Content Analysis of Social Media Related to Left Ventricular Assist Devices

Kristin M. Kostick, PhD, MA; Jennifer S. Blumenthal-Barby, PhD, MA; Lidija A. Wilhelms, BA; Estevan D. Delgado, BA; Courtenay R. Bruce, JD, MA

Background—Social media have the potential to offer important benefits for patient education, support, and shared decision making. Despite the proliferation of social media use during the past decade, little is known about the scope and quality of available information, or the purposes that social media sites serve for patient decisional and support needs.

Methods and Results—We conducted a mixed method study, including content analysis of social media and principal components analysis of data sites discussing left ventricular assist device treatment for heart failure. This study explored aspects of interactivity, user-friendliness, appeal, medium, purpose, audience, and accuracy of information. Higher levels of interactivity (eg, posting comments) seem to enhance the appeal and usability of available information but also introduce greater potential for inaccuracy and inconsistency. The current lack of oversight into the content and quality of available information constitute a challenge for the reliable use of social media as forums for information-seeking and social network–based support.

Conclusions—We conclude that social media outlets constitute a promising source of informational and psychosocial support for patients, caregivers, and candidates, and if used in conjunction with patient-provider dialog, can contribute to informed decision making by facilitating reflection and discussion of personal concerns, values, and informational needs. (Circ Cardiovasc Qual Outcomes. 2015;8:00-00. DOI: 10.1161/CIRCOUTCOMES.115.002032.)

Key Words: caregivers ■ heart failure ■ shared decision making ■ social media ■ social support
WHAT IS KNOWN

- Although there is a growing interest in online educational resources for patients with left ventricular assist device and caregivers, little is known about their scope or content.
- The content of social media are largely unregulated and user-generated, making it imperative that clinicians understand the level and range of potential inaccuracies or inconsistencies in information accessed through this medium.

WHAT THE STUDY ADDS

- We provide a framework for analyzing healthcare-related social media, where there is currently a lack of systematic guidelines for evaluation.
- Our article provides empirical data on active left ventricular assist device–related social media sites that can help providers to refer patients and their caregivers to positive informational and support resources outside of the clinical setting.
- Data presented in this article can also help to alert providers to the need to address potential biases and inaccuracies patients may be receiving from social media sources.

This article presents results from a directed content analysis of social media sites related to LVAD treatment for heart failure, in which existing research on social media usability is used to structure a variable-by-case framework for analyzing the qualitative content of social media sites. We draw from definitions of social media as a group of Internet-based applications that permit users to create and exchange their generated contents, acquire real-time feedback and to continuously adjust content, and assume the characteristics of information openness, participation, interaction, sharing, connectedness, creativity, autonomy, collaboration, and reciprocity. Specifically, we explore the following questions: (1) What is the scope of LVAD-related content available on patient/caregiver-generated social media sites? (2) What is the degree of accuracy of this information? (3) To what extent do sites encourage interactivity and patient engagement? (4) Do any nascent typologies appear across social media sites on the basis of audience, scope/purpose, medium, tone, interactivity, accuracy, or other parameters? (5) Do significant differences exist in social media sites directed at audiences of patients with LVAD, caregivers, candidates, or clinicians?

Methods

Search Strategy

To identify the range and content of LVAD-related social media sites available online, we used targeted Internet Google searches using permutations of relevant terms and acronyms (eg, LVAD, circulatory support, heart failure treatment, etc.), resulting in a nonredundant list of 89 sites found between November 1, 2014 and February 28, 2015, including Facebook pages, Twitter feeds, blogs, YouTube videos, Yahoo Answers, and Pinterest pages. A full list of search terms and resultant sites are listed in Appendix I in the Data Supplement. We limited results to the first 4 pages in response to search terms. Facebook pages constituted both individual and group/community pages, and that YouTube sources were video only (not channels). We excluded sites that were created or maintained by scientific, medical, professional, for-profit, or academic institutions, and advertisements, although not those maintained by professionals blogging independently for patients and caregivers.

Screening and Categorization

A second phase of screening involved dividing the list of 89 sites among the authors (n=5) to further narrow using our criteria, which included the final list to English language LVAD-related social media sites that were created and maintained by nonexpert individuals with site activity and showed recent activity within the past year. Each website in the list was assigned to exactly 2 authors, with each author receiving a total of n=34 sites to evaluate. A total of 55 exclusions were made on the basis that a site was not active within the past year (44), no longer operative/accessible (4), not primarily related to LVAD therapy (3), duplication of another site (2), a choice in focus during the past year away from LVAD issues (1), or run by a medical institution, on closer inspection (1).

Content Assessment

During this same phase, we also engaged in a content assessment of sites from the list of 34 that met our inclusion criteria. Analyzed content included both site information and user comments. Because health-related social media is commonly considered to be a niche-based form of social media (as opposed to mainstream platforms that address a wider range of topics), and also because the study of social media is in its early stages, no systematic criteria for measuring health-related social media currently exist. Currently available social media analytic tools (eg, Hootsuite, Bitly, Symplur, Google Analytics, etc.) are largely geared toward providing analytics for a small number of Websites for personal and commercial use (eg, to quantitatively analyze user access trends and site-sharing) and are not sufficiently equipped to analyze qualitative content across aggregates of social media sites.

Therefore, we developed a conceptual framework for analyzing content, scope, and character of social media sites, informed by aspects common to social media in general, including those recognized for the purposes of marketing and user engagement and other parameters identified by the authors as potentially important for gauging the content, scope, and character of social media sites. Using this framework, each Website received a content assessment from 2 of the 5 authors to ensure inter-rater reliability. In cases of discrepancy, cases were resolved by both authors assigned to the particular case by revisiting and discussing the site and reaching a consensus. All variables except where noted below were scored using a binary scale of 0 (absence) or 1 (presence) of each feature. Our framework for content analysis of social media sites was composed of the following parameters:

1. Interactivity included (1) whether the creator invites user feedback via explicit statement/request, or by providing spaces for feedback in the form of posted comments, personal experiences, etc., and (2) whether there is the ability to like or share.
2. User-Friendliness included (1) whether the interface was easy to navigate, assessed subjectively and consensually across authors based on whether information was clearly presented, links were easy to identify and click among to pursue desired information, the interface was not visually or cognitively distracting, (2) readability, assessed using the Flesch Readability test to calculate readability and grade level, inputting a sample of 2 paragraph-sized samples of text (compromising 5–7 brief comments or posts for sites such as Facebook and Twitter that consist mostly of short text segments) from each Website to...
analyze their web-based algorithm, which takes into account the average number of syllables per word and the average number of words per sentence for every 100 word block of text. Only text-based data (ie, no images or videos) were scored. Scores are reported on a scale from 0 to 100, with higher scores indicating greater readability. In our methodology, text unrelated to content was removed (eg, esoteric characteristics, such as hashtags, emoticons, etc.). The Flesch–Kincaid scale is one of the oldest and most commonly used tools for assessing readability, and has been previously used to assess Website content. A drawback it shares with other comparable tests is that it is not intended for use with short comments, such as those found on Twitter or Facebook. However, no other readability test to our knowledge is better equipped to assess readability of brief comments and posts in the aggregate.

3. Medium documented whether the website was (1) primarily text, (2) primarily visual, containing primarily visuals of family and personal life or visuals of anatomy, medicine, or other technical/medical info, or (3) mixed visual and text. Assessments of medium were based on the subjective consensual evaluation of the authors.

4. Purpose designated whether the Website was primarily (1) an informational resource, providing practical information about the LVAD device, surgery, postoperative lifestyle, clinical practices and expectations, and other useful information, (2) a psychosocial resource, providing emotional and social support for users, (3) a forum for sharing LVAD-related experiences and perspectives, (4) a forum for expressing complaints or concerns, or (5) unclear. These designations were not intended to be mutually exclusive, and a Website could be recorded as having >1 purpose.

5. Audience indicated whether the Website was aimed toward (1) patients, (2) caregivers, (3) candidates, (4) practitioners, or (5) the audience was unclear. A Website could be recorded as having >1 targeted audience.

6. Accuracy and consistency involved documenting the frequency of inaccuracies and inconsistencies appearing on the Website, limited to the first 5 pages of history. Inaccurate information was identified according to the authors’ collective and extensive knowledge about LVADs and verified with cardiologists with expertise in LVAD therapy. Inconsistent information included information that was either contradicted or disputed within a single site and involved at least 1 inaccuracy.

7. Tone was recorded along a 5-point Likert scale, ranging from strongly negative/discouraging versus strongly positive/encouraging to indicate the overall affective tone or mood of a Website’s content. This variable was scored subjectively by each author and averaged across the 2 authors assigned to evaluate each site.

Results

A majority of the active, LVAD-related social media sites were based in Facebook in the form of groups and, to a lesser extent, individual pages. The second most common social media type was YouTube videos, followed by blogs and Twitter feeds (Table 1). Other types of sites were negligible in number. All sites were asynchronous, meaning comments and feedback were not given in real time (eg, in a chat) but rather users could make comments or contribute at different times. On the basis of our inclusion criteria, all sites showed recent activity within the past year. Of these, over a third (n=12, 35%) show activity within the past 6 months and half (n=17, 50%) show activity within the past month. A full list of sites and their ratings on all major variables is presented in the Appendix I in the Data Supplement. Full results for each site are available by contacting the authors.

Purpose

The purpose of most sites is as an informational resource (n=28, 82%), or as a forum for sharing experiences and perspectives (n=27, 79%). Roughly half of the sites (n=18, 53%) were aimed at providing a psychological resource for patients and caregivers, and just under a quarter (n=8, 24%) constituted a forum for expressing complaints and concerns. For a small number of sites (n=6, 18%) the purpose was unclear. A total of 59% (n=20) of sites were multipurpose, with most having ≥2 purposes (n=15, 44%) and a smaller number having 3 (n=4, 12%) or 4 (n=1, 3%) purposes.

Audience

Although most of the social media sites are aimed toward an audience of patients who have an LVAD (n=32, 94%) and their caregivers (n=29, 85%), over half are also intended as a resource for candidates who are undergoing the decision-making process (n=22, 65%). Just over a third (n=13, 38%) explicitly include practitioners as an intended audience. Most sites were intended for ≥1 audience, including at least 2 (n=13, 38%) or 3 (n=12, 35%) different types. A smaller number of sites (n=6, 18%) explicitly included all 4 audience types as intended users.

Medium

A majority of the sites (n=23, 68%) were primarily visual, whereas just over a third (n=12, 35%) were primarily text. Of those that were primarily visual, a majority (n=18, 78%) contained visuals of family and personal life, as well as visuals of anatomy, medicine, or other technical information (n=17, 74%). Most of the sites (n=26, 76%) contained both text and visual information, although there was typically an emphasis on one or the other.
A majority of the sites (n=24, 70%) provide accurate information if desired (n=31, 91%).

Interactivity
Most sites (n=27, 79%) invited feedback to some extent, although the largest number (n=14, 41%) only did so a little, versus somewhat (n=7, 21%) or a lot (n=6, 17%). About a quarter (n=8, 23%) did not elicit feedback from users at all. Almost all the sites (n=33, 97%) offered the ability to like or share the page with others, and to post comments and personal experiences if desired (n=31, 91%).

Accuracy and Consistency
A majority of the sites (n=24, 70%) provide accurate information. However, informational inaccuracies were found in nearly a third of the sites (n=11, 32%), with 1 site (3%) containing 1 inaccuracy, 4 sites (12%) containing 2 inaccuracies, 2 sites (6%) containing 3 inaccuracies, and 4 sites (12%) containing ≥4.

On example of an inaccuracy centered on what patients might expect from different designations of LVAD treatment (eg, bridge-to-transplant versus destination therapy). In response to the request, I need information on Left Ventricle Assistance Device or (LVAD), posted on Yahoo Answers, the following answer was given.

The invasive nature of the device and the high complications rates mean that for the most part, people sit around in the hospital with this. So this is used generally in those people who need a heart transplant now but none is available so this is used as a bridge.

Other inaccuracies were noted on a variety of topics, ranging from driveline maintenance to lifestyle changes to the nature of LVAD designations, such as bridge-to-transplant versus destination therapy. In addition to inaccuracies, inconsistencies were noted across many sites, including the following example posted in response to a question to a Facebook group:

How is everyone taking care of the drive lines and dressings? I have two drive lines an LVad and an RVad. My husband was trained to clean them and all has been going great. We are down to every three days. We watched on YouTube a method where silver was used to sterilize the area. Does anyone do this method?

The answers to this question varied from daily to every other day to once a week, with no definitive answer provided. Another example of inconsistencies is the range of answers to a question posed by another user on a different Facebook site about length of time in between follow-up appointments. Responses included every 2 weeks, once a week for now then maybe every 2 weeks then once a month, once a month, every 4 to 6 weeks, every 6 weeks, every 8 to 10 weeks, every 2 months (2 responses), and every 3 months (7 responses).

Other inaccuracies or inconsistencies in responses concerned whether alcohol or tobacco use is permissible with an LVAD, whether LVAD recipients could vacuum or engage in other activities that might generate static electricity, qualifications for patients to become LVAD candidates (eg, must be a transplant candidate, as 1 user suggested), home requirements for patients LVAD and caregivers (eg, whether backup generators or alternative power sources are needed in cases of emergency), the cost, size and weight of battery packs, potential problems when LVADs interacting with pacemakers or defibrillators, the longevity of LVAD recipients, among many other topics.

User-Friendliness and Appeal
All but one of the sites (n=33, 97%) were found to be easy to navigate, most often fitting into a preordained structure offered by the web hosting site. The ease of readability across sites was found to be moderate (mean=55.10; SD=34.56), based on the commonly used Flesch Readability scale, with significant variation across sites. Sites were scored on a scale of 0 to 100, with higher scores indicating greater readability. The average readability of sites was found to be between the fourth and fifth grade level (mean=4.9; SD=3.6).

Principal Components Analysis of Variables
A principal components analysis of all main variables yielded 4 clear factors related to social media type, comprising purpose, and audience (factor 1), medium, user-friendliness and appeal (factor 2), interactivity (factor 3), and accuracy/consistency (factor 4). Eigenvalues for all 4 factors were similar in size (Table 2), with gradual reductions after the first factor. Similarly, variance accounted for was slightly higher for the first factor, followed by gradually smaller but comparable percentage for the second, third, and fourth factors. Taken together, these 4 factors accounted for 50% of the variance in the data.

Loadings on the first factor reveal that this component represents purpose and content, whereby LVAD-related social media sites may be distinguished into 2 main types, such as for expressing personal complaints and concerns with issues related to LVAD therapy as well as sharing experiences and perspectives, and for providing a psychosocial resource for users. These sites were judged to have a more positive subjective tone, and are primarily visual, with images of family and personal life predominating. Examples of supportive

Table 1. Left Ventricular Assist Device–Related Social Media Sites

<table>
<thead>
<tr>
<th>Sites</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facebook</td>
<td>14</td>
<td>41.2</td>
</tr>
<tr>
<td>YouTube</td>
<td>8</td>
<td>25</td>
</tr>
<tr>
<td>Blog</td>
<td>5</td>
<td>14.7</td>
</tr>
<tr>
<td>Twitter</td>
<td>4</td>
<td>11.76</td>
</tr>
<tr>
<td>Pinterest</td>
<td>2</td>
<td>5.9</td>
</tr>
<tr>
<td>Yahoo answers</td>
<td>1</td>
<td>2.94</td>
</tr>
<tr>
<td>Total</td>
<td>34</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 2. Principal Components Analysis of Variables

<table>
<thead>
<tr>
<th>Component</th>
<th>Eigenvalue</th>
<th>% Variance</th>
<th>Cumulative %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social media type</td>
<td>4.11</td>
<td>14.98</td>
<td>14.98</td>
</tr>
<tr>
<td>User-friendliness/appeal</td>
<td>3.32</td>
<td>13.47</td>
<td>28.45</td>
</tr>
<tr>
<td>Interactivity</td>
<td>2.97</td>
<td>11.18</td>
<td>39.64</td>
</tr>
<tr>
<td>Accuracy/consistency</td>
<td>2.34</td>
<td>11.13</td>
<td>50.78</td>
</tr>
</tbody>
</table>
comments were religious in nature (eg, Happy 1st Year LVAD Anniversary, praying the next year is better and things improve. Stay strong—my prayers are with you.), whereas others were secular and inspirational (eg, Together supporting one another we build a bridge.).

Sites that were more purely informational in nature contained fewer references to personal experiences and perspectives, more visuals of anatomy, medicine and other technical imagery, and more often aimed toward an audience of practitioners. An example of information provided on these sites included postings such as Please share this exciting new (LVAD-related) infographic filled with fun facts about nurse practitioners. (We are) proud to educate legislators and consumers about the excellent healthcare NPs provide.

Sites combining both informational and experiential information are exemplified by 1 blog site describing a man’s recurring experiences with driveline infections, including detailed technical information on how each infection was handled, as well as his perceptions and emotional reactions. This kind of dual type site demonstrates that the typologies documented by principal components analysis are not mutually exclusive.

Variable loadings on the second factor suggested a construct related to user friendliness and appeal, with sites split between primarily text with higher Flesch Readability scores (ie, easier to read), and those with primarily visual mediums. The latter image-dominated sites were also those that were judged easier to navigate than primarily text-based sites.

A third factor was evidenced by variables centering around interactivity, with 1 constellation of features including the presence of a fan page or the ability to like or share the site with others, the ability to post comments and personal experiences, and a creator who invites feedback. An example of an invitation for feedback is So, LVAD Recipients, what do you do to stay active? Let’s share some ideas here. You may inspire someone! These sites were also easier-to-navigate interface, with a more positive subjective tone. These sites tended also to be geared toward an audience of caregivers and had lower overall readability.

Finally, a fourth and related (to the third) factor emerged with regard to accuracy and consistency in user-generated content. Variables clustering together with a higher frequency of inaccuracies and inconsistencies included a greater tendency for creators to invite feedback, and greater ability to post comments, personal experiences, and to share visuals of family and personal life. These sites were more often used by caregivers and patients, rather than by candidates or physicians, and had overall lower readability scores and more negative subjective tone.

**Differences in Content by Audience Type**

Differences in social media content were found on the basis of audience type, as evidenced by the zero-order correlations presented in Table 3. Sites aimed toward an audience of patients were more likely to constitute a psychological resource and to provide forums for sharing, while the purpose was not always as distinct for sites engaging caregivers and candidates. Those sites addressing an audience of practitioners were most likely to act as informational resources and to be relatively absent of psychosocial and experiential components. Caregiver-predominant sites were found to be the most interactive but with a greater number of inaccuracies and inconsistencies than sites predominated by other user types. Sites aimed toward an audience of candidates showed lower readability scores, and more often featured images of family and personal life. Sites with an unclear audience type also tended to have a less clear purpose.

**Discussion**

This analysis revealed that patients and caregivers in the LVAD community are currently using social media not only to obtain information but also to seek psychosocial support. Social media sites may help to fill an important gap in services to address stress, distress, and other psychosocial concerns common among the patients with LVAD and caregiver population.\(^{25}\) In cases where patients or caregivers have limited support, or feel that they cannot or should not voice complaints to one another, a phenomenon noted in recent literature,\(^{26-28}\) social media sites may provide useful outlets for emotional catharsis and support.

**Balancing Convenience and Clarity**

LVAD-related social media sites often serve multiple purposes. This may add to convenience for users, but may also render goal-focused navigation and readability more challenging. Findings from the joint technical committee of the International Organization for Standardization (ISO) and the International Electrotechnical Commission\(^ {29}\) suggest that perceived usability is enhanced when users feel their use of a site achieves a clear set of goals. When different goals are being addressed by a single site, perceived usability and satisfaction decrease. These are important considerations for researchers interested in developing or using current LVAD-related social media sites for the purposes of offering health information and support services.

Furthermore, just as many of the LVAD-related sites were found to be multipurpose, many are also intended for multiple audiences, with over a third simultaneously targeting at least 2 audiences (typically patients and caregivers) or more. Studies\(^ {30,31}\) suggest that sites clearly tailoring information to specific audiences are more effective in conveying health-related messages. For researchers interested in the potentials of social media for health improvement and support, more work is needed to explore the usability and appeal of sites that simultaneously target audiences with disparate informational or support needs.

**Weighing Benefits of Interactivity against Error-Free Content**

The ability to engage with other users and to offer feedback through social media may have both benefits and detriments. On the one hand, site interactivity allows for greater user engagement and a means for both eliciting and providing psychosocial support. However, we found that a high level of interactivity by nonexperts is negatively associated with readability and with higher levels of informational inaccuracy and inconsistency. The potentially dangerous consequences of erroneous health information have incited a recent discourse on the urgency and challenges of monitoring and regulating
Table 3. Significant Correlations With Audience Type

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td>$r=0.35, P=0.04$</td>
<td>$r=0.39, P=0.02$</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
</tr>
<tr>
<td>Caregivers</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
</tr>
<tr>
<td>Candidates</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>$r=0.36, P=0.04$</td>
<td>$r=0.39, P=0.02$</td>
<td>$r=0.35, P=0.04$</td>
</tr>
<tr>
<td>Practitioners</td>
<td>$r=0.43,*$</td>
<td>$r=0.53,* P=0.00*$</td>
<td>$r=0.47, P=0.00$</td>
<td>...</td>
<td>...</td>
<td>$r=-0.43,* P=0.001*$</td>
<td>...</td>
</tr>
<tr>
<td>Unclear</td>
<td>...</td>
<td>...</td>
<td>$r=0.38, P=0.02$</td>
<td>...</td>
<td>...</td>
<td>...</td>
<td>...</td>
</tr>
</tbody>
</table>

A content analysis of social media related to left ventricular assist devices.

*Negative correlations.

user-generated content of health information sites. Although intervention strategies are being developed for handling misinformation (eg, using machine learning and natural language processing algorithms to detect low-quality information and to provide site trustworthiness scores to display alongside site content), reliable solutions are still in their embryonic stages. What we do know, however, is that online resources that are developed and actively maintained by experienced professionals are more likely to contain less variable information and fewer inaccuracies than those left to the free reign of users with less clinical knowledge and expertise. The more users are able to generate and control Website content, the more difficult quality control of information becomes.

Furthermore, even if regulating user-generated content can help to reduce the number of informational errors, it calls into question important ethical issues related to privacy as well as freedom of expression. This area of inquiry is likely to proliferate and potentially come to dominate institutional- and industry-based sources of information in terms of their accessibility and appeal.

Future Potentials of LVAD-Related Social Media

A growing body of research demonstrates that social media, including peer-to-peer sites for information exchange and support, can be effective platforms for hosting health interventions among online communities and for diffusing health information beyond participants through their social networks.

With regard to the LVAD community specifically, sites that seem to be highly visited and appealing to patients and caregivers may serve as models or even direct conduits for disseminating health information to enhance current patient education related to decision making and postoperative care. These sites represent a promising frontier for social networking approaches to patient and caregiver engagement and support. However, greater insight is needed into the quality and content of information disseminated via social media with respect to LVAD treatment specifically, as well as how social media interactions reflect and shape decision making and influence coping behaviors among LVAD caregivers and patients in the postdevice placement setting. Further exploring the effects of exposure to a large variety of user-reported experiences, opinions, and viewpoints—particularly in the absence of professional verification and in the context of highly diverse outcome experiences—remains a ripe area for future research. The use of social media for informally acquiring health information has reached a level where it is imperative for clinicians to become aware of what information is sought out and available. Users should also be encouraged by Website managers and by their clinical teams to bring any significant questions, concerns, or insights taken from social media sites to their doctors for clarification or confirmation, particularly where information can influence health behaviors, such as driveline maintenance, with critical consequences.

Study Limitations

This study did not include a content analysis of provider-generated or provider-curated social media sites, although it is likely that patients and caregivers are also accessing these sites for informational purposes. Therefore, the findings presented here with regard to patient/caregiver-generated social media sites constitute only a portion—although a sizable one—of the content patients and caregivers are exposing themselves to through social media. A comprehensive understanding of LVAD-related content available on the Internet would benefit from a full content analysis of both provider- and user-generated content.

In addition, evaluations for certain content variables (eg, Tone) were inherently subjective and relied on the judgment of the authors. Our method of evaluating each site by 2 independent raters constitutes an attempt to mitigate author bias and enhance reliability.

Conclusions

Social media sites represent a promising resource for patients with LVAD and caregivers seeking information and psychosocial support throughout the processes of decision making, surgery, and postoperative maintenance care. User engagement and feedback make them especially appealing sources of information exchange. Current challenges to the informational validity of social media include a lack of oversight into the content and quality of information these sites provide. More research is needed to circumvent these challenges to more fully capitalize on the many potential benefits of social media as resources for patient education, psychosocial support, and community-building around LVAD experiences.
Content Analysis of Social Media Related to LVADs

29. Bevan N. International standards for usability should be more widely used. JUS. 2009;4:106–113.
Content Analysis of Social Media Related to Left Ventricular Assist Devices
Kristin M. Kostick, Jennifer S. Blumenthal-Barby, Lidija A. Wilhelms, Estevan D. Delgado and Courtenay R. Bruce

Circ Cardiovasc Qual Outcomes, published online July 28, 2015;
Circulation: Cardiovascular Quality and Outcomes is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231
Copyright © 2015 American Heart Association, Inc. All rights reserved.
Print ISSN: 1941-7705. Online ISSN: 1941-7713

The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://circoutcomes.ahajournals.org/content/early/2015/07/28/CIRCOUTCOMES.115.002032

Data Supplement (unedited) at:
http://circoutcomes.ahajournals.org/content/suppl/2015/07/29/CIRCOUTCOMES.115.002032.DC1

Permissions: Requests for permissions to reproduce figures, tables, or portions of articles originally published in Circulation: Cardiovascular Quality and Outcomes can be obtained via RightsLink, a service of the Copyright Clearance Center, not the Editorial Office. Once the online version of the published article for which permission is being requested is located, click Request Permissions in the middle column of the Web page under Services. Further information about this process is available in the Permissions and Rights Question and Answer document.

Reprints: Information about reprints can be found online at:
http://www.lww.com/reprints

Subscriptions: Information about subscribing to Circulation: Cardiovascular Quality and Outcomes is online at:
http://circoutcomes.ahajournals.org/subscriptions/
Appendix

A Content Analysis of Social Media Related to LVADs

A. Methodology

1. Search Strategy
   - **Social media sites considered:** Facebook pages, Twitter feeds, blogs, YouTube videos, Yahoo Answers, and Pinterest pages.
   - **Search terms:**
     - Blogger, Facebook, Twitter, and WordPress: “LVAD”
     - YouTube (searched with the filter “Most Viewed”): “LVAD”, “LVAD Surgery”, “LVAD Driveline”, “LVAD Procedure”
   - **Exclusion criteria:** We excluded sites that were created and/or maintained by scientific, medical, professional, for-profit, or academic institutions, and advertisements, though not those maintained by professionals blogging independently for patients and caregivers.

2. Screening Review
   - **Initial Results:** Blogger- 73,600 results; Facebook- 58 groups/pages; Twitter-25 accounts; WordPress- 74,600 results; YouTube- “LVAD”- 6,870 results; “LVAD surgery”- 3,050 results; “LVAD driveline”- 7 results; “LVAD procedure”- 1,740 results
   - **Inclusion Criteria:** Active within the past year, English-speaking, primarily focused on LVAD treatment and experiences, and posted by individuals/public, not institutions
   - **Exclusion Criteria:** Not active within the past year, not primarily related to LVAD treatment or experiences, intended for commercial marketing or profit, and directly issued by a medical institution.

### Search Strategy

<table>
<thead>
<tr>
<th>Sites Identified:</th>
<th>89</th>
</tr>
</thead>
</table>

### Screening Review - Included Sites (34)

- (17) Active in past month
- (12) Active in past 2-6 months
- (6) Active in past 7 months to a year

### Screening Review - Excluded Sites (55)

- (44) Not within the past year
- (3) Not primarily related to LVAD
- (2) Duplicate site
- (1) Change in focus over past year
- (1) Run by medical institution
- (4) Site not operative or accessible
3. Site Categorization

- **Category and Score Definitions**: Kristin, define the score rankings.

### B. Social Media Site Scores

<table>
<thead>
<tr>
<th>#</th>
<th>Site Name</th>
<th>Site Type</th>
<th>Interactive Score (0-3)</th>
<th>User-Friendly Score (0-1)</th>
<th>Readability Score (0-100)</th>
<th>Accuracy Score (0-2)</th>
<th>Tone Score (0-5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>LVAD Recipients</td>
<td>FB</td>
<td>2.5</td>
<td>1</td>
<td>72.20</td>
<td>1.5</td>
<td>3.75</td>
</tr>
<tr>
<td>2</td>
<td>LVAD Warriors</td>
<td>FB</td>
<td>3.0</td>
<td>1</td>
<td>84.55</td>
<td>1.5</td>
<td>3.50</td>
</tr>
<tr>
<td>3</td>
<td>LVAD Conversations</td>
<td>FB</td>
<td>2.5</td>
<td>1</td>
<td>72.20</td>
<td>1.5</td>
<td>3.75</td>
</tr>
<tr>
<td>4</td>
<td>LVAD Friends</td>
<td>FB</td>
<td>3.0</td>
<td>1</td>
<td>88.80</td>
<td>1.5</td>
<td>3.25</td>
</tr>
<tr>
<td>5</td>
<td>LVAD Warrior Misfits</td>
<td>FB</td>
<td>2.0</td>
<td>1</td>
<td>83.55</td>
<td>0</td>
<td>5.0</td>
</tr>
<tr>
<td>6</td>
<td>LVAD Trooper</td>
<td>FB</td>
<td>2.0</td>
<td>1</td>
<td>85.60</td>
<td>0.5</td>
<td>3.5</td>
</tr>
<tr>
<td>7</td>
<td>MyLVAD</td>
<td>FB</td>
<td>1.0</td>
<td>1</td>
<td>74.75</td>
<td>0.25</td>
<td>4.25</td>
</tr>
<tr>
<td>8</td>
<td>Middle Georgia LVAD</td>
<td>FB</td>
<td>2.5</td>
<td>1</td>
<td>84.80</td>
<td>0</td>
<td>3.75</td>
</tr>
<tr>
<td>9</td>
<td>From the Bottom of My LVAD</td>
<td>FB</td>
<td>1</td>
<td>1</td>
<td>81.85</td>
<td>0.5</td>
<td>5.0</td>
</tr>
<tr>
<td>10</td>
<td>LVAD Patient &amp; Caregiver Researcher- Dr. Casida</td>
<td>FB</td>
<td>1</td>
<td>1</td>
<td>53.35</td>
<td>0</td>
<td>4.0</td>
</tr>
<tr>
<td>11</td>
<td>Heart to Heart LVAD Families</td>
<td>FB</td>
<td>1</td>
<td>1</td>
<td>79.70</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>12</td>
<td>Ken’s LVAD Journey to Transplant</td>
<td>FB</td>
<td>1</td>
<td>1</td>
<td>79.40</td>
<td>0</td>
<td>4.5</td>
</tr>
<tr>
<td>13</td>
<td>Scott’s LVAD Foundation</td>
<td>FB</td>
<td>0.5</td>
<td>1</td>
<td>64.7</td>
<td>0</td>
<td>4.5</td>
</tr>
<tr>
<td>14</td>
<td>Our Life Our Love His LVAD</td>
<td>FB</td>
<td>1</td>
<td>1</td>
<td>81.15</td>
<td>0</td>
<td>4.25</td>
</tr>
<tr>
<td>15</td>
<td>@MyLVAD</td>
<td>TW</td>
<td>1</td>
<td>1</td>
<td>80.80</td>
<td>0</td>
<td>4.5</td>
</tr>
<tr>
<td>16</td>
<td>@LVADone</td>
<td>TW</td>
<td>0</td>
<td>1</td>
<td>61.90</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>17</td>
<td>@LVAD03</td>
<td>TW</td>
<td>0.5</td>
<td>1</td>
<td>78.35</td>
<td>0</td>
<td>3.5</td>
</tr>
<tr>
<td>18</td>
<td>@JasonsLVAD</td>
<td>TW</td>
<td>1.5</td>
<td>1</td>
<td>82.9</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>19</td>
<td>From the Bottom of My LVAD</td>
<td>BL</td>
<td>0.5</td>
<td>0.5</td>
<td>68.45</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>20</td>
<td>Our Life Our Love His LVAD</td>
<td>BL</td>
<td>0</td>
<td>1</td>
<td>56.65</td>
<td>0</td>
<td>4.5</td>
</tr>
<tr>
<td>21</td>
<td>Life at 9200rpms and Beyond</td>
<td>BL</td>
<td>1</td>
<td>0</td>
<td>67.30</td>
<td>0</td>
<td>3.5</td>
</tr>
<tr>
<td>22</td>
<td>Wright on Health</td>
<td>BL</td>
<td>0</td>
<td>1</td>
<td>45.10</td>
<td>0</td>
<td>3.5</td>
</tr>
<tr>
<td>23</td>
<td>HeartMate II LVAD Implantation- Arie Blitz MD</td>
<td>YT</td>
<td>1.5</td>
<td>1</td>
<td>82.90</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>24</td>
<td>Patient 10 Days</td>
<td>YT</td>
<td>3</td>
<td>1</td>
<td>N/A</td>
<td>1</td>
<td>4.75</td>
</tr>
<tr>
<td></td>
<td>after having LVAD</td>
<td>YT</td>
<td>1.5</td>
<td>1</td>
<td>N/A</td>
<td>0</td>
<td>4.25</td>
</tr>
<tr>
<td>---</td>
<td>------------------</td>
<td>-----</td>
<td>-----</td>
<td>---</td>
<td>-----</td>
<td>---</td>
<td>------</td>
</tr>
<tr>
<td>25</td>
<td>Life with an LVAD: Waiting for a Heart Transplant</td>
<td>YT</td>
<td>1.5</td>
<td>1</td>
<td>N/A</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>26</td>
<td>Life with a LVAD</td>
<td>YT</td>
<td>1</td>
<td>1</td>
<td>N/A</td>
<td>0</td>
<td>4.25</td>
</tr>
<tr>
<td>27</td>
<td>LVAD Insertion-Dr. Vivek Rao</td>
<td>YT</td>
<td>0</td>
<td>1</td>
<td>N/A</td>
<td>0</td>
<td>4.25</td>
</tr>
<tr>
<td>28</td>
<td>Minimally Invasive LVAD Implantation</td>
<td>YT</td>
<td>0</td>
<td>1</td>
<td>N/A</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>29</td>
<td>Vincent’s Plan- An LVAD Success Story</td>
<td>YT</td>
<td>0</td>
<td>1</td>
<td>N/A</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>30</td>
<td>UCSF LVAD Driveline Dressing Change</td>
<td>YT</td>
<td>0</td>
<td>1</td>
<td>N/A</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>31</td>
<td>LVAD Removal at Stanford- Donna Jackson’s Story</td>
<td>YT</td>
<td>0</td>
<td>1</td>
<td>N/A</td>
<td>0.5</td>
<td>3.75</td>
</tr>
<tr>
<td>32</td>
<td>Yahoo Question</td>
<td>YA</td>
<td>1.5</td>
<td>1</td>
<td>81.95</td>
<td>0.5</td>
<td>2</td>
</tr>
<tr>
<td>33</td>
<td>LVAD News, Tips, &amp; Resources Pinterest: LVAD</td>
<td>PT</td>
<td>1</td>
<td>0.5</td>
<td>68.30</td>
<td>0</td>
<td>4</td>
</tr>
</tbody>
</table>

**Key:** FB – Facebook, TW – Twitter, BL – Blog (Blogger or WordPress), YT – YouTube, YA – Yahoo Answers, PT – Pinterest.

*Highlighted site numbers show sites with greatest Interactivity Scores.*