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Barriers and enablers to improved access to health information for patients with low health literacy in the radiotherapy department

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ABSTRACT

Introduction: The purpose of this article is to highlight the importance of assessing health literacy in the radiotherapy department and to discuss the challenges in practice. The paper aims to identify factors to facilitate improved access to, and understanding of, health information for patients with low health literacy.

Methods: A literature search was conducted using PubMed, CINAHL, Medline and Cochrane library. Non English language studies and non-healthcare related studies were excluded.

Results: The search identified 9 articles relevant to assessment of low literacy and 16 articles that address communication skills and low literacy. Four key themes were identified from the selected articles:

- Identifying low literacy
- Communication strategies
- Assessing Understanding
- Use of supportive technology

Conclusion: Current health literacy screening tools as a means of identifying patients with low literacy are not suitable for use in the radiotherapy department. Patient factors such as age, socioeconomic status, and education level, as well as the use of patient's evasion techniques can indicate low literacy. To address limited literacy skills, speaking in plain English, encouraging patients to ask questions and assessing patient's understanding are important methods to promote effective communication of information in patients with low literacy skills.

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Introduction

Patient centered care requires patients to be informed about their disease and treatment options to make informed decisions about their care.¹ Literacy refers to a person's ability to read, write and understand information. In the health care setting low literacy has been associated with poor health related knowledge, poor medication adherence, poor control of chronic illness and poor health outcomes.^{2–4} Low literacy skills range from being completely illiterate to advancing reading levels, for example, some people can read very basic text but cannot read and understand long texts such as information leaflets.⁵ In the 2003 National

Assessment of Adult Literacy, results show that 36% of patients within the American health care setting have low or very low literacy.⁶ According to Health Education England (HEE)⁷ 43% of adults do not have the literacy skills enabling them to understand health information. This has significant implications for therapeutic radiographers and other professions whose role involves providing information for patients undergoing radiotherapy.

Patients diagnosed with cancer are given a plethora of written information leaflets along the whole of their cancer pathway. For those patients receiving radiotherapy, information is provided about complex treatment options, treatment preparation and side effect management. Experiences of working with patients in a radiotherapy department highlight a lack of self-care in individuals with limited literacy, especially if they do not have a strong support network. This observation has stimulated interest in the challenges experienced by therapeutic radiographers and the wider

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multidisciplinary team when communicating information and providing explanations to patients with limited literacy.

In the radiotherapy setting, stress and anxiety can be a barrier to effective communication. For patients with low literacy, comprehension of information may be inhibited if they are not supported throughout the process. Practitioners need to overcome literacy barriers to ensure effective information provision for all. Identifying, understanding and overcoming the challenges of low literacy in the radiotherapy setting will ensure that patient information needs are being met.

Current approaches to information provision in radiotherapy practice rely heavily on verbal communication, followed by written information for patients to take home. Patients with low literacy will find limited benefit from the written information⁸ and most rely solely on verbal information. There is evidence that patients with low literacy also have low listening and understanding skills.

Given current drivers to ensure health care providers address the support needs of diverse populations, the purpose of this article is to review the challenges of assessing literacy in the radiotherapy department with an aim to identify enablers for improved access to, and understanding of, health information for patients with low health literacy.

Search strategy

The literature search was carried out using PubMed, CINAHL, Medline and Cochrane library. The key words used included *literacy, health literacy, low literacy, screening, communication and information*. The articles found were reviewed and selected if they related to either identifying or communicating with patients with low literacy. The reference lists of selected articles were then searched to identify further resources. The author decided not to limit the review to radiotherapy as the scope would have been too narrow. Studies were excluded if they were: non English language studies, included patients with learning difficulties, limited eyesight and limited hearing and studies that were not conducted in the healthcare setting. Following this, a search was also made of the Department of health and Health Education England websites to access relevant publications and reports.

Results

Of the 25 studies found from the databases, 9 related to identifying patients with low literacy and 16 related to communicating effectively with patients with low literacy. From the studies found there was limited research pertaining to the radiotherapy setting specifically; however four important themes were identified as indicated below:

- Identifying low or limited literacy
- Communication strategies
- Assessing Understanding
- Use of supportive technology

Discussion

Identifying patients with limited literacy

Identifying patients with low literacy skills can be difficult and HCPs often overestimate patients' levels of literacy.⁹ Patients are often unwilling to disclose their inability to read; for fear of embarrassment or ridicule. If the patient has spent their whole life concealing their low literacy, they will have become very skilled at it.¹⁰

Some common behaviors that may indicate potential low literacy include:

- Evasion of task with polite excuses (e.g. "I forgot my reading glasses" or "I'm too tired to read this now, I will read it when I get home"¹¹)
- Patients following text with a finger as they read.
- Issues with medication compliance
- Missed appointments
- Excuses such as not feeling well but not describe degrees or type of pain/discomfort
- Or telling you in simple language the degree and type of pain/discomfort they have

Screening tools

If a practitioner suspects a patient has low health literacy, there are many tools available to screen for health literacy. The most suitable for use in clinical practice based on efficiency and efficacy of testing include REALM-SF (Rapid estimate of adult literacy in medicine – short form) and STOFHLA (shortened test of functional health literacy in adults).¹² Both tools are validated and designed for use in the clinical setting to measure health literacy.

REALM-SF is used to rapidly evaluate a person's ability to recognise and pronounce seven medical words.¹³ The patient's score is used as an indicator for their literacy level. STOFHLA is a timed test where participants are required to fill in the blanks with multiple choice options in sentences commonly found on consent forms, education leaflets or prescriptions.¹⁴

It should be noted that there are limitations in the use of such screening tools because they do not cover all aspects pertaining to literacy and fail to test for patient understanding. Routine screening is controversial and may cause embarrassment and stigmatisation.¹² The Radiotherapy department is not a suitable environment for a patient to sit literacy tests because the patients are dealing with the stress and anxiety that comes with a cancer diagnosis¹⁶ and it is clear that alternative methods for identifying low literacy in this setting are required.

Chew et al.¹⁷ asked the question "How confident are you at filling out medical forms?" and found it to be a less intrusive method to assess patient literacy. Using REALM and STOFHLA as comparison standards they were able to show that asking that particular question was effective in detecting low health literacy without causing the patient shame or embarrassment. Only 40% of potential test subjects completed the interviews. On average people who declined could be identified as older, lower educated and of lower socioeconomic status (all factors associated with low literacy levels¹⁵) thus limiting the validity of the results. This study was set in America where patients fill in a lot of forms, and it is questionable whether Chew et al.'s¹⁷ method is transferable to a UK radiotherapy department.

Handing patients written information upside down as a simple test is described briefly by Weiss and Coyne,¹¹ patients who can read are more likely to turn the paper to the correct orientation. The effectiveness of handing written information upside down has not been tested. A flaw of this approach is that it only detects illiteracy not low literacy. If the written information contains pictures, illiterate patients may recognise this and correct according to the picture. Another consideration is that if the patient is listening to what is being spoken, they will pay little attention to the paper that has been given.

Strategies for communicating with patients with limited health literacy

To meet the demands of patients with low literacy, HCPs need to adapt communication styles to match each individual. This

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