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Review

An Integrated Model of Health Literacy Using Diabetes as an Exemplar

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ABSTRACT

Health literacy has been associated with a number of healthcare components and outcomes in individuals with chronic illnesses, including those with diabetes. Few models have been proposed to explain the relationships and pathways through which health literacy influences the health of people. Our original objective was to use the existing models to conceptualize how health literacy influences the health of people with diabetes. However, the existing models and frameworks have a number of limitations. After we discuss the limitations of existing models and views, we adapt the Paasche-Orlow and Wolf model using the available literature on health literacy in diabetes. The new model presents a more integrative and comprehensive view of health literacy, and is proposed to help healthcare providers, educators and researchers to better conceptualize and understand how health literacy can influence the health of people with diabetes. Additionally, we discuss the role of healthcare providers with people who have inadequate health literacy, identify research gaps and propose strategies to test the proposed model.

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R É S U M É

La compétence informationnelle en santé a été associée à plusieurs composantes et résultats en soins de santé chez les individus ayant des maladies chroniques, incluant ceux ayant le diabète. Quelques modèles ont été proposés pour expliquer les relations et le cheminement par lesquels la compétence informationnelle en santé influence la santé des gens. Notre premier objectif était d'utiliser les modèles existants pour conceptualiser la manière dont la compétence informationnelle en santé influence la santé des gens ayant le diabète. Cependant, les modèles existants ont de nombreuses limites. Après avoir discuté des limites des modèles existants et des opinions, nous avons adapté le modèle Paasche-Orlow et Wolf en utilisant la documentation disponible sur la compétence informationnelle en santé dans le domaine du diabète. Le nouveau modèle présente une vision plus vaste et détaillée de la compétence informationnelle en santé, et est prévu pour aider les fournisseurs de soins de santé, les éducateurs et les chercheurs à mieux conceptualiser et comprendre comment la compétence informationnelle en santé peut influencer la santé des gens ayant le diabète. De plus, nous discutons du rôle des fournisseurs de soins de santé auprès des gens qui ont une compétence informationnelle en santé inadéquate, déterminons les écarts de recherche et proposons des stratégies pour tester le modèle proposé.

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Introduction

By 2016, 2.4 million Canadians are expected to have diabetes (1), a disease that requires complex self-care management and advanced health literacy skills (2). According to White and colleagues, health literacy is “the degree to which individuals can obtain, process, understand and communicate about health-related information needed to make informed health decisions” (3). Poor

health literacy is a stronger predictor of a person's health than age, income, employment status, education level and race (4), and is associated with a wide range of adverse direct and indirect effects on care processes and health outcomes (5–7).

According to the International Adult and Literacy and Skills Survey (IALSS) (8), 60% of adult Canadians do not have adequate health literacy skills, which, according to the same survey, is lower than the percentage of the United States population who have inadequate health literacy. The IALSS also reported that Canadians with low health literacy are 1.5 times more at risk of reporting fair or poor health, being on income support and not participating in community activities than those with adequate health literacy (8). Additionally, the survey reports that a decreased level of health

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literacy is associated with an increased prevalence of diabetes in the Canadian population.

The influence of low health literacy on several components of diabetes care and management and different diabetes-related outcomes has been investigated in a number of studies that, overall, report worse outcomes associated with low health literacy. Low health literacy was found to be associated with: lack of use of preventive services (9); delayed diagnoses (10); alterations in physical and mental health (11); decreased compliance with medical instructions (12); decreased self-management skills (4,13); misunderstandings about medical conditions (5,13); poor self-rated health; increased mortality risk (7); higher utilization of services, and higher healthcare costs (6). In individuals with diabetes, research studies report the following: an association between low health literacy and worse glycemic control (4,14); higher risk of significant hypoglycemia (15); higher rates of retinopathy (4); less comprehension of medication instructions, dosing, timing and warnings (16); poorer disease knowledge (5,14), and poorer patient-physician communication (17,18).

Although the available literature on the effect of low health literacy on diabetes management and outcomes is limited, there is an indication that low health literacy adversely influences several components of diabetes care. Few experts in the field have proposed models to explain how low health literacy influences healthcare and outcomes. To understand the possible mechanisms and pathways by which low health literacy could affect the healthcare and outcomes of people with diabetes, we propose a model based on the existing models and available literature. This model could serve as a theoretical framework that would help clinicians to conceptualize how health literacy influences diabetes care and to integrate that into the care they provide to people with diabetes.

Understanding Health Literacy

Health literacy has been defined as a set of skills that constitute the ability to perform basic reading and numerical tasks required to function within healthcare environments. Berkman and colleagues have revised the “Healthy People” definition of health literacy to reflect all of its components, i.e. “functional, interactive, and critical” as identified by Nutbeam (19). Functional health literacy focuses on reading and writing skills that enable individuals to function effectively in everyday situations. Interactive health literacy includes advanced skills that allow a person to extract information, derive meaning from different forms of communication and apply new information to changing circumstances. Additionally, critical health literacy encompasses more advanced skills for critically analyzing information and using information to exert greater control over life events and situations (19).

Populations most likely to experience low-literacy levels are among those being asked to manage chronic conditions; these include older adults, ethnic minorities for whom English is a second language, people with low levels of income and education, and people with an already compromised health status (11,20). Individuals often read several grade levels lower than the highest grade achieved in school, and their health literacy may be significantly lower than their general literacy skills because of unfamiliar medical vocabulary and concepts. Thus educational attainment cannot be used as a proxy for health literacy, and consequently, identifying people with low health literacy remains challenging.

Few instruments have been developed to assess or screen for inadequate health literacy skills. These instruments vary in development, structure, measurement scope and measurement properties. The most commonly used instruments to measure health literacy are the Test of Functional Health Literacy in Adults (TOFHLA) and its shorter form s-TOFHLA (21,22), and the Rapid Estimate of Adult Literacy in Medicine (REALM) and its shorter and revised

forms (REALM-SF, REALM-R) (23,24). Other more condition-specific instruments were developed to assess health literacy in specific patient groups such as the Literacy Assessment in Diabetes (25), which was developed based on the REALM. While these instruments directly measure health literacy, they are not practical for use in clinical settings. For that, researchers in the field have developed tools that indirectly measure health literacy, which could be self- or clinician-administered and more appropriate for use in clinical settings. The most commonly used tool is a 1-item screener, the Single Item Literacy Screener (26), and 3 brief screening questions (27) that are part of a longer version of 16 questions (28). While these instruments are all available for use by researchers and clinicians, the 3 brief questions (27) were recommended as the most useful tool to screen for inadequate health literacy.

Health Literacy and Diabetes Management

It is widely recognized that the vast burden of diabetes management rests with those affected. The demands on individuals to manage their illness is complicated by the fact that diabetes has a high level of complexity and requires a significant degree of self-care, understanding of the condition and treatment, and an ability to navigate the healthcare system. Clark and colleagues conducted a review of 70 studies on self-care management in chronic illness and identified skills common to most successful self-care management initiatives (29). These skills include the ability to: recognize and act on symptoms; use medication correctly; manage emergencies; manage diet and exercise; interact effectively with healthcare providers; use community resources; adapt to work; manage relations with significant others, and manage psychological responses to illness. The ability to develop these skills and perform these tasks relies partly on the characteristics of individuals with chronic illnesses and on the healthcare systems' structure and characteristics as well.

There is a large body of literature on the factors that influence self-care management in people with diabetes. In the last few years, health literacy was found to be an important factor influencing various components of diabetes care and outcomes. Studies have reported that individuals with diabetes who have low health literacy have less knowledge and awareness about their illness and self-management behaviours (13,5,30), and have less readiness to take actions to improve their health or to perform self-care activities (14,31), ultimately leading to worsened diabetes health outcomes (4,30,32–36). Additionally, improving health literacy skills was found to lead to better self-care management behaviours in this patient population (37).

The mechanisms by which health literacy is related to health outcomes, and the direct and indirect pathways of how health literacy affects several components of diabetes care and management have not been investigated. A few generic models were developed to explain the pathways linking health literacy and health outcomes. However, these models are not comprehensive enough and do not accommodate the complexity of diabetes care spectrum; therefore, they are not useful to understand and conceptualize how health literacy influences the health of people with diabetes. Based on these models, health literacy literature in diabetes and other similar chronic illnesses, we propose an integrative model of health literacy that would help researchers and clinicians to develop a conceptual framework of health literacy to integrate into diabetes care and research.

An Integrative Model of Health Literacy: The Diabetes Exemplar

Although health literacy is a relatively new concept, a number of views have been proposed to explain the concept; 2 of the most

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