

THE EFFECTS OF LIMITED LITERACY IN THE HEALTHCARE
CONTEXT

BY

MARGARET VANSCHAAYK

A Thesis Submitted to the Graduate Faculty of
WAKE FOREST UNIVERSITY GRADUATE SCHOOL OF ARTS AND SCIENCES
in Partial Fulfillment of the Requirements

for the Degree of

MASTER OF ARTS

Bioethics

May 2018

Winston-Salem, North Carolina

Approved By:

Ana Iltis, PhD, Advisor

Nancy M.P. King, JD, Chair

Mollie Rose Canzona, PhD

TABLE OF CONTENTS

	Abstract	iii
	Introduction	iv
Chapter One	Literacy in the Healthcare Context	1
Chapter Two	Respecting Patient Autonomy and Preventing Exploitation of a Vulnerable Research Population	10
	Requirements of Valid Informed Consent	11
	Low Health Literacy as a Barrier to Understanding	15
	Low Health Literacy as a Barrier to Voluntariness	23
	Low Health Literacy as a Contributor to Negative Outcomes	28
Chapter Three	Intersectionality of Health Determinants: Contributions to Health Disparities	32
Chapter Four	Current Status of Literacy in the Healthcare Context: Opportunities and Barriers	40
	Digitization of Communication Methods	40
	Web-based Dissemination of Health Information	45
	Responsible Parties and Agents of Change	48
	References	53
	Curriculum Vitae	60

ABSTRACT

Within the health care context, patients' literacy abilities affect their involvement in informed consent, adherence to prescribed treatment, and health-seeking behaviors. Unaddressed inadequacies in health literacy limit the abilities of patients and potential research participants to provide valid informed consent. Clinicians and research investigators have a moral duty to recognize and attend to differences in literacy abilities in their patient and participant populations so that they can uphold a high standard of valid informed consent. The causes and consequences of poor population health literacy exist within the context of various other social determinants of health including education, gender, race and ethnicity, and country of origin. Addressing disparities in health literacy may involve advocating more broadly for marginalized groups and physician recognition of intersectional aspects of health literacy. As digital and mobile technologies become more integrated into the delivery of health information, there are new opportunities for use of multimedia to increase patient understanding and internet dissemination of health information to reach broader audiences. At the same time, innovative changes in the dissemination of health information may lead to the exclusion of groups who lack access to newer technologies or have inadequate digital literacy skills, widening health disparities as a result of health literacy.

Introduction

The way that clinicians, researchers, and policy makers view health literacy plays a role in how various ethical foundations, like patient autonomy and health care justice, are upheld or undermined. Educational reform, gender equality, access to the internet, and many other social determinants reflect at least in some respects on population health literacy. This thesis explores the interconnectedness of health literacy with ethical obligations in health care and biomedical research, the benefits of recognizing health literacy as a distinct determinant of health, and how the term has changed over time.

In Chapter 1, I discuss how the empirical inquiry and conceptualization of literacy has evolved over time to meet the changing requirements of success in society. As the skill set necessary for functional literacy has broadened, specific attention has been given to the effect that literacy or illiteracy has on the health care context. The term “health literacy” has emerged in the literature to refer to literacy skills specifically necessary in the health care context, including abilities to understand test results and working knowledge of bodily functioning enough to describe symptoms or understand physician instructions.

I go on to discuss the foundations of informed consent and the role it plays in ethical delivery of health care and enrollment in medical research. The remainder of Chapter 2 focuses on the requirements of informed consent and how poor health literacy limits the ability of patients and research participants to give valid informed consent.

Chapter 3 explores both the causes and consequences of literacy and health literacy limitations in the health care context by considering the intersection of social problems such as poverty, lack of access to health care, and gender disparities.

In Chapter 4, I focus on the current state of literacy limitations in the healthcare context in relation to the integration of new technologies and the increasing influence of computers and internet use. I discuss the ways in which various stakeholders in the health care and political sectors may intervene to promote increased health literacy while also minimizing the negative health consequences associated with low health literacy.

Chapter 1: Literacy in the Healthcare Context

Literacy has been established as a key for advancement, innovation, and prosperity among nations. It is integral to the dissemination of knowledge, culture, and understanding both between and among societies. However, despite the recognized value of literacy, poor literacy skills are not uncommon, even in developed countries. The United Nations reported that 7% to 47% of the population of developed countries lacks basic functional literacy skills (United Nations Development Programme, 2007). Individuals with below basic functional literacy skills are significantly less likely to be employed or to earn over \$500 a week when fully employed, less likely to vote, and less likely to obtain information about current events, public affairs, and the government (Bodie & Dutta, 2008), further distancing them from being able to contribute to the policies that affect themselves, their families, and their communities. The prevalence of limited literacy among the population hinders goals for advancement and exacerbates existing disparities.

Although literacy is commonly understood as simply the ability to read and write, Section Three of the United States Congress National Literacy Act defines literacy as “an individual’s ability to read, write, and speak in English, and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one’s goals, and develop one’s knowledge and potential” (102nd Congress of the United States of America, 1991). The idea that

literacy must be functional for its possessor and that it relates to the environment in which the possessor lives, works, and learns, is relatively new.

Several other refinements of what being literate means or requires have been proposed. Functional literacy may be understood as having knowledge and skills in reading, writing, and counting that enable engagement in all activities of daily life that are standard to that culture or group (Levine, 1982). However, other definitions vary on the importance of numeracy skills, social and cultural contexts, and the extent to which the information consumed must be understood and applied in order to constitute literacy.

While many institutions and organizations continue to evaluate and measure literacy based on skills of reading and writing, the kind of literacy that allows populations to advance, prosper, and work toward nationwide goals seems to require much more of its citizens than reading and writing skills. It probably requires citizens to understand and appreciate the messages presented to them. Furthermore, it seems impossible to separate reading and writing from skills related to information processing that involve numeracy, analytical skills, and sociocultural context cues, especially as the avenues for communicating to the public sector continue to increase. The internet, explosive growth of the smart phone, and the digitization of communicating methods means that the abilities necessary to effectively consume and utilize available information are becoming more complicated and simultaneously more important for individuals' success.

Various subtypes of literacy make up people's overall ability to function in their everyday lives. Forms of financial, political, media, visual, and news literacies specific to societies allow people to operate and engage in the ways that are required for their success and survival. When someone is tasked with budgeting their income, establishing a bank account, paying taxes, or purchasing the goods and services that they need, a substantial amount of financial literacy is required to understand and effectively manage the complexities. Especially in the current political and media environment, there is an increasing need to be a critical consumer of news media presented on television, in print, and on the internet. The types of literacy and levels of proficiency required 20 and 50 years ago are vastly different from what is required now. Consequently, standardizing the evaluation of literacy is becoming increasingly complex (Bodie & Dutta, 2008).

Today, many people who would be considered literate struggle to understand information that they are expected to be able to understand and apply as part of their daily lives. One example is filing taxes. Although every American is expected to have the ability to understand the process by which they are expected to file their taxes, many struggle with this procedure. Similarly, patients receiving medical treatment or participating in biomedical research are presented with health information upon which they are expected to be able to formulate decisions that reflect their goals and values, yet many report difficulties understanding (R. E. Rudd, Moeykens, & Colton, 1999)

Empirical inquiry into the role that literacy plays in the delivery of healthcare began over the past 20-30 years (Raynor, 2012) and the existence of a health-specific literacy subtype has slowly been acknowledged by numerous national and international health organizations. The World Health Organization (WHO) defined health literacy as “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health” (World Health Organization, 2014). The cognitive and social skills that this definition references require cultural knowledge of social norms as well as communication skills to both articulate understanding, thoughts, and feelings, and make decisions about accordant behavior.

The remainder of this definition focuses on individuals’ motivation to seek out information and apply it to themselves, an idea that is echoed in the US Department of Health and Human Services’ Healthy People 2010 report where health literacy is defined as “the capacity to obtain, interpret, and understand basic health information and services and the competence to use such information and services to improve health” (Department of Health and Human Services, 2000, Vol. 1). Also outlined in this report are 3 key abilities necessary for adequate health literacy.

The first is the ability to obtain relevant health information (Department of Health and Human Services, 2000). Barriers to obtaining health information include lack of access to health care, either geographically, due to lack of

insurance or ability to pay, or other logistical circumstances. Evidence shows that Americans are obtaining and acting on an increasing amount of health information that they find online, with more than 63% of regular internet users having sought health information online for personal use (Cline & Haynes, 2001). Without stable access to the internet, many people are unable to as readily obtain health information they may be looking for.

Second is the ability to understand the health information that he/she has been motivated and able to obtain (Department of Health and Human Services, 2000). This ability tends to be more commonly recognized when discussing the meanings and applications of health literacy. For example, this involves being able to read and understand the content of pamphlets provided by doctors or nurses on conditions or treatments, being able to interpret the information provided on food labels and understanding how to comply with a doctor's prescribed orders.

Finally, adequate health literacy requires that individuals have confidence and competence in utilizing the health information they have obtained and understood (Department of Health and Human Services, 2000). This involves applying it to their own lives if it is applicable, possibly altering their behaviors, or asking questions of their doctors, nurses, or health information providers about the information they have received. This final necessary ability for adequate health literacy insures that the capabilities they have are able to have an impact on their health.

A variety of studies have examined health literacy and its effects on health. Patient interviews after meeting with their physicians have allowed researchers to compare what the patient understood about his or her condition, treatment options, and/or recommendations with what the patient's doctor intended to communicate during the discussion. Several studies have exhibited profound discrepancies between each parties' understanding of the interaction and information exchange (Williams et al., 1995)(Flory & Emanuel, 2004).

For example, one study demonstrated that 41.6% of patients presenting for acute care at two urban public hospitals were unable to comprehend the instruction to take medication on an empty stomach, 26% were unable to understand some amount of information involved with scheduling a follow-up appointment, and 60% did not understand a standard informed consent for treatment document. Among this data, individuals 65 and older experienced inadequate health literacy at a rate of 81.3% and those whose first language was Spanish experienced inadequate health literacy at a rate of 82.6% (Williams et al., 1995).

Another study examined health literacy limitations in a medical research context. After providing informed consent for participation in an oncology clinical trial, participant interviews revealed that 30% were under the impression that the treatment being studied had already been proven as the best treatment

for their condition. Forty-four percent did not understand that it was possible that they could receive a placebo drug (Flory & Emanuel, 2004).

Informed consent is a cornerstone value of clinical and research ethics. Various avenues have been explored for increasing the understanding of participants to ensure that the consent they provide is truly informed. Balancing the requirement that participants understand and articulate a decision about participation in research with the potentiality for unfair exclusion of individuals with low health literacy from potentially beneficial research due to their inability to give valid informed consent is difficult in research ethics and requires ongoing inquiry.

Low health literacy among a substantial portion of the population remains a pressing issue in the United States today. Across the nation, and especially across the world, there are enormous discrepancies in the quality of healthcare provided to citizens, and health literacy may be a contributing factor to these disparities (R. Rudd, Kirsch, & Yamamoto, 2004).

Several studies have demonstrated correlations between health literacy and the amount and quality of health care received. For example, a cross-sectional study of patients presenting to emergency care centers at several large public hospitals found that individuals with inadequate health literacy were more likely than those with adequate health literacy to be admitted to the hospital for medical treatment (Baker, 1998). However, those with inadequate health literacy

were less likely to use screening or preventative medical services in the outpatient setting (Davis, 1996).

Similarly, as health literacy increases within a population, utilization of services like pap smears, mammograms, and HIV/AIDS screenings increase, as well as knowledge of health risks associated with smoking and unprotected sex (DeWalt Darren A., Berkman Nancy D., Sheridan Stacey, Lohr Kathleen N., & Pignone Michael P., 2004). Individuals with below basic health literacy are more likely to experience poorer physician-patient communication, participation in unhealthy behaviors, reduced treatment adherence, increased risk for disease, are more likely to place a greater strain on the nation's healthcare expenditures (R. E. Rudd et al., 1999).

Not only do patients with greater health literacy receive more health care, but they also have more positive health outcomes (R. E. Rudd et al., 1999)(Raynor, 2012). Individuals with below basic health literacy have increased mortality rates compared to those who are considered to have adequate health literacy, especially from preventable illness (Raynor, 2012). Disease rates are highest among groups of low socioeconomic status and minorities, which are highly correlated with below basic health literacy (World Health Organization & United Nations Development Program, 2016).

Traditional health information campaigns tend to increase gaps in health literacy by providing information-heavy messages on media formats that are

disproportionately accessed by individuals who already have adequate health literacy. The “digital divide” widens health literacy disparities between groups who have convenient access to the internet and those who do not (Eng et al., 1998). Gaps in health literacy, as well as healthcare quality, continue to widen, even among younger demographics (Perie, Moran, & Lutkus, 2005).

Inadequate health literacy arises from multi-sectoral circumstances that fail to provide individuals with the knowledge and skills necessary to engage the health care system in the ways that it requires. Therefore, policies aimed at improving health literacy among the population must address the multi-sectoral causes, such as education, internet access, environmental determinants of health, and access to preventative health care. Continued research into improving the informed consent process and the efficacy and scope of health education will also contribute to ameliorating the effects of low literacy, or specifically low health literacy, in the health care context.

Chapter 2: Respecting Patient Autonomy in the Clinical Setting and Preventing Exploitation of a Vulnerable Research Population

In the early 20th century, when laws governing medical practice were first enacted, physicians were required to obtain consent from their patients before performing medical procedures. It was not until 1957 that physicians were legally obligated to obtain *informed* consent (*Salgo v. Leland Stanford*, 154 Cal. App. 2d 560, 1957). Today, although informed consent is a commonly accepted cornerstone value for providing ethical health care, providers struggle to determine what is required for valid informed consent.

As an uncompromising legal and moral requirement in the practice of health care (in non-exceptional circumstances), informed consent aims to protect patient autonomy and respect persons, combatting undue paternalism from health care providers, promoting patient satisfaction and well-being in the long run, and protecting potentially vulnerable populations from exploitation in medical research. Because presumably patients know their own goals and values better than anyone else, being able to coordinate their medical care or research participation decisions with these ideals is likely to result in maximum satisfaction. The President's Commission for Bioethics confirmed that "adults are entitled to accept or reject health care interventions on the basis of their own personal values and in furtherance of their own personal goals" (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1982, *Making Health Care Choices*, p 2-3). This idea is the

foundation for promoting patient autonomy and informed consent is the pathway through which autonomy is achieved.

Autonomy and informed consent have significant moral importance because of the nature of the medical field and the role that physicians play in the lives of their patients. Because of the nature of illness, patients are forced to place a higher degree of trust in their health care providers than in their accountants, mechanics, or other service providers, as it may be the case that their lives closely and directly depend on the interactions they have their health care providers. In many instances, patients are involuntarily highly dependent and vulnerable at the time that they are interacting with their physicians (Pellegrino, 1993). These unique situational circumstances may make patients more likely to accept care options that they do not want or do not understand and may make physicians less diligent in upholding a high standard for valid informed consent.

Requirements of Valid Informed Consent

Despite the case- and context-specific nature of informed consent, there are several aspects that stand out as consistently necessary for valid informed consent. First and foremost, the patient must have decision-making capacity, which is comprised of the ability to understand the information regarding the treatment decision, appreciate the significance of that information as relevant to themselves, reason logically among the treatment options based on their own preferences and values, and express their choice (Moskop, 2016, Chapter 8).

Decision-making capacity is typically considered to be task-, time-, and risk- specific. This means that patients may be deemed to have capacity to make some less complex decisions, but not more complicated ones, may have capacity at some moments in time but not others, and may be able to make low risk decisions, but not decisions associated with high risk potential outcomes. In all cases, the judgement of capacity is a threshold judgment in which patients either have capacity or do not have capacity, but physicians should refrain from regarding patients' decisions as coming from a place of partial or incomplete capacity (Moskop, 2016, Chapter 8).

The second necessary element of informed consent is the disclosure of relevant information. In this clinical context, this generally includes information about the patient's condition and expected consequences without treatment, reasonable or standard treatment alternatives, significant expected benefits or harm of treatment alternatives, and usually a treatment recommendation from the physician (Moskop, 2016, Chapter 8).

Compared to clinical informed consent, informed consent for research has many guiding ethical codes that provide recommendations of what relevant information investigators should disclose to potential participants. The Common Rule provides guidelines by which Institutional Review Boards (IRBs) should operate and ethical standards of informed consent that they should enforce (Department of Health and Human Services, 2010, 45 CFR § 46). It recommends

that any research involving human participants be subjected to IRB review and approval. This becomes a requirement for institutions or projects that receive any kind of federal funding (Department of Health and Human Services, 2010, 45 CFR § 46.122).

The “Common Rule,” was influenced by several ethical codes for human subjects research ethics that came previously, including the Belmont Report which was published by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research in 1979 (Department of Health, Education, and Welfare, 1979) and the Nuremberg Code, which was a response to widespread exploitation and abuse of human subjects during World War II (Fischer, 2006). Each of these codes articulates to some extent what information should be disclosed by investigators during informed consent for human subjects’ research.

According to the Nuremberg Code, investigators should make known the “nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonably to be expected; and the effects upon his health or person, which may possibly come from his participation in the experiment” (U.S. Government Printing Office, 1949). The Belmont Report suggests that investigators disclose “the research procedure, their purposes, risks and anticipated benefits, alternative procedures (where therapy is involved), and a statement offering the subject the opportunity to ask questions and to withdraw at any time from the research” as well as

possibly “how subjects are selected, the person responsible for the research, etc.” (Department of Health, Education, and Welfare, 1979, Part C).

Finally, once the information has been disclosed in a way that the patient or potential participant can understand and appreciate, their informed decision must be made and expressed. While there are permissible influences upon patients’ decision-making, for example, a clinician is not barred from expressing why he or she believes the recommended treatment is the option best suited for the patient, this kind of influence should be portrayed based on reason, without duress, unwelcome persistence, or any kind of capitalization upon limitations in the patient’s ability to fully understand the content presented (Quill, 1996). Outside of expressing a recommendation for a certain treatment plan, clinicians should not frame or withhold information selectively to elicit a certain decision from the patient (Moskop, 2016, Chapter 8).

Low Health Literacy as a Barrier to Understanding

The three key abilities for adequate health literacy expressed in the Healthy People 2010 report were the ability to obtain, to understand, and to apply health information (Center for Disease Control and Prevention, 2000, Healthy People 2010, Introduction). These closely match the elements of decision-making capacity. By comparing these accounts of decision-making capacity and health literacy abilities, it is reasonable to conclude that if people do not have adequate health literacy, they may also lack decision-making capacity.

This makes poor health literacy a clear and significant barrier to valid informed consent.

The Common Rule states that “the information that is given to the subject or the representative shall be in language understandable to the subject or the representative” (Department of Health and Human Services, 2010, 45 CFR 46.116). By stating that the information should be provided in language understandable to the subject implies that investigator should not base their information delivery on a reasonable person standard or a judgement of what a colleague in their position would do, but rather they should base their language on what the subject understands.

Of course, for a patient to make an informed decision, they do not need to understand every peripheral detail of their condition and treatment options in the way that their physician does. However, deciding how well information must be understood for an informed decision seems to depend on the nature of the information, the circumstances of the patient’s condition, and the patient’s motivation to consume medical information about his or her condition. This makes conceptualizing and defining the conditions of understanding for valid informed consent particularly difficult to carry out in a medical setting and even more difficult to standardize or enforce.

Misunderstanding or lack of appreciation of health information may be particularly influential in the medical research setting as a result of the

therapeutic misconception or the common failure of potential research participants to appreciate the difference between medical treatment and medical research (Appelbaum & Lidz, 2002). The therapeutic misconception is “the belief that the purpose of a clinical trial is to benefit the individual patient rather than to gather data for the purpose of contributing to scientific knowledge” (National Bioethics Advisory Commission, 2001, *Ethical and Policy Issues in International Research: Clinical Trials in Developing Countries*, p 48). The tendency of potential research participants to overestimate the extent to which the intervention being studied will directly benefit them is a common misunderstanding that may influence their decision to be involved in medical research.

The therapeutic misconception has been recognized and studied since the early 1980s (Appelbaum, Roth, & Lidz, 1982). Consequently, many investigators today are conscious of the role it may play in potential participants’ informed consent and take steps to help potential participants better understand the nature of the study, including the reality that the intervention may or may not have any effect their condition. Despite the development of strategies to overcome the effects of the therapeutic misconception on informed consent (Lidz & Appelbaum, 2002), a study showed that 30% of participants involved in an oncology clinical trial were under the impression that the treatment being studied had already been proven to be the best treatment for their condition (Flory & Emanuel, 2004). This relatively common misunderstanding could substantially

influence potential participants' willingness to consent to research without appreciating accurate costs and benefits.

Although medical research and medical treatment are fundamentally different, limitations in health literacy can have similar consequences in each setting. Patients or research participants with low literacy, or low health literacy specifically, may be more likely to consent to treatments when they do not have an accurate or complete understanding and appreciation of the risks or potential benefits.

Although the ability to understand and reason are noted as important factors for having capacity to provide informed consent (Department of Health and Human Services, 2010, 45 CFR § 46.116), some may object to directly testing patients' understanding through cognitive or comprehension tests. These objections may be based on the stigma and shame associated with low literacy (Parikh et al., 1996) and the desire to avoid deterring low literacy populations from seeking health care because they fear having their low literacy exposed. Some potential patients or research participants may have been unable to attain the level of education necessary to understand the complex information that their doctor provides related to their condition, but obviously this should not mean that they are ineligible for treatment or that the decision must certainly be the authority of a third-party decision-maker or that they are ineligible for medical research. Instead, clinicians and investigators should be watchful for low health literacy in their patient or participant populations and be particularly cognizant

of the individual educational needs of those who appear to have literacy limitations.

Barriers to understanding throughout the informed consent process can arise from a variety of conditions, such as education level, framing, and the future oriented nature of informed consent. In patient-provider interactions, physicians may not accurately match the level of their explanation to the education level of the patient, which could lead to limited understanding. Patients may also be unable to fully grasp the information as a result of being given too much information in a short period of time, being overwhelmed by the unexpected or complicated nature of the information or feeling rushed by the process (Cooper & Roter, 2003). While some barriers to understanding have closer ties to literacy and others appear more situational, overcoming such barriers is important for informed consent.

In the research setting, although it may seem safest to employ a blanket exclusion against involving research subjects whose questionable knowledge or comprehension is questionable, this approach presents its own ethical concerns. This would prohibit those with insufficient knowledge as a result of lack of education or access to information, from being involved in research that could be potentially beneficial to them. Such research may be directly medically beneficial to the potential participant or may contribute to the creation of generalizable knowledge which may be beneficial to them as a means of upholding their goals and values. Furthermore, systematically limiting the access that one group has to

participate in society because of situational factors like education or poverty presents a form of institutional injustice (Landfield, 2018).

In some instances, physicians may readily notice in their conversations with patients that there is a lack of appreciation of the information they are providing. However, depending on communication techniques used or situational circumstances, low literacy may not always be obvious to providers. A study conducted at a large public hospital found that the most commonly used coping mechanism for patients with low literacy was to pretend to read health documentation when a provider was present. Despite their measurable lack of understanding of the information provided, those with low literacy were less likely to bring a spouse, child, or other person to their appointments for support or assistance in reading documentation. They were also less likely to ask their providers for assistance or clarification when compared to individuals with adequate health literacy (Parikh, Parker, Nurss, Baker, & Williams, 1996). These results demonstrate the concealed nature of health literacy limitations among patient populations and therefore the importance of physicians to assume an active, rather than passive, role in confirming patient understanding of provided information. This may mean asking patients to explain in their own words their understanding of the treatment, rather than simply asking if they understand and accepting affirmation (Peter et al., 2015; Hahn, 2009).

Evaluating patient or potential participant literacy or health literacy may be a way to recognize and thus be able to better address specific limitations in these areas. Evaluations of literacy have been used for many years outside of the healthcare setting to gather data and characterize education disparities (Murnane, Sawhill, & Snow, 2012). More recently, evaluation methods for literacy skills specific to health have been developed (Chew et al., 2008). Despite the existence of questionnaires for health literacy evaluation, these are not commonly used in the informed consent process in clinical or research settings (Louis, Arora, Matthiesen, Meltzer, & Press, 2017).

Alternatively, whether explicitly or as part of a broader patient evaluation, providers commonly assess decision-making capacity when patients are making medical decisions. Various scales and evaluation methods have been developed and are widely used to do so, including the Folstein Mini-Mental State Examination and the MacArthur Competence Assessment Tool-Treatment (Sorrentino, 2014). Although definitions of health literacy and decision-making capacity imply that the two are highly co-dependent, the evaluation methods for each are different. This allows ambiguity in drawing clear distinctions between the two concepts and questions how evaluating decision-making capacity can be done comprehensively without specific attention to literacy evaluation. Incorporating health literacy evaluations into patient care may better prepare clinicians to combat barriers to patient understanding.

Common ways that physicians and investigators are encouraged to overcome these barriers to understanding and manage limitations in health literacy include allocating sufficient time to gather, prepare, and present information to patients (Moskop, 2016, Chapter 8). This may involve using the “teach back” (Peter et al., 2015) or “ask-tell-ask” method (Hahn, 2009), using non-technical language, prioritizing information in order to avoid providing too much information and overwhelming the patient, talking to the patient about broader goals of treatment, and focusing on realistic possibilities (Jackson, 1992)(Moskop, 2016, Chapter 8).

Evidence suggests increased patient comprehension and retention of health information and increased self-management of health conditions with the use of Patient-Centered and Provider-Participatory Decision-making communication styles. These types of communication styles involve using open-ended questions to elicit patient understanding, not interrupting patients, expressing empathy, asking follow-up questions, inviting patients to weigh the pros and cons of treatment options, breaking the information into small “chunks,” and asking for patients to explain of the information in their own words (Hashim, 2017)(Heisler et al., 2002). Focusing on patient-provider communication style when delivering health information may be one way of overcoming health literacy barriers to understanding among patient populations.

Developing techniques for overcoming health literacy barriers to understanding should involve the gathering and use of empirical data. For

example, in the research setting, empirical inquiry into the readability of informed consent forms has been used to guide IRBs to create policies that meet the varying needs of potential participants for adequate comprehension. Despite the availability of data concerning grade-level reading abilities among the population, one study that evaluated the reading levels of IRB-approved informed consent forms found that the majority of samples exceeded the reading level defined by the IRB's standard by 2.8 grade levels. These results indicated that it may be very common for IRBs to approve informed consent forms that do not meet their own defined standards (Paasche-Orlow, Taylor, & Brancati, 2003). This further implies that not only the thoughtful, evidence-based development of policies, but also the evaluation of information provision and enforcement of standards are required for potentially improving participant comprehension and overcoming the barriers created by low health literacy.

Clinicians and investigators have a moral obligation to attempt to ensure adequate understanding when gaining informed consent. Hospitals may contribute to overcoming limitations in health literacy by developing educational programming for patient populations both broadly and disease or condition-specific. Hospital programming can educate clinicians on techniques for overcoming barriers to understanding and hospital policies can clarify standards for valid informed consent and emphasize its importance. In the research setting, the responsibility of promoting an appropriate standard for understanding required for informed consent is delegated to Institutional Review Boards (IRBs), but ultimately the investigator must carry out the informed consent process in a

way that abides by the regulatory intentions (Office of Human Research Protections, n.d., Investigator Responsibilities FAQs).

Low Health Literacy as a Barrier to Voluntariness

Each of the previously-introduced foundational ethical codes for human subject research indicates to some extent that the decisions of research subjects may be susceptible to undue influence from a variety of factors. Many of these codes refer to barriers to voluntariness as creating a condition of vulnerability among certain populations. Along with various other factors, low literacy appears across ethical codes as a condition that may create vulnerability.

A key distinction to make is between vulnerability, or voluntariness barriers, and lacking decision-making capacity. Decision-making capacity refers to patients' and participants' ability to understand relevant information, appreciate the information within the context of their own life, reason, and express a choice (Okonkwo et al., 2007)(Moskop, 2016, Chapter 8). While allowing a participant to express a choice about treatment or participation in research without having capacity would certainly make that participant vulnerable to exploitation, vulnerability can arise among populations with decision-making capacity as well.

The Common Rule guides IRBs to be “particularly cognizant of special problems of research when working with vulnerable populations” especially when

“some or all of the subjects are likely to be vulnerable to coercion or undue influence.” It suggests vulnerable populations are “children, prisoners, pregnant women, or the mentally or physically handicapped” as well as the “economically or educationally disadvantaged” (U.S. Department of Health and Human Services, 2010, 45 CFR § 46.111).

The Council of International Organizations of Medical Sciences (CIOMS) describes vulnerable individuals as “those who are relatively (or absolutely) incapable of protecting their own interests” as a result of “insufficient power, education, resources, strength or other needed attributes” (World Health Organization & Council for International Organizations of Medical Sciences, 2017, p 43). Finally, the National Bioethics Advisory Commission (NBAC) suggests that vulnerability results from two circumstances: those in which individuals have “difficulty providing voluntary, informed consent as a result of limited decision-making capacity” and other “situational circumstances” (National Bioethics Advisory Commission, 2001, Ethical and Policy Issues in Research Involving Human Participants, p 4).

Although less explicit about the impact of low literacy on voluntary informed consent, the Nuremberg Code specifies the requirement of informed consent to mean that any potential research subject “should have sufficient knowledge and comprehension of the elements of the subject matter involved, as to enable him to make an understanding and enlightened decision.” (U.S. Government Printing Office, 1949). Because this code specifies that participant

consent must involve a sufficient level of both knowledge and comprehension as necessary elements of ethical research, those without sufficient knowledge or comprehension cannot be involved in the proposed research or that additional protections must be put in place to protect against exploitation. The Nuremberg Code seems to recognize that people with insufficient knowledge or comprehension may be at increased risk for exploitation in research.

Whether consciously or unconsciously, participants' decisions may be influenced by external factors that supersede their abilities to reason rationally when making a decision. For example, in the clinical setting, a pregnant patient may feel that she has no choice but to accept a medical intervention if it has potential benefit for her unborn child, even if the decision is not one that she would otherwise choose for herself. The influence of an unborn child should not mean that all pregnant patients, as a result of their membership to that group, do not have capacity to provide informed consent. However, providers should be cognizant of how undue influences may affect patients' decisions. Although they can still reason and retain capacity, they may be subject to an influence that places them at an increased likelihood to agree to a treatment that they would not without that influence.

From “educationally disadvantaged” (Office for Human Research Protections, 2010, 45 CFR 46.111) to “insufficient... education... or other needed attributes” (World Health Organization & Council for International Organizations of Medical Sciences, 2017, p 22) to “situational circumstances,”

(National Bioethics Advisory Commission, 2001, p 4) all major human subjects research codes in the United States today acknowledge to some extent that low education, a contributor to low health literacy, may interfere with the voluntariness of decisions made by potential research participants.

This focus on low literacy and its contributions to research participant decision-making may be a result of the unfortunate history in the United States of exploitation for the purposes of medical research. From 1932 to 1972, the Tuskegee Syphilis Experiment was conducted on black, mostly illiterate men in the South, a population in which, given their literacy abilities and power status, voluntariness may have been compromised. In this study, 622 men were given the impression that they were receiving free medical treatment for “bad blood” when in reality, investigators were observing the progression of their untreated syphilis. Even after penicillin was confirmed as an effective treatment for Syphilis, the men were left untreated and uninformed of their condition or of the true intent and actions of the investigators (Center for Disease Control and Prevention, 2017).

This historical example demonstrates a capitalization on the illiteracy of a vulnerable population in pursuit of a research goal. While the unethical nature of that study was rather obvious, exploitation of illiteracy could be more veiled in other instances and could be present in studies built upon otherwise ethical foundations, instances which are more likely under present human subject research regulations. For example, because literacy rates are considerably higher

today than previously in history, it is less likely that investigators will be drawing their entire sample from an illiterate population. However, studies of health literacy show that difficulty understanding health information, such as informed consent or prescription instructions, is not uncommon, (Flory & Emanuel, 2004) making it likely that a research sample will include some participants who have limited literacy abilities.

It is important to note the role that framing can play when thinking about patient both patient understanding as well as voluntariness. For providers, phrasing information carefully to ensure understanding is important for conveying a truthful idea of a condition or treatment. Intentionality of phrasing can relatively easily be misunderstood as manipulation of patients' decisions through well-crafted terminologies. For example, using terminology like DNR (Do Not Resuscitate) versus AND (Allow Natural Death) probably changes the way that patients or surrogates perceive and understand the order and its implications (Breault, 2011). In some cases, a provider may judge that one term conveys a more truthful account of the order as it pertains to a patient's situation. Of course, this involves individual providers' judgements of a subjective truth. Making subjective decisions about truth are a part of medical professionalism, but hospital policy makers as well as health care providers should be clear about their use and application of different, potentially charged terminologies and how their use contributes to patient or surrogate understanding of the information involved.

Phrasing and framing affects the ability of patients and surrogates to think about and to use the health information provided. While phrasing and framing of medical conditions or interventions can promote greater understanding among those with low health literacy, the same population may be most susceptible to having their decisions manipulated by phrasing, creating a barrier to voluntariness. Clinicians and investigators should use careful phrasing and framing of health information to convey what they believe to be the most accurate representation of the information in a way that they think will maximize patients' or surrogates' motivation to consume the information and their understanding of it. Phrasing and framing should not be used to coerce or to elicit certain decisions from patients or surrogates. For example, providers may feel pressure from hospital administrators to gain a DNR order for a patient whose treatment is costly and not covered by insurance. Providers may also feel a desire to minimize contact with unpleasant patients or family members. Investigators may be highly motivated to enroll enough participants to reach their necessary sample size. While these extrinsic motivations for providers are often unavoidable, they should not inform clinicians' or investigators' decisions about phrasing and framing of information.

Low Health Literacy as a Contributor to Negative Health Outcomes

The extent to which a patient must understand medical information for decision-making or behavior change purposes varies based on several case-specific factors. Some medical interventions may involve complex follow-up care

that requires the precise understanding and strict adherence of the patient. For example, many weight loss surgeries require patients to make substantial lifestyle changes in order to avoid potentially serious post-surgical complications (American Society for Metabolic and Bariatric Surgery, n.d.). If the patient is unsure about their ability to make necessary behavior changes, performing the surgery could be detrimental to their health. Participation in research may rely similarly on strict adherence to prescribed behaviors for the safety of the participant as well as the validity of the study. In each of these contexts, ensuring understanding of the necessary information during the informed consent process is an integral part of achieving the intended outcome of the clinical intervention or research goal. While failures of adherence may be due to more than just poor quality of informed consent, valid informed consent is important for promoting adherence (Patel, Moore, Craver, & Feldman, 2016).

If physicians do not ensure patients' understanding of the intervention to which they are consenting, patients may not grasp the follow-up care that will be required of them, and in the case of many procedures major or minor, this could be medically detrimental, as well as contra to the patient's goals and preferences. Not taking the necessary steps to overcome limitations to patients' understanding risks both negative health consequences and diminished patient satisfaction and trust in healthcare providers.

Beyond the direct medical consequences that may result from failing to overcome limitations in health literacy, health care providers and investigators

have a professional moral duty to promote patient and participant autonomy by overcoming barriers to understanding and voluntariness. A primary duty of providers is to encourage and equip patients to make decisions that uphold their autonomy, allowing decisions to be made based on the patients' goals and preferences. While simply stating the required information and checking the necessary boxes may keep a provider from legal trouble, not ensuring understanding of the information disregards the ideals that the laws were intended to uphold.

Physicians may commonly experience uncertainty about how well patients comprehend the content they are explaining. Furthermore, the physicians' efforts to obtain informed consent in practice may be accompanied by the constantly ringing pagers, pressure from superiors, and the sense that it makes little difference whether a patient really understands what the procedure entails. Realistically, the average patient will probably receive the treatment needed regardless of whether he understands what is going on or not. Although in some cases, the lack of informed consent may not have foreseeable medical consequences, informed consent is integral not only for adherence with ongoing treatment and surveillance, but for respect for autonomy and patient dignity.

In the end, informed consent is an important factor in promoting patient autonomy and upholding professional moral duties to encourage patients and potential research participants to make decisions that reflect their goals and preferences. This necessarily includes attention to patients' and participants'

understanding of information as well as its implications which may often mean taking steps to overcome limitations in health literacy because poor health literacy limits patients' abilities to give valid informed consent.

Chapter 3: Intersectionality of Health Determinants: Contributions to Health Disparities

Education level, income, country of origin, age, and race and ethnicity have been correlated with health literacy (R. Rudd et al., 2004). The structural inequities that disadvantage individuals in other aspects of society, may contribute to poor health literacy which may contribute to cycles of injustice.

When compared to whites, racial and ethnic minorities are less likely to have stable access to health care and are more like to experience greater burden of disease, including economic burden and the development of morbidities and death (National Center for Health Statistics (US), 2016). These population-level health disparities are largely attributable to chronic preventable diseases such as heart disease, type 2 diabetes, obesity, and some types of cancer (Center for Disease Control and Prevention, 2004). Because these conditions are preventable to some degree, with adequate knowledge, understanding, and access to necessary resources, these conditions could be avoided. Shortcomings in knowledge and understanding of health information, or poor health literacy, could intersect with various other structural factors and increase certain persons' likelihood of experiencing poor health.

Distribution of health is commonly accepted to be a complex social problem (Sørensen et al., 2012). Given a view of health literacy that accounts for motivation, accessibility, understanding, and application of health information, many common reasons for adverse health that disproportionately affect

marginalized groups may be better understood. For example, because racial and ethnic minorities are more likely to experience poverty (Siordia, 2015) and those in poverty are less likely to have stable access to health care (National Center for Health Statistics (US), 2016), racial and ethnic minorities are at a greater risk of experiencing poor health because of inadequate access to health care, which serves as one source of health information. While health literacy is one factor that contributes to health inequities, there are certainly many social determinants of health.

Health may be understood as both a necessary element for social advancement and a manifestation of social status. In other words, social location is reinforced by health status. People with better health may be more able to pursue employment. Because individuals of low socioeconomic status may be more likely to rely on jobs that require physical labor, health problems affect their employment opportunities more drastically than those who have white collar or office jobs available to them. Increased opportunity for employment increases the possibility of income, and in some cases, employment may provide access to health care coverage. This may mean that those who can maintain employment are in a better position to maintain their health (Robert Wood Johnson Foundation, 2013, How Does Employment, Or Unemployment, Affect Health?).

A Policy Brief from the 9th Global Conference of Health Promotion makes the connection between various social problems and health literacy. It illustrates

how poverty, hunger, education, working conditions, economics, and peace are both determinants and manifestations of health literacy. Individuals in poverty or of low socioeconomic status, for example, are less likely to have access to healthcare because of an inability to pay or a lack of steady employment that provides health benefits. They are therefore unable to access the health information that others may receive from their clinicians. Furthermore, those in poverty are less likely to have access to the internet where a large portion of health information is displayed (World Health Organization & United Nations Development Program, 2016, p 2)

Aside from lack of access, individuals living in poverty may be less likely to seek health information because of overriding concerns about finding shelter, employment, or food. Some have argued that health is an affluent concern, as those living in poverty necessarily prioritize more immediately pressing issues. In addition to the extrinsic factors that demand their attention and limited access to health information, understanding and application may also be more difficult for those living in poverty, as they are less likely to have had access to quality education and resources necessary to apply health information to personal behavior change (World Health Organization & United Nations Development Program, 2016, p 2). For example, even with knowledge and understanding of nutrition, those living in poverty may be unable to eat healthy because of the existence of food deserts, lack of access to be able to store or prepare food, or limited funds that encourage purchasing foods that have a maximum calorie per dollar ratio.

Although hunger is often characterized as a problem confined to developing countries, it is very much a complex social problem here in the United States as well. Limitations in health literacy are associated with both malnutrition and over-nutrition which can lead to obesity and other preventable health problems. People may obtain the food they eat from sources that do not provide them with nutrition information such as charitable food donations or soup kitchens, which disrupts their access to nutrition information. In instances where nutrition health information is provided, they may not understand that information as it relates to their health or may be unable to apply it given their resources (World Health Organization & United Nations Development Program, 2016, p 2).

The WHO & UNDP health literacy policy brief also discusses the role that education plays in health literacy development and that health literacy plays in educational development. If individuals have basic health literacy, including understanding of health determinants such as sanitation, sexual transmission of disease, and nutrition, they may be able to stay in school longer and contribute more of their time to education. If students access, understand, and apply health information about nutrition and physical activity, their attentiveness, cognitive function, and information retention may increase (Hardman, Kennedy, Macpherson, Scholey, & Pipingas, 2016).

Furthermore, increases in health literacy specifically pertaining to sexual behavior may help to close the educational gender gap, as women are more likely to absorb the effects of substandard reproductive health education than are men. The side effects of pregnancy, the time or financial sacrifice required for child care, and any post-partum complications primarily affect women, so unplanned pregnancy can significantly hinder their ability to participate in their education. In the United States, an unmarried new mother is automatically awarded sole custody of the child at birth (Community Legal Aid, 2015). This default places the entire responsibility of the child on the mother until paternal assistance can be established, which is often unreliable. If adequate sexual education provides students with adequate health literacy, unplanned pregnancies may be better avoided and females may be able to stay in school longer.

Education contributes to health literacy even when not specific to health. Education contributes basic literacy which better prepares students to build health specific literacy. Engaging students in increasing their own human capital, or their knowledge, skills, and other intangible characteristics that are inseparable from their person that make them better able to succeed in their culture (Becker, 1993), may make them more motivated and confident when seeking information and may encourage them to invest in themselves and consequently in their health and wellness (McDaid, 2016).

Health and health literacy are empowering. Individuals who possess adequate levels of health literacy are more likely to ask their clinicians questions

(Schillinger, Bindman, Wang, Stewart, & Piette, 2004) and hold policy makers accountable for health concerns like prescription drug funding, access to healthcare, or legislation that promotes healthier work environments (McDaid, 2016). Efforts like this help to increase access to health information, which in turn contributes to increasing the health literacy of the public.

Changes in health information delivery and increasing reliance on the internet for the dissemination of health knowledge have allowed health information to reach a larger audience. In reference to information access disparities, the internet has at times been presented as an equalizer (Engelman, 1995) for those who do not have access to healthcare and are not able to obtain information from a clinician. Although it is true that more people have internet access than have healthcare access, trends in internet inaccessibility tend to correlate with low health literacy populations.

This gap is often called the digital divide, which refers to the gap between those who have access to internet technologies and those who do not (Bodie & Dutta, 2008). When compared to white or higher SES individuals, non-white and low SES individuals are less likely to report access to the internet (Campos-Castillo, 2015). Because a substantial portion of health information is accessed on the internet, lacking access to the internet or possessing low digital literacy prevents a person from obtaining health information in this way. Furthermore, without stable access to the internet and therefore limited development of digital

literacy, individuals may be unprepared to appraise or reason critically about health information they access online.

One study reviewed public sentiment and health campaigns pertaining to obesity in Canada. The results showed that in general, obesity is regarded as a complex social and individual problem. However, health campaigns mostly reduced the problem to a lack of information about healthy choices. If solutions disregard the social factors that either discourage or motivate individuals to seek health information and the structural factors that may limit their abilities to understand or apply health information, simply making that information available will only be a small part of a successful campaign (Salas, Forhan, Caulfield, Sharma, & Raine, 2017).

Obesity is one of many health conditions that has been represented as a socially-linked issue but has solutions that aim primarily at changing individual behavior, rather than policies or larger social problems. Individual behavior change campaigns rarely achieve widespread success because they focus on telling people how to behave without focusing on the conditions that restrict the range of behavior choices the individual has available to them. Behavior choice options may be dependent on financial status, logistical obstacles, or understanding and appreciation of information related to the intended behavior change. Recognizing that problems with understanding and appreciation of health information manifest and reinforce social problems, solutions must address health literacy in order to be successful.

Health literacy is correlated with various other conditions such as education level, income, age, and race and ethnicity (R. Rudd et al., 2004). Understanding the interconnectedness of health determinants can aid in the development of solutions that address broad health disparities. Intervening to improve non-health literacy determinants of health in addition to health literacy may lead to more equal opportunity as a result of better health outcomes and less cyclical injustice.

Chapter 4: Barriers and Opportunities for Improving Literacy in the Current Healthcare Context

The types of literacy required in the healthcare setting have evolved significantly in recent years, predominantly because of how the delivery of health care has changed. There has been a slow, but steady shift from clinicians and structured public health campaigns providing the majority of health information to a widespread reliance on web-based technologies for the dissemination of health information (Bodie & Dutta, 2008). Other changes in the delivery of health information include communication with health providers via email, viewing personal health information via an online patient portal or mobile app (mHealth), and the use of tablets or computers to record, access, and evaluate patient health information.

Technological developments have opened new doors for bringing health information to a larger audience and promoting greater understanding among patients. Simultaneously, such changes have excluded those who lack access to newer technologies or lack the skills or confidence necessary to use new technologies, like digital informed consent or mobile health care technologies.

Digitization of Communication Methods

Technological integration into the communication of medical information has appeared as e-mail correspondence between patient and provider, the use of

online patient-portals to post lab result or provider recommendations, and computer-based informed consent, or e-formed consent.

Presenting informed consent on a tablet or computer is becoming increasingly popular in hospitals. The debate over the efficacy of computer-based versus printed informed consent comes at a time when 75% of patients admit to not reading the informed consent forms that they sign (Lorenzen, Melby, & Earles, 2008), indicating the necessity of reform in informed consent protocols.

There are many proposed benefits and drawbacks to digitizing informed consent. Scholars have speculated that it could encourage the replacement of face-to-face interaction between physician and patient, which could keep patients from having individual needs addressed and increase paternalism. Alternatively, because it could allow patients to access the information repeatedly and at their own pace, it may lead to more informed patients. If patients are more informed, this may encourage more involved physician-patient interactions, as they may have more confidence in asking questions. Each of these could lead to digitized informed consent being more efficient than printed (Coughlin, 2015).

While all of these effects seem plausible, currently available evidence seems insufficient to confidently predict how e-formed consent would affect the comprehension of patients, despite research that has been done into the brain's processing of text on a page versus text on a screen. One study showed that readers performed slightly worse on a comprehension test and had less accurate

long-term recall when reading text on a screen versus on paper. If online scrolling was necessary, this further decreased comprehension (Jabr, 2013). While this seems to suggest that computer-based informed consent would be an inferior method compared to printed, this conclusion is based upon the identical display of information on a computer screen as on paper. However, with digital technology, presentation of information can involve PowerPoint slides or videos, graphics, and interactive diagrams or models. While we may be able to conclude that patients will have worse comprehension if they read a PDF of a consent form versus a printed copy of the same document, use of multimedia as part of informed consent could have the opposite effect.

The use of electronic means to communicate health information affects members of different demographics in different ways. Considerable research has been done to explore the effects that transitioning to web-based and digital health communication has on the understanding of older patients (Tennant et al., 2015) as well as low-income old adults (Choi & DiNitto, 2013). This research has primarily suggested that there is a larger gap in the understanding of older adults between digital and printed information than there is for younger adults. This disparity in understanding and internalization of health information among older adults widens with confounding variables like low income or minority status (Tennant et al., 2015) (Choi & DiNitto, 2013).

This shift in information communication methods presents concerns about the comparative validity of informed consent via a web-based platform

versus printed text and the unintended exclusions of populations with inadequate digital literacy. At the same time, this digitization of communication methods opens up new opportunities for conveying information that cannot be done in print, such as multimedia use and interactive visual aids.

Other applications of digitized communications of health information include the implementation of secure patient portals to communicate various personal and educational messages to patients online. MyHealthVet was an online patient portal tool adopted by the Veteran's Authority health system. This portal system has a Blue Button feature that allows patients to download their personal health information including past and future appointments, symptom lists, allergies, medications, laboratory test results, past procedures, past history of measured vitals, and immunization history. A study of this system found that 33% of patients enrolled in this portal have used this relatively new feature to access their health information including their doctors' comments and recommendations, as well as any other chart notations from providers (Turvey et al., 2014).

The most commonly report reason for using the blue button feature within the online portal was that patients felt they were able to better understand their health history because all the information was in one place. Eighty-seven percent of users reported that the having access to their information as well as their doctor's comments in this format was helpful in some way (Turvey et al., 2014). Having the ability to download previous recommendations, comments, and other

provider chart notes, as the Blue Button feature allows, can increase patient-provider communication efficacy as patients may feel overwhelmed as they struggle to take in and encode information during their interaction with their provider. Referencing providers' messages at a later time and being able to confidently recall information may make for a more successful and satisfying patient-provider relationship.

Early success has also been seen in implementing patient portal features that allow patients to communicate with providers more directly. Features have included, e-mail with providers via a patient portal as well as chat or instant message features that have been sometimes called an eVisit (North et al., 2013). Chat threads were most commonly used by patients to contact providers about health issues, renewals and refills, understanding test results, scheduling requests, administrative issues, as well as expressions of gratitude and complaints. Early evidence has suggested the potential benefit of web-mediated direct provider communication, along with limitations related to disparities in use based on internet access and age and safety concerns related to patients opting for an eVisit when emergency medical assistance is required (Shimada et al., 2017).

New technologies for digitizing the communication of medical information have raised concerns about widening health information access disparities, lowering informed consent standards, and creating patient safety concerns. With adequate management of these concerns, more efficient and satisfactory

communication between patient and provider and higher standards of informed consent may result from increased use of digital communication platforms.

Web-based Dissemination of Health Information

Digitization and increasing access to the internet has also led individuals to seek and receive a substantial portion of their health information from a wide variety of online sources, from WebMD to Snapchat. One study estimated that 72% of regular internet users have searched for health-related information online for varying purposes (Fox & Duggan, 2013). The shift from structured health campaigns and in-person patient-provider interactions to internet- and social media- based dissemination of health information means that health literacy now requires skills related to internet use and increasingly requires abilities to critically evaluate the validity of information presented online.

eHealth literacy has been defined as “the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem” (Norman and Skinner, 2006, pg. 1). eHealth literacy involves a considerably more diverse skill set than written and oral health literacy alone. It involves not only the ability to access and navigate digital and online tools, but also the ability to appraise and critically evaluate the information found on online sources and make decisions about the reliability and applicability of that information. Evidence suggests that there is an enduring problem of health information found online being commonly

misleading, inaccurate, or of substandard quality (Eysenbach & Wyatt, 2002; Liang, Xue, & Zhang, 2017).

Prior to widespread internet use, in addition to health campaigns and health care providers, television, magazines, and newspapers provided substantial amounts of health information that required critical evaluation by consumers. Although health information found in these sources may also be misleading or of substandard quality, these types of published media are subject to regulations and typically undergo an approval process that a large portion of internet content does not. Because, for the most part, anyone can publish anything on the internet, those who lack developed critical appraisal skills seem more likely to be manipulated by low quality information now than previously.

Research has shown that adults typically struggle to distinguish whether the health information they find online is credible and whether they should use it as action-guiding (Nilmini, 2008). Presumably, information appraisal skills would be even more diminished in children, yet children and adolescents use the internet more than any other age group (Anderson, Steen, & Stavropoulos, 2017). Little evidence suggests that children have the developmental skills necessary to appraise the information encounter online so that they may use the internet safely and beneficially (Holloway, Green, & Livingstone, 2013). The pervasiveness of false or misleading information pertaining to health, especially weight loss, diet pills, and other appearance-driven health messages, seems to have potential

to be accepted by children or adolescents with detrimental physical and mental health consequences.

There are several modern examples of how low health literacy or limited ability to critically appraise internet-disseminated health information has been taken advantage of in the online marketplace. The advertisement, often targeted, and sale of “miracle” diet pills that guarantee drastic weight loss results is one example of how individuals or corporations have used low population health literacy and web-mediated dissemination of health information for monetary gain. Combined with the desire to maintain ingrained diet and exercise habits, low health literacy may lead to misunderstanding about metabolism and dieting health information may make individuals more likely to purchase “scam” health products online.

Health products are a likely subject for this kind of internet-based scam because of the nature of health literacy and of health information. People may feel less confident in their understanding of health information compared to information about the quality and reliability of other goods and services they buy. If consumers understand less about the product, they are less prepared to make an informed decision about purchasing and using that product. The internet, more so than other information dissemination platforms, provides a relatively convenient medium for this with less accountability for the information provider.

Evaluating the necessary skills for understanding, appraising, and appropriately applying health information found online requires the surveying of a wide variety of health information outlets and their actual access by different populations. Comprehensive research such as this is needed to adequately address the changing concerns related to population health literacy. Applying evidence-based solutions in education and provider training is a starting point for addressing concerns related to the rise of eHealth.

Responsible Parties and Agents of Change

Improving health literacy is a complex problem related to both patient-provider health care and hospital and social policies. Effective efforts will be a combination of hospital-based direct health education, whether in a patient-provider context or broader information provisions, and community-based policy change that allow groups with typically low health literacy to have greater access to information and educational services, which may include improving public school curriculum to promote health literacy, subsidizing internet access, or reforming health care to allow access to more people. As such, there are a wide variety of parties whose involvement is necessary for positive change.

Government players, the media industry, community leaders, research and academic institutions, and individuals can contribute to increasing the health literacy of the population.

Currently, the duty of overcoming health literacy limitations defaults to physicians and investigators in the clinical and research setting. If the burden of low health literacy could be minimized by more comprehensive, longitudinal policy changes, physicians and investigators who are seeking the informed consent of patients or participants would not face as large a task of achieving adequate patient understanding. More importantly, the effects of health literacy on populations that do not regularly access clinicians could be promoted as well.

The government may play the largest role in reforming both policies to increase access to health care and therefore an important access point to health information, as well as policies addressing social issues linked to health literacy (McDaid, 2016), like ensuring public education involves quality health education, increasing access to sources of information like public libraries, subsidizing internet access for underserved populations, and allocating funding for organizations like Planned Parenthood that aim to increase knowledge about health. In addition to making funding decisions that reflect a goal to increase motivation, access, understanding, and application of health information, continuous surveillance and targeted research into monitoring the causes and consequences of low health literacy should be a priority as well.

The media can also contribute to the fight for increased health literacy (McDaid, 2016). Because the media industry, whether web-based, television, radio, or print, serves as a critical platform for relaying information to the public, prioritizing messages that increase knowledge of healthy behaviors especially

through outlets that reach most underserved populations has potential to promote health literacy where it is needed most. Media agencies may also be cognizant about the messages being disproportionately displayed to low health literacy populations, such as fast food and cigarette advertisements, and the negative effects that they are having on the health of an already disadvantaged population. Reevaluation of corporate values with health literacy in mind and the assumption of a level of responsibility as a primary mediator of information could lead to large strides being made in population health literacy.

While the federal government and large media players may seem too large to be accessible, improving health literacy can be done on a smaller scale as well. Academic and research institutions can allocate funding and time into researching the causes and consequences of health literacy and propose and evaluate solutions (McDaid, 2016). As an educational institution, they can encourage students to pursue health information as part of their studies, or even require health literacy-related course work for graduation.

Community leaders can promote health literacy by encouraging the formation of community-based health models and campaigns. Individuals can support and bring expertise to their communities to aid in this effort. They can further contribute to health literacy promotion by understanding and recognizing the intersectional nature of health literacy and fighting for universal health care coverage and increased access to information technologies. Improving population health literacy requires efforts from various professions and demographics.

In 2014, the United Nations General Assembly expressed a similar idea urging governments to “continue to develop, strengthen and implement multisectoral public policies and action plans to promote health education and health literacy, with a particular focus on populations with low health awareness and/or literacy” (World Health Organization, 2014).

Past health promotion campaigns have demonstrated successful techniques for managing health literacy limitations. One example is pictorial health warning on tobacco product labels in Canada. Compared to text warnings, pictorial warnings have a greater impact with longer retention (McDaid, 2016). Because tobacco users are predominantly those of low socioeconomic status, a condition correlated with low health literacy, providing text-only warnings seems to be an inefficient effort. More efforts like this one, that give attention specifically to the literacy limits that members of the population may face, will help to minimize the negative health consequences of poor health literacy.

Campaign techniques such as this demonstrate the value in being cognizant of health literacy limitations and how they related to other social determinants of health. With greater recognition of the influence that population health literacy has on population health from educators, community leaders, physicians, and government officials, more successful and more just health promotion campaigns and interventions can be implemented. With greater health literacy may come more valid informed consent, allowing health care to be

delivered in a way that better upholds ethical standards. Health literacy is not only a problem of the individual, but also a problem that, if recognized and addressed, could lead to social, economic, educational and many other benefits to society.

References

- American Society for Metabolic and Bariatric Surgery (2017). Informed Consent. Retrieved from: <https://asmbs.org/resources/informed-consent>
- Anderson, E. L., Steen, E., & Stavropoulos, V. (2017). Internet use and Problematic Internet Use: a systematic review of longitudinal research trends in adolescence and emergent adulthood. *International Journal of Adolescence and Youth*, 22(4), 430–454. <https://doi.org/10.1080/02673843.2016.1227716>
- Becker, G. S. (1993). *Human capital: a theoretical and empirical analysis, with special reference to education* (3rd ed). Chicago: The University of Chicago Press.
- Bodie, G. D., & Dutta, M. J. (2008). Understanding Health Literacy for Strategic Health Marketing: eHealth Literacy, Health Disparities, and the Digital Divide. *Health Marketing Quarterly*, 25(1–2), 175–203. <https://doi.org/10.1080/07359680802126301>
- Breault, J. L. (2011). DNR, DNAR, or AND? Is Language Important? *The Ochsner Journal*, 11(4), 302–306.
- Campos-Castillo, C. (2015). Revisiting the First-Level Digital Divide in the United States: Gender and Race/Ethnicity Patterns, 2007–2012. *Social Science Computer Review*, 33(4), 423–439. <https://doi.org/10.1177/0894439314547617>
- Center for Disease Control and Prevention. (2000). *Healthy People 2010*. Retrieved from https://www.cdc.gov/nchs/healthy_people/hp2010.htm
- Chew, L. D., Griffin, J. M., Partin, M. R., Noorbaloochi, S., Grill, J. P., Snyder, A., ... VanRyn, M. (2008). Validation of Screening Questions for Limited Health Literacy in a Large VA Outpatient Population. *Journal of General Internal Medicine*, 23(5), 561–566. <https://doi.org/10.1007/s11606-008-0520-5>
- Choi & DiNitto. (2013). The Digital Divide Among Low-Income Homebound Older Adults: Internet Use Patterns, eHealth Literacy, and Attitudes Toward Computer/Internet Use. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3650931/>
- Cline, R. J. W., & Haynes, K. M. (2001). Consumer health information seeking on the Internet: the state of the art. *Health Education Research*, 16(6), 671–692. <https://doi.org/10.1093/her/16.6.671>
- Cooper, L., Roter, D., & Alan R. (2003). Patient-Provider Communication: The

Effect of Race and Ethnicity on Process and Outcomes of Healthcare. National Academies Press (US). Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK220354/>

Coughlin, C. (2015). E-Consent: Can Informed Consent be Just A Click Away? *Wake Forest Law Review*, 50, 17.

Department of Health and Human Services. (2009, June 23). 45 CFR part 46. from <https://www.hhs.gov/ohrp/regulations-and-policy/regulations/common-rule/index.html>

Department of Health, Education, and Welfare. (1979). The Belmont Report. Retrieved from <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html#xapp>

DeWalt Darren A., Berkman Nancy D., Sheridan Stacey, Lohr Kathleen N., & Pignone Michael P. (2004). Literacy and Health Outcomes. *Journal of General Internal Medicine*, 19(12), 1228–1239. <https://doi.org/10.1111/j.1525-1497.2004.40153.x>

Eng, T. R., Maxfield, A., Patrick, K., Deering, M. J., Ratzan, S. C., & Gustafson, D. H. (1998). Access to Health Information and Support: A Public Highway or a Private Road? *JAMA*, 280(15), 1371–1375. <https://doi.org/10.1001/jama.280.15.1371>

Engelman, L. (1995). *The Great Equalizer*.

Eysenbach, G., & Wyatt, J. (2002). Using the Internet for surveys and health research. *Journal of Medical Internet Research*, 4(2), E13. <https://doi.org/10.2196/jmir.4.2.e13>

Faden, R. R., & Beauchamp, T. L. (1986). *A History and Theory of Informed Consent*. Oxford University Press.

Fischer, B. A. (2006). A Summary of Important Documents in the Field of Research Ethics. *Schizophrenia Bulletin*, 32(1), 69–80. <https://doi.org/10.1093/schbul/sbj005>

Flory, J., & Emanuel, E. (2004). Interventions to Improve Research Participants' Understanding in Informed Consent for Research: A Systematic Review. *JAMA*, 292(13), 1593–1601. <https://doi.org/10.1001/jama.292.13.1593>

Fox, S., & Duggan, M. (n.d.). 35% of U.S. adults have gone online to figure out a medical condition; of these, half followed up with a visit to a medical professional, 55.

Hahn, S. R. (2009). *Patient-Centered Communication to Assess and Enhance*

Patient Adherence to Glaucoma Medication. *Ophthalmology*, 116(11), S37–S42. <https://doi.org/10.1016/j.ophtha.2009.06.023>

Hardman, R. J., Kennedy, G., Macpherson, H., Scholey, A. B., & Pipingas, A. (2016). Adherence to a Mediterranean-Style Diet and Effects on Cognition in Adults: A Qualitative Evaluation and Systematic Review of Longitudinal and Prospective Trials. *Frontiers in Nutrition*, 3. <https://doi.org/10.3389/fnut.2016.00022>

Hashim, MJ. (2017). Patient-Centered Communication: Basic Skills. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/28075109>

Heisler, Bouknight, Hayward, Smith, & Kerr. (2002). The Relative Importance of Physician Communication, Participatory Decision Making, and Patient Understanding in Diabetes Self-management. Retrieved from <https://onlinelibrary.wiley.com/doi/full/10.1046/j.1525-1497.2002.10905.x>

Holloway, D., Green, L., & Livingstone, S. (n.d.). Young children and their internet use August 2013, 36.

Jabr, F. (2013). Why the Brain Prefers Paper. *Scientific American*, 309(5), 48–53.

Jackson, L. D. (1992). Information Complexity and Medical Communication: The Effects of Technical Language and Amount of Information in a Medical Message. *Health Communication*, 4(3), 197–210. https://doi.org/10.1207/s15327027hc0403_3

Levine, K. (1982). Functional Literacy: Fond Illusions and False Economies. *Harvard Educational Review*, 52(3), 249–266. <https://doi.org/10.17763/haer.52.3.77p7168115610811>

Liang, H., Xue, Y., & Zhang, Z. (2017). Understanding Online Health Information Use: The Case of People with Physical Disabilities. *Journal of the Association for Information Systems; Atlanta*, 18(6), 433–460.

Lidz, C. W., & Appelbaum, P. S. (2002). The therapeutic misconception: problems and solutions. *Medical Care*, 40(9 Suppl), V55-63. <https://doi.org/10.1097/01.MLR.0000023956.25813.18>

Lorenzen, B., Melby, C. E., & Earles, B. (2008). Using principles of health literacy to enhance the informed consent process. *AORN Journal*, 88(1), 23–29. <https://doi.org/10.1016/j.aorn.2008.03.001>

McDaid, D. (2016). Policy Brief 19: Investing in health literacy. *World Health Organization*, 31.

- Moskop, J. C. (2016). *Ethics and Health Care: An Introduction*. Cambridge University Press.
- Murnane, R., Sawhill, I., & Snow, C. (2012). Literacy Challenges for the Twenty-First Century: Introducing the Issue. *The Future of Children*, 22(2), 3–15. <https://doi.org/10.1353/foc.2012.0013>
- National Center for Health Statistics (US). (2016). *Health, United States, 2015: With Special Feature on Racial and Ethnic Health Disparities*. Hyattsville (MD): National Center for Health Statistics (US). Retrieved from <http://www.ncbi.nlm.nih.gov/books/NBK367640/>
- Nilmini, W. (2008). *Encyclopedia of Healthcare Information Systems*. IGI Global.
- National Bioethics Advisory Commission. (2001). *Ethical and Policy Issues in Research Involving Human Participants*. Retrieved from: <https://scholarworks.iupui.edu/handle/1805/25>
- National Bioethics Advisory Commission. (2001). *Ethical and Policy Issues in International Research: Clinical Trials in Developing Countries*. Retrieved from: <https://bioethicsarchive.georgetown.edu/nbac/pubs.html>
- North, Crane, Stroebel, Cha, Edell, & Tulledge-Scheitel. (2013). Patient-generated secure messages and eVisits on a patient portal: are patients at risk?. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3822104/>
- Office of Human Research Protections. (n.d.). *Investigator Responsibilities FAQs*. Retrieved from <https://www.hhs.gov/ohrp/regulations-and-policy/guidance/faq/investigator-responsibilities/index.html>
- Okonkwo, O., Griffith, H. R., Belue, K., Lanza, S., Zamrini, E. Y., Harrell, L. E., ... Marson, D. C. (2007). Medical decision-making capacity in patients with mild cognitive impairment. *Neurology*, 69(15), 1528–1535. <https://doi.org/10.1212/01.wnl.0000277639.90611.d9>
- Paasche-Orlow, M. K., Taylor, H. A., & Brancati, F. L. (2003). Readability Standards for Informed-Consent Forms as Compared with Actual Readability. *New England Journal of Medicine*, 348(8), 721–726. <https://doi.org/10.1056/NEJMsa021212>
- Parikh, N. S., Parker, R. M., Nurss, J. R., Baker, D. W., & Williams, M. V. (1996). Shame and health literacy: the unspoken connection. *Patient Education and Counseling*, 27(1), 33–39. [https://doi.org/10.1016/0738-3991\(95\)00787-3](https://doi.org/10.1016/0738-3991(95)00787-3)
- Parker, R. M., Baker, D. W., Williams, M. V., & Nurss, J. R. (1995). The test of

functional health literacy in adults: A new instrument for measuring patients' literacy skills. *Journal of General Internal Medicine*, 10(10), 537–541. <https://doi.org/10.1007/BF02640361>

Patel, Moore, Craver, & Feldman. (2016, December 5). Ethical Considerations in Adherence Research. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5147396/>

Pellegrino, E. D. (1993). Societal duty and moral complicity: The physician's dilemma of divided loyalty. *International Journal of Law and Psychiatry*, 16(3), 371–391. [https://doi.org/10.1016/0160-2527\(93\)90004-X](https://doi.org/10.1016/0160-2527(93)90004-X)

Perie, M., Moran, R., & Lutkus, A. D. (2005). The Nation's Report Card. NAEP 2004 Trends in Academic Progress: Three Decades of Student Performance in Reading, 1971-2004 and Mathematics, 1973-2004. NCES 2005?464. ED Pubs, P. Retrieved from <https://eric.ed.gov/?id=ED485627>

Peter, D., Robinson, P., Jordan, M., Lawrence, S., Casey, K., & Salas-Lopez, D. (2015). Reducing Readmissions Using Teach-Back: Enhancing Patient and Family Education. *Journal of Nursing Administration*, 45(1), 35. <https://doi.org/10.1097/NNA.000000000000155>

Presidents Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. (1982, October). Making Health Care Choices: A Report on the Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship Volume One: Report. Retrieved from https://repository.library.georgetown.edu/bitstream/handle/10822/559354/making_health_care_decisions.pdf

Quill, T. E. (1996). Physician Recommendations and Patient Autonomy: Finding a Balance between Physician Power and Patient Choice. *Annals of Internal Medicine*, 125(9), 763. <https://doi.org/10.7326/0003-4819-125-9-199611010-00010>

Raynor, D. K. T. (2012). Health literacy. *BMJ*, 344, e2188. <https://doi.org/10.1136/bmj.e2188>

Robert Wood Johnson Foundation. (2013). How Does Employment, Or Unemployment, Affect Health? Retrieved from <https://www.rwjf.org/en/library/research/2012/12/how-does-employment--or-unemployment--affect-health-.html>

Rudd, R. E., Moeykens, B. A., & Colton, T. C. (1999). Health and Literacy: A Review of Medical and Public Health Literature. Office of Educational Research and Improvement. Retrieved from <https://eric.ed.gov/?id=ED508707>

- Rudd, R., Kirsch, I., & Yamamoto, K. (2004). Literacy and Health in America. Policy Information Report. Policy Information Center, Mail Stop 19-R, Educational Testing Service (ETS), Rosedale Road, Princeton, NJ 08541-0001. Retrieved from <https://eric.ed.gov/?id=ED486416>
- Salas, Z. R., Forhan, M., Caulfield, T., Sharma, A., & Raine, K. (2017). A critical analysis of obesity prevention policies and strategies - ProQuest. Retrieved April 2, 2018, from <https://search.proquest.com/openview/62e0408fddee463cdf1610742docbdba/1?pq-origsite=gscholar&cbl=47649>
- Salgo v. Leland Stanford 154 Cal.App.2d 560. (1957). Retrieved from <https://www.leagle.com/decision/1957714154calapp2d5601626>
- Schillinger, D., Bindman, A., Wang, F., Stewart, A., & Piette, J. (2004). Functional health literacy and the quality of physician–patient communication among diabetes patients. *Patient Education and Counseling*, 52(3), 315–323. [https://doi.org/10.1016/S0738-3991\(03\)00107-1](https://doi.org/10.1016/S0738-3991(03)00107-1)
- Shimada, Petrakis, Rothendler, Zirkle, Zhao, Feng, Fix, Ozkaynak, Martin, Johnson Bengisu Tulu, Gordon, Simon, & Woods. (2017). An analysis of patient-provider secure messaging at two Veterans Health Administration medical centers: message content and resolution through secure messaging. Retrieved from <https://academic.oup.com/jamia/article/24/5/942/3084705>
- Siordia, C. (2015). A Multilevel Analysis of Mobility Disability in the United States Population: Educational Advantage Diminishes as Race-Ethnicity Poverty Gap Increases. *Journal of Studies in Social Sciences*, 12(2). Retrieved from <http://infinitypress.info/index.php/jsss/article/view/1131>
- Sørensen, K., Van den Broucke, S., Fullam, J., Doyle, G., Pelikan, J., Slonska, Z., & Brand, H. (2012). Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health*, 12, 80. <https://doi.org/10.1186/1471-2458-12-80>
- Sorrentino, R. (2014). Performing capacity evaluations: What’s expected from your consult. Retrieved from: <https://www.mdedge.com/psychiatry/article/79219/practice-management/performing-capacity-evaluations-whats-expected-your>
- Tennant, B., Stellefson, M., Dodd, V., Chaney, B., Chaney, D., Paige, S., & Alber, J. (2015). eHealth Literacy and Web 2.0 Health Information Seeking Behaviors Among Baby Boomers and Older Adults. *Journal of Medical Internet Research*, 17(3). <https://doi.org/10.2196/jmir.3992>

Trials of War Criminals before the Nuremberg Military Tribunals under Control Council Law No. 10, Vol. 2. (1949). pp. 181-182. Retrieved from https://www.loc.gov/rr/frd/Military_Law/pdf/NT_war-criminals_Vol-II.pdf

Center for Disease Control and Prevention. (2017, August 30). Tuskegee Study Timeline. Retrieved from <https://www.cdc.gov/tuskegee/timeline.htm>

United Nations Development Program. (2007). Fighting climate change: human solidarity in a divided world. Houndmills: Palgrave Macmillan.

Unmarried Mothers Have Legal Custody. (2015, February 5). Retrieved April 23, 2018, from <https://www.communitylegalaid.org/node/3/unmarried-mothers-have-legal-custody>

World Health Organization & United Nations Development Program. (2016). Policy brief 4: Health Literacy. In World Health Organization 9th Global Health Promotion. Geneva. p. 1-9

World Health Organization (2014) Health literacy and health behaviour. Retrieved from: <http://www.who.int/healthpromotion/conferences/7gchp/track2/en/>

Williams, M. V., Parker, R. M., Baker, D. W., Parikh, N. S., Pitkin, K., Coates, W. C., & Nurss, J. R. (1995). Inadequate functional health literacy among patients at two public hospitals. *JAMA*, 274(21), 1677–1682.

World Health Organization, & Council for International Organizations of Medical Sciences. (2017). International ethical guidelines for health-related research involving humans. Geneva: CIOMS.

102nd U.S. Congress. (1991) National Literacy Act of 1991. Retrieved from <https://www.govtrack.us/congress/bills/102/hr751/text>

CURRICULUM VITAE

PERSONAL INFORMATION

Name: Margaret vanSchaayk
Telephone: (630) 242-0255
E-mail: mmvanschaayk@gmail.com
LinkedIn Profile: <https://www.linkedin.com/in/margaret-vanschaayk-922a30bb/>
Date and Place of Birth: November 7, 1994
The Hague, Netherlands

EDUCATION

Graduate: Master of Arts, Bioethics
Wake Forest University
Winston-Salem, North Carolina
August 2016 – Present
Anticipated Date of Graduation – May 21, 2018

Undergraduate: Bachelor of Arts – Communication
Wake Forest University
Winston-Salem, North Carolina
August 2013 – May 2017

WORK EXPERIENCE

Research Intern Wake Forest Institute for Regenerative Medicine
August 2015 – Present

Emergency Medical Technician Wake Forest Emergency Medical Services
May 2016 – August 2017

PROFESSIONAL MEMBERSHIPS

Tissue Engineering and Regenerative Medicine International Society (TERMIS) November 2017 - Present

PRESENTATIONS

“Effects of bioactive molecules on skeletal muscle development in 3D bioprinted muscle constructs”

Charlotte Biomedical Science and Engineering Symposium	May 2018 Charlotte, NC
Posters on the Hill, Council for Undergraduate Research	April 2018 Washington, DC
Tissue Engineering and Regenerative Medicine International Society (TERMIS)	December 2017 Charlotte, NC
North Carolina Tissue Engineering and Regenerative Medicine Society	November 2017 Winston-Salem, NC
International Biofabrication Society	October 2016 Winston-Salem, NC

PUBLICATIONS

VanSchaayk M, Kim JH, Yoo JJ, Atala A, Lee SJ. Effects of bioactive molecules on skeletal muscle development in 3D bioprinted muscle constructs [abstract]. *Tissue Eng Part A*. 2017;23(Suppl 1):S159.

CERTIFICATIONS

IACUC – Work with Lab Rats	2016, 2017
IACUC – Work with Lab Mice	2017
Emergency Medical Technician	May 2016 – Present
CPR/AED	2011, 2012, 2013, 2015, 2016
CITI	2015, 2017

HONORS/AWARDS

Bioethics Scholarship – Wake Forest University, 2017-2018
Honors Distinction in Communication – Wake Forest University, 2017

