The Instruments used to Assess Health Literacy of Prostate Cancer in Indigenous and Non-Indigenous Population: A Scoping Review

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ABSTRACT

Introduction: Prostate cancer is a major global public health concern, particularly in Canada where it is the third leading cause of cancer-related deaths among men. The economic burden associated with treating prostate cancer is substantial, and patients often experience complex and ongoing care, resulting in decreased quality of life. Indigenous populations face even greater challenges in accessing healthcare services and resources, leading to delayed diagnosis and treatment. Health literacy, the ability to understand and utilize health information, is a major predictor in quality of care and patient outcome. Despite the significance of health literacy and prostate cancer, the tools used to assess it have not been thoroughly assessed. Moreover, health literacy in indigenous populations with prostate cancer is particularly an understudied field.

Aim: This scoping review aims to explore the existing health literacy tools used in prostate cancer cohorts, assess their quality, and identify gaps in the assessment of health literacy in Indigenous populations.

Methods: A systematic search of Medline, Cumulative Index to Nursing and Allied Health Literature were performed and articles assessing health literacy in prostate cancer patients using a questionnaire were extracted.

Results: Total of 421 articles were screened, resulting in the inclusion of 16 studies. The most employed questionnaire was the Rapid Estimate of Adult Literacy in Medicine (REALM) and its variants R-REALM and SF-REALM. Other tools included the Health Literacy Questionnaire (HLQ), Short-Test of Functional Health Literacy in Adults (S-TOFHLA), the Swedish Functional Health Literacy Scale (SFHL), Health Literacy for Iranian Adults (HELIA), Brief Health Literacy Screening tool (BHLS), and others. However, none of these tools were specifically designed for assessing health literacy in prostate cancer, and none have been validated in Indigenous populations. The domains that each questionnaire assessed were explored and their limitations were identified.

Conclusion: This review provides a list of the measuring tools for prostate cancer-related health literacy. None of the tools used in the prostate cancer population were validated for indigenous people and did not consider the unique requirements of that population. Developing a tool for assessing health literacy of indigenous

patients with prostate cancer has the potential to improve patient outcomes and decision-making, leading to better quality of care and disease prognosis.

Keyword: Health literacy, Prostate Cancer, Indigenous people

INTRODUCTION

Prostate cancer is a significant public health issue worldwide, affecting men of all ages and ethnicities. It ranks as the second most common cancer among men globally, with an estimated 238,340 new cases diagnosed annually (National Cancer Institute, 2023). In Canada, approximately 24,600 new cases of prostate cancer are diagnosed every year, making it a major concern (S. Lee, 2022). It is also the third leading cause of cancer-related deaths among Canadian men, with an estimated 4,200 deaths reported annually (S. Lee, 2022).

The costs associated with treating prostate cancer in Canada are substantial (estimated at $1.5 billion per year) and increase as the disease progresses (Garaszczuk et al., 2022). Patients with prostate cancer require a complex and ongoing care, leading to longer hospital stay and decreased quality of life (Houédé et al., 2020).

The burden of prostate cancer is more debilitating in low and middle-income countries or regions with limited cultural and physical access to healthcare services or a shortage of resources that can result in delayed diagnosis and treatment (Nowroozi et al., 2023). Indigenous populations in Canada, including First Nations, Inuit, and Métis, experience a higher incidence and mortality rate of prostate cancer compared to non-indigenous populations (Mazereeuw et al., 2018). This disparity is due to various factors, including genetic and environmental factors, as well as social determinants of health such as poverty, limited access to healthcare services, and discrimination (Matti et al., 2021; Wong & Kapoor, 2017). Additionally, Indigenous populations face unique challenges in the healthcare system, such as language and cultural barriers, geographic isolation, lack of access to specialized care, systemic discrimination and low health literacy (Crengle et al., 2018; Nguyen et al., 2020).

Health literacy (HL) refers to the application of skills such as reading, numeracy and problem solving, which are used to comprehend and utilize health related information (Poureslami et al., 2017). HL can affect patient's health and disease prognosis as it is a determinant of patient's empowerment (Poureslami et al., 2022). Studies have shown that low HL is associated with worse health outcomes in patients with chronic conditions such as diabetes, cardiovascular disorders and cancer (Holden et al., 2021; Kanejima et al., 2022; Powell et al., 2007). Moreover, low HL contributes to lower cancer screening rates, delays in seeking care and misunderstandings about the treatment options (M. Lee et al., 2021). HL plays a crucial role in prostate cancer cohort. In fact, low HL is associated with worse mental well being and increased number of barriers between the patient and health care providers (Song et al., 2012). In contracts higher HL positively improve patients' quality of life, likelihood of early screening and treatment outcome (Beyer et al., 2023; Jamieson et al., 2022). To improve patients HL, it is essential implement a proper and culturally appropriate health literacy assessment tools. However, no study has evaluated the available tools being used in this field. This scoping review aimed to: I. Explore the HL tools used in patients with prostate cancer cohort; II. To assess the quality of the tools employed in both indigenous and non-indigenous populations.

METHODS

Study Question

What are the current prostate cancer health literacy tools, their characteristics specially the psychometrics and the study population reported in the literature?

Aim

This study aimed to synthesize existing evidence to evaluate the prostate cancer health literacy tools in literature and further assess their characteristics.

Study Design

This scoping review was conducted in accordance with PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 (Page et al., 2020). Given the study design, i.e., scoping review, patient consent, and ethical approval for the study were not required. The preferred formatting used was from Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guideline (Page et al., 2021).

Eligibility

To be eligible, the study must assess the health literacy of individuals at risk of prostate cancer (but not other cancers) or currently dealing with only with prostate cancer. No restriction except language (i.e., English) was applied.

Search Strategy

A systematic search of Medline, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Embase from inception to February 2025 was conducted. The search was restricted to the English language. The terms used included “prostate cancer” or “health literacy” and “indigenous people”. The search was individually tailored to each database.

Data Extraction

Articles were initially screened by title, abstract, and subsequently by a full paper review before being included in the final analysis. Two reviewers (AH and VM) independently screened titles and abstracts to exclude the duplicates and irrelevant articles. After confirming the eligibility of the studies, relevant data were independently extracted, including author, year of publication, country, study design, study population, intervention/exposure information, comparators, outcome measures, characteristics of the tool including psychometric characteristics, structure, domains, time needed to complete the survey, and method of scoring. A third party (WS) from the research team was responsible for cross-checking and resolving disagreements. Upon reviewing the articles related to indigenous populations, more information, like specific population (e.g. First Nation, Metis, Inuit, and other First Nation communities), barriers, modification or considerations were extracted.

Risk of Bias

Upon consulting with an expert librarian, the risk of bias assessment was not required in this scoping review due to our aim to only summarize the current tools in literature rather than the quality of the articles (Munn et al., 2018).

Statistical Analysis

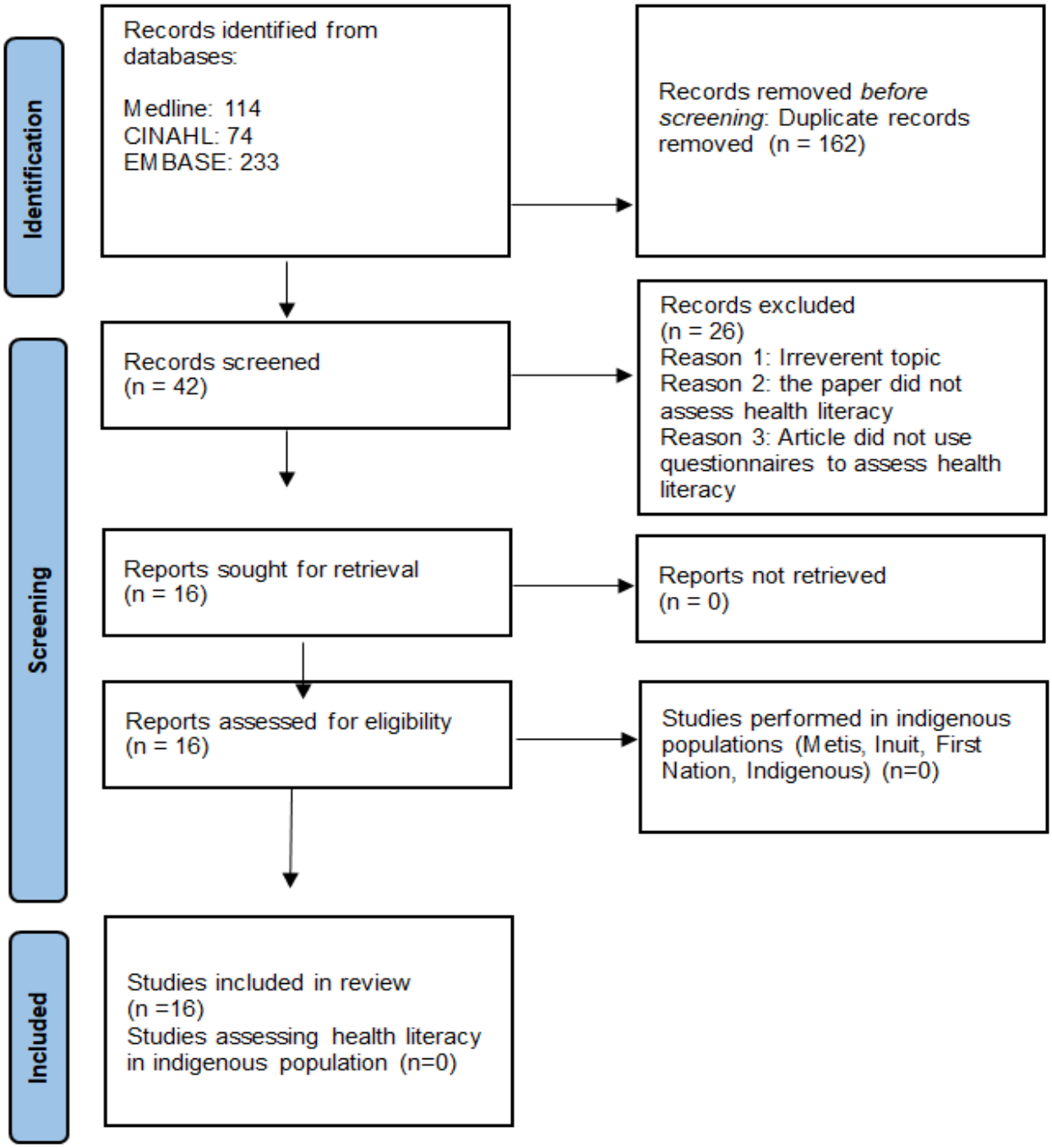
A descriptive synthesis was employed to summarize the study characteristics, patient characteristics, and study results.

RESULTS

Study Screening and Selection

A total of 421 articles were found in the three databases. Upon removing the duplicates and reviewing the titles, abstracts, and full texts, 16 articles were sought for retrieval. The PRISMA flowchart illustrates the screening process (Figure 1). The studies were conducted in USA (n=11), Canada (n=1), Iran (n=1), Denmark (n=1), Sweden (n=1), and Australia (n=1). Five extracted papers were symposium abstracts, and the remaining were published as manuscripts. Throughout our search, no study had clearly identified a specific HL tool designed for indigenous people with prostate cancer.

Figure 1. PRISMA flowchart of the screening process.



Instrument Characteristics

Rapid Estimate of Adult Literacy in Medicine (REALM) and its variants, i.e., rapid-REALM (REALM-R) and short-form REALM (REALM-SF) were the most employed questionnaire.

Among the extracted papers, the Health Literacy Questionnaire (HLQ) was employed in three studies, while the Rapid Estimate of Adult Literacy in Medicine (REALM) was utilized in four papers. The rapid-REALM (REALM-R) was used in two studies, and the short-form REALM (REALM-SF) was employed in one study. Furthermore, the Swedish Functional Health Literacy Scale (SFHL), Health Literacy for Iranian Adults (HELIA), Short-Test of Functional Health Literacy in Adults (S-TOFHLA), Brief Health Literacy Screening tool (BHLS), and two questionnaires consisted of three-items, along with a questionnaire with 27-items, were each employed in one study. Notably, the REALM and its variants (REALM-R and REALM-SF) emerged as the most frequently utilized questionnaires across the included studies. A summary of each instrument's characteristics can be found in Table 1.

Table 1. Summary of instruments used to assess prostate cancer health literacy.

Name of the suvey	Year	original country	Objective/ Subjective (Self-reported)	Time needed (minutes)	total # of questions		Domains						Reliability
						Number of Domains	Access	Understand	Communicate	Evaluate	Numeracy	Apply	Cronbach's alpha
S-TOFHLA(short form-Test of Functional Health Literacy in Adults)	1999	USA	Objective	7	40	Reading comprehension and numeracy assessment	-	Yes	-	-	Yes	-	0.68 Numeracy items and 0.97 for prose items
REALM (Rapid Estimate of Adult Literacy in Medicine)	1991	USA	Objective	2.5	66	Word recognition not comprehension	-	Yes	-	-	-	-	-
REALM-R (Rapid Estimate of Adult Literacy in Medicine-Revised)	2003	USA	Objective	-	11	-	-	Yes	-	-	-	-	0.91
HLQ (Health Literacy Questionnaire)	2013	Australia	Self-reported	7.5	44	1. Feeling understood and supported by healthcare providers 2. Having sufficient information to manage my health 3. Actively managing my health 4. Social support for health 5. Appraisal of health information 6. Ability to actively engage with healthcare providers 7. Navigating the health system 8. Ability to find good quality health information 9. Understanding health information well enough to know what to do	-	Yes	Yes	-	Yes	Yes	0.8
REALM-SF	2018	USA	Objective	1	7	Pronounciation test	-	Yes	-	-	-	-	0.96
BHLS (Brief Health Literacy Screening tool)	2011	USA	Objective	2	4	-	-	Yes	-	-	-	-	-
Health literacy for Iranian Adults (HELIA)	2017	Iran	Self-Reported	15	33	Reading (4), access (6), understanding (7), appraisal (4) and decision making (12)	Yes	Yes	-	Yes	-	-	0.85
Swedish Functional Health literacy Scale	2021	Sweden	Objective	-	36	Functional health literacy, undestanding health information, understanding health instructions, communication with health care providers, navifating the healthcare system	Yes	Yes	Yes	-	-	-	0.87

HLQ

The health literacy questionnaire (HLQ) is a 44 item self-reported questionnaire with high test-retest validity and high internal consistency (Cronbach alpha of 0.8) (Osborne et al., 2013). It is also highly reliable. Strengths of this tool are its ability to assess multiple health literacy domains and it being translated into different languages and validated in different populations. HLQ's limitations include potential self-reported bias and long completion (mean 7.5 minutes). The use of HLQ in prostate cancer population has been supported (Cronbach alpha >0.80), while its use in indigenous individuals with prostate cancer has not been validated yet (Goodwin B.C. et al., 2018).

REALM

REALM is a 66-item objective questionnaire with high construct and content validity (Davis et al., 1991). Moreover, REALM has a high internal consistency and is highly reliable. It is easy to administer, and it has been translated to multiple languages. Despite these, REALM has limitations such as its inability to assess other health literacy domains such as evaluate, communicate, apply and numeracy. Moreover, it is difficult to administer REALM to individuals who have problem reading. REALM has been used in patients with prostate cancer, but its validity of use in prostate cancer and indigenous populations are yet to be assessed.

REALM-R

REALM-R is a 11-item, objective and rapid version of REALM (Bass et al., 2003). Similar to REALM, it has a high content and construct validity with high internal consistency (Cronbach alpha 0.91). REALM-R has high test-retest reliability and is quick to administer. One limitation of REALM-R is that it only assesses the reading ability and other domains remain unassessed. REALM-R has not been validated in patients with prostate cancer and indigenous population.

REALM-SF

REALM-SF is a 7-item the short-form version of REALM (Arozullah et al., 2007). Similar to REALM, it has high content validity and internal consistency (Cronbach alpha 0.96). It is also highly reliable and easy to

administer. REALM-SF has been validated in different populations and is translated to different languages. REALM-SF limitations are similar to REALM; it only assesses the reading capability of participants and other domains remain unassessed. REALM-SF has not been validated in patients with prostate cancer and indigenous population.

S-TOFHLA

S-TOFHLA is an objective 40-item questionnaire with high internal consistency and high validity (Cronbach alpha 0.68 and 0.97) (Baker et al., 1999). It is easy to administer and can be translated to different languages. S-TOFHLA assesses participants' health literacy in understanding and numeracy domains, while the remaining domains remain unassessed. S-TOFHLA has been used in prostate cancer population studies, but its not validated in them or indigenous populations.

BHLS

BHLS is 4-item easy to administer with adequate internal consistency and reliability (Haun et al., 2012). The time needed to complete the questionnaire is rapid (2 minutes). One limitation of this tool is that it doesn't assess the numeracy component of health literacy.

HELIA

HELIA is a 33-item self-reported, multidimensional questionnaire that was proven to be valid and reliable (Cronbach alpha 0.85) (Tavousi et al., 2020). It assesses five health literacy domains (reading, access, understanding, appraisal and decision-making). Despite this coverage, the numeracy domain remains unassessed. Moreover, this questionnaire was designed for the Iranian population, and its validity in other populations is unknown. This questionnaire has been validated in prostate cancer population (content validity= 0.89, Cronbach alpha 0.85), while its validity has not been assessed in indigenous population (Rezaeian et al., 2007).

SFHL

The SFHL is a 36-item valid and reliable functional health literacy tool in the Swedish population (Cronbach alpha 0.87) (Wångdahl & Mårtensson, 2015). It is easy to administer and assesses patient's understanding, communication, and access aspects of health literacy. One limitation of this survey is it has been only validated in the Swedish population who's undergoing bariatric surgery. Moreover, other domains such as numeracy, apply and evaluate are not being assessed.

DISCUSSION

The current review provides a complete list of tools used to assess health literacy in individuals with prostate cancer. HL is a major predictor of patients' health outcome and being able to accurately assess patient's health literacy could play a major role in their prognoses and decision-making.

In this study, we've identified seven validated questionnaires that were used to assess prostate cancer health literacy. Each questionnaire had its unique limitations and strengths. A common limitation among these questionnaires was their inability to assess the numeracy domain of health literacy. All the questionnaires used were able to assess the "understanding" domain of health literacy. Moreover, the study by Jamieson et. al (2022) used a three-item questionnaire BFRSS that only assessed patients in communication and understanding domains. Similarly, Kotwal et al. (2017) used a 27-item scale to assess patients' understanding of commonly used terms. Therefore, the common theme observed in these studies is that they focus on the "understanding" domain and overlook other domains, such as access and numeracy, apply, and evaluate. Moreover, out of the seven questionnaires found, none of the were specifically designed for assessing HL in prostate cancer and only two were validated to be used in prostate cancer population. Due to this generalizability, the questionnaires may be vulnerable to not reporting the most accurate results, misleading the clinicians about patients' HL.

Prostate Cancer Health Literacy in Indigenous Population

Indigenous population is one of the under-represented cohorts in prostate cancer health literacy studies. In fact, none of the studies have used prostate cancer HL questionnaire designed for indigenous populations. This alarming finding is a cause for concern, given the high prevalence of prostate cancer in this population (Wong & Kapoor, 2017). Moreover, none of the employed tools have been validated in the indigenous population, which indicates that conventional health literacy assessment tools may not lead to an accurate representation of this population's health literacy. The existing barriers between the indigenous community and the health settings add complexity to this issue and could negatively impact the quality of care that these individuals receive.

IMPLICATIONS AND FUTURE DIRECTIONS

The current review has demonstrated the tools used to assess prostate cancer health literacy and their limitations. The development of a more comprehensive and objective yet specific questionnaire to assess prostate cancer health literacy is needed. Moreover, the development and validation of a health literacy tool designed for the indigenous population with the barriers taken into consideration are necessary to better assess their health literacy and provide a better holistic care. The created tool could have potential implications for their quality of life and disease prognosis.

LIMITATIONS

This review is subject to limitations. The study only considered works in English.

CONCLUSION

This review provides a list of the measuring tools for prostate cancer-related health literacy. Healthcare professionals and researcher can select and employ the appropriate tool for measuring health literacy in patients with prostate cancer. However, there is still a need to develop a robust and comprehensive health literacy tool for individuals at risk or living with prostate cancer. Moreover, the lack of studies conducted on prostate cancer health literacy in the indigenous population is concerning. A thoughtful health literacy questionnaire should be created for indigenous populations with their unique barriers and culture in mind.

Conflict of interest

All the authors stated that they have no conflict of interest.

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