Information quality and dynamics of patients' interactions on tonsillectomy web resources

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ABSTRACT

Information technologies have drastically altered the way patients gather health-related information. By analysing web resources on tonsillectomy, we expose information quality and dynamics of patients' interactions in the online continuum. Readability was assessed using Flesch Reading Ease (FRE), Flesch Kincaid Grade Level (FKGL), Simple Measure of Gobbledygook (SMOG), and Gunning Fog Index (GFI). Comprehensibility and actionability were assessed using the Patient Education Materials Assessment Tool (PEMAT). Metrics of forums included author characteristics (level of disclosure, gender, age, avatar image, etc.), posts' motive (community support vs. medical information) and content (word count, emoticon use, number of replies, etc.). Analysis of 6 professional medical websites, of 10 health information portals, and of 3 discussion forums totalizing 1369 posts on 358 threads, from January 1, 2007 to December 31, 2014, reveals that online resources exceed understandability recommendations. Women were more present on online health forums (68.2% of authors disclosing their gender) and invested themselves more in their avatar. Authors replying were significantly older than authors of original posts (39.7 ± 0.8 years vs. 29.2 ± 0.9 years, $p < 0.001$). The degree of self-disclosure was inversely proportional to the requests for medical information ($p < 0.001$). Men and women were equally seeking medical information (men: 74.0%, women: 77.0%) and community support (men: 65.7%, women: 70.4%), however women responded more supportively (women 86.2%, men 59.1%, $p < 0.001$). The dynamics of patients' interactions used to overcome accessibility difficulties encountered is complex. This work outlines the necessity for comprehensible medical information to adequately answer patients' needs.

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1. Introduction

While a few decades ago, the only way for patients to gather health-related information was through direct interactions with health professionals, information technologies have dramatically changed this situation. Indeed, the last decades have witnessed a constant migration of information consumption to online spaces, where information becomes dynamic (Brossard, 2013).

Internet accessibility enables rapid retrieval of formerly inaccessible health-related information through a variety of platforms, such as official resources on health associations' websites, health information portals, or community discussion boards, with up to 72% of Internet users seeking health information online (Fox and Duggan, 2013). Patients can not only share information and advice, but also experiences and peer or community support (Klemm et al., 1999; Owen et al., 2004; Blank and Adams-Blodnieks, 2007; Blank et al., 2010), a possibility

that was unconceivable on a large scale before online environments gained such prominence.

From a public health perspective, neglecting this online dimension in population health education has become impossible. Quite logically, both professional medical websites (Eloy et al., 2012; Svider et al., 2013; Kasabwala et al., 2012; Hansberry et al., 2014a, 2014b) and patient discussion boards have become the target of scrutiny (Klemm et al., 1999; Blank and Adams-Blodnieks, 2007; Mo et al., 2009; Blank et al., 2010; Attard and Coulson, 2012; Chen, 2012). However, this field is still nascent, and no attempt has been made to analyse simultaneously the information provided on various health information platforms, and the strategies patients use to overcome accessibility difficulties encountered in terms of readability and content understandability.

We aimed to answer this need by analysing the particular case of tonsillectomy, which represents an ideal model for this purpose. First, tonsillectomy affects a large population, accounting for 1/6th of all surgical procedures in children <15 years old, as well as 26% of all surgical procedures on the nose, mouth and pharynx all ages combined (Cullen et al., 2009). Second, tonsillectomy provides a mixed population both in terms of gender and age, an aspect lacking in the majority of previous

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studies (Klemm et al., 1999; Blank and Adams-Blodnieks, 2007; Mo et al., 2009; Blank et al., 2010; Attard and Coulson, 2012; Chen, 2012). Third, tonsillectomy patients and caregivers, as with any surgery, need to be supplied with adequate information and support throughout the operative period to better manage complications such as throat pain, dehydration, nausea and vomiting, delayed feeding, voice changes and hemorrhage (Baugh et al., 2011). Finally, due to the well-known occurrence of transient – yet unpleasant – side effects following the surgery, tonsillectomy represents an ideal model to study peer or community support. The aim of this study was to analyse simultaneously and for a same pathology 1) the quality of online information available in terms of readability, understandability, and actionability, 2) information seeking online behavior of patients, and 3) how information quality as defined above impacts users' online behavior.

Our study enlightens that patients' needs are not currently fully addressed, and reveals that the online health information gathering strategies of patients are considerably more complex than originally speculated. Furthermore, our data sheds new light on the mechanisms and gender-specificities of community-based online interactions related to health concerns.

2. Materials and methods

2.1. Website selection and analysis

Six official medical webpages on tonsillectomy were selected from websites of professional otolaryngology or pediatric associations from countries having English as a first and native language. Ten health information portal websites were selected from web-portals centered on health education and communication, non-affiliated to a specific medical association, with English as a primary language, and with an active forum (≥ 20 posts monthly) (Fig. 1). References specifically targeted to health professionals (i.e., medical doctors, otorhinolaryngologists, or nurses and other health care professionals) were excluded. The readability, understandability, and actionability of the material presented on these 16 webpages were evaluated in January 2015.

Readability was evaluated with a battery of four tests considered as highly reliable for biomedical context (Meade and Smith, 1991; Friedman and Hoffman-Goetz, 2006; Wang et al., 2013), selected among the most commonly used readability analysis tools in the otolaryngology field (Eloy et al., 2012; Kasabwala et al., 2012; Cherla et al., 2012; Cherla et al., 2013; Svider et al., 2013; Alamoudi and Hong, 2015): the Flesch Reading Ease (FRE), the Flesch Kincaid Grade Level (FKGL), the Simple measure of Gobbledygook (SMOG), and the Gunning Fog Index (GFI). This particular battery has been validated in the context of online materials (Guitton, 2015a, 2015b), including general online material such as posts (Guitton, 2015a), and health-related online material (Guitton, 2015b). As recommended by the NIH (Wang et al., 2013; Anon., 2013a), all the retrieved texts were formatted for readability assessment purposes.

Understandability (the clarity in terms of message processing of the presented material), and actionability (the possibility for patients to take action following the exposure to the presented material) were evaluated using the Patient Education Materials Assessment Tool (PEMAT) for printable material (Anon., 2013b; Shoemaker et al., 2014), which has already been used to evaluate online health-related material (Guitton, 2015b). Two scores on a 100 scale were generated for understandability, and actionability using the PEMAT by two independent judges.

2.2. Forum selection and analysis

Inclusion criteria for web-based medical discussion boards ("forums") included: being in English language, having a significant ear, nose, and throat community within the forum (≥800 total threads), being active throughout 2014 (≥20 posts monthly), and having an embedded search engine allowing specific term search. Discussion boards relating strictly to cancer were excluded. Three separate online discussion groups were identified (Fig. 1). Data was collected on all forum threads relating to tonsil removal or tonsillectomy last updated from January 1, 2007 to December 31, 2014.

For each post's author, the following characteristics were noted: self-reported gender and age when disclosed, forum activity (number of posts), number of days between the user's account creation and thread creation, number of days active on forum (between user's account creation and last post), and finally whether the author associated an avatar image (whatever the nature of this image) to his/her account. In order to avoid bias within threads, personal information was noted only once per user on each thread for analysis purposes (including the initial author of the thread). The total word count and the number of replies to each post were also noted.

For each thread, the target of the initial post (whether the author was posting on his own behalf, for somebody else including a child, or specifically for a child), and the intention of the initial post (seeking
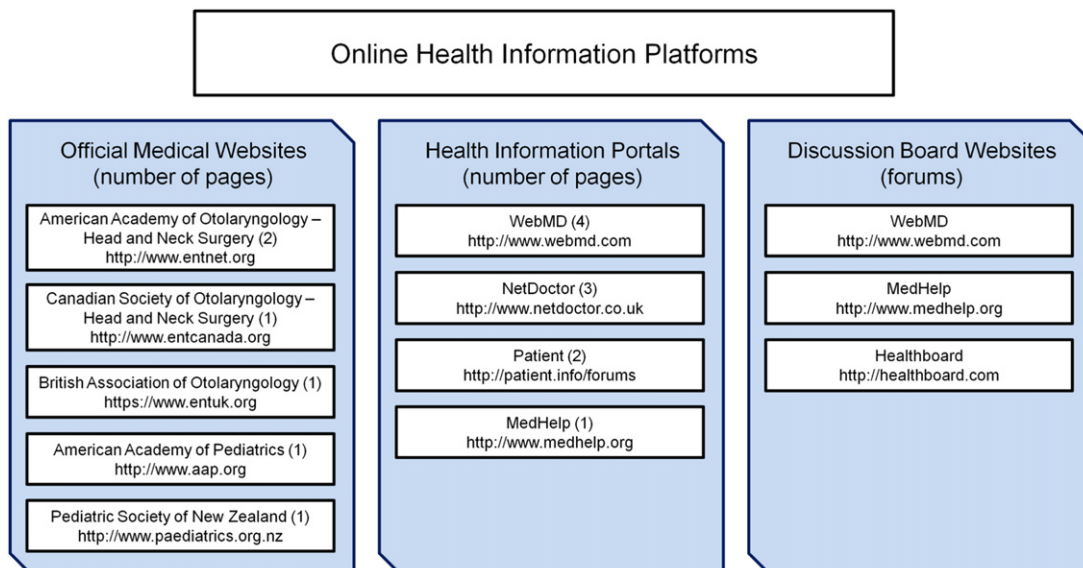
Online Health Information Platforms

Official Medical Websites (number of pages)	Health Information Portals (number of pages)	Discussion Board Websites (forums)
American Academy of Otolaryngology – Head and Neck Surgery (2) http://www.entnet.org	WebMD (4) http://www.webmd.com	WebMD http://www.webmd.com
Canadian Society of Otolaryngology – Head and Neck Surgery (1) http://www.entcanada.org	NetDoctor (3) http://www.netdoctor.co.uk	MedHelp http://www.medhelp.org
British Association of Otolaryngology (1) https://www.entuk.org	Patient (2) http://patient.info/forums	Healthboard http://healthboard.com
American Academy of Pediatrics (1) http://www.aap.org	MedHelp (1) http://www.medhelp.org	
Pediatric Society of New Zealand (1) http://www.paediatrics.org.nz		

Fig. 1. Online health information platforms data sources.