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No data, no justice: The need to study health disparities in municipal long-term care

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This essay highlights the urgent need for comprehensive data collection to address health disparities in Norway's municipal long-term care services. Inspired by the United States, where extensive research has revealed significant health disparities, this essay emphasizes the importance of understanding these issues in Norway. Effective interventions for equitable healthcare cannot be developed without detailed data on, for example, race, ethnicity, and socioeconomic status. The essay also discusses challenges in data collection, such as privacy concerns and universalism, policy and practice changes, and future research initiatives to overcome these barriers.

Imagine Mrs. Johnson, an African American woman in her 70s living in a long-term care facility in the *United States*. Mrs. Johnson suffers from pressure ulcers, a condition that causes her significant discomfort and pain. Through comprehensive data collection on race and ethnicity across all US nursing homes, it was discovered that African American residents had higher rates of pressure ulcers compared to White residents. This crucial insight led to heightened awareness and targeted interventions, such as improved staff training and culturally appropriate care practices. As a result, the incidence and prevalence of pressure ulcers among African American residents were significantly reduced, improving overall quality of life.

In Norway, we currently lack similar data collection, which means we might be missing out on identifying and addressing such disparities within our own healthcare system.

Going to the *United States*, I wanted to learn how to study health disparities in long-term care. The U.S has a long and strong history of studying health disparities and has placed significant focus on this issue, especially over the past two decades. The COVID-19 pandemic, in particular, accelerated research in this area. The term ‘health disparity’ describes differences in access to healthcare and health outcomes between different population groups. These disparities can be measured and often highlight the unequal burden of disease, disability, death, and the quality of healthcare among specific groups (1).

Much of the research on health disparities in long-term care has been conducted in the *United States*. Although the political situation, social challenges, cultural, and historical contexts are different, countries like Norway can still learn valuable lessons from US health disparities research. The experiences of conducting disparities research and the data infrastructure in the US provide valuable insights that we need in Norway to advance our understanding and address health disparities effectively.

Research on health disparities is not just about statistical observations; it often presents living narratives of systemic injustice. There is no reason to believe that health disparities do not or will not occur in Norway. The reality is that our understanding of health disparities in Norway is still developing. While there is some research into disparities in mortality and access to and utilization of certain healthcare services, primarily related to specialist healthcare, we lack comprehensive knowledge about the extent of health disparities in our healthcare services in general. In this essay, I focus on municipal long-term care services, which is my area of research. We know very little about where, when, and how these disparities manifest, why they occur, and what the consequences are for different groups.

Rising need for municipal care services amid Norway’s growing diversity

Norwegian municipal long-term care services are vital for the population’s well-being. In 2020, 7% of the population received these services, and that number is rising (2). As the demographic landscape diversifies, these services face greater responsibility for a more complex population. For example, the number of immigrants over 80 could quadruple in the next 20 years, many of whom will have low educational levels linked to higher care needs (3). Therefore, understanding and addressing health disparities, care quality, and service utilization among diverse groups is increasingly important.

The US experience in disparities research and data infrastructure offers valuable insights for Norway. A key component is the Minimum Data Set (MDS), a standardized tool for collecting comprehensive data in long-term care facilities. The MDS includes crucial variables like demographics, health status, and social factors, with recent expansions in ethnicity and race categorization to promote health equity and aid in identifying health disparity patterns and develop targeted interventions.

Barriers to comprehensive data collection in Norway

One significant challenge in studying health disparities in Norway is the lack of comprehensive and systematic data collection on variables that can be used to analyze health disparities, such as race, ethnicity, disabilities, sexual orientation, income, and educational level. This gap in data hinders our ability to fully understand and address the health needs of a diverse population. One reason we often avoid collecting detailed data is the concern for privacy. While privacy is undoubtedly important, and protecting personal information is a fundamental right, we must also consider the implications of not having this data. If privacy concerns prevent us from collecting information crucial for providing appropriate treatment, care, and support, we are failing to meet the needs of our diverse population. Diaz, Magnus, and Ursin argue that we should not need to compromise on privacy but rather find a balance between protecting personal information and collecting data essential for improving care quality (4).

Additionally, concerns about discrimination and the principle of universalism may lead to the perception that it is unnecessary to collect such data, as everyone should be treated equally. In Norway, like in many other countries, there is a strong emphasis on ensuring equality and preventing discrimination based on race, ethnicity, or religion. Avoiding the collection of data on race and ethnicity has likely been a way to prevent these factors from being used to discriminate and create negative associations towards subpopulations in our society.

The need for comprehensive data

The first step towards meaningful change is the collection of data. As a registered nurse, it is second nature for me to think in terms of the nursing process, where data collection is the initial phase of a problem-solving methodology. We need data first, followed by the interpretation of the collected data to formulate a problem statement. Only then can interventions be planned, implemented, and evaluated. Currently, we are in the initial stage of this problem-solving process for addressing health disparities in municipal long-term care. Without comprehensive data, we cannot accurately identify the issues or develop effective solutions. Therefore, the collection of data is not just a technical necessity but a foundational element in our efforts to promote access, equity, and high-quality care and a responsive healthcare system. To effectively study health disparities in long-term care in Norway, we need to start collecting comprehensive data in the 'Kommunalt pasient- og brukerregister' (Municipal Patient- and Service User Registry) that reflects the diversity of our population, in a standardized and systematic way.

Policy, practice and research

To ensure responsible data collection and enhance the quality of care for all individuals, robust privacy protection policies are essential. While Norway already has implemented some of these measures to a certain extent, it is crucial to continuously discuss and advance the ways we balance data collection needs with personal information protection. For example, strict data security measures like encryption, multi-factor authentication, restricted access, regular audits, and transparency about data usage and protection should be emphasized. Furthermore, engaging stakeholders, including civil society organizations, ensures that the collected data is relevant, accurate, transparent, and aligned with societal goals. This collaborative approach is likely to lead to better outcomes and more informed decision-making.

Both clinicians and researchers should receive mandatory continuous training in handling sensitive data. This training would cover best practices for data security, privacy protection, and ethical considerations in data collection and usage. By ensuring that everyone involved understands the importance of protecting personal information, we can still collect the necessary data to improve care quality.

Providing health researchers with easier and more affordable access to data while ensuring that the information is relevant and sufficiently detailed is essential. For example, aggregating data in a meaningful way is crucial; it must be done at a level that protects privacy while still providing valuable insights. Over-aggregation, such as combining data from individual countries into broad regions, can render the data less useful. Furthermore, establishing clear guidelines and standards for the collection of health data, including race, ethnicity, and other demographic variables, ensures consistency and accuracy across all healthcare facilities. Additionally, introducing legislation that mandates the collection of specific health data variables, such as race and ethnicity, in all healthcare settings is crucial.

Key themes for future research on health disparities

Through my project, several overarching themes emerged that are crucial for future research on health disparities in long-term care (5). To truly address these disparities, future research needs to move beyond merely acknowledging that they exist and delve into the underlying structures, processes, and policies that contribute to these inequities. Understanding how and why these disparities arise and persist is crucial for developing effective interventions. A significant challenge I identified is the predominant focus in previous research on single-axis differences, such as race or gender, which overlooks the complex interplay of multiple identity dimensions. The concept of intersectionality could be promising here, as it encourages us to consider how various social categories intersect and influence health outcomes. Researchers should also examine the broader social, economic, and political contexts that affect these disparities and engage with the communities being studied to ensure the research is relevant and respectful. In addition to quantifying health disparities, it is essential to explore experiences through qualitative research. This approach can provide deeper insights into how individuals perceive their care, helping to tailor interventions more effectively (5).

Towards a healthier and more inclusive society

In summary, tackling health disparities in municipal long-term care through comprehensive data collection and analysis is no small feat. However, it is a game-changer. It allows us to build a healthcare system that truly responds to the diverse needs of our population. By putting privacy protection and transparency at the forefront, we can earn the public's trust and ensure sensitive data is handled with the utmost care. This initiative is not really about data—it is a commitment to justice and equality in healthcare. It is our chance to lead by example, showing how thoughtful and inclusive data practices can spark positive change. Collecting data will provide us with the opportunity to improve the health of various groups and individuals, making sure that everyone, including all the Norwegian Mrs. Johnsons, receives the attention they need.

Impact of the Harkness experience on my career

Reflecting on my fellowship year, I didn't just gain new knowledge and skills about disparities research—I acquired a whole new perspective on leadership. Before heading to the United States, I thought leadership was about big decisions and grand gestures, but I learned that true leadership lies in the everyday actions and interactions—sharing knowledge, offering resources, and helping others shine. This revelation transformed my approach to work, making collaboration and inclusivity my mantra.

Meeting with colleagues from various nations made it clear how universal our healthcare challenges are. We were all grappling with the same issues, albeit in different contexts. Diving deep into the US healthcare system was like a masterclass in innovation, and I realized that many of their solutions could be adapted to our settings. This experience underscored the importance of global collaboration and how interconnected our efforts are in tackling healthcare problems.

Being a Harkness Fellow was like getting a golden ticket to a world of opportunities. The network is a powerhouse of collaboration and idea-sharing. While achieving change is tough and complex, witnessing the determination and innovation in the US was incredibly inspiring. It showed me the magic that happens when diverse perspectives come together and the sheer power of collective effort.

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