

Health Literacy: Insights and Issues

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Abstract. Definitions, by their very nature, establish a shared understanding of words and concepts but also set parameters for inquiry and measures. Health literacy, a term that emerged in the 1990s, has been defined in numerous ways over time and is still considered an evolving concept. This chapter provides a discussion of the difficulties inherent in restricted definitions that have led to research gaps. The discussion highlights the need for an expanded understanding of health literacy and it identifies missing elements. A call for new measures includes attention to a full range of literacy skills including calibrations of health professionals' communication skills. In addition, it argues for an in-depth understanding of health-related tasks and texts that will yield insights for a more thorough analysis of links between and among literacy skills, health system demands, and health outcomes. Finally, this chapter presents an argument for a careful consideration of institutional and system wide norms, policies, and regulations that facilitate or impede access to health information, services, and care. As the definition of health literacy expands so too can the scope and depth of health literacy research, practice implementation, and public policy.

Keywords. Health literacy contexts, health literacy definition, health literacy environments, literacy tasks

1. Introduction

Studies in health literacy have illuminated the well-documented pathway from educational achievement to health. More than two decades of studies indicate that literacy, a foundation stone of education, is linked to a variety of health outcomes and may be a more robust predictor of health than is a measure of educational attainment. The body of literature linking health and literacy is rigorous and the relationship between patients' literacy skills and a variety of health outcomes has been established [1,2,3]. Consequently, *health literacy* has emerged as a new variable for health researchers and as an important consideration for practitioners and policy makers. Analyses are yielding insight into health literacy as a determinant of health with implications for issues of equity as well as for health disparities. Indeed, literacy and its links to health outcomes have become the focus of a growing number of research studies as well as the inspiration for institutional and governmental policy initiatives in many industrialized countries.

The term *health literacy* was formally documented by Nutbeam in the World Health Organization's 1998 Health Promotion Glossary as *the cognitive and social skills which determine the motivation and ability of individuals to gain access to,*

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understand, and use information in ways which promote and maintain good health [4]. Over time, as is often true of many new concepts and areas of study, omissions or errors are corrected, research findings as well as insightful perspectives add to or reshape original ideas, and new paths of inquiry emerge.

The chapter is divided into five sections. The next section focuses on developments in health literacy studies and practice, beginning with links to adult literacy assessments and then, with insights from literacy research, to modifications to the concept of health literacy. The third section addresses research gaps due in part to unequal attention to the full panoply of literacy skills as well as to the initial omission of considerations for the communication skills of health professionals, the quality of health texts, and the context within which health literacy exchanges take place. The fourth section focuses on new directions in health literacy research as well as practice and policy. The concluding section calls for collaborative research, practice, and policy efforts among an array of professionals in health literacy, health communication, literacy, adult literacy, as well as in public health and health care development and reform.

2. The Development and Maturation of Health Literacy

Interest in health literacy had originally been inspired by the various waves of international surveys examining the literacy skills of adults in industrialized nations. Findings from 22 nations participating in the first assessments in the 1990s – the National Adult Literacy Survey (NALS) in the U.S. [5] as well as the International Adult Literacy Surveys (IALS) [6], indicated that general assumptions about literacy skills in industrialized nations were faulty. Indeed, the more recent Adult Literacy and Lifeskills Survey (ALLS) in the early part of this century [7] and from the PIAAC Survey of Adult Skills in 2011 [8] continue to offer problematic findings of limited literacy among large percentages of the population in many countries. Universal schooling, long assumed to secure a highly literate citizenry, did not yield expected skill levels. Instead, results indicated that a majority of adults in most industrialized nations have difficulty using everyday materials to accomplish mundane tasks with accuracy and consistency. Consequently, large numbers of people do not have sufficient literacy or numeracy skills to meet many of the demands and expectations of modern life.

2.1. A New Health Variable

Health literacy research in the U.S. began soon after the findings about adult literacy skills were published and disseminated. The initial National Adult Literacy Survey (NALS) conducted in the U.S. in 1992 involved a rigorous sampling schema with more than 26,000 participants [5]. Findings that a significant proportion of U.S. adults had limited literacy skills were greeted with dismay and generated headlines. They also drew the attention of a small group of health researchers who were curious about links to health outcomes. The initial question posed by these researchers was: *given the limited literacy skills of large numbers of adults in the U.S., are there health consequences?* The answer, now evident, is clearly *yes*. By the first decade of the 21st century, health literacy research studies indicated that those with limited literacy skills face more negative health outcomes than do those with better skills. Limited health

literacy, as initially measured by reading skill components in health settings, was associated with limited participation in health promoting, disease prevention, and early detection activities; with diminished management of chronic diseases; with increased hospitalization and re-hospitalization; and with increased morbidity and mortality [1,2,3].

2.2. Population Based Measures and Findings

Population based measures of health literacy provided additional insight. The Health and Literacy Scale (HALS) was developed in 2002 to offer a direct measure of literacy skills focused on people's use of commonly available health materials to accomplish a variety of health-related tasks. The scale was comprised of items taken directly from the U.S. and international adult literacy assessments conducted between 1992 and 2005. All materials and tasks used in NALS, IALS, and ALLS were coded by Rudd and colleagues as health or non-health related and, if health related, assigned to one of five health activity categories: health promotion, health protection, disease prevention, health care management, system navigation and policy. As a result, the HALS was comprised of 191 health related items and tasks. Each item and every associated task was, of course, already calibrated for level of complexity. Thus, the HALS offered a measure of adults' ability to use a variety of health-related materials to accomplish an array of health-related tasks. The HALS supported analyses of population health literacy for any country that participated in the surveys of the 1990s or during the first decade of the 21st century [9].

HALS findings indicated that about half of U.S. adults, both those without a high school diploma and those who completed high school, have limited health literacy skills. Analyses indicate that the distribution of health literacy as well as general literacy are related to social factors such as employment, income, geography, access to resources, as well as majority or minority status. Adults who are members of a minority or marginalized group, who report living in poverty or without income from savings or retirement, and/or who are immigrants – have lower health literacy than do others with stronger access to resources [9,10]. Similar findings were reported in Canada [11], in the Netherlands [12], and Australia [13]. The HALS set the foundation for examinations of health literacy as a mediating factor in health disparities [10,12].

The U.S. Department of Education launched the National Assessment of Adult Literacy Skills [NAALS] in 2003 and, instead of applying the HALS analysis, inserted a small number of health-related items to be analyzed independently and so serve as a measure of health literacy and as a benchmark for further study [14]. Consequently, 28 new items related to 3 domains of health and health care information and services were added to the literacy assessment survey. The National Center for Education Statistics announced health literacy findings in September 2006. Twelve percent of adults scored in the proficient level and fully 53% of US adults scored in the *intermediate* range, a category indicating a need for literacy skill building. Fourteen percent of adults scored at below basic level and an additional 22% scored at the basic level. The report indicates that the average health literacy score for high school graduates was 232 on a 0 to 500 score range indicating low health literacy skills [14]. Findings, like those from the HALS analysis are troublesome.

Different in construct from the HALS and the NAALS but yielding similar findings, the European Health Literacy Survey (HLS-EU) questionnaire focused on self-perceived health literacy [15]. Participants were queried about their perceived

difficulties related to accessing, understanding, appraising, and applying health information for health promotion, disease prevention, and health care related activities. Researchers found that close to half the population within participating countries of the EU had problematic or inadequate levels of health literacy [15,16]. Data analyses indicate that population groups with lower socioeconomic status and of lower social standing within any given country (due to minority or immigrant status, for example) have lower health literacy skills or perceived more difficulty with health literacy.

Each of the three population measures yielded similar and problematic findings that substantial numbers of adults in most industrialized nations have limited health literacy. Furthermore, each of the measures indicate that health literacy is linked to a variety of social factors.

Even with these strong findings of the prevalence of limited health literacy and with research findings of links between literacy and health outcomes – health researchers, practitioners, and policy makers were somewhat stymied. How, for example, could health professionals increase the literacy or health literacy skills of the public? Wasn't this more appropriately the responsibility of the education sector? Yet, inaction or even patience in face of the documented untoward health outcomes was clearly considered inappropriate. This awareness, coupled by insights from literacy experts, set the foundation for a paradigm shift in health literacy studies. As a result, the concept of health literacy has been changing and a more nuanced understanding of health literacy as a complex variable is emerging.

2.3. Evolving Definitions and Measures

Many researchers and practitioners in this relatively new area of study have revisited the definition of terms over the past decade. Some enthusiastically continue to do so – to the occasional dismay of others who feel that modifications to the concept of health literacy distracts from research efforts and from important work ahead. Yet, a wide variety of researchers and practitioners in medicine, health education, dentistry, nursing, pharmacy, and public health have been contributing to an on-going discussion of the concept of health literacy in reports, editorials, and on line discussion sites [17–20].

A variety of definitions of *health literacy* are currently on the table and need to be carefully examined to see which ones best serve a rigorous research as well as policy agenda. Nutbeam, who provided the first official definition in the WHO Health Promotion Glossary of 1998, noted in 2008 that *health literacy* is an evolving concept [21]. As the concept evolves, so too must the definitions and the measures linked to them. After all, a definition shapes research because it suggests a focus, determines the measures to be used, and specifies who or what is to be measured. To date, most of the measures in health literacy offer a fit with the initial definitions of health literacy focused on individual skills and abilities. Logically then, the focus of the 100 plus measures of health literacy is on the skills and deficits of the public [22]. While the definition and the measures together shaped the focus of work these early definitions also carried an underlying implication that responsibility for accessing, understanding, and applying available health information lies with the patient/lay public.

At the same time, early modifications to the concept, as articulated in the U.S. 2003 Health Communication Objectives for the Nation [23], the 2004 health literacy report from the National Academies of Science [1], and the 2010 National Action Plan [24] suggested that health literacy be understood as an interaction. These reports

continue to inspire reflections about the many stakeholders involved in health literacy, the quality of health information, the skills of health professionals as well as the attributes of health institutions and systems. This broader understanding of health literacy as an interaction identifies other key variables or players, necessitates the development of new measures, and calls for more complex analyses. At the same time, it offers insight for change.

With this broader view comes an understanding that change can be effected through improved skills of the public and/or through a reduction on the demand side. Thus, the dilemma posed regarding action to be taken can be addressed by the education sector focusing on improving the literacy skills of the population and the health sector focusing on improving health information and removing literacy related barriers to services and care. As the field recalibrates focus, definitions, and measures, many research and practice gaps can be addressed.

3. Research Gaps

As noted above, a good deal of effort at the start of health literacy inquiry focused on establishing the links between literacy and health outcomes. In the initial excitement generated by this new variable for health analyses, researchers developed tools for measuring the health literacy skills and deficits of individuals (generally patients) without simultaneously measuring the difficulty of tasks as well as texts, the communication skills of those charged with presenting health information, or the context within which dialogues and interactions were taking place. The problem generated by initial conceptual limitations has led to serious gaps. This section explicates some of the missing components in health literacy. An identification of current limitations and gaps can provide insight and inspiration for further action and new discoveries.

3.1. Multiple Literacy Skills

The most commonly used early measures of individual's health literacy skills were comprised of short tests focused on reading (word pronunciation, reading comprehension skills) and, in a few cases, on use of numbers related to time and dosage [25,26]. These measures of individuals' literacy skills did indeed yield insightful findings and were powerful enough to help establish links between literacy skills and health outcomes [1]. However, because early discussions in health literacy primarily focused on and measured people's skills with the written word, discussion, interpretations, and suggestions for ameliorative action tended to focus on the written word as well. Consequently, little attention was paid to the oral exchange or to the burden of math in health discussions and decision-making. The conceptual error made in these early research efforts was, according to literacy experts such as Purcell-Gates, a limited understanding of literacy. While health literacy experts focused on print literacy, literacy scholars and educators generally think of five interrelated literacy skills: reading, writing, speaking, listening, and computation (math) as well as use of numeric concepts [27].

More recently, health researchers have been expanding the scope of inquiry to examine a broader range of literacy skills. In so doing, some researchers are using tools from other disciplines such as psychology for measuring presentation and listening

skills [28,29] as well as developing new tools that help researchers look more closely at numeracy skills [30]. As a result, studies of listening skills [31], speaking and advocacy skills [32,33,34], and numeracy skills [35] may add further insight to analyses of the links between people's literacy skills and health outcomes. Findings are also providing insights for action and model building [36,37].

3.2. Analysis of Literacy Tasks

Missing from the health literacy inquiries is attention to what it is that people are expected to do – an examination of health-related tasks. In contrast, the adult literacy surveys referenced earlier analyzed the difficulty of tasks people were asked to undertake with the various materials provided them during the survey. Participants were asked to use a variety of commonly available materials as they might in everyday life such as: use a train schedule to determine which train would get them to a specific location at a specific time; complete a bank deposit slip to add funds to an account; use directions on an over-the-counter medicine to determine correct dosage for a child of a specific age; read a newspaper sports article to find the winning team from a recent game; make use of a grocery store sale sign to determine the cost of a food item after discount; read an editorial to determine the paper's perspective or bias; or consult a growth chart to see where a child ranked compared to others. These activities or tasks were analyzed for levels of complexity. The intent, in assessing the tasks, was to be able to focus on 'functional literacy' – to examine how well people are able to use commonly available materials in order to undertake mundane activities. In order to calibrate people's functional literacy skills, the first step was to calibrate the difficulty or complexity of texts and tasks. In so doing, the adult literacy assessments were not like school-based literacy tests with a focus on comprehension of information as presented in text books considered appropriate for a specific grade. Instead, the adult surveys measured the complexity of everyday texts and tasks and then focused on what people can do with texts [38].

Kirsch, one of the developers of the adult literacy surveys, explicates the reasoning and processes that went into the construction of the instruments. Materials were drawn from readily available texts related to six aspects of life: home and family, health and safety, consumer economics, community and citizenship, work, and leisure and recreation. A variety of tasks commonly associated with these materials were then developed. For example, a bus schedule handout would be used by someone seeking to travel to a specific location during a specific time. Thus, the task associated with this specific material focused on travel objectives. Overall, tasks were organized into three major categories with increasing levels of difficulty – locate information, integrate information, and generate information. Finding a specific piece of information (locate) in a simple or even complex text would be easier than finding and comparing several pieces of information (locate, integrate) in a simple or complex text. For example, finding the winning score in a sports article about one team is far less complex a task than finding and then comparing the scores of several teams in a league to determine who is ahead of whom. The ability to discern an underlying bias in a newspaper editorial requires a reader to 'read between the lines' and therefore presents an even more difficult task. First, it requires a more careful reading than does a sports article where the reader can scan for numbers (scores). Next, this task involves interpreting what has been provided and generating a conclusion. The development of the adult literacy survey items and the decisions underlying the scoring for difficulty and

complexity of texts and tasks are delineated in a monogram by Kirsch that provides insight and assistance for health literacy researchers and practitioners wishing to more thoroughly understand barriers to information and action [38]. Evetts and Gauthier developed a workbook that directly applies this kind of analysis to a wide variety of materials [39] but such efforts have not yet been undertaken for an analysis of health materials and for health-related tasks related to the use of the health materials.

In addition, health researchers and practitioners may want to consider both proximal and distal tasks. We must certainly focus more than we have on identifying, analyzing, and simplifying the *proximal* tasks – those tasks involved in working with health texts. In addition, however, we need to consider the more *distal* tasks – those important health tasks people are expected to engage in – after they use the texts. This process would help us understand and perhaps reduce the challenges faced by people as they undertake health related actions. For example, proximal tasks for using a hospital discharge instruction sheet may include locating the section focused on cleaning a wound. The more distal tasks involve assembling needed materials and following the step-by-step procedure outlined in the directions. Needless to say, these activities rely on the clarity of the texts. However, they also involve the processes of moving literacy activities to action. Many health tasks or clusters of activities such as *taking medicine as prescribed* involve multiple *texts* (spoken and written), such as the dialogue with the doctor describing the need for and purpose of the medicine, the print prescription, the dialogue with the pharmacist, the label on the bottle, the marks on the measuring cup. Multiple tasks are involved with each of the texts such as understanding the need, recalling the purpose, filling the prescription, using the label to differentiate the new medicine from other similar bottles, noting the refill date, or calibrating the correct dose (counting or measuring). Filling the current gap in health literacy work with a deeper understanding of texts and associated tasks and of the literacy related burdens accompanying health actions sets the foundation for reducing demands on individuals. This kind of analysis can contribute to the design of more efficacious health materials, tools, and programs [40].

3.3. Conceptual Foundation

Health literacy had been primarily measured in terms of print literacy (word pronunciation, reading comprehension). Missing from the analyses were a simultaneous examination of the materials people were expected to use, as well as other important components of the literacy exchange including the skills of the health communicators – those responsible for crafting health information and delivering information through print materials or for postings on-line, as well as those engaged in interpersonal dialogue and/or in mass communication. Purcell-Gates, noted earlier for the call to expand an understanding of literacy skills, highlights the fact that literacy does not take place in a vacuum. Other players are involved and the context features large as well [1,27].

The early research studies did not contain discussions of conceptual models or theories that shaped the health literacy inquiry. Several such perspectives – from education, health communication, or the social sciences might have fostered an examination of a wider range of variables beyond patients' skills. For example, Kurt Lewin, long considered the 'grandfather' of the social sciences, envisioned and subsequently examined a force field containing both positively and negatively charged elements that influence the change process. These elements address individual as well

as historic, social, and environmental constraints and facilitating factors. Lewin contends that it is imperative to consider these multilayered factors when one is trying to understand or foster change [41]. Applying Lewin's force field analysis, a researcher studying patient engagement, for example, would include measures of the health care institution's norms, policies, and regulations as central variables.

Bronfenbrenner's social ecological model, a theory shaping many educational as well as public health programs, expanded Lewin's notion of a force field and delineated categories for the multiple contexts to be considered. Bronfenbrenner's theory highlights the importance of various layers of personal, community, institutional, physical, social, and political contexts [42]. Here too, application of the social ecological model could contribute to broader health literacy research inquiries as well as to the design of health literacy programs to bring about efficacious change [43]. Such programs would incorporate efforts that address systemic issues and include institutional practices, professional competencies, as well as the individual's skills and deficits. Finally, from a public health perspective, insights can be gained from epidemiology, a foundation stone of public health grounded in the interplay among host, agent, and environment.

The value of such theoretical constructs is discussed in the report of the National Academies of Science's Committee on Science Literacy and Public Perception of Science. Convened in 2016, the committee grappled with the concept of science literacy and the social and political environment that fosters openness or hostility, support or suspicion, to science in general, to scientists, and to scientific findings. The committee focused on the need to understand science as a social process, shaped by scientific methods and practices and on the importance of the comprehension and dissemination of findings and content. The committee report builds on the premise that science is a way of knowing about the world. At the same time, social structures support or constrain the science literacy of individuals. An expanded concept of health literacy helped shape this discussion. The health literacy lens brought to bear on these issues included attention to system demands and content complexities as well as on individual skills and abilities – that of the lay public as well as that of scientists communicating with the public [44]. An understanding of these interplays must similarly shape future health literacy research, practice, and policy.

3.4. Accessible Information

The demand side of the literacy exchange includes health materials designed to help the public understand and use health information, directions, options, and calls to action. Early health literacy studies did include research efforts focused on the difficulty of health texts. However, these efforts were not integrated into the studies of links between health literacy and health outcomes. Instead, the focus was primarily on the 'readability' of health information. For almost five decades now, researchers have been reporting on the reading level or 'suitability' of health materials, tools, and messages designed for public use – primarily related to informed consent, health information, directions, preparations, and self-care.

More than two thousand studies primarily measured 'reading grade level' of a wide array of health materials from various disciplines and covering a variety of topics. Health materials were consistently found to be problematic -- assessed at reading levels or demands that far exceed the average reading skills of the public [45–47]. This represents a serious mismatch, making a good deal of health information relatively

inaccessible. Unfortunately, reading grade tools only focus on word and sometime sentence length – indicative of difficulty in English language texts. This is now considered a relatively superficial indication of text difficulty. In contrast, the adult literacy surveys used commonly available materials, as noted above, that were all carefully analyzed and calibrated for level of complexity. Assessment criteria included attention to text type (such as narration, instruction, argument, description), to whether the presentation was in continuous (prose) or non-continuous (document) format, as well as to the presence or absence of distracting information [38].

For the health field, Doak, Doak, and Root introduced the Suitability Assessment Measurement (SAM) tool that was designed to enable health professionals to more fully analyze materials with attention to aspects of texts that facilitate or hinder reading, such as layout and design, vocabulary and sentence structure, passive or active voice, organization, cultural appropriateness, and use of visuals [48]. However, the vast majority of materials assessment studies reported in the health literature continued to focus on reading grade level, perhaps because the SAM was deemed too lengthy a process. New, shorter measures of text difficulty based on elements of the SAM are now widely available on line from the Centers for Disease Control [49] and the Agency for Healthcare Research and Quality [50].

Of course, health materials are not all prepared in prose format (full sentence and paragraph structure). Many health materials, such as labels, contain lists and many explanatory texts contain charts and graphs. Health information is also delivered via postings and videos. The PMOSE/IKIRSCH, developed by educators interested in the difficulty of lists, graphs, and charts [51], is a useful tool but, thus far, only occasionally used in health studies. In addition, several tools have been developed to help assess a wider variety of web sites and pages and have generated discussions about standards [52]. The report of Health Literacy Roundtable of the U.S. National Academies of Sciences, Engineering and Medicine's workshop on health literacy and technology offers examples of on-going developments that include evaluations of patient portals and eHealth postings [53].

Overall, the very substantial body of literature focused on the quality of health materials was not integrated into the studies of links between health literacy and health outcomes. Instead, in most health literacy studies, the health materials were often taken as a *given* and the focus was on patients' ability or inability to comprehend or use them. This might be appropriate for literacy development in schools, where an ability to read Shakespeare or Twain, for example, is considered a valuable cultural asset. However, health texts are developed for more mundane purposes. A critical research gap will be filled when all health materials are carefully examined and routinely assessed in research studies to make certain that they were developed with rigor and match the needs of the intended audience. Health materials comprise print as well as posted information, on-line information as well as mass and personal communication. Consideration need not be given only for assessing already produced or spoken health information. The readily available assessment tools are quite useful for formative research, in the development stages before health materials, messages, and postings are disseminated through appropriately designated channel of communication. Mass communication research has long indicated that the quality of a message as well as the appropriately chosen channel to be used predict audience comprehension, understanding, and perceived source credibility [54].

3.5. Health Discussions

Health information is often provided through presentations and discussion – delivered in face-to-face encounters, through in-person presentations, or over the airwaves. As indicated above, literacy experts often use the term ‘texts’ to refer to *talk* as well as to written and posted materials. The presentation of information delivered through dialogue in care settings, health related discussions, or public health announcements have not yet been thoroughly examined from a health literacy perspective.

A vast body of literature in health communication examines the relationship between the quality of the exchange in the patient/provider interaction and analyses consider links between the quality of these interactions and health outcomes. However, few studies offer a bridge between health literacy inquiry and provider-patient communication research. In order for health literacy research to expand and more thoroughly examine the oral exchange, existing measures must be adapted to address literacy related issues and thereby capture the ability of patients to articulate issues, listen to, and comfortably interrupt the provider. At the same time, the ‘other side of the coin’ must be measured as well. Characteristics of talk related to literacy such as vocabulary, sequence, highlights, repetition, summary must be captured. Consequently, we need to work closely with communication experts to adopt and adapt existing tools for health literacy research. A richer understanding of the links between literacy and health outcomes might be gleaned from concordant analyses of the ability of patients to provide data, listen, and interact as well as the ability of providers to listen, respond, and present information in a coherent and easily accessible format.

Nouri and Rudd examined health literacy as well as provider-patient literature and found a paucity of studies that included attention to literacy related issues in the critical talk (oral) and listening (aural) that takes place in clinical encounters [55]. Among the few researchers to do so, Koch Weser focused on the use of rare and common words in the clinical encounter [56] and Roter, best known for in-depth analysis of the talk in clinical encounters, included literacy analyses, for example, in genetic testing discussions [57]. In addition, Roter offers a conceptual approach for capturing the oral literacy demand in health care dialogue, provides reviews of several studies that support the predictive validity of the framework and proposes ways to both diminish literacy demand and support more effective health care exchanges [58].

3.6. Professional Training

A recognition of the importance of texts and talks brings needed attention to the skills of those presenting health information in person, of those writing and delivering announcements, of those preparing print or on-line resources, and of those constructing graphic displays. With more balanced examinations of key players in the information exchange process, additional critical variables can be analyzed and influences on health outcomes more thoroughly understood. Unfortunately, the abilities or competencies of those who provide information in health care and public health have yet to be measured with a health literacy lens and the possible contributions to health outcomes are currently unknown. Several studies have begun to assess health literacy awareness and practice in dentistry and nursing, or pharmacy [59,60,61]. Leaders in this effort include Coleman and colleagues who have been examining needed health literacy competencies in medicine [62].

At the same time, the transformation of health data into vital information for the public has not been well documented. The skills and activities of health writers have not been examined. The components of rigorous formative research to be undertaken in the production of materials have been well articulated [48–52] but we lack evidence that such processes are regularly followed. Integration of health literacy insights with professional training for those responsible for the development and design of health texts can be beneficial. Regulations related to the design of both print and eHealth materials may be called for as well [52].

3.7. Health Contexts

Educators remind us that literacy has been found to vary by situation and will be influenced by contextual factors – such as time constraints, distracters, emotion laden circumstances, and the social as well as the physical environment. Literacy experts such as Purcell-Gates and LeVine insist that any measure of literacy must consider the context within which the literacy activities occur [27,63]. Many health activities take place in agencies and institutions such as hospitals, health centers, medical offices, dental clinics as well as in public health departments, workplaces, and social service agencies – all of which are professional workplaces and institutions of considerable complexity. From the educator’s perspective, contextual factors will ease or hinder the application of literacy skills and, subsequently, the interactions. These factors must also be included in an examination of health literacy.

Institutions have expectations for those who come in from the ‘outside’. They also determine the resources available and the actions of professionals within. Behaviors of visitors as well as of workers are encouraged or stymied by cultural norms and demands and, of course, time schedules and time constraints. Thus, the context within which patients, clients, and family members are filling out forms or making decisions, health professionals are providing information, materials are chosen and disseminated, and processes are designed to be carried out – is of prime importance. Contextual attributes and systemic policies affect agency and dignity and carry stress or support for patients, family members, and professionals. When the context is highlighted as a key component of health literacy, various institutional and system factors can be identified and measured and considered in analyses of health outcomes. This process can also yield insight and impetus for needed change.

Several pieces of work have set a strong foundation for this approach. Rudd and colleagues introduced the notion of a health care environment and developed a workbook for capturing key elements and developing a strategic plan for change [64]. Several researchers are using this tool to assess a variety of health care environments such as dental services within community health centers [65] and hospitals [66]. The Universal Tool Kit includes mechanisms for assessing clinical offices and tools for change [67]. Furthermore, the U.S. National Academies Roundtable on Health Literacy introduced the notion of institutional attributes and set out a list of ten attributes necessary for the development of health literacy [68]. This publication has garnered international interest and, as a result, a variety of practitioners, managers, and policy makers are engaged in discussions of needed cultural adaptations or modifications for use in their institutions.

These developments further expand the concept of health literacy. As we examine various definitions of terms and health literacy measures, we might ask: *to what extent does the definition of terms and the accompanying measures include the interactions*

among individuals, materials, and messages designed and delivered by health professionals, as well as the norms, policies, and practices within institutions? A new definition could serve to shift away from a sole focus on the skills of the public to include the capacity of professionals and health institutions that support access to information and the active engagement of people [19,69].

3.8. Health Literacy Outside of Health Care Settings

A good deal of attention in health literacy studies was originally and is still focused on health care settings – the doctor’s or dentist’s office, the pharmacy, the community health center, the hospital. However, health related activities and decisions take place in a variety of contexts that include the home, the workplace, the community, and the voting booth. Health related deliberations and decisions accompany purchases, budgeting, insurance choices, work processes, political choices, as well as action in face of environmental hazards, natural or man-made disasters. However, health literacy studies have not ventured much outside of health care organizations and institutions. In 2000, Nutbeam suggested that health literacy include the development of skills that address social, economic, and environmental determinants of health [70].

Health literacy studies and applications can be expanded outside of the health care setting to play a vital role in each of the public health services of assessment, policy development, assurance, and research. For example, data collection and dissemination are core public health activities. If these efforts are better informed by health literacy insights, might more individuals participate in data collection efforts? If data findings are structured to be more accessible and understandable, might this enhance community action for change? Many health literacy insights and efforts could serve to inform public health programmatic work.

A greater integration of health literacy with health promotion and health protection activities can be fruitful as well [71]. In addition, insufficient attention has been paid to health literacy concerns with issues, policies, and actions related to occupational health, environmental health, or disaster management. A health literacy perspective can be brought to bear on a diverse set of topics, such as water quality, emergency response, food safety, air quality, preparedness, and policy decisions. Evaluation studies can examine efficacious change and outcomes in terms of civic engagement and community action. Research studies can inform the challenges to remove literacy-related barriers from the various local, state, regional, and national public health efforts to support and encourage the capacity of communities. One example of such an effort can be found in Japan where Goto and colleagues offered health literacy workshops for public health nurses charged with addressing community concerns in Fukushima City after the earthquake, tsunami, and power plant disaster [72].

4. New Directions in Health Literacy Research and Practice

As we explore new avenues of health literacy research and study possible ameliorative action, filling the gaps identified above can surely lead to stronger and more rigorous research and discovery as well as more efficacious practice and policies. Health literacy insights can enhance the design of patient portals, the posting of health information, the development of user-friendly consumer labels, the social and physical environment of health care institutions, the design and content of public health messages, disaster alerts

as well as the public's understanding of air or water quality or climate change. In addition, the identification and removal of literacy related barriers to information, decision-making, care, and services will support agency and dignity. As a result, we may be more successful in our efforts to increase the active engagement of health professionals, patients, family members, workers, and community residents in collaborative decision-making, healthful action, and health promoting change. This may also improve individual and community health outcomes.

The current paradigm shift in health literacy studies began with a change from a focus on the skills of individuals to an understanding of the mismatch between the literacy skills of the public and the complexity of health information. Enriching this expanded purview is the current shift from a primary focus on patients' skills as a variable of interest to a research model that includes measures of health professionals' skills as well. Most recently, an additional force for change comes with the recognition that behaviors and practices of both patients and professionals are shaped by physical, social, and political contexts. This necessitates a shift in focus from skills and abilities of lay and professional people to examinations of organizational and system-wide norms, policies, and regulations that influence the actions and resources of those seeking assistance and of those providing needed information, help, and care [73].

4.1. Research to Practice

Many fields are grappling with the dilemma of how to disseminate research findings and how to translate these findings into practice. A long-standing issue related to the development and dissemination of information for the public continues to stymie health literacy efforts. While the use of assessment tools – ranging from reading level measures to the CDC Health Literacy Index, is reported with increasing frequency, insights derived from these same tools are not yet regularly shaping the development and design of health texts. Nor have practitioners consistently adopted plain language initiatives or rigorous formative research guidelines called for in the classic Doak, Doak, and Root work [48], in the planers guide for making health communication work, famously known as the 'pink book' issued by the U.S. National Cancer Institute [74], or in the mandate from the U.S. Congress in the Plain Language Act [75].

As a result, research findings have not yet fully influenced practice. Inquiries need to be launched to enable us to identify barriers and facilitating factors that could lead to change. Those responsible for contracting or developing health materials frequently cite time or budget constraints. Such explanations for omitting rigorous formative research and pilot tests for critical information designed for the public would not be tolerated from those developing medicine, medical devices, or tools. The U.S. Plain Language Act requires attention to language in government documents but there is not yet evidence in the literature that either public health or health care institutions have issued institutional policy mandates that require proof of plain language or other formative research undertakings for materials produced in-house or through contractors. On the other hand, many institutional review boards do now expect a calculation of reading grade level for informed consent documents and other research tools. Greater respect for the power of the word is needed and added rigor must be required through regulations.

In a review of health communication during the Anthrax episode in the U.S., Rudd and colleagues noted the unnecessarily complex words and concepts used in a short postcard mailed to all households. The authors acknowledged that times of chaos do

put added stress on those agencies needing to develop rapid responses and alerts for the public. They suggested the development and training for ‘first responders’ who can be called upon to conduct rapid piloting and health literacy assessments to assure compliance with health literate communication strategies [76].

4.2. Professional Preparation

The early 2004 health literacy report from the National Academies of Science [1], called for raising awareness about health literacy and developing critical communication skills among health professionals in training and in practice. As was noted above, several researchers have examined the knowledge of health literacy amongst health care professionals and have consistently revealed limited knowledge of health literacy insights and findings. These efforts point to the need for awareness raising and skill building. Some professional schools are already engaged in the effort to raise awareness and provide mechanisms for addressing health literacy in practice and workshops are often available at local and national conferences [77,78].

4.3. Government Action and Policies

The U.S. and Canada were the first participants in the assessments of adult literacy in the early 1990s and findings inspired action on many fronts. In Canada, attention to program and policy issues were among the first steps [79]. Rootman and colleagues reviewed the early attention to health literacy in Canada and highlighted the early project on literacy and health undertaken by the Ontario Public Health Association and the establishment (in 1994) of the National Literacy and Health Program housed by the Canadian Public Health Association [80,81].

In the U.S., policy considerations followed the accumulation of research studies linking literacy to health outcomes. The first policy initiatives are evidenced in the inclusion of a health literacy objective in the health goals and objectives for the nation for 2010 [24], in the charge to examine and evaluate the findings in the field [2,3] and in the research funding earmarked for health literacy at the National Institutes for Health. Convened panels, workshops, and dissemination activities were undertaken to inspire policy development amongst professional organizations, regulatory agencies, and government institutions. For example, white papers related to the needed agenda in dentistry [82,83] and for hospitals [84] generated attention and spurred action. After the initial inclusion of improved health literacy among the goals and objectives for the nation, a U.S. Surgeon General’s Workshop on Health Literacy was convened. The ensuing report concluded that limited health literacy is a systemic problem, not an individual deficit, and that health care and health information systems must be aligned with the needs of the public [85]. The report called on public health and health care professionals to provide clear, understandable, and science-based health information to the American people. The follow-up 2010 U.S. National Action Plan to Improve Health Literacy identified key stakeholders, suggested activities and contributions, and delineated seven goals to improve health literacy with a focus on information, communication, informed decision-making, access to services, research, and practice [24].

These and other policy initiatives were not confined to North America as international conferences increasingly included health literacy on the agenda. The U.S. National Academies Health Literacy Roundtable workshop on policy action

highlighted numerous international activities undertaken [86]. Among them are the articulated health literacy goals in the Australian Safety and Quality goals for Health Care [87], the New Zealand Ministry of Health's guide: Building Health Literate Organizations in New Zealand [88]. These and other policy papers could set a foundation for future studies to examine a variety of systemic inhibiting and facilitating health literacy factors influencing health outcomes. Koh and colleagues argue that they also hold promise for moving nations beyond a focus on crisis care [89].

5. Conclusion

Finally, this delineation of gaps and new initiatives in research, practice, and policy highlight the need for collaboration with others well-schooled in fields with a rich and insightful literature, tested measures, and a history of efficacious change. The expanded agenda in health literacy calls for collaborative work with experts in literacy, researchers in health communication, and analysts focused on institutional change. In this way, contributors to health literacy can stand on the foundation set by others and together, forge new insights.

As noted at the outset, as a field of inquiry matures, new insights and perspectives bring about change and growth. Omissions or early errors are corrected, original ideas are reshaped, and new paths of inquiry emerge. As participants in health literacy studies and practice recalibrate definitions and measures and expand inquiry, research and practice gaps are being bridged.

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