

PATIENT EDUCATION

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**The Language of Type 1 Diabetes: Why it Matters in Online Patient
Education**

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ABSTRACT. This article discusses online patient education materials (PEMs) in the context of type 1 diabetes and the language used to describe the condition. The role of healthcare providers and health information professionals in the delivery of online PEMs is described. Relevant theories regarding the impact of language are discussed. A theoretical framework for understanding and assessing PEMs is presented, along with the introduction of in-progress research on the use of language in online PEMs for adults with type 1 diabetes.

KEYWORDS. Online Patient Education, Diabetes, Language, Empowerment, Stigma

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INTRODUCTION

Online patient education is a prominent research area and aspect of patient care. Quality appraisals of online patient education materials (PEMs) ensure that content is readable, useful, accurate, and credible, and various validated tools are used to measure these domains. Patient empowerment is fundamental to disease self-management; and this is especially true with complex chronic conditions like type 1 diabetes. Examining the language of PEMs can support the critical and intentional use of content that supports provider practices and patient outcomes. For the purposes of this discussion, the term language denotes the use of empowering or disempowering terminology in PEMs.

The aim of this article is to discuss online patient education materials in the context of type 1 diabetes and the language used to describe the condition. A theoretical framework is presented, and in-progress research on the use of language in online materials is introduced.

CONSUMER HEALTH INFORMATION AND ONLINE PATIENT EDUCATION

Patient education is a well-known form of consumer health information, and research in this area has been steadily growing. Results of a recent bibliometric overview of consumer health informatics research revealed that research on patient education grew both in centrality and density from 1999 to 2019, with a rapid increase after 2015 (Ouyang et al. 2021). The researchers observed key findings within the patient education theme, including three points relevant to online formats. First, online health information was foundational to the field, and it was expected to develop and grow. Second, the internet was an important tool for patient education, and it was used to deliver self-management education and skills. Third, patient education included quality appraisal of online health information. Interestingly, the most frequently cited paper in this study was a review of empirical studies assessing the quality of Web-based health information for consumers (Eysenbach et al. 2002). Quality criteria included accuracy, completeness, technical features, readability, and design. Assessing the quality of online PEMs is a research priority but examining the use of language has received little attention in this scholarship.

DISSEMINATING PATIENT EDUCATION: HEALTHCARE PROVIDERS, HEALTH INFORMATION PROFESSIONALS, HEALTH LITERACY, AND TIMING

Healthcare Providers

Healthcare providers and health information professionals play a role in the delivery of PEMs by curating, customizing, and sharing these resources. Nurses, for example, rely on online health information to build their knowledge and confidence, and to support and educate patients and families (Grinstead, Sumner, and Inofuentes-Likins 2022). Nurses have reported modifying

content to minimize patient anxiety (Grinstead, Sumner, and Inofuentes-Likins 2022). A Cochrane review evaluating the effects of PEMs found that these materials, including online documents, may improve healthcare professionals' practice (Giguere et al. 2020). Eighty-four studies were included in this review, and the extracted data examined source, channel, message, and format. This review, however, did not consider language or terminology. The researchers concluded that further research was needed to confirm the potential impact on patient health outcomes (Giguere et al. 2020).

Health Information Professionals

Health information professionals also contribute to the delivery of PEMs, and comprehensive cancer centers represent one important setting for their work (Truccolo 2016; Volk 2007). At a center in Italy, librarians contributed to patient information and communication activities by evaluating provider-written patient education handouts, selecting appropriate evidence-based resources, and collaborating in patient education research (Truccolo 2016). Patients and families at a comprehensive center in Michigan reported that the information provided by librarians increased their knowledge and made an impact on treatment or quality of life (Volk 2007). Sources of consumer health information provided by these librarians included the internet and subscription-based databases.

A recent scoping review of the involvement of information professionals in patient- and family-centered care initiatives revealed that all included studies (n=12) described information-sharing or patient education programs (DeRosa et al. 2019). Specifically, information professionals participated by creating standardized patient education materials and tailored patient information handouts, as well as evaluating institutional materials.

Higher education also highlights the role of health information professionals in patient education. Librarians at an academic health sciences center created a continuing education

course to teach nurse educators, patient educators, dietitians, and nurses how to identify and select authoritative and reliable online patient education materials (Blake and Jagers 2019). Medical and health sciences librarians also create Web-based guides containing resources for consumer health information and appraisal, and design and deliver course-embedded instruction and workshops on these topics.

Health Literacy

The delivery of PEMs by healthcare providers and health information professionals, however, is limited by health literacy. Health literacy is a dynamic concept that involves individuals and organizations. Healthy People 2030 (Office of Disease Prevention & Health Promotion, U.S. Department of Health & Human Services 2020) describes personal health literacy as “the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and behaviors for themselves and others,” while organizational health literacy explains the role of organizations – to equitably enable these abilities and functions.

Health literacy influences the ability to understand the language used in PEMs. The health communication literature demonstrates that plain language, alongside structure and design, supports individuals’ understanding and action (Caballero 2021). Empowering language, however, is also fundamental because it facilitates an individual’s ability to implement health information for self-management decisions and behaviors. A systematic review and meta-analysis of health literacy in diabetes management interventions found that empowerment strategies can lead to positive health outcomes for people with diabetes (Kim & Lee 2016). PEMs created, tailored, and selected by healthcare providers and health information professionals should, therefore, incorporate plain language and evidence-based empowering language (Schulz and Nakamoto 2013).

Timing

Evidence suggests that the timing of patient education can have a lasting effect, and the diagnosis of a disease presents a unique opportunity for intervention. A study of patient-physician communication at the diagnosis of type 2 diabetes, for example, revealed that the content and style of communication demonstrated a lasting impact on the well-being, attitudes, and behaviors of people with diabetes (Polonsky et al. 2017). This cross-national survey assessed patient experiences during diagnosis conversations, and the findings highlighted the importance of empowering language in early interactions and education. These results could be applied to the language used in diagnosis-related online PEMs.

Results from the Nursing2020 survey of empowering language in healthcare, however, demonstrated a limited awareness of or education about empowering language (Jones 2020). Language, therefore, remains a primary area for investigation and improvement.

ONLINE PATIENT EDUCATION AND TYPE 1 DIABETES: THE IMPACT OF LANGUAGE

Patient education is especially important for self-managed chronic conditions. Type 1 diabetes is a prime example, because self-management of this condition is complex, ongoing, and demanding. In people with type 1 diabetes, the autoimmune system targets insulin-producing pancreatic cells, and insulin must be administered in order to survive. Balancing insulin with nutrition, activity, and daily stresses requires patient education and support that is empowering. National Standards for Diabetes Self-Management Education and Support (Davis et al. 2022) state that diabetes self-management education and support should be person-centered (Standard 5), and it is recommended for all people with diabetes. Since type 1 diabetes is projected to increase worldwide over the next two decades (Gregory et al. 2022), and

because it necessitates patient education for optimal outcomes, the remaining discussion features online patient education related to this condition.

Language impacts patient behaviors and outcomes, and it is a powerful tool for health-promoting behaviors (Srivastava 2019). The language used in online PEMs can empower people living with type 1 diabetes, or conversely, create anxiety and distress (Dickinson 2018; Browne 2014 et al.; Browne 2013 et al.; Beeney and Fynes-Clinton 2019). Online PEMs can be vehicles for stigmatizing, disempowering, or non-neutral language, which may create or perpetuate perceptions of judgement. People with type 1 diabetes have reported feelings of guilt, shame, blame, embarrassment, and isolation related to the perceptions of others (Liu et al. 2017). Bell, Noar, and Lazard (2021) recommended a dichotomous approach to diabetes-related language that integrates positive emotions with didactic clinical information. Since language can evoke negative emotions, it should be included in quality appraisals of evaluating online PEMs.

Organizations around the world have published diabetes language guidelines, position statements, and consensus statements. The American Diabetes Association and the Association of Diabetes Care & Education Specialists (Dickinson et al. 2017), Diabetes Canada (Banasiak et al. 2020), Diabetes Australia (Speight et al. 2021), and the English Advisory Group (Cooper et al. 2018) describe the importance of language in diabetes care, education, and communication with and about people with diabetes. Indeed, the Language Matters Diabetes (<<https://www.languagemattersdiabetes.com/the-documents>>) movement has gained global recognition and acceptance, promoting the importance of language in type 1 diabetes care. Speaking the Language of Diabetes (<<https://www.diabeteseducator.org/practice/practice-tools/app-resources/diabetes-language-paper>>) offers practical guidance for diabetes-related research, education, and publications.

Research about the language of diabetes has been examined in patient-provider communication (Polonsky et al. 2017), electronic health record documentation (Himmelstein, Bates, and Zhou 2022), and diabetes-specific media (Beeney and Fynes-Clinton 2019), as well as the terminology used in science and research (Lewis 2022; Portillo 2022). To date, however, no published studies have applied language guidelines to online PEMs.

EVALUATING ONLINE PEMs: MEASURING LANGUAGE

Ouyang et al.'s (2021) bibliometric study noted the importance of appraising online PEMs for quality. The most frequently cited paper reported an important limitation in the readability formulas; they lack assessment of the use of nonpatronizing language or motivational phrases, which can also affect comprehension (Eysenbach et al. 2002). Another highly cited paper in Ouyang et al.'s (2021) study described the DISCERN tool, an instrument used to measure the reliability and quality of written information about treatment choices (Charnock et al. 1999). The tool has also been applied to online health information (Alnaim 2019; Novin et al. 2020). One metric in DISCERN assesses shared decision-making. The questionnaire prompts respondents to look for suggestions to discuss treatment-related decisions with healthcare providers, family, or friends when answering this question. Shared decision-making is an indicator of empowering language, and national diabetes guidelines support the use of language that fosters patient-provider collaboration (Dickinson et al. 2017). While the DISCERN tool assesses this aspect of language, it does not address other evidence-based features of empowering language, such as strengths-based, neutral, stigma-free, and person-centered terminology.

Current assessments of online health information require combining multiple tools and strategies to achieve a comprehensive review (Beaunoyer et al. 2017); yet no tools directly

measure empowering language. This is especially important because words perceived negatively by patients can impact how the content is interpreted, (Dickinson 2018; Polonsky et al. 2017), regardless of the source or quality. Including empowering language in routine assessments would enhance quality appraisal and advance online PEMs.

THEORETICAL FRAMEWORK

Two theories can inform the language of online patient education materials related to type 1 diabetes: social stigma in diabetes (Schabert et al. 2013) and diabetes empowerment (Anderson and Funnell 2005). Combining these theories offers a framework for understanding and assessing diabetes-related consumer health information and online PEMs.

Social Stigma in Diabetes

Health-related stigma can be summarized as a negative social judgment based on a condition or its management. The theory of social stigma in diabetes (Schabert et al. 2013) suggests that stigma disempowers people with diabetes. The model identifies aspects of diabetes that contribute to stigma, such as chronicity, greater use of healthcare resources, and deviance from societal values. It also explains sources, experiences, consequences, and mitigating strategies of stigma for people with this condition. Language is not included, but its addition would enhance this model because disempowering words or phrases are a known source of stigma, while empowering terminology is a potential mitigating strategy. For example, Browne et al. (2013) found that diabetes-related language could reduce stigma in adults living with type 2 diabetes in Australia. Moreover, people with type 1 diabetes have suggested avoiding the word ‘diabetic’ to reduce the experience of stigma (Liu et al. 2017). Perceived and experienced stigma is common among people with type 1 diabetes (Browne et al. 2014; Liu et al. 2017).

A recent review of published literature, anti-stigma campaigns, and guidance from public health and advocacy campaigns identified stigmatizing language principles, examples, and alternatives (Healy, Richard, and Kidia 2022). Recommendations to reduce stigma and bias in clinical communication include using person-first and inclusive language, avoiding labels and pejorative terms, and avoiding attributions of responsibility or words that undermine patients' experiences. The American Diabetes Association and the Association of Diabetes Care & Education Specialists guidelines outlined diabetes-specific recommendations and emphasized using language that is free from stigma (Dickinson et al. 2017). These guidelines suggested alternatives for language with potentially negative connotations. For example, the verb 'control' should be replaced with 'manage' or 'checking blood glucose levels' because achieving control in a body with diabetes is nearly impossible (Dickinson et al. 2017). In addition, the use of 'control' can challenge an individual's sense of identity (Broom and Whittaker 2004).

Diabetes Empowerment

The use of empowering strategies, on the other hand, support positive clinical, psychosocial, and self-care outcomes (Baldoni et al. 2017). Language can be an empowering strategy when used appropriately, and a second theory offers a way of understanding its benefits. Anderson et al.'s (1991) diabetes empowerment model positions patient education in an empowering and supportive role. Healthcare providers equip patients with information to make decisions aligned with their priorities and goals, and they collaborate with patients to provide self-management options. The empowerment approach seeks to increase diabetes self-care knowledge, skills, self-awareness, and personal autonomy (Anderson et al. 1991), thereby enabling individuals to participate in their own care. Online PEMs provide an effective means for informing and empowering people living with type 1 diabetes and the general public because they are easily accessed and available.

In diabetes education and care, empowering language is strengths-based and person-first (Dickinson et al. 2017), and it focuses on choices and assets rather than limitations and shortfalls. Strengths-based language recognizes individuals' strengths, values, and circumstances, and it promotes a positive attitude towards the condition. Person-first language recognizes that people are more than diabetes, and it identifies people before the disease. 'People with diabetes,' for instance, prioritizes individuals while 'diabetic' labels people with a disease. While person-first language is not endorsed for all conditions and circumstances, it is recommended for self-managed conditions like type 1 diabetes.

The diabetes empowerment scale has been used to evaluate the effectiveness of diabetes-related educational interventions (Anderson et al. 2000). A novel application could explore the effect of empowering and disempowering language in online PEMs created for people with type 1 diabetes. This line of inquiry could describe to what degree materials support personal autonomy, goal setting, and informed decision-making.

Combined, the social stigma in diabetes (Schabert et al. 2013) and diabetes empowerment (Anderson et al. 1991; Anderson and Funnell 2005) models offer a framework for understanding and assessing the language used in publicly available online PEMs designed for people with type 1 diabetes (see Figure 1).

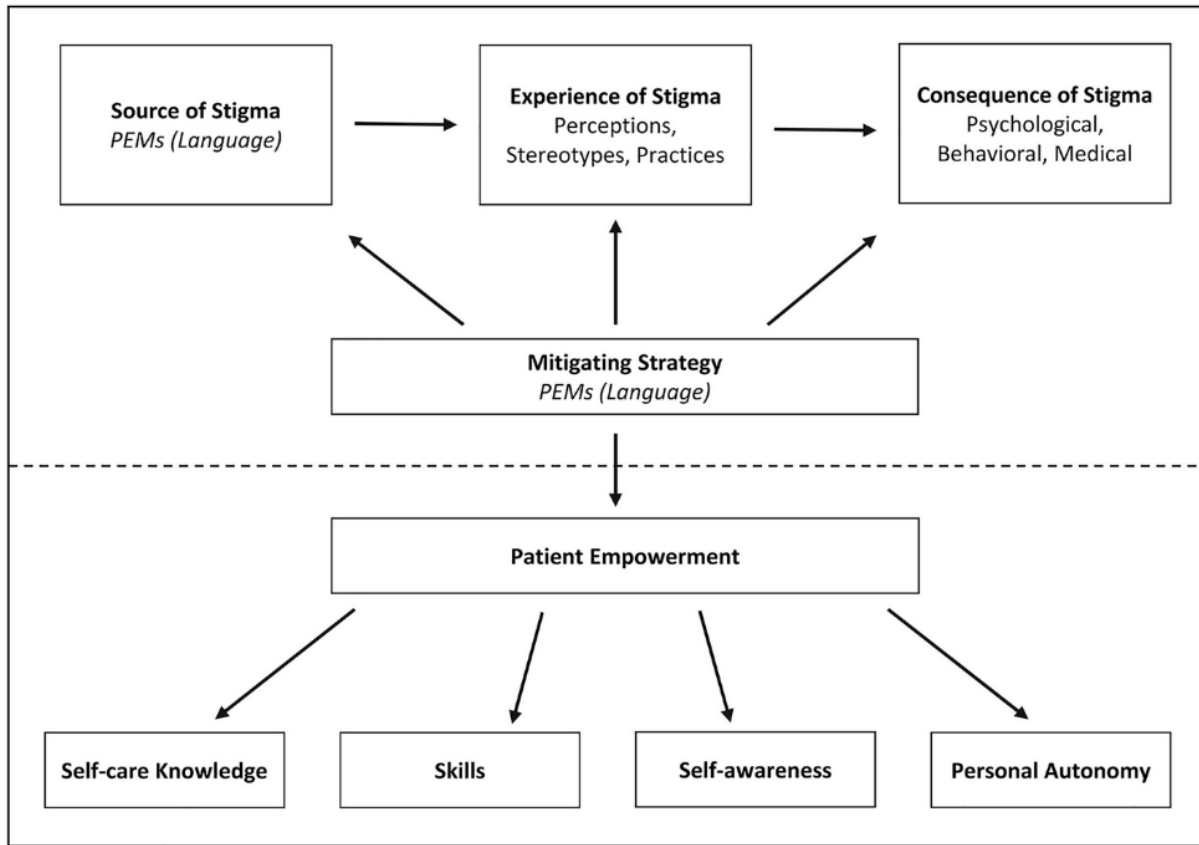


Figure 1. Theoretical Framework

Figure 1. A framework for understanding the use of language in patient education materials (PEMs) for people with type 1 diabetes. This framework combines constructs from two theories: Social Stigma and Diabetes Empowerment (Anderson et al. [1991](#); Schabert et al. [2013](#)). Italics indicate the addition of a new construct.

THE DIABETES LANGUAGE PROJECT

The Diabetes Language Project (DLP) aims to assess the use of empowering and disempowering language in online PEMs designed for adults with type 1 diabetes. This in-progress research is a collaboration of information professionals from two U.S. universities. The initial study will examine publicly available online PEMs from academic, clinical, government, and health-related organizations. Content will be limited to basic information, overview, or content for newly diagnosed patients. Materials will be analyzed for the presence of disempowering words and

phrases, as well as the context of language usage. Results from this study will advance the quality appraisal of online PEMs for people with type 1 diabetes and inform language assessments for other self-managed chronic conditions.

CONCLUSION

Online PEMs designed for people with type 1 diabetes are critical to patient outcomes and care. This article discussed the use of language in PEMs, described relevant theories, and introduced in-progress research. Anticipated results from the DLP study will support the use and inclusion of empowering language in patient education, self-management, and care. Furthermore, the findings will inform the work of healthcare providers and health information professionals and thus contribute to improvements for those living with type 1 diabetes.

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