

Exploring the ethical scope of health literacy – A critical literature review

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Abstract

Aim: Health literacy is named as one prerequisite of promoting patient education and enabling citizens to take informed choices concerning their own health, as well as for the health of their families and communities. Underlying ethical questions become apparent when the problems of limited health literacy are addressed. This paper intends to provide an overview of ethical aspects of health literacy in public health policy and research.

Methods: The basis for this ethical analysis is a framework of seven biomedical and public health ethical principles: beneficence, non-maleficence, respect for autonomy, efficiency, health maximisation, social justice and proportionality. A systematic literature search was conducted for articles on ethical issues of health literacy.

Results: Only 11 articles dealing explicitly with health literacy and ethical issues were identified. The topics most widely discussed relate to the principles of respect for autonomy and social justice.

Conclusions: Awareness of the ethical scope of health literacy is not sufficiently developed yet in health policy and public health research. The study emphasises that a health system change is required and should be induced in order to secure basic rights, transparency and autonomy and to overcome barriers of health literacy. Following ethical practices to improve health literacy will secure just health care, in both prevention and promotion, and eventually better health for all.

Keywords: autonomy, ethics, health literacy, justice.

Introduction

The concept of health literacy broadly relates to an individual's ability to place their own health, their family's health, and the health of their community into context. It is mainly concerned with how people understand factors that may influence their health, and how they understand their own ability to control these factors. Over the last two decades many different definitions of health literacy have been published in international literature. Predominantly, definitions of health literacy diverge between the field of medicine and the field of public health. Definitions derived from either field consistently place emphasis on different dimensions of the concept, such as a particular skill or specific type of knowledge ('e.g. numeracy or knowledge of bioscience). A recent review resulted in an integrative definition, which states: *"Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain and improve quality of life during the life course"* (1).

Although the concept of health literacy was first used in the 1970's (1), in recent years it has become an emergent topic within both health care and public health settings, and is now a key issue in both EU and US political health agendas. In 2007, the European Commission published 'Together for Health - A Strategic Approach for the EU 2008-2013' (2,3), which emphasized the need to improve EU health literacy and aimed to achieve this by promoting health literacy programs. Similarly, in 2010, the US Department of Health and Human Services outlined its 'National Action Plan to Improve Health Literacy' (4) which argued for a more systematic approach to improving the health literacy of US citizens. The high level of political interest in health literacy follows the emergence of evidence that associates limited health literacy to poorer health outcomes and the possibility of increased financial burden to health systems (5,6).

The negative impact of limited health literacy is observable in a broad variety of issues: improper use of medications; inappropriate use or no use of health services; poor self-management of chronic conditions; inadequate response in emergency

situations; poorer health outcomes; lack of self-efficiency and self-esteem; financial drain on individuals and society; social inequity (7). These findings are confirmed, and developed, by Berkman et al. (6) in a comprehensive systematic review of low health literacy and health outcomes. Berkman et al.'s (6) review was also able to demonstrate a disparity between social groups in their ability to understand, evaluate and apply health information within different settings, demonstrating that this can be multifaceted and the result of a variety of different causes.

For any individual with limited levels of health literacy "the capacity to make sound health decisions in the context of everyday life" (8) can be hampered. This can influence life "at home, in the community, at the workplace, in the health care system, the market place and the political arena" (p. 8) (8) and thus raises the following ethical concerns:

- Is limited health literacy and related problems only the concern of *the individual* or is it the responsibility of society and the health system to address?
- What ethical values are relevant to this argument and how can they be used to interpret issues of health literacy?

In spite of the developments in the field of health literacy, little attention has been paid to identifying the ethical issues pertinent to addressing the problem of limited health literacy. This paper attempts to address this issue, performing a review of the literature on health literacy that either directly discusses or indirectly highlights moral issues of limited health literacy. Results are discussed within a combined biomedical ethical and public health ethical framework in order to provide ethical criteria that are easily transferred to either a medical health care or public health setting. Findings may serve as both a point of orientation for literature discussing ethical considerations of health literacy, or as guidance for policy makers, public health professionals and health care professionals when facing potential issues of morality associated with limited health literacy.

Methods

Data were collected through a systematic literature review of the following databases and online resources: PubMed, GoogleScholar, BELIT, Stanford Encyclopedia of Philosophy, and

Routledge Encyclopedia of Philosophy. The following search items were used in different combinations to identify relevant academic work: “ethics”, “health literacy”, “health competences”, “health communication”, “health skills”, “health abilities”, “health education”, “respect for autonomy”, “autonomy”, “social justice”, “justice”, “efficiency”, “respect for human dignity”, “social utility”, “proportionality”. After excluding articles that were not written in English, German, Danish, Norwegian or Swedish, 11 articles remained. The content of each article was then scrutinised in order to identify ethical issues that were relevant to health literacy. Ethical issues that were judged to be relevant to the conceptual dimensions of health literacy were then assessed using a combined biomedical and public health ethical framework.

Biomedical ethical and public health ethical framework

The theoretical framework used for the analysis combines the four principle approach for biomedical ethics by Beauchamp and Childress (9), with the five principles approach of public health ethics proposed by Schröder (10). This synthesis yields an analytical framework of seven core ethical principles: beneficence, non-maleficence, respect for autonomy, health maximisation, efficiency, social justice and proportionality. These seven principles address all dimensions of health literacy derived from the fields of medicine and public health. The use of the combinatory biomedical and public health ethical framework improves the sensitivity of the ethical analysis to issues derived from both medicine and public health, and therefore, enhances the relevance of findings to health policy development, and to either medical or health care settings. Beauchamp and Childress’ (9) four principles frame ethical issues derived from the biomedical realm: respect for autonomy, non-maleficence, beneficence and justice. ‘Respect for autonomy’ demands that an individual’s (negative) freedoms are not violated but rather a person can decide about his or her own life. It demands that there should be no interference with personal choice, as long as this does not have negative impacts on others. ‘Non-maleficence’ concerns the health professional’s obligation not to cause harm to the patient. Whilst ‘beneficence’ is

highly associated with non-maleficence, beneficence more closely mirrors the core of the Hippocratic Oath in that it prioritizes helping the patient. Therefore, when the advantages and disadvantages of health interventions or treatments are judged under beneficence, the benefit to the patient should be of primary concern. The last principle, ‘justice’, demands that benefits, risks and costs are fairly distributed among patients, health care professionals and all other persons involved (9).

Schröder’s (10) five principles of public health ethics are health maximisation, respect for human dignity, social justice, efficiency, and proportionality. The first principle of ‘health maximisation’ corresponds, on a social level, to the individual ethical principle of ‘beneficence’ proposed by Beauchamp and Childress (9). It concerns the maximisation of the overall health of the whole population (or subgroup of the population) for the primary goal of increasing the well-being and utility of all. The second principle, ‘respect for human dignity’, helps protect the individual’s rights by respecting individuals’ free will. It includes the avoidance of constraint, promotion of self-determination and respect of informed consent. Under this principle, respect for free will is considered to be a duty that also helps to prevent individuals from being used (only) for the benefit of others. This principle is highly relevant to Beauchamp and Childress’ (9) principle of ‘respect for autonomy’ and can be considered as (approximately) synonymous with it. The principle of ‘social justice’ is balanced with ‘health maximisation’ which helps to mediate between action that prioritizes overall health gains and action that priorities fair distribution of advantages and disadvantages (i.e. equitable distribution). A strong theme of social justice is to demand the reduction of health inequalities to empower individuals and high risk social groups to gain access to health promotion and maintenance programmes. Social justice also encourages non-discrimination and stigmatisation of disadvantaged social groups. In this respect, empowerment also demands that health information should be accessible to all individuals, that public health decisions are made transparent, and that individuals are free to participate in any related health action. The principle of social justice is incorporated into Beauchamp and Childress’ (9)

principles under 'justice. 'Efficiency' is important as public means are frequently limited. Therefore, the efficient distribution of resources should be considered a moral duty, which can help guarantee that the greatest net benefit for all is attained. It especially applies to the area of research that encourages public health practitioners to use cost-benefit analyses and evidence-based methods for public health interventions. The last principle of 'proportionality' can primarily be understood to, where possible, use the least infringing of all options to act. Furthermore it can be seen as a cross-sectional principle that should be applied to all other principles to balance them well against each other (10).

When excluding duplicate or overlapping principles, a set of seven core principles remain, thus forming the biomedical ethical and public health ethical analytical framework: beneficence, non-maleficence, respect for autonomy, health maximisation, efficiency, social justice and proportionality.

Results

The literature review identified 11 relevant scientific papers dealing with ethical aspects of health literacy, which are shortly introduced. Loss and Nagel (11) focus on ethical conflicts arising in health communication. They propose their own framework of ethical criteria needed to assess health communication. Volandes and Paasche-Orlow (12) summarise empirical evidence of the association between health literacy and poor health outcomes. They elaborate on how limited health literacy is an outcome of injustice in the healthcare system. Along

these lines Goldberg (13), Banja, (14), Schillinger (15) and Trachtman (16) offer similar arguments on health literacy and poor outcomes (12). Goldberg (13) refers to ethical conflicts that arise in clinical research with subjects. Schillinger (15) argues that literacy is a broader issue that is not only confined to areas within the healthcare system. It also affects disenfranchised populations and therefore relates to a wider injustice occurring outside the healthcare context. Banja (14), Trachtman (16), Marks (17) and Gazmararian et al. (18) are especially concerned with the clinician's role with respect to the levels of health literacy of their patients. Both Marks (17) and Banja (14) identify strategies to reduce the negative impact of low health literacy among different groups. Banja (14) for example describes four barriers to health literacy: impact of illness on cognition, inadequate medical knowledge, medical jargon and medical uncertainty. The author also proposes guidelines to help physicians and their patients in overcoming these barriers. Pirsì (19) and Wilson (20) highlighted ethical issues arising from the influence of health literacy levels on health outcomes. Pirsì (19) addresses the issue of inequality in access to care due to varied levels of health literacy. Sass (21) discusses health literacy with respect to health care policy, the status of health care, and health insurance. He points out that there is a moral obligation to empower patients, promote their health literacy, and promote their general health competence.

The ethical aspects were identified and scrutinized according to the seven ethical principles outlined in the analytical framework. The results of the assessment is outlined in Table 1 and described in detail in the following subsections.

Table 1: The characteristics of ethical concerns of health literacy identified in the literature review

Ethical principles	Explanations	Ethical concerns of health literacy identified in the literature
Beneficence	Maximise health of the individual, Hippocratic oath of helping the patient	Communication gap Physician' unaware of her responsibility Lack of skills of the patient Negative impact on health outcome
Non-maleficence	Do not harm the individual, Doctor's obligation to not harm the patient	Harmful consequences of low health literacy: <ul style="list-style-type: none"> • low health, knowledge, • lack of understanding of medical forms and instructions, • increased chronic disease and mortality rates, • limited prevention use, • adherence problems, • compromised information, improper medication use, • missed appointments, • loss of access entitlements, • unwarranted fear, • compromised health outcomes, and • misjudgement of information.
Respect for autonomy	Respect the free wills and decision making capacities of individuals	Loss of autonomy Compromise rights to health Impairs self-determination Risk of victim blaming Manipulation instead of means of empowerment
Efficiency	Use the scarce resources effectively	Economic burden in terms of poor or unrecognised levels of health literacy High program costs to improve health literacy skills. Tax revenues of tobacco to pay for promotion
Health maximisation	Net benefit for the whole population	Impaired political decision-making Inefficiency Lack of knowledge Need of systematic, systemic change Introducing principles of education, solidarity, responsibility and active participation to health systems.
Social justice	Avoid discrimination, stigmatisation, unfairness and exclusion	Unfair system design Unequal access Increased divide between advantaged and disadvantaged groups Disadvantaged groups such as minorities, elderly and mentally disabled Stigmatisation and discrimination Need for transparent information Incorporating people in programmes Solidarity and responsibility
Proportionality	The probable public benefits should outweigh the infringed general moral considerations	Distortion and scandalising of health in media

Beneficence

In relation to beneficence, many of the authors have argued that it is the responsibility of physicians to recognise limited health literacy in their patients and thus to communicate health information according to the patient's level of health literacy. Thus, patients will be able to benefit more from health information (14-18, 20). Gazmararian et al. (18) states that the ethical responsibility of physicians is to formulate health information in a way that is unambiguous to the patients. However, they also stress that such communication issues "address only the 'side effects' of limited health literacy without addressing the underlying problem" (p. 319) (18). In their view, it is necessary to identify people of limited health literacy and educate them in such a way that they become health literate or have the ability to become health literate. The improvement in people's health literacy will simultaneously help improve health, and therefore, is in line with the principle of beneficence. Marks (17) identifies health literacy as a relevant outcome predictor for how well patients are informed and educated by their physicians. If a doctor tried to identify the health literacy level of a patient and adapted the way they communicate health information to them, this would be visible in the degree to which the intended health outcome was achieved. Pirsi (19) proposes that the problem consists of two features: (i) patients are not usually familiar with the vocabulary used by physicians; (ii) physicians are not always aware of this problem. In this respect it would be beneficial for patients if doctors could communicate with them in a way that is in accordance with their own level of health literacy. From this context Wilson (20) points out that doctors should never expect their patients to be health literate and thus to be able to fully understand their advice. Sass claims that health is not merely a status, but "more a balanced result of health-literate and risk-competent care of one's own physical, mental, emotional, and social well-being" (p. 563) (21). Because of this association, Sass implies that a person's health status is directly linked to a person's level of health literacy.

In summary, the main ethical concern under the principle of beneficence is the existence of a communication gap between health professionals and patients. The patient may not have the skills to

fully comprehend the health information they are given and the physician may not be aware of their responsibility to communicate this information in a way that can be understood by the patient. Since patients with limited health literacy may not fully meet the conditions set out by the physician for a particular intervention or treatment, then there is the possibility of an impact on health outcomes.

Non-maleficence

Volandes and Paasche-Orlow, (12) Marks (17), Pirsi (19), and Wilson (20) provide numerous examples of how limited health literacy can negatively influence disease outcomes in a medical setting and lead to poorer levels of health. In particular, the possibility of misunderstanding medication instructions was identified as a major problem associated with limited health literacy that can negatively impact health outcomes and result in poorer health. This contradicts both the principle of non-maleficence and the principle of health maximisation. Volandes and Paasche-Orlow (12) also note that in numerous studies health literacy has been shown to be a more important outcome predictor of health status and health related behaviour than ethnicity or education. They state that "limited health literacy is associated with low health knowledge, increased incidence of chronic illnesses, poorer intermediate disease markers and less than optimal use of preventive health services" (p. 6) (12). Marks (17) lists various problems arising due to poor health literacy: adherence, compromised information and health care seeking practice, compromised and adverse health outcomes, improper medication use, missed appointments, loss or inability to access entitlements and unwarranted fear (19). Wilson (20) considers the strong link between poor health literacy and chronic illnesses and communicable diseases since the incidence of chronic illnesses is higher among the health illiterate. Similarly, mortality in chronic and communicable diseases is also higher with the health illiterate. Trachtman (16) criticizes biomedical research for not fully accounting for the effect of health literacy. Patients' knowledge gaps of fundamental health information lead to misjudgements or miscalculations of risk when evaluating biomedical research on therapeutics. Sass (21) stresses that people

often obtain misleading information from the internet that is frequently incorrect, which might also lead to worse health outcomes.

Accordingly, the primary ethical concern of non-maleficence is that severely negative health consequences may occur when practical issues of health literacy are not taken into account e.g. by healthcare providers.

Respect for Autonomy

First, it is important to note that an improvement in health literacy can increase individual autonomy and decision-making capacities (12). Yet, there are still ethical issues that conflict with respect for autonomy, which arise from the methods used to enhance health literacy. Volandes and Paasche-Orlow (12), Gazmararian et al. (18) and Schillinger (15) point out the general problem that patients with limited health literacy may not understand basic health information such as that contained within medication package inserts. Consequently, they experience a loss of autonomy as they are not able to make fully informed decisions concerning the use of their medication. Several authors emphasize the impact that this problem can have when patients provide informed consent as patients with limited health literacy are often unable to understand consent forms (12,13,17). Volandes and Paasche-Orlow (12) apply this issue to simple educational materials such as the explanation of benefit services, notices of privacy protection and advanced directives, which can often be written in language that is too complex for most people to comprehend. These issues highlight that patients with limited health literacy cannot always provide informed consent, an issue that Goldberg (12) suggests can impact clinical trials. The inability to understand the terms and conditions of a clinical trial can lead to the exclusion of a subject. Therefore, subjects with limited literacy may be more frequently excluded from trials and in turn may bias the trials' outcomes. Schillinger (15), Marks (17) and Wilson (20) further describe how impaired health literacy affects patients' ability to understand their rights and entitlements in health care. In this respect, Wilson (20) argues that people with low health literacy are often unable to express themselves orally and describe what they need. Consequently, patients often do not gain access to medical

procedures that they require and are entitled to receive. Moreover, Schillinger (15) argues that limited literacy in verbal communication impairs the ability of patients and doctors to make decisions together. This can also further inhibit the patient's ability to apply technical information relating to self-care and thus limit the patient's self-determination. Trachtman (16) discusses the problems of only viewing patient autonomy as positive. Often patients have to take decisions by themselves without being sufficiently informed of their options, thus patients may actually lose some autonomy. Loss and Nagel (11) address ethical conflicts that might arise when formulating and promoting health messages. When messages specify a target group they can sometimes be interpreted as accusatory (i.e. victim blaming), and therefore, undermine the human dignity of the target group. The same issues arise when some health messages use manipulative methods over methods of empowerment. Sass (21) accuses current health systems worldwide of not doing enough to empower their patients to be able to avoid health risk and act responsibly with their own health, an issue that Sass argues is evident within developed countries. However, the disease management and insurance systems of poorer countries are not fully developed and there is often inequality in the access of services. Consequently, such systems may withhold their citizens' basic right of education and self-determination within the sphere of health (21). Hence, the main ethical concerns when considering respect for autonomy relate to methods of informed decision making that can impair self-determination and enhance the risk of victim blaming. In addition, when considering preventative health care, the patient's autonomy is undermined when methods are designed to manipulate rather than to empower the patient.

Efficiency

Loss and Nagel (11), Marks (17), Wilson (20) and Sass (21) considered ethical issues that arise when addressing issues of health literacy under resource constraints. Loss and Nagel (11) describe the need to be highly cost efficient in health literacy programs as the costs of interventions to improve health literacy should, ultimately, relate to their utility. Marks (20) identifies the problem of higher health care

costs as a result of poor or unrecognised health literacy. According to Wilson “poor adherence and high hospitalisation rates among people with low health literacy, along with related factors” (p. 875) (20), are responsible for costing the American health care bill an extra \$30 to \$73 billion annually. Sass (21) identifies the positive influence that improving health literacy can have on the efficiency of health care. A more active role for citizens that take greater responsibility for their health in all areas, including disease prevention and health promotion, can improve the efficiency of health care.

Accordingly, the literature reveals that limited levels of health literacy can result in an increased economic burden for the provision of health care. However, an investment in advancing health literacy by promoting and maintaining skills so that patients may take a more active role in their health may be hampered by the high cost of health literacy programs.

Health maximisation

Trachtman (16) and Sass (21) are concerned with the broader influence of limited health literacy on the whole of society. Trachtman (16) states that “health illiteracy is merely one symptom of a broader devaluation and ongoing political assault on science as a worthwhile discipline” (p. 28). He believes the core issue of limited health literacy is a general, widespread deficiency of the population’s knowledge of bioscience. Trachtman (16) reasons that this is most likely due to political decision-making. For Sass (21), improvements in patient health literacy enhances the efficiency of health care systems as patients take on a more active role in decisions concerning their health care, health promotion and disease prevention. Consequently, improving health literacy simultaneously contributes to health maximisation. According to Sass (21), current health systems are ineffectually organised into institutions and financed by insurance providers. They are frequently too focused on the treatment of disease, rather than prioritizing health promotion or disease prevention activities. Sass (21) claims that a restructuring of the system of insurance and health providers is needed in order to promote the principles of education, solidarity and responsibility. Principles which Sass (21) identifies as cornerstones

of a more effective system of the future.

Therefore, the ethical considerations of health literacy, required under the principle of health maximisation, should account for impaired political decision-making, inefficiency within systems and a general lack of bioscience knowledge throughout populations.

Social Justice

Ethical issues concerning social justice were discussed by all authors except for Banja (14). Generally, inequality of access to health care services in individuals with limited health literacy was identified by the authors as the main issue of social injustice. The reasoning behind this was that information is either too difficult to access or too difficult to understand for people with limited levels of health literacy. Loss and Nagel (11) argue that people with limited education are excessively demanding within health care systems yet, their access to health information is limited. Loss and Nagel (11) emphasize the importance of making health information and health campaigns transparent so that people with limited health literacy are able to assimilate the information provided. Despite this, it is also important to consider the population as a whole when developing health literacy programmes. This ensures that interventions do not inadvertently, and unfairly, impact upon populations removed from the issue of health illiteracy. Loss and Nagel (11) suggest that in the context of social justice, health communications may be both positive and negative. Population wide health communications might lead to an improvement in the health of socially disadvantaged groups. However, the communications may overly benefit socially advantaged groups which are more able to assimilate the health information due to higher levels of health literacy. Therefore, a population wide health communication might negatively impact the level of inequality between the two groups, and thus, facilitate a social injustice. Volandes and Paasche-Orlow (12) expand on this type of social injustice and argue that it is unfair that the health care system “is organised for the most literate and powerful members of our society”. Gazmararian et al. (18) also consider how people with the greatest healthcare needs are often those who are unable to

process the information needed to benefit from their respective health care system. Marks (17) builds on this topic, discussing how limited health literacy inhibits the patient's ability to gain access to information relevant for the treatment of their illnesses. He considers limited health literacy as a barrier to equality in the access of care. Wilson (20) connects the health literacy barriers associated with health insurance applications to an inability of patients to access care.

Another problem relates to limited health literacy in disadvantaged groups. According to Marks (17), minority populations struggle more with information and services that are not appropriate for people with limited health literacy. Furthermore he argues that health educators should be providing services that are equitable to all (17). Wilson (20) outlines disadvantaged groups, such as ethnic minorities, where health literacy levels are considerably lower. In these groups it is stated that low levels of literacy are the "result of cultural barriers, language variations, and differing educational opportunities" (p. 876). The socially disadvantaged, mentally disabled, or the elderly may suffer more from limited health literacy. Schillinger (15) addresses this problem and allocates responsibility for limited health literacy to disenfranchised populations outside of the healthcare system who may only occasionally interact with it. Trachtman (16) also identifies that poorer patients are not offered the same treatments or tests as provided to other, richer patients. Goldberg (13) discusses the issue in the context of clinical trials, arguing that some people who "bear a disproportionate burden of disease are dramatically underrepresented in clinical research" (19), possibly due to difficulties in understanding and agreeing to informed consent forms. Such documents are often too long, complicated or entail too many technical terms to be understandable for patients with limited health literacy. Therefore, it can be considered to be an injustice that these groups are not given more attention. Finally, Loss and Nagel (11) and Pirsi (19), touch upon the problem of stigmatisation and discrimination. This can become an issue when health campaigns display certain negative health behaviours in a humorous way, a practice that can make particular social groups appear 'foolish'. Sexual images may also be used to

communicate health messages and thus, can inadvertently impact some social groups (i.e. women) more than others (11). Pirsi (19) sees the stigma attached to people with limited health literacy as a barrier that prevents them from making full use of services and treatments.

Hence, the principle of social justice is associated with numerous concerns with respect to health literacy. It emphasises that the design of healthcare may be unfair and favour social groups that are better off in terms of income or education. Furthermore, when improving health literacy there may be a divide in gains between advantaged and disadvantaged groups that leads to a disproportionate benefit to advantaged groups. Health literacy programs should consider any impact on levels of inequality affecting disadvantaged groups such as minorities, the elderly or the mentally disabled. Limited health literacy can induce a risk of stigmatisation and discrimination in relation to health initiatives.

Proportionality

The principle of proportionality was only addressed by Loss and Nagel (11) and Schröder (10). The authors discuss the principle connecting it to the distortion and scandalising of health issues within the general media. Therefore, issues of health literacy can also apply to methods used to communicate health information to the public, and not only to the health information itself. Scandalising and distortion of health issues in the media can lead to panicked populations, which would not benefit the overall health of the public.

Discussion

The ethics of health literacy is an area of research that is still in its infancy. This is shown by the limited volume of literature attained from the field of health literacy that explicitly discusses issues of morality. The number of occasions where authors have cited each other's work also demonstrates how limited the development of this field has been.

The article by Loss and Nagel (11) focussed primarily on ethical issues concerning the provision of health information and the channel through which it is communicated. The article only indirectly addresses 'health literacy'. For instance, the authors discuss a

variety of problems which they suggest are the result of patients misunderstanding health information. They also discuss relevant moral issues, arguing that health information is a basis for patient empowerment as it enables patients to make their own decisions. However, they do not directly identify or comment on 'health literacy' and just infer (indirectly) that elements of health literacy are important and influential factors of health care.

The article by Volandes and Paasche-Orlow (12) appears as a primary article to which the articles by Goldberg (13), Banja (14), Schillinger (15) and Trachtman (16) relate. It is one of the most detailed articles in the field of ethics and health literacy. The authors are primarily concerned with the issue of justice and the position of the least well-off in health care systems. Contrary to Loss and Nagel (11), Volandes and Paasche-Orlow (12) raise the issue of individual decision making within health care settings and criticise ongoing processes that give more responsibility to individuals. They claim that this does not make the system less complex and more easily accessible since the least well-off, in terms of health literacy, may not have the capacity to make such decisions. Volandes and Paasche-Orlow (12) state "poor health outcomes deriving from limited health literacy ought to be understood as a fundamental injustice of the health care system" (p. 5). According to them, the health care system should be organised in a way that most benefits users with limited health literacy. The approach of Volandes and Paasche-Orlow (12) only concerns the principle of 'social justice' in the proposed framework of this paper. Thus, their discussion on ethics in health literacy is limited to just one domain. This is criticised in articles by Goldberg (13), Banja (14), Schillinger (15) and Trachtman (16), where it is argued that wider ethical issues should be considered.

Generally, the articles discuss health literacy from a medical and health care perspective. Therefore, dimensions of health literacy derived from public health definitions of health literacy are often not addressed. Banja (14) interprets the discussion by Volandes and Paasche-Orlow (12) as only focusing on the situation of socially disadvantaged groups, instead of paying more attention to how limited health literacy affects all patients. Whilst Banja (14)

focuses on the medical context, and in particular to the role of health professionals, Banja (14) also stresses how important it is to consider ethical values in health literacy, even if this seems incongruous at first glance.

Goldberg (13) supports the approach taken by Volandes and Paasche-Orlow (12) to improve health literacy levels in the population in order to reduce poor health. However, he also argues that the approach is a micro-level intervention that will not touch upon the underlying problem of limited health literacy. Goldberg (13) claims that socio-economic disparities are a primary cause of limited health literacy, which in turn may lead to poorer health outcomes. Thus, he questions if interventions intended to address social determinants of health do not also simultaneously address health literacy. Goldberg (13) suggests that narrowing socio-economic disparities through macro-level interventions, while simultaneously attempting to address issues of health literacy directly (i.e. at a micro-level), may lead to better health outcomes.

Schillinger (15) is a proponent of the approach by Volandes and Paasche-Orlow (12), however, Schillinger (15) also argues that their perspective is too narrowly focused on the health care system. Limited health literacy in underprivileged populations is the result of a basic form of social injustice which occurs outside the health system but might only manifest itself in a clinical context. If physicians' were to share this opinion, they may limit themselves in promoting the health literacy of their patients because the problem may appear to be beyond their capacity to act. However, Schillinger (15) does not elaborate on this claim, and instead, focuses on the issue of ineffective communication and how this might influence health outcomes. Schillinger (15) also discusses how health care systems and clinical trials can act to improve health outcomes when included in strategies to improve communication. However, the article does not provide any further insight into issues of morality concerning health literacy. It only provides examples relevant to principles of social justice and autonomy.

Trachtman (16) criticises Volandes and Paasche-Orlow (12) for concentrating primarily on the socioeconomically deprived when addressing groups with limited health literacy, a view that is also

shared by Banja (14). Trachtman (16) claims that all patients experience shortcomings in health literacy, arguing that the ongoing “medicalization of contemporary life” (p. 27) increases the number of options for diagnosis and treatment. An effect that requires patients to perform increasingly more comprehensive evaluations of health information. As patients frequently lack general knowledge of the biosciences they are not always able to manage their own health, which in turn leads to a loss of autonomy.

Gazmararian et al. (18) points out that health information is only useful if the intended audience is capable of accessing it, and understanding it. Gazmararian and colleagues (18) provide a broad and comprehensive definition of health literacy, where they introduce the concept of functional health literacy. They elaborate on a set of steps which act at multiple levels to improve health literacy amongst the population, and ultimately, achieve a public health literate society. These steps demand the following action: to define and measure levels of health literacy, to evaluate communication techniques (especially those of physicians), to be aware of other influential factors on behaviour change, and to encourage collaboration between all stakeholders. Gazmararian et al. (18) actually anticipate most of the problems raised by Volandes and Paashe-Orlow (12), Goldberg (13), Banja (14), Schillinger (15) and Trachtman. They argue that closing the gap in health literacy provides advantages for the groups at highest risk and will also benefit the population as a whole. Whilst they state that this will improve overall health, they also argue that the underlying problem must be addressed instead of just ‘treating the symptoms’ of limited health literacy. The main shortcoming of the article was that it focussed on the “ethical responsibility to clearly communicate information that affects the public” (p. 319) (18) rather than discussing in detail which ethical challenges might arise from issues of health literacy.

Marks (17) primarily focuses on the role of health educators in bridging the gap between limited health literacy (and other cross-cultural factors) and the negative impact this can have on health outcomes. He provides a detailed description of the different aspects of health literacy, outlines the key problems that arise from it, and identifies the most likely social

groups to have limited health literacy. However, whilst the problems identified may be relevant to ethical principles, these principles are not discussed in the article. For example, Marks (17) describes issues of limited health literacy and how they may result in impaired decision making, diminished ability to critically reflect on situations, and reduced self-management. These issues are all relevant to the principle of respect for autonomy, however, this is never discussed within the article. He also refers to peoples’ dignity, which is diminished if health literacy remains unrecognised, or if the delivery of health messages (particularly to diverse groups) does not ensure equity. Though the article states that it discusses the ethics of patient education, a profound ethical discussion linked to any ethical theory is missing.

Pirsi (19) summarises the findings of health literacy research concerning the physician’s role, access of care and the influence of limited health literacy on health outcomes. She also discusses how other factors relate to health literacy, such as cultural, language and age related factors. Pirsi (19) argues that it is the responsibility of physicians to communicate medical information in a way that is understandable to patients. However, as identified by Goldberg (13) no discussion is made of the underlying causes of health literacy, therefore, the strategy may only address the surface of the problem.

Wilson (20) elaborates on the association between health literacy and health outcome, summarising the results of previous studies addressing this association. Many of these factors are linked to the ethical principles applied in this paper. She also proposes reasons for the limited health literacy of certain risk groups. However, this article also focuses primary on the physician’s role.

Sass (21) argues in favour of changing the current organisation of health care systems worldwide. He critically assesses the current systems, especially those of Germany and the United States, for being based only on the principle of solidarity. He argues that health care systems should instead be built upon a combination of new principles namely “education, solidarity and responsibility” (p. 563) (21). In any system based on these principles, Sass (21) stresses that health literacy will have significant value. He suggests that health literacy will enable patients to make autonomous decisions concerning their health,

and therefore, encourage them to act in an educated and responsible way for their own benefit and for the benefit of their community (solidarity). Sass (21) also emphasizes the responsibility of governments to change current health care systems so that they are able to function more efficiently and encourage educated patients to take greater responsibility of their own health care. He further accuses the current healthcare systems of not recognising the individual's right to decide on their own care and argues that health systems should instead promote self-determination in patients. However, contrary to Sass's (21) opinion, the problem of health literacy may lie elsewhere. In recent years, patients have actually received (and taken) more opportunities for decision making regarding their own health care. The problem however, is that many patients are still unable to make such decisions due to their limited health literacy.

Limitations of the theoretical framework.

Only articles published in English, German, Danish, Norwegian and Swedish could be considered. While using the framework to analyse the sampled literature it became clear that some issues could be allocated to more than one ethical principle. For example, limited health literacy leading to poorer health outcomes is connected to the principles of non-maleficence, health maximisation, and the principle of social justice (people with higher health literacy levels often experience better health outcomes which is an injustice). It is also clear that by applying the proposed ethical framework of the seven principles, the attention was drawn to specific dimensions of moral issues within health literacy that might have resulted in the neglect of other ethical issues that are still relevant to the topic. Furthermore, only articles that explicitly discussed ethical issues were considered. Other ethically relevant issues that were implicit may have inadvertently been omitted. Finally, some of the aspects of health literacy that were ethically evaluated in the sampled literature were often built upon assumptions made by the authors, and were not evidence based. For example, some authors assumed that health care systems may become more efficient when the health literacy of the population was improved (6). Therefore, one should remain critical of some of the aspects that are discussed.

Conclusions

This paper has provided an overview of ethical concerns currently discussed in the area of health literacy. The ethical scope was developed on a framework based upon seven principles combining both biomedical ethics and public health ethics: beneficence, non-maleficence, respect for autonomy, health maximisation, efficiency, social justice and proportionality. In accordance with the theoretical framework, a critical literature review provided eleven articles explicitly concerning both health literacy and ethical issues. Respect for autonomy and social justice were the principles most widely discussed however, some issues that were identified could not be allocated to just one ethical principle. This illustrates that the separations of principles or domains of public health and biomedical cannot be considered as rigidly set. This is especially true if one would separate the biomedical or clinical world (of patients) too rigidly from the world of public (population) health. Rather, the division of these domains within the context of health literacy, which appears to be relevant to all fields of health, requires a holistic discussion and should therefore not be too strict.

The results of this critical review of ethical issues emerging from the health literacy literature calls for action in several key areas. First, there is a need to improve health literacy in order to overcome or change current disease and mortality patterns that are associated with limited health literacy. Second, health professionals must adapt their role to meet the health literacy needs of patients and their communities. The physician must develop the skills needed for overcoming limited health literacy and take greater responsibility for promoting health literacy in their patients and their communities. Third, patients should be encouraged to take a more active role in shared decision-making, self-management and self-determination in order to improve personal health literacy. Fourth, there is a need to change the unjust design of health systems to account for health literacy and avoid compromising basic rights to health.

The ethical scope of this paper serves as a starting point for decision makers that wish to stimulate action to improve public health literacy in response to the moral obligation, and growing political

relevance, of this issue. The findings of this review support the argument that health system change must be induced to overcome barriers of health literacy. Such change will secure basic rights, promote transparency and deliver autonomy in providing more just health care to the benefit of all.

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