For consideration as a Short Paper in JMIR: Cardio.

“Obviously, you can’t give me medical advice over the internet, but…” : Quality of Medical Advice Provided Between Members of an Online Message Board for Implanted Defibrillator Patients

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Abstract word count: 199 ; Main body word count: 2168
Abstract

Objective: To characterize quality of medical information provided between members of an anonymous internet message board addressing treatment with an implanted cardioverter-defibrillator (ICD).

Method: Two years of discussions were qualitatively analyzed using a mixed inductive-deductive framework, first for instances in which members provided medical advice, then for the quality of the advice itself.

Results: We identified 82 instances of medical advice within 127 discussions. Advice covered six topical areas: 1) Device Information, 2) Programming, 3) Cardiovascular Disease, 4) Lead Management, 5) Activity Restriction, and 6) Management of Other Conditions. Across all advice, 50.0% was deemed Generally Appropriate, 24.4% Inappropriate for Most Patients, 6.1% Controversial, and 19.5% Without Sufficient Context. Proportions of quality categories varied between topical areas. Representative examples are included.

Conclusion/Practice Implications: Patients use online medical information to understand cardiovascular conditions and treatment options. A number of efforts have been made to understand the quality of professionally-created educational content, while ours describes the quality of advice being provided between anonymous members of an online message board. The quality of advice varied considerably, both by topical area and the specificity of advice. This brief report provides a model by which to describe the quality of patient-generated material available online.

Key words: Patient education; Cardiovascular care, Online medical information; Message boards
1. Introduction

The vast majority of adults use the internet to research health issues to inform decisions, including whether or not to accept certain tests, medications, or devices\textsuperscript{1,2}. Sources of online information include both professionally-created websites (e.g. WebMD, Mayo Clinic, industry materials) and user-created content on social media\textsuperscript{3}. Online medical information fills a critical need for patient education, decision making, and emotional support\textsuperscript{4,5}. Therapeutic interventions in many areas of medicine are becoming more complex, patients will forget 40-80% of information presented during medical appointments\textsuperscript{6}, and patients can access online information at any time and review it indefinitely. Online information fills educational needs of patients outside of appointments as patients report acting on advice they find\textsuperscript{7} and report satisfied with the information and support they receive online\textsuperscript{8}.

The quality of information patients encounter online varies, however, including in materials created by professionals. One investigation found internet resources for ventricular assistance device candidates universally discussed benefits of therapy, but only half reported risks, and only 2 (of 77) mentioned palliative care or hospice\textsuperscript{9}. Another examination of webpages of 262 transcatheter aortic valve replacement centers found that all discussed benefits of treatment, but only 26% mentioned any risk\textsuperscript{10}. Such limitations within resources created by professionals are likely reflected in information shared between anonymous members of web-based communities, where patient-users logically have less access to the population-based information needed to contextualize advice about complex therapies. Nevertheless, patients who engage in a comprehensive online search will encounter both forms of information.
We chose implantable cardioverter defibrillators (ICDs) as a model to explore the quality of user-provided information appearing on medical message boards. Decisions regarding whether or not to implant an ICD involve trade-offs. ICDs may lengthen patients’ lives, but have potential risks including infection, lower quality of life, increased hospitalizations, and potential suffering at the end of life. Ongoing self-management and decision making are critical in ICD care, there it is important to ensure the accuracy of advice being acted upon by patients. While our prior work demonstrates patients report learning about their ICDs from internet message boards, the quality of this information is unknown. This project sought to characterize the quality of medical information provided between commenters on an internet message board for patients with ICDs.

2.1 Method & Data Source.
We utilized a mixed inductive-deductive approach to characterizing and quantifying the quality of medical information shared on an ICD message board. This approach was adapted from one used previously by our group. To focus the content of discussions under analysis, we limited our search to comment threads appearing on one ICD-specific message board. We included all discussions posted between 1/1/2015 and 12/31/2016. Each discussion was uploaded into Dedoose analytic software (v 7.1.3: SocioCultural Research Consultants, Los Angeles, CA) to facilitate team based analysis. No member of the research team had known relationships with commenters, and no attempt made to identify or contact commenters (whose posts were labeled with self-chosen avatars). The project was deemed exempt by the local Institutional Review Board.

2.2 Analysis.
Analysis was conducted using a progressive deductive, inductive, and quantifying process adapted from our earlier inductive/deductive toolkit. Each stage included perspectives of
multiple research team members. First, the complete online discussion threads were
deductively coded for instances in which one commenter provided another with any form of
medical advice. This included coding by at least two primary analytic team members (CK, HS,
AS), with any differences adjudicated by team consensus. Next, the primary author and a
board-certified cardiac electrophysiologist (CK, LM) inductively coded each instance in which
medical advice was provided by one commenter to another, creating a framework for analyzing
both the topic discussed and the quality of advice. Resulting quality categories included: 1)
Generally Appropriate, 2) Controversial, 3) Inappropriate for Most Patients, or 4) Without
Sufficient Context to Support. Finally, we quantified the proportions of the quality of advice
provided between commenters within each topical area.

3.1 Results
We identified 102 separate instances (from 127 threaded discussions) during the study period in
which one member provided advice to another. We excluded 20 comments which discussed
psychosocial adjustment to ICD placement or shock, leaving 82 pieces of explicit medical
advice.

3.2 Topical Areas & Quality
Commenters provided advice in six conceptual areas, 1) Device Information [19 instances], 2)
Programming [17], 3) Cardiovascular Disease [9], 4) Lead Management [4], 5) Activity
Restriction [15], and 6) Management of Other Conditions [13]. The overall quality of advice
provided was mixed, with 50% deemed Generally Appropriate, 24% Inappropriate for Most
Patients, 6% Controversial, and 20% Without Sufficient Context. However, the proportionate
quality of advice provided within each of these categories varied considerably (Table 1).
Representative examples within each category, as well as the quality category assigned to
topical area.
Device Information. Information pertaining to ICD devices themselves, including basic functionality, battery life, and typical care processes was generally appropriate (63.2% appropriate, 21.1% inappropriate). This advice typically focused components of ICD systems, terminology, and capabilities.

“They can implant a 3 lead with a defib as you stated.....or deactive it and give you a S-ICD....defib only.” (Generally Appropriate)

Programming. The quality of advice regarding the ICD programming, particularly pacing parameters, anti-tachycardia pacing, and arrhythmia detection algorithms, was mixed (41% appropriate, 18% inappropriate, and 36% without sufficient context).

“After the MADIT-RIT study, ICDs are very rarely programmed to shock at heart rates lower than 200 or 220.” (Generally Appropriate)

Comments coded as being without sufficient context included information regarding specific programming parameters and algorithms which may be appropriate in some, but not all, clinical circumstances.

“AAIR (atrial rate adaptive) pacing may be preferable to DDDR (dual chamber rate adaptive) by avoiding an abnormal ventricular activation pattern”

“The pacemaker part of your implant does not limit you to 80 bpm” (Without Sufficient Context)
Cardiovascular Disease. The quality of information addressing cardiovascular disease was similarly mixed, with 56% Generally Appropriate, 33% coded as Without Sufficient Context to Support, and 11% Inappropriate.

“SSS stands for sick sinus syndrome. The sinus node is the heart's natural pacemaker. The SA node sends the electrical impulse to the atria to initiate a beat. When the SA node doesn’t work properly, the PM steps in.” (Generally Appropriate)

Pieces of advice coded as being Without Sufficient Context to Support again owed to information only accurate to some clinical situations.

“you could be in the 10% to 13% of patients (depending on which scientific publication you read) whom experience early heart failure hospitalization associated with "conventional pacing." Historic pacing bypasses the cardiac conduction system” (Without Sufficient Context).

Lead Management. Only four instances included advice regarding lead management were identified, and these were split between being Generally Appropriate (50%) and Controversial (50%). These comments were related to the advantages and disadvantages of lead extraction, a potentially high-risk procedure associated with ICDs.

“They can be capped off and left there indefinitely. Extraction is a more specialized surgery, requiring an expert in the field and it has some risk. I would not do it unless it was necessary. There are no additional precautions to follow.” (Generally Appropriate)
“They do not have to leave leads in. I for one am not a damn junk yard and will not accept unused trash to be left behind…lead removal is quite common and not much of a big deal.” (Controversial).

Activity Restriction. Advice addressing whether or not patients with ICDs should avoid certain activities or environments was common (15 instances) and Generally Appropriate (66.7%, 33% Generally Inappropriate).

“When people say 8 weeks, that's for lifting heavy and raising the arm overhead. Most docs say 4-6 weeks for that. And other than those two limits- overhead and lifting heavy- you can and should use the arm normally” (Generally Appropriate)

Instances in which commenters incorrectly advised patients to avoid small electrical devices (electric razors, tattoo needles, etc.) were particularly common among those coded as Generally Inappropriate.

“Just don’t get a tattoo directly over the device. Anywhere else is ok.” (Generally Inappropriate)

Procedures. While less common (6 instances), advice related to procedures was more problematic. All instances in this category were determined to be either Generally Appropriate (33%) or Inappropriate for Most Patients (67%). The specificity of the advice related to quality, with general advice being coded as appropriate and specific advice being inappropriate.

(In reference to a question regarding an upcoming non-CV procedure) “Just make sure the surgeon and anesthesiologist know in advance.” (Generally Appropriate).
“You were one of the less than 1% of PM patients that is inflicted with an infection. Should you need surgery again they will take extra precautions as a result. That makes the likelihood of another infection even less than 1% for you.” (Generally Inappropriate)

Other Disease Management. Advice regarding other approaches to managing cardiovascular disease and arrhythmias varied considerably in terms of quality, with 23% of such comments being coded as Generally Appropriate, Generally Inappropriate, or Controversial, and 31% deemed to not have sufficient context to support. Within this category, more specific advice (e.g. to begin or stop specific medications or vitamins) were likely to be categorized as Generally Inappropriate or Controversial.

“I would advise you to start taking some vitamins; I buy them from this web site that I found here: (redacted) and I buy from this site: (redacted) I don’t know if you can buy them from UK, but try to find similar ingredients. Also, doctors recommend to stay always hydrated which is mean to drink water with a bit sea salt or buy smart water that already have some ingredients.” (Generally Inappropriate)

“If your ICD was implanted because you were losing consciousness, removal of that device or turning it off could mean that you lose consciousness while driving and would possibly kill yourself and/or someone else. Also if your heart has actually stopped and an ICD was implanted to restart your heart, turning it off could have fatal consequences” (Controversial)

4. Discussion & Conclusion
This analysis of the quality of medical information exchanged between members of an ICD-specific online message board provides unique insight into the quality and accuracy of the advice patients will find on such websites. An accurate understanding of the quality of this
information is critical as patients or caregivers will use online resources to help navigate complex decisions regarding ICDs. Since the use of online resources is an important component of more general efforts to learn and guide disease self-management behaviors, providers can use these findings to help guide patients to appropriate, accurate, and helpful resources, and warn them of dangers particular to others with inaccurate, decontextualized, or controversial advice.

While the quality of advice shared between members of an ICD-specific online forum was mixed, half of such advice was generally appropriate. The proportion of appropriate advice differed among aspects of ICD treatment. As little as a quarter of the advice regarding other disease management, and as much as two-thirds related to activity restriction was of generally good quality. In many cases, the quality of any individual piece of advice was inversely related to its specificity. That is, nonspecific and context-independent advice is of higher quality in this venue. Examples include descriptions of cardiovascular disease, the general utility of devices, and encouraging patients to discuss individual questions with their healthcare providers. Conversely, controversial or inappropriate advice featured prominently in more specific discussions, including those addressing specific device programming parameters (which vary depending on individual patient characteristics), and discussions of device and procedure risks. Interestingly, risks associated with device implant and lead extraction procedures tended to be understated, while risks associated with everyday activities (use of electronic devices in particular) were generally overstated.

In cases where members sought general information about ICDs and their functionality, the advice provided on this message board provides a succinct, accessible, and well-organized resource of basic information of interest to ICD patients and candidates. In this sense, anonymously submitted information appearing on this internet message board acts as a
resource which might help avoid gaps in fundamental understanding among patients observed previously\textsuperscript{16-17}. Unfortunately, other recent investigations into how patients with cardiovascular disease act on the information they find on message boards suggest that they go online suggest that they are likely seeking answers to highly specific questions\textsuperscript{7}, which in our sample were more likely to produce problematic information.

While these findings are relevant to patient education, they should be considered within several limitations. We analyzed conversations occurring on a single message board and the quality of information elsewhere may differ. Additionally, discussions between individuals interested in ICDs and other therapies are also occurring on social media platforms (e.g. Facebook, LinkedIn)\textsuperscript{5}, which allow for conversations on member and organization pages, in addition to dedicated message boards. The anonymity offered by the avatar-based system used on the site we analyzed may increase the honesty and frankness of discussion\textsuperscript{18}, but may alter the questions asked and advice provided if compared to a similar discussion occurring on Facebook. Nonetheless, these data may be representative of the quality of medical information appearing on many unmoderated, anonymously-sourced message boards specific to cardiovascular and other treatment experiences.

5. Funding
This study was not funded by any entity. Dr. Matlock was supported by the National Institute on Aging (K23AG040696, Matlock).

6. Conflicts of Interest
The authors have no relevant conflicts of interest to disclose.

7. Authors’ Contributions
All authors contributed to the design of the study, collection and interpretation of data, and creation of the manuscript. All authors have approved the final draft of the manuscript as submitted.

References


### Table 1: Quality of Information By Topical Category

<table>
<thead>
<tr>
<th>Topic Category</th>
<th>Total n</th>
<th>Generally Appropriate n (%)</th>
<th>Controversial (%)</th>
<th>Inappropriate (%)</th>
<th>Without Sufficient Context (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Device Info</td>
<td>19</td>
<td>12 (63)</td>
<td>0 (0)</td>
<td>4 (21)</td>
<td>3 (16)</td>
</tr>
<tr>
<td>Programming</td>
<td>17</td>
<td>7 (41)</td>
<td>0 (0)</td>
<td>3 (18)</td>
<td>6 (35)</td>
</tr>
<tr>
<td>CV Disease</td>
<td>9</td>
<td>5 (56)</td>
<td>0 (0)</td>
<td>1 (11)</td>
<td>3 (33)</td>
</tr>
<tr>
<td>Lead Management</td>
<td>4</td>
<td>2 (50)</td>
<td>2 (50)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Activity Restriction</td>
<td>15</td>
<td>10 (67)</td>
<td>0 (0)</td>
<td>5 (33)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Procedures</td>
<td>6</td>
<td>2 (33)</td>
<td>0 (0)</td>
<td>4 (67)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Other Disease Management</td>
<td>13</td>
<td>3 (23)</td>
<td>3 (23)</td>
<td>3 (23)</td>
<td>4 (31)</td>
</tr>
</tbody>
</table>

#### Quality Category Totals

<table>
<thead>
<tr>
<th>Category</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generally Appropriate</td>
<td>41 (50)</td>
</tr>
<tr>
<td>Controversial</td>
<td>5 (6)</td>
</tr>
<tr>
<td>Inappropriate for Most Patients</td>
<td>20 (24)</td>
</tr>
<tr>
<td>Without Sufficient Context to Support</td>
<td>16 (20)</td>
</tr>
<tr>
<td>Topic Category</td>
<td>Quote</td>
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<td>--------------------------------</td>
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<tr>
<td>Device Information</td>
<td>“An ICD is a defibrillator but may or may not pace your heart, depending on why you need it and how it is programmed. You have 3 leads so you have a CRT...cardiac resynchronization therapy. The 3rd lead paces the left ventricle so that both ventricles beat in sync, improving the pumping function of the heart. From the model number you entered on your profile, you have a CRT-P.” (Generally Appropriate)</td>
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<td>“They can implant a 3 lead with a defib as you stated.....or deactivate it and give you a S-ICD....defib only.” (Generally Appropriate)</td>
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<td>Programming</td>
<td>“After the MADIT-RIT study, ICDs are very rarely programmed to shock at heart rates lower than 200 or 220.” (Generally Appropriate)</td>
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<td>“If the pacemaker function of your ICD is activated, and you are being paced (a lot) in the right ventricle, this could be a cause of your Afib, too. Doesn’t happen that often, but it’s still a well known complication of right ventricular pacing.” (Generally Inappropriate)</td>
</tr>
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<td>Cardiovascular Disease</td>
<td>“SSS stands for sick sinus syndrome. The sinus node is the heart’s natural pacemaker. The SA node sends the electrical impulse to the atria to initiate a beat. When the SA node doesn’t work properly, the PM steps in.” (Generally Appropriate)</td>
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<td>“I have had my PM for 30 years and one of my two leads is the original. There is no reason to think that your leads won’t last 30 years also.” (Controversial)</td>
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<td>Activity Restriction</td>
<td>“When people say 8 weeks, that’s for lifting heavy and raising the arm overhead. Most docs say 4-6 weeks for that. And other than those two limits- overhead and lifting heavy- you can and should use the arm normally” (Generally Appropriate)</td>
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<td>“Just don’t get a tattoo directly over the device. Anywhere else is ok.” (Generally Inappropriate)</td>
</tr>
<tr>
<td>Procedures</td>
<td>“The battery change-out is nothing like what you went through initially. It is an out-patient procedure and very quick and easy. Most of us go in the morning and are home eating lunch a few hours later. It is really easy. Nothing to worry about there.” (Generally Inappropriate)</td>
</tr>
<tr>
<td></td>
<td>“You were one of the less than 1% of PM patients that is inflicted with an infection. Should you need surgery again they will take extra precautions as a result. That makes the likelihood of another infection even less than 1% for you.” (Generally Inappropriate)</td>
</tr>
<tr>
<td>Management of Other Conditions</td>
<td>“Let’s face some facts here. ED pills are big business and ED is a problem for a lot of men over 60. A fair number of men with ICDs are over 60. So whether anyone mentions it or not, there must be a lot of 60+ men with ICDs already popping these pills.” (Generally Appropriate)</td>
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<td></td>
<td>“I would advise you to start taking some vitamins; I buy them from this web site that I found here: (redacted) and I buy from this site: (redacted) I don’t know if you can buy them from UK, but try to find similar ingredients. Also, doctors recommend to stay always hydrated which is mean to drink water with a bit sea salt or buy smart water that already have some ingredients.” (Generally Inappropriate)</td>
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