

Health Information as a Human Right: From Justification to Practice

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ABSTRACT

The COVID-19 pandemic has illuminated how necessary clear and accurate health information is and yet how vulnerable people are to mis- and disinformation. The objective of this article is to put forth a sound argument, based on both policy and philosophical doctrine, on why people—regardless of citizenship—have a right to accurate, current health information. Evidence is provided to show that access to quality health information is a human right asserted by the United Nations, and academic writing from scholars of philosophy is explored to put forth a moral assertion that agrees. Finally, practical measures are offered for librarians and other information professionals to promote these rights in their institutions and communities—for example, by teaching health and information literacy skills while pushing back on disinformation flooding communities in times of crisis.

Librarians have long been at the forefront of information literacy promotion and the fight against misinformation. In this regard, COVID-19 presents the library profession with an admittedly ill-won opportunity. Never before has the public been so aware of the need for reliable health information and yet so vulnerable to the growing threat of mis- and disinformation. During the pandemic, leaders of privileged institutions have weaponized misleading or false health information to benefit their own self-interests (Limaye et al. 2020). This behavior, along with mirrored responses by their constituencies, has quickly affected the social construction of reality and habituated into a pervasive societal mistrust that spans the globe (Berger and Luckmann 1966).

There have been dire consequences for the public. Early in the pandemic, people across the world demonstrated a distrust of authoritative medical advice by trusting remedies such as eating large amounts of garlic, ingesting large quantities of vitamins, and drinking cow urine. Some of these measures were potentially fatal, such as drinking bleach and other disinfectants (Coleman 2020). In the United States in June 2020, for example, the Centers for Disease Control and Prevention reported a 59% increase in calls to its poison control line due to people eating or inhaling disinfectants (Nelson et al. 2020). Although the vaccines have proven to be safe and effective, stories about people dying after receiving a shot were among the most widely shared social media articles in January–March 2021 (Parks 2021). A story about a doctor who received a

shot and died 2 weeks later was shared more than 5 million times, despite the fact that the death was found to be unrelated to the vaccine. Finally, people who believe COVID-19 misinformation are less likely to get vaccinated and more likely to contract the virus, and unvaccinated people have a significantly higher likelihood of severe illness and death due to COVID-19 (Roozenbeek et al. 2020; Kricorian, Civen, and Equils 2021; Moore et al. 2021; Scobie et al. 2021).

Unfortunately, the general reluctance of some world leaders to send unified messages, to wear masks, to adequately embrace practical public health measures (e.g., limiting public events and mandating quarantines), and to send consistent messages about the severity of the epidemic to their citizens has incited already contrary groups within their countries and caused mass dissent in people responding to the epidemic. In particular, scholars have found that the leaders of some countries, such as Jair Bolsonaro of Brazil, often contradicted their public health professionals' messaging to the detriment of their citizens as measured in deaths per million people (Lilleker et al. 2021).

I bring up these points not to criticize but rather to highlight the significance of public health messaging and the receipt of correct health information by the public. In contrast with the handling of the pandemic by some nations, countries such as New Zealand and South Korea have had extraordinary success by issuing firm, transparent, and accurate messaging about the severity of the pandemic, as the information was known, and then implementing decisive public health protocols quickly and effectively through centrally coordinated responses to localized needs (Sales et al. 2021).

The United Nations (1948) "Universal Declaration of Human Rights" asserts that all human beings are born free and equal in dignity and in rights. If this is true, then why should a person's citizenship and the whims of their government officials determine the health information that they are given and, potentially, the resultant health outcomes that they experience in a time of crisis? In this article, I argue that it should not. In doing so, I ask the question, Is access to quality health information implicit in the United Nations Universal Declaration of Human Rights?

Amartya Sen (2008) wrote, "A human right can serve as a parent not only of law, but also of many other ways of advancing the cause of that right." The objective of this article is to put forth a sound argument, based on both policy and philosophical doctrine, as to why people—regardless of citizenship—have a right to accurate, current health information. First, I provide evidence that access to quality health information is a human right asserted by the United Nations. Second, I explore academic writing from scholars of philosophy to determine a moral assertion that agrees. Third, I offer practical measures that librarians and other information professionals can take to promote these rights in their own institutions—for example, by teaching health and information literacy skills to patrons while pushing back on disinformation flooding communities in times of crisis.

It may seem like these practical measures are unrelated to the latter points. How can something as consequential as health information access as a global human right be related to the

need to promote health literacy education in the community library? There is a direct relationship between a population of people who are able to perceive the difference between disinformation and quality information and people who are able to advocate for the proper receipt of that information to be guaranteed as one of their rights as citizens. If an argument can be made that health information should be a guaranteed human right, then it follows that for that right to be enabled, people need to be able to discern the quality of the health information that they receive. Another way to look at it is that the relationship between building health literacy within communities and health information as a human right is the same as civics education being foundational to building an educated electorate.

This inquiry is based on the theoretical framework of Kantian ethics, which assert that actions can be right only as they work in accordance with moral law (Wood 2008). "Moral law" is built on Immanuel Kant's philosophical concept of the *categorical imperative*, which is a set of principles for evaluating the morality of an action or law. Kant disagreed with the modern philosophy of his time, which he found largely concerned with hypotheticals, and he developed the concept of the categorical imperative as a requirement for action if all moral principles are met (Cholbi 2016). The original basis in the creation of the categorical imperative was that people should "act only according to that maxim whereby you can, at the same time, will that it should become a universal law" (Gregor 1997, 421). The principles, or formulations, that dictate a categorical imperative are universality, humanity, autonomy, and the "kingdom of ends." For an action to be acceptable, it must be applicable to all people universally, without contradiction. It must treat humans as an end in themselves rather than as a mechanism for another purpose. Human beings must be self-legislating and follow the imperative autonomously (i.e., of our own free will). And, finally, an action cannot be a law if it is autonomous. To determine whether a law would be moral, we should consider whether it would be appropriate to govern a hypothetical ideal kingdom—the kingdom of ends (Wood 2008).

If an action is one that cannot be applied universally to all people, that is not motivated by treating people with respect as an end to the means, that people would not follow autonomously, or that would not be an appropriate law to govern a kingdom of ends, Kantian ethics assert a "perfect duty" to *not* initiate the action. In a perfect kingdom, for example, no one would commit murder. Murder violates the formulations of autonomy and humanity of the categorical imperative. Therefore, we have a perfect duty to not commit murder. However, if the opposite is true, that the action passes Kant's four formulations, we have a categorical imperative to proceed. Using Kantian ethics as the theoretical basis for this work, I determine whether people have a categorical imperative to access to health information.

A note going forward—this article discusses *health literacy*, which is defined as "the ability to obtain, process, and understand basic health information and services needed to make appropriate health decisions and follow instructions for treatment" (Institute of Medicine 2004). Health literacy is a set of skills involving an intricate piecing together of numeracy and textual

literacy, plus practical abilities such as understanding prescription bottle labels and hospital maps, communicating with medical professionals, and understanding medical forms (Zimmerman and Rodgers 2022). As challenging as these skills may be to delineate, in the current world, “eHealth literacy”—the ability to leverage electronic sources for health information and apply the knowledge gained from them to the health decision-making process—is also required to fully engage in the health-care system (Norman and Skinner 2006).

Human Rights Justification

Is access to quality health information implicit in the United Nations (1948) Universal Declaration of Human Rights? I believe that access to quality health information as a right can be affirmed by the application of three articles of the declaration: article 19 asserts the right of people “to hold opinions without interference and to seek, receive and impart information”; article 25 guarantees “the right to a standard of living adequate for the health and well-being of himself and of his family”; and article 27 promises the right “to share in scientific advancement and its benefits.” These articles attest, in turn, that all people have the right to information that has not been deliberately altered or corrupted, the right to as healthy of a life as they are capable of having without their well-being being unduly undermined by their leaders, and the right to benefit from advances in science. I contend that these advances include advancement in the areas of infectious disease control, including testing and vaccination, and learning about the efficacy of simple, lifesaving measures, such as mask wearing and social distancing.

There is precedent for these arguments. Amy Dickens (2020) comments on risks related to the commercialization of health data. Collaborations between tech giants, such as Google, and health-care providers would compromise the public sector’s ability to compete in scientific advancement and limit public access to health data and its benefits, creating inequity of access. Privatization of health data also limits privacy and makes users more susceptible to commercially driven misinformation and manipulation. If private companies own data and the technology created from it, they can and will create paywalls for access or exploit that data in harmful ways. Public agencies and health nonprofit organizations would be incapable of providing similar care to their clients (Dickens 2020).

Trudo Lemmens (2013) uses human rights legal analysis to make a similar argument, claiming that privatization, commercialization, and industry control of this health information is a public health issue and a human rights concern. Lemmens demonstrates how drug regulations create industry control over this health information, thereby violating human rights doctrine stating that the benefits of scientific research must benefit health care and humankind in entirety (UNESCO Office in Brasilia 2000). In “The Universal Declaration on the Human Genome and Human Rights,” the UNESCO Office in Brasilia makes the argument that access to such health information exists in tandem with the right to benefit from scientific progress. In addition, UNESCO’s declaration states that there should be a relationship with the government’s

role “in contributing to the progressive realization of the right to health” and that “with finite resources, citizens can expect that governments behave rationally when they invest in the development of health care goods and technology that can assist with, or affect the realization of, the right to health” (170).

James Griffin (2021) argued that human rights doctrine, emphasized by a statement from the United Nations High Commissioner for Human Rights (OHCHR 2020), asserts that human beings have the right to access not only information but also information made accessible in relation to their ability to comprehend it (Malloy 2021). Individual comprehension relies on language and accessibility. Information should be understandable in many languages and formats and by people with limited literacy or no internet access.

The 2010 Brisbane Declaration stated that “the right to information is critical for informed decision-making, for participation in democratic life, for monitoring of public actions, and for enhancing transparency and accountability” (UNESCO 2010). The Brisbane Declaration did not specifically discuss health information but discussed information as integral to exercising other human rights. The full participation of citizens in democratic life during the first 2 years of the COVID-19 pandemic necessitated clear, accurate, and inclusive health information, just as it did in West Africa during the ebola outbreak of 2015 and during the HIV/AIDS epidemic in the 1980s and 1990s. These extreme examples of health crises are major events in comparison to ongoing health information mandates that are largely agreed upon by the international community—for example, sexual health education, food labels, and medication side effects (Thornton 2004; Roden, Schmidt, and Holland-Hall 2020; Constantin et al. 2021).

It is clear that the UN declarations suggest that citizens should also have the right to make informed decisions about their other human rights, including the right to a standard of living to maintain health and the right to benefit from scientific advancement. I argue that the right to information works in concert with the right to a standard of living to maintain health, in that the former supports the latter. Although information is a direct, stated human right, it is also a foundation for the acquisition of other rights. After all, what possible means could a citizen have to advocate for their rights without being informed of them? How does a person advocate for proper infectious disease protocol (or reproductive health, or childhood vaccinations, or end-of-life care, etc.) if they do not have proper, accurate, current scientific information to do so? Human rights doctrine should be the foundation on which governments design and implement methods to combat pandemics and other crises.

By agreeing that these conditions are basic human rights, a counterargument can be made that it is a violation of human rights to knowingly promote health strategies that do not work or that cause harm. It is a violation of human rights to deliberately obfuscate the public health recommendations of experts, particularly in times of crisis, when the population is the most vulnerable. And it is a human rights violation to impede the scientific community from promoting validated, evidence-based, credible research knowledge that may save lives and prevent

infections, particularly while favoring false cures and pseudo-science. Scientists can contradict each other, be wrong, and make mistakes in good faith—errors are part of the scientific process. However, this work is concerned with the purposeful promotion of inaccurate health information or the hinderance of credible research to the disadvantage of the public. So, is access to quality health information implicit in the United Nations (1948) Universal Declaration of Human Rights? I assert that the answer is yes. With a close reading of the United Nations Universal Declaration of Human Rights, it is clear that all human beings have a right to accurate, credible health information. I also contend that to conceal or obscure such information is a direct abuse of these rights.

Philosophical Justification

In addition to the human rights justification, there is legitimate philosophical reasoning for access to health information to be recognized as a human right. "Personalism" has had many interpretations since it was first coined in 1799 by Friedrich Schleiermacher; however, its central tenet is that "person" has the highest intrinsic value of all things (Burrow 1997). Twentieth-century personalism evolved to a philosophy that contends the individual, inclusive of their dignity and freedom, is the most significant value in the universe, inherently sacred, and that everything else is an instrument to this ultimate end. Boston University clergyman and philosopher Borden Parker Bowne, an early American leader in the movement, believed that only people were real—the rest of the universe comprised simple particles of matter—and that the universe exists only as a person experiences it (Dirksen and Schotsmans 2012).

This Boston personalism later produced Bishop Francis John McConnell (1927/2010), who was interested in an ethical and metaphysical social personalism. A devout theist, McConnell's primary concern was the place of human beings in the world and how it related to scripture (Burrow 1993). His interest was applying the ideals of personalism to people in concrete situations. By appreciating the person as possessing ultimate worth and being inherently good and believing in a god that is also good and using his power for the "highest possible outcome," McConnell determined that personalism and his religious beliefs necessitated that all people are deserving of compassion and equity. He argued for the application of personalistic ideals to social ills, stating that "two motives must work together—a rational regard for humanity in oneself and a like regard for humanity in others" (McConnell 1924, 205).

This personalism evolved into what we would regard today as having a social justice bent, insisting on the equal worth of all humanity for all people everywhere (Burrow 1992). By regarding the person as the highest value in the universe, all human beings must have equal value. To accept the former necessitates affirmation of the latter; otherwise, by diminishing some human beings, all are diminished. A common belief in personalism is that reality is communal. These ideals—personalism is fundamentally and literally idealistic—require the belief that dignity and freedom must be maintained equally for all people everywhere.

In my interpretation of personalism through the lens of these philosophers, the commonality is that the person is of utmost importance over other societal structures, that all human beings are of equal value, and that their dignity, freedom, and lived experience must be honored. Free will requires dignity (Kane 1998). The person should be the ontological starting point for all aspects of collective decisions or moral justifications. Therefore, the practical application of personalism would require that individual people be free to make their own decisions and given the dignity to do so with as much accurate information as possible. To deny a group of people this ability is to deny the ultimate value of humanity, regardless of which people are being subjugated. In all decisions related to things that affect human happiness, safety, and dignity, the value of the person is greater than the value of the institution, and decisions regarding such instances should prioritize individual well-being. In every possible way, this worldview condemns the promotion of disinformation in a health crisis.

The foregoing discussion has established that human dignity and freedom are the basis of this philosophical doctrine. This line of thinking has been applied to health care before. Donald G. McCarthy (1978) stated that personalism mandates that health-care workers should consider patients to be people with value and dignity equal to their own. McCarthy's article is primarily about the difficulty of respecting the rights of severely ill patients in health-care settings, describing the care that health-care workers provide as a "covenant" between them and their patients. In another article, Marcum (2015) describes health-care personalism, in which each member of the health-care team and the patient are all held to be of equal significance. Marcum expands on McCarthy's approach in considering personalistic ethics in the health-care system not only to imply respect and dignity for the patient but also to value the experiences of the medical team. This health-care personalism strives to achieve the goal of health care by relieving human suffering, including the potential distress of the health-care workers.

Personalism has also been used in literature to justify the health-care system. Andrzej Bielecki and Sylwia Nieszporska (2017) determined that a tenet of personalism is that the person has the right to be an active participant in anything relevant to them, as the basis of freedom and human subjectivity. They state that the person is more important than economic aspects of society and that they have inalienable rights, including the right to health care.

At this time, I could not find literature on personalism as a philosophical justification for a human right to accurate and current health information, which makes this approach novel.

But why does philosophical justification matter? Philosophical, or moral, human rights are often the basis for legal doctrine and can help determine legal scope and content (Griffin 2021). In personalism, as described, the individual should be the chief concern above any other societal or civic issues. In practice, these issues should be considered in such a way that would be of greatest benefit to individual people—not bureaucrats, dictators, or political parties. In protecting the person, it is fundamental to preserve their free will and, subsequently, their dignity and freedom. It cannot be true that a person's free will is maintained by feeding them falsehoods

or by obfuscating facts so that they are misinformed or uninformed about critical health information to their potential detriment.

Logically, it follows that giving people accurate information is necessary for them to maintain their free will, to secure their dignity, and to have the freedom to make the best possible decisions that they possibly can for themselves and their families. Finally, personalism insists that all people, everywhere, are alike in being of the highest possible value—regardless of gender, race, sexuality, educational attainment, economic status, or nationality.

Practical Implications for the Field

Olivier de Schutter (2021) wrote that “human rights in times of crisis are both a shield against abuse, and a map for recovery” (xix). Socrates observed, “Once a man knows good from evil, nothing on earth can compel him to act against that knowledge” (Allen 1960, 256). Having asserted human rights and moral justifications for the right to accurate, current health information, and moving away from grandiose ideals, now comes the question, What practical measures can information professionals take to advocate for this cause on an individual—or single institutional—level? How can a librarian make a difference?

As information professionals, the day-to-day labor of our actual jobs is not typically political advocacy, although an argument can be made that librarianship is intrinsically a radical field (Lankes 2016). However, librarians can go to work each day and take action to promote the right to quality health information for people in their communities. This approach is two-fold. First, in times of repose, librarians must prioritize building individual and community health literacy in their communities. Second, information professionals must combat misinformation in times of crisis.

Textual and information literacies have long been considered within the purview of librarianship (Marcum and Stone 1991; Harding 2008). Adding health literacy to this umbrella is within the bounds of library-based community advocacy work, especially as so much of health literacy is information literacy, plus numeracy and communication, within a medical context (Lawless, Toronto, and Grammatica 2016; Whitney, Keselman, and Humphreys 2017). Both health literacy and information literacy start with an information need. They proceed through similar channels of processing and comprehending information based on the information seeker’s abilities to discern the information and use whatever technology is relevant to that context. If an information-literate person can find and use information, a health-information-literate person can do so for a health-related information need. As stated by Spencer Thompson (2003), “Health information is a unique axis for information literacy, as illnesses are often a powerful motivation for families to become information literate” (3).

Many information professionals have long advocated, successfully, for health literacy to be promoted within the library (Arndt 2016; Barr-Walker 2016; Popoola 2019). The most recent population-level study of health insurance ability in the United States determined that 35%

of the population is deemed to have basic or low health literacy. Only 12% of adults in the United States can competently navigate medical documents to define a medical term or calculate an employee's share of health insurance costs. In addition, 35% of the population cannot adequately read and understand a prescription medication label or childhood vaccine schedule, and 14% cannot circle the date of a medical appointment on a hospital appointment slip (Kutner et al. 2006). If these findings reflect the state of health literacy in the United States, this is a crisis. In a pandemic, how could such a population be expected to understand social distancing, exponential curves, and herd immunity? How could they be expected to discern between credible health information and myth? How could they be expected to react with appropriate significance, when health literacy is a necessary component of risk comprehension (Housteen et al. 2020)?

It is not enough to promote these skills to willing individuals who are conveniently located within the walls of a library. The pandemic demonstrated that health literacy is both an individual and a community issue and must be addressed as such. Accepting that there are people in positions of power who are willing to compromise people's health for the benefit of inciting fear, creating polarization, and maintaining influence (Ball and Maxmen 2020) compels resistance from those of us with a social justice bent. This can be accomplished by dedicated health literacy advocacy work that starts in the library and reaches out deeply into the community around our buildings.

What can librarians do? They can create health literacy education programming and share it with community stakeholders, such as local resource groups dedicated to improving the lives of disadvantaged populations. They can build relationships within their neighborhoods and leverage them to do health literacy education outreach to as many people as possible. Teaching citizens adequate health literacy is a way of weaponizing the populace against health disinformation.

There are already examples of this advocacy going on today. One example is the Online Computer Learning Center's opioid crisis response toolkit, which arms public librarians with the skills to examine local data and conduct outreach to people with opioid use disorder to improve their access to health care (Allen et al. 2020). Another example is a health literacy workshop being taught to refugee women by library science master's-degree students (Zimmerman and Rogers 2022). Many libraries offer health literacy and e-health programs for older adults, underserved populations, and the general public (Xie 2012; Barr-Walker 2016). The American Library Association (2017) website has suggestions for health literacy programming in the library, and the National Network of Libraries of Medicine has small grants available to fund them.

In my own work, I found collaborating with medical librarians and public health workers from local nonprofit organizations to be both helpful and rewarding. The skill set for health literacy is broad, and librarians may not have the expertise to design this outreach on their own. Developing partnerships with the local health department and nonprofits that specialize in the population or the need to be addressed enables librarians to create credible health literacy education programming while capitalizing on the community connections of both organizations.

Calling in medical librarians to teach skills like e-health can be invaluable to both the patrons and the librarians themselves.

Information professionals must combat misinformation in times of crisis. Much has been written on the need for librarians to combat mis- and disinformation, so I will simply add this: If there is a “new normal,” it will likely be characterized by repeated upheaval brought on by issues such as climate change, endemic income disparity, or the opioid crisis. Librarians have already been active in each of these examples, providing education on environmental literacy and practice, bridging the digital divide and promoting equity, and even administering naloxone to people experiencing opioid overdose (Scott 2011; Hawco 2019; Real and Bogle 2019). However, our primary expertise as information professionals is just that: information. During crisis, it is our responsibility to reach into our communities and promote credible, accurate health information, which is fundamental to positive health outcomes (Young et al. 2021).

How can librarians meet this responsibility? Young et al. (2021) suggest a three-pronged approach in which librarians create replicable programming on mis- and disinformation, develop tools that keep people up to date on relevant misinformation, and continue to intervene in political contexts that interfere with the ability of librarians to engage in controversial topics. Saunders and Budd (2020) suggest that librarians move away from task-based instruction and promote critical-thinking skills to help patrons evaluate information. Libraries around the country now offer workshops on “fake news” and fighting health misinformation. In my work, I have found that connecting with the populations I want to reach and evaluating their health information needs from their perspective, through a community participatory approach, has been the best way to establish the relationship necessary to introduce them to appropriately leveled health information resources, such as those written with plain language resources. Regardless of how we do it, it is imperative that we do everything within our power to discredit misinformation, vigilantly, using the skill set that is foundational to our profession (Veil and Bishop 2014; Sullivan 2019).

Conclusion

The right to information implies that the recipient of information will be put in a position of being able to make informed decisions.

—Malloy 2021, 55

Having evaluated access to health information as a human right according to human rights doctrine and personalism, and having discussed practical implications for our field, I return to the theoretical framework of this article: Kantian ethics. Can access to quality health information be considered a categorical imperative? I believe it can. Access to health information can and should be universally available to all human beings—at least, as it is possible and is not

obfuscated by others. The formulation of universality is highly congruent with the principles of human rights doctrine. Such health information access treats human beings as an end in themselves and respects their humanity—Kant's second formulation. This formulation resonates deeply with the virtue of dignity present in personalism. Both the United Nations (1948) Universal Declaration of Human Rights and personalism regard human beings as having free will or being self-legislating. Consequently, both agree with the third formulation of autonomy. Finally, access to quality health care is appropriate to an ideal kingdom of ends. According to Kantian ethics, this understanding compels our moral duty (imperative) to act according to this determination.

Most nations do not place the responsibility of upholding human rights on individual citizens, nor should they. It is not a reasonable burden of responsibility that most people can live up to. This burden should be on our leaders, both in governments and community organizations. Unfortunately, since the beginning of the pandemic, it has become clear that some people in positions of privilege, with the power to act in the best interests of the many, choose not to. Regardless of the actions of our leaders, the United Nations mandates that all people, regardless of citizenship or other factors, have the right to uncorrupted information in order to lead as healthy a life as possible and to benefit from advances in science. Furthermore, individual people are the most critical element of society and, as such, should have their freedom, dignity, and health prioritized above any other agenda.

Now is the time to call on leaders in our field, such as the American Library Association and the International Federation of Library Associations and Institutions, to speak out about the right to health information for all people, to develop national and international standards for the field, and to develop guidelines and practical tools to implement in our communities. As information professionals in the midst of a misinformation war (Becker 2016), we are in a unique position to strengthen our communities in the interest of elevating their well-being. Librarians have long been literacy advocates of all kinds and are a natural fit for the promotion of individual and community health literacy. We have the skill set to combat mis- and disinformation and the local inroads to do so. We have the opportunity to assist our patrons in not just receiving health information but enabling them to discern and use what is credible. After all, each individual that we serve has a basic human right to obtain accurate health information.

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