# Looking beyond literacy

Understanding and approaching barriers to refugee health in 2 cases of vitamin D-deficiency rickets

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hen the concept of health literacy is applied as a lens to vitamin D deficiency from a lack of vitamin D supplementation, it reveals a labyrinth of barriers to positive health outcomes within refugee communities in Canada.

Usually, health literacy is taken to mean literacy and its relationship to health outcomes. Recently, the Expert Panel on Health Literacy has extended the meaning of this concept beyond literacy alone to reflect a process of empowerment, noting that it refers to the "ability to access, understand, evaluate and communicate information to promote, maintain and improve health in a variety of settings across the life course."1 In this context, access is thought to be "mediated by education, culture and language, by the communication skills of professionals, by the nature of materials and messages, and by the settings in which health-related supports are provided."1

## Challenges

The refugee families described in our case report (page 641)2 exhibited low levels of health literacy. Such families must contend with economic challenges that prevent them from easily accessing vitamin D; institutional barriers as a result of lacking cultural knowledge of health care structure and risk; possible uncertainty in carrying out medical recommendations in relation to low levels of literacy; and, last, written medical instructions that do not take into account diversity in language or cultural interpretation.

Some families might not purchase vitamin D despite encouragement from public health services and their family physicians. From a health literacy standpoint they might face financial hardship: perhaps they are unable to benefit from social assistance drug coverage but cannot afford basic necessities. Families who are refugee claimants have lost access to any medication coverage since the cuts to the Interim Federal Health Program in June 2012.3 There is a substantial cost to vitamin D supplementation (\$15.00 for a 1-month supply in Newfoundland and Labrador, for example). A process of financial prioritization occurs in situations of economic struggle. For a family to prioritize the purchase of vitamin D supplements, the risks and outcomes

associated with not taking this vitamin need to be crossculturally translated.

In Canada, primary health care is founded on the biomedical concept of risk reduction. Patients are frequently encouraged to make changes in their lives and to take certain medications that will not produce immediate tangible or perceived outcomes and benefits. Vitamin D deficiency has a cumulative effect. There are no immediate consequences observed the next day, week, or even month after not taking supplementation when it is needed. Compliance with medical recommendations requires patients to attribute meaning to the concept of risk as it relates to their illness.3 Vitamins might not be seen as "medicines" that are important to take. Risk is extremely difficult to translate across cultures from physician to patient in the face of previous cultural beliefs, language barriers, and infant feeding traditions.

In Newfoundland and Labrador, government-assisted refugees receiving social assistance have the option of acquiring drug cards that would cover vitamin D for their infants. Considerable institutional navigation and literacy are needed to acquire and properly avail oneself of a drug card. What is this card? What does it cover? Where is the card obtained? Is transportation a barrier? Are there language and literacy barriers to completing the necessary forms? Negotiating a new health care system often requires initiative, orientation, and cultural courage to ask for help. All of these efforts are daunting if, for cultural reasons, a person is ashamed to show that they do not understand, cannot communicate in the local language, or fears discrimination.4

Next, consider the literacy requirements involved in following instructions for vitamin D supplementation. An eyedropper is used to pipette a specific amount of medicine into a baby's mouth. Instructions must be read in order to know this. One must understand how to read number measurements to know how much to pipette. If oral instructions are given, understanding of the language is required to fully appreciate the message that is conveyed. A recent study examining women's vitamin D-supplementation practices in the general population in Montreal, Que, highlights that, in general, guidelines are poorly understood if health literacy is not

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taken into account. Gallo et al noted that "a large number of exclusively breastfeeding mothers thought that they were following Health Canada guidelines, but when frequency and dose were assessed, a large portion (26%) were incorrectly following the recommendation."5

Research looking at multimedia representations of medical information suggests that oral and written instructions are ineffective mediums in the setting of cultural diversity, poor literacy, or language barriers.<sup>6-9</sup> At the time that public health services and physicians discussed vitamin D supplementation with the refugee families described in our case report,2 only written instructions were shared, as no free samples were available for demonstration and no information was available in picture form.

Our aboriginal and Inuit populations might face similar barriers. Studies of vitamin D deficiency within aboriginal and Inuit populations in Canada suggest that vitamin D supplementation is influenced by local cultural and economic contexts. A documented study of vitamin D-deficiency rickets in Northern Manitoba highlighted "cultural custom, lactose intolerance and the unavailability of fresh milk" as reasons for the avoidance of milk supplemented with vitamin D.10 It is, therefore, not surprising that milk fortified with vitamin D is consumed less by Inuit preschool children than by average Canadian children.11 Previously, Inuit in Nunavut used to consume more naturally vitamin D-rich foods, like beluga oil, arctic char, and white fish. However, with the greater availability of market-based foods, there is now an observed substitution of traditional meats with foods containing less vitamin D.11

### Needed change

Given the importance of vitamin D supplementation and refugee vulnerability to becoming vitamin D deficient, the medical community needs to be aware of the challenges encountered by patients who have lower health literacy in Canada. Extra efforts in orienting refugees within the health care system and offering creative, culturally appropriate representations of health instructions and meanings of "risk" are needed. One researcher suggests empowering cultural groups in co-creating culturally appropriate photonovels to share health-related messages.7

Efforts to make health resources more accessible are also needed. Interdisciplinary approaches involving community health workers have been shown to be an effective way to promote preventive health care and bridge health literacy gaps within community and social service systems. As Brownstein et al suggest in their article looking at health promotion of blood pressure control in disadvantaged communities in the United States, community health workers become "patient and community advocates, 'coaches' for disease management,

and ... 'navigators' for patients, guiding them through the healthcare system."12 By making health care systems more accessible, community health workers also address racial and ethnic inequality that often emerges from this structural discrimination. 12,13

Initiatives making vitamin D more readily available might also be warranted. A recent randomized controlled trial in Norway found that the provision of free vitamin D supplements could reduce vitamin D deficiency and rickets in immigrant populations.14 Indeed, a medical student initiative in St John's, Nfld, has since led to free samples being made available to all refugee babies at their well-baby checkups.

Addressing need due to lower health literacy requires time and dedication and extends beyond the medical setting. Increasing health literacy among the refugee population in Canada and eliminating further cases of vitamin D-deficiency rickets will require the collaboration of the entire community and a desire to understand the sociocultural and economic complexity of refugee issues.

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#### Competing interests

None declared

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