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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

# What Does Disability Justice Require of Antimicrobial Stewardship?

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**Abstract**

This commentary on a case argues that antimicrobial stewardship requires an intersectional disability justice approach if it is to be equitable, particularly for multiply marginalized patients with disabilities residing in nursing homes, who are more susceptible to antibiotic under- and overtreatment. Disability justice concepts emphasize resistance to structural and capitalist roots of ableism and prioritize leadership by disabled persons. A disability justice perspective on antimicrobial stewardship means prioritizing clarification of presumptive diagnoses of infection in vulnerable patients, clinician education led by disabled persons, and data collection.

## Case

Dr S is a resident physician responsible for admitting patients overnight. A patient, M, is being transferred from a nursing home (NH) for tachycardia and hypotension. The NH's physician, Dr P, started M on a broad-spectrum antibiotic prior to M's transfer. Dr S notices in M's record that M has had multiple episodes of being treated with antibiotics in-hospital or in the NH, but with no specific infection diagnosis. Dr S worries about exacerbating this pattern of possible excessive antibiotic use that might expose M to unnecessary toxicity and threat of antibiotic resistance. Dr S plans to be judicious with antibiotics when treating M.

M arrives on the unit and is now under Dr S's care. M is 57 years old with a history of cardiac arrest resulting in anoxic brain injury. M has a tracheostomy and normally breathes on her own without a ventilator; however, for transport from the NH to the hospital, she has been connected to a ventilator. M turns her head to look at Dr S when Dr S speaks to M, but M cannot speak while connected to the ventilator, appears to Dr S to be uncomfortable, and does not reliably signal "yes" or "no" in response to Dr S's questions. Now that Dr S has met M, Dr S questions her initial instinct to limit antibiotics for M.

## Commentary

Up to 70% of NH residents are prescribed antibiotics over the course of a year, and 40% to 75% of such prescriptions may be inappropriate or unnecessary.[1] Many residents live

in NHs for years, compounding the effects of prescribing practices.[2] Factors driving antibiotic overprescription in NHs include the complexity and frailty of the patient population and concerns about infection control in a congregate setting. On-site testing for infectious diseases is not reliably available, leading to empirical treatment without definitive diagnosis; furthermore, prescribers are typically off-site, leading to treatment decisions that are often based on nurses' evaluations.[2,3,4,5]

While there is extensive literature on the particular importance of antimicrobial stewardship in NHs, the issue has not been addressed from the perspective of disability as a social identity. Disabled people[6] (a term we use in place of "people with disabilities," in recognition of the stated preference for identify-first language of multiple disabled activists and scholars) are at risk for both over- and underprescribing of antibiotics and subsequent antimicrobial resistance (AMR). People with certain disabilities, such as intellectual and developmental disabilities and functional disabilities requiring heavy nursing contact, are particularly vulnerable to AMR.[7,8] Furthermore, NH residents are a vulnerable group of disabled people facing disproportionately high rates of AMR.[7] Principles of disability justice (DJ) hold significance for understanding disabled people's vulnerability to both over- and underprescribing of antibiotics by framing disability oppression from intersectional, historicized, and structural perspectives. In particular, the principles of *intersectionality*, *leadership by those most impacted*, and *anticapitalist politics* inform this article.[9]

## Disability Justice and Nursing Homes

From a DJ perspective that foregrounds systemic forms of ableism in a capitalist society, we consider what makes disabled persons like M susceptible to infections and to AMR in the first place. The DJ commitment to anticapitalist politics refers to resistance to exploitative wealth accumulation and labor productivity as a measure of human worth. This resistance comes readily to many disabled people who face exclusion from labor markets. Perceptions of disabled people as non-contributors to market economies drives prejudice, including against increased numbers of people who are institutionalized outside their communities. Access to community-based long-term care is limited by long wait lists and states' allocation of Medicaid funding to NHs as opposed to community care.[10] Systemic prioritization of NH care results in disabled people's relegation to congregate care sites where their susceptibility to both infection and antibiotic misuse increases. NHs are a setting for pathogenic vulnerabilities, which arise when something "intended to ameliorate vulnerability has the paradoxical effect of exacerbating existing vulnerabilities or generating new ones."[11]

Disabled people also face barriers to outpatient care that may lead to underuse as well as overuse of antibiotics, such as lack of physical access to clinicians' offices or outpatient diagnostic evaluations, in addition to experiences of ableism that lead to avoidance of primary and preventive care. Biased views among physicians that might lead to such avoidance are well documented, as are accessibility needs.[12,13] Both dangers of antibiotic over- and underprescribing are present in the case of M: the NH doctor gives broad-spectrum antibiotics before any diagnostic workup, and Dr S considers withholding antibiotics in reaction to a pattern of overprescribing.

DJ requires overhauling systems of care that perpetuate pathogenic vulnerabilities, as well as social disparities.[14] Attitudinal, architectural, and institutional barriers to health care contribute more generally to disability-based health disparities and to delayed care and undertreatment of disabled people.[12,15,16,17] Disabled people of color are more likely

than their White counterparts to be in lower-quality NHs, which have performance deficiencies, higher occupancy, lower nurse staffing, and fewer financial resources.[18] Moreover, institutional racial segregation among NHs is associated with negative facility-level quality indicators, as demonstrated by exacerbated racial inequities among NH residents during the COVID-19 pandemic.[18,19,20] Underinvestment and inequity may also have downstream effects on AMR, as the COVID-19 pandemic was associated with high rates of antimicrobial misuse, especially in low- and middle-income countries.[21] Disability activists have raised concerns for years about for-profit NH facilities, including deficiencies in funding, staffing, regulatory and accountability mechanisms, and opportunities for patient self-determination. The NH industry has resisted regulatory action based on this activism for decades.[22,23]

### Caring for Patient M

Bioethicist Jackie Leach Scully argues that nondisabled people tend to assume that if a disabled person is vulnerable in one area of life, they are globally vulnerable in all areas of life, a phenomenon that "is especially pernicious because of the insidious damage it does to other people's attitudes toward disabled people's own agency."[24] In M's case, the ascription of global vulnerability could lead to false assumptions that M is incapable of communicating or participating in decision making. M's anoxic brain injury and her initial inability to indicate "yes" or "no" reliably could mean her decisional capacity is diminished, temporarily or permanently. Nevertheless, with additional support, M could potentially relay key information about her experiences, what she values, and whom she trusts to a surrogate decision-maker. (Even if M or a surrogate would not then dictate all aspects of antibiotic treatment, such input has diagnostic and therapeutic utility.) Participation in treatment discussions is a health care right that can be neglected when patients have cognitive- or speech-related disabilities, especially when institutional resources are limited.[24,25] Dr S's team should work to safely remove the temporary ventilator and explore other means of communication and sources of information to facilitate M's agency. Infections, antimicrobial side effects, pain, and delirium also affect cognition, underscoring the urgency of addressing M's medical issues properly.

Resident Dr S faces a challenging situation in determining whether to provide or withhold antimicrobials for M. M's medical record lacks important details about the causes or types of infections she has experienced; she has quickly received antimicrobials and then been transferred back to the NH without clarification on these points. Without clarification of the presumptive diagnosis of infection, NH residents like M—particularly those multiply marginalized by race, class, and insurance status—will become stuck in a hospitalization carousel, suffer preventable harms from both infections and medications, and contribute to AMR risks for other NH residents.

At a 2019 conference hosted by The Joint Commission and Pew Charitable Trusts, the expert panel emphasized "diagnostic stewardship," which includes reducing testing that could have false positive or difficult-to-interpret results and thereby lead to unnecessary antimicrobial prescribing.[26] We contend that another diagnostic stewardship priority should be ensuring equitable, thorough investigation of infections in vulnerable patients before starting broad-spectrum antibiotics and ongoing evaluation to consider stopping antibiotics. The option for continued intravenous medication administration in NHs makes it easier to transition patients back to their facility without seriously interrogating whether antibiotics should be stopped.

These complex considerations make it clear that it is problematic to have an overnight resident take on all the responsibilities of antimicrobial stewardship and caring for M. We recommend that Dr S reattempt communication with M in collaboration with a consulting speech pathologist, identify alternative sources of information about M's interests, and start a thorough diagnostic evaluation for causes of hypotension and tachycardia, including but not limited to infections. Beyond the individual case, residents like Dr S should be supported with hospital leadership commitment, multidisciplinary expertise, and decisional aids, all informed by principles of DJ and overseen by the hospital's antibiotic stewardship program.

## Stewardship Recommendations

The Centers for Disease Control and Prevention recommends tracking data related to antibiotic prescriptions and indicators of AMR as one mechanism to monitor adherence to stewardship guidelines.[1] In accordance with the DJ principle of intersectionality, we recommend incorporating demographic data related to disability status as well as other social identity factors, such as race and class, that shape how people's disabilities are interpreted and what explicit or implicit biases they may face in health care systems.[27,28,29,30] Given well-documented inequities in myriad health care settings where antibiotics are prescribed, we can expect these inequities to manifest in antibiotic prescribing practices.[31] Since inequitable care may show up as both under-and overprescribing, data tracking and analysis processes must incorporate data on the health care side (prescription and prescriber details, diagnostic workup, and treatment outcomes), as well as on the patient side (disability status and other sociodemographic details).

To improve care and mitigate disability-related bias, we further recommend anti-ableism training for health care professionals in connection with antibiotic stewardship programs.[32,33] Training should be provided by members of disability communities in alignment with the DJ principle of leadership by those most impacted. Interaction with disabled people in contexts outside of the patient-clinician dynamic can disrupt stereotypical perspectives of disabled people. Such training might include identification of common harmful assumptions about disability, such as global vulnerability. Clinicians should be cautioned to avoid conflating speech disabilities or nonverbal communication with impaired decision-making capacity. Although underused in hospital settings, augmentative and alternative communication strategies are important for providing equitable care to patients who are nonspeaking due to disability or critical illness, particularly for pain management and for communication about treatment goals.[34,35,36] Finally, training should incorporate intersectional perspectives on disability and explain how racial and ethnic biases influence disability-related biases. For example, danger and criminality are associated with men of color with disabilities,[37] particularly those with intellectual and developmental disabilities, psychiatric disabilities, and substance use disorders,[37,38,39] and higher tolerance for pain is associated with Black people, as evidenced by the disproportionate undertreatment of pain in Black patients with chronic pain.[40,41,42]

## Conclusion

A DJ perspective on antimicrobial stewardship entails diagnostic stewardship that prioritizes clarification of presumptive diagnoses of infection in vulnerable patients, clinician education led by disabled people, and data collection incorporating disability status as part of intersectional analyses of antimicrobial stewardship practices, each of which promotes anti-ableist practices and more equitable health care for disabled

people. Communication with patients about their symptoms, medical history, and goals for care is essential, particularly among multiply marginalized patients, even and especially if it takes additional steps to find the appropriate support. When it comes to mitigating disparate outcomes for disabled patients like M, time, though always at a premium for health care professionals, may be one of the few tools to redress long-standing health inequities and optimize antimicrobial prescribing.

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Authors disclosed no conflicts of interest.

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