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Original Paper

A Platform to Record Patient Events During Physiological Monitoring With Wearable Sensors: Proof-of-Concept Study

Jonathan Duc Vinh Vo[1], BS; Alexander M Gorbach[1], PhD

[1] Infrared Imaging and Thermometry Unit, National Institute of Biomedical Imaging and Bioengineering, National Institutes of Health, Bethesda, MD, United States

Corresponding Author:
Jonathan Duc Vinh Vo, BS
Infrared Imaging and Thermometry Unit
National Institute of Biomedical Imaging and Bioengineering
National Institutes of Health
9000 Rockville Pike
Bethesda, MD, 20814
United States
Phone: 1 3173850919
Fax: 1 3014966608
Email: jonathan.vo@nih.gov

Abstract

Background: Patient journals have been used as valuable resources in clinical studies. However, the full potential value of such journals can be undermined by inefficiencies and ambiguities associated with handwritten patient reports. The increasing number of mobile phones and mobile-based health care approaches presents an opportunity to improve communications from patients to clinicians and clinical researchers through the use of digital patient journals.

Objective: The objective of this project was to develop a smartphone-based platform that would enable patients to record events and symptoms on the same timeline as clinical data collected by wearable sensors.

Methods: This platform consists of two major components: a smartphone for patients to record their journals and wireless sensors for clinical data collection. The clinical data and patient records are then exported to a clinical researcher interface, and the data and journal are processed and combined into a single time-series graph for analysis. This paper gives a block diagram of the platform's principal components and compares its features to those of other methods but does not explicitly discuss the process of design or development of the system.

Results: As a proof of concept, body temperature data were obtained in a 4-hour span from a 22-year-old male, during which the subject simultaneously recorded relevant activities and events using the iPhone platform. After export to a clinical researcher's desktop, the digital records and temperature data were processed and fused into a single time-series graph. The events were filtered based on specific keywords to facilitate data analysis.

Conclusions: We have developed a user-friendly patient journal platform, based on widely available smartphone technology, that gives clinicians and researchers a simple method to track and analyze patient activities and record the activities on a shared timeline with clinical data from wearable devices.

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KEYWORDS

data collection; mobile phone; mobile-based platform; patient journal; sensors

Introduction

There have been an increasing number of telehealth and mobile device health care management approaches based on the emerging field of patient-centered outcomes, which focuses on medical outcomes related to metrics of physiology and quality of life. For example, one modern care management approach used an electronic health record system as a child physical abuse alert system [1]. Additionally, care management has been implemented with information technology to improve asthma outcomes in adult populations and mobile apps have been used to encourage compliance with oral chemotherapy and symptom management [2,3]. The Institute of Medicine has reported that improvements in communication between patients and clinicians are needed to reduce health inequalities, and these improvements have begun to focus on telehealth and the use of mobile devices. One example of such an improvement is the use of mobile devices in sleep medicine [4,5]. One possibility to bridge the gap in communication between patients and clinicians is through the use of mobile-based digital records that function as journals for patients to record their events and activities securely and remotely. These have potential uses in clinical research, as well as in clinical practice.

Currently, handwritten patient-recorded events are typically incomplete or used inefficiently due to ambiguity about what should be reported, absence of standard vocabulary to describe events, the inconvenience of reporting events at the times they occur, inaccurate timing, and difficulties with reading patients' handwriting and aligning the records with clinical physiological data. However, there is limited peer-review science comparing handwritten patient journals to electronic journals.

Moreover, although there are current options for health and symptom-logging apps on smartphones, these apps lack the ability to use voice dictation for hands-free recording, preset graphical images to facilitate use by English as a second language (ESL) or nonliterate patients, data export, integration of events with physiology data, or data analysis features [6-9].

To collect physiological data and patient reports on the same timeline on a single mobile device, we propose a proof of concept to simplify patient reporting by using iMessage on a dedicated iPhone and to combine and align clinical data with patient-reported data in a unified digital journal. The aim and expectation, pending confirmation in future clinical trials, is that the smartphone's ability to collect physiological data wirelessly and to have multiple options for recording patient events will allow for increased ease of use for patients and for more accurate characterization of clinically valuable events, as determined by researchers, during long-term monitoring by reducing barriers that limit the accuracy of the patient record such as limited proficiency in English or limited motor function in the extremities.

Continuous temperature monitoring with skin temperature patches has been performed by a previous group [10] that focused on using wearable electronics or cell phones. Our approach for this proof of concept was to use iMessage software on iPhone in conjunction with temperature patches to combine skin temperature data with patient reports of events and symptoms on the same timeline.

Methods

Concept and Block Diagram

We implemented the concept of using a secure iPhone, along with its various capabilities in iMessage, for clinical research purposes, as seen in Figure 1.

The Patient Interface consists of body sensors (electrocardiogram, EKG; temperature; etc) and a dedicated iPhone wirelessly connected via Bluetooth to the sensors. iPhone capability includes the built-in iMessage app, which allows simple texting; texting with replacements of abbreviations, which can be used to implement a preset vocabulary for specific clinical research; dictation (voice recognition); graphical stickers, which are preset graphical images or icons designed for specific clinical research, for example, monitoring of heart fibrillation with EKG, circadian temperature changes, and pain scores in time and location; and photo images collected by the patient.

The Clinical Research Interface consists of a Mac Pro desktop (2013, Apple Inc), a lightning cable to export reportable events, and a portable flash drive (c20i JumpDrive, Lexar) to export physiological data from apps (in future versions of the platform, the flash drive can be replaced with a more secure cloud solution that is encrypted in both directions). The desktop software includes iMazing (2.5.3, DigiDNA) to export reportable events to an Excel (15.34, Microsoft) format and MATLAB (R2017a, Mathworks).

First, a dedicated iPhone will be given to each patient. Patients will then text, dictate, use graphical stickers, or collect photo images in iMessage to report events predesignated by clinicians. Physiological sensors will be placed on the patients' bodies. Applications will be activated, and patients may then go to their hospital room or possibly to their home. The duration of monitoring is dependent on acquisition frequency and the battery capacity of the iPhone and sensors. Second, at the end of the monitoring period, patients will send the iPhone back to the clinical facility where the clinical researcher will download the reportable events by connecting the iPhone and Apple desktop via the lightning cable, and after that, the researcher will export physiological data via a portable flash drive. Third, data will be reformatted on the desktop through Excel, which allows them to be readable by a MATLAB script. Finally, the MATLAB script will generate a graph that fuses the physiological data and reportable events, allowing visualization of physiological changes and subsequent reportable events on the same time scale. These data can be filtered based on specific reportable events, duration of the events, or any other clinical research criteria.

Hardware

For the Patient Interface, we used an iPhone (version 6, Apple Inc), though more recent versions should work as well, and a HomePod (2017 version, Apple Inc), which acts as a microphone for patients to use Siri dictation. For temperature monitoring demonstration purposes, we used the Temp Pal skin temperature sensor (model STP-MB01-1, iWEECARE Co) [9]. On the Clinical Researcher Interface, we used a Mac Pro (2013, Apple Inc), a Lightning-to-USB cable (Apple Inc), and a portable flash drive (model c20i JumpDrive, Lexar Inc).

We implemented the temperature acquisition process using wearable skin temperature patches connected via Bluetooth to an iPhone, which allowed us to also create patient reports and combine them with physiological data on a dedicated iPhone device.

Software

There are several iPhone capabilities that we used to create the patient reports. First, with Apple's intelligent personal assistant, Siri, it is possible to use voice recognition so that patients will be able to dictate their records. Second, Siri can be used in a hands-free manner by speaking the keywords “Hey Siri.” Next, with Apple’s instant messaging service, iMessage, patients can securely create time-stamped logs of their events and activities. iMessage has the capability of using both texting and voice dictation. With either method, patients send themselves a text message containing what they wish to record, and the text message serves as a digital log of their activities and events. Third, iPhones come with a text replacement feature for typing, whereby users can set keywords or letters that will then autocomplete to form predefined words, phrases, or sentences. This will allow patients to type their records easily and accurately (with fewer keystrokes and fewer typing mistakes or misspellings) while also avoiding slightly different written versions of the same type of event. This will also give patients a standardized dictionary for specific keywords and events. Finally, iMessage allows for the use of “stickers” in addition to text, so patients can generate messages visually and quickly from a standardized dictionary preset by the clinical researchers. Using the iPhone app *Assembly* (version 1.5.7, Pixite LLC), which allows for the creation and customization of stickers, we have a set of 20 stickers that patients can choose from to use in their journals (Figure 2) [11]. The stickers are converted to text using MATLAB (R2017a). The stickers in Figure 2 respectively represent: “Fever,” “Heating,” “Sweating,” “Changing Clothes,” “Standing,” “Sitting,” “Walking,” “Running,” “Outside,” “Inside,” “Air Conditioner,” “Washing Hands,” “Sleeping,” “End,” “Hot Drink,” “Cool Drink,” “Waking Up,” “Eating,” “Bathroom,” and “Shower.”

Figure 1. Block diagram depicting the fusion of physiological data and patient-reportable events data into one time-series graph. EKG: electrocardiogram.

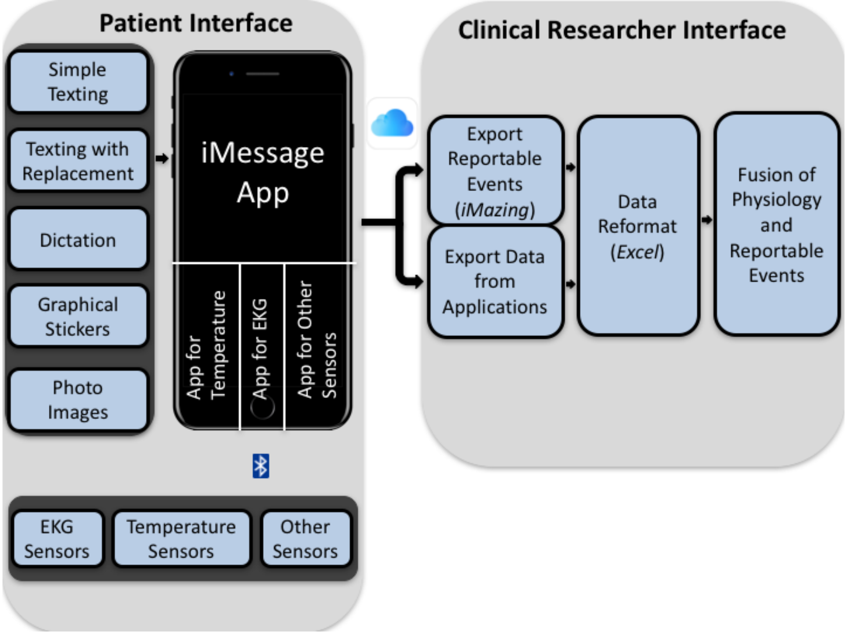


Figure 2. Twenty stickers preset in Assembly for use in patient journals.

Along with iMessage, we used the *TempPal* app (version 1.5.1, iWEECARE Co) to record skin temperature simultaneously with the reportable events [11]. Finally, we used the *MobileManager* app (1.2.0, Lexar Inc) on iPhone to transfer temperature data from iPhone to Mac.

On Mac, we used the third-party app *iMazing* (version 2.5.3, DigiDNA Sàrl Inc) to export iMessage texts into a.csv format [12]. *iMazing* is a simple and user-friendly back-up and transfer or export app for iPhone. We used *Excel* (version 15.34, Microsoft Co) to reformat the temperature data and reportable events data. Finally, using MATLAB (version R2017a, MathWorks Inc), we created a simple script to extract data from both files and combine and align the temperature data with patient-recorded events into one single graph. If patients used stickers in their journals, the stickers are converted to text in the script as well. Multimedia Appendix 1 presents a more in-depth operating procedure.

Results

As a simple test of our prototype, a healthy 22-year-old male used the platform described here to record his activities and events over a 4-hour session, while a sensor recorded his body temperature. The data were processed on a Mac Pro desktop and combined into a single time-series graph, an example of which is shown in Figure 3. The sensor was placed on the right chest of a healthy 22-year-old male. The patient logged activities and events using iMessage text-typing and Siri. Below the time axis is the dictation axis, which shows the patient-recorded notes at each corresponding time point. The words "END" denote that the prior event or activity has been completed.

The journal was filtered using the keywords "eating" and "outside," resulting in a time-series graph (Figure 4) highlighting the times at which the subject logged any activities with the words "eating" or "outside." The words "END" denote that the prior event or activity has been completed. The blue vertical line denotes the point when the patient was outside, and the red lines denote the points when the patient is eating. The variable blue line shows a temperature decrease as the patient walks outside, which matches the drop in temperature moving from a heated room to outside the building.

Using the filtered time-series graph, we can easily see that when the subject moved outside, his body temperature decreased, and when he began eating, his body temperature began to increase. Although the patient only recorded his daily activities while temperature was measured, in a more clinically relevant study, other physiological metrics, such as cardiac data, might be used.

Figure 3. Temperature data taken for 4 hours of using a TempPal temperature sensor.

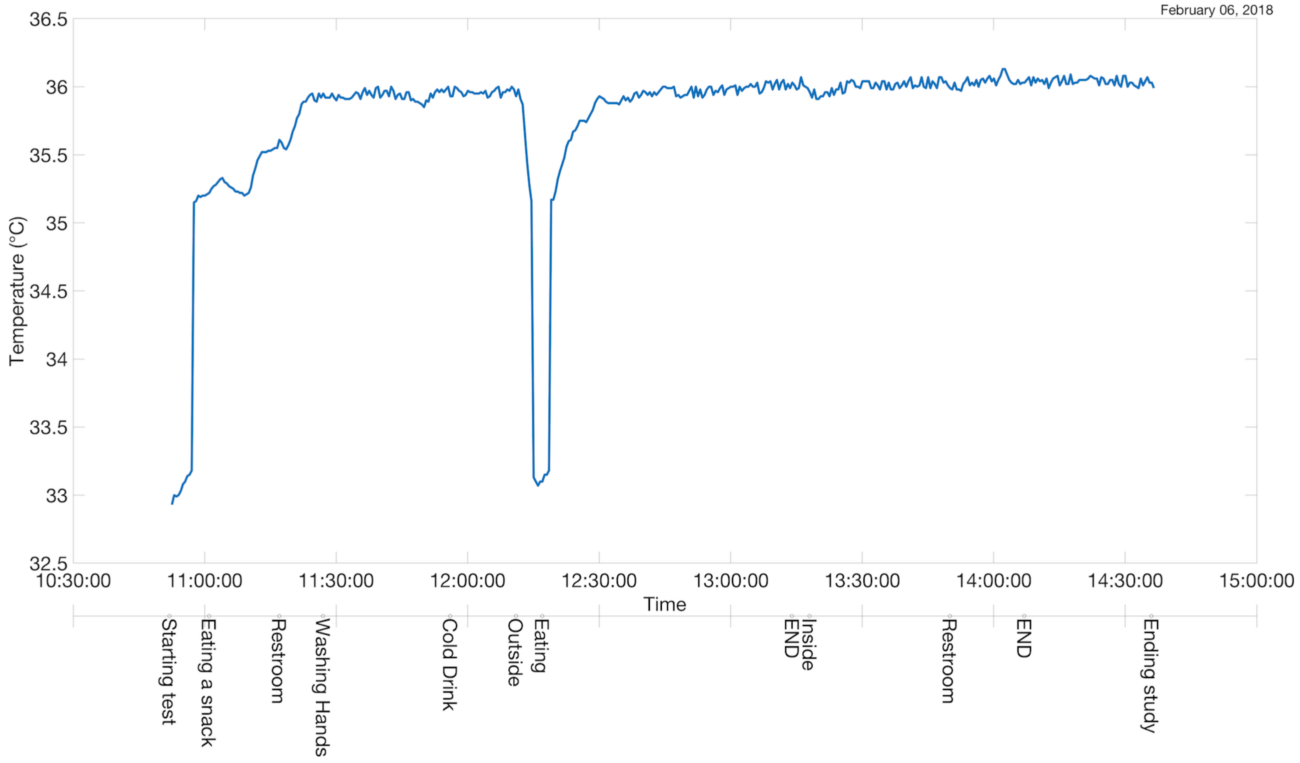
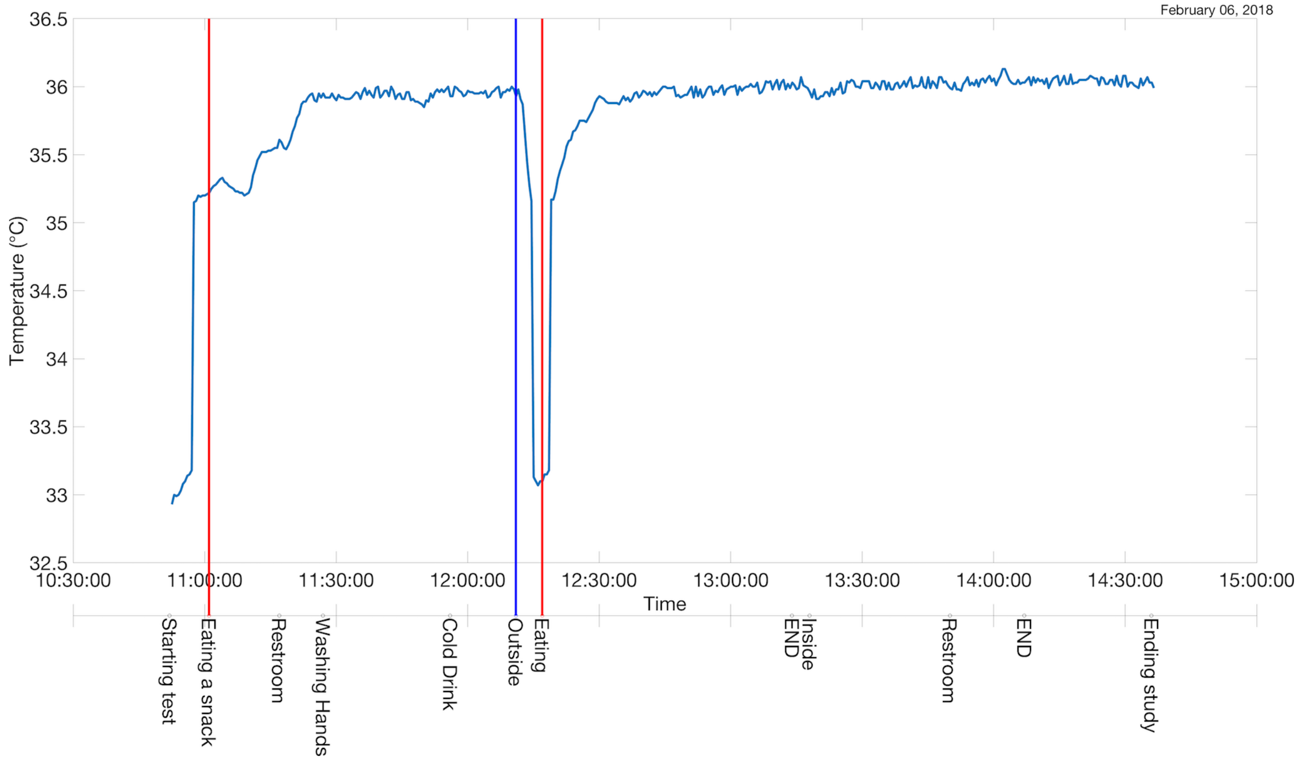


Figure 4. Filtering of the patient journal using two keywords: “eating” and “outside”.



Discussion

Principal Findings

We have designed and tested a prototype capable of recording a patient’s comments synchronously with physiological data (such as temperature, as used in this paper) from wearable devices. A shared timeline for comments and data is essential for accurate interpretation of data that can be influenced by the patient’s activities (exercising, eating, showering, etc) or mood. Our prototype served as a proof of concept and demonstrated that this can be accomplished, without the need for continuous involvement of medical personnel. Voice dictation and graphical “stickers” are offered as alternatives to texting, opening the availability of the method to a wide population of patients, including ESL and nonliterate patients or those without the ability to type. The particular texting system used in our prototype (iMessage) is extremely secure due to end-to-end encryption. The method is also able to combine patient comments (journals) and physiological data into a single graph and filter the journal entries with specific keywords for ease of data analysis.

Our method may also be applied to the field of predictive medicine, which aims to identify patients who are at risk of disease and thereby facilitating steps to treat the disease early or even to prevent it. These goals benefit from accurate, patient-recorded events combined and aligned with physiological data. Although we chose to focus on temperature monitoring in this demonstration, our mobile-based platform is, of course, usable with other sensors. For example, patients can undergo remote cardiac monitoring using either wearable devices that send data to medical personnel or devices that could contain automated detection algorithms themselves [13,14]. Because our platform is already mobile, switching to cardiac monitoring from temperature monitoring would just involve switching the temperature sensors to EKG sensors. Unlike traditional cardiac monitoring sessions, however, our platform does not use handwritten diaries [15].

Limitations

There are some drawbacks to our methods. The prototype currently relies on having a connection to either Wi-Fi or cellular data networks, which may be difficult in some settings. One of the configurations for the future could be a system that is locally based on the device (ie, does not require a constant network connection). Such versions could record all patient event data locally and automatically synchronize the data with the cloud the next time that the device has network access, which would also remove the need for a portable flash drive. This is a common technical problem that has been solved in other mobile apps where there is no continuous network access.

Additionally, because of the secure end-to-end encryption of Apple’s iMessaging app, our prototype currently focuses on iPhone and Apple systems exclusively and not on Android phones. This, however, is a relatively minor drawback as the basic principles for our proof of concept can be easily transferable to Android phones.

We have also not evaluated the usability or user friendliness of our platform with patients, researchers, or clinicians at this time; however, we hope to test our platform in the future in clinical studies.

Finally, although the use of a portable USB drive for data transfer between iPhone and Mac desktop may prove more cumbersome than wireless or cloud-based transfer methods, this was done to ensure the physical security of our data.

Table 1. Features of current approaches to monitor patient-recorded events.

Apps	Journal options	Integration with physiology	Analysis features
Diary Health App	Voice dictation; text with autocomplete	Yes	No
Symple App	Text with autocomplete	No	No
Penzu Health Diary	Text with autocomplete; photo images	No	No

Furthermore, in future iterations, the portable USB drive will be replaced with a cloud solution that is secured by encryption.

Comparison With Prior Work

The *Diary Health App* (version 2.4.8, The Diary Co) allows for voice dictation and text options for patient-recorded events, and the app has some integration with basic physiological measures, such as heart rate and body temperature; however, the app does not allow for combining and aligning of the patient-recorded events and physiological data. It also does not offer user-friendly options of preset graphical Sticker images or photos in the patient journal [6].

The *Symple App* (version 2.1.9, Symple Health Inc) allows for text options for patient-recorded events; however, there is no integration with physiological data, and there are no options for preset stickers or photos [7].

The *Penzu Health Diary* (version 3.4.2, Penzu Inc) app allows for text and photo images for the patient-recorded events; however, there are no options for preset stickers, voice dictation, or integration with physiological data [8].

These apps also do not contain any data analysis or graph-generating features. Table 1 shows the features of current approaches to monitor patient-recorded events. None of the approaches allow patients to use graphical stickers.

Conclusion

The current standard of care (written journaling by the patient during physiological data collection) can be inaccurate in timing, inconvenient for patients to use, and difficult for researchers to interpret due to poor handwriting or lack of alignment of the journal entries with physiological data. By taking advantage of a smartphone’s capabilities and third-party programs, the proposed method offers greater convenience for the patient through choices of data entry methods, enables accurate journal recording and data collection on a single, shared timeline, and eliminates the common illegibility of written records. Other features, such as text filtering options also facilitate analysis.

This work is offered as a proof of concept. Future work could include evaluating the method’s performance in clinical trials that involve physiological monitoring. Additional developments could focus on reading iMessages on Mac directly from the iMessage database. This would remove the need to move the iPhone physically back to the medical facility for data transfer, though the iPhone and Mac would need to have the same dedicated iCloud account. Finally, a more ambitious goal may be to build a custom app and not use iMessage at all. This would allow researchers to have more control over the data format and input, for example allowing for only certain preset inputs rather than free-form texting. It would also allow for improved data management by having the data sent to a secure server or stored remotely via CloudKit. Furthermore, the app could run on the Apple watch, so that the data could be shared with family members and other members of the health care and research team. This would also give patients the ability to use their own iPhones and remove the need for special, dedicated iPhones. Additionally, the custom app would be able to include other iPhone features, such as the TrueDepth camera on iPhone X, which performs facial recognition. This could be developed with Apple’s publicly available face detection and recognition app program interface and used as part of a pain scale for patients.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Step-by-step operating procedure for platform.

[PDF File (Adobe PDF File), 35KB - ijmr_v8i1e10336_app1.pdf]

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Abbreviations

EKG: electrocardiogram
ESL: English as a second language

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Original Paper

Internet Usage by Polish Patients With Multiple Sclerosis: A Multicenter Questionnaire Study

Andrzej Potemkowski[1*], MD, PhD; Waldemar Brola[2*], MD, PhD; Anna Ratajczak[3*], MD, PhD; Marcin Ratajczak[4*], MD, PhD; Jacek Zaborski[5*], MD, PhD; Elżbieta Jasińska[6], MD, PhD; Anna Pokryszko-Dragan[7*], MD, PhD; Ewa Gruszka[7*], MD, PhD; Marta Dubik-Jezierzańska[8*], MD, PhD; Aleksandra Podlecka-Piętowska[9*], MD, PhD; Monika Nojszewska[9*], MD, PhD; Krystyna Gospodarczyk-Szot[9*], MD; Adam Stępień[10*], MD, PhD; Katarzyna Gocyła-Dudar[10*], MD; Marzena Maciągowska-Terela[10*], MD, PhD; Jacek Wencel[11*], MD, PhD; Radosław Kaźmierski[11*], MD, PhD; Alina Kułakowska[12*], MD, PhD; Katarzyna Kapica-Topczewska[12*], MD, PhD; Witold Pawełczak[13*], MD; Halina Bartosik-Psujek[14*], MD, PhD

[1]Department of Clinical Psychology and Psychoprophylaxis, University of Szczecin, Szczecin, Poland
[2]Institute of Physiotherapy, Faculty of Medicine and Health Sciences, Jan Kochanowski University, Kielce, Poland
[3]Pomeranian Medical University, Szczecin, Poland
[4]Clinical Trial Centre, EuroMedis, Szczecin, Poland
[5]Department of Neurology, Specialist Hospital in Międzylesie, Warsaw, Poland
[6]Clinical Center, RESMEDICA, Kielce, Poland
[7]Department of Neurology, Wroclaw Medical University, Wroclaw, Poland
[8]Outpatient MS Clinic, Lower Silesian Specialistic Hospital, Wroclaw, Poland
[9]Department of Neurology, Medical University of Warsaw, Warsaw, Poland
[10]Department of Neurology, Military Institute of Medicine, Warsaw, Poland
[11]Department of Neurology and Cerebrovascular Disorders, L Bierkowski Hospital, Poznan University of Medical Sciences, Poznan, Poland
[12]Department of Neurology, Medical University of Białystok, Białystok, Poland
[13]Department of Neurology, Specialist Hospital, Kalisz, Poland
[14]Medical Faculty, University of Rzeszów, Rzeszów, Poland
[*]these authors contributed equally

Corresponding Author:
Waldemar Brola, MD, PhD
Institute of Physiotherapy
Faculty of Medicine and Health Sciences
Jan Kochanowski University
IX Wieków Kielc 19
Kielce, 25-317
Poland
Phone: 48 413902259
Fax: 48 413902364
Email: wbrola@wp.pl

Abstract

Background: The internet is a source of knowledge and medium widely used in services that facilitate access to information and networking. Multiple sclerosis (MS) patients find the possibility of acquiring information relating to their condition particularly rewarding.

Objective: We aimed to identify Polish MS patients' preferences by analyzing a percentage of internet users and determining the most common search subjects and patients' approach to information on the internet. Disability connected with the condition, its duration, and other factors that influence patients' internet use were examined along with instances of relations established through the internet and their durability.

Methods: The study examined 1045 patients (731 women, 314 men) treated in 10 Polish MS centers, of whom 932 (89.19%) declared to be internet users. Their average age was 40.65 (SD 11.06) and average MS duration was 9.08 (SD 6.97) years. The study used a proprietary survey on information seeking, the range of searched subjects, and internet usage frequency.

Results: The majority of the patients (494/932, 53.0%) used the internet 6-7 times per week and 4.3% (40/932) declared they spent minimum 2 hours per day. The most commonly searched subjects were world news (604/932, 72.9% of patients using the internet); 60.8% (504/932) searched for information on their condition, particularly for new treatment methods (562/932, 67.8%) and the course of illness (520/932, 62.7%). One's sex had no impact on internet usage (female vs male, odds ratio [OR] 1.13, 95% CI 0.72-1.77), although a patient's age might, at varying degrees. We found several significant associations using a .05 significance level: a patient with higher education used the internet 9 times more often than one with primary education (OR 8.64, 95% CI 3.31-22.57); lasting relationships increased chances of internet usage by 10-fold compared to widowers (OR 0.12, 95% CI 0.05-0.31); living in a city with a population over 100,000 increased chances by nearly 6 times compared with the countryside (OR 5.59, 95% CI 2.72-11.48); the relapsing-remitting MS type saw a 2-fold increase compared with the primary progressive MS type (OR 0.47, 95% CI 0.29-0.75); and those needing assistance were 2 times less likely to use the internet than patients who could move independently (OR 0.53, 95% CI 0.31-0.89). More than half of the patients (489/932, 52.5%) did not discuss the information found on the internet with their neurologists; 15.9% (148/932) believed that relationships established through the internet can be stable.

Conclusions: The majority of Polish patients use the internet as a crucial information source on their condition and innovative treatment methods. The internet can be helpful in establishing new relationships, which are usually short-lived. Polish patients do not frequently discuss the information gathered on the internet with their doctors.

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KEYWORDS

multiple sclerosis; internet; information seeking; doctor-patient relationship

Introduction

The internet is one of the most popular sources for information and entertainment. Multiple sclerosis (MS) makes day-to-day functioning difficult because it limits interpersonal relationships and presence in societal life. Communication and exchange of information, ideas, and feelings' grow more and more troublesome [1]. Studies on direct verbal communication show that almost half of the examined participants (46%) claimed poor or very poor ability to undertake social roles. Half of the participants claimed they were unhappy with their interpersonal activity [1]. Communication problems indeed influence restrictions in many social roles common in adult life, including work, home management, and leisure activities. Yorkston et al identified 5 variables (cognitive skills, speech severity, speech usage, physical activity, and education) that were the most important predictors of communication participation [1]. These restrictions would seem to be an important target for intervention.

Some studies reveal that internet use leads to deepened psychopathology, alienation, and loneliness, but those results are ambiguous. In their longitudinal studies of 1998, Kraut et al initially claimed that using the internet contributed to one's sense of loneliness and higher depression rates, but when the same trial was repeated in 2002, it failed to confirm previous conclusions [2,3].

The subject of patients' condition is of particular interest to them; the amount and incomprehensibility of medical terminology and the uncertainty connected with the clinical course of the disease all serve as motivation for further research on the internet. From the very time the internet became widely accessible, scientists have conducted studies on human behavior, the influence of the internet on one's life and the correlations between its usage and one's living standards and psychical and societal life, as well as those suffering from MS [4,5,6,7].

Internet communication may happen synchronously or asynchronously. Forum users may be online at the same time and communicate verbally on a given subject, having relatively high control over their answer and the ability to edit it if needed [8].

From a psychological point of view, verbal communication, with sounds and vision, is preferred. It is important for those suffering from MS as a supporting tool or even in psychological therapy [9,10]. Nevertheless, text dialogue grants more comfort to those having difficulties with communication because it provides anonymity and allows one to stop the contact at any given moment [11]. Atreja et al indicated that MS patients typically search for information right before or after a doctor's appointment and use the information available online to check medical terminology [12]. Hay et al showed that majority of MS patients surfed the internet before their first appointment [13]. Even though the information found on the internet cannot replace that provided by a doctor, two-thirds of patients were reluctant to share the information gained independently with their doctors—which suggests that patients fear that their research could be understood as a lack of trust toward their doctors [13]. The quality and content found online and available to MS patients were assessed as varied, although some websites did offer almost all crucial information [14].

The studies also focused on personal traits, language barriers, and the impact other illnesses have on societal life [15-18]. The results indicated that the internet might have a positive impact on establishing new contacts, especially in the case of patients struggling with their symptoms. In high neuroticism, a limited amount of stimuli proved to be helpful in communication and relationship building [15]. Establishing and maintaining new relations constitutes one of the most significant psycho-social needs of MS patients that can be met through internet usage [18-20].

The aim of our study was to determine the percentage of Polish MS patients using the internet, the most commonly searched subjects, patients' approach to the information found on the internet, and assess the impact of the condition's duration, different levels of disability, and other demographic factors on the frequency and durability of relationships established online.

Methods

Design

We carried out the assessment in 2 stages: (1) the pilot study (drafting and verification of the questionnaire) and (2) the survey proper. The first stage (September-December 2015) consisted of a pilot examination in a group of 83 MS patients who declared to be using the internet; its aim was to evaluate the research tool developed for the study [18]. The questionnaire was developed by the authors and based on their experiences. The data collection was carried out at the Department of Clinical Psychology and Psychoprophylaxis of the University of Szczecin in Szczecin. The second stage included the proper survey conducted in 10 centers of MS diagnosis and treatment in 7 Voivodeships of Poland (8 clinical wards and outpatient MS clinics, an MS rehabilitation center, and a center for clinical trials related to MS). An anonymous questionnaire containing 11 questions on demographic data and 14 connected to one's internet usage was filled out by patients during their appointments.

Setting and Participants

Participants were recruited between February 2016 and December 2016 for the cross-sectional study. Patients were invited to fill out a paper version of the survey. The study included patients over the age of 18 years suffering from MS (clinically defined according to the McDonald criteria, 2010). Informed consent was obtained from all individual participants included in the original clinical studies.

Statistical Analysis

All the continuous variables were verified owing to normal distribution with the Kolmogorov-Smirnov test. They were described using means, SDs, medians, quartiles, and minimal and maximal values. Verification of statistical differences between 2 groups was done using the Student *t* test and Mann-Whitney *U* test. For many groups, the analysis of variance and Kruskal-Wallis tests were used. Discontinuous variables were described using the quantity and frequency of occurrence. For studying statistical relations among discontinuous variables, the Pearson chi-square test or the Fisher exact test were used. For studying correlations among discontinuous variables, sequential and nominal (dummy variables: 0/1) and continuous variables the Pearson or Spearman rank correlations were used. The results were described using the correlation coefficient *r* and probability *P*. For the Pearson correlation, the regression line equations were also provided. A *P* value of <.05 was considered statistically significant. Data were analyzed using SPSS software, version 17.0 (2008; SPSS Inc, Chicago, IL, USA).

Ethics Approval

The study received ethics approval from the Department of Psychology, University of Szczecin Ethics Committee (#17/2015), and all participants received explanations of the study objectives and signed informed consents.

Results

The study involved 1045 people (731 female and 314 male) with an average age of 40.65 (SD 11.06) years. The average MS duration was 9.08 (SD 6.97) years (Table 1). The majority of participants (89.19%) used the internet (932/1045 patients: 652 females and 280 males); only 10.81% (113/1045 patients) did not use the internet. In the internet user group, 53.0% (494/932) stated they used the internet more than 4-5 times a week, and 56.4% (526/932) of the patients spent an average of 1-4 hours per week browsing the internet. Only 4.7% (44/932) of the patients claimed to use the internet more than 14 hours per week (at least 2 hours per day; Table 2).

Subjects that were most commonly searched were world news (604/932, 72.9% of patients using the internet); 60.8% (504/932) searched for information on their disease and 54.5% (452/932) looked for information on treatment. Over half of the patients examined (423/932, 51.0%) communicated with others via the internet. Only 1.8% (15/932) used it to search for job offers (Table 3).

Nearly 15% (120/932) of participants used the internet to establish new relationships and find new communities of MS patients. Relationships developed through the internet were deemed to be unstable by 32.9% (307/932) of patients and durable by 15.9% (148/932); 28.8% (268/932) of the examined patients sustained such relations. Only 13.2% (123/932) reported meeting other MS patients online.

While searching for information on MS, 67.8% (562/932) of the patients were looking for data on innovative treatment methods; 62.7% (520/932) focused on the course of the disease and 41.9% (347/932) on estimates concerning lifespan and diagnostic methods (Table 4).

The study showed that internet usage does not depend on sex (female vs male, odds ratio [OR] 1.13, 95% CI 0.72-1.77), although it might depend on age (Table 5).

Table 1. Demographic and clinical characteristics of study participants (N=1045).

Characteristics	MS[a] internet users (n=932)	MS internet nonusers (n=113)	*P* value
Patients invited, n (%)	932 (89.18)	113 (10.81)	<.001
Female	652 (62.39)	79 (7.55)	.99
Male	280 (26.79)	34 (3.25)	
Age (years), mean (SD)	40.51 (10.94)	41.84 (12.05)	.23
Female	40.64 (11.12)	41.24 (12.38)	.6
Male	40.24 (10.54)	43.22 (11.29)	.12
Disease duration (years), mean (SD)	8.99 (6.86)	9.81 (7.87)	.24
Female	9.13 (7.00)	10.08 (7.82)	.26
Male	8.62(6.69)	9.17 (8.01)	.66
Education, n (%)			<.001
Primary	36 (3.9)	8 (7.1)	
Secondary	358 (38.4)	34 (30.1)	
Higher	409 (43.9)	32 (28.3)	
Vocational	129 (13.9)	39 (34.5)	
Marital status, n (%)			.01
Married	612 (65.7)	73 (64.6)	
Divorced	84 (9.0)	11 (9.7)	
Unmarried	217 (23.3)	21 (18.6)	
Widow or widower	19 (2.0)	8 (7.1)	
Employment, n (%)			.003
Full-time	508 (54.4)	55 (48.7)	
Part-time	65 (6.9)	6 (5.3)	
Pension	300 (32.2)	34 (30.1)	
Never worked	59 (6.4)	18 (15.9)	
Residence, n (%)			.29
Countryside	361 (38.7)	44 (38.9)	
City of up to 10,000	145 (15.6)	17 (15.0)	
City of up to 100,000	165 (17.7)	13 (11.5)	
City of over 100,000	261 (28.0)	39 (34.5)	
Living with, n (%)			.3
Partner and children	467 (50.1)	56 (49.6)	
Partner	154 (16.5)	18 (15.9)	
Children	50 (5.4)	5 (4.4)	
Parents	162 (17.4)	15 (13.3)	
Alone	99 (10.6)	19 (16.8)	
MS type, n (%)			.80
Relapsing-remitting multiple sclerosis	360 (38.6)	45 (39.8)	
Secondary progressive multiple sclerosis	348 (37.3)	44 (38.9)	
Primary progressive multiple sclerosis	224 (24.0)	24 (21.2)	
Mobility, n (%)			.88
Without assistance	736 (79.0)	90 (79.7)	

Characteristics	MS[a] internet users (n=932)	MS internet nonusers (n=113)	*P* value
Independently, with orthopedic device	135 (14.5)	17 (15.0)	
With assistance	61 (6.6)	6 (5.3)	

[a] MS: multiple sclerosis.

Table 2. Internet use by patients with multiple sclerosis (n=932).

Internet use	Patients, n (%)
Frequency of browsing websites on the internet	
Once a week	78 (9.4)
2-3 times a week	120 (12.9)
4-5 times a week	130 (13.9
More often	494 (53.0)
Difficult to determine	110 (11.8)
Hours on the internet per week	
1-4	526 (56.4)
5-7	182 (19.5)
8-14	57 (6.1)
More	44 (4.7)
Difficult to determine	123 (13.2)

Table 3. Internet services used by Polish patients with multiple sclerosis (n=932).

Service	Patients, n (%)
World news	604 (72.9)
MS[a] information	504 (60.8)
Shopping	458 (55.6)
Treatment information	452 (54.5)
Communication	423 (51.0)
Entertainment, movies	408 (49.2)
New acquaintances	120 (14.5)
Meeting people and communities with MS	117 (14.1)
Other—job seeking	15 (1.8)
Other—scientific research	11 (1.3)

[a] MS: multiple sclerosis.

Table 4. Type of health information sought about multiple sclerosis at the time of most recent search (n=932).

Type of health information sought	Patients, n (%)
Innovative treatment methods	562 (67.8)
Course of MS[a]	520 (62.7)
Medication reviews (efficiency)	407 (49.1)
Diagnostic methods in MS	347 (41.86)
Prognosis and lifespan	347 (41.9)
MS treatment costs	336 (40.5)
MS diagnosis—criteria	324 (39.1)
New medication—analysis	285 (34.4)
MS treatment centers’ reviews	238 (28.7)
MS doctors’ reviews	196 (23.6)
Stem cells treatment—results	192 (23.2)
Alternative methods—reviews	184 (22.2)
MS and pregnancy	158 (19.1)
Treatment center using stem cells	158 (19.1)
MS and marriage	104 (12.6)
MS and sexuality	97 (11.7)
Raising children	96 (11.6)
MS and chronic venous insufficiency (results)	54 (6.5)
MS and diet	5 (0.6)

[a] MS: multiple sclerosis.

Higher education was associated with almost a 9-fold increase in internet usage compared with primary education (OR 8.64, 95% CI 3.31-22.57) and widows or widowers tended to use it 10 times less often than those in a partner relationship (OR 0.12, 95% CI 0.05-0.31). Living in a city with a population greater than 100,000 increased the chances 6-fold compared with living in the countryside (OR 5.59, 95% CI 2.72-11.48). Patients requiring assistance were 2 times less likely to use the internet compared with those that were able to move independently (OR 0.53, 95% CI 0.31-0.89) and patients with relapsing-remitting MS were 2 times less likely to use the internet than those suffering from primary progressive MS (OR 0.47, 95% CI 0.29-0.75). A stable course of condition (with no relapses) increased the chances by 1.5 times compared with relapsing-remitting MS (OR 1.50, 95% CI 0.87-2.57).

Over half of the participants (489/932, 52.5%) did not discuss the information on MS found on the internet with their neurologists. Moreover, 75.2% (676/932) recommend other patients to use the internet, but 82.4% (768/932) warned about the application of data about MS found online. The study also evaluated the credibility of the websites according to the patients (0: unreliable and 10: reliable). The participants of this part of the study decided that the most reliable websites belonged to the MS communities and other patients suffering from MS, that is, blogs (Table 6).

Table 5. Internet usage according to sociodemographic and health-related factors.

Categories	Odds ratio	95% CI	*P* value
Sex: men vs women	1.13	0.72-1.77	.59
Age (years)			
33-48 vs <33	0.31	0.13-0.75	.01
>48 vs <33	0.08	0.03-0.18	<.001
Duration MS[a] (years)			
4-12 vs <4	1.09	0.62-1.91	.78
>12 vs <4	0.48	0.27-0.87	<.001
Education			
Secondary vs primary	1.94	0.83-4.51	.13
Higher vs primary	8.64	3.31-22.57	<.001
Vocational vs primary	0.68	0.29-1.64	.39
Employment			
Part-time vs full-time	0.25	0.11-0.55	.001
Pension vs full-time	0.18	0.11-0.29	<.001
Never worked vs full-time	0.49	0.18-1.36	.17
Marital status			
Divorced vs married	0.91	0.46-1.79	.78
Miss or bachelor vs married	2.31	1.23-4.34	.01
Widow or widower vs married	0.12	0.05-0.31	<.001
Residence			
City of up to 10,000 vs countryside	0.96	0.57-1.60	.87
City of up to 100,000 vs countryside	3.47	1.68-7.18	.001
City of over 100,000 vs countryside	5.59	2.72-11.48	<.001
MS course			
Stable without relapse vs with relapse	1.50	0.87-2.57	.14
Progressive vs with relapse	0.47	0.29-0.75	.002
Mobility			
Independently with devices vs without help	0.53	0.31-0.89	.02
With help vs without help	0.18	0.10-0.33	<.001

[a] MS: multiple sclerosis.

Table 6. Credibility of websites dealing with multiple sclerosis.

Internet website	n	Average credibility (0-10)
MS[a] communities' websites	153	7.25
Blogs written by patients	151	6.26
MS services' websites	147	5.47
Doctors' blogs or websites	130	6.37
Foreign websites	115	6.65

[a] MS: multiple sclerosis.

Discussion

An examination of how MS patients use the internet may result in a range of observations and conclusions, as shown in previous findings [4,5,6,21]. Our multicenter study confirmed that discovering the preferences of Polish MS patients in connection to internet usage has many practical implications.

As the study revealed, the way Polish individuals suffering from MS use the internet does not depend on their sex but on their age. Similar dependency was also found in the case of the general Polish population [22].

Our study shows that patients with shorter disease duration tend to seek information on the internet more often, which confirms the conclusions of studies on the importance of the information presented to newly diagnosed patients with MS [23,24]. Although the internet was a significant source for obtaining MS-related information, most participants did not find this information suitable for discussion with their doctors, which may stem from the uncertainty connected with treatment methods, the course of the disease, and its possible outcomes. Lack of communication involving the information found on the internet might constitute a potential harmful factor for the patient-doctor relationship.

The accuracy and reliability of health information introduced on the internet and its impact on health care have been frequently discussed [5,6,7,9]. The majority of the examined patients claimed that they pay attention to the information source and would rate its credibility. Websites belonging to MS communities were deemed the most reliable—7.25 on a scale of 0-10, which underlines the importance of discussing the information found online with a medical professional, as well as the significance of the subject on patient-doctor relationships and impact on adherence [21,25].

Cyberpsychological studies are helpful in evaluating whether more engaged patients see medical improvement stemming from deeper adherence and a better understanding of preventive examinations. It is known that the availability of information changes the patients' expectations in the area of decision making during the treatment [26,27]. All medical treatments, including those for MS, become a cooperative process led by both doctors and their patients. The latter is given a chance to engage and actively participate in choices regarding their health and condition [28].

The internet also provides a new field for innovative forms of psychological help and control of medical suggestions (telemedicine). Auto-diagnosis, including that for MS, is a separate risk connected with the accessibility of the internet, so a person who believes they are suffering from a disease based on information found online should consult a neurologist and follow a doctor's professional opinion. MS websites (eg, SMsocialnetwork.com) were perceived by patients to be a useful tool to support health-related coping and social interaction and may suggest a new kind of therapeutic alliance between physicians and people with MS [29].

Building new relationships online has long been a matter of interest for psychologists, who recognize its potential dangers and undeniable advantages facilitating social life for those finding direct communication difficult [4,15,19]. In the case of MS patients, particularly in the later stages of the disease, maintaining contact with others through internet communication from their homes might be a helpful tool for coping with isolation and its negative impact on one's life [1].

Studies have confirmed that Polish MS patients use the internet to build new relationships, which usually remain outside of the direct communication zone. This might be caused by specific methods of taking care of oneself and one's family in the face of illness [26]. A similar examination conducted on bigger groups of MS patients confirmed that certain Web-based environments might impact one's standard of living, which is caused mainly by meeting new people and maintaining contact with them [2,3,17].

Our examination of 1045 MS patients resulted in an objective assessment of many aspects of data collection and was helpful in defining the preferred form of websites. The data on internet browsing behaviors, including the frequency and usage of internet services, facilitate the development of websites to be tailored to the needs and habits of the audience. It is important to note that certain MS patients may encounter problems accessing the websites owing to disabilities, disease symptoms, difficulties with vision, cognitive disorders, and impaired memory, as indicated before [12]. Such adjustments might prove supportive and helpful for MS patients who wish to experience modern medicine's benefits—personalization and active participation in the treatment process.

Our study, the first of its kind in Poland, describes the relationship between the clinical and demographic factors of MS patients and their approach and methods applied when searching the internet for information. The results suggest that patients are eager to use the internet to learn about their condition. Although the information found online is rarely discussed with doctors, the possibility of maintaining contact between a patient and their doctor may grant the patient better access to credible information, which may have a positive impact on his or her treatment process. The availability of internet data might aid in the improvement and personalization of health care, answering patients' specific needs and providing information tailored to one's stage of disease, disability level, employment situation, and computer skills (including the ability to use the internet).

Authors' Contributions

All authors contributed toward data analysis, drafting and revising the paper, and agree to be accountable for all aspects of the work.

Conflicts of Interest

None declared.

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Abbreviations

MS: multiple sclerosis

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Original Paper

Health Topics on Facebook Groups: Content Analysis of Posts in Multiple Sclerosis Communities

Sara Della Rosa[1*], PhD; Falguni Sen[1*], PhD

Global Healthcare Innovation Management Center, Department of Management Systems, Fordham University, New York City, NY, United States

[*] all authors contributed equally

Corresponding Author:
Sara Della Rosa, PhD
Global Healthcare Innovation Management Center
Department of Management Systems
Fordham University
45 Columbus Avenue
New York City, NY,
United States
Phone: 1 347 277 9131
Email: sdellarosa@fordham.edu

Abstract

Background: Social network sites (SNSs) are being increasingly used to exchange health information between patients and practitioners, pharmaceutical companies, and research centers. Research contributions have explored the contents of such exchanges discussed online. They have categorized the topics discussed and explored the engagement levels of these discussions.

Objective: This research aimed at investigating the potential role of SNSs in health care. Specifically it provides an information-clustering analysis of the health information available on SNSs and develops a research design that allows an investigation of this information in enhancing health care research and delivery. In addition, this research aims at testing whether SNSs are valid tools for sharing drug-related information by patients.

Methods: This research is based on a specific chronic disease: multiple sclerosis. We searched Facebook to identify and research the social media groups related to this condition. The analysis was restricted to public groups for privacy concerns. We created a database by downloading posts from two main groups (in the English language). Subsequently, we performed a content analysis and statistical analysis; this allowed us to explore the differences between categories, their engagement levels, and the types of posts shared. The mean level of engagement for each topic was analyzed using a 1-way analysis of variance.

Results: From a sample of 7029 posts, initial results showed that there were 8 information categories that resonated (percentage of times the topic appears in our sample) with those who post on Facebook: information and awareness (4923/7029, 70.04%), event advertising and petitions (365/7029, 5.19%), fundraising (354/7029, 5.04%), patient support (217/7029, 3.09%), drug discussion (144/7029, 2.05%), clinical trials and research studies (59/7029, 0.84%), product and drug advertising (48/7029, 0.68%), and other (919/7029, 13.07%). Initial analysis showed that comments and likes (as measures of engagement level) are the most frequent indicators and measures of level of engagement. Our results show a high engagement level (in terms of views, likes, comments, etc) for patient support and information and awareness. In addition, although drug discussion had a low resonance, it had an unexpected highly engagement level which we found worthy of further exploration.

Conclusions: SNSs have become important tools for patients and health care practitioners to share or seek information. We identified the type of information shared and how the public reacted to it. Our research confirmed that the topics discussed in social media related to specific diseases such as multiple sclerosis are similar to the information categories observed by other researchers. We unexpectedly found other categories such as drug discussion. These and other results of our study enhance our understanding of how content is disseminated and perceived within a specific disease-based community. We concluded that this information has useful implications in the design of prevention campaigns, educational programs, and chronic disease management.

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KEYWORDS

social network; health information; health care internet; content analysis; Facebook

Introduction

Social network sites (SNSs) are “Web-based services that allow individuals to (1) construct a public or semipublic profile within a bounded system, (2) articulate a list of other users with whom they share a connection, and (3) view and traverse their list of connections and those made by others within the system” [1]. In health care, social networks have been adopted relatively late with respect to other industries due to privacy, reliability, and ethical issues. However, there has been a huge increase in the number of information and communication technologies applied within this sector leading to an increased use of social networks. As a result, researchers have focused their attention either on a specific online service such as health social networks (eg, PatientsLikeMe) or on the use of existing SNSs (eg, Facebook) for the purpose of researching health care discussions. Although there is some published research on the use of SNSs in health care demonstrating positive contributions, studies are mostly focused on the usefulness of SNSs in clinical trial recruitment and patient-initiated studies [2-4] . In addition, some papers study patient interactions within online health communities in terms of the effect of the data these interactions generate in advancing health care by creating higher levels of efficiency in the delivery of care and more effective patient-centric outcomes [5-7] .

Facebook is a popular SNS used in the study of health care–related discussions. Bender et al [8] investigated the purpose and use of Facebook groups related to breast cancer. Their research was based on the result of a content analysis of the statements of each group (eg, title of group, description of group, information in the Recent News section, discussion posts, and wall posts). They found that on Facebook there were about 620 breast cancer groups and they were created for fundraising (44.7%), awareness (38.1%), product or service promotion related to fundraising or awareness (9%), and patient/caregiver support (7%).

Setoyama et al [9] studied the participation in online communities by patients affected by breast cancer and the related benefits thereof. They found that there is a difference between posters and lurkers and that posters felt they received more benefits from online communities than lurkers did. The benefits perceived included emotional support, helping other patients, and an opportunity to express their emotions. Researchers found that even lurkers gained a certain amount of peer support especially related to getting advice and insight/universality.

Moorhead et al [10] reviewed the literature to identify the uses, benefits, and limitations of social media for health communication. They found that 6 key benefits characterize SNSs: (1) increased interactions with others; (2) more available, shared, and tailored information; (3) increased accessibility and widening access to health information; (4) peer, social, and emotional support; (5) public health surveillance; and (6) potential to influence health policy. They also identified limitation such as quality concerns and lack of reliability, confidentiality, and privacy. Given the growth of SNSs, studies have now tried to analyze how the information available is actually structured in terms of content and topics discussed. Hale et al [11] searched the top 20 health conditions on Google and selected the Facebook pages that corresponded to them. In doing so, they compiled a list of the top 50 Facebook pages for each health condition and analyzed them. They employed a content analysis technique on 522 pages and found that the most common type of page was marketing and promotion (32.2%) followed by information and awareness (20.7%), Wikipedia-type pages (15.5%), patient support (9.4%), and general support (3.6%). In that paper, they showed how the type of page was different for different health conditions.

Studies from Bender et al [8] and Hale et al [11] focus on content analysis of the information that is publicly available at the groups/pages level (eg, group purpose statement) but not at the posts level (all posts shared by individual users). Our study, on the other hand, develops a method to categorize online content from actual posts. This allows us to simplify the large number of members posting on the sites selected (24,915 members participating).

There are a number of challenges to doing research using content analysis of information in SNSs. The first one is getting the data from an SNS. This requires access to the data and an application program interface (API) that allows the researcher to collect the data. The second challenge is to develop an algorithm that is able to detect the type of post. This is a complex task requiring a deep understanding of the words used by patients in their posts. The researcher needs to be able to recognize how single words are used in every type of post in order to develop the algorithm. In this study, we aimed at developing a framework for categorizing online content in clusters of related terms. This allowed us to interpret the huge amounts of data available online and make them usable for further analysis. Clustering information has always been a valuable practice and, with the increasing use of the internet, it becomes even more important because it provides a practical tool for using information publicly available online [12]. This clustering will enable an analysis of public reaction to types of information shared online and provide a more complete understanding of the usefulness of SNS-generated data for policy and management purposes.

There is little investigation in the literature of online drug discussions. There is probably an assumption that patients do not discuss use of drugs due to privacy concerns. It also appears that the methodology used by other researchers in gleaning content from posts does not allow for the investigation of drug-related discussions. This study explores the existence of drug-related discussions in public Facebook posts by patients. We further explore if the posts on specific drug use in a disease-focused SNS receive the same level of attention given to other categories such as awareness and marketing. We feel that this is indicative of how transparency and accurate information by gatekeepers may be important in proper adherence to therapy by patients. It may also suggest the need for pharmaceutical companies to create more interactive sites providing more transparent information and quicker response to drug-related issues of concern to patients. This patient feedback could also give useful information on the pros and cons and effectiveness of some therapies.

In this paper, we looked at the following research questions:

- Do our results using multiple sclerosis (MS) public posts confirm, disconfirm, or integrate the results of Bender et al [8] and Hale et al [11] in terms of categories of posts?
- Do patients share information on medication in public posts? If so, what is the nature of these posts? Is the attention received by such posts similar to the attention received for other types of posts?

Methods

Data Collection

This work is based on an SNS dataset of MS groups on Facebook that were investigated. MS is a neurological condition that affects the central nervous system. Patients with this condition have very active online communities, and this allows for good data availability. The dataset is composed of posts collected from 2 different MS groups for which the data were available: Multiple Sclerosis Foundation, with 16,376 members, and Multiple Sclerosis Trust, with 8539 members, for a total of 24,915 members. Both groups are public. We downloaded all available posts from both groups (4000 posts from the first group and 7900 from the second group). The next step involved cleaning the posted data by removing those shared by administrators of the groups and blank posts (where only links were shared). This resulted in 1071 posts from the first group and 5958 from the second group for a total of 7029 posts. We downloaded the data using Facebook's Graph API available online, which is developed using Python. This program allowed us to get the posts' message and other variables including those described in Table 1. The data collection was completed from April to May 2017 and included posts dating from October 11, 2011, to May 16, 2017. The data analysis was performed from May to August 2017.

We developed a qualitative content analytic model in-house using the approximately 1000 posts from the first group (also referred to as the small dataset). We then applied this model to the full dataset.

The model was developed in the following way:

- Step 1: We manually tagged the small dataset looking for 8 categories of topic, some of them selected from the literature and some of them built by us while reading the posts and realizing the presence of certain recurring topics in the dataset.
- Step 2: We identified those words that were more frequent for each category. For example, the drug discussion posts had a unique characteristic of having the unigram mg (for milligrams), name of an MS drug, pills, etc. All of the categories have unique characteristics, and we used these to identify the category and teach the code how to recognize a certain post.
- Step 3: We assigned high weights to the words that were obvious indicators of a certain category. We assigned these weights based on relatedness of the word to that category. For example, it is clear that the use of the word Copaxone is related to drug discussion. Thus, we would give Copaxone a high weight for the category drug discussion. Similarly, use of mg in a discussion also indicates inclusion in the category drug discussion. This system of weighting obvious words helps control for ambiguity in classification of posts.
- Step 4: We ran the code on the full dataset.

Data Analysis

Table 2 provides the description of each category of post. As mentioned in the earlier section, the descriptions were derived from previous literature or created by us and represent the synonyms and related terms captured by our coding algorithm.

Table 1. Variables available in the dataset and their brief description.

Variable	Description
status_id	Status message ID
status_message	Status message in the post
link_name	Name associated with the link shared in the post
status_type	Description of the type of a status update
status_link	Unique link that allows post to be retrieved
status_published	Date and time the post has been shared
num_reactions	Sum of total reactions (likes, loves, wows, hahas, sads, angrys)
num_comments	Count of comments the post received
num_shares	Count of how many times a post has been shared
num_likes	Count of the like reactions the post has received
num_loves	Count of the love reactions the post has received
num_wows	Count of the wow reactions the post has received
num_hahas	Count of the haha reactions the post has received
num_sads	Count of the sad reactions the post has received
num_angrys	Count of the angry reactions the post has received

Table 2. Content shared on multiple sclerosis groups in our sample by cluster.

Category	Description
Clinical trials and research studies (new category)	Advertising or sharing experience of participation in clinical trials, research studies, and testing medical devices.
Drug discussion (new category)	Asking for or giving information about drugs and treatments. Patients usually ask for other patients' experiences or suggestions associated with a specific drug. Only posts that included a specific drug name were included in this category.
Event advertising and petitions	Advertising an event's purpose, time and location. Petitions are usually addressed to the government as requests for actions.
Fundraising	Post asking for money donations created to attract financial resources for multiple sclerosis events, products, services, etc.
Information and awareness	Patients talk about their experience living with the condition in order to receive impressions from others or users that aim at rising awareness by sharing research pages, recommendations, etc.
Patient support	Emotional and informational support for patients. This type of content helps to improve their sense of the condition and to accept it and may include motivational messages from others.
Product and drug advertising	Advertising from pharmaceutical companies (or related) to promote drugs, products, services, treatments, devices, etc.
Other	Posts that don't belong to any of the described categories.

Regarding the first category, clinical trials usually involve the participation of human volunteers who receive an intervention, while research studies, in this specific setting, require less invasive participation that may include, for example, participation in a survey for medical or pharmaceutical purposes.

We used R (R Foundation for Statistical Analysis) software for data analysis, and we used nonparametric analysis of variance (ANOVA) to answer our research questions. Frequency counts and box plots provided a description of the importance of categories. We tested whether difference in the level of engagement is statistically significant in different categories using a 1-way ANOVA. We tested normality with a Shapiro test (only on the first 5000 observations due to this test limitation in R), histograms, and boxplots. Our data are not normally distributed, and we addressed this by using a nonparametric 1-way ANOVA.

Results

General Findings

On a sample of 7029 posts, initial results show that there are 8 categories of topics discussed in the posts related to multiple sclerosis on Facebook. Table 3 provides the percentage of posts for each category in our sample.

Information and awareness was the most discussed topic, followed by event advertising and petitions, fundraising, and patient support. Three clusters that are directly related to pharma-centered topics are at the bottom of this ranking: drug discussion, clinical trials and research studies, and product and drug advertising. Some of the posts could not be located in any of the topics and were classified as other.

Most Shared Topic

As mentioned before, the information and awareness content shared in the analyzed MS groups is dominant. Investigating this category further, we wanted to understand if there were any additional subcategories that could be detected in this topic such as people who share personal health stories or people who talk about others' experiences. We found that, in fact, posts related to information sharing and awareness about MS are shared by patients themselves, a third person (including parents, relatives, friends, etc), and those unrelated to any person. We developed an algorithm that allowed us to detect the 3 subcategories based on the unigrams and bigrams (a contiguous sequence of n items from a given sequence of text, respectively size 1 and size 2) that were selected in accordance to the definition of the searched subcategories. Words included in the search for the first person category were those associated with sharing a personal story, such as "I am" and "I experienced" while words associated with the third person category were those who indicated a post generated by someone talking about a friend or a relative and include the words "she is," "he is," etc. All posts that were not detected as first or third person but had words such as awareness, aware, etc, and so were part of the information and awareness category were included in the general subcategory without first/third person attribution; 236 posts were not assigned to any of the 3 subcategories detected. We found that 41.39% (1940/4687) of the posts available in this category belong to the first person subcategory meaning that more than 1/3 of the content shared in this category was generated by the patients themselves. A total of 7.68% (360/4687) of the posts were generated by people who had a friend or relative affected by MS. More than half of the posts in this category (2387/4687, 50.93%) were general posts that shared information with no particular references to a person.

Pharma-Centered Topics

The data show that clusters directly related to pharma-centered topics (drug discussion, clinical trials and research studies, and product and drug advertising) represent only a small portion of the posts (251/7029, 3.57%). It is also possible that privacy concerns dissuaded participants from sharing information.

Table 3. Topics discussed and frequency of posts (N=7029).

Category	Value, n (%)
Clinical trials and research studies	59 (0.84)
Drug discussion	144 (2.05)
Event advertising and petitions	365 (5.19)
Fundraising	354 (5.04)
Information and awareness	4923 (70.04)
Patient support	217 (3.09)
Product and drug advertising	48 (0.68)
Other	919 (13.07)

However, the fact that there was indeed social network discussion on pharmaceutical-related issues was unexpected due to privacy concerns and may provide us with useful information.

Within this category, the high percentage of drug discussion was intriguing. The timeline in Figure 1 shows how discussion in this area has grown in the last few years. Looking through the posts, we find that this discussion centers on the effectiveness of other patient's therapies, side effects, contraindications, natural therapeutic alternatives, and potential new drugs. If the popularity of these posts grows, we may find useful information guiding the treatment and development of new drugs.

We believe that the drug discussion category is worthy of further investigation because this is where patients share detailed information about their treatments and their related experience. The analysis indicates that a spike was observed starting from 2015—35.4% (51/144) of the drug discussion posts were published in 2017, 52.8% (76/144) in 2016, 1.4% (2/144) in 2015, 67.4% (97/144) in 2014, 2.8% (4/144) in 2013, 2.1% (3/144) in 2012, and 0.7% (1/144) in 2011. No further information was available to investigate the reasons. This phenomenon may be due to the fact that Facebook groups have marketing campaigns to increase the participation or incentivize the participation in the social group by changing the group policies. While we have no systematic evidence, it may be possible that endogenous factors such as a price reduction due to patent expiration may have increased the availability and use of MS drugs resulting in greater discussion.

We developed an algorithm that allowed us to detect 5 subcategories based on the unigrams and bigrams selected in accordance to the definition of the searched subcategories. Words included in the search for the request drug information category were those associated with words such as "does anyone," "experienced," etc. Words associated with the side effect category were those such as side effect, problem, hate, etc. In the new treatment category, we looked for words such as "approved," "FDA," etc. For the alternative medicine category, we detected words such as "marijuana." In a total of 144 posts, 138 posts related to drug discussion were clustered in subcategories and 6 posts were not assigned to any subcategories, hence not included in the analysis.

We find that patients frequently (62/138, 44.9%) ask their peers for information on drugs.

> *I seen my doctor today and wants me to try the new once a month shot called zinbryta does anyone take this.* [Patient]

Patients also have a high level of information-sharing related to their side effects (48/138, 34.8%).

> *Hi all Is anyone here on Zinbryta (daclizumab)? Previously was on Gilenya but had to come off due to really low blood count and skin cancer as side effects. Was on tecfidera but hate it so now going to try this as a once a month injection. Feedback appreciated.* [Patient]

Patients also showed a certain propensity to discuss topics related to new treatments (15/138, 10.9%).

> *I've been searching to find out if Ocrelizumab has been approved by the FDA today, as scheduled. Can't find anything about it. Has anyone else heard anything? I just checked the FDA.gov site and they don't yet list any drugs approved for today.* [Patient]

Alternative medication posts have been found in this study shared by Facebook users that actively participate in the analyzed groups (11/138, 8.0%).

> *Medical Marijuana in the Form of Controlled-dose Capsules Now Available in New York.* [Facebook group participant]

Patients discuss medical contraindications in relation to certain drugs (2/138, 1.4%).

> *Diagnosed May 2012. I was on Copaxone for 1 year and I relapsed every 6 to 8 weeks for a year. I stopped it and have been on Tecfidera just shy of 3 years. I have decided to pull the plug on Tecfidera due to the fact I am JCV+ and at 1200 right now, from 2400 3 months ago. WHAT medication should I consider? I'm so lost on what to take now. I want to take something and have always been aggressive with my treatment, but I feel lost now that I am JCV+ and stopping Tecifdera. HELP!* [Patient]

Figure 1. Drug discussion posts timeline.

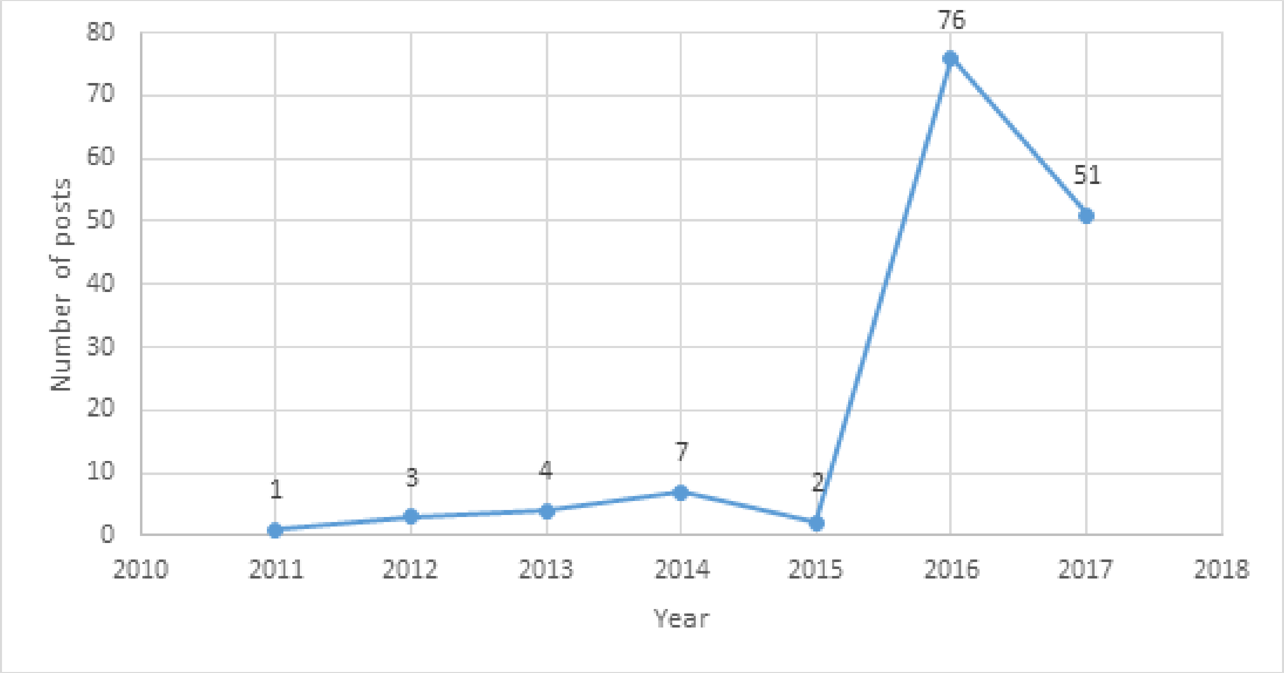


Table 4. Main statistics describing topics and engagement level variables for the whole dataset.

Variable	N	Mean (SD)	Median	Minimum	Maximum
Reactions	124,726	17.7 (44.1)	4	0	965
Comments	54,371	7.7 (21.7)	2	0	624
Shares	12,139	1.7 (14.2)	0	0	593
Like reactions	101,987	14.5 (36.4)	3	0	793
Love reactions	9000	1.3 (5.0)	0	0	144
Wow reactions	1627	0.2 (1.6)	0	0	69
Haha reactions	2228	0.3 (2.3)	0	0	71
Sad reactions	8702	1.2 (8.6)	0	0	452
Angry reactions	1170	0.17 (2.6)	0	0	192

Main Statistics for Our Sample

In Table 4, the main statistics for all variables available in our dataset are shown.

From the main statistics, it appears that number of likes and number of comments have the highest engagement values in the available dataset. The number of shares and the single reactions love, wow, haha, sad, and angry have lower values in mean and median. The number of reactions variable counts all the online activity variables and reflects the positive values found in all other variables.

Discussion

Principal Findings

In this work, we wanted to offer a deeper interpretation of the engagement level by examining its level for each category that we found. The results in Figure 2 show that there are high engagement levels for certain categories (more than 2 points in engagement level value) such as patient support (4.64), information and awareness (3.43), drug discussion (2.37), and fundraising (2.06). On the other hand, there are low engagement levels in other categories (less than 2 points in engagement level value) such as event advertising and petitions (1.65) and very low engagement levels in clinical trials and research studies (0.58) and product and drug advertising (0.10). Furthermore, we tried to understand the differences in terms of types of post used for each category, and in Figure 3 we offer a visualization of the use of wall post, link, photo, and video.

The results show that wall posts and links are the 2 main types of post used within our dataset followed by a good portion of photos and a little percentage of videos. Wall posts are the most used type for 4 categories of content—patient support, information and awareness, event advertising and petitions, fundraising, and drug discussion—while links are the main type for 2 categories only: product and drug advertising and clinical trials and research studies. In addition, we tried to understand if the engagement is higher with respect to the type of post as shown in Figure 4. The chart clearly shows that engagement level is higher for photo posts no matters which topic.

Figure 2. Engagement level measured as the average of 8 online activity variables (comment, share, like, love, wow, haha, sad, and angry) by the 7 topics detected in our analysis with standard error.

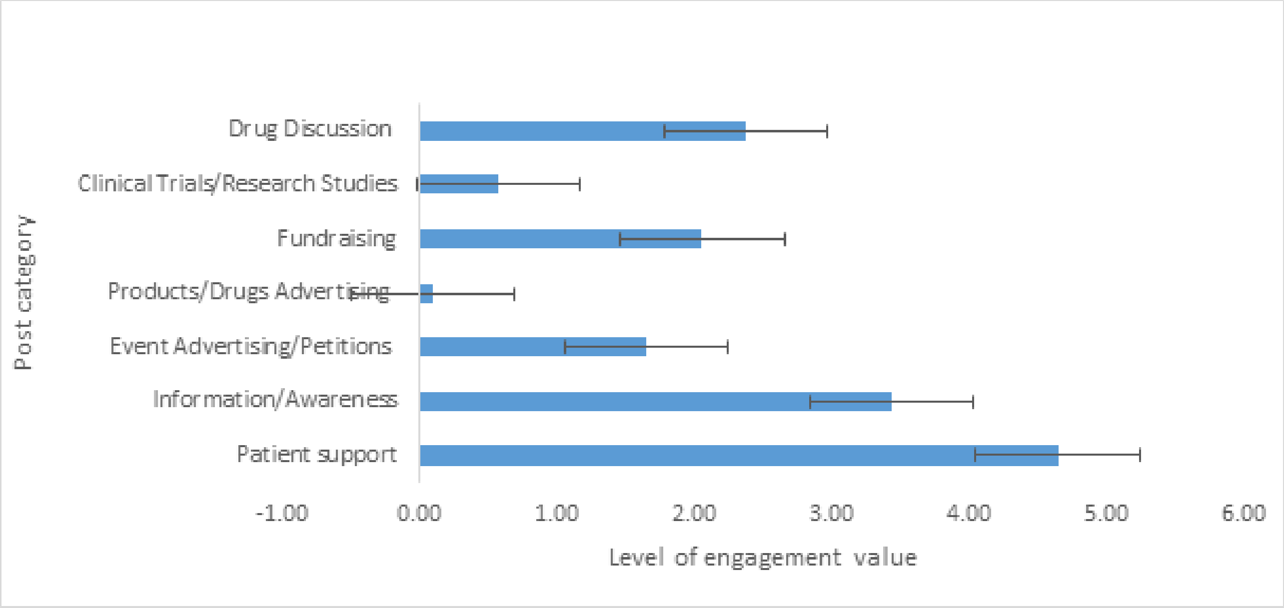
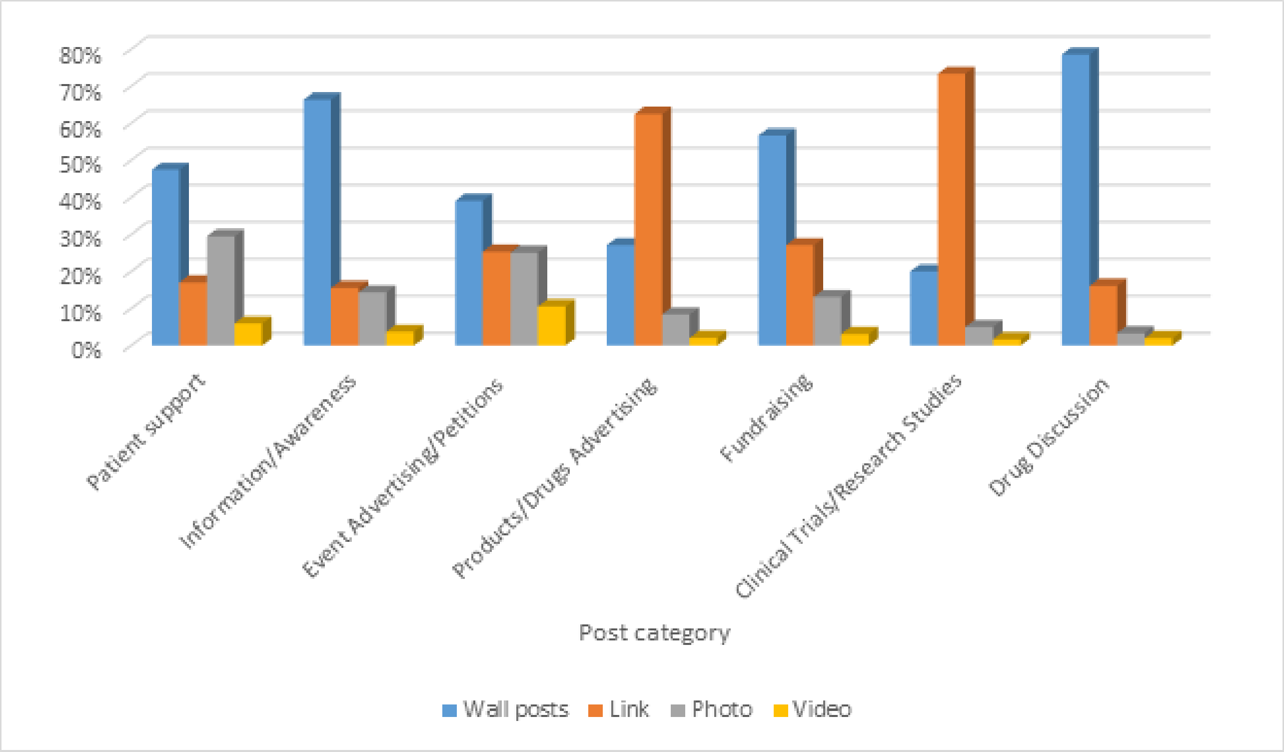


Figure 3. Type of post shared (wall post, link, photo, and video) by category in percentage.



Results of Analysis of Variance

One of the aims of this research was to test if SNSs are valid tools to share drug information by patients. For this reason, the means of the engagement for each topic was analyzed using 1-way ANOVA. Our objective was to see if the drug discussion category received as much attention as the most well-known topics: patient support and information and awareness. In fact, according to other research, these last 2 topics seem to be recurrent topics [8,11]. For the purpose of the ANOVA, the topics have been coded as follows: drug discussion (A), information and awareness (B), event advertising and petitions (C), product and drug advertising (D), fundraising (E), clinical trials and research studies (F), patient support (G), and other (H). The results of the ANOVA in Table 5 show that *P*<.001, so we clearly reject the null hypothesis of equal engagement means for all topics, and we claim that at least one category in our topics is different from the others in terms of engagement means.

Figure 4. Average engagement level by type of post (event, link, photo, wall post, and video) with respect to the belonging topic with standard error.

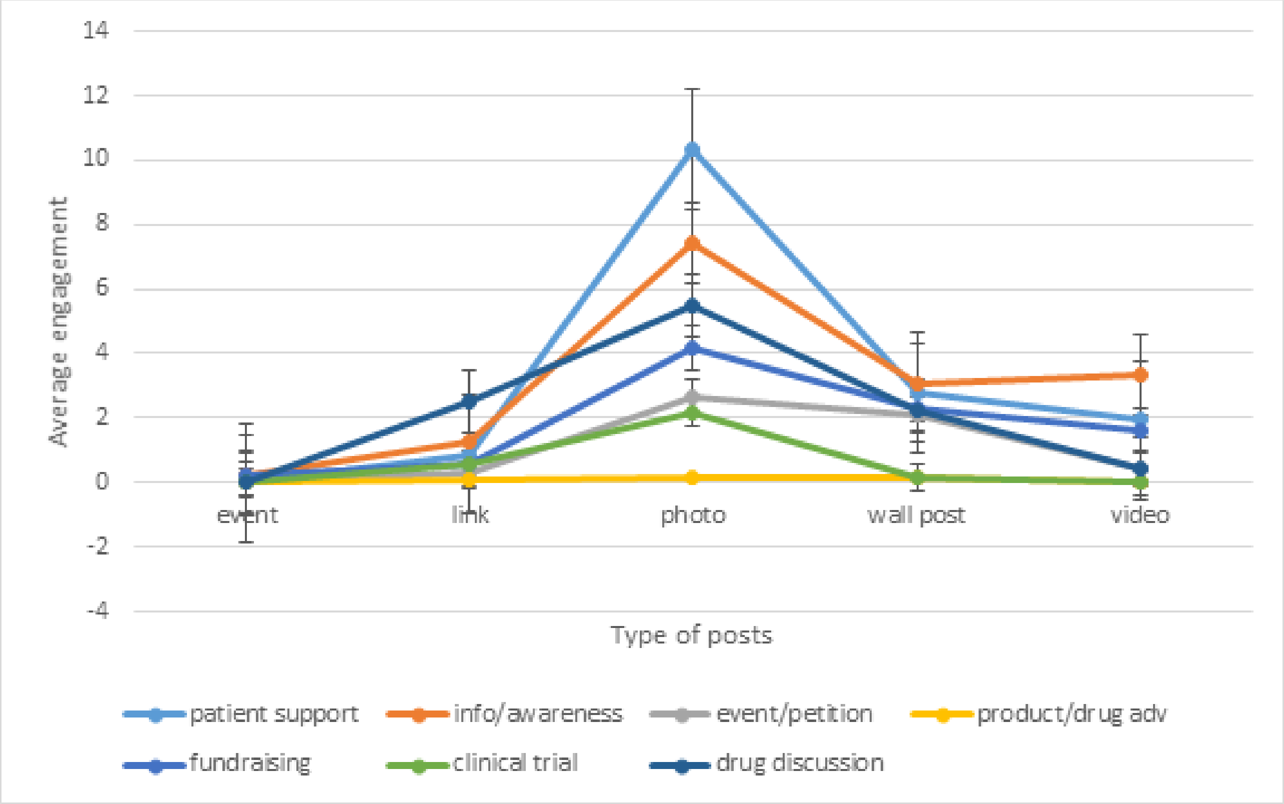


Table 5. Analysis of variance.

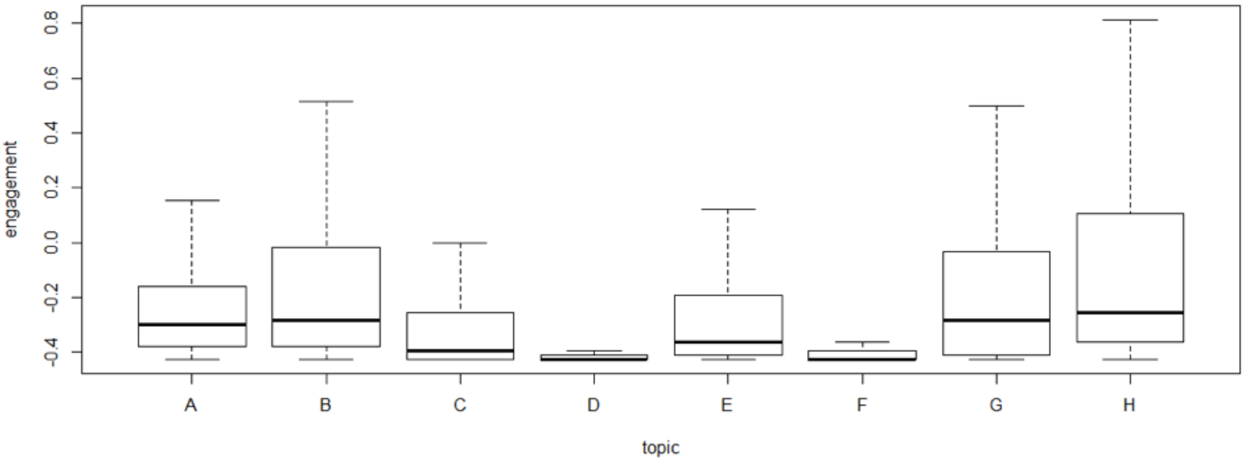
	Degrees of freedom	Sum of squares	Mean square	*F* value	Pr(>F)[a]
Topic	7	65	9.259	9.335	1.46e–11[b]
Residuals	7021	6964	0.992	__[c]	—

[a] Pr(>F): significance probability value.

[b] *P*<.001.

[c] Not applicable.

Figure 5. Boxplot showing engagement mean by category.



To test which categories differ, we analyzed a boxplot chart, shown in Figure 5, that shows that drug discussion (A), information and awareness (B), and patient support (G) have higher engagement means with respect to the other categories (H includes posts not belonging to any topics and so not considered in this discussion).

Limitations

This research is based on a dataset that comes from 2 Facebook groups, and this may represent a limitation since there might be different online behaviors in other social groups. Furthermore, this study focuses only on MS groups, and we cannot argue that the results of our analysis might apply to other conditions and that we could expect the same behavior for other diseases. Another limitation of this study is represented by the fact that we don’t have demographics for the authors of the posts collected in this study. This doesn’t allow us to analyze differences based on background and demographics such as age, gender, etc.

This work has many limitations, but it represents a starting point that can be used for similar problems that attempt to structure health information. The development of dictionaries to study health-related posts can be considered one of the main potential uses of this study that can be applied to others. In fact, this methodology can be reproduced on other groups or documents that contain medical contents (with English as primary language) and express patient opinions on medical topics.

Conclusions

SNSs have become important tools for patients and health care practitioners to share or seek information. In particular, they have often been studied in relation to chronic diseases. Other works have highlighted the use of SNSs and their level of engagement for these types of diseases. For example, Hale et al [11] showed that the engagement level for chronic diseases such as cancer and diabetes is very strong in terms of likes. Setoyama et al [9] studied the participation in online communities by patients affected by breast cancer and the related benefits. They found that there is a difference between posters and lurkers and that posters felt they received more benefits from online communities than lurkers did.

We think there is a need to understand how the information shared by patients affected by chronic diseases can be structured and used for medical research advancement. This research was a first attempt to identify the type of information shared, its structure, and its relation to the public reactions. From the initial results we were able to classify 8 different categories: patient support, information and awareness, event advertising and petitions, product and drug advertising, fundraising, clinical trials and research studies, drug discussion, and other. These findings give us a better understanding of what kind of health contents are disseminated within a community of people that hold an interest in health care and in a specific condition (eg, MS). Our results also show how content is perceived by the public. This may lead to useful applications in terms of prevention campaigns, educational programs, and therapy management. Certain information belonging to categories such as patient support, information and awareness, and drug discussion received higher attention from the public and this implies that SNSs may be used as an educational and prevention tool by increasing awareness. At the same time, patients sharing information about the treatment they are undergoing and its interaction with other medications and circumstances may represent useful insights for pharmaceutical companies or regulatory institutions to consider new scenarios and variables that were not included in their studies. As pointed out by Moorhead et al [10], SNSs are powerful tools that offer collaboration between users and provide a social interaction mechanism for many individuals. We believe that SNSs can be useful to enhance medical research and consequently health care delivery.

Our assumption was that if we were able to observe patients sharing specific drug information which then have the same level of attention as other types of posts (such as awareness, patient support, etc), we could use SNSs for gathering drug-related information. Further, the public is indeed interested in this information. We have observed this in our study and can claim that policy makers should address this phenomenon by motivating pharmaceutical companies to create SNS groups, pages, and other internet tools to provide locations where patients can publicly share the pros and cons associated with treatments they are taking.

These findings suggest that Facebook and SNSs may be valuable for disseminating health information and promoting healthy behavior by providing support and useful information that may not be available using more traditional tools.

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Conflicts of Interest

None declared.

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Abbreviations

ANOVA: analysis of variance
API: application program interface
mg: milligram
MS: multiple sclerosis
SNS: social network site

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Original Paper

Awareness and Level of Knowledge About Surgical Site Infections and Risks of Wound Infection Among Medical Physicians in King Abdulaziz University Hospital: Cross-Sectional Study

Wahbi Albishi[1], MBBS; Marwan Ahmad Albeshri[1], MBBS; Hatan Hisham Mortada[1], MBBS; Khaled Alzahrani[1], MBBS; Rakan Alharbi[1], MBBS; Farrah Aljuhani[1], MBBS; Saleh Aldaqal[2], MD

[1]College of Medicine, King Abdulaziz University, Jeddah, Saudi Arabia
[2]Department of Surgery, King Abdulaziz University Hospital, Jeddah, Saudi Arabia

Corresponding Author:
Marwan Ahmad Albeshri, MBBS
College of Medicine, King Abdulaziz University
Abdullah Alsulaiman Road
Jeddah,
Saudi Arabia
Phone: 966 582903138
Fax: 966 5555656665
Email: albeshrimarwan@gmail.com

Abstract

Background: Surgical site infections (SSIs) are one of the leading causes of death, and its prevention is a key element of applying the concept of patient safety and quality care.

Objective: This study aimed to assess the level of knowledge about SSIs and risks of wound infection among medical physicians in King Abdulaziz University Hospital.

Methods: All surgical and medical consultants, specialists, residents, and medical interns were invited to participate in the study. A 20-Item multiple-choice questionnaire was developed by reviewing the previous literature and with the help of a group of certified surgeons to assess the level of knowledge in all participants.

Results: A total of 119 doctors were included in this study. Among all respondents, 92 (77.3%) were intern doctors, 16 (13.4%) were resident doctors, and 11 (9.2%) were specialist doctors. Moreover, 66 (55.5%) doctors knew the definition of SSI. Only one-quarter, that is, 30 (25.2%) doctors knew about the incidence of SSI. In addition, 8 doctors (6.7%) had good knowledge, 75 (63.0%) had fair knowledge, and 36 (30.2%) had poor knowledge regarding SSI according to this study.

Conclusions: Level of knowledge about SSIs and risks of wound infections among medical physicians should be improved to ensure better wound care and quality care for the patients.

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KEYWORDS

surgical site infections; knowledge; attitude; infection

Introduction

Background

Health care–associated infections (HCAIs) are one of the leading causes of death that involve a huge number of patients every year worldwide [1]. Surgical site infection (SSI) accounts for more than 20% of HCAIs, and it is the most frequent HCAI in low-income and middle-income countries [1,2]. A study conducted in England, Wales, Northern Ireland, and the Republic of Ireland among 75,694 patients showed that the overall prevalence of HCAIs was 7.59%, with SSI accounting for 14.5% of these infections [3]. According to the World Health Organization and the Centers for Disease Control and Prevention (CDC), SSIs are considered one of the most preventable HCAIs [4]. SSI can be prevented by many infection control methods including surgical hand preparation, enhanced nutritional support, preoperative bathing, surgical site skin preparation, hair removal, mechanical bowel preparation, and the use of oral antibiotics [1,5]. Proper hand hygiene and the correct use of basic precautions during invasive procedures are simple and of low cost but require staff education and surveillance systems [5]. As known, SSI prevention is the key element of applying the concept of patient safety and quality care [6]. In the literature, most of the studies described the level of knowledge and awareness of SSI among nurses but not doctors [7]. Although nurses play an important role in preventing SSI, interns, residents, specialists, and consultants are also involved in patient care, and their role should be studied.

Objective

In this questionnaire-based survey, we aimed to analyze the current awareness and level of knowledge about SSI and risks of wound infections among physicians (interns, residents, specialists, and consultants) in King Abdulaziz University Hospital (KAUH), Jeddah, Saudi Arabia.

Methods

Study Design and Participants

We conducted this hospital-based cross-sectional study at the Department of Surgery at KAUH between January 2018 and June 2018. All surgical and medical consultants, specialists, residents, and medical interns were invited to participate in the study. KAUH is located in Jeddah, Saudi Arabia, which is the second largest city in the kingdom of Saudi Arabia. It is a tertiary care center with a bed capacity of 876 including inpatient beds, intensive care unit beds, and emergency rooms.

There were a total of 450 interns working at the hospital at the time of this study, and all of them were invited to participate in the study. The total number of consultants and specialists working at the hospital at the time of this study could not be estimated. However, the questionnaire was distributed to all of the included departments by the departments' coordinators and secretaries.

A 20-item multiple-choice questionnaire was developed by reviewing the previous literature and with the help of a group of certified surgeons to identify the important factors and knowledge that must be followed to reduce SSIs and to develop a valid questionnaire to properly assess the level of knowledge about SSIs and risks of wound infection among physicians in KAUH. The questionnaire was distributed randomly among the included sample.

After recruitment, the participants were asked to specify their position. After that, the questionnaire was distributed among the participants, and they were asked to answer the questions according to their knowledge about SSIs and risks of wound infections. Then, the level of knowledge was assessed for all participants.

Ethical approval was obtained from the Department of Bioethics at KAUH before the start of the study.

Statistical Analysis

Job position and answers to the SSI-related questions were presented as frequencies and percentages. One point was assigned for each of the correct answers to 20 SSI-related questions and 0 point was given for wrong answers. So, the obtainable points range between 0 (if all answers were wrong) and 20 (if all answers were correct). The mean (SD) knowledge score for all respondents and categorized by job position were presented. Furthermore, the respondents were categorized as having good knowledge (for ≥80% correct answers), fair knowledge (for 50%-79% correct answers), and poor knowledge (for <50% correct answers). The analysis was performed with 95% CI using Statistical Package for the Social Sciences (SPSS), version 23 (IBM, Armonk, NY, USA).

Results

A total of 119 doctors were included in this study. Among all respondents, 92 (77.3%, 92/119) were intern doctors, 16 (13.4%, 16/119) were resident doctors, and 11 (9.2%, 11/119) were specialist doctors (Figure 1).

Moreover, 66 (55.5%, 66/119) doctors knew the definition of SSI according to the US CDC. Almost half (50.4%, 60/119) of the doctors knew that the superficial SSI meant an infection of the skin and subcutaneous tissue and 58.8% knew that the superficial SSI was responsible for more than half of all SSIs. A total of 47 respondents (39.5%, 47/119) knew about the most common organisms causing SSI: *Staphylococcusaureus* and *Escherichia coli*. Most of the respondents (78.2%, 93/119) knew about the best time for administering prophylactic antibiotics, which was within 1 hour before surgery. Only one-quarter, that is, 30 (25.2%, 30/119) doctors, knew about the incidence of SSI, which was 1% to 3%. A total of 39.5% of study participants identified fidaxomicin as an antibiotic that was not commonly recommended for SSI. Moreover, 58 (48.7%, 58/119) of the respondents knew that a clean-contaminated wound was defined as an incision under sterile condition with an incision into a hollow viscus with no active infection. Less than half (46.2%, 55/119) of the doctors knew that the hairy skin was less likely to be associated with SSI. The majority (84.0%, 100/119) of the doctors knew about the complications of SSI, whereas about one-third (34.5%, 41/119) of the doctors knew about the correct recommendations for preoperative SSI prevention. A total of 89.1% (106/119) of the doctors answered that the infected wounds could exhibit purulent pus. About half of them stated the correct time for hair removal, but only 22.7% (27/119) knew about the preferred hair removal method, which was by clipping. Steroid use association with SSI was known by 83.2% (99/119) doctors. Furthermore, 83 (69.7%, 83/119) doctors answered that the serum albumin level was the most commonly used marker to assess nutritional status. The fourth step in hand hygiene was correctly stated by the relatively small number of doctors (20.4%, 24/119), but most of them knew about the first step (69.7%). In addition, 80.7% (96/119) of doctors correctly answered that the purpose of preoperative skin cleansing was to reduce the burden of skin flora, thus reducing the risk of SSI (Multimedia Appendix 1).

A total of 8 doctors (6.7%, 8/119) had good knowledge, 75 (63.0%, 75/119) had fair knowledge, and 36 (30.2%, 36/119) had poor knowledge regarding SSI according to this study. The mean (SD) knowledge score of all respondents was 10.93 (SD 3.24). The mean (SD) knowledge score of interns, residents, and specialists was 10.40 (SD 3.10), 12.13 (SD 3.70), and 13.64 (SD 1.69), respectively (Tables 1 and 2).

Figure 1. Distribution of all respondents by their position (n=119).

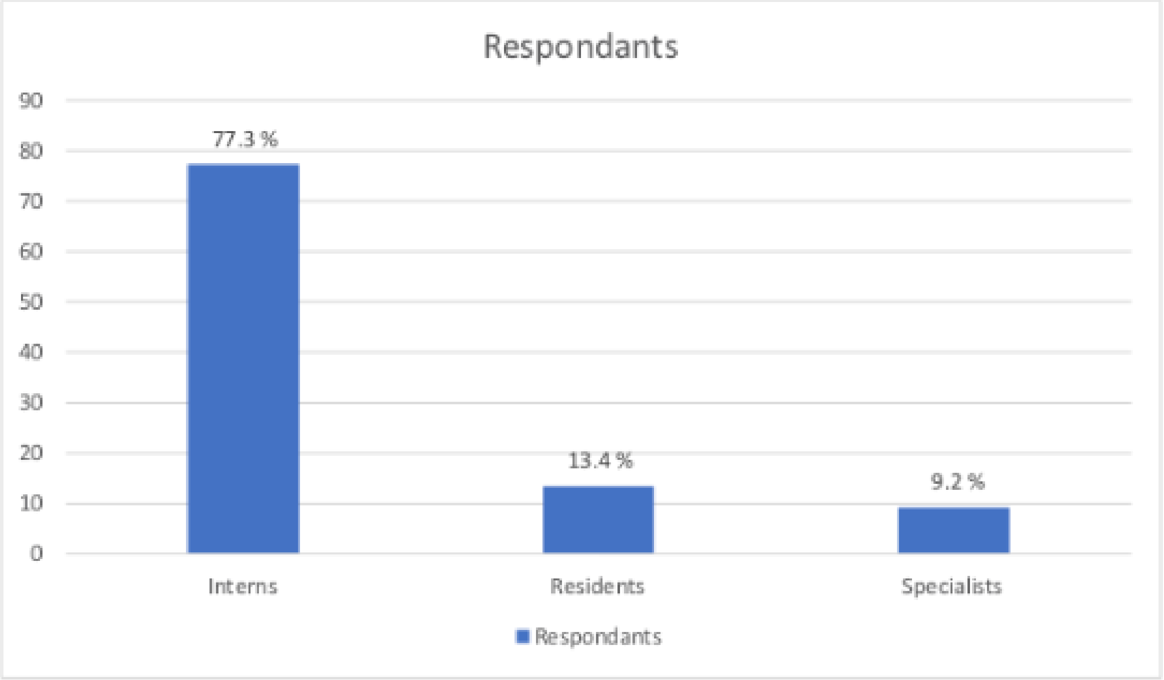

Table 1. Distribution of all by knowledge level regarding surgical site infections and risks factors for wound infection in 119 physician respondents at King Abdul-Aziz University Hospital between January and June 2018 (n=119).

Level of Knowledge	Score
Good knowledge (≥80% correct answer), n (%)	8 (6.7)
Fair knowledge (50%–79% correct answer), n (%)	75 (63.0)
Poor knowledge (<50% correct answer), n (%)	36 (30.2)
Mean knowledge score of all respondents, mean (SD)	10.93 (3.24)

Table 2. Distribution of mean knowledge score of all respondents by their job position (n=119).

Job position	Mean knowledge score, mean (SD)
Intern	10.40 (3.10)
Resident	12.13 (3.70)
Specialist	13.64 (1.69)

Discussion

Principal Findings

SSI is defined by the CDC as a proliferation of the causative micro-organisms, which can be superficial (colonization in an incisional site within the skin or subcutaneous fat), deep (colonization in musculofascial layers), or in an organ or cavity [7]. Between 3% to 5% of all the patients who undergo surgery will experience SSI, as mentioned in the literature [8]. The incidence of SSI is 15 times higher in unindustrialized countries than in industrialized countries, for example, 38% in Nigeria [3], 12% in India [9], and 19% in Ethiopia [10]. A study conducted in India in 2016 mentioned that the perception of health care staff about SSIs was good enough (94%), but the practices were inadequate (47%) [11]. On the other hand, a study conducted in Bangladesh reported that the perception of majority of nurses (70%) was inadequate regarding the SSI prevention, but the practices of most of the nurses were higher (98.3%) [12]. However, in the literature, most of the studies described the level of knowledge and awareness of SSI among nurses but not doctors. Although nurses play an important role in preventing SSI, interns, residents, specialists, and consultants are also involved in patient care, and their role should be studied. In this questionnaire-based survey, we analyzed the current awareness and level of knowledge about SSI and risks of wound infections among physicians (interns, residents, specialists, and consultants) in KAUH.

A total of 119 doctors were included in this study. A similar number of participants were reported in different studies [4,5,13]. Most of the study participants (77.3% 92/119) were intern doctors, which is comparable with a study conducted by Patil et al on the prevention of SSI [4]. A total of 55.5% (66/119) of doctors knew the definition of SSI according to the US CDC. In contrast to a study conducted by Labeau et al, which showed that only 7% of nurses knew the correct classification of SSI [14], in our study, almost half of the doctors knew that the superficial SSI means an infection of the skin and subcutaneous tissue and 58.8% (70/119) knew that the superficial SSI is responsible for more than half of all SSIs.

A total of 47 respondents (39.5% 47/119) knew about the most common organisms causing SSI (*S aureus* and *E coli*). Most of the respondents (78.2% 93/119) knew about the best time for administering prophylactic antibiotics, which was within 1 hour before surgery. A lower rate (57.58%) was observed in a study conducted in Nigeria among doctors and nurses to assess the knowledge and infection control practices [11].

Only one-quarter (30/119 doctors) knew about the incidence of SSI, which was 1% to 3%. A total of 39.5% (39/119) of the study participants identified fidaxomicin as an antibiotic, which was not commonly recommended for SSI. Moreover, 58/119 (48.7%) of the doctors knew that a clean-contaminated wound was defined as an incision under sterile condition with an incision of a hollow viscus with no active infection. Less than half (46.2% 55/119) of the doctors knew that the hairy skin was less likely to be associated with SSI.

The majority (84.0% 100/119) of the doctors knew about the complications of SSI, whereas about one-third (34.5% 41/119) of the doctors knew about the correct recommendations for preoperative SSI prevention. A total of 89.1% (106/119) of the doctors answered that the infected wounds can exhibit purulent pus. About half of them stated the correct time for hair removal, but only 22.7% (27/119) knew about the (clipping) preferred hair removal method, in contrast to the study by Labeau et al, which showed that only 26% knew the correct time for hair removal, whereas 50% (60/119) knew that electric clippers were recommended [5]. Steroid use was associated with SSI was known by 83.2% (99/119) doctors. A total of 83/119 (69.7%) doctors answered that the serum albumin level is the most commonly used marker to assess nutritional status.

The fourth step in hand hygiene was correctly stated by the relatively small number of doctors (20.4% 24/119), but most of them knew about the first step (69.7% 83/119). Moreover, 80.7% (96/119) of doctors correctly answered that the purpose of preoperative skin cleansing is to reduce the burden of skin flora, thus reducing the risk of SSI (Multimedia Appendix 1).

A total of 8/119 doctors (6.7%) had good knowledge, 75/119 (63.0%) had fair knowledge, and 36/119 (30.2%) had poor knowledge regarding SSI according to this study. Similar rates were observed in different studies (2.08%, 33.3%, and 64.58% and 15.4%, 56.4%, and 28.2%, respectively) [4,15,16].

Conclusions and Recommendation

In this study, only 6.7% of doctors had good knowledge, so we recommend increasing the level of awareness and knowledge of SSI among medical interns, residents, and specialists in KAUH by providing more courses and sessions.

This study was subject to some potential limitations. It was carried out in a single center. Therefore, to get a global result, we recommend the initiation of future multicenter studies.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Questionnaire-based survey regarding awareness and level of knowledge about SSI and risks factors for wound infections among 119 physician respondents with answers to SSI-related questions in King Abdul-Aziz University Hospital between January and June 2018.

[PDF File (Adobe PDF File), 99KB - ijmr_v8i1e12769_app1.pdf]

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Abbreviations

CDC: Centers for Disease Control and Prevention
HCAI: health care–associated infection
KAUH: King Abdulaziz University Hospital
SSI: surgical site infection

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Review

Diet and Multiple Sclerosis: Scoping Review of Web-Based Recommendations

Jeffrey M Beckett[1], PhD; Marie-Louise Bird[2], PhD; Jane K Pittaway[1], MBiomedSc; Kiran DK Ahuja[1], PhD

[1]School of Health Sciences, University of Tasmania, Launceston, Australia

[2]GF Strong Rehabilitation Research Program, Department of Physical Therapy, University of British Columbia, Vancouver, BC, Canada

Corresponding Author:
Kiran DK Ahuja, PhD
School of Health Sciences
University of Tasmania
Locked Bag 1322
Launceston, 7250
Australia
Phone: 61 3 6324 5478
Email: Kiran.Ahuja@utas.edu.au

Abstract

Background: There is currently no scientific evidence supporting the use of specific diets in the management of multiple sclerosis (MS); the strongest dietary associations are observed with vitamin D and omega-3 fatty acid supplementation. Despite this, there are many websites that provide advice or suggestions about using various dietary approaches to control symptoms or disease progression.

Objective: The objective of this study was to assess the dietary advice for the symptomatic management of MS available on the internet.

Methods: This study was a systematic review of webpages that provided dietary advice for the management of MS. Webpages were selected from an internet search conducted in November 2016 using Google, Yahoo, and Bing search engines and the search term “MS diet.” The first two pages of results from each search engine were included for the initial assessment. Duplicates were removed. Data extracted from websites included specific advice relating to diet and its rationale and the citation of supporting scientific literature. Authorship and credential information were reviewed to assess webpage quality.

Results: We included 32 webpages in the final assessment. The webpages made a wide variety of specific recommendations regarding dietary patterns and individual foods to help manage MS. The most common dietary pattern advised on these webpages was the low-fat, high-fiber balanced diet, followed by the low-saturated fat diet, near-vegetarian Swank diet, and the Paleo diet. The main categories of individual foods or nutrients suggested for addition to the diet were: supplements (especially omega-3 and vitamin D), fruits, vegetables, and lean protein. In contrast, the most commonly recommended for removal were saturated fats, dairy, gluten-containing grains, and refined sugar. These recommendations were often accompanied by rationale relating to how the particular food or nutrient may affect the development, prevalence and symptoms of MS; however, very little of this information is supported by the current scientific evidence between diet and MS. Only 9 webpages provided full authorship including credential information.

Conclusions: There is a wide variety of Web-based dietary advice, which in some cases is contradictory. In most cases, this advice is the result of peoples’ individual experiences and has not been scientifically tested. How people living with MS use this information is not known. These findings highlight the important role health professionals can play in assisting people living with MS in their health information-seeking behaviors.

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KEYWORDS

multiple sclerosis; diet; evidence-based medicine; internet

Introduction

People are increasingly turning to the internet for health information. While health professionals remain important and trusted sources of health advice, most people search the internet as their first source of information [1-3]. The Web-based recommendations may come from respected sources such as government organizations or association websites specific to medical conditions, but increasingly, personal websites, blogs, and other forms of social media offer advice and give descriptions of individual's experiences [4]. This easy access to information is beneficial in some respects; patients can better inform themselves about their health, and health messages can be delivered to those reluctant to engage face-to-face with health care professionals. The ability to make good health decisions based on such information forms an important part of an individual's health literacy. This skill can be compromised if people are not able to appraise the quality, accuracy, or applicability of Web-based information. The type of information that is readily available to people in the community searching for information about diet and MS is not known.

Most people begin a Web-based search by using a search engine such as Google, Bing, or Yahoo [2]. Search engines use algorithms including, among other factors, the number of incoming links from other pages, meaning popular websites rank highly. Paid advertisements are also prominent in search results, and therefore, there is no guarantee to the scientific reliability of information found in a search [5].

Multiple sclerosis (MS) is an incurable autoimmune inflammatory disease leading to demyelination in the central nervous system, affecting approximately 2.5 million people worldwide. Presentation varies widely, with symptoms relating to neurological degeneration such as motor impairment, fatigue, pain, and sensory and cognitive disorders [6]. Around 85% of people will begin with relapsing-remitting MS, where relapses or exacerbations are followed by periods of partial or total recovery. Many of these people will eventually develop secondary progressive MS, in which there is gradual progression of the disease and incomplete recovery from relapses or exacerbations. In contrast, around 10% of people will follow a progressive course from onset, in which they suffer progressive disability in the absence of relapses or exacerbations [6]. As MS is currently incurable, treatment aims to manage symptoms, limit the frequency or severity of relapses, and slow the overall rate of disease progression. Treatments are often expensive, have varying efficacy, or involve significant side effects. As a result, many MS patients seek alternative therapies [7], including dietary modification, and the internet is the first source of information on such approaches [8,9].

There is currently no scientific evidence supporting the use of specific diets in the management of MS [10-13]; the strongest dietary associations are observed with vitamin D and omega-3 fatty acid supplementation [12]. Despite this, there are many websites that provide advice or suggestions about using various dietary approaches to control symptoms or disease progression [10], or even, as one website has claimed, "Defeating progressive multiple sclerosis without drugs" [14]. It is possible that individuals may identify alternative approaches that do offer some benefit. However, there is a risk of adopting treatments that are ineffective or even detrimental to patient health, may be arduous to follow, and also potentially expensive (spending on complementary and alternative medicines in the United States in 2007 was estimated at US $34 billion) [15].

There are many webpages providing advice about the use of diet to manage MS, despite the lack of supporting scientific evidence. This problem is exacerbated by the fact that MS patients often do not discuss information related to alternative therapies with their clinicians [8]. The aim of this study was, therefore, to determine what information people encounter from an initial internet search for MS-related dietary advice, its rationale, and sources.

Methods

This review of Web-based dietary advice for the management of MS symptoms was performed in accordance with a protocol described previously [16], with some minor amendments. Briefly, Google, Yahoo, and Bing search engines were used within a new Incognito window on the Chrome browser to conduct a search using the term "MS diet." The search was performed by a single investigator (MLB) in November 2016 and included no search limitations (eg, date). The first 2 pages of results from each search engine were included for initial assessment. Each webpage that resulted from this search strategy was archived using the FireShot extension for Chrome, for later assessment. The initial webpage linked-in search results, and any other relevant webpages within the same website, were included as one result. Duplicate results between search engines were removed, and any advertisements with no relevance to MS were excluded. Scientific papers on journal publisher websites were excluded as they are often not free to access and people without scientific training may lack the knowledge to properly interpret the findings of the paper. It would also be inappropriate to depend on results of individual studies. Other relevant links (related to the topic of MS diet) from webpages found in the primary search were included for assessment if they met the inclusion criteria.

Data from the included webpages were extracted by two reviewers (KDKA and JKP) in January 2017. Each included source was classified by the type of webpage and the type of website that it was published on. A webpage was defined as an individual document displayed by a browser; a collection of webpages grouped together was defined as a website. Webpages were classified as articles or blogs. Articles were documents presenting information but with no provision for publishing comments, feedback, or discussion from readers. Blogs were considered as webpages that may have presented information in a similar manner to articles but allowed for readers to add comments or questions on the same webpage. Initially, the information on the "About" page of each website was intended to be used to help determine the website classification; however, not all websites provided useful information. Websites were therefore classified by assessing the source of the information (government-endorsed vs nongovernment-endorsed website) and whether it was an MS-specific or a general health information site. Websites were classified as government websites, nongovernment general health websites, nongovernment MS-only websites, and personal websites.

Data were extracted for the date of last update, country of origin, provision of specific advice relating to diet and its rationale, and the citation of supporting scientific literature. Webpages were assessed to determine if they provided specific guidance to consult a health professional in relation to the dietary advice given; general website legal disclaimers were not included. During data extraction, webpage authorship was assessed as NA (author information not available on the webpage), A (only author's name provided on the webpage), or FA (full authorship: author's name and relevant credentials provided).

Results

Searches using the term "MS diet" returned 62,300,000 results for Google; 13,600,000 for Bing; and 7,590,000 results for Yahoo. The first 2 pages from these sites contained links to 25-38 pages (Figure 1), making a total of 92 webpages. At the first pass check for duplicates within, and between, search engines and for advertisements not related to MS diet (eg, Weight Watchers), 58 webpages were removed. Screening of the remaining 34 pages generated an additional 26 new webpages (criteria—listed under sources). During the second pass, we removed 28 webpages (including advertisements, broken links, duplicate pages, scientific journal articles, and pages not relevant to MS diet), leaving 32 webpages for data extraction.

The year of the last update was included in 25/32 webpages. The oldest recorded update was dated 2011, and the most recent was dated 2016. Most of these webpages (n=19) listed the United States in their contact details, followed by Australia (n=6) and the United Kingdom (n=4). We were unable to identify the country of origin for 4 webpages. Targeted advertisements were included in 12 webpages.

The 32 webpages assessed (Table 1) came from four different types of websites including government websites (1 article); nongovernment MS-only websites (10 articles and 1 blog), personal websites (2 articles and 1 blog), and nongovernment general health websites (14 articles and 3 blogs). The single government website [17] included a scientific overview of MS discussing the types of MS, symptoms, treatment, and alternative therapies including diet that may or may not be effective. This webpage did not include any information on authorship and did not provide any direct link to scientific citations.

Nongovernment MS-only websites included 10 webpages from advocacy, not-for-profit organizations including MS Australia (4 webpages), MS Society UK (1 webpage), National MS Society USA (2 webpages), Swank MS foundation (1 webpage), Overcoming MS (1 webpage), and Direct MS (1 page). There was 1 webpage (MS Discovery Forum) that was designed as a Web-based resource and discussion forum for researchers, rather than for the general public. Only 1 webpage [18] provided full authorship information.

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses flowchart for the selection of webpages. MS: multiple sclerosis.

Table 1. Webpages included in data extraction.

Type	Title	Authorship
Government websites		
Article	Multiple Sclerosis (MS) [17]	NA[a]
Nongovernment MS-only websites		
Article	Australian researchers find ‘bad’ fats major culprit in MS progression [19]	NA
Article	High salt diet linked to autoimmunity[b] [20]	NA
Article	New dietary research looks into fatty acids, vitamins, and lipids in MS[b] [21]	NA
Article	Fish and flaxseed oil linked to improved quality of life and MS disease activity[b] [22]	NA
Article	Treatment of MS via Diet[b] [23]	NA
Article	Diet & Nutrition [24]	NA
Article	Diet-live it well [25]	NA
Article	Overcoming Multiple Sclerosis-diet [18]	FA[c]
Blog	Multiple Sclerosis Discovery Forum: Does diet matter in MS? [26]	A[d]
Article	Diet [27]	NA
Article	Roger MacDougall’s Story [28]	A
Personal websites		
Article	Multiple Sclerosis and food hypersensitivities [29]	A
Blog	The MS Diet-MS Diet for Women [30]	A
Article	Suggestions for the Newly Diagnosed [31]	A
Nongovernment general health websites		
Article	Treating Multiple Sclerosis with Diet: Fact or Fraud? [32]	FA
Article	MS foods to avoid [33]	FA
Article	Everyday health: 7 foods to avoid when you have MS [34]	FA
Article	Medical Daily: Multiple Sclerosis diet: Doctor Terry Wahl’s reverses MS with diet alone [35]	A
Article	Is there a Multiple Sclerosis diet? [36]	NA
Article	An MS-Stricken Doctor Changes Her Diet [37]	A
Article	Dr. McDougall’s Health & Medical Centre: Diagnosed with MS, food became my medicine [38]	A
Article	What to eat when you have Multiple Sclerosis [39]	A
Blog	How to treat Multiple Sclerosis with diet [40]	FA
Article	Dietary therapies for MS [41]	FA
Blog	The MS recovery diet [42]	NA
Article	Multiple Sclerosis & dietary intervention [43]	A
Article	The Best Bet Diet for MS [44]	FA
Article	My experience with Multiple Sclerosis and my route to becoming symptom-free [45]	A
Article	Swank Diet information [46]	A
Article	Does Your Diet Affect Your MS? [47]	A
Blog	Doctor reverses MS in 9 months by eating these foods [48]	FA

[a] NA: author information not available on the webpage.

[b] Webpage no longer available (checked on July 14, 2018).

[c] FA: full authorship, author’s name, and relevant credentials reported on the webpage.

[d] A: author’s name given on the webpage.

There were 2 personal websites by people living with MS about the diets they were following and that they claimed to work for them. The third personal website presented a reproduction of an article written in the style of a scientific research article, which included the pathogenesis and potential environmental and dietary factors associated with MS, authored by a relative of a person living with MS. None of the authors fitted the criteria for full authorship. Nongovernment general health websites included Web-based health magazines with webpages on MS and diet and websites on specific diets such as the Paleo diet and its purported association with MS. Of the 17 websites, 7 webpages provided full authorship information.

Social media links enabling the sharing of information from the individual webpages were included on all sites. While most websites contained disclaimers or legal terms and conditions indicating that the information provided did not constitute medical advice, only 11 webpages included specific advice to consult a medical practitioner, neurologist, health care provider, or dietitian before making any changes to the diet.

The webpages made specific recommendations regarding dietary patterns (Table 2) and individual foods to help manage MS (Tables 3, 4, 5, and 6). The most common dietary pattern (Table 2) advised on these webpages was the healthy balanced diet (low fat and high fiber) based on American Heart Association recommendations (7 webpages), followed by the low-saturated fat, near-vegetarian Swank diet, including the Overcoming MS and MS Recovery diets (6 webpages); the Paleo diet (low processed, low-grain foods) and its modifications, including Wahl's diet (4 webpages); and Ashton Embry's Best Bet diet and its modifications (2 webpages). Combining the information from dietary patterns and individual food recommendations, the main categories of individual foods or nutrients suggested for addition to the diet were: supplements (especially omega-3 and vitamin D), fruits, vegetables, and lean protein (including skinless poultry, grass-fed meat, and organ meat; Tables 4 and 5). In contrast, the most commonly recommended for removal were fats (saturated, heated, etc), dairy, gluten-containing grains, and refined sugar (Tables 3 and 6). These recommendations were often accompanied by rationale relating to how the particular food or nutrient may affect the development, prevalence, and symptoms of MS (Tables 2, 5 and 6).

Table 2. Recommendations and rationale for the dietary patterns recommended by the websites.

Dietary pattern	Major characteristics	Rationale for this diet
Healthy balanced diet	Low-fat, high-fiber diet with whole grains and fish (similar to the diet recommended by the American Heart Association)	Increases the time between relapses and promotes overall health [24,25,34]; controls weight and fatigue, better bladder and bowel function [24,25]; reduces inflammation [47]; low vitamin & mineral intake can worsen multiple sclerosis (MS) symptoms [36]
Swank diet and its modifications including Overcoming MS and MS Recovery diet	Low-saturated fat, near-vegetarian diet with no red meat in the first year; dairy with <1% fat; no processed foods; saturated fat <15 g/day; unsaturated fat 20-50 g/day; cod liver oil and multivitamin every day	Low prevalence in population on low-saturated fat diets [32], low-saturated fat, near-vegetarian diet arrests or cures MS and slows progression [38]; fruits and vegetables reduce constipation and reduce weight [32]; lower frequency and severity of attacks [40]; better health outcomes; cow milk protein is similar to myelin and initiates autoimmune reaction in MS [18]; Swank diet reduces death rate [46]
Paleo diet and its modifications including Wahl's diet	Includes free-range meat and organic fruit and vegetables. Excludes grains, dairy, soy, legumes, and sugar	For optimum mitochondrial, myelin, and neurotransmitter functions [35,48]; to slow MS decline [35]; animal-based omega-3 to lessen progression and relapses [35]; seaweed for iodine, iron, calcium, and fiber helps increase alertness and mental clarity [35,48]; vitamins A, B, C, and K for myelin and brain health [27,48]; sulfur-rich vegetables for removing toxins and formation of neurotransmitters [27,48]; colorful fruits and vegetables for antioxidants [37]; grains are health destroying [37]; omega-3, creatine, and coenzyme Q10 help in mitochondrial function [48]
Best Bet diet	Includes vitamin, mineral, and herb supplements. Excludes dairy, refined sugar, eggs, yeast, gluten, and legumes	Remove proteins that resemble myelin [44] and act like allergens [45]

Table 3. Number (proportion) of recommendations to remove foods.

Foods to remove	Recommendations[a] to remove foods (n=79), n (%)
Fats	16 (20)
Dairy	12 (15)
Sugar	10 (13)
Grains (gluten)	10 (13)
Eggs	7 (9)
Caffeine and Alcohol	5 (6)
Condiments (including salt)	4 (5)
Meat and Poultry	4 (5)
Legumes	4 (5)
Processed Food	3 (4)
Yeast	3 (4)
Fruit (citrus)	1 (1)

[a] Some webpages made multiple recommendations for addition or removal of foods from the diet; therefore, number of recommendations may be greater than the number (32) of included webpages.

Table 4. Number (proportion) of recommendations to add foods.

Foods to add	Total recommendations[a] to remove foods (n=62), n (%)
Fruits	11 (18)
Vegetables	11 (18)
Supplements	10 (16)
Fish	6 (10)
Meat and Poultry	5 (8)
Other Grains	4 (6)
Oils and unsaturated fats	3 (5)
Condiments (including salt)	3 (5)
Nuts and Seeds	2 (3)
Dairy Alternatives	2 (3)
Lentils and Legumes	2 (3)
Water	2 (3)
Eggs	1 (2)

[a] Some webpages made multiple recommendations for addition or removal of foods from the diet; therefore, number of recommendations may be greater than the number (32) of included webpages

Table 5. Recommendations and rationale provided by the websites for foods or nutrients to be included in the diet.

Foods or nutrients to add to diet	Foods to add	Rationale for change
Drinks	Plenty of water	Neuron activity and brain functionality [30]
Supplements	Fish oil, B1, B2, B12, biotin, iodine, vitamin A, vitamin E, creatine, coenzyme Q10, antioxidants, probiotics, vitamin D, omega-3, omega-6, evening primrose oil, magnesium, vitamins, and minerals	Omega-3, vitamin D: reduce frequency of attacks [18,21,22,46]; omega-3 an essential fatty acid as these fatty acids make myelin [31]; vitamin D: regulator of immune system [31]; vitamin B12: helps reduce exacerbation of multiple sclerosis (MS) [31]; low vitamin D: development of MS [39,48]; low vitamin D: more aggressive progression [39]; evening primrose and fish oil supplements to reduce severity and length of attacks [17]; omega-3 and -6 and vitamin A and E combined delay time to progression [23]
Egg	White only	N/A[a]
Meat and poultry	Grass-fed, organ meat, lean, skinless chicken	As a replacement for high-fat meats [28]; lean protein to combat fatigue [29]
Lentils and legumes	N/A	N/A
Oil or unsaturated fats	Olive, sunflower, safflower, flaxseed, fish	As a replacement for animal fats [28]; extra virgin olive oil rich in omega-9; anti-inflammatory [30]; fish oil reduces progression [30]
Other grains	Whole grains, brown rice	N/A
Fish	Oily fish, seafood	Build up and repair myelin sheath, reduce inflammation, decrease certain immune reactions, improve relapse, slow progression, and improve MS symptoms [30]; lower relapse rate [22]; slows progression and less relapse [35]
Nuts and seeds	Flaxseed	Energy and nutrients for stable blood sugar and omega-3 rich for improved metabolism [30]; lower relapse rate [22]
Condiments	Himalayan pink salt, sea salt, fermented vegetables, seaweed	Fermented vegetables for gut bacteria and health [48]; seaweed for iodine, iron, calcium, and fiber help increase alertness and mental clarity [35,48]
Dairy alternatives	Rice milk, almond milk, soy milk	Replacement for dairy [30]
Fruit	Berries, brightly colored, antioxidant rich, raw	High in antioxidants, but no link provided to symptoms [30]; high in vitamins, minerals, and antioxidants for optimal mitochondrial, myelin, and neurotransmitter functions [35,48]
Vegetables	Green, brightly colored, white, raw	Immune system health [30]; reduce inflammation [30]; high in antioxidants to help fight MS symptoms [30]; high in vitamins, minerals, and antioxidants for optimal mitochondrial, myelin, and neurotransmitter functions [26,48]; vegetables rich in antioxidants and vitamins help reducing toxins and creating neurotransmitters [37]

[a] N/A: not applicable.

Table 6. Recommendations and rationale provided by the websites for foods or nutrients to be removed from the diet.

Foods or nutrients to remove from the diet	Foods to remove	Rationale for change
Fats	Saturated fat, heated fats, margarine, trans fats, fatty foods, coconut oil, palm oil, animal fats, cholesterol, highly marbled meat	High blood cholesterol and LDL[a]: greater number of new lesions [19,21], higher rate of disability progression [19]; saturated fat: inflammation [18] and breaches blood-brain barrier, which precedes immune hypersensitivity in the CNS[b] [30]; heated fats (fried food): cannot be absorbed and cause damage to cells [30]; margarine contains trans fats and causes inflammation [30,34]; fried food hard to digest [28]; trans fats and cyclic fats embed in cell membrane and distort cellular function [48]; high fats may be a risk factor for multiple sclerosis (MS) development [26]; development of MS [18,39]; slower progression of MS [18,32]; prevalence [29]; MS patients at high risk of CVD[c]: saturated fat increases risk [34]
Dairy	Cow's milk, full-fat milk, pasteurized milk, butter fat, casein	Development of MS [30]; prevalence [29,30,48]; to improve overall health [33]; allergy leading to attack [28,45]; may be detrimental [34]; aggravates condition [42]; immune hypersensitivity and cross reactivity [18,29,44]
Grains	Gluten-containing foods, processed grains, starches, cereals	Causing autoimmune response [29,30]; grains are totally health destroying [37]; prevalence [29]; MS population at high risk of celiac disease [34]; processed carbohydrates leading to high blood sugar and CVD [34]
Sugar	Refined, artificial sweeteners, fructose, sweetened and fizzy drinks	Fatigue [33,34,39]; weight [34]; inflammation and regulation of immune system by insulin (due to sugar) and artificial sweeteners, candida overgrowth leading to leaky gut syndrome [30]; development of MS [48]; increase uric acid, which increases inflammation [48]; aspartame metabolizes to methanol, which is a potent neurotoxin [48]; artificial sweeteners can irritate bladder [39]; sugary snacks can cause energy crash [39]
Legumes	N/A[d]	Can cause reaction and lectin from green beans can reduce absorption of certain nutrients [30]; immune hypersensitivity [29]
Meat and poultry	Land animals, highly marbled meat	To reduce saturated fat [30]
Eggs	Egg yolks	To reduce saturated fat [30]; immune hypersensitivity [29]; allergic reaction [45]
Fruit	Citrus	May affect MS symptoms [30]
Condiments	Salt	Dietary sodium may be a risk factor and may also exacerbate disease activity [20,26]; worsen symptoms [20]; high sodium associated with poor prognosis [39]; risk of relapse and new lesions [34]; risk factor for heart disease [34]
Drinks	Alcohol, whiskey, gin, vodka, caffeine	Caffeine: blocks adenosine receptors, hence lowering the effect of adenosine in suppressing inflammation [30]; to avoid insomnia [39]; alcohol intensifies feelings of fatigue [36]
Yeast	N/A	Immune hypersensitivity [29]
Processed foods	N/A	None provided

[a] LDL: low-density lipoprotein.

[b] CNS: central nervous system.

[c] CVD: cardiovascular disease.

[d] N/A: not applicable.

Discussion

Predictably, there is a wide range of dietary advice solicited on the internet for treating MS and its symptoms. The unexpected result was that the advice not only ranged from recommendations for the addition or removal of individual foods and nutrients but also to broader changes affecting entire dietary patterns, with two dominant and significantly different patterns emerging. These were a Paleo-style diet, low in processed and grain foods but including animal fats such as lard, and the low-fat, near-vegetarian Swank diet. The advice was generally poorly backed by scientific evidence and often purported by people who claim to have controlled or even reversed their MS symptoms by making changes to their diet.

There is only weak scientific evidence for a relationship between diet and MS [10,12]. Associations such as the MS Societies, and government health sites, perhaps considered as the most esteemed places to look for advice, have taken this on board and appropriately recommend a low-fat, high-fiber, healthy balanced diet. While this approach is in line with the scientific evidence, the information on these websites is often presented in a bland and matter-of-fact manner with little or no authorship, author credential information, or citation of supporting scientific evidence. This is despite the fact that the public is often advised that webpage credibility should be judged on transparency and the inclusion of authorship, credentials of the authors, and citation of scientific literature [49,50]. Admittedly, these websites are commonly written by a team rather than an individual and include little or no scientific jargon or citations in an attempt to make the information easier to understand. This, however, may lead to unintended consequences for the message and its credibility.

In contrast to the advocacy sites, personal websites are often visually attractive and as well as including authorship, the author possesses the credential of "MS sufferer," making it a site for and about people who know the disease intimately. These sites often include citations to the scientific literature, which may or may not have supported their claims, but their presence can potentially still give credibility to the site or person. Nongovernment general health websites (more like internet magazines) commonly include authorship and the credentials of the writers (often a person with medical or nutrition background) and opinions from people living with MS who claimed to have "tried and tested" a number of approaches. These people report on what they felt worked best for them to control their MS symptoms and, more importantly, encourage others to make similar changes and assess the suitability for themselves. This encouragement and the suggestion to individuals to tailor their diet to suit themselves may potentially lead to a feeling of improved self-worth, by having a greater input in their own treatment.

Webpages that advise consuming a healthy balanced diet do so without reference to scientific literature and simply state that there is no evidence for adopting a specialized diet for MS. In contrast, webpages that gave recommendations to change individual foods or nutrients, or entire dietary patterns, attempted to provide a rationale for the changes and often some citation of scientific literature. This approach, regardless of how strongly the advice might be supported by scientific evidence, potentially provides a more compelling case to the reader to try these alternative diets. On webpages that suggested the addition or removal of specific foods or nutrients in the diet, there was commonly an explanation provided as to what benefit the change would provide in relation to MS symptoms or the underlying mechanisms. Often, recommendations to remove a food were given alongside alternative foods that could be used as substitutes. For example, dairy products were commonly recommended for elimination from diets because it was reported that milk proteins mimic parts of the myelin sheath protein, leading to autoimmune reactions [28], and suitable alternatives such as rice and almond milk were suggested [30]. Recommendations to change dietary patterns took a similar approach by attempting to explain the rationale behind the dietary changes. The Wahl's Paleo diet recommended consumption of 3 cups of leafy green vegetables daily because it was considered that they are rich in vitamins A, C, K, and B and various minerals, which are essential for brain function and the protection of mitochondria.

Given the complexities of many diseases, individually tailored approaches to treatment may be more effective, and a number of writers on webpages included in this study did advise trialing their suggested changes to see whether they were effective for the individual. If the level of success in treating MS symptoms using dietary approaches is similar to that suggested by these internet sources, the scientific community perhaps needs to work toward testing the basis of some of the dietary approaches that have become popular in this population, such as the Swank and Wahl's diets.

The desire for many patients to follow an alternative approach to try to improve their health cannot be ignored by clinicians. The internet is a readily accessible source of advice and information for patients; however, the advice could be ineffective or even detrimental to the patient's health. It is known that patients frequently do not actively seek to discuss alternative therapies with their clinician [8], and as evidenced in this study, the information available about such therapies can vary considerably. Clinicians should seek to open a dialogue with their patients to determine if they are considering alternative therapies and help to direct them to reliable sources of information. By doing this, health professionals can improve a person's health literacy and assist them in appraising information and empower them to make appropriate health decisions [51].

The search strategy was designed to be similar to an initial search that a member of the public, with no particular training, may undertake. Therefore, we sought to use a simple search term and popular search engines. It could potentially be considered that using a single search term such as "MS diet" was a weakness of the study design. However, the suitability of this term was informed by a pilot study using Google Trends [52], where "MS diet" was the top trending search query on this topic between March 2010 and March 2016. Other proposed search terms were found to have very low numbers of search queries on Google Trends, indicating that they were not commonly used search terms and, therefore, were not included in the study. Similarly, the decision to limit the search to the first two pages of search results was based on reported behavior analysis indicating that the first page of search results receives approximately 92% of all traffic and the second page perhaps as little as 5% of traffic [53]. Including results beyond these two pages would, therefore, mean including pages that were rarely visited in most everyday searches. We acknowledge that social and patient networks are likely to become important sources of information as the patient or carers search more intensely and change their information-seeking approach. The inclusion of only English language websites may also be considered as a limitation.

The search strategy used an Incognito browser to avoid the influence of past searches on our results, but geolocationing was not disabled. This may affect the generalizability of our results; however, we note that only 16% (5/32) of included webpages had an Australian domain. Information on the internet is continually evolving, and the total number of possible search hits is often very large. However, we do not consider that this affects the validity of the data presented as the aim of the study was to review the webpages that were most likely to be accessed on an initial search.

In conclusion, there is a wide variety of Web-based dietary advice that, in some cases, offers contradictory advice. In many cases, this advice is the result of peoples' individual experiences and has not been scientifically tested. The public is advised to assess the reliability of health information provided on the internet by looking for details such as authorship, and supporting evidence, such as the citation of scientific literature. However, we found webpages that would normally be considered reliable (eg, MS Society) did not perform well in this regard. Conversely, some webpages appeared credible due to the provision of links to scientific literature, but the cited material did not always support the advice given. Patients without scientific training, and likely to lack the knowledge required to interpret the conflicting and often unsupported advice given, are left to assess whether the information being provided is reliable. These findings highlight the role health professionals can have in providing the best quality information to consumers on relevant topics in a way that is easy to understand, accurate, and accessible. Future work should focus on determining what decisions people make from accessing Web-based information and the proportion of people who actually follow the different dietary regimes promoted on the Web, what factors led them to choose that particular approach, and what, if any, effects (positive or negative) have resulted from making these dietary changes.

Authors' Contributions

KDKA conceived the study, MLB conducted the internet search, KDKA and JKP extracted the data, KDKA and JMB analyzed the data, and JMB wrote the first draft of the paper. All authors reviewed and critically edited the final manuscript and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. KDKA acts as guarantor of the study.

Conflicts of Interest

None declared.

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Abbreviations

MS: multiple sclerosis

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Original Paper

Evaluating Information Quality of Revised Patient Education Information on Colonoscopy: It Is New But Is It Improved?

Matthew Tyler Bernstein[1,2], BA (Hons), MA; James Kong[2], BSc; Vaelan Sriranjan[2]; Sofia Reisdorf[2]; Gayle Restall[3], BOccThy, MSc, PhD; John Roger Walker[1,2], BA (Hons), MA, PhD; Harminder Singh[2,4], MBBS, MD, MPH

[1]Department of Clinical Health Psychology, University of Manitoba, Winnipeg, MB, Canada
[2]Inflammatory Bowel Disease Clinical and Research Centre, University of Manitoba, Winnipeg, MB, Canada
[3]Department of Occupational Therapy, University of Manitoba, Winnipeg, MB, Canada
[4]Section of Gastroenterology, Department of Internal Medicine, University of Manitoba, Winnipeg, MB, Canada

Corresponding Author:
Matthew Tyler Bernstein, BA (Hons), MA
Department of Clinical Health Psychology
University of Manitoba
M4-Street Boniface Hospital
409 Tache Ave
Winnipeg, MB, R2H2A6
Canada
Phone: 1 2042936286
Email: umbernsm@myumanitoba.ca

Abstract

Background: Previous research indicates that patients and their families have many questions about colonoscopy that are not fully answered by existing resources. We developed revised forms on colonoscopy bowel preparation and on the procedure itself.

Objective: As the goal of the revised materials is to have improved information relative to currently available information, we were interested in how revised information compared with what is currently available in terms of information quality and patient preference.

Methods: Participants were asked to review one at a time the Revised and Current versions of *Colonoscopy bowel preparation instructions* (study 1) and *About Colonoscopy* (study 2). The order of administration of the Revised and Current versions was randomly counterbalanced to assess order effects. Respondents rated each form along the following dimensions: amount, clarity, trustworthiness, readability and understandability, how new or familiar the information was, and reassurance. Participants were asked which form they preferred and 4 questions about why they preferred it. Open-ended questions asked participants to describe likes and dislikes of the forms and suggestions for improvement.

Results: The study 1 and study 2 samples were similar. Overall, in study 1, 62.4% preferred the Revised form, 28.1% preferred the Current form, and 6.7% were not sure. Overall, in study 2, 50.5% preferred the Revised form, 31.1% preferred the Current form, and 18.4% were not sure. Almost 75% of those in study 1 who received the Revised form first, preferred it, compared with less than half of those who received it first in study 2. In study 1, 75% of those without previous colonoscopy experience preferred the Revised form, compared with more than half of those who had previously undergone a colonoscopy. The study 1 logistic regression analysis demonstrated that participants were more likely to prefer the Revised form if they had viewed it first and had no previous experience with colonoscopy. In study 2, none of the variables assessed were associated with a preference for the Revised form. In comparing the 2 forms head-to-head, participants who preferred the Revised form in study 1 rated it as clearer compared with those who preferred the Current form. Finally, many participants who preferred the Revised form indicated in the open-ended questions that they liked it because it had more information than the Current form and that it had good visual information.

Conclusions: This study is one of the first to evaluate 2 different patient education resources in a head-to-head comparison using the same participants in a within-subjects design. This approach was useful in comparing revised educational information with current resources. Moving forward, this knowledge translation approach of a head-to-head comparison of 2 different information sources could be taken to develop and refine information sources on other health issues.

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KEYWORDS

colonoscopy; evaluation methodology; information science; information dissemination; information literacy

Introduction

Background

Colorectal cancer is the second most common cancer diagnosis and cause of cancer-related deaths among men and the third most common cancer diagnosis and cause of cancer-related deaths among women [1]. Many of these deaths can be prevented by screening for colorectal cancer and colorectal polyps. Colonoscopy is an essential initial test or follow-up for other positive tests for colorectal cancer screening. Colonoscopy is widely used for assessing and removing the polyps that can lead to colorectal cancer and early detection of colorectal cancers as well for evaluating a range of different gastrointestinal symptoms. To ensure that the colonoscopy procedure is successful (ie, accurate viewing of the colon), an individual must undergo a demanding preparation, which involves cleansing of the colon of residual materials. Inadequate cleansing of the colon can lead to missed detection and diagnosis of colorectal pathologies such as colorectal cancer and polyps. However, 10% to 20% of colonoscopies fail because of poor preparation [2]. Poor preparation can also lead to increased duration and repetition of the colonoscopy [3], which, in addition to recipient inconvenience and worse health care outcomes, leads to increased costs [4]. One way to safeguard against poor preparation is by educating patients about best preparation practices with information that is clear and engaging [5-7]. Recent systematic reviews found that patient education interventions improve the quality of bowel preparation [7] and reduce anxiety about the procedure [8]. Clinical practices use a range of different materials to inform patients about colonoscopy preparation [9], but there has been limited evaluation of the quality of the materials used and limited efforts to improve the quality of these materials.

A recent study by our group [10] explored the information needs and preferences of patients undergoing colonoscopy. The results of this study indicated that some patients feel inadequately informed about the colonoscopy procedure, and those receiving their first colonoscopy felt less informed than those who had received one in the past. Most participants (90%) also indicated that speaking with a family doctor about a colonoscopy would have been helpful or very helpful; however, only 20% to 26% reported having received the right amount of colonoscopy information from their family doctor.

Recent studies have compared different approaches of providing information to patients about colonoscopy. A randomized controlled trial (RCT) compared standard written instructions with written instructions plus a video that provided visual instructions about the preparation process as well as figures depicting optimal and poor bowel preparation [11]. Patients in the video condition had better ratings of bowel preparation than those in the standard instructions condition, but there was no difference in satisfaction with the procedure. Another RCT compared patients who were having a first-time screening colonoscopy after reviewing the American Gastroenterological Association colonoscopy educational pamphlet in addition to the standard pamphlet, compared with those who had standard written instructions only [12]. Those in the augmented education group reported lower levels of anxiety, had reduced sedative use during the procedure, and better preparation as rated by the endoscopist [12]. These studies suggest the importance of providing patients with high-quality information before the colonoscopy procedure. Kurlander et al [7] conducted a systematic review of patient education interventions to improve colonoscopy preparation. A total of 7 full-text studies were included in the final analysis. These studies took place in the United States, China, Korea, and Taiwan. In each study, participants were randomized to receive an augmented educational intervention, compared with the educational materials used in usual care. The augmented interventions involved including additional written material (3 studies), videos (2 studies), telephone calls the day before the colonoscopy (1 study), and in-person education by physicians (1 study). In 6 of the 7 studies, there was a significant improvement in bowel preparation scores, compared with usual care [7]. These findings are also supported in a recent meta-analysis that included 8 RCTs [13]. People who received enhanced instructions (ie, regular written and/or verbal instruction plus improved written materials, visual aids, smartphone apps, or additional instruction over the telephone) showed significantly better bowel preparation quality than those receiving standard instructions. Furthermore, individuals who received enhanced instructions were more willing to repeat the procedure than those who did not receive enhanced instructions [13].

Prior studies have often not asked participants about their information needs and/or their assessment of the quality of the provided information and have rather focused on measures such as bowel cleansing on colonoscopy. More importantly, no studies have compared the quality of different augmented interventions or enhanced instructions and hence, it is impossible for guidelines to recommend a standardized or preferred approach [7].

Information Quality

A considerable amount of research in the social psychology area has used the same participants to evaluate characteristics of two or more different targets (eg, photos or information about persons who may be seen during social contacts). On the other hand, few studies have used this comparison methodology in evaluating the information quality of two (or more) patient information resources. Arazy et al [14] have developed an approach to information quality focused on heuristic principles as a multidimensional construct including dimensions such as accuracy, completeness, objectivity, and representation. Recently, Fidler and Lavbic [15] enrolled university students in an online survey in which they were asked to evaluate 3 selected and rewritten papers from Wikipedia, presented in a random order, on the following dimensions: accuracy, completeness, objectivity, and representation. They found that Wikipedia papers can be enhanced for students by using more socially relevant wording [15]. Yaari et al [16] used a similar design. With a sample of university students, they compared the responses of 1 group of participants to 2 different information sources (using a within-subjects design). The advantage of this methodology is that using the same participants allows for clearer judgments as to whether the characteristics of 1 resource were evaluated more positively than the other.

Order Effects

In a seminal paper by Murdock [17] on serial order effects in short-term memory, he found there to be a U-shaped (ie, nonlinear) serial position curve regarding recall. This U-shaped curve represents better memory for stimuli presented first (primacy effects) and stimuli presented last (recency effects) and worse memory for stimuli presented in between. Furthermore, there has been a lot of research suggesting that individuals prefer to recall information from memory in forward serial order even when it is not required by the task at hand [18-20]. Although these models have mostly focused on numbers, letters, and words, very little research has been conducted on the order effects of larger quantities of information. Due to this limitation in previous research, we decided to evaluate order effects by using random assignment to counterbalance the order of presentation of the materials being evaluated.

This research builds on the existing research in the evaluation of patient-oriented educational information by having the same individuals compare 2 sources of information. This project involved 2 studies with the purpose of determining individuals' opinions of the characteristics of information about 2 aspects of colonoscopy: Study 1 evaluated *Colonoscopy bowel preparation instructions* that included time of day to take the bowel preparation, food and drink restrictions, and type of bowel movements to expect. Study 2 evaluated educational material called *About Colonoscopy* that included reasons and risks for having a colonoscopy as well as what happens on the day of the procedure. As the goal of the revised materials is to have improved information relative to currently available information, we were interested in how the revised information can be compared with the currently available information in terms of information quality and patient preference. The currently available material was developed locally, 1 year before our group developed revised materials; revised materials were developed based on feedback from patients and health care providers. Feedback was gathered after using the current materials and then used to improve the revised materials. Patient and provider advisory groups allowed for feedback in developing the revised materials.

Methods

Revised Form Development

In 2017, our research team focused on a project titled *Optimizing colonoscopy procedures and reducing unnecessary and over use* and developed revised educational resources for patients referred for colonoscopy. The materials went beyond simply explaining the preparation instructions, and instead, used visual aids and information using clear language with less medical jargon, short sentences, and brief paragraphs with the goal of making the information clearer to the average reader [21,22]. The reader may access these and other educational materials developed by our research team (including videos) at mycolonoscopy website [23]. The written materials have Creative Commons licenses, so they may be used in other settings.

Readability

In developing patient education materials, developers strive to have content that can be understood by patients who are comfortable reviewing materials at lower reading levels. Studies of material available on the Web [24] indicate a wide range of reading levels in educational materials on the Web—with many materials being so high in reading level that they are difficult for patients to understand. Keeping the reading level of materials at a comfortable level can be challenging in the health area because of the medical terminology used to describe health concerns. Accurate readability calculators are now easily available on the Web. They consider factors such as the length of the words in a passage and length of sentences and paragraphs. We used the version available at [25] to calculate the readability score of the Revised and Current versions of the materials evaluated in Study 1 and Study 2 (ie, the Simple Measure of Gobbledygook [SMOG] Index) [25].

Participants

Patients were recruited from the waiting room of gastroenterology and urology clinics at the largest hospital in the province of Manitoba, located in Winnipeg's inner city. The patients were seen in this setting for consultation around a wide variety of gastrointestinal and urological problems. A research assistant approached patients and those accompanying them in the waiting area and invited them (patients and accompanying adults) to complete a survey evaluating 2 sets of information materials. The information materials reviewed by participants in this study were in paper format. The mycolonoscopy.ca website that contains the Revised information allows for downloading and printing of the information materials in addition to viewing them on a Web browser.

Measurement

Respondents in study 1 were asked to review one at a time the Revised and Current versions of the *Colonoscopy bowel preparation instructions* (order of administration was randomly counterbalanced) and to rate each along the following dimensions: amount of information, clarity, trustworthiness, readability and understandability, how new or familiar the information was (very familiar to very new), and reassurance (very worried to very reassured). These dimensions were rated using 5-point Likert-type scales. Open-ended questions included likes and dislikes about the information form and suggestions for improvement. After participants viewed both forms and responded to these questions, they were asked "Which form do you think would be most helpful for people who are considering having a colonoscopy?" Afterwards, they were asked 4 comparison questions along similar dimensions to those described above (ie, clarity, trustworthiness, readability and understandability, and reassurance). Finally, they were asked an open-ended question about why their preferred form is better than the other form. Participants were also asked some background questions including age, sex, primary language spoken, education, history of gastroenterology visits, and history of a colonoscopy. Participants in study 2 took a similar approach for evaluating the revised and current resources titled *About Colonoscopy*. Survey questions used in this study are shown in Multimedia Appendix 1. Multimedia Appendices 2-5 contain the educational material (Current and Revised forms) on the 2 topics. This study was approved by the University of Manitoba Health Research Ethics Board.

Statistical Methods

The Web-based calculator available was used to calculate the SMOG readability score for the different forms [25]. Briefly, the SMOG formula counts the number of words with 3 or more syllables from a sample of at least 30 sentences and then takes the square root and adds 3 to obtain the readability score.

IBM SPSS statistics version 24.0 was used to conduct the data analysis. Descriptive statistics (including means and proportions) were used to summarize sociodemographic information and the responses to questions about information form ratings and preferences. CIs were reported, as they are typically used in survey research, and they allow for convenient comparisons within and across different survey questions and groups of respondents. CIs have been recommended rather than pairwise significance tests for this type of comparison because they help the reader to understand the magnitude of differences rather than simply concluding whether or not a difference is statistically significant [26,27].

Logistic regression was used to examine the predictors of preference for the Revised form. The following predictors were used: order, previous colonoscopy, gender, age, education, and language most often spoken at home. A median-split approach was used to transform age and education into dichotomous variables.

Pearson correlations of the variables used to evaluate the 2 forms were calculated to assess whether they assessed different concepts or if some variables were redundant and could be deleted in future surveys. The open-ended questions were analyzed using a descriptive content analysis approach [28]. Authors MTB and GR coded these responses and organized codes into categories.

Results

As can be seen in Table 1, overall, the samples in study 1 and study 2 were similar. More than half of each sample was female, and they had about 2 years of education after high school. Most of each sample had previously seen a gastroenterologist and previously had a colonoscopy. One noteworthy difference was that the mean age was about 10 years lower in study 1 than in study 2. The study 1 response rate was 78.8% (178/226), compared with a study 2 response rate of 78.5% (219/279). Nearly all the participants in both studies completed the survey if they had started it (96% completion rate in study 1 and 94% in study 2). The Revised forms in both studies yielded SMOG indexes equal to a Grade 8 reading level. The Current form yielded a SMOG index=Grade 7 reading level in Study 1 and a SMOG index=Grade 10 in Study 2.

Overall, in study 1, 62.4% preferred the Revised form, 28.1% preferred the Current form, and 6.7% were not sure. Overall, in study 2, 50.5% preferred the Revised form, 31.1% preferred the Current form, and 18.4% were not sure. Table 2 displays the results for participants' preferred form based on the order of presentation. Interestingly, almost three-quarters of participants in study 1 who received the Revised form first, preferred it, compared with less than half of those who received it first in study 2. Furthermore, in Study 1, three-quarters of those without previous colonoscopy experience preferred the Revised form, compared with more than half of those who had previously undergone a colonoscopy, whereas in study 2, close to 50% preferred the Revised form irrespective of whether they had a previous colonoscopy or not (Table 3).

Table 1. Sociodemographic characteristics of respondents with each order of presentation.

Characteristics	Study 1		Study 2	
	Revised form first (N=86)	Current form first (N=92)	Revised form first (N=103)	Current form first (N=103)
Age (years), mean (95% CI)	42.0 (38.7-45.3)	46.6 (43.4-49.8)	55.2 (52.3-58.1)	55.0 (52.0-8.0)
Female proportion, n (%); 95% CI for %	54 (63); 52-73	61 (66); 56-76	53 (51.4); 41-61	63 (61.2); 51-71
English main language proportion, n (%); 95% CI for %	75 (87); 78-93	87 (94); 88-98	95 (92.2); 85-97	97 (94.2); 88-98
Mean years of education, mean (95% CI)	14.9 (14.2-15.6)	15.2 (14.4-16.0)	14.6 (14.1-15.2)	15.0 (14.3-15.7)
Seen gastroenterologist before? (% yes), n (%); 95% CI for %	61 (71); 60-80	61 (66); 56-76	66 (64.1); 54-73	69 (66.9); 57-76
Colonoscopy before? (% yes), n (%); 95% CI for %	62 (72); 61-81	59 (64); 54-74	67 (65.0); 55-74	66 (64.1); 54-73
Reason for visit, n (%); 95% CI for %				
Seeing a gastroenterologist	—[a]	—	51 (49.5); 39-59	31 (30.1); 21-40
Seeing a urologist	—	—	9 (8.7); 4-16	13 (12.6); 7-21
Accompanying a patient	—	—	43 (41.7); 32-52	59 (57.2); 47-67

[a] A question about the reason for the visit was not asked in study 1.

Table 2. Preferred form related to the order of presentation.

Preference	Study 1, n (%); 95% CI for %		Study 2, n (%); 95% CI for %	
	Revised form first (N=86)	Current form first (N=92)	Revised form first (N=103)	Current form first (N=103)
Prefer revised	61 (71); 60-80	50 (54); 44-65	48 (46.6); 37-57	56 (54.4); 44-64
Prefer current	17 (20); 12-30	33 (36); 26-47	35 (34.0); 25-44	29 (28.2); 20-38
Not sure	7 (9); 4-18	8 (9); 4-16	20 (19.4); 12-28	19 (18.5); 12-27

Table 3. Preferred form related to having previously undergone a colonoscopy.

Preference	Study 1, n (%); 95% CI for %		Study 2, n (%); 95% CI for %	
	Previous colonoscopy (N=116)	No previous colonoscopy (N=56)	Previous colonoscopy (N=133)	No previous colonoscopy (N=73)
Prefer revised	68 (58.6); 49-68	42 (75); 62-86	69 (51.9); 43-61	34 (46); 35-59
Prefer current	38 (32.8); 24-42	10 (18); 9-30	39 (29.3); 22-38	26 (36); 25-48
Not sure	9 (7.8); 4-14	4 (7); 2-17	25 (18.8); 13-27	14 (19); 11-30

Table 4. Predictors of preference for the Revised form.

Predictor	Study 1 (N=154), odds ratio (95% CI)	Study 2 (N=206), odds ratio (95% CI)
Order (0=Current form first, 1=Revised form first)	*3.49 (1.61-7.78)*[a]	0.707 (0.37-1.36)
Previous colonoscopy (0=yes, 1=no)	*2.69 (1.16-6.42)*[a]	1.42 (0.72-2.81)
Gender (0=male, 1=female)	1.76 (0.81-3.74)	1.63 (0.84-3.14)
Age[b] (0=44 years old or younger, 1=older than 44 years)	1.79 (0.85-3.93)	0.706 (0.36-1.39)
Education sum (0=older than 14 years, 1=14 years old or younger)	1.09 (0.50-2.26)	1.90 (0.99-3.64)
Language spoken at home (0=not English, 1=English)	1.67 (0.39-7.05)	1.82 (0.49-6.79)

[a] Italicized values indicate that the CIs between groups do not overlap.

[b] In study 2, the median split for age used in regression was 0=58 years old or younger, 1=older than 58 years.

Table 4 examines the predictors of preference for the Revised form. In considering the 6 predictors, 2 were significant in study 1. Participants in study 1 were almost 3.5 times as likely to prefer the Revised form if they viewed the Revised form first, a clear order effect. No previous experience with colonoscopy was also associated with a higher preference for the Revised form. In Study 2, none of the 6 variables assessed were associated with preference for the Revised form.

In considering the evaluation of the 2 information forms by colonoscopy experience (Figure 1), the overall pattern of responses in each study was similar. The Revised form in study 1 was given significantly higher ratings of clarity, readability and understandability, and reassurance by participants than the Current form. Not surprisingly, individuals who had previously undergone a colonoscopy indicated that information in both forms was more familiar than those who had not previously undergone a colonoscopy (see Multimedia Appendix 6 for means with 95% CI). In study 2, ratings were more similar between forms, regardless of the colonoscopy experience.

In considering the evaluation of the 2 information forms by the order of presentation (Figure 2), the Revised form was rated as significantly clearer, easier to read or understand, and more reassuring than the Current form, regardless of the order it was viewed in study 1. Furthermore, those who viewed the Revised form second in study 1 rated it as significantly more trustworthy than the group that viewed the Current form second (see Multimedia Appendix 7 for means with 95% CI). In Study 2, ratings were more similar between forms, regardless of the order.

In comparing the 2 forms on amount of information (Table 5), most respondents (more than 80%) in Study 1 and Study 2 indicated that the Revised form had just the right amount of information, which was higher than the ratings of just the right amount of information for the Current form. The layout of the educational material using short paragraphs and subheadings allow the reader who is not interested in a topic to skip that topic. They also allow readers to find topics that are important to them. Respondents to the survey, on the other hand, were asked to read all topics of both sets of educational materials—creating a situation where information could have seemed like too much. The proportion of respondents finding information either too little or too much was modest in most cases.

Figure 1. Evaluation of characteristics of the Current and Revised form depending on colonoscopy experience. Yes=previous colonoscopy; No=no previous colonoscopy. Clarity, Trust (=trustworthiness), and readability (=readability/understandability) variables were rated on scales from 1 (strongly disagree) to 5 (strongly agree). Familiarity (=familiarity) variable was rated on a scale from 1 (very familiar) to 5 (very new). Reassurance (=Reassurance) was rated on a scale from 1 (very worried) to 5 (very reassured).

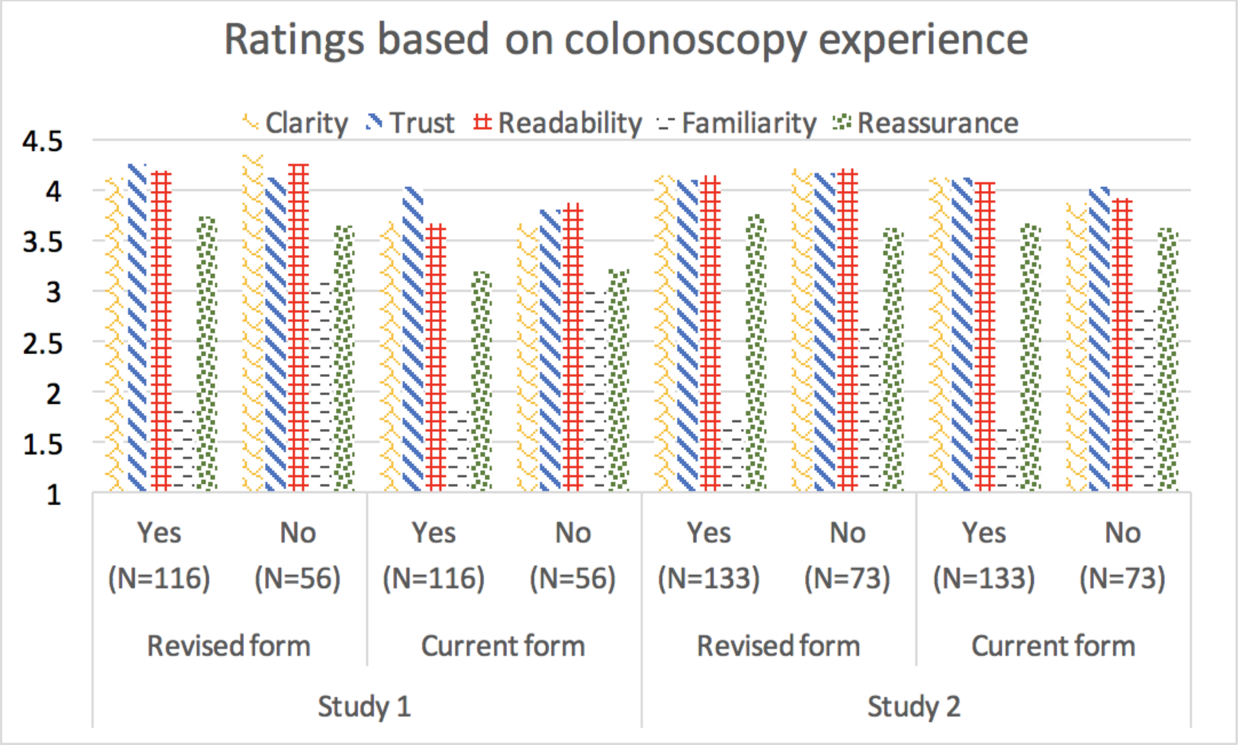


Figure 2. Evaluation of characteristics of the Current and Revised form depending on the order of presentation. Clarity, trust (=trustworthiness), and readability (=readability/understandability) variables were rated on scales from 1 (strongly disagree) to 5 (strongly agree). Familiarity (=familiarity) variable was rated on a scale from 1 (very familiar) to 5 (very new). Reassurance (=Reassurance) was rated on a scale from 1 (very worried) to 5 (very reassured).

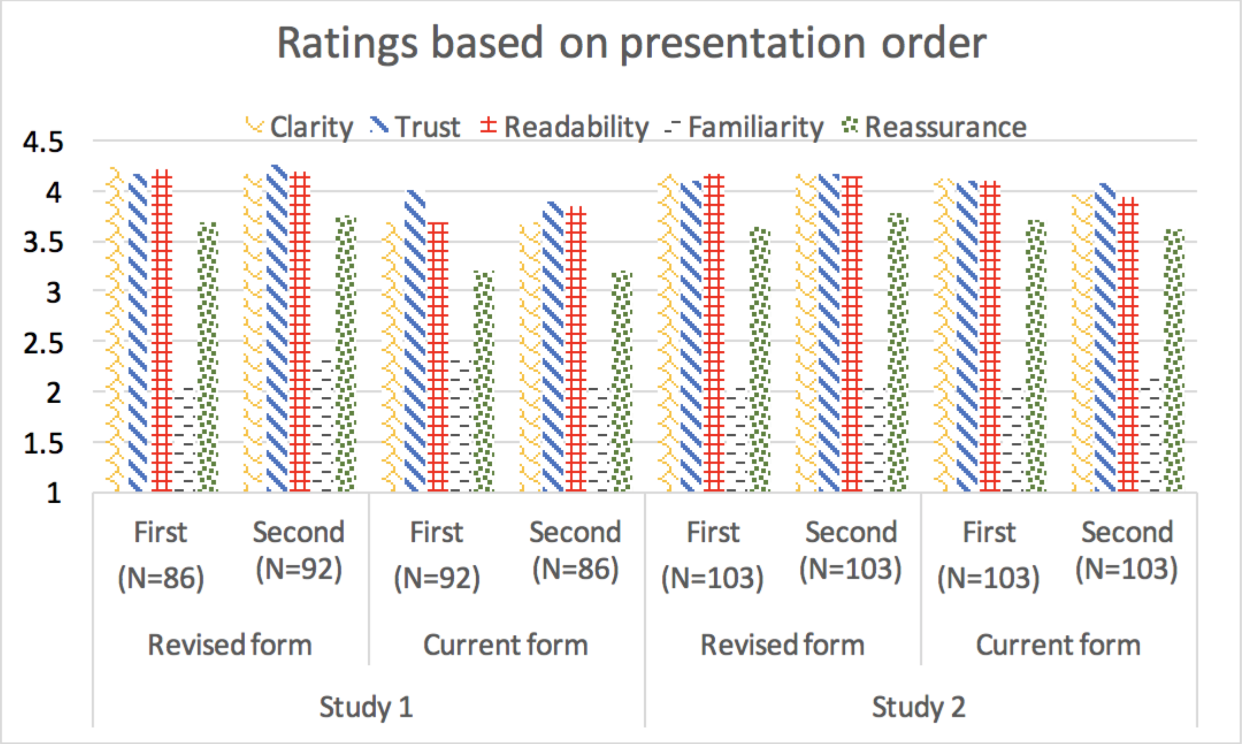


Table 5. Proportion of ratings of the amount of information in the educational resource in Study 1 and Study 2. Amount variable was rated on a scale from 1 (*much too little*), 2 (too little), 3 (*just right*) 4 (*too much*), to 5 (*way too much*).

Amount	Study 1 (N=178), n (%); 95% CI for %		Study 2 (N=206), n (%); 95% CI for %	
	Revised form	Current form	Revised form	Current form
Much too little	0	0	1 (0.5); 0-3	1 (0.5); 0-3
Too little	2 (1.1); 0.01-4	55 (30.9); 24-38	6 (3.4); 1-6	17 (8.3); 5-13
Just right	142 (79.8); 73-85	110 (61.8); 54-69	179 (86.9); 82-91	181 (87.9); 83-92
Too much	25 (14.0); 9-20	9 (5.1); 2-9	19 (9.2); 5-14	4 (1.9); 0.5-5
Way too much	7 (3.9); 2-8	0	1 (0.5); 0-3	2 (1.0); 0.1-4

In comparing the 2 forms head-to-head (Figure 3), participants who preferred the Revised form in study 1 rated it as significantly clearer compared with those who preferred the Current form (see Multimedia Appendix 8 for means with 95% CI).

Multimedia Appendix 9 examines the Pearson correlations of the variables used to evaluate the 2 forms. Cohen [29] discusses suggested cut-off scores for small (r=.1), medium (r=.3), and large (r=.5) Pearson correlations. For the Revised form, there were moderate and significant correlations for clarity and trustworthiness, readability and understandability, and reassurance. In addition, moderate and significant correlations for trustworthiness and readability and understandability and trustworthiness and reassurance were found. Finally, there was a moderate and significant correlation between readability and understandability and reassurance. A very similar pattern was observed for ratings of the Current form. The size of the correlations suggests that the concepts are related but not completely overlapping.

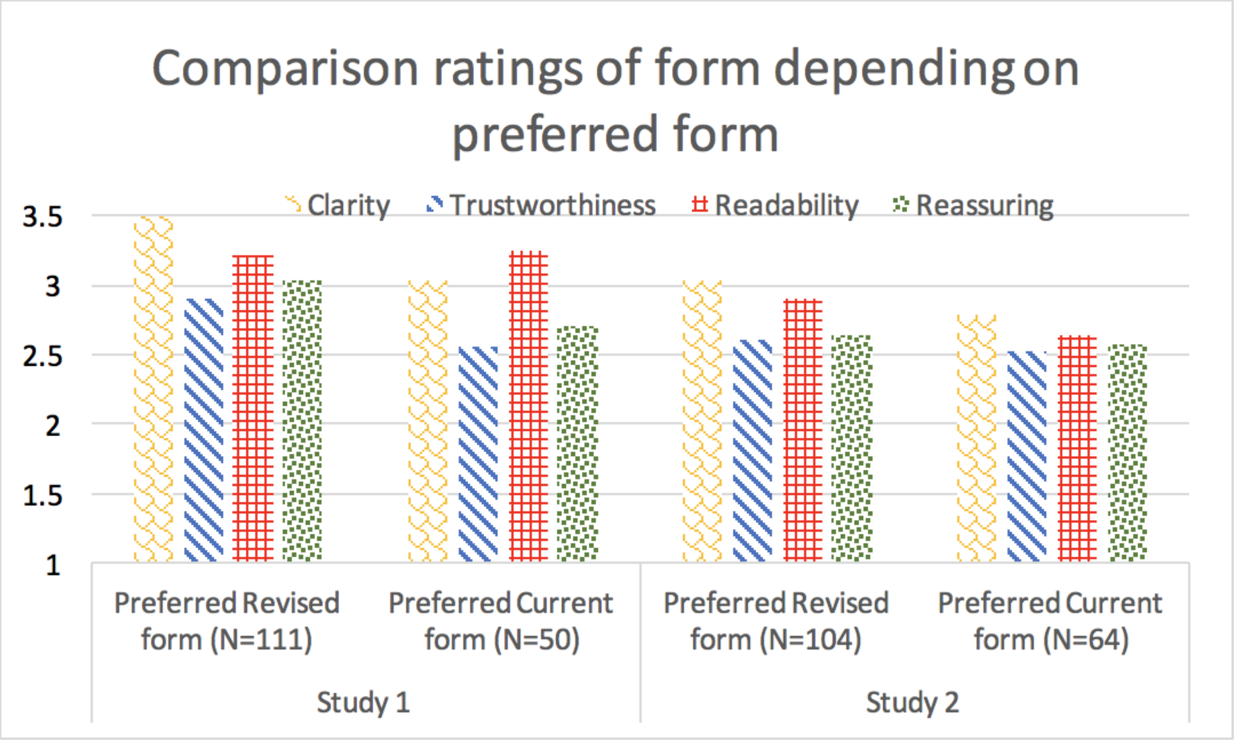
In the content analysis of open-ended questions, we found the following in study 1:

- 41 participants liked the length of the Current form because it was shorter than the Revised form.
- An area of confusion was having instructions for more than 1 type of bowel preparation on the information sheets.
- Terminology was problematic for some participants including words such as “endoscopist” and phrases such as “if unable to tolerate the split bowel prep.”
- Many participants commented on the importance of having a section on problem solving and suggestions that includes common issues and concerns with bowel preparation; this was identified by several as a strength of the Revised form.
- Some respondents noted that referring people to a website for more information would be problematic for some people who do not use the internet.
- Others felt that connection with a person to go through the information would be helpful for some patients.
- Many of those who preferred the Revised form indicated that they liked it because of the following features:
  - More information than the Current form;
  - Good visuals;
  - Good layout was important;
  - Colors and highlighting of particular points was helpful;
  - Better spacing and lines between sections were important for a few of the respondents;
  - Slick and professional look; and
  - Clarity of instructions.

The qualitative data obtained in study 2 tell a slightly different story. The following was observed in study 2:

- There was not as strong a preference for the Revised form compared with the Current form.
- Many participants liked the clarity of the Revised form and found it easy to read and understand.
- Many participants liked the shorter length of the Current form and also found it clear and easy to read or understand.
- Some participants indicated that the more information contained in the Revised form was the reason they preferred it.
- Some participants wanted more information about risks and complications, whereas others found the discussion of risks to be “scary.”
- Some participants also found the visuals in the Current form to be a strength, particularly for those who preferred the Current form.
- Format and language of both forms were also found to be important to participants in study 2.

Figure 3. Evaluation comparison ratings of form depending on participants' preferred form. Rating scale for clarity: 1 (less clear than the form I did not prefer), 2 (about as clear as the form I did not prefer), 3 (somewhat clearer than the form I did not prefer), and 4 (much more clear than the form I did not prefer). Rating scale for trustworthiness: 1 (less trustworthy than the form I did not prefer) to 4 (much more trustworthy than the form I did not prefer). Rating scale for readability: 1 (less easy to read and understand than the form I did not prefer) to 4 (much easier to read and understand than the form I did not prefer). Rating scale for reassuring: 1 (more worrying than the form I did not prefer) to 4 (much more reassuring than the form I did not prefer).



Discussion

Principal Findings

This study is one of the first studies to evaluate revised educational materials in a head-to-head comparison with existing materials using the same participants (a within-subjects design). This is significant, as it involves developing a novel approach to comparing consumers' judgments concerning information quality of different sources of information. This study will contribute to the methodology for evaluating the quality of newly developed information in comparison with existing sources of information.

A recent study by our research group found that patients do not feel adequately informed about the colonoscopy procedure [10]. One way to address this is to provide high-quality educational material to patients before colonoscopy. The 2 main advantages of written educational materials are that they have a low cost (particularly when available on the Web), compared with a telephone or in-person consultation, and patients can review the specific sections of information that are of interest to them. In regular use of health information, consumers may only read the information that is of interest to them (eg, on a specific treatment). The responses from participants in this research will assist in developing improved educational material focused on the information needs of patients.

Another important contribution of this study was the evaluation of order effects. We examined how strongly people are influenced by order effects (ie, primacy or recency effects) when evaluating information. There has been little previous research done in this area, particularly around health information. In study 1, the order of the 2 forms influenced ratings; viewing the Revised form first predicted preference for the Revised form. However, the order did not predict preference for the Revised form in study 2. This is in contrast to the results of a recent study that investigated the order of the presentation of psychological symptom information [30]. The authors found that the order of symptom description predicted the correctness of diagnostic decisions by clinicians; correct diagnostic decisions occurred more often when the symptom information was presented last (ie, a recency effect) [30]. In this study, memory was not an outcome of interest, as participants had access to both forms when making their ratings, and hence, recency did not have a positive effect on ratings. Our study results confirm our hypothesis that counterbalancing is essential in within-subject designs to assess possible order effects, which can vary depending on the material assessed.

Furthermore, ratings of the 2 forms were more similar in study 2 than in study 1. In considering the reason for this, we examined the responses to the open-ended questions; participants especially liked the visual aids, the step-by-step instructions, and the problem-solving section in the study 1 Revised form. Although the Revised form in study 2 was broken down into short sections, there was less use of graphics and the procedure was not considered in a step-by-step process. Moving forward, when developing high-quality information on health procedures, laying out information in a format that the general public is most receptive to is essential.

Another important issue that this study aimed to address is the issue of health literacy. Health literacy is defined as “the personal and relational factors that affect a person’s ability to acquire, understand, and use information about health and health services” [31]. Hence, information materials on a given health issue need to be clearly understandable by persons of varying backgrounds. Previous research has found that health literacy is related to comprehension of colonoscopy information and illustrates the importance of developing materials for people with various levels of health literacy [32].

Regardless of experience, colonoscopy is a procedure that can cause patients considerable anxiety. Some may feel worried about the discomfort of using the bowel preparation laxative, whereas others worry about the outcome of the procedure. Providing quality education materials to patients about colonoscopy (especially for those undergoing a colonoscopy for the first time) is an important step to assist in reducing this anxiety. This study found that the Revised form helped readers to feel more reassured compared with the Current form, which is important in alleviating some of this anxiety. Moreover, the Revised form was also more reassuring for individuals who had never previously undergone a colonoscopy. This is a crucial finding, as no previous colonoscopy experience is typically associated with the most anxiety [33].

Limitations

This study had a few limitations. The first is that participants were enrolled in this study through waiting room recruitment. Therefore, the number of participants who responded was a factor of how busy the waiting room was at the time and whether they could complete the survey before their appointment. However, the response rate was still reasonable (79%). Some participants were called in to see their physician before they had an opportunity to complete the survey. The survey also included a reasonable number of people (25% to 33%) with no previous experience with colonoscopy. The survey included mainly older adults and had a limited number of people who were younger, who did not use English at home, and who had very limited education. This may limit the generalizability of the findings to these other groups. The experiences in specific stratified sociodemographic groups such as young adults, persons with less education, differing cultural backgrounds, or those with less experience with colonoscopy need additional study. Finally, the information materials were presented in a paper format, and this information is available on our research team’s website. Whether the experience will be different when viewed only on the Web is not known. However, the focus of this study was on the content and layout of the material, as opposed to the usability or navigation ability of the website. Usability is something that should be further studied with the Web version of these information materials.

Conclusions

Our survey approach with the counterbalanced presentation of information provides a useful approach in comparing revised educational information with resources that are already used in the area and/or alternate revised educational information materials. Moving forward, this knowledge translation approach of a head-to-head comparison of 2 different information sources could be taken to develop and refine information sources on other health issues.

Acknowledgments

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Authors' Contributions

MTB participated in study design, data analysis, data interpretation, and prepared the manuscript. JK participated in study design, data collection, and manuscript preparation. JRW participated in the study and survey design, data interpretation, and manuscript preparation. VS and SR participated in data collection. GR participated in qualitative data analysis and interpretation and manuscript preparation. HS participated in study design, data interpretation, and manuscript preparation. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Survey questions.

[PDF File (Adobe PDF File), 43KB - ijmr_v8i1e11938_app1.pdf]

Multimedia Appendix 2

Colonoscopy bowel preparation instructions Revised form.

[PDF File (Adobe PDF File), 715KB - ijmr_v8i1e11938_app2.pdf]

Multimedia Appendix 3

Colonoscopy bowel preparation instructions Current form.

[PDF File (Adobe PDF File), 314KB - ijmr_v8i1e11938_app3.pdf]

Multimedia Appendix 4

About colonoscopy Revised form.

[PDF File (Adobe PDF File), 638KB - ijmr_v8i1e11938_app4.pdf]

Multimedia Appendix 5

About colonoscopy Current form.

[PDF File (Adobe PDF File), 318KB - ijmr_v8i1e11938_app5.pdf]

Multimedia Appendix 6

Evaluation of the characteristics of Current and Revised form depending on colonoscopy experience.

[PDF File (Adobe PDF File), 28KB - ijmr_v8i1e11938_app6.pdf]

Multimedia Appendix 7

Evaluation of the characteristics of Current and Revised form depending on the order of presentation.

[PDF File (Adobe PDF File), 28KB - ijmr_v8i1e11938_app7.pdf]

Multimedia Appendix 8

Comparison ratings of the forms depending on the preferred form.

[PDF File (Adobe PDF File), 22KB - ijmr_v8i1e11938_app8.pdf]

Multimedia Appendix 9

Correlations among evaluation variables.

[DOCX File, 72KB - ijmr_v8i1e11938_app9.docx]

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Abbreviations

RCT: randomized controlled trial
SMOG: Simple Measure of Gobbledygook

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Original Paper

Impact of Emotional Support, Informational Support, and Norms of Reciprocity on Trust Toward the Medical Aesthetic Community: The Moderating Effect of Core Self-Evaluations

Jyh-Jeng Wu[1], PhD; Haider A Khan[2], PhD; Shu-Hua Chien[3], PhD; Yu-Peng Lee[1], MBA

[1]Department of Business Management, National United University, Miaoli, Taiwan

[2]Josef Korbel School of International Studies, University of Denver, Denver, CO, United States

[3]Department of Insurance and Finance, National Taichung University of Science and Technology Taichung, Taichung, Taiwan

Corresponding Author:
Jyh-Jeng Wu, PhD
Department of Business Management
National United University
1, Lien-Da, Kung-Ching Li
Miaoli, 36003
Taiwan
Phone: 886 373618
Fax: 886 372229
Email: jjwu@nuu.edu.tw

Abstract

Background: The consumption of medical aesthetic services has become popular in recent years. Many people have purchased medical aesthetic services and treatments in pursuit of self-beauty. When members of online medical aesthetic communities actively participate in discussions and encourage and support one another, there is an increase in community commitment, trust toward each other, and trust toward the community, ultimately promoting social sharing in an environment of positive feedback.

Objective: This study aimed to explore via the theory of social support—grounded in a deeper social capabilities framework developed by Khan following the Nobel laureate Amartya Sen's groundbreaking work—whether emotional support, informational support, and norms of reciprocity in online communities impact group members in terms of creating trust toward other members. This enhances trust toward the community and generates a sense of community commitment, ultimately impacting social buying intention and social sharing intention.

Methods: This study used IBM SPSS and AMOS to analyze data. Data were collected through online questionnaires in online medical aesthetic community forums, thereby producing samples that were both representative and accurate. To understand whether core self-evaluation (CSE) is a moderator in the relationship between social sharing intention and social buying intention, this study averaged the point of CSEs in the sample after statistical analysis, dividing the sample into 2 groups.

Results: The results showed that emotional support and norms of reciprocity positively impact trust toward members, and trust toward members positively impact trust toward the community. This generates trust transfer, which positively impacts social buying intention and social sharing intention. At the same time, CSE is a moderator variable between trust toward the community and social buying intention, but CSE is not a moderator variable between trust toward the community and social sharing intention.

Conclusions: This study revealed that when members of online medical aesthetic communities actively participate in discussions and encourage and support one another, community commitment, trust toward each other, and trust toward the community increases, ultimately promoting social sharing and buying intentions.

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KEYWORDS

informational support; emotional support; norms of reciprocity; trust transfer theory; core self-evaluation

Introduction

Background

The consumption of medical aesthetic services has become popular in recent years. Many people have purchased medical aesthetic services and treatments in pursuit of self-beauty. In 2017, the market size of global medical aesthetics was nearly US $230 billion. The growth of Taiwan's medical aesthetic device market was ranked among the top 3 in Asia. Nearly 60% of Taiwan's working class spent US $2300 to US $6700 on plastic surgery and microsurgery each year. On average, hyaluronic acid injections were used 193 times daily, and 30% of visitors from Mainland China came exclusively for *beauty* purposes. As such, the medical aesthetics industry contributes around US $1.4 billion to Taiwan's gross domestic product and continues to rise.

As technology advances and online communities continue to prosper, consumers often search for answers and support from various online communities before making a decision to purchase [1]. When searching for answers and support from online communities, consumers' trust toward other members and the community is a key factor impacting the decision to purchase [2].

According to the survey results of the *Word-of-Mouth Demand of Online Communities* conducted by the Market Intelligence and Consulting Institute, in 2014, nearly 81% of consumers searched the internet for word-of-mouth information via social network sites (45.8%), discussion forums (44.7%), and blogs (33.1%). At present, the exchange of word-of-mouth information among consumers in Taiwan remains concentrated on frequently visited social network sites. On the basis of product type, consumers choose channels with different levels of trust regarding word-of-mouth information. Therefore, businesses should understand consumers' word-of-mouth demands and internet search habits and should treat such data as important reference when introducing new products or planning annual marketing strategies. Medical research institutes can effectively communicate and connect with more people via online communities [3]. The literature also indicates that consumers tend to believe in and are eager to obtain medical information from online communities [4].

On the basis of the trend described above, this study explored whether a sense of trust is generated in consumers of the medical aesthetics industry from the community support they experience before purchasing or sharing and whether this will ultimately increase their intention to share or purchase.

Theories of Social Support and Social Capabilities

Social support theory explains how resources and help are acquired through interpersonal interaction within a community unit. There are 2 types of social support, namely structural and functional. Structural social support emphasizes community size, operating systems, relationship intensity among community members, and whether a sense of belonging to the community is generated after interpersonal interaction [5]. On the basis of relationship intensity, structural social support can be further classified as formal structural social support from organizations such as hospitals and schools and informal structural social support from intimate relationships such as families, friends, and peers [6].

Functional social support refers to the subjective feeling formed by an individual after interacting with others. The acquired support intensity is evaluated using the relationship, process, and results of interaction [7]. Support can be categorized as tangible support, informational support, emotional support, esteem support, and network support [8]. Furthermore, functional social support can be delineated as esteem support, instrumental support, informational support, and emotional support [9]. As subjective feelings vary between people, the definition of social support has not yet been standardized in academic research. However, consensus has been reached on the 3 major types of social support, namely tangible support, informational support, and emotional support [10] as the bases for further extension and adjustment.

Social support can also be regarded as a reward acquired from interpersonal interaction. In other words, social support can be viewed as resources acquired by an individual who has exchanged something with others based on the purpose or needs of the individual [11]; examples are tangible support such as monetary assistance and gifts [12] and intangible support such as caring, listening, and giving advice [1]. The higher the social support intensity an individual feels after interacting with others in a group, the higher the individual's intention to establish an intimate interactive relationship in the group [13].

The theory of social support can be expressed in a more rigorous form by nesting it into a theory of social capabilities–based flexicurity in a learning economy. The basic idea has been developed by various theorists [14-24] who drew upon the insights of Adam Smith; they have proposed a theoretically rigorous and elaborate evaluation of well-being [25,26]. Sen is the originator of this *capability approach* in recent years [27]. The theoretical criticisms of the utilitarian approach by Sen et al—this approach reduces all qualities into the quanta of utilities—are serious ones. Khan et al has pursued a similar line of criticism in a number of recent papers and in his book *Technology, Development, and Democracy* [28-31]. This approach makes the capabilities explicitly social and asks what concatenation of institutions, both economic (real and financial) and other (eg, political and social), will allow social support and trust to increase steadily and at the same time equalize them among diverse individuals [32]. In effect, as the following discussion makes clear, we are asking how we can increase and equalize real positive freedom for individuals in specific social contexts—in this study, specifically for online communities and individuals. In his book, *Technology, Development and Democracy*, Khan points out that trust and freedom are interactive arrangements in a society where concrete institutions at many levels and technologies of production and exchange, all play definite roles [33]. The social support theory can be elaborated in a deeper way by building on these foundations and applying them dynamically to (post)modern networked online communities, with social capability–building through causal connections and positive feedback loop mechanisms. In this approach, methodologically, confirmatory factor analysis can support or disqualify the particular causal mechanisms that are proposed in this study and others in this area of research. We now turn to the specificities of social support in an online environment.

Social Support

As the use of the internet has grown rapidly in recent decades, more people engage in online communications every day. In particular, as social network sites proliferate, easy exchanges among users are facilitated by the online environment, in which social support has gradually transformed into social support communication [14]. Online social support refers to information and emotional exchanges in the virtual space and is provided through informational support and emotional support [15]. Social support and online communities are closely related [16]. Previous studies showed the connectedness between social support and trust [17]. In this study, we believed that informational support and emotional support benefit the relationships of all related parties and are conducive to relationship building and maintaining a good online environment.

Emotional Support

Emotional support refers to demonstrating to others empathy, care, love, understanding, or encouragement [18], making them feel they are being given attention. In contrast to informational support, emotional support emphasizes the emotional side of social support, which may indirectly help overcome problems [34]. Emotional support enables community members to obtain help from other members. Specifically, love is the foundation for developing trust [18]. Therefore, people develop community exchanges and trust through emotional exchange and contact with other members in the community. In addition, if a member obtains love and warmth from other members in the group who have similar experiences of pain and challenges, he/she will often feel more comfortable remaining in the focus group. This is because emotional responses such as love and care satisfy members' needs for respect and social attention, enabling them to identify as members of the group with a sense of belonging [35].

Informational Support

Informational support provides individuals with advice, guidance, or useful information that helps them solve problems, generate new ideas, or make good decisions [36]. If people continue receiving positive help such as valuable recommendations or instant help from network friends or online groups, they are more likely to show benevolence, integrity, and capability to the other party, further enhancing their trust toward members who provided the related information [37].

As mentioned, interest in a relationship is necessary in the development of cooperative relationships [38]. Therefore, if group members can benefit from others' opinions, they are likely to agree on the values of the focus group and maintain a long-term relationship with it.

Norms of Reciprocity

Norms of reciprocity are behavior norms in a social community that obligate people who have received help from others in the community to offer similar help in return in the future [39,40]. When community norms are gradually transformed into individual values in a community, members consider exchange behavior based on a friendly interactive relationship as natural, which impacts their sharing intention in the future [41]. Thus, the higher the intensity of norms of reciprocity, the higher will the frequency of exchange activities be [42]. Furthermore, members' knowledge collection behavior is enhanced if the knowledge provided on knowledge sharing platforms is reliable and comprehensive [2]. As such, the more the knowledge is aligned to members' needs, the more willing they will be to offer useful knowledge to other members to help them resolve their problems. Previous studies indicated that norms of reciprocity promote trust in a community [43]. Thus, we hypothesized that norms of reciprocity have a significant positive impact on trust toward members.

Trust

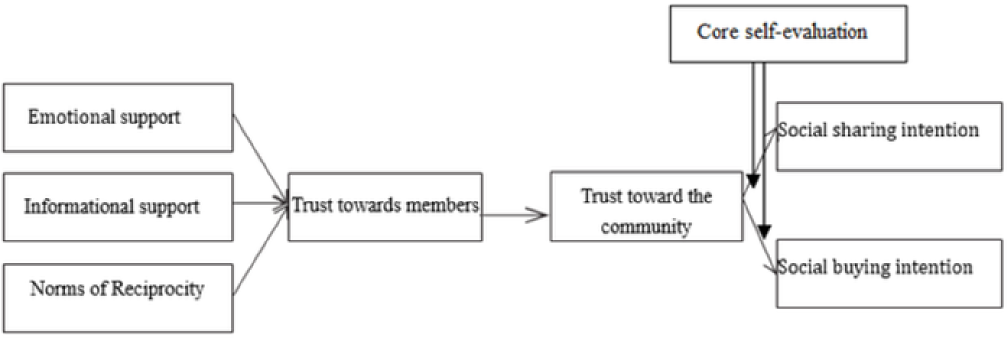
Trust is considered a basic factor in the formation of successful relationships [38]. In particular, recent studies focused on the relationship between trust toward providers of products and services and customers' online purchase intention [44]. As retrieving information from the internet becomes more popular, consumers ask for recommendations from social communities and people they trust. On the contrary, privacy issues mean that consumers are more likely to share their own information with someone they trust [45]. Past studies also confirmed the relationship between brand community and consumer participation [46]. Therefore, the impact of trust on social sharing intention and social buying intention—as well as trust toward members and the community—is discussed in this study.

Trust Toward Members

In this study, trust toward members is defined as an individual's intention to rely on and believe in other community members, such as believing the information they provide and taking action and making decisions based on other members' recommendations. Previous studies found that trust toward members impacts online participation behavior such as seeking and providing information in focus groups [47], because in an environment with mutual trust, people often help each other, which develops into common community activities. In particular, information obtained from credible sources is often considered more useful and treated as the basis for decision making [48]. In addition, people are more likely to share their consumption experience of products or services afterward.

When other members display reliable characteristics of the individuals seeking information, such as benevolence, integrity, capableness, or have had a similar experience, information-seeking members feel comfortable talking to one another as they share a common knowledge background. As such, any suspicion or doubts in each other are alleviated.

Figure 1. Research model.



Trust Toward the Community

Trust toward the community refers to the extent to which people rely on and trust a community. Generally accepted standards are enforced by online communities to instill norms of reciprocity among their members. In addition, benevolence and integrity in a community can lower doubts among members. The relationship between trust toward the community and customer loyalty has been confirmed [49]. Essentially, the stronger the trust an individual has for a community, the higher the tendency that individuals will seek advice from that community on products or services they are interested in buying and share their consumption experience within the community afterward.

Community Commitment

Relationship commitment reflects many aspects of the long-term relationship [38]. Previous studies confirm the relationship between commitment and users [36], indicating that when users are committed to an online community, they contribute and participate more in the online community [50]. Previous studies also found that online brand community commitment significantly impacts consumers' decision making [51]. In an online business community environment, the network platform provides a shared space within which users can exchange information and communicate. Users can share their consumption experiences with friends in online communities or seek product recommendations from their network of friends. If users are committed to maintaining a sustainable commitment relationship with an online community, they will strive to maintain this commitment and are more likely to participate in various group activities to help grow the community.

Trust Transfer Theory

According to the trust transfer theory, interpersonal trust develops into trust toward the community for 2 reasons. First, trust among members makes users believe that information provided in the community is more credible, which reassures members that the community will continue to improve its service quality and provide effective management in building a credible communication environment [52]. Second, previous studies pointed out that trust among members increases members' trust toward the community [53]. Previous studies reported that when people trust sellers in a Business to Consumer online community, their trust could be transferred to the related applications [54]; to give an example, Asia's famous and successful retail drugstore brand, Watsons, has its own online community and app. Other studies confirmed the relationship of trust transfer between brand community and consumer participation [46]. When members trust one another, a bigger and stronger community is created, enabling members to consider the community a suitable venue for communication.

Core Self-Evaluation

In the past, much research focused on core self-evaluation (CSE) when studying different kinds of human behavior, for example, the relationship between CSE and social support [55]. CSE is defined as the basic evaluation of one's own values, potential, capabilities, and talents [56]. This study hopes to understand the mediating role of CSE on social sharing and buying intentions. Therefore, we hypothesized that CSE is a moderator variable between trust toward the community and social sharing and buying intentions.

In sum, this study explored whether emotional support, informational support, and norms of reciprocity have an impact on social sharing and social buying intentions through trust toward members and trust toward the community using CSE as the moderator variable. The framework of the study is provided in Figure 1.

Methods

The participants in the pretest were members in online medical aesthetics communities. A total of 50 questionnaires were retrieved and after selection, a consistent scale was developed for informational support, emotional support, norms of reciprocity, trust toward members, trust toward the community, and CSE. The questionnaire was created using Google Forms. The link to the questionnaire was disseminated on Facebook and LINE, which are among the most popular forms of social media in Taiwan. The questionnaires were placed in online medical aesthetics communities with the hope of collecting data approaching that of the population and understanding the true focus and recognition of online medical aesthetics communities' users, thereby producing samples that were both representative and accurate. Using previously validated instruments, questionnaire items based on a 7-point Likert scale ranging from 1 (*Strongly Disagree*) to 7 (*Strongly Agree*) were borrowed from the literature and adapted to this study to measure the constructs. To address measurement concerns, this study referenced the research of past scholars regarding each dimension.

Results

Demographics

The questionnaires were released on January 11 to 31, 2018, and a total of 565 valid questionnaires were collected. Before we started the survey, we first contacted 800 online medical aesthetics community users and asked if they were willing to participate in the survey. A total of 780 online users indicated a willingness to take part in the survey. We then sent questionnaires to those users. The returned surveys yielded a response rate of 78.2% (610/780). After deleting 45 incomplete responses (eg, respondents answered *Strongly Disagree* or *Strongly Agree* to all questions), a total of 565 valid observations were collected (a response rate of 70.6%). Table 1 shows the demographic characteristics of the participants. Most of the samples were female, aged 18 years older, and most of them were university graduates. Most of the samples had less than 2 years of community experience, and most of them were willing to spend less than US $10,000 on medical aesthetics.

Reliability and Validity Tests

We analyzed data using SPSS 12 and AMOS 22. The measurement model fit indices (v2/*df*=2.39; root mean square error of approximation, RMSEA=0.05; confirmatory fit index, CFI=0.982; adjusted goodness of fit index, AGFI=0.906; and Bollen fit index, IFI=0.982). The most widely used incremental fit index, CFI, has a value of 0.982, which exceeds the guideline value of 0.90 for a model of this complexity and size. This model has not been compared with other models; however, the value of parsimony index AGFI (0.90) reflects a good model fit. All these absolute, incremental, and parsimony fit indices suggest an acceptable fit for the measurement model.

Table 2 shows the results of reliability and validity testing. Regarding the reliability of the question items, the factor loading of all the items ranged between 0.7 and 0.95. With their factor loading values being greater than 0.5, these items exhibited high reliability. Average variance extracted (AVE) testing was used to assess the convergent validity of the items. It demonstrated that the set of indicators had an AVE greater than the 0.5 threshold. The composite reliability (CR) of measured variables was estimated to test their internal consistency in the measurement model. CR indicates how well these variables represent latent variables; a CR value of greater than 0.7 generally shows high internal consistency. In this study, the CR values of all constructs in the corrected model ranged between 0.89 and 0.96, indicating that the question items of the constructs had sufficient reliability.

Table 1. Respondent profiles.

Measure	Frequency	Statistics, n (%)
Gender		
Male	134	23.7
Female	431	76.3
Age		
<18	5	9
19-30	308	54.5
>31	252	44.6
Education		
Junior high school	13	2.3
High school	124	21.9
College or postgraduate	428	75.8
Usage experience of online community		
<1 year	244	43.2
1-2 years	75	13.3
2-3 years	72	12.7
3-4 years	43	7.6
>5 years	131	23.2
Willingness to spend on medical aesthetics (US $)		
<10,000	353	62.5
10,000-50,000	110	19.5
50,000-100,000	66	11.7
>100,000	36	6.4

Table 2. Results of confirmatory factor analysis.

Constructs	Loadings	Square Multiple Correlation
CSEs[a] (CR=0.962; AVE=0.710; Cronbach alpha=.960; Judge et al [56])		
I am confident I get the success I deserve in life.	.772	.596
When I try, I generally succeed.	.797	.635
Usually, I feel happy.	.829	.687
When I fail, I don’t feel worthless.	.813	.661
I complete tasks successfully.	.886	.785
Usually, I feel in control of my work.	.876	.767
Overall, I am satisfied with myself.	.884	.781
I am filled with confidence about my competence.	.879	.773
I determine what will happen in my life.	.785	.616
I feel in control of my success in my career.	.864	.746
I am capable of coping with most of my problems.	.863	.745
There are times when things look pretty hope to me.	.849	.721
Emotional support (CR=0.922; AVE=0.866; Cronbach alpha=.903; Liang et al [36])		
When faced with difficulties, some people on this website are on my side with me.	.910	.828
When faced with difficulties, some people on this website comforted and encouraged me.	.944	.891
When faced with difficulties, some people on this website expressed interest and concern in my well-being.	.937	.878
Informational support (CR=0.940; AVE=0.893; Cronbach alpha=.952; Liang et al [36])		
On this website, some people would offer suggestions when I needed help.	.939	.882
When I encountered a problem, some people on this website would give me information to help me overcome the problem.	.950	.903
When faced with difficulties, some people on this website would help me discover the cause and provide me with suggestions.	.946	.895
Norms of reciprocity (CR=0.896; AVE=0.828; Cronbach alpha=.953; Chen and Hung [2])		
I believe that members of this shared platform will help each other.	.912	.832
I should maintain a good interaction with the members of this shared platform.	.914	.835
In this shared platform to trade goods or services, both parties can meet the demand.	.903	.815
Trust toward members (CR=0.934; AVE=0.884; Cronbach alpha=.961; Liang et al [36])		
Members on this website will always try and help me out if I get into difficulties.	.931	.867
Members on this website will always keep the promises they make to one another.	.951	.904
Members on this website are truthful in dealing with one another.	.939	.882
Trust toward the community (CR=0.941; AVE=0.894; Cronbach alpha =.973; Liang et al [36])		
The performance of this website always meets my expectations	.944	.891
This website can be counted on as a good social networking site.	.946	.895
This website is a reliable social networking site.	.947	.897
Social sharing intention (CR=0.935; AVE=0.886; Cronbach alpha=.966)		
I am willing to provide my experiences and suggestions when other members on this website want my advice on micro cosmetic surgery.	.941	.885
I am willing to share my own micro cosmetic surgery experience with other members on this website.	.953	.908
I am willing to recommend micro cosmetic surgery that is worth buying to other members on this website.	.929	.863
Social buying intention (CR=0.892; AVE=0.823; Cronbach alpha=.874; Liang et al [36])		

Constructs	Loadings	Square Multiple Correlation
I will consider the experiences of other members on this website when I want to have micro cosmetic surgery.	.914	.835
I will ask other members on this website to provide me with their suggestions before I have micro cosmetic surgery.	.932	.869
I am willing to have micro cosmetic surgery that recommended by other members on this website.	.875	.766

[a] CSE: core self-evaluation.

Table 3. Pearson correlation coefficients.

Pearson correlation coefficient constructs	1	2	3	4	5	6	7	8
1. Emotional support	(.930)	—[a]	—	—	—	—	—	—
2. Informational support	.791[b]	(.944)[c]	—	—	—	—	—	—
3. Norms of reciprocity	.750[b]	.782[b]	(.909)	—	—	—	—	—
4. Trust toward members	.742[b]	.673[b]	.764[b]	(.940)	—	—	—	—
5. Trust toward the community	.679[b]	.662[b]	.746[b]	.849[b]	(.945)	—	—	—
6. Social sharing intention	.615[b]	.675[b]	.644[b]	.629[b]	.645[b]	(.941)	—	—
7. Social buying intention	.605[b]	.666[b]	.675[b]	.595[b]	.666[b]	.717[b]	(.907)	—
8. Core self-evaluations	.400[b]	.417[b]	.445[b]	.391[b]	.387[b]	.471[b]	.397[b]	(.842)

[a] Not applicable.

[b] *P*<.01.

[c] Parentheses signify the square root of each construct's average variance extracted.

Table 4. Path coefficients.

Hypothesis testing	Path value	CR	*P* value	Research assessment result
Emotional support → Trust toward members[a]	0.347	6.094	—[b]	Yes
Informational support → Trust toward members	–0.151	–2.222	.026	No
Norms of reciprocity → Trust toward members[a]	0.695	10.146	—	Yes
Trust toward the community → Social sharing intention[a]	0.932	19.144	—	Yes
Trust toward the community → Social buying intention[a]	0.849	18.466	—	Yes
Trust toward members → Trust toward the community[a]	0.890	28.528	—	Yes

[a] *P*<.001.

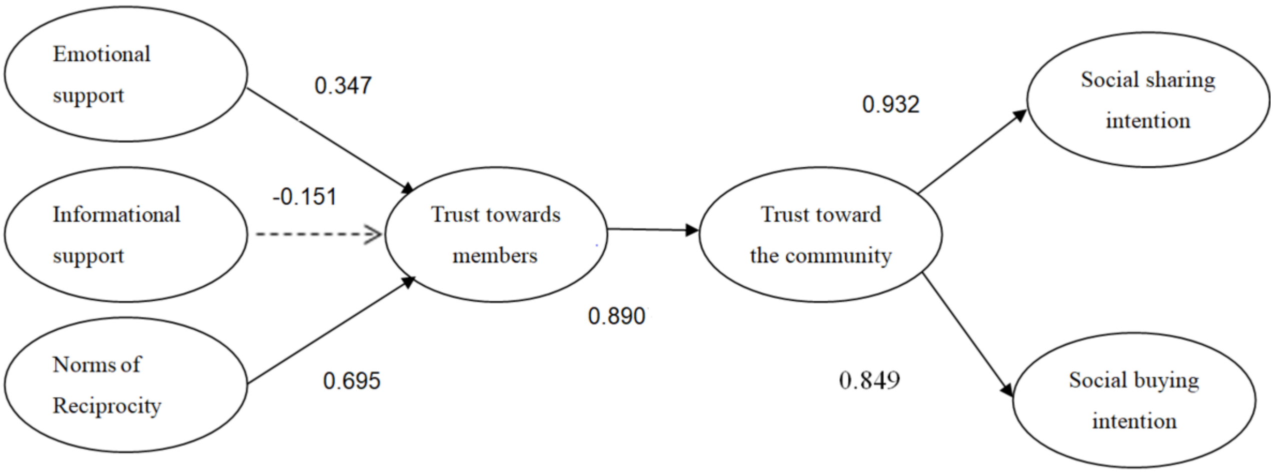
[b] Not applicable.

Table 3 tabulates the Pearson's correlation coefficients of the variables. Significant positive correlations were observed among emotional support, informational support, norms of reciprocity, trust toward members, trust toward the community, social sharing intention, social buying intention, and CSEs. In addition, all constructs achieved discriminant validity, because the square root of each construct's AVE was higher than its correlation between any of the constructs [57].

This study performed a structural equation model analysis using Amos 22. The model fit indices (v2/*df*=2.39; RMSEA = 0.05; CFI = 0.98; AGFI = 0.906; and IFI = 0.982) suggested that the model represents a satisfactory fit to the data [58]. The model fit indices supported a good model fit. Therefore, further analyses of the relationships among the modeled constructs were conducted.

The results showed that emotional support and norms of reciprocity positively impact trust toward members, and trust toward members positively impact trust toward the community. This generates trust transfer, which positively impacts social buying and sharing intentions. However, the informational support did not have a significant effect on trust toward members, possibly demonstrating consumer distrust toward medical advertising. The path coefficients of hypothesis testing are summarized in Figure 2 and Table 4.

Figure 2. Results of research model. Numbers represent path coefficients.



After all the hypotheses were validated, a Sobel test was conducted to assess mediating effects among variables. A value lower than 0.05 in AMOS and a z score of greater than 1.96 in the Sobel test results indicate significant mediating effects [59]. The Sobel test results showed that emotional support affected trust toward the community through trust toward members (Sobel z=5.99); norms of reciprocity affected trust toward the community through trust toward members (Sobel z=9.55); trust toward members affected social sharing intention through trust toward the community (Sobel z=16.03); trust toward members affected social buying intention on the basis of trust toward the community (Sobel z=15.45). In sum, trust toward members mediated the effects of emotional support and norms of reciprocity on trust toward the community, whereas trust toward the community mediated the effects of trust toward members on social sharing intention and social buying intention.

To understand whether CSE is a moderator on the impact of social sharing and buying intentions, this study averaged the point of CSEs in the sample after statistical analysis and, referring to the past research methods [60], this study divided the sample into 2 groups: high CSE (Average point of CSE>4.85) and low CSE (Average point of CSE<4.85), and compared the group differences based on the past research [61]. Table 5 shows that CSE is a moderator variable between trust toward the community and social buying intention, but CSE is not a moderator variable between trust toward the community and social sharing intention. The path coefficients of hypothesis testing are summarized in Table 6.

Table 5. Path coefficients of hypothesis testing by group differences.

Hypothesis testing by group differences	High core self-evaluation		Low core self-evaluation		Z score
	Estimate	*P* value	Estimate	*P* Value	
Emotional support → Trust toward members	0.366	.000	0.301	.000	–0.604
Informational support →Trust toward members	–0.174	.058	–0.163	.105	0.081
Norms of reciprocity → Trust toward members	0.784	.000	0.703	.000	–0.541
Trust toward members → Trust toward the community	0.948	.000	0.918	.000	–0.411
Trust toward the community → Social sharing intention	0.744	.000	0.868	.000	1.214
Trust toward the community → Social buying intention	0.682	.000	1.111	.000	3.748[a]

[a] *P* value<.01.

Table 6. Path coefficients.

Compare groups	Path Value	CR	*P* value	Research assessment result
High CSE[a]				
Trust toward the community → Social sharing intention	0.858	14.724	<.01	Y
Trust toward the community → Social buying intention	0.806	12.114	<.01	Y
Low CSE				
Trust toward the community → Social sharing intention	0.742	9.757	<.01	Y
Trust toward the community → Social buying intention	0.915	11.139	<.01	Y

[a] CSE: core self-evaluation.

Discussion

The topic of CSE is widely discussed in the field of human resources, but not many scholars have applied it to the discipline of the medical industry. This study introduces CSE into a research framework to investigate the social sharing and buying intentions of members of medical aesthetics communities. Furthermore, this study contributed to a theoretical deepening of the approach by grounding it into a causally deeper social capabilities framework developed by Sen et al.

Thus, grounded theoretically, the results of the study showed that when members of medical aesthetics communities experience emotional support, their trust toward other members strengthen and trust transfer occurs, which reinforces trust toward the community and enhances commitment. Similarly, when norms of reciprocity among community members are high, members' trust toward other members also strengthen, bringing about trust transfer, which reinforces their trust toward the community and increases commitment.

In addition, CSE is a moderator on the impact of social buying intention. The relationship between social support and trust can be explained to a large extent by considering the deeper causal relations between community norms and individual values [62]. When community norms gradually transform into individual values, community members come to consider the exchange behavior built on friendly interactive relationships as natural, which impacts future sharing intention behavior. This study also revealed empirically that when members of online medical aesthetics communities actively participate in discussions and encourage and support one another, community commitment, trust toward each other, and trust toward the community increases, ultimately promoting social sharing intentions in a positive feedback loop.

This study explores consumers' social sharing and buying intentions for medical aesthetic products or services and the relationship among variables. Therefore, the medical aesthetics industry can use this study to understand the thoughts and needs of the public to facilitate more effective marketing strategies for related online communities.

For doctors, after surgery, they can encourage patients to share what they liked about the surgery in the online community, who will in turn earn discounts for their next purchase. By doing so, the happy patients will feel confident and satisfied based on the attention of other members in the online community. For patient education, the medical aesthetics industry can increase trust from its customers through recommendations from other network friends who have had positive experiences of the surgery, which can lead to a positive feedback loop of growing trust. For population health or clinical care, the medical aesthetics industry has grown so much that competition is intensifying. Our results are consistent with the normative prescription that practitioners in the medical aesthetics industry offer discount programs as incentives for customer sharing in online communities. From our result, the medical aesthetics industry can support a public forum to provide trust, emotional support, and informational support to forum members, because trust toward the community positively affects social buying and sharing intentions.

In the end, we focused on the medical aesthetics industry, which has grown rapidly in recent years. Future studies can explore whether the same causal and empirical analysis applies to online communities in other growing industries. As the number of online community platforms has grown in recent years, future studies could explore different platforms and compare the results to provide a wider spectrum of contributions to the field of online communities.

Conflicts of Interest

None declared.

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Abbreviations

AGFI: adjusted goodness of fit index
AVE: average variance extracted
CFI: confirmatory fit index
CR: composite reliability
CSE: core self-evaluation
IFI: Bollen fit index
RMSEA: root mean square error of approximation

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Phone: (+1) 416-583-2040
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