

Factors Affecting Health Literacy as Related to Asthma and COPD Management: Learning from Patient and Health Care Professional Viewpoints

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ABSTRACT

Background: Studies have identified health literacy (HL) as an important determinant of asthma and chronic obstructive pulmonary disease (COPD) management. There are, however, limited data on patients' and health care professionals (HCPs') insights about the link between HL and management of asthma and COPD. **Objective:** The aim of this study was to elicit patients' and HCPs' perspectives with respect to factors affecting HL in the context of asthma and COPD management. **Methods:** A total of 16 semi-structured focus groups (10 in English and 6 in French) with patients with asthma or COPD (n = 93) and 45 interviews with HCPs, researchers, and policymakers were conducted between June 2015 and April 2017. Participants were asked to share their perspectives with respect to five predefined HL domains—accessing, understanding, evaluating, communicating, and using health-related information—in relation to disease self-management practices. Data were analyzed qualitatively, using a content analysis approach. **Key Results:** Most patients and HCPs reflected on factors hampering HL in relation to asthma and COPD management. Thoughts such as “not having enough time during medical consultations,” “not receiving consistent messages from different health care professionals,” and “language or cultural differences” were frequently mentioned by both patients and HCPs. **Conclusions:** We identified multiple factors affecting communication between patients and HCPs as it relates to the self-management of their disease. These included inconsistent messages from different providers, limited consultation time, use of technical language, failure to account for cultural differences, and reduced health literacy, especially as it related to written communication. Future interventions that aim to enhance HL skills in the context of asthma and COPD self-management should consider these issues. [*HLRP: Health Literacy Research and Practice. 2021;5(3):e179-e193.*]

Plain Language Summary: The current study advances the health literacy (HL) knowledge base by adding patients' and health care professionals' valuable insights on factors that hamper or facilitate HL in relation to asthma and chronic obstructive pulmonary disease (COPD) management. An important insight from this study is that receiving conflicting information from different health care professional's hampers HL in patients with asthma and/or COPD.

In 2017, more than 544 million people worldwide had a chronic airways disease (Soriano et al., 2020). Asthma and chronic obstructive pulmonary disease (COPD) are the most common chronic airways diseases, placing a high burden on health care systems and negatively affecting people's quality of life and well-being (Global Initiative for Asthma, 2018;

Global Initiative for Chronic Obstructive Lung Disease, 2019; World Health Organization, 2021).

An important determinant of asthma and COPD self-management that is increasingly receiving attention is health literacy (HL) skills (Berkman et al., 2011). HL has been defined as a person's ability to access, understand, evaluate,

communicate, and use health-related information (ie, the five-domain HL model) (Coleman et al., 2008; Rootman & Gordon-El-Bihbety, 2008; Sørensen et al., 2012).

HL is thus a multicomponent concept, covering inter-related domains and skills and referring to verbal, print, and digital information. The five-domain HL model has been infrequently applied in the literature, mainly because most often HL measures that are being used do not specifically distinguish between the five HL core domains. This has limited our understating of the impact of HL as a comprehensive phenomenon on chronic airways disease management.

Strengthening HL has been shown to build people's resilience and to improve a person's health and well-being as well as lower health care costs (Kickbusch et al., 2013). In patients with asthma and COPD, strengthening HL skills can contribute to a better understanding of disease self-management practices by applying prescribed action plans, better medication adherence, and appropriate use of inhalers (Brigham et al., 2016; Federman et al., 2014; O'Connor et al., 2015; Soones et al., 2017).

As indicated by Nutbeam (2008), HL can be regarded as an important individual asset—a means to exert greater control over health and the personal, social, and environmental determinants of health. However, HL is not merely an individual attribute, but rather a construct that emerges from

the interaction between patients and health care professionals (HCPs) or health care systems (Mitic & Rootman, 2012; van der Heide et al., 2018). This implies that HL is not only determined by patient-related influences (such as cognitive abilities or literacy skills), but also by HCP-related influences (including communication skills), as well as health system provision of easy access to needed information and services.

As part of a larger research program developing a comprehensive HL measurement tool for asthma and COPD management (Poureslami et al., 2020), this study aims to explore what factors affect HL in the context of asthma and COPD self-management according to the perspectives of patients, HCPs, researchers, and policy makers. There is a paucity of information in this regard in the literature, especially insights from the perspectives of patients and HCPs (Howard Wilsher et al., 2017).

METHODS

Research Team and Reflexivity

A project manager (I.P.) and a research coordinator (J.S.) conducted the focus groups and interviews. Both are trained and experienced researchers in the field of HL and diversity as well as in qualitative research methods. The researchers did not know the study participants beforehand. The participants received basic background information on the researchers and on the purpose of the study.

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Theoretical Framework

The methodological orientation that underpinned the study was deductive thematic analysis. The five HL domains (accessing, understanding, evaluating, communicating, and using information) were used as a theoretical framework to guide the focus group sessions and interviews as well as the content analysis.

Participant Selection, Setting, and Data Collection

Focus groups sessions. English-speaking and French-speaking female and male adults with asthma or COPD were invited to participate in separate focus group sessions at participating centers in Vancouver, Toronto, Ottawa, Montreal, and Quebec City (Canada) between June 2015 and April 2017 (Table A). In each group session, the same patient group (asthma or COPD) with a mix of female and male patients participated and shared their insights. Patients were eligible for participation if they were fluent in English or French, diagnosed as having asthma or COPD by a physician, routinely used at least one type of medication, and were age 19 years or older. Potential participants were initially identified by collaborating respiratory clinicians at each study site and were asked to provide their name and contact information on an initial consent flyer. Interested participants were then contacted by the research staff for an initial screening assessment and signing of the informed consent form to participate in the group sessions. Ethics approval was obtained by the participating centers. Focus groups were scheduled at a time convenient for the participants. The sessions were approximately 90 minutes in length and conducted in the participants' preferred language (English or French) by an experienced research coordinator and assistants. The sessions were audiotaped for verbatim transcription purposes. Transcripts were not returned to participants for comment or correction. An honorarium of \$25, as well as refreshments, was provided to participants to compensate for parking and travel.

Interviews with key informants. Of the 45 participating key informants, 30 were HCPs (including respirologists, respiratory therapists/educators, family physicians, and pharmacists) and 15 were health literacy researchers, clinician scientists, or policy makers. The key informants were recruited for participation in an individual interview via snowball sampling, introduced by study team members and an international expert panel that consisted of HL experts recruited for the parent study, between June 2015 and April 2016 (Table B). Because the majority of the key informants were HCPs, we will refer to all interviewees as HCPs. The HCPs were eligible for participation if they worked with patients

with asthma or COPD (as a clinician, researcher, or policy-maker) and were willing to share their thoughts and insights via a personalized interview. The potential participants were contacted by the research coordinator for consent and asked either to sign an informed consent form if interviewed in person or provide email consent if interviewed by phone. The interviews were in English or French and were audiotaped for verbatim transcription.

Focus Group and Interview Questions

The focus group questions were based on a literature review and feedback from the advisory panel and study team and covered issues related to HL and management of asthma or COPD. The main aim was to determine patients' experiences with respect to each of the five HL domains in relation to their disease management. A group of 14 English-speaking patients (who were not invited to the focus group sessions) were asked to review and comment on the group session questions before they were finalized. The final draft of the focus group questions was translated into French for use in the French-speaking sites (Quebec City and Montreal).

A similar approach was applied in developing a draft list of questions to be asked during each HCP interview. Specific emphasis was given to HCPs' experiences regarding the HL of patients with asthma or COPD in relation to disease management. A version of the interview questions was pilot tested with a separate sample of nine HCPs and then necessary modifications were applied.

Data Analysis

The audiotapes were transcribed verbatim by experienced English and French transcriptionists. The French language data were translated into English by a professional translator before data analysis. Transcripts of all focus groups and interviews were coded by a researcher (J.S.) who was trained in nVivo coding. A content analysis approach (Green & Thorogood, 2004; Miles & Huberman, 1994) was applied and the data were analyzed deductively, using the HL framework including the five domains. First level coding was performed on the raw data, which led to the grouping of comments of both patients and HCPs in multiple categories, including the five HL domains. The data that were clustered within these five categories was further analyzed by another researcher (I.vdH.), who coded comments of patients and HCPs that referred to factors hampering or facilitating HL. All factors mentioned by patients and HCPs were listed and other members of the research team (J.S., I.P.) reviewed the identified factors, and any disagreements were resolved during a consensus meeting.

RESULTS

A total of 16 focus groups were conducted (7 with patients with asthma [$n = 40$] and 9 with patients with COPD [$n = 53$]), of which 10 were in English and 6 were in French. The number of participants per focus group varied between two and nine. In total, 45 key informants agreed to participate in telephone or in-person interviews (see **Table A** and **Table B** for focus group and interview details). **Tables C-G** provide an overview of patient and HCP quotes per HL domain.

General Observations

A total of 32 factors affecting HL were discussed by patients and HCPs during the focus groups and interviews (**Table 1**). The factor discussed most often related to the understanding of information ($n = 14$), and the factor least discussed related to the evaluation of information ($n = 6$). Some factors were mentioned in relation to multiple HL domains (e.g., HCPs providing consistent information). Most factors were mentioned only by HCPs ($n = 15$), or by both HCPs and patients ($n = 12$) (**Table 1**). The least-discussed factors were mentioned only by patients ($n = 5$).

Domain-Transcending Factors

Whereas some factors were discussed in relation to just one of the HL domains, others were discussed in relation to multiple HL domains and, therefore, can be seen as domain transcending. One of these domain-transcending factors, mentioned by both HCPs and patients, was HCPs providing consistent information. According to HCPs, providing consistent health messages affects the understanding, evaluation, and use of attained information. One HCP mentioned:

...so the providers have to be all on the same page giving evidence-based research and relaying that information along and I think a lot of time that comes – that plays a role in the mistrust. They don't have a clue who to listen to and how often do your patients say to you, everybody is telling something different?

Also, the lack of time that HCPs have during medical consultations was discussed by both patients and HCPs as a factor affecting almost all HL domains, in particular communication between patients and HCPs. A patient stated:

Well, it is true that, in medicine, there are some who give five minutes or ten minutes, then, it happened with my family doctor, there are doctors who tell you, you have the right to one question today. So, listen, medicine... [Laughs] There are problems somewhere. [sic] We are told, I was told that: 'There, you asked two questions sir, you don't have the right to a third.'

In parallel, HCPs mentioned that there was often little time during medical consultations to check whether patients had really understood the instructions that were given to

them. Additionally, it was mentioned by several HCPs that the lack of time to support patients in their decision-making process might affect the evaluation of information by patients.

Language and cultural differences were mentioned by both patients and HCPs as a factor affecting the access to and understanding of information as well as the communication between patients and HCPs. One HCP expressed: "And not just language but also assumptions about chronic disease. [...] How do you capture different cultural perspectives? We all come in with biases."

Factors Affecting Accessing Information

Patient perspectives. With respect to access to information, patients often referred to situations in which they did not get (enough) information from their family physician or did not receive a referral from their family physician to see a respirologist or other HCP who could provide them with more information. On the other hand, patients mentioned several ways that enabled them to access the information that they needed, such as pamphlets or videos. Low literacy skills were discussed as a factor hampering the access to information. One patient mentioned:

What I like to say is I have a problem of reading (sic) or writing that much I'd like to see more tapes and videos out there, instead of writing it. My problem is reading and writing all the time.

HCP perspectives. HCPs stated that there was a lack of ongoing education to learn how to provide patients with all the information that they need to manage their condition. Access to information and education was considered especially problematic in rural areas, where patients have to travel long distances to see an HCP. Furthermore, it was mentioned that older patients are not always able to access information on the internet. Other patient-related factors that were mentioned by HCPs included a lack of functional skills among some patients (e.g., ability to read appointment cards). Also, the willingness of patients to accept help and the motivation to search for information were discussed as factors that affect patients' access to information.

Factors Affecting the Understanding of Information

Patient perspectives. The use of medical jargon hindered patients' understanding of the information provided. In line with that, patients mentioned that the complexity of information affected their understanding and, therefore, providing handouts or pamphlets with information that is written in plain language would positively affect their understanding. Moreover, patients suggested that receiving information on multiple occasions as opposed to receiving all information

TABLE 1

Factors Affecting Health Literacy Across Five Domains of Health Literacy (N = 32)

Factor	Health Literacy Domains						Mentioned by	
	Access	Understand	Evaluate	Communicate	Use	Patients	HCPs	
Lack of time during medical consultations	+	+	+			+	+	
Language and/or cultural differences	+	+		+		+	+	
Format of information	+	+				+	+	
Patient's functional skills	+						+	
Patient's literacy skills	+					+		
Patient's acceptance of help	+						+	
Patient's motivation	+				+	+	+	
Type of health care provider	+					+		
Location of health care facilities	+						+	
Availability of information/education	+					+	+	
HCPs providing consistent health messages		+	+		+		+	
HCPs use of medical jargon/power imbalance		+		+		+	+	
Context (receiving information in a stressful situation)		+		+			+	
Patient's attitude		+			+		+	
Patient's cognitive abilities		+					+	
Patient's computer skills		+					+	
Timing of providing information		+				+	+	
Singularity of information		+					+	
Repetition of information		+					+	
Professional support with understanding		+				+		
Complexity of information		+				+		
Patient's trust in information			+			+	+	
Patient's lack of ability to judge the credibility of information			+			+		
HCPs attitude			+				+	
Inaccuracy of online information			+				+	

TABLE 1 (continued)

Factors Affecting Health Literacy Across Five Domains of Health Literacy (N = 32)

Factor	Health Literacy Domains					Mentioned by	
	Access	Understand	Evaluate	Communicate	Use	Patients	HCPs
Patient's understanding of their condition				+		+	+
HCPs (nonverbal) communication skills				+		+	+
Patients' ability to ask questions				+		+	+
Patient's ability to make decisions					+		+
Relevancy of provided information (whether it is personalized)					+	+	+
Family member or caregiver involvement					+		+
Peer involvement					+		+

Note. HCPs = health care professionals.

at once would positively affect their understanding of it, as well as demonstrating specific self-management tasks instead of merely describing them. In addition, patients said that receiving more explanation from an HCP (e.g., a nurse or educator) could positively affect understanding of information.

HCP perspectives. Several HCPs mentioned that the use of medical jargon hampers the understanding of information by patients. Another factor hampering the understanding of information is the fact that patients often receive this information while being in a vulnerable and stressful situation (e.g., when in the hospital due to an exacerbation), thus making them less receptive to the processing of new information. One HCP said:

A lot of that is the stress of the situation. I mean, we meet with people when they are the most vulnerable and they are sick and then you are asking them to process complex information and it's not ideal at all.

HCPs also mentioned that receiving too much information at the same time hampers patients' understanding of information. Furthermore, several patient-related factors were mentioned by HCPs that may affect patients' understanding of information, such as the cognitive abilities of patients (including how patients process information) and their attitude toward health care services.

Factors Affecting the Evaluation of Information

Patient perspectives. Patients only talked about judging the credibility of online information, not of other formats, such as information in print. The attitude of HCPs was mentioned as a factor that can affect trust in provided information. One patient stated:

It was just because of what she said made you feel – like her attitude made you feel like you could trust her. Immediately and then that's why – like, because you trusted what she said that's why you decided to try it.

HCP perspectives. The evaluation of online information by patients can be affected by the fact that websites discussing disease management often provide inaccurate information. One HCP suggested that HCPs need to check what patients already know and adapt further communication to that. In line with the findings based on the patient focus groups, HCPs mainly referred to the evaluation of online information.

Factors Related to Communication

Patient perspectives. When it came to communication, it was mentioned by patients that it can be difficult to ask questions during medical consultations because HCPs may operate under the assumption that the patient fully understands the provided information, and the patient may feel

uncomfortable in stating that in fact, they do not understand it. Furthermore, one patient mentioned that as a patient, he does not have the same vocabulary (medical terms) as the health care professional, making it more difficult to express her/himself. Nonverbal communication skills of HCPs were also frequently mentioned as a determinant of communication. In contrast, several patients said that some doctors are simply better communicators than others.

HCP perspectives. HCPs mentioned that patients do not always feel comfortable or confident in asking questions or might not know what to ask, which affects communication between patients and HCPs. A lack of a basic understanding among patients about their condition was also mentioned as a factor affecting communication. HCPs also mentioned factors related to the performance of HCPs, including the use of medical jargon and inadequate nonverbal communication skills. The context in which communication takes place was also considered to be a determinant of effective communication. One HCP mentioned:

And the whole health environment is – we just – if you are trying to communicate with somebody who is wearing a gown that is open in the back and they are freezing sitting on an exam table, I mean, this is not a good environment to be trying to help people learn information.

Factors Related to the Use of Information

Patient perspectives. An important factor that can determine the use of information according to patients is whether information is personalized, such as the information that is provided on an action/management plan. Being motivated to use the information by understanding the benefits of using it was also mentioned as a factor affecting its use, as well as trust in the information. One patient stated:

Well, for me it's going back to getting the information from a source, usually a trusting source, [...] once I've researched it enough and I feel comfortable and part of it is your intuition too that comes into play.

Being able to understand information was listed by various patients as a precondition to being able to use the information.

HCP perspectives. Providing personalized information was mentioned by HCPs as an important determinant of the uptake of information. HCPs mentioned that both family member and peer patient involvement in disease management could affect the use of information. When patients share their experiences with other patients that suffer from the same condition, they might be more likely to be introduced to new information and be able to correct any misconceptions, thus leading to correct use of information. HCPs

also discussed a number of patient-related competencies that were considered to affect the use of information. These included patients' trust in the information, motivation to use the given information, their attitude, their ability to make decisions, and their understanding of their health problem.

DISCUSSION

The aim of this study was to provide insight into factors that affect the HL of patients with asthma or COPD as reflected by five domains and in relation to the management of their chronic airway disease. Insights were based on interviews with key informants and focus group sessions with patients.

Although there often seemed to be consensus among patients and HCPs in identifying factors that affect HL, some patients referred to factors not mentioned by HCPs and vice versa, which is something that has also been reported by others (Poureslami et al., 2017a; Sadeghi et al., 2013). Three factors that were identically identified by both patient and HCP groups seemed especially important because these were mentioned in relation to multiple HL domains: (1) the need for adequate time during medical consultations, (2) the impact of language and/or cultural differences on HL and disease management, and (3) provision of consistent health messages by HCPs.

Other studies also show that patients place high importance on being given enough time during medical consultations to ask and discuss their questions (Anderson et al., 2007; Mazzi et al., 2016). In addition, there is ample evidence that language and cultural differences form a huge barrier for some patients to interact with their HCPs and, therefore, hamper the management of their condition (Cabana & Shannon, 2007; Jacobs et al., 2006; Poureslami et al., 2011; Schouten & Meeuwesen, 2006). However, to our knowledge, no studies exist that focus on the consequences of patients with asthma or COPD receiving conflicting information from different HCPs.

Racial/ethnic minority groups are disadvantaged when it comes to health care (Matthews, 2015). This has been historically documented but more recently emphasized during the coronavirus 2019 pandemic. It is, therefore, critically important to establish cultural and linguistically competent health care systems (Anderson et al., 2003). When patients struggle to communicate effectively with their HCPs and when HCPs are insensitive to cultural and linguistic differences, the quality of health care will be compromised and unnecessary pressure on health care systems will remain.

Becoming a culturally and linguistically competent health care system, in part, means establishing "health literate health care organizations" (Brach et al., 2012). One practical recommendation in this respect is that health care

organizations should provide patients with easy-to-read pamphlets or plain language videos that contain essential information (Poureslami et al., 2016; Poureslami & FitzGerald, 2017b). To date, educational materials are still too complex for many patients to fully understand (McInnes & Haglund, 2011; Rowlands et al., 2015).

With respect to asthma and COPD self-management, it is recommended to provide patients with an individualized action plan to manage their condition (based on their disease severity and medication use). Such an action plan has shown to foster the correct use of their medication and take necessary steps to prevent worsening of their symptoms (Gibson & Powell, 2004; Lefevre et al., 2002). Verbal instructions on how to use this action plan should be provided in a way that is supportive of the patient's educational needs as this improves self-management skills and behavior (Paasche-Orlow et al., 2005).

This implies that HCPs should communicate in a way that is sensitive to the patients' level of HL. Improving HCPs' communication skills, as well as their understanding of the impact of culture on health outcomes, should be given greater prominence in undergraduate medical curriculum. Such education at the early stage of medical school can empower HCPs to become informed care providers (i.e., agents of change) and to exercise cultural competence in clinical practice while simultaneously promoting HL. These educational efforts need to be integrated into continuing professional development educational programs for practicing clinicians.

A final practical recommendation to enhance HL and self-management is for health care organizations to offer multiple sessions of supervised peer-to-peer educational programs (Monninkhof et al., 2004; Poureslami et al., 2017a). Ideally, family members or other informal caregivers should be involved in the patient education and empowerment process as well, so as to foster the patient's implementation of the given information and gained knowledge in daily life (Ingadottir & Jonsdottir, 2010).

STUDY STRENGTHS AND LIMITATIONS

An important strength of the current study is that it highlights both patients' and HCPs' perspectives on factors affecting HL in the context of asthma and COPD management. To date, the voices of patients and HCPs are infrequently heard simultaneously in the HL research paradigm. The current study also underlines the importance of not only focusing on individual skills when studying HL and chronic disease management, but also of considering the role of health care systems, organizations, and professionals (Kickbusch et al., 2013; Parker, 2009).

A limitation of the present study is that only English- and French-speaking patients and health care professionals

were included, even though Canada is a multicultural and multilingual country. It should be noted that we observed similar concerns when we developed educational interventions among Punjabi-speaking and Cantonese/Mandarin-speaking patients with asthma and COPD (Poureslami et al., 2016, 2017b).

Another limitation is that we had no insight into the HL level of the participating patients; therefore, we were not able to draw a distinction between the perceptions of those with higher and lower HL skills and, thereby, to be more nuanced in our reporting.

CONCLUSIONS

The overall control of asthma or COPD (i.e., prevention of exacerbations) is unlikely to be successful if a patient does not comprehend self-management guidelines (e.g., difficulty following their action plan). Similarly, difficulty accessing health information and the necessary health care services may be attributed to ineffective communication between provider and patient, and collectively contribute to unsuccessful management of one's health condition. The same is true if the treating doctor does not understand the patient or the cultural context within which the patient receives health information or care services. Future HL measurement instruments and interventions to enhance HL in the context of asthma and COPD management should take these issues into account.

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TABLE A
Characteristics of the Patient Focus Groups

Patient Focus Group	Participants, <i>n</i>			Asthma or COPD	Language
	Total	Female	Male		
FG1-Vancouver	2	0	2	COPD	English
FG2-Vancouver	5	3	2	Asthma	English
FG3-Vancouver	7	3	4	COPD	English
FG4-Vancouver	8	2	6	COPD	English
FG5-Vancouver	6	3	3	Asthma	English
FG1-Toronto	5	2	3	COPD	English
FG2-Toronto	7	3	4	COPD	English
FG3-Toronto	6	2	4	Asthma	English
FG4-Toronto	5	2	3	Asthma	English
FG5-Toronto	5	3	2	Asthma	English
FG1-Ottawa	6	3	3	COPD	French
FG1-Montreal	7	2	5	Asthma	French
FG2-Montreal	5	3	2	Asthma	French
FG3-Montreal	7	3	4	Asthma	French
FG1- Quebec City	5	3	2	Asthma	French
FG2- Quebec City	7	2	5	COPD	French
Total	93	39	54	16 (7 COPD; 9 asthma)	16 (10 English; 6 French)

Note. COPD = chronic obstructive pulmonary disease; FG = focus group.

TABLE B
Characteristics of the Key Informants Interviews (N = 45)

Position	Gender	Language
Pulmonary disease educator	Female	English
Respiratory technician/educator	Female	English
Respiratory technician/educator	Female	French
Nurse coordinator respiratory	Female	French
Community respiratory therapist and respiratory educator	Female	English
Family practitioner	Female	English
Respirologist/researcher	Female	English
Respirologist/researcher	Female	English
Respirologist/researcher	Female	English
Researcher/nutritionist	Female	French
Respiratory technician/educator	Female	English
Respirologist/researcher	Male	English
Neurorehabilitation researcher	Female	English
Physiotherapist works with respirology patients	Female	French
Respiratory technician/educator	Female	English
Family practitioner	Female	English
Respirologist/clinical professor	Female	French
Researcher/professor/nutritionist	Female	English
Clinical pharmacist	Female	English
COPD nurse clinician, COPD program	Female	French
Professor of medicine, respirologist	Male	English
Professor of medicine, respirologist	Male	English
Professor of medicine, respirologist	Male	English
Director, BC Lung Association	Female	English
Respiratory patient educator	Female	English
Professor of medicine, respirologist	Male	English
Respiratory technician/educator	Female	English
Respiratory technician/educator	Male	English
Professional physiotherapist, works with COPD patients	Female	English
Professor and physiotherapist, works with respiratory patients	Female	English
Professor of public health, health economist	Male	English

TABLE B (continued)
Characteristics of the Key Informants Interviews (N = 45)

Position	Gender	Language
Professor, health literacy researcher	Female	English
Professor of public health	Female	English
Professor, health literacy researcher	Male	English
Respiratory nurse/educator	Female	French
Health literacy senior scientist	Male	English
Professor, National Director, Department of Health Education and Promotion	Female	English
Director, Centre for Collaboration, Motivation, and Innovation	Female	French
Respiratory educator	Female	English
Associate professor, director e-health literacy	Male	English
Professor, health literacy researcher	Male	English
Senior policy researcher; professor	Female	English
Professor, health literacy researcher	Male	English
Health literacy senior scientist	Male	English
Respiratory nurse and researcher	Female	English

Note. BC = British Columbia; COPD = chronic obstructive pulmonary disease.

TABLE C

Factors Mentioned by Health Care Professionals and Patients that Affect Access to Information

Factor	Quote
Availability of information/ education	"I think it's also being able to probably access education – I can only tell from my perception as an educator that there is probably not enough ongoing education outside of the contact with the – either primary care physician or a specialist" (HCP quote)
Format of information	"Especially when I'm sick or depressed, I don't retain just purely you know vocal and I need something in writing to refer back to" (patient quote)
Type of health care provider	"I wish my family doctor would have been like, 'hey, you've had asthma your entire life and you're still on a puffer, hey I see you've never been to a respirologist before, let's do something about that'" (patient quote)
Patients' literacy skills	"What I like to say is I have a problem of reading or writing that much. I'd like to see more tapes and videos out there. Instead of writing it. My problem is reading and writing all the time" (patient quote)
Patients' computer skills	"A good portion of my patients are older so I think a lot of more current information is available online nowadays and they are not necessarily comfortable accessing that or they don't have access to internet or computer where they can get that information" (HCP quote)
Patients' acceptance of help	"Also just the willingness of somebody to accept help, they may be referred to our program but that's coming from their physician it may not be something that they are ready to accept themselves" (HCP quote)
Location of health care facilities	"We're a big province and a pretty spread out population so we can reach patients who live in our health region or who are within 30 minutes of Saskatoon no problem but one of those rural and remote communities, aren't getting the same level of health information because our programming, I talked about kind of like eligibility for like patients to meet with us on a monthly basis. Well someone from northern Saskatchewan, that's just not an option for them" (HCP quote)
Patients' motivation	"I mean they feel very good and healthy so to go to find, that is, that is something very challenging to motivate people to go and find information when they don't need honestly" (HCP quote)
Patients' functional skills	"The lack of that executive functioning translates in the healthcare system to you know, they had an appointment booked with a specialist, lost the appointment card, maybe couldn't read the appointment card and don't show up and when you miss that appointment with your specialist, you aren't getting the most up to date treatment, not getting optimal treatment, you're not seeing your chronic disease nurse so there's that piece" (HCP quote)

Note. HCP = health care professional.

TABLE D

Factors Mentioned by Health Care Professionals and Patients that Affect the Understanding of Information

Factor	Quote
HCPs use of medical jargon/ power imbalance	"So many doctors I know put it – they rattle it off in medical terms and you are sitting there, what does that mean? And then you go -- I've done it myself – I got home and looked up the term. I Googled the term to see what it means" (patient quote)
Complexity of information	"Right, thank you. But it would help people if everything is sort of compacted into some, to some pamphlet" "And easy reading" "Well, that's it yeah" "Easy reading" (patient quote)
Timing of information	"One of the most important things is not to give too much information all at once. [...] Because it's very easy for these patients to get overwhelmed [with too much information] and they are – I think we know that they are less inclined to ask questions and that makes it harder for them to follow instructions or feel confident with asking questions as well" (HCP quote)
Format of information	"I can't tell you how to knit but I can show you how to knit. So I need that same back and I've got a lot from her and it would be the same thing probably with a DVD to have actually somebody show me. I'll read it and I'll – yeah, okay? What the hell does that mean?" (patient quote)
Professional support with understanding	"I would read the page, it could be the same page over and over and it wouldn't stick. Nothing would. So I'm trying to learn to do this until one of the nurses came up one night and sat there and said, "Okay [patient name], I'll help you." Do you know who that was? So the nurses learned that I needed a little bit more help with understanding things" (patient quote)
Context (receiving information in a stressful situation)	"A lot of that is the stress of the situation. I mean, we meet with people when they are the most vulnerable and they are sick and then you are asking them to process complex information and it's not ideal at all" (HCP quote)
Patients' cognitive abilities	"Again their literacy level, their cognitive issues, you know if they have dementia or any kind of cognitive issues then they aren't able to comprehend the information that we are giving [...]" (HCP quote)
Patients' attitude	"[...] or their attitude, if they have a poor attitude about the health care system, they may not be able to perceive the information that are provided, and also trust in the healthcare provider, and in the previous experience [...]" (HCP quote)
Singularity of information	"[...] and also the information and the level of the singularity of the information, to provide the information in a clear and concise way [...]" (HCP quote)
Repetition of information	"And we also know that the need to repeat that information is really important as well. Hearing it once isn't enough. And if you are talking about strategies, there needs to be repetition at suitable intervals for reiterating what the key information is and what they should be doing and making sure that they've got appropriate follow through with that as well" (HCP quote)

Note. HCP = health care professional.

TABLE E

Factors Mentioned by Health Care Professionals and Patients that Affect the Evaluation of Information

Factor	Quote
Patients' lack of ability to judge the credibility of information	"And internet – so much information out there but learning how to interpret it – first of all learning if the source is reputable is actually quite difficult when you are not in the medical field and then once you find out that it is a reputable source, is it relevant to what is going on for you. And I think only a physician or a pharmacist can actually answer that question" (patient quote)
HCPs' attitude	"It was just because of what she said made you feel – like her attitude made you feel like you could trust her. Immediately and then that's why – like, because you trusted what she said that's why you decided to try it" (patient quote)
Inaccuracy of information	"[...] sometimes the internet can be a problem as well because it's not always accurate. But I think we have to check what they've [BK: the patient] actually heard and listened and then use that to sort of to adapt our further communication or information that is provided to them depending on what is needed" (HCP quote)

Note. HCP = health care professional.

TABLE F

Factors Mentioned by Health Care Professionals and Patients that Affect Communication

Factor	Quote
Patients' ability to ask questions	"It depends, but you know sometimes there are doctors that, basically, how can I explain, they assume that you know what they are talking about. So you feel kind of bad, you feel bad, you're like okay, I should know, good, well, yes, then after that, you look it up by yourself in another way, but you know sometimes it seems that we feel bad saying no, I didn't know that, then you know, sometimes you're also kind of afraid to waste their precious time" (patient quote)
HCPs use of medical jargon/ power imbalance	"The doctor who studied, he is a great specialist, when you get to specialties, it's even worse. So, if he tends to be above it all and not wanting to make it accessible, easy for patients, well, then it becomes hard for a patient first to be understood, then to be able to express it right, you don't have the words. As a patient, we don't have the words unless we do some research, and we say ah this is my problem, I think that's it, I'll try to put in a word when I see him" (patient quote)
HCPs (nonverbal) communication skills	"With my doctor, I guess she must be really stressed and overloaded and everything. There's no even eye contact anymore, she just stands, she sits in front of the computer, she's just more or less writing out the prescription" (patient quote)
Patients' understanding of their condition	"I think chronic disease management depending on the disease can definitely be quite complex so for a patient with limited health literacy skills, it can be very difficult to understand and process the information that is given in a clinical visit about what to do when they become ill or what to do when it is worsened or what happens when it starts being worsened so as a result it makes it difficult to communicate when the patient doesn't have that basic level of understanding about their condition" (HCP quote)
Context (receiving information in a stressful situation)	"And the whole health environment is – we just – if you are trying to communicate with somebody who is wearing a gown that is open in the back and they are freezing sitting on an exam table, I mean, this is not a good environment to be trying to help people learn information" (HCP quote)

Note. HCP = health care professional.

TABLE G

Factors Mentioned by Health Care Professionals and Patients that Affect the Use of Information

Factor	Quote
Relevancy of provided information (whether it is personalized)	"The factors are how personalized the information is. There is information and then there is your patient or the person whom you want that to be used by. So how personalizing you made that message, that is really, really important and we know that from other research that if you make it personalized then it is more likely to be taken up" (HCP quote)
Patients' trust in the information	"Well, for me it's going back to getting the information from a source, usually a trusting source, go and research it from 20 different reputable sites and then become the guinea pig and for me, it's worked the majority of it because once I've researched it enough and I feel comfortable and part of it is your intuition too that comes into play" (patient quote)
Patients' motivation	"I guess number 1, the patient has to be motivated to make a change" (HCP quote)
Patients' understanding of their condition	"But sometimes you say these things and the patient says, look doctor. I can't even decide. I don't know what to do. I don't understand this problem. You just tell me what to do and I'll do it" (HCP quote)
Family member or caregiver involvement	"Absolutely and in many, certainly in the case of dementia and advanced frailty, the family member's literacy is probably more important than the patient" (HCP quote)
Peer involvement	"And what we have learnt is that that motivation to change or do something differently much better taken when it comes from your peer than somebody like me who is standing at the head of the class telling them what to do [...]" (HCP quote)
Patients' attitude	"One is knowledge and the other one is attitudinal so there is an attitudinal thing around concern about side effects, you could be a PhD Nobel winning prize laureate with a very high levels of literacy but you could still have attitudinal concerns that you don't want to or don't prefer to take" (HCP quote)
Patients' ability to make decisions	"But even after the physician-patient interaction I still have some patients who even after I've spoken to them for 10 or 15 minutes, I am not 100% sure they understood it all or they may be unwilling or unable to come to a decision at that moment" (HCP quote)

HCP = health care professional.