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# Supporting Radiation Therapy Patients with Limited Health Literacy

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**Abstract:** Health literacy is one of the most important determinants of patient outcome. Literacy levels are influenced by factors such as formal education status, socioeconomic circumstances, age, language, cultural background, and employment status. Few health professionals are aware of health literacy issues, and even fewer can accurately address them. The purpose of this review article was to bring attention to the issue of health literacy, to provide information on how to identify patients at risk of limited health literacy, and to develop communication strategies designed to support cancer patients and their families. This article also aimed to develop and identify specific tools for radiation therapists and the radiation medical science community based on literature, evidence, and educational material from nursing and other allied professions. Health care organizations and professionals need to be aware of their duty to ensure that patients fully comprehend both the complex and simple information presented. Improving comprehension related to health choices leads to better decision making by the patient, improves patient outcomes, reduces hospitalization rates, and cuts health care costs.

#### **RÉSUMÉ**

La littératie en matière de santé est l'un des plus importants patient, à déterminants des résultats pour le patient. Le niveau de littératie des coûts Keywords: education; health literacy; literacy strategies; medical radiation science; radiographer

est influencé par des facteurs comme l'éducation formelle, la condition socioéconomique, l'âge, la langue, le contexte culturel et le statut d'emploi. Peu de professionnels de la santé sont conscients des enjeux de littératie en matière de santé et moins encore peuvent les aborder avec exactitude. Le but de cet article est sensibiliser les lecteurs à la question de la littératie en matière de santé, de fournir de l'information sur la façon de reconnaître les patients susceptible d'être à risque en matière de littératie et de développer des stratégies de communication visant à soutenir les patients atteints de cancer et leur famille. L'article vise également à développer et à recenser des outils spécifiques pour les technologues en radio-oncologie et la communauté des sciences de la radiation médicale à partir de la documentation scientifique, des données probantes et du matériel de formation des sciences infirmières et autres professions connexes. Les organisations et les professionnels de la santé doivent être conscients qu'ils ont le devoir de faire en sorte que les patients comprennent bien les renseignements complexes qui leur sont présentés, autant que les renseignements simples. L'amélioration de la compréhension des choix en matière de santé conduit à une meilleure prise de décision par le patient, à l'amélioration des résultats pour le patient, à une réduction des taux d'hospitalisation et à une réduction des coûts de la santé.

#### Introduction

According to the Canadian Literacy and Learning Network, 55% of people over the age of 16 years and 88% over the age of 65 possess inadequate literacy skills [1]. Low literacy skills not only affect personal economic and social circumstances but also have a profound impact on one's ability to understand health care needs, options, and possible consequences related to health care choices [2]. The World Health Organization highlighted the concept of health literacy in the 1990s, and Canada responded by creating an Expert Panel on

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Health Literacy [3]. Several health literacy definitions have since been established, but the panel suggests health literacy is "the ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course" [3]. The World Health Organization and the panel explain that people should be able to comprehend, analyze, and apply health information to make the best possible decision for their health [4]. Health literacy is linked to outcomes and quality of care, and, thus, individuals should be concerned about this issue. Poor health literacy increases the likelihood of medical errors, difficulties interpreting labels and instructions, and the use of emergency services. It also "lower[s] use of preventatives such as mammography and vaccination and [results in] poorer overall health status and higher risk of mortality rates for

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seniors" [5]. Health literacy levels are important for care facilities and the government because reduced literacy increases hospitalization rates and health care costs [1, 3, 5].

#### Literacy Levels and Awareness

The notion of literacy is not as straightforward as the ability or inability to read and write. There are many different levels of literacy skills [3]. An International Adult Literacy Survey reported that 48% of Canadians have either low or very low literacy skills, which means that essentially half of patients in the current medical system have difficulty understanding the information presented [3]. Even more surprising, a survey of health care providers and policy makers concluded that the term "health literacy" is rarely used in the workplace and that there is a low level of awareness and understanding of how literacy level affects a patient's health [3, 6]. The Canadian Literacy and Learning Network concluded that "health care experts . . . have, for the most part, ignored a huge problem that may be too obvious to notice: [one] must be functionally literate to navigate the health system" [1]. Health administrators, policy makers, health care providers, and the general public must become aware of the magnitude of literacy issues and their influence on outcomes [3]. The ability to understand health information and how to best use that information for decision making is essential to help improve quality of life.

The capacity to effectively take control and manage one's health needs is influenced by age, sex, native language, cultural background, formal education, employment status, and socioeconomic environment [1–3]. Stress and anxiety can also affect one's ability to understand health information [7]. Literacy levels influence many aspects of daily life and are in fact more strongly linked to mortality rates than an individual's income or education status [3]. People with limited literacy skills not only have poorer health outcomes, but they also engage in fewer health-promoting behaviors and lifestyle, participate less in screening programs, and generally report themselves as being in poorer health [3–5]. Although many Canadians are able to function day to day with limited health literacy, they often do not have the capacity to comprehend multiple linked sentences or

grasp complex topics, such as the risk and benefits of treatment options and medications [1, 2].

Well-educated health care providers may not always be able to identify or recognize that certain patients are not able to comprehend and follow instructions even though they are literate [3]. What is often referred to as "lack of compliance" by health providers is more likely that the patient did not understand the complicated verbal or written instructions provided. The shame and fear associated with low literacy, especially for foreign language patients, results in fewer questions to doctors and pharmacists [7]. Because most people do not disclose their limited literacy due to shame, fear, and embarrassment, awareness about this issue is critical. Additionally, health care providers have a legal and professional obligation to ensure patients fully comprehend the information provided [2, 3, 6].

## Implications for Radiation Therapists

Effective strategies to reduce current communication gaps for patients and families with limited literacy capabilities have been established by nursing and other allied health groups [3, 5, 7, 8, 10]. The medical radiation science community and related journals lack published health literacy information. Consequently, there is a necessity to provide specific information about how to address and alleviate the issue of health literacy. Radiation therapists (RTs) educate patients regarding a range of sensitive and timely topics including the side effects of radiation therapy treatments, medications, skin care, nutritional information, exercise, and other psychological issues. It is imperative that patients and their families genuinely understand instructions and advice being provided by RTs in order to reduce acute and chronic side effects and improve the overall patient experience.

#### Implications for Organization

Although the primary focus of this article is to highlight implications for RTs and provide appropriate intervention strategies, the implications of health literacy on health care organizations cannot be ignored. For example, organizations influence the amount of time RTs are allocated to spend with patients to assess literacy levels, which subsequently

Table 1 Literature Search Results

Search database	Keywords	Publication Date	Results	Refined Search	Results
CINAL PLUS	Medical radiation science AND health literacy	1997–present	1	NA	NA
	Nursing AND health literacy	1997–present literacy	3,183	Allied health AND health literacy	838
		•		Keywords in abstract	3
PubMed (NML)	Medical radiation science AND health literacy	1997-present	2	NA	NA
	Nursing AND health literacy	1997–present	289	Keyword in abstract	
Academic Search Complete	Medical radiation science AND health literacy	1997–present	4	NA	NA
	Nursing AND health literacy	1997–present	2,813	Keyword in abstract	52
	Allied health AND health literacy	1997-present		Keywords in abstract	8
Proquest Nursing & Allied Health Source	Medical radiation science AND health literacy	1997–present	436	Keywords in abstract	284

NA, not applicable.

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