A Review of the impact of the health literacy status of patients on health outcomes. Type of Article: Review

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ABSTRACT

Background

Providing quality health information is at the core of health service provision. Patients need access to impartial and high quality health information to make informed decisions on health matters. Poor health information can prevent people from making effective choices. Besides, lack of health information can be damaging for patients, their relatives, health professionals and the entire society. The objective of this review is to examine the extent and impact of low health literacy among patients by focusing on its health, economic and social impacts; it will also discuss the implications for health service providers and other stake holders by focusing on strategies that will help improve patients' health literacy status so that they can achieve good clinical outcomes.

Methods

A search of some standard books and relevant articles on health literacy among patients and its implications for health service providers was done using the Google and Yahoo search engine as well as EMBASE and OVID MEDLINE data bases. Keywords employed were low health literacy, healthcare impact and health outcomes.

Results

The problem of low literacy exists in several countries; most adults lack basic literacy skills as well as basic numeracy skills. The Health literacy statistics report of the Institute of Medicine (IOM) 2004) shows that nearly half the United States of America population has difficulty understanding and using health information.

Conclusion

Low health literacy incurs significant costs to society, investing in health literacy will improve population health outcomes and reduce health care costs.

Key words: Low health literacy, healthcare impact, health outcomes.

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INTRODUCTION

Patients and the public have many decisions to make about their healthcare and like all decision makers they require health information to inform their choices. This information which should be timely, relevant, reliable and easy to understand should be from reliable sources in order to achieve greater patient involvement in healthcare¹. Health Information is an essential component of any strategy to promote health literacy, self care, choice, shared decision making, medication adherence and self management of chronic diseases¹.

Providing quality health information is at the core of service provision, people need access to impartial and high quality information to enable them make informed decisions to empower themselves and the society ². Poor health information can prevent people from making effective choices and without information people have no real choices at all. However, lack of information can be damaging for patients, their relatives, health professionals and the entire society ². The aim of this review is to draw attention to the importance of health literacy as a major tool to improving patients' health outcomes.

Types of literacy

The field of literacy studies is active with the debate about different 'types' of literacy and their practical application in everyday life. According to Freebody and Luke, one approach to the classification of literacy simply identifies the types of literacy not as measures of achievement in terms of reading and writing, but more in connection with what literacy enables people to do for themselves and the society ³. However, Nutbeam classified literacy as follows:

Basic liferacy: This entails sufficient functional skills in reading and writing for one to be able to function effectively in everyday situations.

Communicative literacy: Involves more advanced cognitive and literacy skills which, together with social skills, can be used to actively participate in everyday activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances.

Critical literacy: An equally a more advanced cognitive skill which, together with social skills, can be applied to critically analyze information, and to use this information to exert greater control over life events and situations⁴.

The classification indicates that the different levels of literacy progressively allow for greater autonomy and personal empowerment. Progression between levels is not only dependent upon cognitive development, but also exposure to different information. This in turn, is influenced by variable personal responses to such communication which is mediated by personal and social skills, and self efficacy in relation to clearly characterized issues⁴.

The World Health Organization (WHO) defines health literacy as follows: 'Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to understand and use information in ways which promote and maintain good health' ⁵. Health literacy means more than being able to read pamphlets and successfully make appointments. In fact, it is critical to empowerment and helps to improve people's access to health information and their capacity to use information effectively. In contradistinction to the definition of basic health literacy which is not comprehensive. The WHO's definition incorporates elements of communicative and critical literacy. Besides, it significantly broadens the scope of the content of health education and communication. More so, it indicates that health literacy may have both personal and social benefits, and has profound implications for education and communication methods⁴.

In terms of 'content' the definition reveals that efforts to improve people's knowledge, understanding and capacity to act, should not only be directed at changing personal lifestyle or the way in which people use the health services. But health education could also raise awareness of the social, economic and environmental determinants of health, and be directed towards the promotion of individual and collective actions. In terms of 'health benefit', the definition implies that health literacy is not only a personal resource which leads to personal benefits, for example; healthier lifestyle choices and effective use of available health services. It also implies that the achievement of higher levels of health literacy among a greater proportion of the population will have social benefits. In terms of the 'method of education' and communication, such a definition challenges people to communicate in ways that invite interaction, participation and critical analysis⁴.

Health literacy is clearly dependent upon levels of fundamental literacy and associated cognitive development. Individuals with undeveloped skills in reading and writing will not only have less exposure to traditional health education, but also less developed skills to act upon the information received ⁴. For these reasons, strategies to promote health literacy will remain inextricably tied to more general strategies to promote literacy. But beyond this fundamental link between literacy and health literacy, much of the richness of health literacy implied by the WHO definition is missed in approaches to the promotion of basic health literacy. However, it is important to recognize that high literacy levels (assessed in terms of ability to read and write) are no guarantee that a person will respond in a desired way to health education and communication activities⁴.

Some researchers who have modeled their education programs ⁶ have shown that working to raise the 'critical consciousness' of those with little or no skills in reading and writing can undertake activities and achieve outcomes which are closely aligned to the definition of critical literacy. Furthermore, Healthy People 2010 in the United States defines health literacy as "the degree to which individuals have the capacity to obtain process and understand basic health information and services needed to make appropriate health decisions⁷. This definition has both clinical and public health approaches that tend to focus on some aspect of an individual's ability to find, understand and evaluate information which the individual could use to improve decision making that are related to health and thus, improve health and/or reduce inequities in health.

As people become more comfortable with making choices about their own health and healthcare, so the public demand for information grows. Basically, there are two types of information, both of which people need. First, general information which should be available to all about lifestyle options, care providers, diagnoses, self care management and treatment options and Second, personalized information which specifically deals with the individual's own condition, care options and possible outcomes⁸. Health literacy is "a stronger predictor of a person's health than age, income, employment status, education level, and race"⁹.

The growing emphasis on health literacy actually evolved from a long history of both successful and unsuccessful strategies of health promotion and health education. However, the clinical approach to health literacy developed mainly within the United States to assist both physicians and patients to communicate better ¹⁰. Although, the clinical approach has aggressively pursued development of diagnostic tools of health literacy for clinical settings, the public health approach has made more progress in the development of conceptual frameworks and theories of health literacy ¹⁰.

The relationship between poor literacy skills and health status is well recognized and better understood and that the interest in this relationship has led to the emergence of the concept of health literacy which emerged from two different roots; clinical care and public health ¹¹. In the clinical care concept, a strong science has developed to support screening for literacy skills in clinical care and this has led to a range of changes to clinical practice and organization which focus on obtaining information about and from the patient ¹¹. Whereas, the public health concept focused on community and preventive healthcare which has gained more ground. The conceptualization of health literacy as an asset has its roots in educational research into literacy. However, both conceptualizations are very important and are helping to stimulate a more sophisticated understanding of the process of health communication in both clinical and community settings¹¹.

Besides, the clinical and public health approaches to health literacy offer differing conceptualizations of the relationship between knowledge and health literacy. This difference reflects the core activities in clinical and public health contexts. However, the public health approach to health literacy sees acquisition of health knowledge as an integral part of health literacy rather than a separate outcome^{4,12-14}.

On the contrary, a purely clinical perspective that knowledge is a resource in individuals that 'facilitates health literacy but does not in itself constitute health literacy' has been highlighted ¹⁵. This sort of difference in conceptualization contributes to an increasingly well recognized health literacy measurement issue as, especially from a public health literacy perspective, current measures assess only limited aspects of health literacy (reading and, more rarely, limited numeracy skills)¹⁶⁻¹⁹.

Evidence of low health literacy

The problem of low literacy exists in several countries; most adults lack basic literacy skills as well as basic numeracy skills. The Health literacy statistics report of the Institute of Medicine (IOM) in 2004 shows that ninety million people in the United States (US), nearly half the population, have difficulty understanding and using health information²⁰. A study of patients at two American hospitals revealed that one third could not read and understand basic health related materials, 42% could not understand directions for taking medicine on an empty stomach and 60% could not understand a standard consent form²¹. The complex demands of modern health systems do not match up with people's knowledge and skills²². Although, a review of 178 leaflets on asthma that were being provided by general practitioners in southern England by Smith et al revealed that only 3% of leaflets were written at the reading grade that could be understood by the majority of the population 23 .

Health literacy tests

Health literacy tests are important in the evaluation of patients' reading skills, of the many tests that actually measure reading skills in adults, the one most often used in the setting of clinical medicine is the Rapid Estimate of Adult Learning in Medicine (REALM). The REALM test was designed for use in public health, primary care and medical research settings to identify patients with low (below the ninth grade) reading levels ²⁴. This test may be administered in one to two minutes and is based on word recognition. Subjects are asked to read lists of medical terms arranged in order of increasing complexity. When the subject either mispronounces a word or does not attempt to pronounce it, points are deducted as errors and the resulting score is used as a measure of their literacy in medicine and linked to reading grades used in the US²⁵. Test words relating to medicine include pills, dose,

prescription, medication and antibiotic, when scored, the test yields an approximate reading level that providers may use to tailor patient educational efforts to the needs and ability of a specific patient ²⁵.

Besides, there is another type of health literacy test known as the 'Test of Functional Health Literacy in Adults' (TOFHLA) which is used to measure functional health literacy and it requires 15 to 20 minutes to administer, both numeracy and reading comprehension are tested using actual health related materials such as prescription bottle labels and appointment slips. For example, a patient might have a prescription bottle with the label "take one tablet by mouth every 6 hours as needed". To test numeracy, the patient would be asked "if you take your first tablet at 7am, when should you take the next one?" The correct answer is "1 pm". In fact, most people are faced with the problem of understanding and interpreting numbers ²⁶. The use of these health related tools, especially in high risk environments, may appropriately target high risk patients. Interventions can be taken immediately, thereby potentially reducing the negative consequences that may result from not being able to understand or act on healthcare information. Recently, a short test of Functional Health Literacy in Adults (S-TOFHLA) has come into use in the clinical setting. The shorter version takes no more than 12 minutes to administer²⁶.

Impacts of low health literacy

Health:

Low health literacy has been linked to higher rates of hospitalization and higher use of expensive emergency services. Schillinger et al in their study revealed that among primary care patients with Type 2 diabetes, inadequate health literacy is independently associated with worse glycemic control and higher rates of retinopathy. In addition, it may contribute to the disproportionate burden of diabetes related problems among disadvantaged populations ²⁷. Williams et al in their study revealed that inadequate literacy was common and strongly correlated with poorer knowledge of asthma and improper metered-dose inhaler (MDI) use. More than half of patients reading at a sixth-grade level or less report they go to the emergency department when they have an attack compared with less than a third of literate patients. Less than one third of patients with the poorest reading skills knew they should see a physician when their asthma was not symptomatic as compared with 90% of literate patients²⁸.

The annual healthcare costs for individuals with low literacy skills are four times higher than those with higher literacy skills ²⁴. Patients with low health literacy and chronic diseases, such as diabetes, asthma, hypertension, etc, have less knowledge of their disease and its treatment. Moreover, patients with low literacy skills were observed to have a 50% increased risk of hospitalization, compared with patients who had adequate literacy skills ²⁸.

Socio-economic:

Low health literacy contributes to socioeconomic disadvantage and may prevent individuals from fully engaging with society and achieving their life goals. It is a critical component of social capital and should be treated as such in policy debates not just in health but across all sectors ²⁹. An American study estimated that low health literacy costs the American economy up to \$73 billion per year ⁹. Europe is spending millions on the healthcare sector that may easily be prevented with improved health literacy ³⁰.

However, improvements in health literacy will help overcome health inequalities ³¹. Yet policies promoting more choice for citizens may run the risk of creating a two tiered system in terms of access, where individual with health literacy are able to exercise greater choice, whilst vulnerable groups, such as the elderly, disabled, less educated, or socially excluded, 'fall through the net' ³¹. Health is not just the product of professional activities. It is a resource for individuals and society, a co-produced good and a shared responsibility across many sectors and social areas. It follows that health literacy is a shared responsibility amongst all actors of society, with citizens at the core³⁰. To improve health, policymakers, governments, citizens, public health agencies, employers, health professionals, social services, insurers, patient groups, the media and many more need to collaborate to take common action³⁰. It is clear that health literacy which is not only related to the possession of knowledge about health but an individual's ability to communicate and relate with society could be linked to personal, community and social empowerment which is very crucial to the development of society because it means that the concept of health literacy can be seen as the fundamental building block for health empowerment that can aim at reducing health inequalities and enabling communities to tackle health issues²⁹.

Strategies that will help improve patients' health literacy status

The use of adequate patient information materials:

Only few of the patient information materials give adequate health information. Far too many adopt the paternalistic view that patients cannot cope with bad news and must be kept ignorant of medical uncertainties ³². Patients are seen as lacking medical knowledge and are in dire need of instruction and reassurance, rather than as experts in their own needs and preferences. Benefits of interventions are emphasized, risks and side effects overlooked, and scientific controversies hardly ever mentioned. In too many cases the information contained in patient information leaflets is inaccurate or misleading ³². Leaflets and other information packages (video and audio tapes, computer programs, and websites) have long been seen as integral to educational strategies designed to promote health, persuade people to adopt healthy lifestyles, and increase uptake of screening ³². They have

also been developed to educate patients in self care of such chronic conditions as arthritis, hypertension and how to take medicines correctly.

There is now growing interest in providing information to support patients' participation in choosing treatments and deciding on strategies for managing their health problems ³². If patients are to be active participants in decisions about their care the information they are given must agree with available evidence and be presented in a form that is acceptable and useful. Although information materials are no substitute for good verbal discussions, consultations are usually short and plenty of evidence exists that patients do not receive the information they want and need during routine clinical consultations ³³. Leaflets and other materials can therefore play an important part in supplementing and reinforcing information provided by clinicians, but the it is important to emphasize that the information they contain must conform to the highest standards of scientific accuracy and must be tested for comprehensibility and relevance.

Researchers like Entwistle et al, and Silberg, et al, have proposed various checklists to enhance the quality of health information ^{34,35}. These cover the following issues: accessibility; acceptability; readability and comprehensibility; style and attractiveness of presentation; accuracy and reliability of content; coverage and comprehensiveness; currency and arrangements for review and updating; reference to sources and strength of evidence; reference to sources of further information; credibility of authors, publishers, and sponsors; relevance; utility. In general, far more attention has been paid to presentation and readability than to content ^{34,35}.

The use of strategies that target patients:

A traditional strategy for addressing health literacy problems has focused on developing educational programs to help increase the literacy levels of healthcare consumers. Schools, colleges, hospitals, clinics, and libraries are just some of the institutions that can offer educational programs to increase public health literacy levels ³⁶. Often this intervention strategy involves the design and redesign of health communication materials such as pamphlets, instruction guides, package inserts and websites to promote understanding. Typically, this involves translating complex terms and medical jargon into more easily understood terms, phrases, and simple sentences that the individual can understand. Charts, diagrams, and photographs are often used to help explain complex health procedures and to illustrate anatomical and biological processes ³⁶.

The use of plain language message design programs has some limitations. One potential problem is its static nature. That is, once produced, plain language documents are often used with audiences with differing literacy levels; they cannot match the language use level of all audiences. In fact, healthcare consumers, providers, and caregivers are likely to represent a range of different health literacy abilities; therefore it is best to employ the simplest possible use of plain language for documents ³⁶. Following on from this, engaging consumers in developing health communications and incorporating their insights into health messages is very important ²⁰. A variation of the message design strategy for nonnative speakers of English is to translate health information documents and materials into other languages. This process is tricky because the English language, especially technical language concerning complex medical topics, does not always translate very well into other languages, sometimes resulting in misrepresentations and misunderstanding ³⁶.

The use of strategies that target health professionals

Health information providers need to learn how to evaluate the literacy levels of those they interact with and to use this information to develop messages their audiences can understand. This also involves increasing providers' sensitivity to how anxious and ashamed many people are about having difficulty understanding health messages ³⁷⁻³⁸. Health information systems need to help create a culture where communication strategies are routinely adapted to match the literacy levels of unique audiences. Help should be routinely offered in interpreting complex health messages, as well as for completing important documents and practitioners should also consider using non written materials to convey important information to patients with limited health literacy. Even patients who read well often prefer non written materials, including straight forward picture books, videotapes, audiotapes, or multimedia presentations. Written materials from health professionals should be in plain language at the fifth grade level or lower³⁸.

Many standard patient education materials are written at a high school or college level, they are often inaccessible to patients. During clinical encounters, health practitioners need to make their communication "fit" their patients' actual level of health literacy³⁷. Sometimes, both clinicians and health educators often inadvertently hinder communication by providing too much complex background information that has little to do with what patients need to know about self care. Instead, more needs to be done to ensure real patient understanding, which is a key ingredient in adequate health literacy. Health professionals should advocate a 'teach back' or 'show me' approach and should demonstrate to patients a desired skill (for example, how to give subcutaneous insulin injection) rather than asking patients to read about the skill.

Essential skills such as listening and empathy can make a significant difference to patient outcomes and are fundamental to shared decision making and partnership care. To support this, communication skills to facilitate shared decision making should become part of core professional training at all levels. The skills needed to deliver information are in no way restricted to professional groups; every healthcare worker potentially has a role to play in acting as an information source, or signposting to the correct areas. This may be addressed through training appropriate to the level of contact with the public, patients and carers; this could range from brief instruction as part of an induction programme through to detailed training programmes which is presently lacking in most medical schools⁸.

The placing of health messages within their appropriate social context

Single issue health campaigns are unlikely to be effective if the social context for health is not targeted at the same time. Health messages and solutions must be placed within settings relevant to their target audiences and encompass both a social and health dimension³⁰. Information needs to be sensitive to culture, attitudes, competing stresses and priorities of the individuals they are targeting. Individuals facing health decisions belong to families, relationships, communities and social groups. Too often, public health campaigns make the mistake of not taken into consideration the social context of the target audience. Input from target audiences is needed to make sure the most effective and meaningful language and communication is used. Moreover, adopting a gender perspective is important; men and women may have very different attitudes towards health and health seeking behaviors. Women are considered the key conduit to health promotion within communities and are more likely to take responsibility for the health of their children and relatives³⁰.

Greater diversity is needed in how information is made available to people. Everyone should have the opportunity to access generic health information through ways that are personally acceptable. A more proactive approach is required in targeting and reaching out with information that is presented in a manner suited to personal needs. Health literacy issues and ineffective communications place patients at greater risk of preventable adverse events. If a patient does not understand the implications of his or her diagnosis and the importance of prevention and treatment plans, or cannot access healthcare services because of communication problems, an untoward event may occur³⁰. The same is true if the treating physician does not understand the patient or the cultural context within which the patient receives critical information³⁰.

The use of alternative format resources

With advances in information technology, alternative methods for making health information accessible to consumers have been developed. Foremost among such developments is the internet, through which patients can receive health information and advice. Research on alternative format resources has largely focused on the same outcomes used in the evaluation of written patient information (e.g. knowledge/recall, health behaviours, health status and health services utilisation)³⁹. The internet is an important source of health information, but

a 'digital divide' has been widely documented, with access and use more prevalent among younger, more affluent and more advantaged groups ⁴⁰. However, given the unregulated nature of the internet there is the possibility of patients having wrong information that can cause harm arising from the use of internet health information because much of the material from the internet is inaccurate or misleading and it is difficult for non specialists to sort out the wheat from the chaff ³⁹.

Coulter and Ellins reviewed the evidence for the use of audiotapes in communicating health information. They were specifically concerned with audiotape recordings of health information, delivered as educational interventions for patients and carers ³⁹. They found that patients appreciated receiving recorded information even where this did not lead to an increase in knowledge or recall.

The use of targeted mass media campaigns

The mass media is a major and influential source of consumer information. It is no surprise, then, that it is widely used for the disseminatifon of health information to patients and the general public. The strength of mass media campaigns is their potential to reach large sections of the population³⁹. This broad reach is achieved through traditional mass media vehicles such as television, radio, newspapers, posters, leaflets and booklets, as well as emerging interactive mass media applications. Mass media campaigns are most effective at raising awareness and creating a positive background context in which other interventions can be successfully deployed. Therefore, mass media campaigns are likely to be most effective when used in combination with other approaches (e.g. community outreach workers)⁴⁰.

As revealed by the various studies discussed above changes to the way patient information materials are designed and delivered have actually proved to be effective one way or the other in meeting the information needs of patients with low health literacy. The placing of health messages within their appropriate social context and the use of patient care advisors to guilderr patients through the choice process and helping them make a decision have contributed immensely to its success. Furthermore, information design that uses plain English language and the production of a single leaflet in a simple format coupled with the use of alternative formats like the use of audio-visual materials and the internet (despite its lapses) are very effective in meeting the information needs of patients with low health literacy³⁹.

Meanwhile, health literacy must be raised to the political agenda and should have designated advocates within the political process for its promotion. The voluntary sector should also be well mobilized and sensitized to provide adequate health literacy information as well as advancing policies on health literacy as the government makes commitments to long term investment in health and healthcare³⁹.

CONCLUSION

Health is too important a facet of society to be the sole responsibility of the healthcare sector alone, there should be the urgent need to build partnerships to promote health literacy ³⁹ because it is part of the fundamental skills needed to function in a modern society, just as there is a universal right of access to healthcare, the universal right of access to health literacy must be recognized by all stakeholders ³⁹. The more health literate an individual is, the healthier is the individual. So, patients need to be empowered with good information on health matters that will allow them make the right choices concerning health matters for themselves and families. Low health literacy which incurs significant costs to society worldwide will be eradicated when the strategies discussed above are put into use by all the stakeholders ¹⁴.

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