Evaluating and Using Consumer Health Information

Jody Nelson, Librarian
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Consumer health information

Any information that enables individuals to understand their health, & make health-related decisions for themselves and their families.

(Patrick & Koss, 1995 as cited at www.uhn.ca)
Online consumer health information

- Websites, blogs, apps
- Chat rooms, online forums, wikis
- Youtube channels
- Facebook groups
- Twitter feeds... and more...
Google

"skin rash" site:mayoclinic.org

About 6,220 results (0.53 seconds)

Slide show: Common skin rashes - Mayo Clinic
https://www.mayoclinic.org › skin-rash › sls-20077087 ▼

Skin rashes can occur from a variety of factors, including infections, heat, allergens, immune system disorders and medications. One of the most common skin disorders that causes a rash is atopic dermatitis (ay-TOP-ik dur-muh-TI-tis), also known as eczema. Atopic dermatitis is an ...

What does online consumer health activity look like?

mayoclinic

“Skin rash”=6,220
What does online consumer health activity look like?

"Skin rash" = 22,500
What does online consumer health activity look like?

“Skin rash”=49,700
What does online consumer health activity look like?
What does online consumer health activity look like?
What does online consumer health activity look like?

Sharing and empathy in digital spaces: qualitative study of online health forums for breast cancer and motor neuron disease (amyotrophic lateral sclerosis)
S Hargreaves, PA Bath, S Duffin, J Ellis - Journal of medical Internet ..., 2018 - jmir.org
Background The availability of an increasing number of online health forums has altered the experience of living with a health condition, as more people are now able to connect and support one another. Empathy is an important component of peer-to-peer support, although ...

 Visibility Online: The Benefits of Online Patient Forums for People with a Hidden Illness: The Case of Multiple Chemical Sensitivity (MCS)
T Phillips, T Rees - Medical anthropology quarterly, 2018 - Wiley Online Library
Sufferers of medically unexplained conditions that are not observable in the clinic can experience multiple layers of invisibility: a lack of biomedical diagnosis; legal skepticism; political disinterest; and a loss of their prior social identity. For those with environmental ...

Online communities for breast cancer survivors: a review and analysis of their characteristics and levels of use
JL Bender, MC Jimenez-Marroquin, LE Ferris... - Supportive Care in ..., 2013 - Springer

The contribution of online peer-to-peer communication among patients with renal disease to patient-centered care
auw, H Repping-Wuts, A Noordzij... - Journal of medical ..., 2015 - jmir.org
“Our job isn’t to **fight** misinformation with science - it’s to **help** our patients understand how misinformation impacts them. And to do that, we have to **connect wholeheartedly.**”
Discussion Questions

1. Why do people go online with health questions or health concerns?

2. Considering there are so many different reasons, platforms, and types of information available to health consumers online, what might nurses and other health professionals need to be aware of?
Key strategies

*Start with reliable sites

*Know how to evaluate
Where to start?

Authoritative Health Sites (myHealth.Alberta.ca)

Sites for Traditional & Complementary Health (fnha.ca Traditional Healing)

http://libguides.macewan.ca/HLST152

How to evaluate?

uhn.ca: How to Review Online Health Info

nccih.nih.gov: Finding & Evaluating Online Resources
Evaluating Online Consumer Health Information Sites

Topic: Tick Borne Lyme Disease

Topic: Tick Borne Lyme Disease

In the news?!

Mystery?

Fear.

Frustration.

Controversy.
Fear, misuse of information, & unproven claims, on one hand...
Everything about Lyme disease is steeped in controversy. Now some doctors are too afraid to treat patients

January 16, 2019

The so-called controversy of Lyme disease is simple. On one hand, there is a sea of ignorance within the medical profession, and an ongoing denial by doctors that this tick-borne zoonosis exists. On the other hand, there is a concentration camp full of frustrated patients who can't get prompt diagnosis and treatment. Unfortunately, the majority of patients become chronic, and can't go to school or can't work. The medical establishment refuses to accept the fact that the Lyme disease bacterium, Borrelia burgdorferi, sequesters and hides in deep-seated tissue, such as ligaments, tendons, bone, brain, eye, and scar tissue. This stealth pathogen is persistent in the body, and is hard to treat. Even though persistence was not mentioned, it is the overriding stumbling-block.

https://tinyurl.com/LymeDiseaseControversy
Motivations and Experiences of Canadians Seeking Treatment for Lyme Disease Outside of the Conventional Canadian Health-Care System.

Boudreau CR¹, Lloyd VK¹, Gould ON².

Abstract

OBJECTIVE: We aimed to describe the experiences of Canadians who seek diagnosis and treatment for Lyme disease outside of the conventional Canadian health-care system.

METHODS: Forty-five individuals who had sought treatment for Lyme disease outside of the conventional Canadian health-care system were recruited from Lyme support and advocacy groups across Canada to answer open-ended questions about their experiences.

RESULTS: Respondents sought treatment outside of the conventional medical system due to extensive diagnostic procedures and treatments that did not resolve symptoms. Escalating health concerns, lack of effective treatment, and stigma produced a sense of abandonment and desperation. Respondents accessed alternative forms of care based on the recommendations of peers, yet considerable financial and emotional stress was experienced.

CONCLUSIONS: Many individuals with Lyme or Lyme-like diseases are deeply dissatisfied with the care received within the conventional Canadian health-care system and therefore felt both pushed and pulled to seek treatments either from international physicians using different treatment protocols or from alternative medicine providers in Canada.
Article

Parenting When Children Have Lyme Disease: Fear, Frustration, Advocacy

by Emilie M. Gaudet 1, Odette N. Gould 1,* and Vett Lloyd 2

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Abstract: Increasing numbers of Canadians, including children and adolescents, are being infected with Borrelia burgdorferi and contracting Lyme disease. In the present study, we provided a qualitative analysis of written correspondence produced by 23 parents of children and adolescents with Lyme disease. The goal of this study was to investigate how medical and psychological issues were highlighted by parents describing their family’s Lyme disease experiences. The results suggest a series of four stages in these families where satisfactory treatment had not been obtained over months or years. The experiences of parents evolved from feelings of worry for the child to frustration with the lack of a helpful treatment, to mistrust of physicians’ actions, and, in some case, to a rejection of the conventional health care system as a whole. Improved diagnostic testing and treatment guidelines, as well as family-centered practices of medical care were proposed as important features for improving the experiences of families living with Lyme disease.

Keywords: Lyme disease; children and Lyme disease; Lyme families; children with complex medical conditions; parents as advocates; Lyme disease in Canada
Topic: Tick Borne Lyme Disease

Group Activity: Team Task #1

1. In your groups, first assign roles:
   ○ Navigator - *Locates & navigates website*
   ○ Recorder - *Records answers & takes notes*
   ○ Reporter - *Provides brief visual & verbal report*
   ○ Press secretary - *Answers questions about relevance*

2. Go to your assigned website (on navigator’s computer)

3. Answer **Task 1** questions as a group (recorder takes notes)

4. Be sure you have consensus on answers
Reporting Back: Information Evaluation Matrix

**Reporter:** Use sticky to note site & place on matrix. Prepare brief explanation.

**Press secretary:** Prepare to be asked about the relevance of the source, & why your team placed the source differently from other teams.

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<table>
<thead>
<tr>
<th>Reliable</th>
<th>Irrelevant</th>
<th>Questionable</th>
<th>Relevant</th>
</tr>
</thead>
</table>

**Is it Reliable?**
- Who is responsible for the info?
  - What is their *expertise*?
- What *quality of* evidence is used?
- What is the point? Any *bias*?

**Is it Relevant?**
- Does it apply to your *context*?
  - *Useful* for patient situation?
- What is the purpose? *Who is it for*?
Consider:

- Source
- Evidence
- Context
- Currency
Credible, relevant, sources are required!

Find all weblinks from today’s class at:

http://libguides.macewan.ca/HLST152

Start with a reliable source

Know how to evaluate
Thank you!

Your feedback is appreciated:
libguides.macewan.ca/HLST152 ➔ Feedback for Jody