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Ethical and human rights considerations related to access to anemia diagnosis

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Important disparities exist in anemia diagnosis globally. We examine individuals' and populations' access to anemia diagnosis, the accuracy of diagnostic tests, and the interpretation of test results through the lens of key ethical considerations. These include the human right to health and the Rawlsian concept of the social contract, as well as ethical principles, such as autonomy, self-liberty, beneficence, and nonmaleficence. We discuss factors that influence individuals' and communities' access to high-quality health services, including geography, gender, age, and socioeconomic status. Geographic and other differences exist in the types of diagnostic equipment and methods used to diagnose anemia, potentially leading to differential classification of anemia across individuals and populations. A diagnosis of anemia also requires follow-up to understand etiology and appropriate treatment. However, this is not done consistently, in clinical care or in population-based surveys. To better understand the problem and track countries' progress, a need exists for disaggregated, longitudinal quantitative and qualitative data on disparities related to anemia. Moving forward, it will be important for countries to improve equitable access to high-quality health services, particularly primary health care services, and to address barriers to the ability of individuals or communities to effectively enjoy the right to health.

Keywords: ethics; human rights; equity; anemia

Introduction

Health, defined by the World Health Organization (WHO) as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity,” is broadly recognized as a human right.¹ At the same time, it is known that not all individuals or populations enjoy this human right to the same degree. Health disparities, defined as “differences in health that adversely affect economically or socially disadvantaged groups,”² are well documented within and across populations, including with respect to anemia prevalence. For example, the global prevalence of anemia in 2013 was estimated at 27%, but the burden was highest among children under the age of 10 and females of reproductive age in central and western sub-Saharan Africa, where a majority of countries have an anemia prevalence

over 40%.³ Similar disparities likely exist in the diagnosis of anemia, with differences that adversely affect the ability of some groups to obtain accurate diagnoses and treatment. Anemia, in this sense, is representative of a broader issue in global health, as described by Paul Farmer: “The just and equitable distribution of the risk of suffering and of tools to lessen or prevent it.”⁴

Health as a human right is highly dependent on an individual's well-being, their agency of social standing, and structures and access to social changes in society. The capability approach, as defined by Amartya Sen, suggests that the freedom to achieve well-being is of primary moral importance and is to be understood in relation to people's capabilities, that is, their real opportunities to achieve the kind of lives they have reason to

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value. To achieve this freedom, one needs “functioning,” or states of being and doing, such as having good health or being well-nourished. Capabilities are the set of “functionings” to which a person has access.⁵ Nussbaum took this capabilities approach one step further to list aspects of life that are so central that they seem definitive of a life that is truly human. One such aspect is health.⁶

WHO takes a rights-based approach to health, with a view toward the elimination of health disparities. This approach emphasizes the principles of nondiscrimination, availability, accessibility, acceptability, quality, accountability, and universality.⁷ The rights-based approach is rooted in ethics, which involves understanding, defending, and recommending concepts and standards of right and wrong conduct. This conduct is usually described with reference to what humans should do to benefit society, that is, to do no harm and promote fairness and equality through a rights-based lens. While there is a need to further incorporate rights and ethics frameworks into public health planning,⁸ some ethics frameworks have been adopted to provide practical guidance for public health professionals on how to “highlight the defining values of public health, values that differ in morally relevant ways from values that define clinical practice and research.”⁹ These frameworks examine issues of autonomy/self-liberty, stigmatization, paternalism, human rights/justice, beneficence, and nonmaleficence.

Human rights and ethics are especially relevant to fulfilling the right to human health, as well as fulfilling that right through better diagnostics, treatment, and access to health care. The diagnosis of anemia is one means to achieve the right to health because anemia is associated with several adverse health outcomes. These outcomes, including poor cognitive development in children and reduced cognitive performance and work capacity in adults, can further exacerbate health disparities through their impact on schooling attainment and earnings.¹⁰ However, to our knowledge, no published work exists that addresses anemia and human rights or ethics. The objective of this paper is therefore to examine individuals’ and populations’ access to anemia diagnosis, the accuracy of diagnostic tests, and interpretation of test results through the lens of key ethical considerations. While a vast body of literature exists on health equity, our aim was not a broad

review of this evidence but a practical application of key considerations for anemia. This work will focus on presenting an ethics perspective on anemia diagnosis and will include recommendations for future research and policies.

Access to health care for anemia diagnosis

Access to health care services can be conceptualized in many ways. Levesque *et al.* define access as “the opportunity to reach and obtain appropriate health care services in situations of perceived need for care.”¹¹ Their conceptual framework of accessibility of services includes dimensions relating to health providers and systems (supply side) as well as individuals and populations (demand side).¹¹ On the supply side, the dimensions include approachability, acceptability, availability, affordability, and appropriateness.¹¹ On the demand side, the dimensions relate to the ability to perceive the need for health care, to seek out, reach, and pay for health care, and to engage with the health care provider.¹¹ These dimensions can depend on a wide range of individual- and community-level factors (e.g., geography, gender, age, disability, language, literacy, ethnicity, culture, conflict or humanitarian crises, distance to a health facility, and socioeconomic status and resources), which may interact to further limit equitable access to health services.^{11,12}

Some of the same factors that may affect access to services may also affect the quality of services received. WHO defines quality of care as “the extent to which health care services provided to individuals and patient populations improve desired health outcomes. In order to achieve this, health care must be safe, effective, timely, efficient, equitable, and people-centered.”¹³ In promoting quality of care, WHO emphasizes the competence and motivation of health care professionals, effective communication, and community engagement.¹³ However, factors, such as language and literacy, may impede effective communication; and discrimination based on ethnicity may impede community engagement, for example.

Others use different conceptualizations of quality. Donabedian defines and measures quality of care through consideration of structures (e.g., the physical infrastructure of facilities, equipment, drug supplies, and organizational structure of staff), process (e.g., health seeking and interactions with the

health provider or system), and outcomes (e.g., the patient's knowledge, health status, and satisfaction with care).¹⁴ The more recent *Lancet* Global Health Commission on High-Quality Health Systems in the Sustainable Development Goals Era conceptual framework for high-quality health systems has three domains: foundations, processes of care, and quality impacts.¹⁵ These three domains are broadly similar to those of the Donabedian framework. The commission additionally defines equity in health care quality as "the absence of disparities in the quality of health services between individuals and groups with different levels of underlying social disadvantage."¹⁵ The authors emphasize that adequate foundations are not enough and that inequities in processes of care may lead to disparities in impacts.

These conceptualizations illustrate the many dimensions and aspects of access and quality, and the many factors that can influence anemia diagnosis. Considerations related to access to high-quality health services are especially relevant to anemia diagnosis because those most at risk of anemia may also be most at risk of lacking access to high-quality health services. Although the etiology of anemia and associated risk factors vary geographically, in general, populations considered to be at higher risk of anemia include young children, pregnant women and women of reproductive age, and the elderly, as well as individuals with health conditions, such as certain chronic diseases, helminth infection, and hemoglobinopathies.¹⁰ Poverty is also considered to be an underlying determinant of anemia.¹⁶ Particularly in some low- and middle-income countries (LMICs), women, children, the elderly, and the poor may all have limited access to health services owing to social, physical, or other constraints on their mobility, autonomy, and economic resources.¹⁷ Thus, those who are most vulnerable to anemia may also have the most limited access to high-quality health services for anemia diagnosis. These vulnerabilities could be additionally compounded by inequalities related to race, ethnicity, or other factors.

For women, in particular, several additional barriers may exist, related to normative gender beliefs. Amartya Sen, in his work on adaptive preferences, has explored gender differences in health in India and found that women, despite being objectively less healthy based on medical examinations, had better self-reported health status than men.¹⁸ He

attributed this to gender differences in social expectations: women had lower expectations of good health and thus reported higher satisfaction with their (objectively poor) health status than men.¹⁸ This may explain why, as reported by Iyer *et al.*, "not only is non-treatment higher among women than among men, but women are more likely to self-treat or to receive treatment from informal health providers, or receive treatment for shorter periods of time than men."¹⁷ While these observations were related to women's health in general, they likely apply to attitudes and health-seeking behaviors related to anemia diagnosis specifically.

Several ethical issues are relevant to access to anemia diagnosis. Fundamentally, the concept of human rights and justice applies to the basic human right to access health care. Rawls argues that social justice is about ensuring the protection of equal access to rights, which includes taking care of the least advantaged members of society and allocating a fair share of benefits, in this case, health benefits, to those members. The Sustainable Development Goals (SDGs) have adopted this approach through the use of other language known as "no one left behind." This social justice concept is developed around the idea of a "social contract" in which all members of a society agree to follow certain rules and be duty bearers for the betterment of all and to create equity.¹⁹ In this social contract, it is understood that everyone deserves equal access to health care, and if some have less access, others (e.g., the state and other entities) serve as duty bearers to ensure that they are not left behind.

Other relevant ethical concepts include autonomy and self-liberty, which relate to health seeking. In particular, many women lack the decision-making autonomy and freedom of movement to seek out and visit a health care provider. Similarly, for the poor and disadvantaged, the financial and opportunity costs of accessing high-quality care may make it difficult or impossible for them to seek health care.^{11,20} The concept of nonmaleficence is important in relation to the burden or harm involved in obtaining diagnosis and, conversely, the long-term harmful consequences of not obtaining diagnosis.

The accuracy of diagnostic tests

Accurate measurement of hemoglobin concentrations for diagnosis of anemia is important in

many clinical settings, including blood donation centers, hospitals, primary health clinics, and antenatal and pediatric clinics. The gold standard methods for hemoglobin measurement include the cyanmethemoglobin method and automated laboratory hematology analyzers.²¹ However, these methods require advanced laboratory equipment, infrastructure, and trained staff. Their geographic availability, therefore, varies across and within countries, with many populations, particularly rural populations in LMICs, lacking access to these methods.

Other methods include point-of-care (POC) devices, which are portable devices that do not require laboratory equipment. These are common in clinics in both high-income countries and LMICs as well as in field research (e.g., population-based surveys). These devices require standardized collection techniques, and even in high-income countries, geographic and other disparities exist in the ability of health systems to provide the necessary training and support to ensure reliable results from these methods.²² In low-resource settings, a lack of available equipment means that health providers may not have access to either laboratory methods or POC devices and must use less accurate diagnostic methods. For example, in many primary health clinics in resource-limited settings, the WHO Hemoglobin Color Scale (HCS) is the only available method for quantitatively measuring hemoglobin concentrations. However, a recent meta-analysis noted substantial heterogeneity in the sensitivity and specificity of results using HCS across study settings.²³ Alternatively, healthcare providers may diagnose anemia on the basis of conjunctival, palmar, and nailbed pallor, which is considered inaccurate by clinical standards.²³ These gaps can lead to differential classification of anemia across individuals and populations.

Accurate diagnosis of anemia is important not only as the first step in treatment, but also as part of a differential diagnosis process to distinguish anemia from alternative conditions that may have similar symptoms. For example, studies have observed an association between anemia and depression among women in the postpartum period as well as among otherwise healthy adults.^{24,25} Anemia and depression may have some similar symptoms, including fatigue and difficulty concentrating. In these cases, an accurate diagnosis of anemia would be an essen-

tial component of a broader strategy to improve health states.

Several ethical issues are relevant to the accuracy of anemia diagnosis. As with access to health care, access to accurate anemia diagnosis is a human right, as a necessary component of the right to health. All individuals and populations should have equal rights to accurate diagnostic equipment regardless of geography, income, or other factors. Similarly, the concept of nonmaleficence is again relevant in relation to the burden or harm resulting from a lack of an accurate diagnosis or from an inaccurate diagnosis. An additional ethics principle of note is beneficence, in the sense of trying to create public health good by ensuring that diagnostics are reaching those who need them.

Interpretation of test results, follow-up, and the treatment of anemia

Even with equal access to health services and accurate diagnostic tests, interpretation and follow-up is a necessary component of any diagnosis. At the most basic level, diagnostic test results must be interpreted by comparing them to a threshold or cutoff value to determine whether an individual is anemic. However, the current threshold values were established on the basis of studies of primarily Caucasian men and women in North America and Europe. It is not known whether different threshold values may be appropriate for different populations, for example, on the basis of ethnic origin.²⁶ If these threshold values are inappropriate for some or all populations, their use in interpreting hemoglobin concentrations may contribute to misdiagnoses.

Interpretation, follow-up, and treatment are especially relevant for anemia because diagnosis does not identify the cause of anemia or a clear course of treatment. While most cases of anemia are due to iron deficiency, the etiology of anemia varies widely.³ Other potential causes include genetic hemoglobin disorders, such as the thalassemia syndromes and sickle cell disorders; inflammation, chronic disease, and acute illness leading to bleeding; and deficiencies of vitamins (e.g., folate, B2, B6, and B12) and minerals (e.g., zinc and copper).^{27,28} Determining the cause of anemia requires additional diagnostic tests, ranging in invasiveness from blood tests to a bone marrow biopsy. Similarly, treatment depends on the identified cause and may range

from relatively simple and inexpensive interventions to highly specialized and expensive treatments that are not affordable to many individuals living in LMICs. Each step in this process requires access to high-quality health services with trained providers and appropriate infrastructure and equipment. This process may also require effective systems for referral and follow-up.

In some cases, appropriate follow-up and treatment may involve addressing inequities beyond access to health services. This requires viewing the causes of anemia not only through a biological lens but also through a biosocial lens, in which diseases are “best understood as interactions of biological and social processes.”²⁹ This, in turn, may require incorporating broad principles of equity in health care delivery systems. For example, the nongovernmental organization Partners in Health operates a comprehensive primary health care delivery model that includes ensuring access to basic needs, such as food, housing, and psychosocial assistance.³⁰ Given that equity is known to be an underlying determinant of anemia,¹⁶ appropriate treatment may include improving access to nutritious food, housing (with insecticide-treated bed nets in malaria-endemic areas), water and sanitation infrastructure, and income-generating activities.

Follow-up tests and treatment can be expensive and may require additional laboratory equipment, which may be cost-prohibitive in LMIC settings. Within a fixed health budget, the provision of these tests and treatments could imply trade-offs in care for other medical conditions. Therefore, context-specific data may be needed to allow decision makers to assess the cost–benefit and cost-effectiveness of different options for testing and treatment. This would include data on costs associated with equipment, training, and service provision as well as on outcomes related to the quality of health services, health outcomes, and health equity. These data would allow decision makers at all levels to identify the components of follow-up and treatment that most effectively contribute to the goals of improved health outcomes and health equity.

The need for appropriate interpretation and follow-up also applies to population-based surveys and other research studies that include hemoglobin measurement. The principles of research ethics suggest that individuals and communities taking part in these studies have a right to receive some bene-

fits in exchange for their participation. Several justice frameworks exist to guide researchers in the ethics of providing these benefits, from the selection of research targets to provision of ancillary care or collateral health services, strengthening of global research capacity, and facilitation of sustainable poststudy benefits.³¹ Some ethicists further argue that these benefits should contribute to “relief of oppression” rather than being purely transactional.³² In the case of anemia, this suggests that researchers should not only provide study participants with their test results (i.e., their hemoglobin concentration) and refer them to the health system as needed, but should also take steps to remove potential barriers to care. To our knowledge, no published discussion exists of these obligations in the context of studies of hemoglobin and anemia.

The interpretation, follow-up, and treatment from an anemia diagnosis—or the lack thereof—can create several types of burden in individuals and populations. Without adequate interpretation and treatment, the frequency and severity of symptoms can place a physical, emotional, and economic burden on patients. The symptoms of anemia include weakness, fatigue, and difficulty concentrating.³ These may not be severe enough for a person to perceive a need for follow-up care and treatment. However, anemia is associated with a range of adverse health outcomes as well as general decreased quality of life.³ Thus, the burden or harm resulting from incomplete interpretation can include incomplete or lower quality treatment services resulting in poorer health outcomes and, indirectly, in lower work productivity and income. A lack of treatment can, therefore, “lead to, exacerbate and perpetuate poverty,” potentially compounding vulnerabilities and inequalities.²⁰ At the population level, this can lead to substantial macroeconomic impacts associated with loss of productivity, with the impacts being most severe in low-income countries.¹⁵

At the same time, treatment itself can create a burden, when it requires that patients commit time, energy, and resources to obtain necessary treatments. Treatment burden is considered to have five dimensions: financial, medication, administrative, lifestyle, and time/travel.³³ The burden varies with the severity of the condition and the associated treatment.³⁴ It can also be influenced by the

individual's age, gender, socioeconomic status, and other characteristics.³⁴ The extent to which patients are able to manage this burden can determine the outcome of the treatment and its ultimate impact on their health and well-being.³³ Treatment burden is typically discussed in the context of chronic disease but can apply to anemia as well, and as with any disease, is often distributed inequitably.

These burdens may be distributed differently on the basis of the underlying prevalence of anemia in a given population. Whereas the accuracy of a diagnostic test is a characteristic of the test itself, the positive and negative predictive values of a test are based on the population in which the test is being done. In populations with a high prevalence of a given disease, the likelihood that a positive test result reflects the actual presence of the disease is higher than in a population with a low prevalence.³⁵ Thus, a positive diagnosis of anemia in a population with a low anemia prevalence is more likely to lead to unnecessary follow-up tests and treatment burden. Conversely, a negative diagnosis in a population with high anemia prevalence is more likely to lead to incomplete follow-up and treatment.

Several ethical issues underlie the questions around interpretation and follow-up with respect to test results. As with all other issues related to anemia diagnosis, the human right to health dictates that individuals have a right to comprehensive follow-up tests and treatment for anemia. In addition, the concept of nonmaleficence applies in relation to the burden or harm resulting from incomplete follow-up for referral and treatment. Finally, the concept of beneficence suggests that anyone who requires additional services based on an anemia diagnosis should be able to receive the necessary interpretation, follow-up, and treatment.

Discussion

This paper has reviewed the ethical and human rights considerations related to individuals' and populations' access to anemia diagnosis, the accuracy of diagnostic tests, and interpretation of test results. In particular, we find that the ethical principles of autonomy, self-liberty, beneficence, and non-maleficence are especially relevant. Especially given that those most vulnerable to anemia are also those most likely to be marginalized in the health sys-

tem, we argue that these ethics and human rights considerations are essential to any discussion of anemia diagnosis. In this section, we offer recommendations for research, programs, and policies for the way forward.

Recommendations

The Global Nutrition Report 2017 indicates that 125 countries face a serious burden of anemia (defined as prevalence $\geq 20\%$) among women ages 15–49 years old, with the prevalence of anemia increasing globally.³⁶ Anemia in this population falls under SDG 2: end hunger, achieve food security and improved nutrition, and promote sustainable agriculture. Member states of the WHO adopted a global nutrition target of a 50% reduction in anemia among women of reproductive age for measuring progress toward SDG 2.³⁶ However, no country is on course to meet this target.³⁶ To meet this target and reduce the geographical disparities in anemia prevalence, it will be important for countries to consider ethics and human rights.

Improved access to high-quality health services, particularly primary health care services, is imperative for improving equity in anemia diagnosis. Given the restricted mobility of many individuals and population groups who are at highest risk of anemia, integrating community-based platforms within the primary health care system may be a promising strategy for improving access to diagnosis. Community health workers may be paid or unpaid and can work at the household or community level. Community-based distribution of iron-folic acid supplementation has been shown to be effective for reducing anemia prevalence in some settings.³⁷ On a broader scale, a number of countries have successfully implemented a community-based approach to primary health care, including Brazil, Cuba, and Ethiopia, with positive health outcomes.³⁸ Evidence exists that well-designed community health worker programs can “promote equity of access and utilization for community health” and also “contribute towards more equitable uptake of referrals at the health facility level.”³⁹ This approach has been broadly recommended for promoting equity while improving maternal and child survival.⁴⁰

The need for improved access to high-quality health services has additional policy implications for countries and health systems. The text of the

SDGs says, “To promote physical and mental health and well-being, and to extend life expectancy for all, we must achieve universal health coverage and access to quality health care. No one must be left behind.”⁴¹ WHO defines universal health coverage as “ensuring that all people have access to needed promotive, preventive, curative and rehabilitative health services, of sufficient quality to be effective, while also ensuring that people do not suffer financial hardship when paying for these services.”⁴² To make a positive impact on access to high-quality health services, governments should bear equity considerations in mind and should make special efforts to bring the poor and disadvantaged into the health system.^{15,43} A discussion of policies around universal health coverage, resource allocation, priority setting processes, and health care financing systems is beyond the scope of this paper but must be part of any effort to promote equity in anemia diagnosis and treatment.

To improve the accuracy of diagnostic tests across populations, one recommendation may be to explore public–private partnerships. Specifically, the research and development capacities of the private sector should be leveraged to reduce geographic disparities. This could follow the approach of the Mectizan Donation Program (MDP), in which Merck partnered with the WHO, the Centers for Disease Control and Prevention, the World Bank, the Task Force for Child Survival, and a number of other organizations and individuals to fight onchocerciasis.^{44,45} Companies currently developing noninvasive testing methods for anemia could explore a similar model of technical, scientific, and operational coordination. This could present a valuable opportunity for the private sector to accelerate the pace of innovations by testing the effectiveness of products in resource-constrained settings, for the benefit of individuals in those settings.⁴⁶ Making those products available in LMICs, where they arguably have the most value, would present a mutually beneficial avenue for future research and innovation as well as for health equity.

With respect to interpretation, follow-up, and treatment following anemia diagnosis, one recommendation may be for research studies to consider providing more than a simple output of hemoglobin concentration to study participants. The extent to which researchers choose to engage with study populations will vary on the basis of the type, intensive-

ness, size, and duration of the study as well as the local context, including the availability of healthcare services.^{47–49} No single guiding principle exists to help researchers identify their ancillary-care obligations under all circumstances. However, researchers and funders should allow time in the study design process to consider the ethical questions and frameworks relevant to their work.

On a broader scale, countries should consider the principles of health equity and human rights when developing national action plans to strengthen health systems and meet the SDGs. This includes addressing the social determinants that may contribute to anemia, including those relating to gender equality, food and nutrition security, water and sanitation, and socioeconomic status.⁵⁰ These are not only social determinants of health, but also standalone SDGs and should, therefore, be included in country strategies. Indeed, any barrier to the ability of individuals or communities to effectively enjoy the right to health should be addressed.⁵¹

Data gaps

A need exists for quantitative and qualitative data on disparities related to anemia, including longitudinal data to document changes over time. This includes country-level monitoring and surveillance data to identify high-risk and vulnerable populations who should be targeted with services. Countries should monitor coverage and effectiveness of health services, while also measuring other components of health system quality, such as user experience and confidence in the health system.^{15,20} The data should be representative not only at the national level, but also at key levels of disaggregation, to assess equity. At a minimum, within countries, data should include disaggregation by sex, age categories, urban-rural residence, and wealth quintile. All of these data can contribute to integrated, multisectoral country-level development planning processes.⁵⁰ They can also inform rights-based assessments of countries’ progress toward reducing anemia prevalence and meeting the SDGs.⁵¹

Population-based surveys and other research studies in LMICs may consider oversampling from populations known to be at higher risk of anemia, including children under the age of 10, females of reproductive age, and the elderly. Data from these populations can inform future processes to assess the appropriateness of current thresholds values

of hemoglobin concentrations to diagnose anemia. For these purposes, data may additionally be needed on ethnic groups that were not originally included in the processes that led to the current threshold values.

Conclusion

As of 2013, anemia is estimated to affect 1.9 billion people, causing 61.5 million years lived with disability (YLD).³ As reported by Kassebaum *et al.*, this is “greater than disability owing to asthma, diabetes, and cardiovascular disease combined (61.3 million YLDs).”³ The authors note that anemia “is also much more amenable to prevention and treatment than many of those conditions.”³ In many cases, anemia is a wholly preventable condition whose existence reflects the manifestation and interaction of inequities at many levels. Countries have a moral and ethical responsibility to reduce these inequities. A human rights perspective provides the guidance needed to improve anemia-related health services for the most vulnerable.

Author contributions

S.S.S. conceptualized and drafted the manuscript, with input from J.F. Both authors critically reviewed and approved the manuscript.

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Statement

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Competing interests

The authors declare no competing interests.

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