmatized notions of being "crazy" or "insane."

Unintended Consequences of the Medical Model

However, framing disability using the medical model can have unintended negative consequences. Focusing on physical functioning may cause HCP to overlook individuals' holistic psychosocial needs. For instance, Ormond, Gill, Smeik, and Kirschner (2003) found that when medical students, medical residents, and genetic counseling students were assessing QOL for people with genetic disabilities, they focused more on

medical or functional aspects of disability instead of personal and social variables—more accurate QOL parameters. In addition, narrow definitions of "medical necessity" can lead to oppressive, ableist policies. For instance, Medicare denies coverage of motorized wheelchairs for people who can navigate their homes without one—a policy that assumes that PWD do not participate in society outside of their home, and that denies these people a mobility aid that would help them to do so (Palsbo & Kailes, 2006). This policy implicates another model of disability, the economic model, which "assumes that people with disabilities are less efficient human resources than people without disabilities" (Hubbard, 2004, p. 185), despite the fact that reduced reliance on physical labor, flexible work arrangements, and telecommuting have made it easier for people with alternative abilities to participate in the workforce. The economic model of disability gives additional power to HCP, who determine whether their patients can "claim" disability, not as an identity category, but as a marker of their inability to contribute economically to society.

Stuck in the sick role: stigma and the medical model. Both the medical and economic models compel PWD to occupy the "sick role" (Parsons, 1951) depicting them as pitiable, dependent victims who should not be expected to fulfill typical social and economic obligations, but who should be expected to strive toward overcoming (rather than accepting and embracing) their disability (Fine & Asch, 1988; Linton,1998). These models create and reinforce stigma, or socially negative attitudes held by others. Attitudes towards people with disabilities sometimes reflect social discomfort, may include fear of being contaminated by a disability, and may cause HCP to exhibit exaggerated empathy (Thomas, Palmer, Coker-Juneau, & Williams, 2003). HCP, particularly nurses, are more uncomfortable treating patients with intellectual disabilities than patients who have physical disabilities (Temple & Mordoch, 2012). Similarly, people with mental health conditions are likely to be associated with stigmatizing stereotypes. For instance, researchers have found that nurses perceived people with mental health-related disabilities as being risky, different, and lacking stability—all of which indicate a non-person-centered view that is "more stereotyped than specialized" (MacNeela, Scott, Treacy, Hyde, & O'Mahony, 2012, p. 209). Certain types of mental health conditions, such as borderline personality disorder (BPD), were prone to more negative attitudes from mental health nurses, resulting in nurses' counter-therapeutic responses (Dickens, Lamont, & Gray, 2016). While framing mental health conditions via the medical model may seem to reduce stigma by removing blame from the patient, Sayce (2014) posited that this strategy actually promotes stigma and discrimination because it leads providers to assume that PWD are unpredictable and lacking

judgment, and therefore should be avoided. These negative attitudes persist when HCP have little education about, or interaction with, PWD. Indeed, several researchers have noted that HCP typically receive inadequate training in disability-related issues, and recommend that disability-specific training be integrated into nursing and other health professions' curricula (McDonald & Raymaker, 2013; Sahin & Akyol, 2010; Seelman, 2004; Temple & Mordoch, 2012).

Dignity deficits in care: **Disempowerment and the medical model.** Clinical practice is affected by professional attitudes, including stigma, which shape how HCP communicate with their patients (Ormond et al., 2003). For example, Duggan, Bradshaw, and Altman (2010) noted that providing training that focuses solely on medical aspects of disability "may perpetuate the belief among physicians and other providers that if a cure is not possible, then there is 'nothing to be done' and may lead to unease, avoidance, and less than optimal care" (p. 336). Dehumanizing, and sometimes abusive, treatment occurs when healthcare interactions produce "dignity deficits in care" (Caspari, Aasgaard, Lohne, Slettebø, & Nåden, 2013, p. 2319). Dignity involves ensuring that patients have respect, privacy, and control (Caspari et al., 2013). Dignity deficits emerge and persist when: (a) inaccessible facilities force PWD to ask for assistance, (b) HCP focus on the diagnosis or disability itself and not the person, (c) HCP assume patient incompetence and/or do not seek their consent for procedures, (d) HCP don't engage patients and/or their support persons in problem-solving and decision-making, (e) HCP override or ignore patient preferences and decisions, (f) HCP impose their own values on PWD, (g) HCP do not offer the same treatment options or screenings to PWD as they would to their able-bodied population, and (h) HCP perceive and treat PWD as low priority patients (Caspari et al., 2013; Turnbull & Chapman, 2010).

Self-stigma: Identity challenges and the medical model. In addition to potentially producing dignity deficits in care, the medical and economic models of disability may cause PWD to experience self-stigma, where a person applies a negative stereotype to him or herself. Self-stigma prevents individuals from accepting their disability and negatively affects both their mental and physical health outcomes. For instance, Boyd, Adler, Otilingam, and Peters (2014) measured self-stigma in people with mental health conditions and found that self-stigma correlated with higher levels of depression, lower self-esteem, and higher symptom severity. Similarly, Berglund, Mattiason, and Nordstrom (2003) found that when patients with a connective tissue disorder had a higher level of acceptance of their disability, they reported a higher level of sense of coherence and better functional, physical, and psychosocial health statuses.

The experience of self-stigma is likely linked to the

degree to which PWD feel that they can accomplish their goals and participate in society. For example, people with multiple sclerosis demonstrated higher levels of self-stigma when their disability progressed to the point where independence was lost and a caregiver was needed (Anagnostouli et al., 2016). Working full-time has been linked to higher acceptance of disability (Berglund et al., 2003), indicating that preserving and promoting independence can alleviate feelings of self-stigma.

The way in which disability is framed, however, likely also contributes to the amount of self-stigma that people with disabilities experience. PWD draw on cultural discourses of disability as part of the sense-making process of narrating their lives. For instance, Cardillo (2010), a communication scholar, applied narrative theory to examine autobiographies written by PWD. She found that some writers engaged the discourse of embodied difference as devaluation, where they felt diminished by their disability and described their different selves as "unacceptable, defective, passively suffering victim; rejected, abandoned, isolated, ashamed, inferior, humiliated, helpless, ugly" (p. 534). Others engaged the discourse of embodied difference as hard reality, where they felt that their disability was an unavoidable burden and source of alienation, and felt that they had to adapt their different, "abnormal" self to accommodate "society's taken-for granted attitudes, rules, prejudices" (p. 534).

Disability Reframed: Applying Social Models of Disability

Cardillo's (2010) research highlights the idea that effectively coping with self-stigma involves altering personal perception of the stigma, which subsequently increases self-esteem and empowerment (Mittal, Sullivan, Chekuri, Allee, & Corrigan, 2012). Indeed, Cardillo (2010) found that some autobiographers engaged in the discourse of embodied difference as oppression to recognize the ways in which they had been unjustly treated by society, and mobilized the discourse of embodied difference as integrated to accept, embrace, normalize, and value their disability. Similarly, Parsloe (2015) found that members of an online community (re)claimed their autistic identity by reframing normalcy as a spectrum of difference, reframing "symptoms" of autism as strengths, and reclaiming agency by embracing a self-advocate identity and forging common cause with other historically marginalized groups.

More empowering discourses of disability draw on alternative models of disability that have risen to prominence alongside the disability rights and self-advocacy social movements. Disability activists have endorsed various forms of the social model of disability, which reframes physical and mental differences as natural and valuable forms of human variation worthy of both acceptance and pride. This model politicizes disability, shifting attention away from physical impairment to reframe disability as a social construction "shaped by physical characteristics of the environment, cultural attitudes and social behaviors, and the institutionalized rules, policies, and practices of private and public organizations" (Hayward, 2004, para. 14). Rather than representing an *individual* pathology, disability captures the oppressive experiences of a disenfranchised *group*—a social justice problem, not a biomedical one. For instance, one version of the social model, the minority group model, compares disability to other historically segregated and oppressed groups, such as women and African Americans, and pushes to make similar strides in securing equal rights (Block et al., 2001). Framing disability in this way activates new metaphors, including disability as culture, disability as politics, and disability as community (Coopman, 2003).

Holistic Empowerment: Engaging the Integrative Model of Disability

As the social model of disability gains traction, PWD are being inspired to reimagine their identities, while HCP are being compelled to reconsider the assumptions of the medical model that shaped their training (DeVault et al., 2011; Hayward, 2004; Roush & Sharby, 2011; Seelman, 2004). Given that the goals of the medical and social models often appear diametrically opposed, this cultural shift can be a source of tension. Critiques of the healthcare system may elicit defensiveness from HCP who perceive an attack on the culture of medicine, and who may resist ceding some of their medical authority by recognizing patients' embodied knowledge. Alternatively, some PWD may embrace the medical model in hopes of eliminating some of the very real physical challenges they face. This might be particularly true of people defined by disability studies scholar, Wendell (2001), as the "ill disabled" (p. 19)—individuals who face significant amounts of pain or unpredictable or worsening health threats because of their condition. The integrative model, also referred to as the biopsychosocial model or the functional-limitation paradigm, provide a productive middle ground that acknowledges the intersection of physical impairment and its biological causes with environmental, social, and political factors that constrain PWD.

Embracing the integrative model might encourage HCP to view their patients more holistically, and to cultivate more empowering communication environments. In cases where patients are experiencing self-stigma, HCP might act to reframe disability by guiding them through the four stages of empowerment associated with self- and collective-advocacy: (a) recognizing discrimination, (b) exchanging a focus on limitations and impairments for a recognition of personal strengths, (c) gaining competence in identifying needs and self-efficacy in pursuing them, and (d) collaborating with supportive others (Block et al., 2001). In cases where

PWD embrace disability as a culture and identity category, HCP might develop an empowering communication environment by validating patients' feelings of disability pride, using their preferred identity terminology (i.e., asking patients whether they prefer to identify as a person with autism or as autistic), finding ways to work with patients' individual physiology to help them achieve self-defined goals (rather than pushing strategies to fix their bodies in order to conform to markers of "normal" physical functioning), and acting as an ally to identify and eradicate institutionalized ableism.

While these recommendations provide broad guidelines for HCP, research that identifies specific empowering and disempowering communication strategies used by nurses during healthcare encounters can help educators to develop more effective training curricula. For example, communication scholars Duggan and colleagues (2009, 2010) video recorded and analyzed 138 Tufts University School of Medicine students' interactions with a standardized patient educator (SPE) who had a visible physical disability (i.e., cerebral palsy, muscular dystrophy, blindness, respiratory failure). Their analysis of these interactions revealed that 26% of participants did not ask about the disability at all. Further, respondents sometimes did not respond to disability-related cues articulated by the SPE (in 27 interactions), and reverted to biomedical, physical functioning-focused questioning even when the patient mentioned broader psychosocial challenges (in 20 interactions). When patients did ask about the disability, they sometimes asked via indirect or general ways (i.e., asking about previous medical history), framed the condition as a medical "problem," quickly changed topics, and offered overly positive affirmations when patients disclosed achievements that would be considered relatively unremarkable for an able-bodied person. Of the 106 participants who did ask about the disability, relatively few (i.e., 26) integrated disability with their assessment of the shoulder pain by considering how life activities tied to living with a disability, such as using a wheelchair, might have contributed. The researchers concluded that when HCP fail to integrate disability disclosures, switch topics, revert to biomedical questioning, and/or engage in overaccommodation, they may offend patients by communicating discomfort, negativity, and avoidance and by appearing to treat disability information as irrelevant.

In a related study, Duggan, Bradshaw, Carroll, Rattigan, and Altman (2009) found that interactions with the SPE helped medical students to recognize the importance of learning about daily life with a disability so that they can integrate psychosocial factors into a more holistic medical assessment. Students also learned to consider both aspects of the disability and use of outside services in developing treatment plans (i.e., recognizing that patients who

rely on their arms for transportation might be advised to make use of personal care attendants to transfer in and out of a wheelchair, rather that requesting that the patient avoid using his or her arms). Finally, students realized and reconsidered previously-held attitudes and assumptions, and reported "learning the ways the patient avoid using his or her arms). Finally, students realized and reconsidered previously-held attitudes and assumptions, and reported "learning the ways the SPEs lived independent and physically active lives, and learning that disability may be more appropriately interpreted as affecting, rather than limiting, the patient's life" (p. 806). The promising findings reported in this research highlight the important contributions that scholars of nursing, communication, and disability studies might make as they develop future research projects.

An Agenda for Future Research

The persistence of disability-linked health disparities is more than a medical issue; it is also a communication issue and an issue of social (in)justice. For this reason, future research should engage an interdisciplinary approach to secure accessible, equitable, and empowering healthcare services for PWD. Below, we outline several points of entry for researchers seeking to contribute to this goal.

First, future research should aim to identify and address barriers to developing accessible communication environments in healthcare contexts. In particular, researchers should focus on opportunities for participatory action research, where patient and caregiver perspectives might be harnessed to identify communication challenges that remain unacknowledged, and to propose alternative solutions. For instance, this research might uncover factors that discourage patients from bringing, and making use of, AAC systems in hospital settings. Further, this research might lead to HCP training curricula that educates about life with CCN from the patient perspective, emphasize the patient's right to self-determination and the assumption of competence, and provide strategies for managing apprehension and frustration related to communication challenges. Further, narrative scholars might attend to how the stories HCP tell about difficult communication encounters might perpetuate perceptions of patients with CCN as "difficult" or "burdensome," or might support creative and collaborative problem-solving driven by a desire to protect patients' health and to preserve their dignity. Additionally, scholars who study organizational communication might explore how the language of policies regarding AAC, as well as they ways in which these policies are framed, perceived, and enacted, contribute to or ameliorate issues of accessibility. Finally, researchers may attend to how emerging and evolving assistive communication technologies might be effectively employed in

healthcare settings to both enhance patient-provider relationships and reduce health disparities.

Second, future research should consider how communicative patterns present in the patient-provider encounter create (dis)empowering communication environments in healthcare settings. New research might extend the work conducted by Duggan and colleagues (2009, 2010), identifying communication patterns that occur in cases where the disability is less visible (i.e., a mental health condition or a condition that involves joint or nerve pain). These projects might also reveal how condition-specific stereotypes and sources of stigma shape both treatment plans and patient-provider relationships. Additionally, consideration as to whether stereotypes associated with specific types of disabilities—physical disabilities, learning and developmental disabilities, mental health conditions—are linked to systematic differences in access to particular forms of care (i.e., screening for sexually-transmitted diseases) will be particularly important. Alternatively, researchers might examine the strategies that patients use to manage healthcare providers' negative attitudes and assumptions, potentially educating providers in ways that develop more collaborative and respectful relationships. Although some communication researchers have studied self-advocacy as a communicative phenomenon in the case of chronic illnesses like AIDS (Brashers, Haas, & Neidig, 1999), additional research should explore how PWD develop and enact their identity as a self-advocate in healthcare settings.

Third, future research should consider the ways in which HCP draw alternatively on ideas from medical, economic, social, and integrative models of disability in their interactions with PWD, as reflected in the terminology they select. Do HCP mirror the terminology used by their patients, or adhere to using terms from biomedicine? What cues do HCP use to evaluate the ways in which their patients conceive of disability and disability identity? Educational models emphasizing exposure to PWD and disability culture issues could be created and studied with respect to influence on HCP perspectives.

Nursing research has identified the importance of engagement, empathy, communication, and trust in developing therapeutic, patient-centered relationships with PWD (Crotty & Doody, 2015). For instance, Parker and Yau (2011) consider how HCP can support women with spinal cord injuries as they (re)develop their sexual identities. As patients cope with the social and emotional challenges of having an intellectual disability (Crotty & Doody, 2015), or with the psychological challenges associated with having a newly acquired disability (see Larner, 2005), how might HCP make use of discourses drawn from integrative and social models of disability as scaffolding for patients to develop more positive disability identities? Alternatively, how might HCPs

inadvertently contribute to patients' development of self-stigma?

To recognize the importance of these research questions, one need only consider the current controversy swirling around right to die policies in America and elsewhere. In September, 2016, 14-year old Jerika Bolen, a black, gay teen with spinal muscular atrophy (SMA) type II, decided to enter hospice and seek help in ending her life. Disability activist groups such as the grassroots organization, Not Dead Yet, protested the media's framing of Bolen's decision as "brave" and "inspirational," and asked the public to consider if factors such as inadequate access to pain management and mental health care contributed to her choice. Research on the attitudes of PWD toward physician-assisted death (PAD) or physician-assisted suicide reflect a variety of positions, including the idea that this option preserves an individual's ability to choose to live their life (or die) on their own terms (Hwang, 2005). However, PWD and disability studies scholars also recognize that lack of equitable medical care, the threat of institutionalization, negative representations of disability in the media and in medical culture, and the experience of social stigma might push people to elect PAD, particularly in times of physical or psychological crisis, when they might otherwise have elected to live (Hwang, 2005; Kaufert et al., 2012). Additionally, the lived experience of disability might vary immensely from an HCP understanding of what life in a disability means, shaping the way in which HCP frame a patient's options. As Kaufert et al. (2012) explained, "an intensive care specialist's assessment of 'futility,' 'effectiveness,' and the perceived quality of life achieved through initiating or continuing to provide mechanical ventilation, may contrast dramatically with the perspective of long-term users of portable ventilators who have lived independently" (p. 126). This particularly contentious topic of PAD highlights the ethical implications of understanding how HCP communication about disability influences patients' self-concept.

A final branch of future research should consider the role that HCP might play as allies for PWD, particularly as they learn about structural inequalities affecting their patients. Researchers might attend to the communication strategies that HCP enact as they engage in allyship. As allies, how do they leverage their medical authority to resist ableist practicing while navigating institutional and other restraints tied to the professional role? As allies, how might they speak *with* their patients rather than speaking *for* them in ways that appropriate and exploit their experiences?

Conclusion

Taking the perspective of an ally of PWD, HCP would reimagine communication practices in the context of accessibility, acceptance, and equality.

Doing so would mitigate disability-linked health disparities that are prevalent among PWD. Scholars in nursing and communication, drawing on a disabilities studies framework, are in an ideal position to promote a research agenda which supports patient-centered accessible and empowering communication environments for PWD in healthcare contexts. The ultimate goal is for PWD to feel respected, valued, and understood so their own perception of QOL can be met.

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