The Prevalence of Health Literacy in Cancer Care

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Introduction

As patients are expected to assume increased responsibility for their care and the decisions involved, health literacy has become key to a treatment's positive outcome. Health Literacy (HL) is easily defined as the patient's ability to comprehend and use medical information to make informed decisions in one's own healthcare (Fox Chase Cancer Center, 2022). In the United States, 78% of adults do not have proficient health literacy which shows how prevalent an issue of poor HL is (Lopez et al., 2022). The statistic goes down to 18% for cancer patients, which makes sense because those who are diagnosed with cancer and are undergoing treatments will have better knowledge over their illness and the healthcare system as they are living in it and have exposure (Dumenci et al., 2014). Most adults in the US do not because they are not in and out of hospitals and so these proficient levels of HL do not extend to most people who do not need to know how it works; they are not involved. Nine out of every fifty cancer patients may not have the ability to effectively communicate with providers or adhere to their medication regimes. Cancer health literacy has become central to a treatment's positive outcome, and it acts as a predictor of health status. It is vital for patients, especially those dealing with such a fatal diagnosis like cancer, to understand exactly what is going on with their health and care.

This poor HL, leading to demonstrably worse treatment results, is further compounded as a problem when the projections of cancer numbers are considered. It is believed that between 2015 and 2050, there will be a 50% increase in cancer cases due to increased risk factors (Weir, 2021). The current cancer care treatment services are dealing with these surges directly, although they predominantly focused on using throughput as an outcome metric to gauge effectiveness of

their service. The more people they can see and get treatment from, the better they are. The technical work being conducted for my capstone project focuses on increasing throughput, more specifically the utilization rates of infusion chairs, for outpatient infusion centers, which largely treat cancer cases and are facing growing demands. This STS research paper will complement my technical work by looking at this other dimension of patient care that also factors into cancer outcomes, health literacy. With the increased demands infusion centers are facing, cancer HL becomes more important to properly get across to as many patients as possible. It must be understandable, comprehensive, and accessible to everyone, no matter their circumstances or characteristics. Discrepancies in cancer HL rates can be seen across varied populations and characteristics so understanding why this is and the best systematic approaches to getting valuable resources in place are essential. Cancer HL must be equitable across the entire system and finding the means to do this begins with the examination of current practices and what is working for which groups and most importantly, why.

Literature Review

The research question I will be investigating is: *in cancer care, where do the commonalities and differences arise because of the needs of different populations of patients, and what are the systemic solutions to improve health literacy considering this?* The official and established efforts towards improving HL can be encompassed with The National Action Plan to Improve Health Literacy. This government endeavor focuses on high level solutions and goals that should be strived for and calls for improvement in changes and processes to better HL across the health system (U.S. Department of Health and Human Services, 2010). A publishing by the CDC works to detail the difference between personal health literacy and organizational health literacy and provide the basis for a commonality that will be discussed in depth throughout this

paper (Centers for Disease Control and Prevention, 2022). These two government sources, however, lack breakdowns based on different populations and the quantitative differences that exist in HL between them as well as a specific focus into cancer care which is what the topic of the research paper is about.

Literature about cancer specific initiatives to better HL also exists, including the continuing medical education programs that teach physicians cancer risk communication and how HL is improved across different patient populations (Price-Haywood et al., 2010). Another study is about "designing and delivering cancer communication messages to match the specific communication skills, needs, and pre-dispositions" (Sparks & Nussbaum, 2008). Yet another study focuses on the implementation of easy-to-understand print-out and digital materials for best HL and relaying of critical information (Simmons et al., 2017). These references to existing literature offer potential organizational studies but there is no comparison to personal HL practices. However, studies about personal HL practices do exist separately. One develops and identifies content for a HL curriculum to help make an individual cancer caregiver as helpful as possible (Wittenberg et al., 2020). Another one reviews and evaluates information needs from non-patients, patients, and caregivers and the channels they used to find it (Jo et al., 2019). Yet again, a gap exists where it does not allow for commonalities to be seen across practices.

Another gap in literature being reviewed and analyzed for this paper is that two studies previously referenced: "Health Literacy and Cancer Communication with Older Adults" and "Health Literacy: Cancer Prevention Strategies for Early Adults," only focus on a specific demographic of cancer patients with little to no consideration of their potential application to others. The literature does cover typical practices that should be implemented. There is a wealth of literature to understand how patient groups rank with their HL and options to improve HL. It

does, however, lack the connection of these two ideas across several levels. Literature has gaps in the understanding of the commonalities and nuances that must be considered by the cancer health system which this paper will strive to untangle and explore more deeply.

Methodology

Literature review, synthesis of findings, and the Social Construction of Technology (SCOT) framework will be utilized to investigate the research question I have posed. Quantitative and qualitative data from the numerous studies I have identified in this paper, all dealing with the topic health literacy with a focus on cancer treatments, will be examined. These studies and articles chosen are written within the past two decades, with a focus on the more recent, and come from reputable sources, as they are mainly observational and experimental studies. Because of this chosen methodology, I will rely on secondary sources for my analysis while also using the statistics published to support my research. Descriptive analysis will back up my findings and work in tandem with the SCOT framework to help organize and examine the breadth of work which has not been done before by other literature for this topic. SCOT is made up of four components which are as follows: relevant social groups, interpretive flexibility, closure and stabilization, and the wider context (Klein & Kleinman, 2002). It works to form an approach that will illuminate how social structures can influence the development of technology, if we consider health literacy practices a technology, to better understand and address the issues in low HL rates and understand commonalities and nuances across different populations.

Body

Defining Social Groups

The first component of the SCOT framework is concerned with how the diverse groups in society have entered the population and designed the technology seen today. These groups can

be most easily divided by the social division of labor and with HL the split is most clearly

defined between healthcare provider and the patient. More simply put, it is the people who

provide the information and the people who need it. Neither group could exist without the other,

yet they access the health system from opposite ends and therefore there is a structural factor

influencing the groups.

The second component of SCOT, interpretive flexibility, explains that social groups have

different interpretations of meaning and therefore interact with the technology differently. HL

has different meanings, personal or organizational, based on where the responsibility is perceived

to lie and where these groups feel they have the most control. Personal HL is the "the degree to

which individuals have the ability to… inform health-related decisions and actions for

themselves," and organizational is the "the degree to which organizations equitably enable

individuals to… inform health-related decisions and actions for themselves" (Centers for Disease

Control and Prevention, 2022). The current field is moving towards the organizational HL

definition as cancer care is already a complicated and stressful process and has individual

challenges. Evidence shows that when physicians intervene to improve an individual patient's

self-care, there are "documented improvements in self-efficacy," which greatly impacts the

patient's approach to their own personal HL (Paterick et al., 2017). Even European health

policies have recently recognized the importance of improving cancer literacy and have

impressed the need for "[i]mplementation of comprehensive programs and strategies… through

coordinated efforts among providers, organizations, patients, and research" (Sørensen et al.,

2020). Measures to improve the communication between the social groups involved in cancer

HL are being evaluated to enhance cancer risk communication and decision-making with low HL

patients, for example with programs like continuing medical education, or CME (Price-Haywood

et al., 2010). Physician-patient communication, impelled by the system and physician's side is the cornerstone for improving HL, one that will be examined in detail further on. Organizational HL puts responsibility back into the systems' hands and therefore has the potential to reach a greater audience while alleviating the burden of cancer patients and their caretakers.

Prioritizing Organizational Health Literacy

Some argue that better personal HL should be the priority. Organizational cancer HL is harder to improve than personal cancer HL because every physician and medical professional will have to work on their communication abilities and better their resources. A study found two important facts: the first is that "each year there is a growing interest in cancer-related information," the secondly, the three most popular searching channels for cancer-related information are primarily doctors, then the Internet, and thirdly the media (Jo et al., 2019). While medical professionals are the most used source, the Internet follows very closely behind and this makes sense because most everyone has access to the unlimited information it can provide Family members and caregivers without direct access to doctors can look up treatments, healthy individuals looking for preventative information do not have to pay for a consultation, and psychosocial support can be explored easily. However, shifting back to personal HL and leaving organizational HL as is, is not an adequate solution.

The cornerstone of organizational HL is that the organization enables equitable education of necessary information for cancer. If the organization is not responsible or does not feel responsible for improving cancer HL numbers, the patients will react, and they have. The Internet is the second most popular source of information for a simple reason, the patient does not understand. The Internet, however, is incredibly prone to misinformation and biases, more so than physicians who are licensed, have training, and a Hippocratic oath to uphold. "[O]ne-third

of popular cancer articles on social media from 2018 and 2019 contained misinformation" from the platforms YouTube, Pinterest, Reddit, and Facebook and therefore can harm the patient (Johnson et al., 2021). Approximately 77% of videos disseminating information about prostate cancer on YouTube for example, were found to contain "potentially misinformative and/or biased content within the video or comments section" (Loeb et al., 2019). Significant persuasion was also uncovered to try "guideline-discordant treatment or unproven natural remedies' which highlights the danger of finding information on the Internet (Loeb et al. 2019). It is unverified information and can become harmful.

It is true that patients cannot be informed about cancer health and treatments if cancer health care fails to educate about it and that is why people turn to YouTube and Facebook. It is clear a disconnect exists and the patients are trying to supplement their education. Organizational HL can erase the disconnect itself and improve communication within the system. It places responsibility in the hands of those who should be making and giving decisions, medical professionals with training who are not dependent on clicks or views for success. It is true that a YouTube creator might try to give helpful information, but if it is monetized then the creator will make more money the better the video does, not the better the advice is. The system has the responsibility to correct this misinformation and lay groundwork for improving their role in physician-patient communication. That is why it is essential for the cancer health care system to understand where HL is failing and more specifically why certain populations may be affected more so than others and what can be done differently to ensure the equitable improvement of cancer HL as it differs demonstrably for different populations.

Disparities in Cancer Health Literacy

This is another dimension of social groups, outside physician, and patient, which cannot be overlooked. The fourth component of SCOT also comes into play, in a wider context. It helps identify and explore the background conditions in which the technology, cancer HL, developed. When it comes to the health system, institutionalized biases regarding race are at the forefront. This component is extended to help focus on power differences that exist, which is usually a limitation of the SCOT framework. Racial, as well as income, gender, and age differences are pervasive in HL rates as each group of people must develop this technology, health literacy, differently to suit their individual needs. A direct example of how cancer health literacy can suffer because of the social group of the patient is within a study which found that providing messages that motivate African American men to act and promote self-efficacy improved preventative behaviors with prostate cancer (Friedman et al., 2009). This population of cancer patients felt they had limited resources for screenings or visits and were less likely to talk about it and the application of a HL approach that recognized these problems and worked to promote and deliver information to a lacking population worked (Friedman et al., 2009). It is key to improving HL to not only understand where the help should come from but what might be blocking access to it.

Financial differences also affect cancer HL rates. "Women who are employed have increased odds of having high breast cancer literacy" as well as those "with a college degree or higher" showing a correlation between financial well-being and HL as well as education opportunities (Zambrana et al., 2015). Information can only be disseminated if there is an avenue to do it. Spanish speaking women do not often discuss these topics and therefore have much lower knowledge about subjects, in this case breast cancer. Only "30% of Latina women had

high breast cancer literacy" even though they had access to materials in Spanish because of these kinds of nuanced biases (Zambrana et al., 2015). Another example of what could block access to information based on a characteristic out of the patient's control is age. Older adults face barriers to communication as they age, with the processing of information and the introduction of newer complex technology. This is also compounded by the estimate "that 70% of all cancers will occur in older individuals by 2030" (Sparks & Nussbaum, 2008). Communication demands change as the patient ages and so health care must be able to design messages to get cancer information to match their needs.

Assessments of Health Literacy Levels

The last component of SCOT to be explored is closure and stabilization. For the technology of cancer health literacy, these are the necessary steps that make the playing field even and as stabilized as possible across the patient population. This technology must fit everyone and work equitably and this is while keeping these cultural biases and accessibility inequalities that exist in the different social groups in mind.

As established throughout, the health care providers and the cancer health care system are the ones who should carry most of the responsibility; good HL starts with them. The first step for developing a framework that improves organizational HL should be the development of health literacy assessments to figure out the level of HL the patient has and maybe why they struggle accessing or understanding information. Screening of HL levels allows the care provider to identify patients who may require support and therefore can provide better resources and address their needs specifically. Women who have gone to college for example, have a better grasp on breast cancer HL than those who have not but the physician does not know that their HL varies so greatly unless they assess the individual (Zambrana et al., 2015). This can only be done if the

physician takes the initiative in that interaction to understand where the patient is at with their

HL, and this can easily be done by assessing their HL during an encounter.

There are several avenues to conduct these HL baseline tests: formal assessment, take-home surveys, in-clinic questionnaires, etc. The Agency for Healthcare Research and Quality and the Institute for Healthcare Improvement have recommended use of the teach-back method as an easily implementable way to assess a patient's HL (Yen & Leasure, 2019). The teach-back method involves oral verification of a patient's understanding and is done in a more casual setting and is an easy addition to current medical encounters. 96% of patients in a teach-backs study rated it as effective or higher and found the method statistically significant at improving patients' understanding of self-care and disease self-management (Yen & Leasure, 2019).

Information Comprehension

Teach-back method and other much needed assessments of cancer HL can be conducted during actual appointment, but some information still must be disseminated or taken home for retention. It all must follow the same rules: easily added into the healthcare processes and highly effective for comprehension. There are three main ways that instructions are given to patients for their understanding: medical advice, oral instruction, and written instruction. Of the three, medical advice is the best understood across the board as a medium to disperse information, as only 5.16% have trouble understanding it among cancer survivors (Coughlin et al., 2022). Written and oral instruction doubles in difficulty understanding getting as high as 21-25% for those with less than a HS diploma (Coughlin et al., 2022). Take-home resources provided by the cancer care providers "are often written at reading levels mismatched to those of the intended audience" (Garcia et al., 2010). This can be evidenced by the fact that of all age ranges, the 65+ population has a higher percentage of people who do not understand the written instructions they

are given (Coughlin et al., 2022). The aging population already has a hard time comprehending new information as their health and mental being changes so the need for plain language in their written materials is essential to proper health literacy.

"[P]lain language includes using familiar words and the active voice, avoiding or defining medical jargon and technical terms, simplifying grammar, breaking information into understandable chunks preceded by headings, and presenting key information first and reiterating it later" (Garcia et al., 2010). Those without a strong educational background struggle with their HL partly due to some of these components, the same was older adults do. Written materials also are not the only thing that must be presented in plain language. The core of the teach-back method is to get feedback from the patient that they understood the material and if they did not need to re-explain it. This is essentially adjusting speech to their needs and presenting it in plain language that anyone at any level could understand. The way health information is disseminated is essential to a patient's HL and again, it begins with the system improving their interactions and instructions with patients.

Conclusion

Low health literacy in cancer directly impacts a patient's outcome and is one that affects 18% of all cancer patients. HL needs to be improved so that the patient can have the greatest opportunity possible for the best outcome of their treatments. There are two main kinds of ways to think about HL, personal and organizational, and they place the responsibility of HL on different populations. To improve HL in a feasible and equitable way, an organizational approach must be taken to improve HL. Good cancer HL and promotion of it, begins with the healthcare system as they are the ones who have the medical knowledge and are responsible for their patient and their treatments. It takes the burden off the individual to find and verify the

information they may gather from other outlets, not committed to their personal health like their care providers are. While good personal HL is a necessity, it begins with how well the organization can position the individual to learn and receive the proper resources.

The first step to systematically improve cancer HL is for the care providers to assess their patient's HL levels. Different social groups affected by cancer diagnoses have varied levels of ability to make informed decisions about their healthcare. This can be seen with characteristics such as race, age, and education. Difficulty comprehending medical problems and treatments is the most common reason cancer patients face low HL and it is on the system to make sure why their advice and treatment plans are not getting across. HL assessments must be conducted for each encounter so that interactions and resources can be more tailored to each patient's needs. Comprehension levels may not be recognized if the physician does not take the initiative to do so which leaves the patient in an unfavorable position regarding their cancer health. The teach-back method is an assessment tool that can be easily incorporated by physicians today and will inform them about how well the patient understands their treatment. After assessment of cancer HL, proper materials can be assigned and disseminated for the greatest and most equitable impact on HL possible. Plain language should also be used and emphasized by cancer care providers to help mitigate both the issue of HL across the entire population as well as the disparities that exist within it.

My research is limited by current healthcare system challenges, such as staffing shortages and implicit biases, which impact the implementation of such improvements. There are also other factors that need to be explored for HL trends, as well as their interaction with the ones discussed: having a caregiver and strong familial support system, marriage, and health insurance status. Other limitations to the actual implementation of this solution include the challenge of an

additional labor a care provider must add to undertake these assessments as this strategy is implemented at an individual level, although should be systemically propagated. The logistics must be worked out as well as the challenge that is included when this assessment would not be a reimbursable aspect of the interaction and appointment. Additionally, this work can also be expanded upon by looking at these factors and producing an actual administration plan for HL assessments. These can be recorded, quantified, and analyzed for a more in depth and accurate reading of HL challenges in cancer and illuminate more systematic solutions to improve HL across the population.

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