

# Patient and Professional Perspectives on Nutrition in Chronic Respiratory Disease Self-Management: Reflections on Nutrition and Food Literacies

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## ABSTRACT

**Background:** Nutrition literacy (NL) and food literacy (FL) have emerged as distinct forms of the multifaceted concept of health literacy (HL). Despite convincing evidence that changes in dietary behavior can improve health, the role of nutrition in supporting self-management in patients with chronic respiratory disease tends to be overlooked. **Objective:** This study examined patient and key informant (health care professionals, researchers, and policymakers) perspectives on nutrition in the context of self-management practices in asthma and chronic obstructive pulmonary disease with implications for NL and FL. **Methods:** Data were collected during 16 focus groups with 93 English- and French-speaking patients in the Canadian Provinces of British Columbia, Ontario, and Quebec, and in-depth interviews with 45 key informants mainly from Canada. Participants' comments, including dietary perception keywords, were extracted and classified using NVivo software. Thematic analysis was applied. **Key Results:** Patients' perspectives on nutrition reflected three broad themes: (1) importance of nutrition knowledge in self-management, (2) applying nutrition knowledge in self-management, and (3) challenges in applying nutrition knowledge in self-management. Embedded within the third theme were six sub-themes: Limitations in "accessing nutrition information," "understanding nutrition information," "basic literacy skills," and "ability to act on nutrition information," along with "lack of supports to act on nutrition information," and "competing daily demands in mealtime and medication management." Although less than 10% of key informants provided nutrition-relevant comments, their comments reinforced patients' concerns about barriers to accessing, understanding, and using nutrition information in self-management. **Conclusions:** Our findings suggest that more attention be directed to nutrition in the self-management of chronic respiratory disease and warrant further research on the roles of NL and FL in this health practice context. Such research could also contribute to the broader agenda of understanding NL and FL and applying them as subconcepts of HL in chronic disease self-management interventions. [*HLRP: Health Literacy Research and Practice*. 2018;2(3):e166-e174.]

**Plain Language Summary:** Growing evidence supporting the role of diet in chronic disease calls for more attention to nutrition literacy. This study explored patient and key informant viewpoints on engaging with nutrition information in self-management of chronic lung disease. Findings suggest patients encounter many challenges in accessing, understanding, and acting on relevant nutrition information.

Health literacy commonly refers to a person's capacity to engage with information relevant to promoting and managing their health, viewed through both clinical care and public health lenses (Nutbeam, 2008).

## NUTRITION AND FOOD LITERACIES AS SUBCONCEPTS OF HEALTH LITERACY

Notions of nutrition literacy (NL) and food literacy (FL) stem largely from evolving understandings of health literacy

(HL) (Gillis, 2016; Velardo, 2015). Although multiple definitions are emerging in the literature (Perry et al., 2017; Velardo, 2015), NL and FL commonly refer to people's capacity to engage with information relevant to promoting and managing health within food and nutrition contexts. Like HL, they incorporate the ability of users of information, such as patients, as well as the capacity of practitioners and the systems through which relevant information and services are provided. According to the Calgary Charter on Health Literacy

(Coleman et al., 2009, p. 2), “an individual can be health literate by using the skills needed to find, understand, evaluate, communicate, and use information. Healthcare professionals can be health literate by presenting information in ways that improve the understanding and ability of people to act on the information” (Coleman et al., 2009, p. 2). Competencies integral to HL (Sørensen et al., 2012)—accessing, understanding, evaluating, communicating, and ultimately applying information in decision-making—are reflected in several emerging definitions of NL (Krause, Sommerhalder, Beer-Borst & Abel, 2016) and to a lesser extent in FL (Truman, Lane & Elliott, 2017). Like HL, food and nutrition literacies reflect both clinical and broader public health approaches (Nutbeam, 2008).

Whereas NL tends to focus on the abilities of people to obtain and understand relevant nutrition information to make healthy dietary choices (Krause et al., 2016), FL is more broadly viewed as a diverse set of related skills, knowledge, and behaviors needed to put nutrition recommendations into practice in everyday life (Vidgen & Gallegos, 2014). In addition, FL covers various factors affecting health disparities relevant to engagement with food including the impact of food choices on personal health as well as on the broader society and environment (Cullen, Hatch, Martin, Higgins & Sheppard, 2015; Krause et al., 2016; ). Links between FL and food security appear particularly pertinent given growing concern about the prevalence of food insecurity in developed countries (Nyambayo, 2015), including Canada (Tarasuk, Mitchell & Dachner, 2016).

## NUTRITION AND SELF-MANAGEMENT OF CHRONIC RESPIRATORY DISEASE

Chronic respiratory disease (CRD), including chronic obstructive pulmonary disease (COPD) and asthma, is a serious public health concern (Ferkol & Schraufnagel, 2014) and a demanding condition requiring patient-clinician interaction to support patient self-management practices (Lenferink et al., 2017). Self-management refers to the tasks that people living with a chronic disease must master to gain control of their condition and to deal successfully with associated lifestyle changes. (Coleman & Newton, 2005; Richard & Shea, 2011).

Current evidence suggests that many patients with COPD are unlikely to meet their daily requirements for energy and nutrients (Chambaneau, Filaire, Jubert, Bremond, & Filaire, 2016; Yilmaz, Capan, Canbakan, & Besler, 2015). Risk of malnutrition is highest among those in the most severe stage of COPD (Arslan, Soylu, Kaner, İnanç & Başmısırlı, 2016; Yoshikawa et al., 2014). Because malnutrition is not easily reversed, preventive actions are important to reduce morbidity and mortality in those with acute COPD exacerbations (Law, Kumar, Woods, & Sriram, 2016). Increased respiratory muscle activity and lower breathing efficiency increase demand for energy intake in patients with COPD. At the same time, potential impairment in chewing and swallowing, early gastric filling, fatigue from dyspnea, and time demands for eating can lead to inadequate energy intake (Brug, Schols, & Mesters, 2004). Obesity can also negatively impact respiratory function in COPD patients (Poulain et al., 2006).

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In patients with asthma, chronic inflammation of the airways can be modulated by diet. Consumption of a high-fat diet has been associated with increased inflammation (Berthon, Macdonald-Wicks, Gibson, & Wood, 2013; Wood, Garg, & Gibson, 2011). In contrast, reducing saturated fat intake (Scott et al., 2013) and increasing fruit and vegetable consumption can decrease airway inflammation (Wood, Garg, Powell, & Gibson, 2008). Obesity may also negatively impact asthma outcomes. Patients who are obese and have asthma tend to have more frequent exacerbations, worse asthma control, and a lower quality of life (Forno & Celedon, 2017). The Global Initiative for Asthma, a global strategy for asthma management and prevention, recommended following a healthy diet as a nonpharmacological intervention and encouraged patients to consume more fruits and vegetables for general health benefits (Global Initiative for Asthma, 2018).

Lifestyle modifications, including daily exercise and dietary modifications, are widely supported as practical strategies to improve self-management of COPD and asthma (Berthon et al., 2013; Chambaneau et al., 2016; Farooqi, Nordström, Lundgren, Sandström & Håglin, 2011; Guilleminault et al., 2017; Li et al., 2017a,b; Schols et al., 2014; Wood et al., 2008; Wood et al., 2011; Yilmaz et al., 2015).

## AIM OF STUDY

To our knowledge, no published study has explored the viewpoints of patients or health professionals on the importance of supporting nutrition as part of disease management in chronic airways diseases. The aim of this article is to examine patient and key informant (knowledgeable health care professionals, researchers, and policymakers) perspectives on nutrition in the context of self-management practices in asthma and COPD, and to explore implications for NL and FL as sub-concepts of HL.

## METHODS

### Data Collection

Data examined in this article was drawn from a large ongoing multicenter study designed to explore patients' perspectives on HL and their self-management of asthma and COPD, and ultimately develop a new HL measurement tool for these patients. We examined insights of key informants familiar with issues related to the connection between HL and chronic disease management. For the present study, patient and key informant comments considered relevant to nutrition were extracted as an indirect measure of interest in and concern for nutrition and dietary advice. Participants in

the patient-oriented focus groups and individual key informant interviews were not asked any direct questions about the role of healthy eating or nutritional aspects of asthma or COPD management. The study, including patient focus groups and key informant interviews, was approved by the Behavioral Ethics Committee at the University of British Columbia, Vancouver, Canada.

### Patient Focus Groups

A total of 93 English- and French-speaking patients in the Canadian provinces of British Columbia, Ontario and Quebec participated in 16 focus group sessions. Seven sessions were conducted with patients with asthma and nine with patients with COPD. Ten sessions were conducted in English and six in French. Patients were recruited between April 2015 and February 2017 using a purposeful sampling approach. The homogenous sampling method was intended to reduce variation between two target diseases and two language groups, and to facilitate effective focus group discussion. Inclusion criteria included being diagnosed with asthma or COPD by a physician, being age 19 years or older, being able to communicate in English or French, using medication for their asthma or COPD disease regularly, and physically able and willing to attend group sessions.

The semi-structured focus group sessions were held in hospital or academic institution meeting rooms in the collaborating sites. Patients were encouraged to discuss perspectives, approaches, and factors they believed affected their ability to access, understand, evaluate, communicate, and use health information in making informed decisions about their disease. Each focus group consisted of 5 to 7 patients and lasted on average 90 minutes. Discussions were audio recorded, then transcribed and translated verbatim. French data were translated by professional translators and all data were transcribed by professional transcribers. Consent forms were signed by all participants prior to entering the study. Participants received modest compensation to cover transportation costs.

### Key Informant Interview

Forty-five health care professionals, researchers, and policymakers knowledgeable in HL were recruited by the research manager from the list of experts identified by the research team and advisory panel members. Snowball sampling was applied to recruit the professionals able to share their perspectives on optimal disease self-management. Candidates were approached by phone, in person, or email and invited to join the interview. Interview details and timing were provided to those who agreed.

Semi-structured interviews were conducted individually in person, via telephone, or video conference call by the project manager (I. P.) or a master-level research assistant between December 2015 and April 2016. The aim of the interview was to acquire their perspectives on barriers to patient engagement in self-management practices, as well as their thoughts about HL competencies as related to COPD and asthma management, including lifestyle, behavioral modification, and functional skills to perform disease management practices.

Each interview was recorded digitally and lasted 30 to 45 minutes. All interviews were conducted in English and participants provided their consent to engage in the interview either by signing an informed consent form or agreeing by e-mail prior to the interview.

### Data Analysis

Two master-level research assistants experienced in qualitative data analysis and skilled in using NVivo software (Version 11) coded the transcripts from the patient focus groups and key informant interviews. Prior to the actual coding, inter-rater agreement was assessed, which showed an agreement of 94% between the two coders (Miles & Huberman, 1994). Data were coded for multiple categories including beliefs, attitudes, practices, and factors influencing competencies of HL (Sørensen et al., 2012; Coleman, 2009) in asthma and COPD.

Thematic analysis (Green & Thorogood, 2004; Miles & Huberman, 1994) was conducted to identify the extent to which participants' viewpoints reflected the role of nutrition in the context of self-management of CRD. The nutrition-relevant data were classified in categories to identify thematic patterns (by R. H.). Each comment from the patient focus group data was then assessed for dietary perception by the research team. Duplicated and nonrelevant comments, such as those that reported "low energy" without any explicit dietary perception implication, were excluded. The remaining patient comments were further analyzed through comprehensive coding to generate initial patterns. All candidate themes and sub-themes were critically analyzed to contribute to more coherent understanding. A similar approach as that used with the patient focus group data was applied (by R. H.) to identify explicit nutrition-relevant comments extracted from the key informant data. Comments were then carefully examined by the research team to ascertain nutrition perception implications for self-management of asthma and COPD. The 37 comments (Table 1) identified from the patient focus groups were categorized into three distinct themes and six sub-themes.

## RESULTS

Table 2 describes characteristics of both patient and key informant participants. Comments highlight the daily challenges inherent in self-management and the importance of clinician-patient interaction in supporting effective treatment regimes (Table 1).

### Perspectives on Nutrition from Focus Group Patients

Several themes emerged from the analysis of patient comments as shown in Table 1. Although there was a basic awareness of the importance of nutrition knowledge in self-management of COPD, little reference was made to particular abilities or necessary skills. Nutrition was often tied to other lifestyle practices, such as exercise. Most notable was patients' identification of the personal challenges they encountered. These challenges related to barriers to accessing relevant nutrition information, not understanding information, not having basic literacy skills, limited ability and few supports to act on information, and lastly, the constraints of daily demands in managing their COPD.

### Perspectives on Nutrition from Key Informants

Key informant comments reflecting the awareness of links between nutrition information and CRD self-management were scant. Four (less than 10% of those interviewed) commented specifically on nutrition.

One researcher with a nutrition background referred to the difficulties that patients with limited functional literacy skills face in the food marketplace. "Patients should be able to read nutrition fact labels, the ingredient list, and health claims that are on food in addition to having the ability of comparing and evaluating foods in order to make a decision." This comment points to the importance of being able to not only access, but also appraise information and apply it in making informed food choices. A respiratory educator noted the difficulties that patients have in understanding dietary advice received from their health care providers. "Patients need to be able to understand treatment and advice given by doctors such as exercise, diet, other daily lifestyle." Acquiring healthy lifestyle skills, including healthy eating, needs to be applied in self-management according to this respirologist who said: "We can all read about diet, exercise, smoking cessation, and so on, but unless we actually practice it in our real life, how does it really change our lives. I think change or reinforcing healthy lifestyle should be part of your (HL) framework." This respiratory educator referenced personal experience and challenges in adhering to nutrition advice and maintaining lifestyle practices: "I'm an exercise professional, and I go through periods that I exercise a lot, and then I go through a period where I eat a lot of junk

TABLE 1

**Patients' Dietary Perceptions and Their Views on the Role of Nutrition in Disease Management of Asthma and COPD (16 Focus Groups)**

Themes	Patients' Comments	Disease
1. Importance of nutrition knowledge in self-management	1.1 Nutrition is important.	COPD
	1.2 Nutrition is a part of self-management.	COPD
	1.3 It is very important that you know your disease and how to deal with it, and knowing you have asthma consider other factors like the weather, food, you have to learn your body and if you are having some reaction and if it will trigger your asthma.	Asthma
	1.4 That is very important what kind of nutrition [you should have].	COPD
	1.5 For the nutrition, dietitian for example [is] very helpful.	COPD
	1.6 [Interviewer: I learned that you are not eating that much processed oil or something, so [are you] talking about nutrition as a part of your self-management? Patient: Yes]	COPD
	1.7 [It is important that] you know about food allergies. . .	Asthma
	1.8 It is very important that you know your disease and knowing other factors like weather, food, and . . . or if it will trigger your asthma.	Asthma
	1.9 It is your choice. Are you going to go for fast food every day or are you going to go to the farmer markets in the summer time to get fresh food and cook yourself a good meal?	COPD
	1.10 Exercise and a better diet [are parts of self-management].	COPD
	1.11 Better lifestyle and [better] eating habits [are parts of self- management].	COPD
	1.12 Diet and exercise . . . they go together.	COPD
	1.13 Diet, like nutrition, supplementation, deficiencies, you know? I think that's all really important. I've had to learn through alternative physicians.	Asthma
2. Applying nutrition knowledge in self-management	2.1 I seem to be doing okay, you know, with good food, good nutrition, some supplements to help.	COPD
	2.2 Well, I read a lot and by using good nutrition and exercise and having good doctors to look after me, I am able to still do [self-management of my disease].	COPD
	2.3 Right now, also when it comes to nutrition, you know, I change; you know, my style of eating and everything. It helps me a lot.	COPD
	2.4 It is taking responsibility for yourself and making sure that you eat healthy, that you do exercise sometimes.	Asthma
	2.5 I never knew anything about diets and now I do. I've learned how to control my asthma a lot better.	Asthma
	2.6 I drink a lot of rooibos tea. I drink a lot of white tea, which is wonderful for asthma. I eat a lot of green, like, my diet is really green and alkaline so all these different things you research and then you test it on yourself. And then you come up with, okay, this does work, at least for me it does.	Asthma
	2.7 Usually I learn it by myself when I eat something that doesn't agree, then I start to learn books again and Internet, and then I realize, "oh, this is from the other also that it cause asthma today" so I learn that, "oh, these are my triggers."	Asthma
	2.8 I just want to say that we developed some videos and pamphlets on the self-management and nutrition and avoid smoking. That is good, honestly, most people are giving a good feedback!	COPD

food and I don't exercise, and I know better, but I think it's just a human thing, and it's for a lot of our patients."

**DISCUSSION**

Awareness of the value of accessing, understanding, and using nutrition information for asthma and COPD self-

management was apparent throughout patients' comments with a prominent focus on barriers. Although few key informants' comments reflected awareness of links between nutrition information and CRP self-management, they also centered on barriers that confront patients in accessing, understanding, and applying nutrition information (Perkins & Cohen, 2008).

TABLE 1 (continued)

**Patients' Dietary Perceptions and Their Views on the Role of Nutrition in Disease Management of Asthma and COPD (16 Focus Groups)**

Themes	Patients' Comments	Disease
3. Challenges in applying nutrition knowledge in self-management	We know what we should do - we should eat healthy and we should exercise, but sometimes there are barriers that stop us from doing those things that we have little control over.	Asthma
3.1 Limited access to nutrition information	3.1.1 Where do you learn about, you know, the food triggers? Where do you go to find that information?	Asthma
	3.1.2 Let's say - you are not feeling so well today. How would you know what to do? What kind of diet should you have?	COPD
3.2 Limited understanding of nutrition information	3.2.1 I read pamphlets to learn. . .and try to learn more about my diet, but I don't ever walk away feeling that I learned much.	Asthma
3.3 Limited basic literacy skills	3.3.1 I get [sic] like a grade 5 level, so I always have to explain it like you would explain it to a kid. Because some of the words, I don't know what they are. Since I come here I've learned about the diaphragm. I've learned about your [sic] diet.	COPD
3.4 Limited ability to act on nutrition information	3.4.1 You know. . .They say well "just lose weight and quit smoking!" Very easy [to say]!	COPD
	3.4.2 I've heard, you know a few of you mentioned like the lifestyle goals and the diet and things like that, and like just quitting smoking. So it's really easy for people. . .to say these things. . .	COPD
	3.4.3 I am not going that far, I'm not telling my weight! Within a matter of two weeks [I am] eating the same foods!	COPD
	3.4.4 Then, among other things there's nutrition. I learned that at Mount Sinai as well. It's important, even if I forget about it. . .I'm not always reliable on that. I like to eat, I like. . .and that's it. I think there are some. . .nutrition, it would be important for it to be included in our training. . .	COPD
3.5 Lack of supports to act on nutrition information	3.5.1 The thing is that, you're saying eating habits. . .like I was saying earlier, higher end foods. I can't eat the hamburgers and stuff like that. And it is harder, it's much harder. . . [patient continued. . .more expensive]	COPD
	3.5.2 Lifestyle and eating habit. So, I have to eat the high ends and. . .and I lost it again!	COPD
	3.5.3 Exercise and diet. . .Mmmm. . .[affordability]	COPD
3.6 Competing daily demands in mealtime and medication management	3.6.1 Look at all my medication I take. You know it's so hard I mean I have 6 or the 7 (medications) and I have to always wait a half an hour before I eat. So, it makes it really hard, you have to be really on time to do all this, you know.	COPD
	3.6.2 Sometimes you eat only at 1 o'clock, you go out, oh I forgot to have an hour before you know(sic). So that makes it a little bit hard.	COPD
	3.6.3 The routine here is you gotta go for a blood test and then you gotta see your doctor after so what do I do, I'm not supposed to eat before a blood test so I'm saying okay. . .so I can't eat all that time so what do I do?	COPD
	3.6.4 My pharmacist tells me exactly how to take it, you know. I take 8 pills in the morning and including my puffers. And she tells me, "take these ones, have something to eat then take your puffers." At night time I have 3 more pills, take them with a meal and then take my puffer with milk, so [pause]. There's. . .that's how she tells me how to do it. The doctor just says, "here, here's your pills, go take 'em."	COPD

Note. COPD = chronic obstructive pulmonary disease.

**TABLE 2**  
**Characteristics of Patient Participants and Key Informants**

Characteristic	<i>n</i> (%)
Patients ( <i>N</i> = 93)	
Gender	
Male	49 (53)
Female	44 (47)
Disease	
Chronic obstructive pulmonary disease	53 (57)
Asthma	40 (43)
Location	
Ontario	37 (40)
British Columbia	28 (30)
Quebec	28 (30)
Language	
English	57 (61)
French	36 (39)
Key informants ( <i>N</i> = 45)	
Gender	
Female	30 (67)
Male	15 (33)
Location	
Canada	40 (89)
United States	3 (7)
United Kingdom	1 (2)
Australia	1 (2)
Health care professionals	
Respiratory educator	15 (33)
Respirologist	9 (20)
General practitioner	3 (7)
Researchers	
Health literacy researcher	8 (18)
Other researcher	5 (11)
Nutrition researcher	2 (4)
Policymakers	3 (7)

The importance of food and nutrition knowledge in the self-management of COPD and asthma was emphasized by focus group patients. Patients with other chronic disease conditions have made similar claims (Heo, Lennie, Moser, & Okoli, 2009). Patients in our study considered applying nutri-

tion knowledge acquired from various resources important in managing their conditions. Viewed as part of a healthy lifestyle strategy, they offered practical examples including seeking out and applying relevant nutrition material in their daily food-intake, consulting with health providers about the role of nutrition in their disease management, and acknowledging the need to take personal responsibility for eating well.

Variable access to reliable nutrition information has been reported in patients with other chronic disease conditions (Prince, Moosa, Lomer, Reidlinger, & Whelan, 2014) and is not surprising given the plethora of nutrition information available to the public. One study, for example, revealed that commercial websites accounted for nearly 80% of the online nutrition and health information searched by Canadians (Ostry, Young, & Hughes, 2008). Difficulty in accessing and understanding nutrition information was highlighted by one key informant's example of using food labels, emphasizing the challenge of empowering patients/clients to fully understand and evaluate information in making healthy food choices for chronic disease self-management. The importance of using nutrition fact labels in chronic disease management was confirmed in a large-scale nationally representative, cross-sectional study in the United States in which reading the nutrition fact labels was associated with following a healthier diet (Post, Mainous, Diaz, Matheson, & Everett, 2010).

Patients' identification of numerous barriers to applying nutrition information in managing their condition was most striking in the present study. Similar findings have been reported by other researchers exploring patients with chronic conditions (Heo et al., 2009). Key informant participants also recognized barriers to applying understandable and relevant food and nutrition information in supporting daily dietary practices. In addition, some patients focused on the difficulties in accessing reliable information about types of diets to follow and identifying what foods trigger asthma attacks. Lack of personal supports to make lifestyle changes, managing the daily tasks of the timing of food and medication intake, and having the resources to acquire healthy and affordable food to meet their dietary goals were also key patient concerns.

Of the 45 key informants initially interviewed, only four made any reference to food or nutrition in self-management of CRD. This limited response is consistent with the recent claim that the role of nutrition in supporting self-management in patients with chronic disease conditions tends to be overlooked (Kahan & Manson, 2017). The development of effective self-management skills among patients with chronic conditions depends on the HL competency of health care systems and providers who care for patients

(Poureslami, Nimmon, Rootman, & FitzGerald, 2017). This relevance was also supported in a study, in which patients' willingness and ability to follow dietary recommendations and apply food label information, improved when they received support from their health care professional (Heo et al., 2009; Post et al., 2010). Together, these patient and key informant perspectives reflect aspects of both NL and FL and the many challenges to integrating nutrition and food information into patients' self-management of their respiratory conditions.

## STRENGTHS AND LIMITATIONS

The present study has strengths and limitations. In describing characteristics of patients who participated in focus group sessions, we were limited in gathering information on type of respiratory disease, geographic location, gender, and language. We did not collect other potentially relevant but personally sensitive descriptors such as age or literacy level. Both a strength and a limitation of this study is that it drew upon data from a larger study exploring HL and CRD in which neither patients nor key informants were asked directly about nutrition.

## CONCLUSION

In summary, patients' and key informants' perspectives reflected key HL competencies within the context of food and nutrition, and associated barriers to NL and FL. Although nutrition was not a salient concern among key informants (mostly health professionals), the few key informants referencing nutrition reinforced patients' perspectives on their challenges in accessing, understanding, and using nutrition information in their CRD self-management.

It appears timely for health practitioners, and the health care systems and organizations through which they provide health information and care services, to pay greater attention to the role of nutrition in CRD self-management and support more patient-provider interaction within the context of managing this chronic disease. Insights from this study are useful for further conceptualization and development of frameworks and assessment tools for better understanding and applying nutrition and food literacies as evolving sub-concepts of HL.

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