Googling Self-injury: The State of Health Information Obtained Through Online Searches for Self-injury

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**Importance**
Nonsuicidal self-injury (NSSI), the deliberate destruction of one’s body tissue without suicidal intent, is a significant issue for many youth. Research suggests that adolescents and emerging adults prefer the Internet as a means to retrieve NSSI resources and that important others (e.g., caregivers) may also seek this information online. To our knowledge, no research to date has examined the quality of health information regarding NSSI on the Internet.

**Objectives**
To examine the scope and nature of web searches for NSSI websites and to evaluate the quality of health-information websites found via these online searches.

**Design, Setting, and Participants**
Ninety-two NSSI-related search terms were identified using the Google AdWords Keywords program. The first page of Google search results for each term was content-analyzed for website type and health-information websites were further coded for credibility, NSSI myth propagation, and quality of health information.

**Main Outcomes and Measures**
Frequency of NSSI web searches and indices of health information quality.

**Results**
Nonsuicidal self-injury–related search terms were sought more than 42 million times in the past year and health-information websites were the most common website type found (21.5%). Of these, a health and/or academic institution endorsed only 9.6%. At least one NSSI myth was propagated per website, including statements that NSSI indicates a mental disorder (49.3%), a history of abuse (40%), or the notion that primarily women self-injure (37%). The mean quality of health information score on these websites was 3.49 (SD = 1.40) of 7.

**Conclusions and Relevance**
Nonsuicidal self-injury–related search terms are frequently sought out worldwide and are likely to yield noncredible and low-quality information that may propagate common NSSI myths. These data suggest health professionals need to be aware of what information is online and should refer young patients and their families to reliable online resources to enhance NSSI literacy. Efforts to facilitate people’s access to credible NSSI resources via the Internet are also needed.
Most adolescents and emerging adults access the Internet daily.\textsuperscript{1-4} For many, the Internet is used to obtain health information,\textsuperscript{2,5-7} and this may be particularly salient for issues that are sensitive or stigmatized.\textsuperscript{8-10} One such issue, nonsuicidal self-injury (NSSI), has received growing attention from researchers and health professionals.\textsuperscript{9-15} Global media attention has focused on NSSI content online, with more than 400 news articles published in 2011\textsuperscript{12,16,17} continuing well into 2012.\textsuperscript{16} Defined as deliberate destruction of body tissue (eg, cutting, burning) in the absence of conscious suicidal intent,\textsuperscript{18,19} nonsuicidal self-injury has a consistent lifetime prevalence of 13.9% to 21.4% in youth and young adults,\textsuperscript{19} though some reported rates are even higher.\textsuperscript{20} Nonsuicidal self-injury confers risk for physical injuries, scarring, psychiatric difficulties, and elevated suicide risk.\textsuperscript{18-20}

Adolescents and emerging adults who self-injure may use the Internet more than youth who do not self-injure.\textsuperscript{21,22} Young people, who potentially compose a significant portion of individuals seeking NSSI information online,\textsuperscript{10-12,14} report a preference for the Internet as a means to obtain NSSI information compared with other resources.\textsuperscript{23} Accordingly, it is important to understand the extent to which NSSI websites are sought online and the quality of available health information. In light of the risks associated with NSSI,\textsuperscript{18-20} access to quality information is critical and may also be important for those who do not self-injure. Recent research suggests that while people who self-injure compose a significant proportion of those who seek NSSI content online, individuals who wish to help those who self-injure may also seek this information online (eg, parents and peers).\textsuperscript{24} Low-quality NSSI information found through online searches may impact these individuals’ effectiveness as sources of support. Health and mental health professionals can also benefit from knowing the quality of NSSI information online to be able to provide reliable, research-informed resources to young patients and families. The current study was conducted to understand the quality of online health information regarding NSSI.

The most common way to retrieve information on the Internet is through the use of search engines. Google represents the most frequently used search engine online, preferred by more than 80% of Internet users compared with other search engines,\textsuperscript{24,25} as well as the most commonly used website worldwide.\textsuperscript{24,25} Google may be a primary means to obtain NSSI information online. This study is the first, to our knowledge, to systematically examine (1) the extent to which NSSI websites may be sought worldwide, as indexed by some of the more common search terms entered in Google, (2) the nature of websites corresponding to these search terms, and (3) the quality of health information provided on these websites. To index the nature of searches for NSSI information, we used Google AdWords Keywords,\textsuperscript{26} a program that allows users to determine some of the actual search queries used in Google, search query data (eg, frequency), and explore corresponding search results. We used this program to generate NSSI search terms with the goal of determining the scope and nature of websites found in the query results. From here, we evaluated the quality of health information on these websites.

Methods

Search Term and Website Retrieval

Google AdWords Keywords\textsuperscript{26} is a free online program where users can enter keywords to determine some of the search terms (including keywords themselves) related to the originally entered keywords. The program also provides data related to each search term, including the average number of global monthly searches and the geographical regions associated with these searches. We consulted with our research ethics board at the University of Guelph prior to conducting this study. Because our study involved the use of websites retrieved through Google and all websites were in the public domain, a formal ethics submission was not required.

We entered 13 keywords based on prior research that examined NSSI content online\textsuperscript{9-15} into the Google AdWords Keywords program. Terms initially entered included self-injury, self-harm, self-mutilation, self-cutting, pro SI, pro self-injury, pro self-harm, pro self-mutilation, pro self-cutting, self-injury help, self-harm help, self-mutilation help, and self-cutting help. This yielded a large set of queries, some of which were general (eg, self-injury cutting) and others more specific (eg, how to hurt myself). Consistent with past research using this program to identify proanorexia websites,\textsuperscript{27} terms receiving at least 1000 global monthly hits were retained (n = 92).

We analyzed content from all websites that appeared on the first page of search results for each keyword, as research has shown people tend to focus on the initial search results page when conducting online searches.\textsuperscript{28,29} In total, 962 websites were examined (ie, 10-12 sites for each of the 92 keywords). Of these, 340 were unique websites.

Coding Rubric

To develop a coding rubric, we met 3 times to review websites corresponding to the originally entered search terms, excluding sites used in the final analysis beyond the first page of search results. We studied websites inductively to generate an initial set of codes and consulted previous research examining online NSSI content\textsuperscript{9-15} to identify potential codes. Next, we carefully and independently examined 130 websites excluded from the final data set (ie, beyond the first page of search results) but based on the search terms generated in order to determine viability of the rubric. Another meeting followed to discuss results and finalize the rubric.

The final rubric was tested on a new set of 130 websites to assess reliability with the goal of establishing at least 80% agreement for each individual code. These websites were also based on the search results corresponding to the search terms generated beyond the initial page of retrieved results. Reliability was initially less than 0.80 for some codes so 2 additional meetings took place to discuss and further finalize the rubric, troubleshooting discrepancies that may have occurred in coding. Coders then tested the rubric with 130 new websites and reliability exceeded 0.80 across all variables, rendering the rubric ready for analysis.
Final Codes
During final coding, 10% of actual data (ie, websites) was coded to determine if interrater reliability was retained. Agreement exceeded 0.80 for each variable. All variables below were coded dichotomously (ie, absent [0] or present [1]). Websites were first coded for type and included health-information websites, an NSSI picture/video, and an NSSI website. Health-information websites were further coded for credibility, NSSI myth propagation, and health information quality.

Credibility was coded as present when websites were developed and endorsed by an official health (eg, hospital) or academic (eg, university) institution. Additionally, other indices were examined as credibility may be just one indicator of quality information and may not necessarily indicate information quality.

We coded for the presence of common myths identified in empirical literature on NSSI.30-32 We first coded for statements indicating NSSI was a marker for borderline personality disorder (BPD) or other mental illnesses. This appeared in contrast to research signifying NSSI is neither sufficient nor necessary for any diagnosis. While NSSI associates with various mental illnesses (including BPD), it also frequently co-occurs with psychiatric symptoms that do not meet criteria for a diagnosis.18-20,33-35 We then coded for statements indicating NSSI is the result of past abuse/trauma. This view is inconsistent with research indicating that abuse is a nonspecific risk factor for NSSI and does not play a causal role in NSSI, as most individuals who self-injure do not have an abuse history.18,30,36 We also coded for statements indicating NSSI is chiefly a female behavior, which does not align with research suggesting that there is little to no difference in the proportion of adolescent and young adult males and females who report NSSI.18-20,34,37 From here we coded for statements indicating NSSI is attention-seeking, which is incongruent with a large body of research that reports most people self-injure to regulate emotion.18,20,38-41 We then coded for indications that NSSI is a teen fad. Although NSSI typically begins in adolescence, it is not circumscribed to this demographic. Several studies report NSSI beginning in childhood or after adolescence18-20,37,42 and for some, NSSI may also last for many years.18 Finally, we coded for statements indicating NSSI is nonserious and superficial, whereas research suggests that NSSI is associated with psychiatric difficulties and confers suicide risk.18-20,33-35

Next, the quality of health information was coded by determining how many criteria established by the Health On the Net (HON) Foundation43 were met. The HON Foundation was founded in 1995 and aspires to promote reliable and usable health information online. The HON criteria represent some of the most commonly used mechanisms to identify online health information on a global level and researchers indicate that websites meeting HON criteria are of higher quality and accuracy.44-46 Therefore, the more criteria websites meet, the higher the quality and reliability of health information on the website. In this study the presence of the following HON criteria was coded: (1) authoritative (the information provided comes from medically trained/qualified professionals or has a clear statement indicating otherwise), (2) complementarity (the information is intended to support vs replace health care), (3) privacy (a clear privacy policy statement must be provided with respect to how individual information is treated), (4) attribution references (when appropriate, information posted online will have corresponding references), (5) attribution date (a specific date is posted indicating when the website was last updated), (6) justifiability (statements regarding treatment will be supported empirically), and (7) transparency (the site owners will provide relevant contact information).

Results
The NSSI-related search terms (n = 92) with at least 1000 monthly searches yielded more than 42 million global searches over the past year. Most searches occurred in the United States, United Kingdom, Canada, Australia, and Ireland. In all, there were 962 websites corresponding to the first page of results for these search terms. Of these, 340 were unique websites that were subsequently coded for website type. Results indicated that 21.5% of websites were health-information websites (Figure 1); 14.1% pertained to pictures or videos relating to NSSI and 12.9% were not applicable to NSSI. Other websites were a composite of blogs, news articles, scholarly articles, or book-related websites.

As search terms may have yielded similar websites when entered in Google, frequency counts were computed to account for duplicate websites. This provided an index of the overall scope of websites accessible when using the resultant NSSI search terms (Figure 1). Similar to the trend observed for unique websites, when accounting for all websites, those with health information were most common, followed by NSSI websites. Other website types were less frequent. To further assess website prominence, frequency counts were computed for the type of website occurring first and second in the search results. In both cases, health-information websites were most often the website type in the first (53.80%) and second (55.90%) position of the search results.

Given their presence, health-information websites were further coded for credibility, myth propagation, and HON criteria. Overall, endorsement by a health and/or academic institution (eg, National Institutes of Health) was indicated on 9.6% of the websites. The average number of NSSI myths per health-information website was just over 1 (mean [SD], 1.44 [1.18]) while 26.7% contained none of the myths examined. Almost half (49.3%) had statements indicating that people who engage in NSSI have BPD or another mental illness. This was closely followed by websites stating that individuals who engage in NSSI have a history of abuse (40.0%) and that primarily women self-injure (37%). A small percentage (8.0%) claimed that NSSI was an attention-seeking act. Other myths were reported less often (Figure 2).

The mean Quality of Health Information score across health-information websites was 3.49 (SD = 1.40) of 7. One website met all 7 HON criteria. When broken down by the most commonly represented criteria (Figure 3), most websites (91.8%) provided adequate transparency in the form of a contact address. Privacy guidelines were shown by 67.1% of websites. Just over half of the health-information web-
sites cautioned users that the information provided on the website was intended to support but not replace the physician/patient relationship (54.8%), and just fewer than half stated whether advice provided was given by a qualified professional (47.9%) or indicated the date when the content was last modified (45.2%). Fewer health-information websites provided credible references to support website content (31.5%). Only 11.0% followed the justifiability guideline by providing evidence for claims that specific treatments would be useful for NSSI.
Table. Credible Health-Information Websites That Can be Recommended to Patients Who Self-Injure

<table>
<thead>
<tr>
<th>Organization Name</th>
<th>URL</th>
<th>Description</th>
<th>Stakeholders</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Injury Outreach and Support</td>
<td><a href="http://www.sioutreach.org">www.sioutreach.org</a></td>
<td>International nonprofit outreach initiative providing information, family and professional resources, and coping guides for NSSI</td>
<td>Individuals who self-injure, families, friends (other youth), romantic partners, physicians, mental health professionals, school professionals</td>
</tr>
<tr>
<td>Self-Abuse Finally Ends</td>
<td><a href="http://www.selfinjury.com">www.selfinjury.com</a></td>
<td>Offers a recognized treatment approach for NSSI; also serves as a professional network and resource website</td>
<td>Individuals who self-injure, families, mental health professionals, school professionals</td>
</tr>
<tr>
<td>Cornell Research Program on Self-Injurious Behavior in Adolescents and Young Adults</td>
<td><a href="http://www.crpsib.com">www.crpsib.com</a></td>
<td>Summarizes research and provides resources related to understanding, identifying, treating, and preventing self-injury</td>
<td>Individuals who self-injure, families, mental health professionals, school professionals</td>
</tr>
</tbody>
</table>

Discussion

In the past year there were more than 42 million unique searches for NSSI websites worldwide based on the search terms identified via Google AdWords Keywords. We focused only on terms receiving a minimum of 1000 monthly searches (n = 92). Since the program does not capture every possible search term and we narrowed our focus to 92 keywords, the actual number of searches for NSSI-related terms on a global level is arguably much higher. Most searches occur in the United States, United Kingdom, Canada, Australia, and Ireland, likely reflecting the use of English search terms. Health-information websites were the most common website type that appeared when accounting for the nature and number of identified search terms, duplicate websites, and websites presented first and second in the search results. Given their prominence, it is possible that health-information websites are more likely to be accessed by those who search for NSSI websites using Google. This is worrisome because most websites come from noncredible sources, propagate NSSI myths, and do not meet established criteria for their quality of health information.

Academic and health institutions/organizations endorse a paucity of health-information websites. If websites do not have the endorsement of a recognized institute/agency, it may be that the quality of information provided is low and that websites with endorsements are not easily retrieved through several common Google searches; however, this finding is perhaps not surprising given the vast number of websites with NSSI information reported in our study and elsewhere.9-15 Moreover, the lack of endorsement from a health or academic agency does not necessarily imply that the information is of low quality and we accordingly explored other indicators of health information quality. On average, NSSI health-information websites propagated at least 1 NSSI myth. This mostly pertained to statements indicating that those who self-injure have BPD or another mental illness, have a history of abuse, or are women. These statements do not cohere with current literature.30-42

Limitations

Google AdWords Keywords does not generate data for all possible search queries and it cannot be assumed that we captured all possible NSSI searches or that findings mirror searches using different search engines. The terms we used arguably reflect our scientist-practitioner perspective.

Though the nature of search data generated in this study is extensive, it does not provide demographic data about individuals performing NSSI searches. Research suggests that youth primarily search for NSSI content online. Moreover, we surmise that many searches were conducted by youth in our study as some of the search terms identified in our study reflect the types of questions young people ask about NSSI when online (eg, how to hurt myself).14

In this study we focused on English search queries and realize that future work may need to examine NSSI searches in other languages, as adolescent NSSI is a significant issue in several non-English speaking countries.47-48 Additionally, the frequency counts associated with each search term may not represent the total number of individuals conducting the searches, as some search counts may represent individuals doing multiple searches. We also circumscribed our analysis to the first page of search results, a decision based on research indicating that individuals chiefly attenuate focus to these search results.28-29 It cannot be assumed this is how all NSSI websites are found.

Implications and Future Directions

Individuals may be exposed to potentially unreliable and inaccurate information when searching for NSSI content online using common NSSI search queries. Access to poor-quality information may impact decisions to seek help for those who self-injure. In this study we found that minimal information about treatment effectiveness was available, and that some Internet users may be left with the belief that options to assist with recovery are scant. This view is not uncommon for many who self-injure and who engage in online NSSI activity.11-13 If this is the case, individuals accessing these websites may be reticent to seek formal help, which research has indicated is low.37-49 For those who do not self-injure, inadequate information may reinforce NSSI misconceptions and render individuals less able to adequately understand and offer support to those who engage in NSSI.

The volume of NSSI searches we identified suggests that many individuals are seeking NSSI websites. Although it is promising that health-information websites are the most common type of website accessible, their content should be interpreted cautiously, as casual online searches may yield low-quality results that may not provide helpful and accurate information. Future studies should focus on expanding the scope of search terms to include terms associated with online NSSI self-help that are available on the Internet and other media. It is possible that individuals seeking resources for NSSI self-help may have access to inadequate, inaccurate, or even incorrect information.

Discussion

Self-Injury in Adolescents Finally Ends www.selfinjury.com Offers a recognized treatment approach for NSSI; also serves as a professional network and resource website Individuals who self-injure, families, mental health professionals, school professionals

Abbreviations: NSSI, nonsuicidal self-injury. URL, uniform resource locator.

Although not accessible on the first page of Google search results, these websites meet most (if not all) of the Health on the Internet quality of health information criteria, are current and up to date, do not propagate NSSI-related myths, and are sponsored by credible academic institutions.
quality information. Medical and mental health professionals working with youth who self-injure need to be aware that young patients and families may be accessing low-quality NSSI information.⁴⁹ Professionals may benefit from a list of high-quality NSSI websites that can be recommended to young patients and their families. The Table outlines recommended evidence-informed NSSI websites that meet most, if not all, HON criteria.

Conclusions

From a youth public health perspective, NSSI is poorly understood and often stigmatized.⁹,¹⁰-¹² This may contribute to reticence to seek professional help and disclose NSSI.⁴⁹-⁵¹ Efforts to enhance NSSI literacy and increase access to credible resources via the Internet are needed. One approach is to improve how Internet users make sense of e-health information and to increase individuals’ abilities to identify high-quality sources. Another strategy is to increase the likelihood that high-quality NSSI resources are accessible when searched for online. This can be accomplished using search engine optimization and through efforts to provide NSSI resources in search results prior to the point of access and on the first page of search results. Similar initiatives have already begun in the United States and United Kingdom for suicide-related searches.⁵²-⁵³

Researchers ought to investigate what different stakeholders (e.g., youth who self-injure and their caregivers) need and whether these needs are met online. As search term use may temporally fluctuate, future work should examine these trends and further explore various indices of health information quality, including and beyond those used in this study. Finally, future work should consider how youth conduct searches in tandem with how they make decisions about what constitutes a quality website. We are presently conducting studies in which youth and young adults can generate search terms and then select which websites they find useful.

ARTICLE INFORMATION

Accepted for Publication: February 5, 2014.
Published Online: March 24, 2014.

Author Contributions: Dr Lewis had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. Study concept and design: All authors. Acquisition, analysis, or interpretation of data: Lewis, Mahdy, Michal. Drafting of the manuscript: All authors. Critical revision of the manuscript for important intellectual content: Lewis. Statistical analysis: Lewis, Mahdy, Michal. Administrative, technical, or material support: Lewis. Study supervision: Lewis.

Conflict of Interest Disclosures: None reported.

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