HEC Forum (2019) 31:177–199
https://doi.org/10.1007/s10730-019-09369-5

Talking the Talk: Enhancing Clinical Ethics with Health Literacy Best Practices

Jamie Carlin Watson[1]

Abstract

A significant proportion of the U.S. population exhibits low health literacy. Evidence suggests that low health literacy is correlated with higher medical costs and poorer health outcomes. Even more concerning, evidence suggests that low health literacy threatens patients' and families' autonomy and exacerbates injustices in patients who are already vulnerable to difficulties navigating the health care system. There is also, however, increasing evidence that health literacy interventions—including initiatives such as plain language practices and teach-back—improve comprehension and usefulness of health care information. I show how health literacy best practices can enhance the work of clinical ethicists in their primary roles of policy, consultation, and education. In the final section, I suggest ways health literacy initiatives may be enhanced with insights from clinical ethicists.

Keywords Consultation · Policy · Education · Health literacy · Plain language

> *I think we should adopt the method of investigation that we'd use if, lacking keen eyesight, we were told to read small letters from a distance and then noticed that the same letters existed elsewhere in a larger size and on a larger surface. We'd consider it a godsend, I think, to be allowed to read the larger ones first and then to examine the smaller ones, to see whether they really are the same.*
> (Socrates in Plato, *Republic*, 368d, Grube trans.)

✉ Jamie Carlin Watson
jamie.c.watson@gmail.com

[1] University of Arkansas for Medical Sciences, 4301 W. Markham St. #646, Little Rock, AR 72205, USA

The Problem of Low Health Literacy for Clinical Ethics

Health literacy is the ability to access, understand, and use health information to make appropriate health care decisions for yourself or others (Somers and Mahadevan 2010).[1] Patients with low health literacy ask fewer questions during medical visits (Legare and Witteman 2013; Menendez et al. 2017), have less self-confidence when making medical decisions (Yin et al. 2012; McCaffery et al. 2013), are less adherent to medical advice (Miller 2016), seek unnecessary emergency department visits (incurring excess costs) (Balakrishnan et al. 2017) are overprescribed treatments whose outcomes they do not value(O'Connor et al. 2007), and experience worse overall health outcomes than their health literate counterparts (Berkman et al. 2004; 2011).

These correlations are especially concerning given how widespread low health literacy seems to be. Studies conducted by the U.S. Department of Education show that just over 80 million people in the general population demonstrate low health literacy (Kirsch et al. 1993; Kutner et al. 2006). More recent studies show that some social variables are strongly correlated with low health literacy, namely, non-white ethnicity, low socio-economic status, low education level, and advanced age (Berkman et al. 2011).[2] Despite a growing body of research confirming these results, as of 2012, at least 30% of medical schools are not teaching health literacy practices (Coleman and Appy 2012).

If low health literacy is really a cause of these results and not simply correlated,[3] they raise at least two concerns of special interest to clinical ethicists. First, they suggest that many patients are not sufficiently informed to make autonomous health care decisions. Second, they suggest that vulnerabilities of already vulnerable patient groups are being compounded—albeit unintentionally—by communication structures that prevent them from accessing, understanding, or using relevant health information.[4] Health literacy interventions, such as plain language writing and teach-back, aim to address low health literacy by improving communication in the informed consent process and mitigating the effects of those structures so that a larger population of patients has better overall health outcomes. In this paper, I argue that clinical ethicists can enhance their own skills by learning and implementing

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[1] Definitions vary slightly, but this is one of the most widely cited.

[2] Note that this is not evidence that members of these groups face inherent obstacles to health literacy. According to a recent study by Wu et al. (2017), low health literacy in China is correlated with low economic status and education level, but not with ethnicity or advanced age. See Guidry-Grimes and Victor (2012) for more on how cultural factors compound or alleviate vulnerabilities.

[3] Whether all these studies track the same phenomenon identified as "health literacy," whether health literacy is measured the same across experiments, and just how "low" health literacy must be to suggest these effects is unclear. However, research on strategies purporting to address low health literacy has demonstrated promising results for reducing the problems associated with low health literacy.

[4] There is growing empirical evidence that any given social structure can have exclusionary effects that can contribute to certain types of injustices even absent conscious intent to construct those obstacles. See, for example, the special issue of *Cambridge Quarterly of Healthcare Ethics* on "Bioethics and Health Disparities" (Stone and Dula 2012). For more on how *communication* structures in particular create these obstacles, see Katz et al.(2007), O'Connor et al. (2010), and Marshall et al. (2011).

health literacy best practices in each of their primary roles: policy, consultation, and education.

Definitions of health literacy vary slightly in the literature. With respect to the aim of health literacy, Stephen A. Somers and Roopa Mahadevan (2010) say it is “to make appropriate health decisions,” while the European Health Literacy Consortium (2012) says it is “to make judgements and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course,” and the Medical Library Association (2008) says it is “to make good health care decisions.” There are philosophical reasons to be concerned about the differences. For instance, the phrase “appropriate decisions” is ambiguous, implying either good from a purely medical perspective (decisions based solely on what is medically indicated) or good from a values-based perspective (decisions based on a shared understanding of the patient’s interests). I contend that the ambiguity should be resolved in favor of the latter, as I explain in “Enhancing Clinical Ethics with Health Literacy Practices”. But until then, any of these conceptions will suffice as all of them have three key elements in common: *accessibility* (people can read the words); *understandability* (people know what the words mean for them); and *usability* (people can make decisions for themselves based on their understanding of the words).

A core interpersonal skill of clinical ethics practice is communication, whether in documenting consultations, engaging with clinicians, families and patients, writing and revising policies, or creating and presenting education materials (American Society for Bioethics and Humanities 2011). Having accessible and accurate information relevant to a decision is critical for the exercise of and respect for autonomy. If health information is not clear or accurate, a patient’s evaluation of the risks and benefits is not informed, and therefore, not autonomous. If health care providers do not provide patients with information relevant to their decision in a way they can understand, they fail in the duty to ensure that consent or refusal is informed, that is, to respect them as autonomous persons.

Further, ethicists owe special attention to social and institutional structures that are likely to unjustly exclude vulnerable populations.[5] Further still, ethicists often have opportunities to strengthen the therapeutic alliance between patients/surrogates and the health care team by asking questions that help clarify the medical picture and viable options, that help clarify the values at stake, and that reveal new opportunities for compromise or benefit. Therefore, if there are empirically supported practices that enhance clinical ethicists’ abilities to assist clinicians, patients, and families in making good medical decisions—for instance, practices that improve understanding and appreciation among decision-makers or remove barriers to participation—there are good reasons to include these practices in clinical ethics training.

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[5] Again, the point here is not to accuse anyone of nefarious intent. Structures can exclude a population by default.

From Plain Language to Health Literacy

Interest in clear communication has a long, if spotty, history. The sophist Thrasymachus, in a moment of irony, says that Socrates must say “clearly and precisely” what he means if their debate is to be meaningful (*Republic*, 336d). Aristotle devotes a large portion of *Topics* to the importance of clarity, and in *Rhetoric*, he argues that clarity is the primary virtue of style: “[S]peech, if it does not make the meaning clear, will not perform its proper function; neither must it be mean, nor above the dignity of the subject, but appropriate to it” (1404b, pp. 1-2).[6] The Roman rhetorician Quintilian wrote that “clearness is the first virtue of eloquence” (*Institutio oratoria*, II, iii, 8). And George Campbell, following Quintilian, says that perspicuity is the “first and most essential” quality of style (see Walzer 2003). Praise for clarity extends beyond philosophers and rhetoricians. Respected writing teachers generally champion the virtues of clear, simple writing.

William Strunk and E.B. White’s classic, *The Elements of Style*, advocates many of the principles identified in the plain language literature, such as: use active voice, avoid unnecessary words, use short sentences, keep related ideas together. C.S. Lewis, literary critic and author of *The Chronicles of Narnia*, gives similar advice: “Always prefer the plain direct word to the long, vague one. Don’t *implement* promises, but *keep* them;” “Never use abstract nouns when concrete ones will do. If you mean ‘More people died’ don’t say ‘Mortality rose’” (Lewis 1956). Nationally acclaimed writing instructor William Zinsser advises, “Simplify, simplify,” and:

> Look for the clutter in your writing and prune it ruthlessly. Be grateful for everything you can throw away. Reexamine each sentence you put on paper. Is every word doing new work? Can any thought be expressed with more economy? (Zinsser 2001, p. 17)

The aim in each case is to make it easy for your audience to know what you mean—the primary function of plain language. “Always try to use the language so as to make quite clear what you mean and make sure your sentence couldn’t mean anything else” (Lewis 1956).

In the 1940s, the U.S. and U.K. governments started taking an interest in “plain language” for official memos. In 1942, for example, a U.S. military memo told war manufacturers:

> Such preparations shall be made as will completely obscure all Federal buildings and non-Federal buildings occupied by the Federal government during an air raid for any period of time from visibility by reason of internal or external illumination.

Frustrated with the “gobbledygook” [a term coined around the same time by Maury Maverick to describe this problem (Willerton 2015, p. 4)], President Franklin Roosevelt ordered it to be revised: “Tell them that in buildings where

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[6] See Willerton (2015) for other historical examples from Geoffrey Chaucer and Robert Cawdrey.

they have to keep the work going to put something across the windows" (Zinsser 2001, p. 8). Since then, additional government departments and several presidents have adopted and promoted plain language practices. This culminated in President Barack Obama's Plain Writing Act of 2010, which requires every federal agency to have a senior official who trains agency employees in plain writing and ensures that plain writing is used in all new or substantially revised documents and website information (Willerton 2015; Plainlanguage.gov 2019).

In its technical sense, plain language means written or oral communication that is "clear, concise, organized, and jargon-free" (U.S. Department of Health and Human Services 2012). Communication is considered plain language if "its wording, structure, and design are so clear that the intended readers can easily find what they need, understand what they find, and use that information" (Center for Plain Language 2012). The World Health Organization adds that people should be able to understand and act on the information "the first time they read or hear it" (Center for Plain Language 2012; World Health Organization 2013). For these reasons, plain language writing is largely regarded as a core skill-set in addressing health literacy.

This broader interest has been taken up by researchers interested in improving critical communication in applied contexts, such as finance and health care. In a recent publication, Kristie Hadden, Latrina Prince et al. (2016) distill this research into a list of eleven best practices for plain language writing:

1. Use active voice.
2. Make sentences direct, simple, and short.
3. Delete unnecessary information.
4. Use personal pronouns.
5. Use common, everyday words and not jargon.
6. Place the main message at the beginning, most important information first.
7. If you use a technical word, define it.
8. Use headings to guide readers and "chunk" information.
9. Use bullets or numbered lists or tables instead of large blocks of text
10. Use simple fonts.
11. Use ample white space.

While it may seem odd that anyone would oppose the idea of communicating in a way that is easy to understand, there are noteworthy objections to plain language initiatives. Some argue, for instance, that emphasizing *plain* language leads to imprecision, oversimplification, and a loss of importantly nuanced technical vocabulary. These objections have largely been met in the literature (Kimble 2006, 2012), and I address the concern about the responsible translation of jargon below. But it is worth reviewing the complexity of rendering technical language "plain."

What makes any given word or concept plain depends on a number of factors. Readability software programs, such as the Flesch-Kinkaid and SMOG Index (Simple Measure of Gobbledygook), use algorithms to calculate a grade-level score. Research suggests that most Americans read at an average level (Kutner et al. 2006), which is often assessed as falling between a 6th and 8th grade reading level. Yet, the majority of patient information is written above that threshold. Informed consent forms for medical research tend to start at the 10th grade level (Denzen et al. 2012; Paasche-Orlow et al. 2013).[7] Some patient education materials are written at the college level (grade level 15+) (Hadden et al. 2016).

On the face of it, this may seem like a failure of health care (indeed, it is treated as such by some health literacy researchers). However, it is unclear how significantly readability impacts understanding (positively or negatively). This is because readability is only one dimension of health literacy and difficult to distinguish from other contributing factors in empirical research.[8]

Some patients with poor health literacy, for instance, have become savvy with the terminology relevant to their chronic conditions and may be able to understand higher grade-level words. Yet, these patients may have deficient numeracy skills, and thus struggle to understand percentages, frequencies, and risk assessments relevant to their medical decisions (Apter et al. 2008; Hoffmann and Del Mar 2014).[9] Further, patients who may have adequate health literacy in their own cultures or with health care providers who speak their first language, can find it difficult to make sense of the materials available in other cultures (Zanchetta and Poureslami 2006; Andrulis and Brach 2007). Further still, some words are more recognizable when people hear them than when they see them written, such as *colonel*, *commode*, and *could've* (often written "could of"). This suggests that even patients with high verbal health literacy may not adequately understand printed materials. There is a large and growing literature in behavioral economics showing that humans in general are poor at assessing risk and making decisions in their own interests (see Gilovich 1991; Thaler and Sunstein 2009; Ariely 2010; Kahneman 2012).

Even if patient education were to address these concerns, there would remain the worry that plain language just "dumbs down" complex material in problematic ways. Every time we replace one phrase for another, we risk losing part of the intended meaning or adding unintended meanings. Choosing replacements requires careful consideration of the context and a thorough sense of the goal of the communication: *What do we want patients to understand? What do we want them to do?* For example, changing "Have a conversation with your primary physician about…" to "Talk with your doctor about…" seems uncontroversial. But changing "Your mother's baseline will not improve, and she has a less than a 1 in 10 chance of living longer than a month" to "Things are not looking good, and there's not much more we can do," is highly problematic from both a clinical and an ethical standpoint. I

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[7] Tamariz et al.(2013) found that, irrespective of readability, large numbers of participants did not understand key elements of their study after the informed consent process.

[8] The U.S. Department of Health & Human Services warns health care providers and educators to be cautious of readability formulas for this and other reasons (Agency for Healthcare Research and Quality 2015a).

[9] It is also important to note that physicians also suffer significant deficiencies in numeracy (Wegworth and Gigerenzer 2002), and therefore, the burden of patient education cannot be expected to fall solely on their shoulders.

will say more about the role of framing in health literacy practices in "Enhancing Clinical Ethics with Health Literacy Practices".

Finally, all of these considerations must be balanced against simplifying words so obvious that patients would recognize them despite a high readability rating. These "high frequency" words (Zeno et al. 1995), such as tyrannosaurus, cholesterol, and gynecologist, are so common in popular culture that even people with low health literacy can typically understand them, and changing them may actually confuse rather than elucidate an important concept. Even Aristotle notes that, "Using words that draw their authority from being part of the vernacular creates clarity" (*Rhetoric*, 1404b, pp. 5–8). Further, if patient education materials are not sensitive to which words are common knowledge, they can make patients feel infantilized and give them the sense that physicians are even more out of touch with their social situation than they already feared, lowering their already fragile trust.[10] For instance, a brochure that uses the word "urine" but then puts "pee" in parentheses, or that uses the word "education" and puts "school" in parentheses, may be insulting to people who regularly submit urine samples at work and who have school-age children.

These complexities suggest that increasing accessibility, understanding, and usefulness requires a great deal of linguistic competence and context-sensitivity, and cannot be reduced to a simple algorithm, such as a readability score. It also suggests that plain language, while an essential aspect of all health literacy interventions, cannot be neatly separated from broader strategies to improve health literacy, such as pedagogical techniques (e.g., teach-back) and clinical skills (e.g., shared decision-making).

To this end, health literacy researchers have developed interventions that combine an array of practices.

Health Literacy Best Practices

Clifford Coleman, Stanley Hudson, and Lucinda Maine (2013) surveyed 23 health professionals and education experts in attempt to detect a consensus on a set of best health literacy practices. They discovered unanimity on 15 of 95 practices. More recently, Coleman, Hudson, and Ben Pederson (2017) worked with 25 participants to reduce these to 8 best practices:[11]

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[10] This may also contribute to the increasingly visible problem of epistemic injustice. Epistemic injustice is a type of "wrong done to someone specifically in their capacity as a knower" (Fricker 2007, p. 1). This wrong can take different forms, but a common one is "testimonial injustice," which occurs when biases and prejudices cause a hearer to discredit or deflate the credibility of someone's testimony. In health care, this occurs when vulnerable patients (whether because of advanced age, ethnicity, socio-economic status, educational background, pregnancy, etc.) are regarded as lacking credibility or authority to speak about their experience of their illness or their preferences and interests when making medical decisions (See, for example, Carel and Kidd 2014).

[11] While these sample sizes are small, they are comparable to other sample sizes in the field, and the authors note in both studies that there is no known optimal size for Q-sort studies.

1. Routinely use a “teach back” or “show me” technique to check for understand and correct misunderstandings in a variety of health care settings, including during the informed consent process.
2. Consistently avoid using medical “jargon” in oral and written communication with patients, and define unavoidable jargon in lay terms.
3. Consistently elicit questions from patients through a “patient-centered” approach (e.g., “What questions do you have?” rather than “Do you have any questions?”)
4. Consistently use a “universal precautions” approach to oral and written communication with patients.
5. Routinely recommend the use of professional medical interpreter services for patients whose preferred language is other than English.
6. Consistently negotiate a mutual agenda with patients at the outset of encounters.
7. Routinely emphasize one to three “need-to-know” or “need-to-do” concepts during a given patient encounter.
8. Consistently elicit the full list of patient concerns at the outset of encounters.

While some of these are intuitive, others benefit from explanation. Practice 1 is motivated by research suggesting that most patients—regardless of age or educational background—retain less than 50% of what they hear in clinical conversations (Sheridan et al. 2011). Further, we are not always clear or thorough in our explanations. Closed-ended questions, such as “Do you understand?” and “Does that make sense?” discourage patients and surrogates from exploring complexities that may affect their decisions.[12] Teach-back is a teaching strategy that helps health care professionals know whether a patient or surrogate understood what they were told regarding their treatment, medications, or post-op or ongoing care. It involves using low-stakes questions designed to identify the level of a patient’s or surrogate’s comprehension, such as:

- I want to be sure I was clear, so can you explain that back to me in your own words?
- What questions do you have about…?
- Based on what I have said, what would you do if X happens?
- Just so we’re on the same page, when would you do Y?

Teach-back helps ensure both that providers have said all they need to say as providers and that patients and surrogates got the message.

Universal precautions, in practice 4, refers to three directives aimed at guiding health literacy practices (Paasche-Orlow et al. 2006). The first precaution is that, regardless of background or education, professionals should treat all patients as having inadequate health literacy. Anecdotally, clinicians cannot easily identify people with low health literacy. A patient or surrogate may speak eloquently and competently about a wide range of topics despite lacking basic literacy skills. Further,

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[12] Though closed-ended questions can sometimes help facilitate comprehension when structuring meetings. See American Society for Bioethics and Humanities (2017, pp. 15–19).

even some people with advanced degrees or high literacy skills in a profession may exhibit low *health* literacy (Agency for Healthcare research and Quality 2015b). The second precaution is that professionals should assess understanding throughout the communication process. Even patients or surrogates with adequate health literacy may not attribute the same meaning to health terms and information as health care professionals. This may be because of personal or cultural associations, or the stress, pain, or fear associated with their or their loved ones' medical situations. The idea is to use teach-back throughout the conversation and not simply at the end. The third precaution is that professionals should make health-related tasks easier, for example, by offering to help fill out forms or providing easy-to-use charts for taking medications.

Practice 7 is grounded in research showing that people—and especially people in stressful situations—can only process small chunks of information at a time. Having too many options can trigger decision fatigue and confusion, especially when reasoning about one's own condition as opposed to helping others.[13] If health care providers cannot avoid presenting a lot of information, they should stop every three to four points to check for understanding and accuracy. Decision items should be grouped.

In addition to these and the plain language practices above, my own department has started keeping a list of high frequency words (words commonly understood despite having more letters or syllables than most plain language words) that we can test in focus groups and then incorporate into plain language editing and writing. Knowing which words are apt for which audiences can foster trust and professional respect. We also emphasize actionability, so patients know what is expected of them. For example, in written documents, we tend to rephrase headings as first-person questions and organize content so that it answers those questions clearly and directly.

The Impact of Health Literacy Interventions

Even if there is a clear problem of health literacy, and even if there are practices aimed at addressing that problem, there remains a question of whether those practices are effective in addressing health literacy.[14] So far, the extant data are promising. Early research on literacy interventions focused on government documents.

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[13] See Thaler and Sunstein (2009, pp. 161–167) on Medicare Part D and Polman and Vohs (2016).

[14] I have left "addressing" intentionally vague. This is because there are two ways of conceptualizing health literacy. The first is as a set of skills on the part of patients. Addressing health literacy as a skills problem would mean interventions that "raise" or "improve" or "enhance" health literacy skills. The second is as a set of tools to help people with low health literacy by rewriting health information at the level of their competency. Addressing health literacy as a demands/expectations problem would mean developing or revising content so that it meets the needs of people with low health literacy where they are. This distinction is important for the theory and organization of health literacy interventions. In practice, however, it is difficult to tease these apart—our primary indicators are whether health behavior/outcomes "improve" according to some meaningful standard of improvement.

Joseph Kimble (1996, 1997) cites a study of a U.S. Department of Veteran Affairs benefits letter. The department estimated that around 750 copies of their original letter were sent out, and they generated 1100 calls from people who needed clarification. The letter was revised using plain language practices, and 710 copies were sent out. The department received just under 200 calls about the revised letter.[15] In addition to reducing confusion, literacy initiatives have also shown positive results in improving comprehension. Martin Cutts (1998) showed that a law school test revised according to plain language practices was not only more favorable to law students, but students performed better on 9 out of 12 questions.

Partially because of these early successes, there are now large research programs dedicated to studying initiatives specifically aimed at health literacy. A health literacy intervention in pediatric emergency departments in UCLA resulted in a 13% reduction in patients who said they would go to the emergency department first if their child got sick and a 30% reduction in reported visits to the emergency department in the six months following the intervention (Herman et al. 2009). An education-based intervention with patients with chronic diseases increased disease-specific knowledge and improved patients' participation in their own care (Eckman et al. 2012). These results seem representative. In a review of 71 studies examining the effect of health literacy interventions, Miller (2016) found that 65 showed statistically significant positive results.

There is still much work to be done in assessing just how well literacy interventions improve health literacy. Referring to the studies above: How should researchers measure the degree to which a patient participates in her own care? Does a reduction in reported visits to the emergency room indicate better understanding or simply fewer emergencies? We also need more evidence regarding which aspects of health knowledge health literacy initiatives can improve (e.g., understanding, comprehension, actionability, satisfaction), which practices improve which aspects, and which outcomes are the best predictors of those aspects (fewer emergency department visits, higher patient satisfaction, overall improved health, etc.). Despite these limitations, health literacy practices are intuitive enough and consistent enough with classic pedagogical techniques that they do suggest some clear best practices for clinical ethicists.

Enhancing Clinical Ethics with Health Literacy Practices

The key insight behind the best practices listed above is that obscure, difficult, or poorly aimed communication alienates your audience, while clear, simple, logical communication invites them into dialogue. Communication that alienates people from conversations in which they have a vested interest threatens their autonomy

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[15] Such studies are clearly subject to self-selection bias, but they are suggestive of how clarity can reduce obstacles to usefulness. See Thaler and Sunstein (2009, pp. 164–167) for an example of how lack of clarity—in addition to the sheer volume of choices—caused problems for Medicare Part D. See Jereb (1991) for other examples of how plain language can reduce negative feedback from clients.

and risks creating or perpetuating injustice. While the work of bioethicists, in the academy, politics, and the clinic, has significantly improved the visibility and importance of autonomy and justice as guiding principles in health decisions, findings from health literacy research offer clinical ethicists additional help in protecting and promoting patients' moral interests in all three major areas of practice: policy, consultation, and education.

Happily, clinical ethicists are already involved with a number of initiatives shown to either help improve health literacy or help avoid some negative consequences of low health literacy, including training health care providers on informed consent, autonomous decision-making, and shared and supported decision-making. Notably, these examples come almost exclusively from our role as clinical educators. It is less clear that health literacy practices are currently informing our policy and consultation work. What follows is a set of suggested best practices for enhancing clinical ethics in each of these areas.

Policy

Policies often dictate which and how information is given to patients. For example, patient rights and responsibilities posters and pamphlets are often the products of hospital policies on those topics. The sorts of orders that families can be asked to sign, such as POLST (Physician Orders for Life Sustaining Treatment[16]) forms and advance directives are often written by policy committees and sub-committees dedicated to producing those documents. Competency with health literacy best practices can help clinical ethicists serving on those committees improve the way hospitals communicate with patients by suggesting plain language edits that can help make those materials accessible and useful to a much wider population of patients.

Further, health literacy best practices are not only useful for helping people with inadequate health literacy. They also benefit medical professionals and clinical ethicists by helping them craft meaningful options for patients. When policies are unclear or inconsistent, physicians and ethicists find it difficult to practice efficiently. Precious time is lost in requesting help from the legal department and the ethics committee to interpret and apply obfuscating policy language. In the meantime, patients and family members are left with too little information or conflicting stories about their plan of care.

For example, a policy that refers to "medically ineffective" treatment is ambiguous given the state of medical and ethical terminology. It could mean a treatment that does not accomplish its physiologic goal (known as "futile"), or a treatment that does not accomplish a goal consistent with the patient's values and interests (known as "medically inappropriate") (American Thoracic Society 2015). Disambiguating this phrase in a policy can reduce apprehension and delay when

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[16] In Oregon, the state that first initiated this type of order in 1990, the "P" stands for "portable." Many other states, including mine (Arkansas), use "Physician," to explicitly limit who has the authority to write this type of order. States who wish to broaden the authority to other medical providers, such as nurse practitioners, commonly use "M" (MOLST), for "Medical Orders for Life Sustaining Treatment."

communicating available care options. Similarly, a policy that defined “placebo” as “any agent used deceptively in lieu of standard therapies” would allow non-inert drugs, like acetaminophen, to be used as placebos. Resolving the vagueness in this policy is paramount for thorough informed consent on the part of clinical research participants. When writing or reviewing policies, clinical ethicists competent with health literacy best practices are equipped to help ensure that policy language is clear, unambiguous, and consistent for all clinical staff, while maintaining fidelity to federal and state laws.

A potential obstacle to improving policy language is that, in many cases, policy language was handed down by state or federal statute. Hospital attorneys often advise committees to preserve obfuscating and ambiguous legal jargon. There is concern that rendering this language clearer will expose the institution to greater liability. While this conservatism serves a risk-management function, it can be a barrier to high quality medical care. Fortunately, many legal scholars are now pushing back on the intuition that simplifying legal language entails greater liability. Kimble (2012), Garner (2013), and Christopher Trudeau (2011–2012, 2012, 2016), for example, offer numerous examples of how legal language can be enhanced with plain language and health literacy practices without sacrificing its effectiveness in protecting hospitals from unnecessary litigation. Further, it is helpful to remember that every legal statute must be interpreted and applied in every individual cases, and one function of hospital attorneys is to defend the hospital’s use of those laws. Policy committees concerned about the constraints of legal language can often work with their legal departments on plain language versions of legal statutes that provide real guidance for clinicians while still protecting the institution from liability.

Consultation

As consultants, clinical ethicists engage with everyone in the hospital, from physicians, to attorneys, to nurses, to environmental services, to patients and families. Most of these people have little to no training in the technical language of the others, whether that language comes from medicine, research, law, institutional policy, or bioethics. Therefore, the ability to clearly and succinctly explain what we understand of the medical situation, as well as our ethical concerns, to a wide audience helps facilitate the clarification of values and informed decision-making. What might this mean for clinical ethics training?

Most clinical ethicists learn early not to attempt Kantian analyses or utilitarian calculi in clinical discussions. But this does not always eliminate the tendency to be overly technical with patients. Consider the wording that clinical ethicists Courtney Bruce, Martin Smith, and Laurence McCullough (2013) say “should be used” in the informed consent process for patients considering ventricular assist devices (VADs):

> VAD implantation is a surgical introduction of a life-sustaining intervention (nature) that is designed to prolong life with the goal of an acceptable outcome from continued clinical care (purpose), secondary to (as Moazami and Feld-

> man have proposed) end-stage heart failure refractory to medical therapy (p. 1424).

While Bruce, Smith, and McCullough doubtless have supportable philosophical reasons for preferring this wording, it is certainly not comprehensible or useful to anyone not already steeped in medicine and bioethics. Plain language guidelines suggest, instead, to explain the most important aspects of an option at a level accessible to people with inadequate health literacy. For example:

> Your heart is not working properly, and nothing we are doing is making it better. There is a machine called a VAD that we can put in your heart with surgery that will help keep you alive. It will let you live longer and possibly better. But you will need help from us and others to make sure it does its job.

Plain language guidelines can also demystify moral language. For example, even though the Georgetown Mantra of autonomy, beneficence, justice, and non-maleficence is widely taught to medical students, each of these concepts is philosophically complex and, despite appearances, cannot be applied neatly to difficult cases. Not only must the terms be clarified, for example, but the specific autonomy interests at stake in any given case will vary widely, and what counts as beneficent may *include* respect for persons. However, if clinical ethicists can clearly and simply explain the moral concern at the heart of, say, autonomy interests, in any given case, their discussions and recommendations may be more fruitful.

When writing recommendations in a patient's chart, for example, it is tempting to be overly succinct with moral terms. Imagine a patient who seems to agree with everything the medical team wants to do but has moments where she cannot explain the consequences of her options. If consulted, a clinical ethicist might write, "To respect the autonomy interests of the patient, the medical team should conduct a capacity assessment." Yet, even though we have used the moral term "autonomy," this sentence obscures the central moral issues: What *are* the patient's autonomy interests in this case, and how would a capacity assessment help us *respect* those?

Instead, we might trade succinctness for clarity. Rather than a single sentence in the chart, a CEC could elaborate with three bulleted points:

- The patient's fluctuating mental status raises serious questions about her ability to understand and appreciate her medical situation and options.
- Someone who does not understand the implications of their decisions cannot make an autonomous decision, in other words, a decision that reflects their sense of self and values.
- To protect the patient's ability to make an autonomous decision, the medical team should conduct a capacity assessment. If she is capacitated, the team should discuss a strategy for ensuring that her decision-making is informed. If she is incapacitated, the team should follow the ethical guidelines for identifying a surrogate to make decisions on behalf of the patient.

The revised note is thorough without attempting to be exhaustive. Though it is longer, it has two advantages over the first version.

First, it tells the medical team precisely what is at stake, ethically, so they know what they are trading off if they do not conduct a capacity assessment. If we simply say the team should "respect" her autonomy by performing a capacity assessment, that might suggest capacity is all there is to autonomy. The revised note indicates that there is more to do even given a positive assessment. Further, if the patient is incapacitated, the first note may leave the team with the sense that the patient no longer has autonomy interests. The revised note tells the team that the patient still deserves to have someone speak on their behalf. Second, the note is actionable in a way that the previous note is not. In the first note, the ethicist recommends the patient be checked for capacity. But then what? In the revised note, there is a clear decision-tree informed by clinical ethics practices.

A further benefit of health literacy for clinical ethicists is its nudge to enhance our own understanding of how medical details are perceived by others. For those clinical ethicists with a strong clinical background, having a grasp of health literacy research can help clinical ethicists know which phrases or jargon are not clear or useful. For those clinical ethicists without a strong clinical background, health literacy research can help us ensure our own understanding of the relevant descriptive features of a medical situation. Health literacy training can help us overcome the natural tendency to hide our own ignorance. It can also help us develop the courage to press clinicians to explain the medical situation in ways *we* can understand.

This, in turn, helps consultants model the medical outsider's perspective for patients and loved ones. While some clinical ethicists have backgrounds in medicine, others come from outside, disciplines such as philosophy and law. Those of us who come from outside have the daunting task of learning medical language in the clinical context, much like patients and families. Yet, since we are not under the same stress and we have some familiarity with the clinical context, we have an opportunity to ask clarifying and informational questions that patients and surrogates might not consider or be afraid to ask.

Using non-aggressive leads, such as, "Doctor, correct me if I'm wrong, but it seems like you're saying…. Is that right?" and "Doctor, I'm not quite clear on what you mean by…. Would you mind explaining?" clinical ethicists can model health literate practices at the bedside, where they benefit patients and families immediately and in subsequent medical encounters.

An underdiscussed skill of ethics consulting training involves our role in family meetings (see, however, American Society for Bioethics and Humanities 2017). ASBH's *Core Competencies* rightly highlights the need for skills in representing "the views of the involved parties to others," enabling "the involved parties to communicate effectively and be heard by other parties," and recognizing and attending "to various relational barriers to communication" (see American Society for Bioethics and Humanities 2011, I-4,I-5,I-6, p. 25). But it does not reflect research that shows physicians and nurses often overestimate patients' health literacy (Bass et al. 2002) and their understanding of medical terms (Byrne and Edeani 1984; Spees 1991; Schillinger et al. 2004). This means that the tasks of gauging the health literacy of families and patients, translating medical jargon into plain language appropriate for their (and our) understanding, and ensuring understanding through techniques such as teach-back, regularly fall to us. Equipped with this information and skilled in health literacy practices, clinical ethicists can fill a much-needed gap in supporting the patient/surrogate-physician relationship.

Education

As educators, clinical ethicists have a responsibility to give clinicians access to ethics information and skills relevant to their various jobs. As noted above, clinical ethicists are already involved in a variety of educational initiatives. Clinical ethicists competent in health literacy best practices can enhance ethics education by disseminating information on the pervasiveness of inadequate health literacy, the difficulty of identifying it in clinical practice, and the negative impact it can have on patients.

Health literacy best practices can also improve the content of clinical ethics education by removing structural obstacles to accessing information. Ethics educators who use font that is too small, include too much information on a slide or page, do not organize that information intelligibly, use colors that do not contrast well, or use a serif font, risk alienating clinicians who are often short on time, very tired, and have little background in ethics, or who have learning disabilities like dyslexia. This can compromise understanding and useability even if the clinician has otherwise adequate health literacy. On the other hand, clinical ethicists who use health literacy practices to organize material into clear, digestible chunks with easy-to-apply implications for the audience's role in the clinic can help demystify moral reasoning and improve how ethical language is used around the hospital.

Is Health Literacy Ethical?

Although health literacy interventions and plain language practices are growing in popularity, there are reasons to be cautious. For instance, one might argue that plain language practices dumb down important medical information, rendering it overly simplistic or flatly misleading patients into thinking their medical decisions are easier than they really are. In most cases, health literacy interventions are developed intentionally to avoid such concerns. Technical medical terms are still used, but they are explained. Teach-back and supported decision-making techniques help ensure patients and surrogates do not walk away with misconceptions.

But even with precautions, there is a further concern grounded in the structure of how we communicate. Every act of simplification involves an aim and a judgment. Every time we present people with choices, especially in health care, we construct an internal narrative about the information we have. We emphasize certain options and deemphasize others.[17] We are conflict-averse, so we strategically avoid saying what people do not want to hear, sometimes explicitly but also unintentionally. There is a growing body of research showing that this "choice architecture"[18] is guided by

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[17] See Tom Gilovich (1991, pp. 90–94) on "sharpening and leveling."

[18] Thaler and Sunstein coined this phrase to describe how we organize the context in which people make decisions (2009, p. 3).

a host of subconscious cognitive biases and heuristics, such as stereotypes (representativeness bias), overconfidence in our own abilities, inertia (status quo bias), and conflict avoidance (optimistic framing; conformity bias), among many others.

This research suggests that, like the rest of us, clinicians sometimes frame decisions in ways that powerfully and unconsciously influence, or "nudge" (Thaler and Sunstein 2009), patients and families into choosing the physician's preferred option. Consider the case of decisions with defaults. A default option is an option that will ensue if someone does not intentionally choose an alternative option. A common example is employee benefits. In most workplaces, unless you change your benefit elections at the beginning of a new benefits cycle, they default to your previous elections. The choice architecture of defaults raises difficult questions in health care, as Moti Gorin et al. (2013) explain:

> Patients completing advance directives in which comfort-oriented care was the default were significantly more likely to choose comfort-oriented treatment options than were patients completing directives without specified defaults. Correspondingly, patients completing advance directives in which life-extending care was the default were less likely to choose comfort- oriented treatments than those in either of the foregoing groups (Gorin et al. 2013, p. 33).

Unless they had strong values-driven objections, patients chose the defaults. What is more, even after patients were told that their options were manipulated in this way, they uniformly endorsed their choices.[19]

The importance of these findings cannot be overstated, for at least two reasons. First, we are now aware that we unconsciously frame decisions in ways that favor our own values and outcomes. Nudging is sometimes unavoidable. Second, they offer insights into how we might avoid the worst effects of these tendencies. The difficulty comes in identifying precisely what the "worst" effects are.

Some argue that clinicians should use this understanding of ourselves to improve medical outcomes, that is, to improve health as it is understood clinically (see Devisch 2011; Quigley 2013; Voyer 2015). For example, many argue that the U.S. should change its organ donation policy to an opt-out system rather than an opt-in system. This is because cognitive inertia (the status quo bias) makes it less likely that people will change whatever default is set for them, even though they are completely free to do so (Childress and Liverman 2006). A more clinical suggestion is to use checklists to nudge providers to avoid preventable medical errors (Gawande 2009). Yet, these are among the least controversial examples of nudging in health care.

Shlomo Cohen (2013) suggests physicians alter informed consent forms to nudge patients away from non-ideal choices, even to "prevent the very formation of unhealthy preference[s]" (p. 5). Others suggest nudging patients to include

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[19] Whether this actually counts as a nudge has been challenged by Saghai (2013). Gorin et al.(2013) conclude that most of these patients had no settled views of these matters to manipulate, and thus, no authentic beliefs about the decisions, so therefore, nudges are justified. Saghai argues that, if choice architecture creates a belief de novo rather than changing a belief, it is not technically a nudge.

their medical information in public databases that trade off some privacy interests for public health benefits (see Munoz, Fox, and Gomez 2013).

The problem in the latter cases is that the nudges presuppose that the choice architects know, while constructing the choice architecture, which outcome is best—which preferences are "unhealthy" irrespective of patients' goals for medical care. In some cases, like the less controversial examples, the right outcomes seem obvious. But there are many clinical cases where the fitting, reasonable, or best outcome is precisely what is under discussion.[20]

Imagine a medical team that is genuinely uncertain as to whether it would be in a patient's best interests to receive aggressive, long-term treatment or to be transitioned to comfort measures. They have not yet approached the patient's surrogate decision-maker because they know that people generally take the first choice offered and then retrospectively endorse that choice. Getting their input requires giving them the choice. But giving them the choice influences their decision. Given the team's ambivalence, it would seem odd to present comfort measures first *solely* on the basis of evidence that a majority of informed patients would choose that. Is this patient more like the majority or minority? This is a genuine dilemma.

Now imagine, instead, the team has a very clear sense of what they think the patient should receive that is based, not on general moral concerns such as the best interests standard or values the patient has expressed, but solely on the evidence of what a majority of patients would want. Behavioral economists and cognitive psychologists would likely say this is a good strategy: you cannot go wrong following the numbers. But given the many, many complex features of each patient's social, religious, and medical situation, we know you can go wrong by following *only* the numbers. This case, it turns out, is no better than the previous.

To be sure, patients have a vested interest in their health and bear some responsibility for pressing physicians to make health options, benefits, and risks as accessible as possible. However, given the foreign nature of the clinic, the cognition-compromising features of health problems (fear, pain, anxiety), and the presumed expertise of the physician, even patients with adequate health literacy are vulnerable (see Sheridan et al. 2011; Grisso and Appelbaum 1998, pp. 73–75). This diminishes the responsibility generally assigned to capacitated citizens. Since patients with low health literacy ask fewer questions than patients with adequate health literacy, the burden falls on providers to facilitate informed consent.

This sort of framing effect is a serious problem that affects all medical decision-making. However, health literacy initiatives need not bear the burden of solving it alone, and I will not attempt to solve it here. The upshot for my purposes is that, in cases where biased framing is not inevitable, health literacy initiatives can wittingly or unwittingly construct choice architectures that serve a variety of ends, not all of them ethically justifiable. For health literacy to be ethical, it must be guided by ethical goals. This means that health literacy practitioners must (a) be aware of

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[20] See Douglas and Proudfoot (2013) for an argument along these lines with respect to cancer treatments.

the ways that choice architecture affects decisions, (b) avoid, to the extent plausible, structures that give disproportionate weight to values other than the patient's, and (c) choose, to the extent plausible, structures that improve reason and empower autonomous decision-making, rather than those that by-pass reason or restrict autonomy.[21]

Recall from "The Problem of Low Health Literacy for Clinical Ethics" the limitations in some definitions of health literacy. Somers and Mahadevan say health literacy should promote "appropriate health care decisions," which is ambiguous between what some providers consider medically appropriate and what patients consider a valuable outcome. The European Health Literacy Consortium says its goal is to support decisions that maintain or improve quality of life, which could imply that health literacy is inconsistent with decisions that forego some treatments for the sake of personal values. Health literacy interventions guided by ethical goals, however, can plausibly aim to promote, as the Medical Library Association puts it, "*good* health care decisions" (italics mine).

Happily, many professionals working in health literacy embrace this message. Senior leaders Karen Baker and Don Kemper, of Healthwise, Inc., note that, for their company, plain language is a means to an ethical end: "It's really all about informed decision-making. The goal isn't plain language; the goal is informed decision-making or informed action" (Willerton 2015, p. 78). Megan Rooney, manager of plain language programs at Health Literacy Missouri, says, "We believe it is unethical to expect a person to make good health care decisions without fully understanding the information given to them" (Willerton 2015, p. 143). This overlap in interests suggests obvious opportunities for partnerships between clinical ethicists and health literacy professionals, and training in both is likely to enhance both.

Enhancing Health Literacy with Clinical Ethics

In addition to benefiting from health literacy practices, there are a number of ways clinical ethicists can contribute to those practices. First, and very broadly, clinical ethicists can help cast a moral vision for the goals of plain language and health literacy, highlighting research on choice architecture and suggesting communication frameworks that help further empower patients (such as Martin Buber's I-Thou dialogic framework) (see Willerton 2015, pp. 43–53). As noted above, while the goals of literacy interventions include improving patients' comprehension and behavior related to their health, the outcomes most valuable to those patients can sometimes be obscured by the interests of health care providers, that is, the outcomes *they* think patients should find most valuable. Clinical ethicists can help clinical educators organize and present information in ways that improve informed consent, promote autonomy, and prevent injustice.

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[21] See Saghai (2013) for more on the distinction between autonomy-empowering nudges and autonomy-undermining nudges. See Watson (2017, pp. 127–130) for more on the distinction between reason-improving and reason-avoiding nudges.

A second contribution is more accurate bioethics language and conceptual clarity. Anecdotally, many clinicians seem to conflate "vegetative state," "persistent vegetative state," and "permanent vegetative state" (if they were trained on them at all), despite differences that carry ethical weight. Many also tend to use "futile" and "potentially inappropriate" interchangeably. In one patient information document I reviewed, the word "terminal" was revised to "dying," despite a significant medical difference with implications for goals of care. Another document used "advance directive" and "living will" interchangeably, which can obscure distinctions between expressed wishes and persons named as surrogate if the patient loses capacity. In all of these cases, clinical ethicists can help health literacy researchers draw these distinctions so that terminology used in policies, patient information, consultation, and education is consistent, informative, and supportive of the overall ethical goals of health literacy.

A third way that clinical ethicists may help enhance health literacy is by bringing health literacy concerns from the bedside or care team meeting to the attention of health literacy researchers. Health literacy researchers are already working on ways to improve informed consent forms for research. Similarly, ethicists regularly encounter clinicians, patients, or families who are struggling with written material directly related to their medical care, whether complicated transfer orders like POLST, complex advanced planning materials, or misleading or obfuscating patient information posters. Ethicists who are aware of the problems associated with inadequate health literacy can help health literacy researchers identify content that needs attention either from further health literacy research or from health literacy interventions that have already been developed.

Conclusions

A growing body of research shows that a large portion of the population has inadequate health literacy and that this leads to more expensive health care and worse outcomes than patients with adequate health literacy. These findings raise ethical concerns about how to help patients with inadequate health literacy give genuinely informed consent to medical care and how to prevent inadequate health literacy from further disadvantaging already vulnerable patients. Health literacy interventions, which include plain language writing, chunking information, and using teach-back, have a promising track record of addressing inadequate health literacy. In this article, I have argued that the work of clinical ethicists can be enhanced by incorporating health literacy best practices in each of our major roles in the hospital.

Our contributions to hospital policies can benefit from health literacy practices by providing patients with clearer more useful written documents and forms that are easier to fill-out, as well as by helping physicians frame timely, meaningful options for patients. Our work as consultants can benefit from health literacy best practices through better organized and more informative chart notes and improving communication between physicians and patients or families. Our work as educators can benefit through including the prevalence of inadequate health literacy and its effects in our educational activities and using health literacy best practices to enhance our teaching even for audiences with adequate health literacy.

There remain important questions about how to design health literacy interventions in ways that reduce biases and unintentional nudges. However, the nature of these dangers suggests some precautionary strategies in the meantime. The most significant of these is to include ethicists in the process of designing health literacy interventions. Ethicists can help craft the goals of these interventions, help increase conceptual clarity and consistency when translating jargon, and help health literacy researchers identify obstacles to accessing, understanding, or using health information.

This discussion is clearly incomplete. There are surely many other ways that clinical ethicists and health literacy researchers can benefit one another, and the suggestions here are intended only as a starting point. Where might the discussion go from here? In addition to identifying additional ways to incorporate health literacy into clinical ethics, one next step would be to include health literacy discussions along the lines of what I've offered here in ethics committee meetings, whether as part of regular committee education or for broader discussion about how to improve communication throughout the clinic. Another would be to incorporate health literacy research and best practices into clinical ethics training programs. Ideally, clinical ethicists would work directly with an experienced plain language editor to practice skills. It turns out that plain language editing is quite difficult, especially for those of us trained to write for academics and professionals. But ultimately, I think, cultivating a relationship with health literacy researchers, for both mutual education and collaborative research, will help us individually achieve our shared goal of improving patient care.

Acknowledgements Thanks to Kristie Hadden, D. Micah Hester, Laura Guidry-Grimes, and three anonymous reviewers at HEC Forum for comments on earlier versions of this paper.

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