

# An Analysis of Online Health Counseling Content on a Website Administered by a Nursing College

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## 英文抄録

**Background** : A large amount of health information is accessible through the Internet. It is necessary for private citizens to be able to understand this information so they can make sound health decisions. This study investigates the implementation of the Kango-Net (“Nursing-Net”) website, which administers nursing advice and health information to its users.

**Method** : This study aimed to obtain suggestions regarding the health information required by website visitors and to examine consultation content available on Kango-Net’s “Online health counseling” page. We collected notes posted on the online health counseling page regarding consultations for dilated cardiomyopathy and Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome. We then categorized and qualitatively analyzed the notes. Initial analysis involved the extraction of the smallest units of meaning for each note ; the notes’ contents were subsequently coded and classified.

**Findings** : Forty-one notes written by 24 users and 136 notes written by 60 users were collected from Kango-Net’s online health counseling pages for MRKH syndrome and dilated cardiomyopathy, respectively. The collected notes were posted over a period of approximately seven years, from April 26, 2006, to May 13, 2013. The extracted categories were very similar between the two diseases ; therefore, we combined them to come up with the following 7 categories of content for analysis : Disease Experiences, Current Thoughts or Feelings,, Feelings Upon First Learning About One’s Illness, Information Availability, Consultations Concerning Therapeutic Methods, Messages, and Advice.

**Discussion** : Users with these two diseases who visited Kango-Net’s online health counseling page found concrete information concerning topics such as therapeutic methods, continuing with everyday life, and disease convalescence. Patients with diseases such as dilated cardiomyopathy and MRKH syndrome are more likely to communicate on the Web, and the information sharing on Kango-Net encourages them to fight against their illnesses. However, some improvements need to be made to the site to ensure that the Web exchanges become more active.

**Key words** : health literacy, website, dilated cardiomyopathy, Mayer-Rokitansky-Küster-Hauser (MRKH), health counseling

## I. Background

Many universities are presently required to promote partnerships with their local communities (i. e., implement community outreach activities). In Japan, community outreach systems and methods remain rudimentary. St. Luke’s College of Nursing believes that the key

to addressing health-related problems is to encourage citizens to make their own decisions in obtaining healthcare information and in choosing how to interact with medical institutions and maintain a healthy lifestyle. This is the central concept behind the launch of “Kango-Net,” (“Kango” means “Nursing” in Japanese) which aims to promote communication and collaboration between citizens and nursing personnel through the distribution of healthcare information accumulated



Figure 1 Screenshot of Kango-Net (<http://kango-net.luke.ac.jp/Nov.27,2015>)

by the nursing personnel (Figure 1). Kango-Net's full-scale services were launched on February 28, 2005 (only in Japanese). St. Luke's uses this website to release useful healthcare information to citizens, including that which pertains to activities related to education, research, and practice. Kango-Net attracts approximately 70,000 hits per month. Kango-Net's main content areas are information (topics and events, knowledge of nursing, health literacy) and the nursing community (essays by nurses, online health counseling, Nursing-Net Kids).

There is a large amount of health information available on the Internet; however, citizens need to understand this vast online literature in order to make good decisions in managing their own health. Kango-Net is a point of contact that is administered by a nursing college. It allows for health information to be provided to the public and for nursing students to gain work experience in dealing with community residents. This study aimed to obtain suggestions regarding the health content required by website visitors and to examine the consultation content that is provided on Kango-Net's "Online health counseling" page.

## II. Method

This study examined consultations on dilated cardio-

myopathy, which is defined as a rapidly fatal congestive heart failure and idiopathic mural endomyocardial disease Stedman (2012), and MRKH syndrome (also known as Rokitansky's syndrome), which is a rare condition characterized by absence of the vagina and uterine abnormalities RightDiagnosis.com (2014). These diseases, in particular, were most featured in viewers' information searches and discussion responses over the course of approximately seven years, from April 26, 2006, to May 13, 2013. The other consultations concerned how to use a catheter (Response 31), sedation in endoscopy (Response 11), and how to best cool a fever (Response 11). We qualitatively analyzed the collected data's content by extracting the smallest meaningful units of content from the sentences, forming consultation notes before coding, and classifying the notes.

## Ethical considerations & COI

The data used in this study were anonymously posted on the Internet with the subjects' full knowledge. On the site's home page, users are informed that "the content of the writing is published." Because the user content is freely submitted and anonymity is ensured, approval from the research ethics committee was not needed. We have the Kango-Net committee's consent to publish. Furthermore, we declare that no potential conflicts of interest exist.

### III. Findings

Online health counseling notes concerning dilated cardiomyopathy were written to 60 individuals in 136 cases ; notes addressing issues relating to MRKH syndrome were written to 24 individuals in 41 cases. Tables 1 and 2 present the analysis and classification of the notes' contents. The extracted categories were very similar between the two diseases, and the following seven content categories were extracted : Disease Experiences, Current Thoughts or Feelings, Feelings upon First Learning about One's Illness, Information Availability, Consultations Concerning Therapeutic Methods, Messages, and Advice.

Note that the content extracted concerning dilated cardiomyopathy and MRKH syndrome addressed five of these categories (Disease Experiences, Current Thoughts or Feelings, Messages, Feelings upon First Learning about One's Illness, Information Availability). Additionally, the notes' contents reflected these categories. The notes discussed sharing one's experience of being with, giving consideration to, and receiving consideration from other people with the same illness ; recalling one's initial emotional reaction to one's illness ; and acquiring information about one's illness. Further, users who wrote notes on Kango-Net encouraged one another and indicated their gratitude for the encouragement they received.

The informational content concerning the two diseases were classified in the same category, but the sub-category and the detailed contents were different. Content regarding dilated cardiomyopathy concerned the condition's pathology, how patients could best live their daily lives, and the necessary medication. In contrast, questions regarding MRKH syndrome concerned surgical procedures and therapeutic methods. Questions regarding how family members and others should treat the patient were common to both diseases. Particularly, many notes regarding MRKH syndrome concerned therapeutic methods and the discomfort individuals felt in their marriages because of the disease. Notes regarding dilated cardiomyopathy concerned the remaining days of one's life, especially considering patients with this disease have generally been given a life sentence.

### IV. Discussion

Approximately 400 consultation topics are listed on Kango-Net's Online Health Counseling page ; however, as only two or three questions have been posted for

each topic, the number of questions posted regarding MRKH syndrome and dilated cardiomyopathy was notable. Prominent topics posted regarding the former—the chief complaint of which is vaginal aplasia— included “consultations about therapeutic methods” and “anxiety regarding one's marriage.” In contrast, those posted regarding the latter included “how to live my daily life” and “thoughts regarding being told by the doctor how much time is left for my life.” The sentiment “I'm perplexed that there is no available information” was common to both diseases. Users seeking consultations searched for detailed information about the diseases, which led them to the conclusion that information about the diseases was difficult to obtain.

Questions posted on Kango-Net's Online Health Counseling page were answered by site visitors, rather than by experts in specific fields. The lively exchanges that emerged on the site thus indicated that users who had experienced various diseases in the past wrote detailed posts. The counseling content on Kango-Net's Online Health Counseling page were not specified ; therefore, we anticipated that users seeking consultations about dilated cardiomyopathy and MRKH syndrome would likely have visited various sites before arriving at Kango-Net and would require the ability to search for effective health-related information.

Tian et al. (2014) importantly noted that, “There are few data on the quality of... online materials from a health literacy standpoint or whether they address patients' perceptions”. The present findings illuminate a portion of patients' perceptions : users of Kango-Net perceived its online counseling pages' content as useful.

Health literacy is defined as an individual's degree of ability to obtain, process, and understand basic health information and the services needed to make appropriate health decisions US Department of Health and Human Services (2010). Health literacy is needed for a healthy life. Much information is available on the Internet, and we often turn to the Internet to obtain health information. Christmann (2005) said, “Health literacy is crucial to use the Internet in an effective way and being capable to assess the available health information” Therefore, Kango-Net's users' health literacy was sufficient to enable them to locate the information they required for using the site. In addition, the development of a method to obtain literacy that enabled the assessment of Internet information was also necessary.

We also noted that users seemed perplexed regarding the lack of relevant health information for both diseases, which falls under the category of Information

**Table 1 Post content : Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome**

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<p>Disease Experiences (67)</p> <p>[Patient history (13)]</p> <p>I discovered my disease after visiting my OB-GYN after failing to get my period by the age of 18 years.</p> <p>[Current patient situation (11)]</p> <p>I've been talking to several other people with Rokitansky syndrome on the Internet, but we are all troubled by the fact that there is no information available.</p> <p>I'm doing my best to support people I've met who have the same symptoms.</p> <p>[Vaginal morphology (11)]</p> <p>Following the advice of my doctor and other information, I had a vaginoplasty done.</p> <p>[Issues related to the patient's relationship with her partner (5)]</p> <p>I revealed everything to the person I am seeing.</p> <p>[Uneasiness in one's marriage (5)] I married someone who understands my situation.</p> <p>[The behavior of those around the patient (5)] My mother cried and apologized to me.</p> <p>[Gathering information (2)] I searched the site but had a hard time finding articles</p> <p>[Announcing one's disease to family members (2)] I [the patient] told my daughter right then and there.</p> <p>[Other (13)] Relationship with one's mother, sexual relations, experiences of other patients, etc.</p> <p>Current Thoughts or Feelings (48)</p> <p>[Expressing thoughts or feelings (11)]</p> <p>I'd like to get married in the future, but I'm worried about whether anyone will accept my illness.</p> <p>[Surgery (5)] I decided to have surgery because I'd like to have sex when I find a boyfriend.</p> <p>[Hopes (5)] I would like a forum where I can reveal my troubles and exchange opinions.</p> <p>[Sense of perseverance (4)]</p> <p>I'll do my best because I have realized that there are many different circumstances in life.</p> <p>[The future (4)] I intend to reveal everything to the man who would marry me no matter what.</p> <p>[The current situation (3)] I don't think I should consider myself as the heroine of a tragedy.</p> <p>[About MRKH syndrome (2)]</p> <p>I felt that the name of the disease and the condition were things that I cannot consult others about too easily.</p> <p>[Things discussed with one's partner (2)] I was fearful of his reaction, but I prepared myself to do it.</p> <p>[Reading posts (2)] I was helped by the words in the posts ; I'm thankful for this site.</p> <p>[Other (10)] Thoughts about one's mother, looking back on when one first learned of the illness.</p> <p>Feelings upon First Learning about One's Illness (16)</p> <p>[Listening to what the doctor had to say (3)] It felt unreal.</p> <p>[Issues related to the patient's relationship with her partner (3)] I felt relieved after telling him.</p> <p>[Patient's situation (3)] I felt like giving up in despair.</p> <p>[When the patient understood the facts (2)] I felt like all I had believed in came crashing down.</p> <p>[Other (5)] Observing one's mother's behavior and the words of those around one</p> <p>Information Availability (10)</p> <p>Many people underwent vaginoplasty at [a hospital].</p> <p>Consultation Concerning Therapeutic Methods (10)</p> <p>[Surgical procedures (5)]</p> <p>I was very concerned when people with the same symptoms had surgery and what the results were.</p> <p>[Details of available information (1) (from consultations with nurses)]</p> <p>I wasn't sure what kind of information I should provide to patients.</p> <p>[Regarding treatment methods (pressure method) (1)]</p> <p>What is the prognosis of those who undergo the pressure method as compared to those who undergo surgery?</p> <p>[About sexual intercourse (1)] I want to know how to engage in sexual intercourse and how it feels.</p> <p>[Dealing with the patient (1) (from consultations with family members and others)]</p> <p>I worry every day about what I should do because I cannot talk with the patient (daughter) about the specifics.</p> <p>[How to keep in touch (1)] Is there some way I can keep in touch with people I've been posting to?</p> <p>[Good hospitals (1)]</p> <p>I'd like you to tell me about hospitals and doctors who have a lot of experience doing this kind of surgery.</p> <p>Messages (8) [Encouragement] I hope you feel better...</p> <p>Advice (6) Regarding information gathering, surgery, managing patients, etc.</p>	<hr/> <p>Category (no.), [Subcategory (no.)], Example of detailed content</p>
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Availability. This one factor and Consultations concerning therapeutic methods for MRKH syndrome, for which a specific therapeutic method was needed, were negatively related to emotional and sexual wellness

Liao et al.(2011). It is difficult for someone to hear that no one knows anything about her disease, so that she is not given adequate information about it. Purcell (1990), who was a nurse in the U. S., said, "the

Table 2 Post contents : Dilated cardiomyopathy

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Disease Experiences (126)
[The current situation (69)]
Continuing with ordinary life. Taking medicine. There is nothing abnormal at the check-up.
[History of illness (29)] Collapsing, night sweats, hard to breathe
[When I first learned of my illness (20)]
It was a severe heart failure ; it will be difficult to return to society
[Other (8) : travel overseas, general anesthesia, regarding other patients.]
Current Thoughts or Feelings (87)
[Thoughts about the illness (20)] I had a shock.
[Encouragement (13)] Encouraging and being helpful
[Outpouring of thought (12)] I'm very worried about the future.
[Thoughts about others with the same illness (10)] I wish to give hope to patients with the same illness
[Expectations for future treatment progress (4)] Expectations of the possibility of internal medicine
[Exerting myself (8)] I exert myself to the degree that doesn't require force.
[Life plan (4)] Trying to return to work
[Thoughts or feelings about the diagnosis (2)] I am unstable.
[Things noticed after developing an illness (3)]
The really important thing is a connection of the heart with another person.
[Negative opinion on the post (1)]
How is it a life spent in desperation? Actually, I am irritated.
[Other (14) : Authorization for incurable disease, travel overseas, job, etc.]
Messages (43) Thoughts for people who posted (gratitude)
Feelings upon First Learning about One's Illness (30)
[Feeling like one received a life sentence (10)]
I could not believe it and was so shocked when I heard about my illness and how much danger I was in.
[Feelings while in the hospital (4)] I was nervous.
[Feelings after being discharged from the hospital (2)] My heart seemed to break.
[When I saw the posts.(2)] There was not so much useful information, but it helped me a lot.
[Other (12)]
Advice (20) how to live everyday life, clinic visits, medicine
Consultations Concerning Therapeutic Methods (17) :
[Condition of one's disease (5)], [How to live everyday life (4)], [Medicine (3)], [Test results (2)],
[Medical diagnosis (2)], [Social resources (1)]
Information Availability (15)

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Category (no.), [Subcategory (no.)], Example of detailed content

nursing care of the patient with dilated cardiomyopathy focuses on assisting the patient/family to maintain hope during the often lengthy and crisis-filled wait for a donor heart.” Heart transplant is a therapeutic method for dealing with the expansion type of cardiomyopathy, but many patients in Japan live with this disease unable to receive the necessary treatment for it. Therefore, they need to be able to communicate with other patients on Kango-Net. They seek information about how best to live their daily lives, and this is reflected in the subcategory [How to live everyday life].

Both diseases are characterized by very low numbers of cases, which means they are unfamiliar to most. This makes it difficult to locate relevant information. Patients and families therefore tend to use the Internet to look for information about these diseases ; however, the paucity of accurate information available on the Internet can also make it difficult to locate relevant information. Individuals with rare diseases are often

dependent on the Internet for obtaining health-related information. Health literacy is therefore particularly important to such individuals, because it is difficult to obtain a detailed book written about their disease. Therefore, they need access to accurate Internet information concerning their health and their specific condition. In particular, MRKH syndrome is a disease of the reproductive organs, and patients often hesitate to consult with a doctor about such diseases. Instead, they collect information from the Internet ; thus, health literacy is an indispensable skill for them. Unfortunately, their lack of communication with their doctors persists.

Analysis of the numbers of questions in each category indicated that many posts concerning information, questions, and consultations described experiences or thoughts regarding the illness, or they contained messages of encouragement. Patients used Kango-Net's Online Health Counseling page as a place to express their thoughts, suggesting that “communicating on the

Internet” is itself a form of care. Particularly, this may be because users are able to anonymously conduct consultations about diseases concerning their reproductive organs. This study aimed to obtain suggestions regarding required health care communication. The results showed our website may facilitate consultations concerning the rare diseases people may feel too embarrassed to discuss. Kango-Net must be improved in the future to facilitate this communication even more.

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## 和文抄録

# 看護系大学が運営する Web サイトにおける「よろず相談」内容の分析

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**はじめに** : 聖路加国際大学では, 市民と看護職を結ぶ Web サイト「看護ネット」を設置し, 市民への意思決定への寄与を目的に健康情報の提供を行っている。今回, サイト訪問者の求める健康情報を得ることを目的に, 「看護ネット」内「よろず相談所」に書き込まれた相談内容の分析を行ったため報告する。

**方法** : 「よろず相談所」への相談のうち, 返信数の多い「拡張型心筋症」「ロキタンスキー症候群」の2つの相談の書き込み内容を分析した。まず, 書き込み内容を意味ある最小単位の文章で抽出し, その後, コード化し分類した。

**結果** : 2006年4月26日～2013年5月13日までの約7年間で, 「よろず相談所」への「拡張型心筋症」についての書き込み件数は136件(書込者数60人), 「ロキタンスキー症候群」は41件(書込者数24人)であった。相談されている内容は, 先天性腔欠損等を主訴とする「ロキタンスキー症候群」においては, 「治療方法についての相談」, 「結婚への不安」などについての書き込みが多かった。難治性の「拡張型心筋症」では, 「日常生活の過ごし方」, 「余命を宣告された思い」などの内容があった。両疾患に共通していたのは, 「情報が無いことへの困惑」であった。

**考察** : この2つの相談において相談者は, 治療方法・日常生活の過ごし方や予後などの具体的情報を求めている。「拡張型心筋症」や「ロキタンスキー症候群」などの症例の少ない疾患患者にとって, Web 上でやりとりし, 情報共有することは闘病への励みにつながる。看護ネットにおいても, Web 上でのやりとりがさらに活発になるよう改善する必要であることが示唆された。

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**キーワード** : ヘルスリテラシー, Web サイト, 拡張型心筋症, ロキタンスキー症候群, よろず相談