A Direction for the Next Decade of NIH-Funded Health Literacy Research

Elaine C. Khoong, MD, MS; and Dean Schillinger, MD

Over the past 2 decades, there has been increasing recognition of the importance of health literacy (HL) with respect to health outcomes. This has been paired with investments in HL-related research from the National Institutes for Health (NIH) (Kindig et al., 2004), particularly since the publication of the 2004 National Academy Report on HL (Institute of Medicine, 2004). Villani and Trivedi (2020) describe NIH research funded between 2004 and 2017 that focused on HL and disease prevention. Their study attempts to summarize the effect and current state of HL-related research.

The authors found that, from 2004 to 2009, the amount of funding distributed for HL-related prevention research increased each year both in terms of dollar amounts and as a proportion of NIH research project grants R01, R03, and R21 funding. But from 2009 to 2017, the funding remained consistent, at approximately 0.19% of total NIH funding. Across this time period, more than 20% of HL-related studies focused on cancer-related conditions, followed by general health and infectious diseases. Nearly all studies focused only on HL at the patient or family caregiver level, rather than HL-related interventions targeting clinicians or health systems (Villani & Trivedi, 2020).

Importantly, the authors reported that funded studies provided good representation of vulnerable populations such as racial/ethnic minorities, low-income, and rural/urban sub-populations that have been found to have higher rates of limited HL and experience worse health outcomes. However, the authors were only able to report the recruitment goals as stated in grant applications and, therefore, it is unknown if the populations that ultimately were recruited represent the aspired diversity. Further, the authors did not assess if the HL measures used in funded studies have been validated for the vulnerable and diverse groups under study. Finally, the effect of grants was assessed only by the relative citation ratio, which focuses on how frequently an article has been cited relative to other articles in its field. Although this is a common metric for academic dissemination, arguably there are more relevant measures that should be considered related to research translation, such as dissemination, adoption, and implementation of findings in the real world or effects on clinical outcomes or population health.

Despite the study's limitations, a few important considerations and next steps for all stakeholders interested in HL-related research can be made, including implications for health system leaders, researchers, funders, clinicians, and patients.

Elaine C. Khoong, MD, MS, is an Assistant Professor of Medicine and a Primary Care Clinician. Dean Schillinger, MD, is a Professor of Medicine and a Primary Care Clinician. Both authors are affiliated with the Division of General Internal Medicine, Department of Medicine at Zuckerberg San Francisco General Hospital, University of California San Francisco; and the Center for Vulnerable Populations at Zuckerberg San Francisco General Hospital, University of California San Francisco.

Address correspondence to Elaine C. Khoong, MD, MS, Division of General Internal Medicine, Department of Medicine at Zuckerberg San Francisco General Hospital, University of California San Francisco, 1001 Potrero Avenue, Building 10, Ward 13, San Francisco, CA 94110; email: elaine.khoong@ucsf.edu.

BETTER ALIGNING FUNDING WITH THE SCALE OF THE PROBLEM

Although the NIH investment in HL research to date has been critical to the field, the fact that only 0.19% of the NIH budget has been targeted to HL research means that funding is inadequate given the magnitude of the problem from clinical, public health, and economic perspectives. Limited HL affects between one-third and one-half of US adults and has been estimated to generate excess annual health expenditures of more than $100 billion (2.8% of total US health care expenditures) (Vernon et al., 2007).

The Villani and Trivedi (2020) study also highlights some of gaps between what has been funded for HL-related research versus where HL-related research may have the largest public health affect. To date, the plurality of NIH-funded HL prevention research has been devoted to cancer prevention. An argument could be made that funding for HL research should disproportionately focus on conditions that are common and are most affected by limited HL, such as chronic diseases that require self-management and/or are communication-sensitive (e.g., diabetes, HIV, hypertension, heart failure, end-of-life care). Similarly, funding for HL-related research could focus on populations most affected by limited HL: low-income populations; people who are chronically ill, disabled, or elderly who are taking multiple medications; racial/ethnic minorities; and people with limited English proficiency, limited education, or learning differences (Kindig et al, 2004). It is not known if these groups are over-represented in NIH-funded HL research. In addition, funding for HL-related research should focus on settings where limited HL more commonly affects care, including practice-based research in "safety-net" settings. Finally, without ensuring that HL measures are valid across diverse populations, and without adequate representation of the aforementioned vulnerable groups and settings that are disproportionately affected by limited HL, HL-related studies may be limited by internal and external validity concerns.

EXPANDING CONCEPTIONS OF HEALTH LITERACY

Although conceptual models of HL have matured and expanded in the past decade (Sørensen et al., 2012), HL studies for the most part have not evolved to match this expanded construct. Most HL measurement tools, including the majority of those used in these NIH-funded studies, represent only a subset of the dimensions that would comprise a comprehensive measure of HL. Few studies have included all four competencies required for adequate HL: (1) ability to access health information, (2) understand the information, (3) appraise its quality, and (4) apply the information to one's own

decisions (Sørensen et al., 2012). For example, some tools only assess the ability to read health-related words of varying difficulty without an assessment of patient understanding of what is read (Haun et al., 2014). Future research should focus not only on development and use of more comprehensive measures of HL, but also ensuring that these measures are validated and applicable to diverse groups by carefully considering factors such as cultural and linguistic differences.

One of the most prominent gaps in the HL literature is the dearth of studies about HL-related measures or interventions at the clinician or system level rather than the individual patient level. Specifically, in the study by Villani and Trivedi (2020), fewer than 5% of studies involved HL issues or interventions at a clinician or system level. As such, NIH-funded research appears to be promoting a framework that favors patient-level HL as the primary way to address HL-related disparities. However, a 2012 National Academy of Medicine report (Brach et al., 2012) focuses attention on the attributes of a "health literate health care organization." These organizations make a concerted effort to "make it easier for people to navigate, understand, and use information and services to take care of their health" (Brach et al., 2012). For example, health-literate organizations ensure that HL is factored into strategic and operational planning, including explicit consideration of HL when evaluating patient outcomes and implementing quality improvement efforts. Health-literate organizations also prepare their clinicians to consider HL in their patient care. These types of design thinking and structural changes could promote equity for populations with limited HL by sharing the responsibility for mitigating negative health consequence of limited HL with clinicians and health systems. The lack of scales to measure clinicians' or organizations' accommodations for populations with limited HL may be one of the reasons for the relative lack of systems-level research. As noted by Villani and Trivedi (2020), such measures have been recently proposed and will hopefully facilitate this systems-level research.

Extant HL literature has also primarily focused on a person's health care-related or medical literacy. However, HL is relevant not only for a person's medical care (i.e., within the health care system), but also for other communal aspects of health (such as risks and exposures) related to disease prevention or health promotion (Sørensen et al., 2012). This type of HL, which has to do with critically appraising the social and environmental conditions that can generate health or illness, has been called public health literacy and has been defined as "the degree to which individuals and groups can obtain, process, understand, evaluate, and act upon information needed to make public health decisions that benefit

the community"(Freedman et al., 2009). The evolving public perception on the harms of cigarette smoke is an example of increasing public HL. As the public recognized the direct health harms of cigarette use, regulations and taxation became more prevalent. As the harms of secondhand smoke became more apparent, public support for cigarette taxes grew further and smoking bans in public venues became more common. Funding research to gain insights into how to enhance public HL would undoubtedly generate discoveries that could yield significant health impacts. Because vulnerable populations are more likely to have limited HL and are also disproportionately exposed to unhealthy social determinants of health, this research would also provide avenues to reduce health disparities (Schillinger, 2019).

ELUCIDATING THE PATHWAYS THROUGH WHICH HEALTH LITERACY AFFECTS OUTCOMES

Although limited HL is known to be associated with health outcomes, there is not much research on the pathways through which HL affects outcomes. In addition, little is known regarding the relationship between limited HL and health disparities by race/ethnicity, socioeconomic status, educational attainment, and other patient risk factors for poor health outcomes (Mantwill et al., 2015). The grant awardees described in the study by Villani and Trivedi (2020) did not specify the role of HL in nearly one-third of HL-related NIH grants. Moreover, HL was investigated as a mediator or moderator of health outcomes in only approximately one-quarter of studies.

As the US population ages and becomes increasingly diverse, and as medical care and self-management become more complex, the importance of limited HL will only grow. As such, it is crucial that we better understand the pathways between HL and health outcomes. If the research community does not better elucidate how HL is associated with outcomes and disparities—whether it is a root cause, a mediator, a moderator, has relationships that are confounded by other factors, or is simply a marker for either social disenfranchisement or historic oppression—the field will suffer from a lack of focus that will undermine advocacy efforts in support of appropriate levels of funding and program implementation. Newer approaches that automate the assessment of patient HL using computational linguistics and machine learning show promise in that they could enable researchers to discern HL-related pathways and understand the role of HL in explaining disparities based on socioeconomic status and race/ethnicity (Balyan et al., 2019).

MOVING TO INTERVENTIONS

Although there is certainly a need to improve descriptive and observational research about HL—specifically by expanding the use of comprehensive and validated measures of HL and creating studies designed to elucidate the pathways between limited HL and health outcomes—it is equally important that we move toward adopting effective HL interventions, especially using practice-based research methods and implementation science. Although it is promising that nearly three-quarters of NIH-funded HL-related prevention grants involved an intervention or trial, the lack of a comprehensive definition of HL that includes all four competencies likely has limited the effectiveness of interventions to date, as has the absence of interventions targeting clinician and organizational level HL as well as public HL. Well-designed effectiveness-implementation hybrid study designs (Curran et al., 2012) can expedite the translation of research findings into routine practice, facilitate understanding of which interventions work for whom, and also allow for exploration of any mediational or interactional effects of HL interventions on health outcomes.

In summary, over the last 15 years of NIH-funded research our understanding of HL has expanded greatly, but there remain important gaps in our knowledge about HL and significant gaps in translating new knowledge into practice. As HL researchers and clinicians practicing in safety-net health care systems, considering the future of HL research funding, we advocate for a deeper NIH commitment to HL research in line with the human and economic costs resulting from limited HL. Research should expand across (1) multiple dimensions of HL, (2) diverse sets of at-risk populations, (3) various medical conditions, (4) underserved clinical settings, and (5) levels in the socioecological model of health (Sørensen et al., 2012). Delineating the pathways through which HL affects health will provide additional motivation to enable the study of the uptake and dissemination of evidence-based HL interventions so as to promote higher-quality care and better health care outcomes, reduce health disparities, and advance population health.

REFERENCES

Balyan, R., Crossley, S. A., Brown, W., III, Karter, A. J., McNamara, D. S., Liu, J. Y., Lyles, C. R., & Schillinger, D. (2019). Using natural language processing and machine learning to classify health literacy from secure messages: The ECLIPPSE study. *PLoS One, 14*, e0212488. https://doi.org/10.1371/journal.pone.0212488 PMID:30794616

Brach, C., Keller, D., Hernandez, L., Baur, C., Parker, R., Dreyer, B., Schyve, P., Lemerise A.J., & Schillinger D. (2012). *Ten attributes of health literate health care organizations.* Retrieved from National Academy of Medicine website: https://doi.org/10.31478/201206a

Curran, G. M., Bauer, M., Mittman, B., Pyne, J. M., & Stetler, C. (2012). Effectiveness-implementation hybrid designs: Combining elements of clinical effectiveness and implementation research to enhance public health impact. *Medical Care, 50*, 217-226. https://doi.org/10.1097/MLR.0b013e3182408812 PMID:22310560

Freedman, D. A., Bess, K. D., Tucker, H. A., Boyd, D. L., Tuchman, A. M., & Wallston, K. A. (2009). Public health literacy defined. *American Journal of Preventive Medicine, 36*, 446-451. https://doi.org/10.1016/j.amepre.2009.02.001 PMID:19362698

Haun, J. N., Valerio, M. A., McCormack, L. A., Sørensen, K., & Paasche-Orlow, M. K. (2014). Health literacy measurement: An inventory and descriptive summary of 51 instruments. *Journal of Health Communication, 19*, 302-333. https://doi.org/10.1080/10810730.2014.936571 PMID:25315600

Kindig, D. A., Panzer, A. M., & Nielsen-Bohlman, L. (Eds). (2004). Health literacy: A prescription to end confusion. Retrieved from National Academies Press website: https://www.nap.edu/catalog/10883/health-literacy-a-prescription-to-end-confusion

Mantwill, S., Monestel-Umaña, S., & Schulz, P. J. (2015). The relationship between health literacy and health disparities: a systematic review. *PLoS One, 10*, e0145455. https://doi.org/10.1371/journal.pone.0145455 PMID:26698310

Schillinger, D. (2019). *Health literacy, oral health, and general health*. Retrieved from National Academies Press website: https://www.nap.edu/catalog/25468

Sørensen, K., Van den Broucke, S., Fullam, J., Doyle, G., Pelikan, J., Slonska, Z., Brand, H., & the (HLS-EU) Consortium Health Literacy Project European. (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 PMID:22276600

Vernon, J., Trujillo, A., Rosenbaum, S., & DeBuono, B. (2007). *Low health literacy: Implications for national health policy*. Retrieved from George Washington University Himmelfarb Health Sciences Library website: https://hsrc.himmelfarb.gwu.edu/sphhs_policy_facpubs/172/

Villani, J., & Trivedi, N. (2020). Health literacy research funded by NIH for disease prevention. *HLRP: Health Literacy Research and Practice*, *4*(4), e212-e223. https://doi.org/10.3928/24748307-20200928-01