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ORIGINAL RESEARCH

Ethical Data Management Practices: A Prerequisite for Disability Equity

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People with disabilities (PWDs) experience worse health outcomes than people who do not have disabilities. Making meaningful progress on disability equity requires new ways of thinking about disability, new tools and processes, and new ways of working within the existing health care system. Immediate actions to increase disability equity include expanding data collection including patient-reported outcomes measures; more transparent, person-centered data governance and management; integration of public health and clinic-based health data; and renewed efforts to communicate with and treat PWDs with respect. Actions to prevent threats to disability equity are critical. These threats include a resurgence in the practice of eugenics, the misuse of emerging technologies such as CRISPR, and technologies that promote surveillance.

Keywords: Health equity; disability; health disparities; interoperability; public health

Introduction

The importance of meeting the care needs of all individuals, regardless of personal characteristics or circumstances, is a longstanding goal of the health care system and a commitment that health care professionals make when they enter the field. In modern medicine, efforts to achieve this objective are frequently organized around the Triple Aim – improving the experience of care, improving the health of populations, and reducing per capita costs of health care[1] – embedded within a learning health care system. Triple Aim's work is supported by iterative research, data analysis, and intervention planning and execution. Yet despite concentrated informatics development and implementation efforts, disparities continue, with health inequity the result.

Research that explores access to and use of health care services reveals significant differences in the experiences of people with disabilities (PWDs) compared to people without disabilities. Adults with vision impairments have lower rates of health insurance coverage, of having a regular health care provider, or having had a dental visit within the past year. They are also more likely than people without disabilities to have gone without needed care because of cost within the previous year.[2] Deaf and hard-of-hearing people who use American Sign Language experience communication barriers and discrimination and have lower health literacy and poorer preventive screening outcomes than hearing people.[3–5] People with mobility impairment report higher levels of depression, lower levels of life satisfaction, and more difficulty coping than people without disabilities, which make it more difficult to manage health conditions that result from sedentariness.[6] People with intellectual and developmental disabilities (IDD) experience inequities as a result of stigma and exclusion, underrepresentation in research, and lack of access to health and social services.[7] To further complicate matters, health care professionals and PWDs may have different understandings of disability, which may be compounded when invisible disabilities are undisclosed, perhaps leading to implicit ableism in any data collected. Health informatics initiatives that intend to help people to avoid or manage a disability can inadvertently create intervention-generated inequalities by disproportionately aiding more advantaged people, in the process creating or exacerbating health inequities.[8]

To appreciate the effect of disability on health, one need look no further than the COVID-19 pandemic. The presence of a disability of any type increases the likelihood, and negatively affects the severity, and outcome of COVID-19 infection.[9–11] Disability- and disease-related factors (eg, reduced lung function), as well as environmental circumstances (eg, congregate living, lack of personal protective equipment), contribute to health outcomes worse than those of people without a disability.[10,12] Lower economic status is common among PWDs, and is frequently associated with less access to care and medical equipment, and to supportive services such as home grocery delivery.[13] COVID-19 screening and home test kits may be unavailable or inaccessible to PWDs,[14,15] and when they are, diagnosis may be delayed because of atypical presentation.[16,17] Public health requirements to

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control COVID-19 transmission limited people's activities, impaired pain management, and have reduced overall fitness levels, leading to an increase in illnesses associated with a sedentary lifestyle.[18,19] COVID-19 mortality has been higher among people who self-reported a disability that caused minimal to significant limitation;[20] the risk factors where excess mortality was greatest included learning disability, dementia, and severe mental illness.[21] People with IDDs have greater difficulty accessing care, experience a higher risk of infectious disease-related emergency room visits, have more serious symptoms at admission and deteriorate more quickly than non-IDD patients, have a higher hospitalization rate, and die younger than people without IDDs.[22–25] When inpatient care is required, people with IDDs remain in the hospital longer, are readmitted more frequently, and are more likely to have serious outcomes, including death.[26–28] Being under age 65 with a disability was a significant predictor of higher COVID-19 case and death rates in New York City.[29] The intersection of race and disability also affects the likelihood of COVID-19 infection; African Americans with a disability are more vulnerable than Whites.[30]

The presence of a disability adds complexity and challenge to people in accessing and benefiting from health care services, and even when PWDs can obtain care, disparities in health outcomes are apparent. Though the COVID-related outcomes data offer insights into PWDs' lived experiences of COVID, much of what has been learned comes from public health-driven efforts to manage infectious diseases, which are not in place for common chronic conditions such as high blood pressure and osteoporosis. Achieving equity for PWDs will require focused efforts that target gaps in multiple levels of the health care and social systems, strategic development and deployment of technology, and policy and regulatory shifts that support person-centered – rather than system-centered – organization of health care.

Although the refinement of electronic health records (EHRs) continues, the collection and use of disability-specific personal data needed to better understand the sources of health inequities experienced by PWDs and highlight opportunities to mitigate such inequities remain inadequate. Also lacking is the collection of data that describe health outcomes that are of interest to PWDs and their caregivers, such as quality of life and functional status measures, beyond mandated quality measures. Even when health systems and government organizations collect disability-related information, PWDs have little awareness of what data are being collected and how this information is being used. As with information about non-disabled people, there is little communication between systems used by clinical practices and public health infrastructure, thereby missing opportunities to identify and treat health-related needs.

Making Equity Happen

Achieving meaningful progress on disability equity requires new ways of thinking about disability, new tools and processes, and new ways of working within the existing health care infrastructure. As health information technology systems evolve, the opportunities will change, but the following approaches offer a place to start.

Expanded data collection

Although much information related to disability and functional status is gathered during clinic visits and resides in EHRs, a purposeful effort to organize, analyze, and respond to resulting insights is currently lacking. Structured data collection within the EHR, as well as more variable collection of data in clinical research, are needed to make significant progress. Data collection initiatives that target knowledge gaps related to disability will facilitate identification of PWDs' health care needs, permitting more nuanced understanding of disparities, and enabling the development of population health initiatives to mitigate inequities. The US Department of Health and Human Services adopted a set of standardized, validated questions for the collection of disability-related data (REALD) in 2011,[31] which subsequently has been adopted at the state level[32] and validated for use in youth populations.[33] The United States Core Data for Interoperability Version 4, an initiative of the US Office of the National Coordinator for Health Information, includes health concerns, functional status, disability status, mental/cognitive status, and other data elements that will support the collection of disability-related data.[34] Expanded and more consistent efforts are needed.

More effective use of patient-reported outcomes measures

The use of patient-reported outcomes measures (PROMs) has become standard practice in many types of clinical research, as well as in cancer clinical care.[35,36] PROMs provide a close-up view of the lived experience of people, including PWDs, as they engage with health care systems. PROMs implementation should be equitable and inclusive,[37] thereby allowing assessments to function as a starting point for disparity reduction. PROMs use currently is uncoordinated and lacks standardization across health care systems, resulting in a failure to confer all the benefits of assessment.[38] Four gaps in outcome measures and data sources applicable to adult PWDs have been identified: inadequate standardized measures and standardized data collection tools, reliability and validity issues with existing measures, exclusion of personal preferences in existing PROMs, and lack of capture for multiple outcome domains in existing data.[39] Addressing these gaps will advance health equity for PWDs. When PROMs relevant to the needs and experiences of PWDs are unavailable, the conceptual framework created for development of new PROMs for reproductive health care for women PWDs may provide a starting point.[40]

Transparent, trustworthy data governance

Data sharing practices that are private, secure, and ethical, and that support research and clinical care, follow appropriate data collection practices. Privacy and confidentiality of personal health information are important to PWDs whether disabilities are visible or invisible; and transparent data governance and management practices demonstrate respect for PWDs. Data sharing practices and PWDs' options for sharing must be clearly communicated in formats that are accessible to the individual,[41] and the data choices available to PWDs should mirror those available to people without disabilities or who don't identify as having a disability. A health data justice lens that recognizes that exclusion "from the generation, collection, and use of data implied by that participation" confers injustice[42] offers a starting point from which to develop data governance approaches that serve the PWDs' interests.

Integration of public health and clinical health information

Health data generated through public health measures, such as screening clinics, may be relevant in the clinical setting; and health data originating in clinical care settings may provide important context within the public health environment. Integration of public health and clinical health information is a basic requirement for coordinated care management that, to date, remains unfulfilled.[43] The need for such integration was demonstrated during the COVID-19 pandemic and, as such, the integration of public health and clinical health information remains a primary focus of health IT policymakers in the United States.[44] PWDs often have more complex health needs than individuals without disabilities and, as a result, are served particularly poorly by a lack of interoperability. Integrated health information systems can support a more rapid, appropriate response to personal and population-level health crises such as the COVID-19 pandemic.[45,46]

Sincere, respectful patient engagement efforts

The accumulation of negative care experiences over time may traumatize PWDs, resulting in mistrust, ambivalence about seeking care, and communication barriers.[47] Implicit bias against disability and PWDs is real and compounds the challenges inherent in interpersonal communication and, as a result, the provision of care.[48–50] Sentiment analysis of social media posts by PWDs during the COVID-19 pandemic showed a perceived lack of concern that mirrors the poorer outcomes described previously.[51] Technology adoption is a complex process that requires effort over time before the benefits are realized. Starting the journey from a place of respect supports PWDs in their role as partners in achieving equitable health care.[52,53]

Threats to Disability Equity

Successfully closing the health inequity gap that PWDs experience requires not only taking steps to reduce barriers but also preventing new practices and circumstances that permit or promote inequitable health care. Historical threats to the health of PWDs, such as eugenics and misuse of technology, must be proactively addressed as part of the disability equity strategy.

Resurgence of eugenics

Enhanced efforts to gather data about PWDs for developing strategies to better meet their needs are not without risk. The collection of demographic data developed alongside,[54] which in the 20th century was used to justify the institutionalization and sterilization of PWDs.[55,56] Although laws that permit or promote eugenic interventions have been repealed, attitudes based on eugenic and ableist tenets continue to influence science within fields such as evolutionary biology.[57] For example, during the COVID-19 pandemic, providers in at least five US states failed to comply with federal law that prohibits discrimination based on disability.[58–62] Ensuring that informatics-based strategies and technologies advance disability equity will require revisiting such discredited doctrines and constructing implementation models based on current medical and social models.

Misuse of emerging technologies

New analytical capabilities that bring together the potential of EHR data, advanced data collection and management tools, and emerging technologies such as gene editors (eg, CRISPR) may be used both to reduce and to exacerbate health inequities experienced by PWDs.[63,64] Review by Institutional Review Boards (in research) and ethics consultation services (in clinical practice) can help to ensure that evolving standards of care center the needs and goals of PWDs within the health care system.

Surveillance-supporting technologies

Personal care services that are accessed through government programs (eg, Medicaid) may require digitally based documentation such as electronic visit verification (EVV).[65] Although EVV provides administration of services that benefit PWDs, devices that facilitate EVV (eg, smartphones) may transmit geolocation or other information about PWDs that in other situations are considered private. PWDs may experience the collection and reporting of such data as a form of surveillance[66] and forego needed care to avoid being monitored.

Conclusion

The health inequity experienced by people with disabilities is both real and complex, and disassembling it requires a multifaceted approach. Process-based efforts, such as a renewed commitment to the collection of relevant data and transparent data governance, and technology that supports the integration of clinical and public health data have central roles to play in the promotion of disability equity. Initiatives that are focused on more respectful engagement, clearer and more accessible communication, and the development of trust by PWDs are critical to the use of health information technology for the realization of inclusive, equitable health care.

Competing Interests

The author has no competing interests to declare.

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