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Viewpoint

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WhatsApp Messenger as an Adjunctive Tool for Telemedicine: An Overview

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Abstract

Background: The advent of telemedicine has allowed physicians to deliver medical treatment to patients from a distance. Mobile apps such as WhatsApp Messenger, an instant messaging service, came as a novel concept in all fields of social life, including medicine. The use of instant messaging services has been shown to improve communication within medical teams by providing means for quick teleconsultation, information sharing, and starting treatment as soon as possible.

Objective: The aim of this study was to perform a comprehensive systematic review of present literature on the use of the WhatsApp Messenger app as an adjunctive health care tool for medical doctors.

Methods: Searches were performed in PubMed, EMBASE, and the Cochrane Library using the term “whatsapp*” in articles published before January 2016. A bibliography of all relevant original articles that used the WhatsApp Messenger app was created. The level of evidence of each study was determined according to the Oxford Levels of Evidence ranking system produced by the Oxford Centre for Evidence-Based Medicine. The impact and the indications of WhatsApp Messenger are discussed in order to understand the extent to which this app currently functions as an adjunctive tool for telemedicine.

Results: The database search identified a total of 30 studies in which the term “whatsapp*” was used. Each article’s list of references was evaluated item-by-item. After literature reviews, letters to the editor, and low-quality studies were excluded, a total of 10 studies were found to be eligible for inclusion. Of these studies, 9 had been published in the English language and 1 had been published in Spanish. Five were published by medical doctors.

Conclusions: The pooled data presents compelling evidence that the WhatsApp Messenger app is a promising system, whether used as a communication tool between health care professionals, as a means of communication between health care professionals and the general public, or as a learning tool for providing health care information to professionals or to the general population. However, high-quality and properly evaluated research is needed, as are improvements in descriptions of the methodology and the study processes. These improvements will allow WhatsApp Messenger to be categorically defined as an effective telemedicine tool in many different fields of health care.

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KEYWORDS

whatsapp; telemedicine; smartphone; mobile application

Introduction

Telemedicine is defined as the use of electronic information and communication technologies to provide health care support when distance separates the client (the patient or health care worker) from the health care professional with expertise in the relevant field [1,2]. The information transmitted between the two parties can take many forms including data and text, audio, still images, and video [3].

The use of mobile technologies in general and mobile phone specifically, is a rapidly expanding field within telemedicine [4]. Audiovisual communication in health care aided by smartphone apps is a novel concept that is rapidly gaining ground in all areas of medicine [5]. A nationwide survey performed in the United States in 2011 included 3306 medical providers and found that more than half used various apps in their clinical practice, some of which had not been specifically developed for medical purposes [6].

Currently, one of the most popular nonmedical mobile apps is WhatsApp Messenger, which has been downloaded in 40 countries in Europe, Asia, the Middle East, and the Americas. After reaching 1 million users at the end of 2009, WhatsApp Messenger app downloads increased tenfold in 2010 [7]. WhatsApp Messenger is a communication tool that allows users to send instant messages, photos, video, and voice messages and to make voice calls over an Internet connection [8]. Its main feature is to help people stay connected by sending and receiving messages at no per-message cost to the user (in contrast to original texting [short message service, SMS] services on mobile phones). The requirement of only a mobile Internet connection (whether via a data plan or Wi-Fi) explains the app's widespread success [5].

Although scientific studies on the use of WhatsApp Messenger remain scarce in the medical literature, increasing numbers of health professionals have adopted it as a communication interface and for the exchange of images and videos [9,10]. Its use does not seem to reduce image quality in the conversion from analog to digital formats, thus providing the ability to identify sufficient details for an adequate diagnosis and initial treatment with better efficacy than other modalities used for the same purposes [11-13].

The aim of this study was to perform a comprehensive systematic review of current literature on the use of the WhatsApp Messenger mobile app as an adjunctive health care tool, as there is some evidence that this app can be an effective, safe, and economical telemedicine tool for professionals from all fields of health care (nurses, psychologists, dentists, physical therapists, and physical and sports educators, among others).

Methods

Search Strategy and Study Selection

A systematic electronic search of the PubMed, EMBASE, and the Cochrane Library databases was performed to find all literature using the term "WhatsApp[All fields]" and published before January 2016.

The inclusion criteria included (1) an evaluation of the impact of WhatsApp Messenger as one of the primary outcome measurements, (2) a conclusion containing clear indications for the use of the app, and (3) adult patients over the age of 18 years. The exclusion criteria included (1) case reports or case series with fewer than 5 patients, (2) other reviews of the literature, (3) meta-analyses, and (4) letters to the editor. No study was excluded due to the original language in which it was written.

Data Extraction

The main author of this study (VG) evaluated all of the articles and applied the inclusion and exclusion criteria. Each relevant study was obtained and reviewed in its entirety. The level of evidence was determined according to the Oxford Levels of Evidence ranking system produced by the Oxford Centre for Evidence-Based Medicine [14].

The basic information about the article was extracted from the eligible articles. This basic information included the original language, the country where the research was performed, the type of participants (medical professionals, other health care professionals, or the general population), the medical specialty considered, the number of participants in the study, mean participant age, the results, and any problems observed.

Sensitivity Analysis

A sensitivity analysis was performed to determine the robustness and reliability of the results of this study. Literature reviews, letters to the editor, and low-quality studies were excluded from the final analysis.

Results

Literature Search Strategy and Quality Assessment

Using the search term "WhatsApp," 30 articles were initially identified from the electronic databases consulted. After a detailed assessment of all references, followed by a screening process and a quality assessment (Figure 1), a total of 10 studies were determined to be eligible for inclusion in this systematic review.

Figure 1. Study selection flowchart.

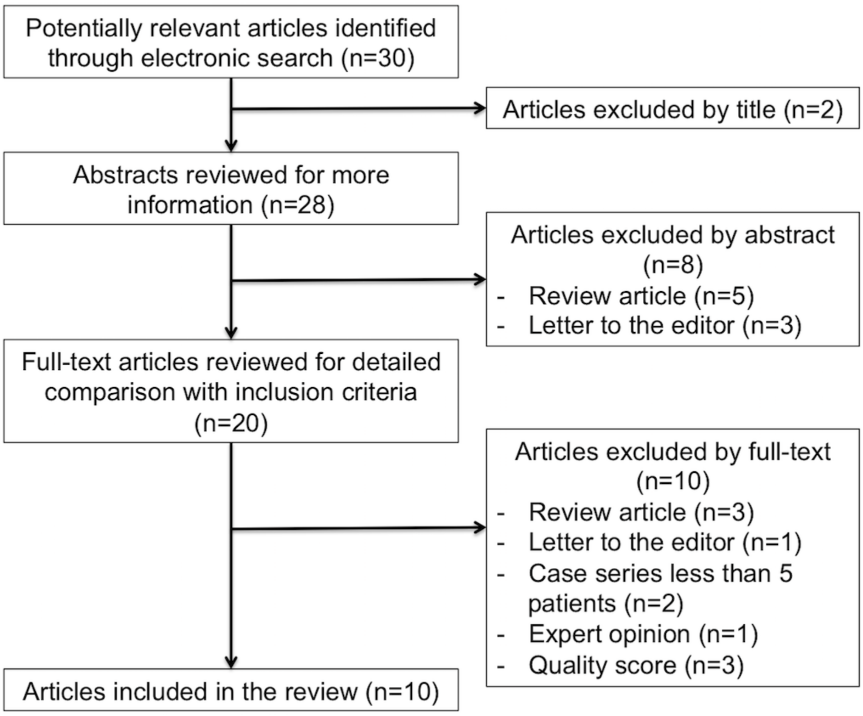

Table 1. Summary of each study's features and Oxford Levels of Evidence.

Authors	Year	Type of study	Level of evidence	Journal
Abanmy et al [15]	2012	Nonrandomized cohort study	III	Saudi Pharm J
Giordano et al [12]	2015	Individual cross-sectional study	II	Int J Med Infor
Khanna et al [16]	2015	Observational study	II	Eur J Orthop Surg Traumatol
Zotti et al [17]	2015	Randomized trial	II	Angle Orthod
Montag et al [5]	2015	Cohort study	III	BMC Res Notes
Willemse [18]	2015	Nonrandomized cohort study	III	Curationis
Vásquez-Silva et al [19]	2015	Nonrandomized cohort study	III	Rev Peru Med Exp Salud Publica
Muntaner-Mas et al [20]	2015	Observational study	II	J Sports Med Phys Fitness
Cheung et al [21]	2015	Randomized trial	II	J Med Internet Res
Dorwal et al [22]	2016	Nonrandomized cohort study	III	J Med Syst

According to the Oxford Levels of Evidence, there was no Level I study, though there were 5 Level II studies (1 individual diagnostic cross-sectional study with consistently applied reference standards and blinding, 2 randomized risk or benefit assessment trials, and 2 risk or benefit observational studies), and 5 Level III studies (1 prognostic cohort study, 1 treatment benefits nonrandomized controlled cohort study, and 3 screening nonrandomized cohort studies).

The summary of each study's features and level of evidence is shown in Table 1.

Basic Information About the Articles

All of the articles were originally written in English, with the exception of one article written in Spanish. Of the included studies, 2 were performed in India, and 1 was performed in each of the following countries: Brazil, China, Germany, Italy, Peru, Saudi Arabia, South Africa, and Spain. Five studies were conducted by medical professionals, 4 by other health professionals, and 1 by kinesthetic and sports professionals. Five studies investigated the applicability of the WhatsApp Messenger as either a communication tool between health care professionals or as a learning tool [12,16,19,21,22]. In the other 5 studies, the app was used either as a communication tool between health care professionals and the public or as a teaching tool to provide information on health care to the general population [5,15,17,18,20].

Among the studies conducted by medical professionals, 2 were performed by orthopedic surgeons, 2 were performed by general practitioners, and 1 was performed by pathologists. A brief summary of these papers is provided in Table 2.

Table 2. Summary of the studies conducted by medical professionals.

Authors	Specialty	Aim	Methods	Results	Conclusions
Giordano et al [12]	Orthopedics	To evaluate inter- and intraobserver agreement in the initial diagnosis and classification of images from tibial plateau fractures	Plain radiographs and CT[a]scans were obtained from 13 cases of tibial plateau fractures Images were photographed with a smartphone and sent to 6 observers via WhatsApp Messenger Observers were asked to determine standard deviation and type of injury, classification according to the Schatzker and the Luo classifications, and whether the CT scan changed the classification	Inter- and intraobserver agreement for both periods of the study ranged from excellent to perfect across all survey questions	Systematic use of the mobile app facilitated faster documentation and acquisition of the opinion of an experienced consultant when not on call
Khanna et al [16]	Orthopedics	To report the impact of the introduction of WhatsApp as an intradepartmental communication tool	25 consecutive admissions before and after the introduction of WhatsApp were included in the study 8 orthopedic residents answered 50 randomly arranged questions based on the 25 patients in each study period	Significant improvement observed in scores after introduction of WhatsApp	Introduction of WhatsApp as an intradepartmental communication tool can bring about improvements in patient-related awareness, in communication, and handovers among orthopedic residents
Vásquez-Silva et al [19]	Internal medicine	To assess the access, use, and preferences of information and communication technology by physicians who practice at a general hospital in Lima, Peru	A questionnaire explored the availability of ICT[b], and physicians' skills, time constraints, educational activities, and preferred search engines and technological applications, as well as their ICT preferences in education 211 physicians were surveyed	One in every 2 doctors use WhatsApp to exchange information and images and to perform interactive consultations within the hospital Different groups were formed according to specialty or department (cardiology, emergency, general practitioners, medical residents, etc)	Use of and access to ICT is common among doctors in this general hospital, and there is positive interest in its use in education
Cheung et al [21]	Internal medicine	To determine the effectiveness of WhatsApp and Facebook groups for preventing smoking relapses among quitters	Single-blinded, parallel, 3-arm pilot cluster randomized controlled trial allocating recent quitters, who had completed an 8-week treatment and reported abstinence for at least seven days Participants were allocated into a WhatsApp group (n=42), a Facebook group (n=40), and a control group (n=54) Two intervention groups participated in a 2-month Web-based group discussion with either WhatsApp or Facebook moderated by a trained smoking cessation counselor and received a self-help booklet on smoking cessation Control group only received the booklet	Fewer participants in the WhatsApp group reported relapse than the control group at the 2-month follow-up (OR[c]= 0.27, 95% CI 0.10-0.71) and 6-month follow-up (40.5%, 17/42 vs 61.1%, 33/54; OR=0.43, 95% CI 0.19-0.99); WhatsApp groups had more posts from moderator (median 60, IQR[d]25 vs median 32, IQR 7; *P*=.05) and from participants (median 35, IQR 50 vs median 6, IQR 9; *P*=.07) than their Facebook counterparts, but the difference was not significant	Intervention via the WhatsApp group was effective in reducing relapse probably because of enhanced discussion and social support Inactive discussion in the Facebook social group may have attributed to the lower effectiveness

Authors	Specialty	Aim	Methods	Results	Conclusions
Dorwal et al [22]	Pathology and Laboratory Medicine	To look at the impact of using the WhatsApp Messenger service in the laboratory management system by forming multiple groups of the various subsections of the laboratory	Thirty five members used this service for a period of 3 months, and their responses was measured on a scale of 1 to 10	Significant improvement in communication (the sharing of photographic evidence, information about accidents, critical alerts, duty rosters, academic activities, and getting directives from seniors) Some increase in the load of adding information to the application and disturbance in the routine activities, but the benefits far outweighed the minor hassles	Results suggest and reflect another communication revolution that will change the way information is shared in a health care sector, with hospital-specific apps

[a] CT: computerized tomography.

[b] ICT: information and communication technology.

[c] OR: odds ratio.

[d] IQR: interquartile range.

Discussion

Principal Findings

The development of smartphones has created new opportunities for integrating mobile technology into daily clinical practice in several fields of health care, mainly due to the ability to download and install custom apps [23]. Due to their portability, speed, simplicity, and ability to update, mobile apps are an ideal tool for quick reference and learning purposes or for communication between health professionals and the general public [23,24]. Due to these characteristics, mobile apps are currently one of the most commonly used tools for telemedicine worldwide.

WhatsApp is a recent technology startup founded to build a better short message service alternative [24]. Its use has increasingly drawn a wider range of interest as a communication and imaging chat system between health care professionals and patients, as well as among health care professionals themselves. In several regions around the world and particularly in rural areas and low- and middle-income countries, the use of WhatsApp has been shown to facilitate communication among health care professionals in terms of faster problem identification and immediate acute management [4,11,25]. Recently, studies have reported the increased presence of WhatsApp in medicine and many other health care fields, which reflects the increased acceptance of its use. This phenomenon is attributed to the fact that WhatsApp is a cost-effective, quick, reliable, and user-friendly tool. It is therefore able to provide a greater proportion of patients and the general public with guideline recommendations and treatment [9,12,13].

In this systematic review of the literature, we relied on a search for the term “WhatsApp.” The medical search was based on information from the standard MeSH medical ontology. Three different electronic databases were searched. They were chosen because they are high-quality representative Web pages written in plain English and provide good linkages between medical terminology and plain English words [26]. A total of 30 articles were initially identified, but after a detailed assessment of all of the references, a subsequent screening, and a quality assessment, 10 studies were determined to be eligible for inclusion [5,12,15-22]. Although our study demonstrates a positive role of WhatsApp usage for health care purposes, the studies found in the literature were found to be substandard in quality. In addition, there is a clear publication bias in the majority of the papers included in this review. The negative trial results were typically not reported by authors, which was the major reason for the publication bias and which was therefore one of the exclusion criteria. None of the studies were double blinded, and only one trial was single blinded. The remaining trials were either nonrandomized, observational, or cohort studies.

We analyzed and evaluated the quality of the studies by grading their level of evidence. Despite our findings of the utility of WhatsApp in the health care field, the level of evidence in each of the 10 studies included in this systematic review was relatively low. There were no level I studies, a finding which clearly demonstrates weaknesses and inconsistencies among the studies on this topic. Among the trials conducted by medical professionals, 3 were found to have a level II of evidence. The main reasons for this discrepancy were the lack of randomization, the irregular use of a methodology, and issues in data acquisition. In addition, the study PICO (acronym for P-problem, I-intervention, C-comparison, and O-outcome) did not match the question PICO in many of the trials. We know by far that in many instances, it is very difficult to frame a research question; however, a successful research project depends upon how well an investigator formulates this question based on the problems faced in day-to-day research activities and clinical practice [27].

Although issues of ethics and security were not discussed in any of the 10 trials included in this systematic review, new users of WhatsApp for medical and other health care–related purposes must consider cyber security and the ethical implications of telehealth. As stated by Gerard et al, when citing the American Medical Association’s Code of Medical Ethics, the information disclosed to a physician during the course of the patient-physician relationship is confidential to the utmost degree [28]. The incorporation of telemedicine as a clinical enterprise should be strongly consistent with ethical practices. The American Telemedicine Association has recently updated the policy with the caveat that telemedicine per se is “not a practice in and of itself” [29]. One of the greatest barriers to the use of telehealth is fear. For patients, this often means the fear of intrusion or becoming distanced from their provider. For providers, this fear is associated with the lack of security to prevent unauthorized access sensitive patient information. Being sensitive and responsive to these concerns, as well as to the human factors that impact mobile app use by patients and health care providers alike, will all be crucial for the present and future success of any telehealth system or app [30].

Limitations

This paper presents several limitations. First, the authors studied only the WhatsApp Messenger app, although many other similar and popular messaging applications exist as social media. One of the major advantages of instant messaging for medical and other health care professionals include their capacity to identify, diagnose, and treat many life-threatening conditions in the acute scenario remotely. Preventing and minimizing the impact of noncommunicable diseases are some of the greatest challenges facing modern society [31]. In the actual study, we have tried to look at the impact of using the WhatsApp Messenger service for this purpose, as other studies have shown a higher effectiveness of this platform in terms of participation over other social media [21,23,32]. In reality, the use of WhatsApp Messenger can provide a solution to this by providing subtle structure to an erratic environment [32,33]. In addition, WhatsApp is seen to be a simple, cheap, and effective means of communication within the clinical health sector, and its use will grow [33,34].

Second, although we could find 10 papers eligible for inclusion in this systematic review, medical professionals conducted only 5 studies. Health professionals and kinesthetic and sports professionals conducted the other 5 studies. Therefore, the authors decided to make a brief summary of the medical papers. This study was a pragmatic evaluation of the impact of WhatsApp Messenger as an adjunctive tool for telemedicine, broadly defined as the “use of electronic information and communication technologies to provide and support health care when distance separates” the patient and the medical professional [1-3,35].

Third, a relatively small number of eligible studies were identified, and in general, they were very heterogeneous and presented a relatively low level of evidence, which reduces the trust that can be placed in their findings. These factors limited our ability to synthesize data and reach definitive conclusions. Maher et al identified the same problem in their systematic review of the effectiveness of online social network health behavior interventions [31]. As stated by these authors, “there is a possibility that studies with null findings have not been published and that the synthesis of data presented here gives an overly favorable account of effectiveness” [31,36].

Conclusions

In conclusion, the pooled data presents compelling evidence that the mobile app known as WhatsApp Messenger is a promising system when used as a communication tool between health care professionals and the general public, as a method of communication among health care professionals themselves, or as a learning tool for providing information on health care to professionals or to the general population. However, high-quality and properly evaluated research is urgently needed, as are improvements in descriptions of the methodology and the study processes. These improvements will allow WhatsApp to be categorically defined as an effective telemedicine tool in many different fields of health care.

Conflicts of Interest

None declared.

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Original Paper

Willingness to Pay for Elderly Telecare Service Using the Internet and Digital Terrestrial Broadcasting

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Abstract

Background: In Japan over the past few years, more attention has been focused on unnoticed solitary death in the context of an aging society and the trend toward nuclear family. A number of institutions and companies have implemented a prevention measure with digital terrestrial broadcasting telecare services for the elderly: Hokkaido University; TV-Asahi Corporation; Hitachi, Ltd; Iwamizawa City; Hokkaido Television Broadcasting Co, Ltd; and Hamanasu Information Co, Ltd. Although this system is provided free of charge as a demonstration test, determining the appropriate price for the service is required for its sustainable operation.

Objective: The aim of this study was to quantify individual willingness to pay (WTP) so as to test the tenability of digital terrestrial broadcasting service for elderly telecare.

Methods: We used the contingent valuation method (CVM) to estimate the WTP for this service among 305 citizens (valid response rate 76.0%) living in Japan. A questionnaire survey was conducted for people aged 18 to 100 years according to Japanese age distribution from September 2016. To elicit WTP, we adopted a *double-bound dichotomous choice method* to ask the respondents whether they agree or disagree with the price we offered.

Results: The median WTP for this service’s monthly fee is estimated to be 431 JPY (approximately US $3.7). The finding suggests that gender (0.66, *P*=.01), health consciousness (1.08, *P*=.01), willingness to use (2.38, *P*<.001), and seeing others less than once a week (1.00, *P*=.06) made a positive effect on WTP.

Conclusions: We conclude that reliable WTP was elicited by CVM based on an Internet survey. Calculated median WTP for digital terrestrial broadcasting service for elderly telecare was 431 JPY (approximately US $3.7). In the analysis of factors that affect WTP, *constant factors*, *log-bid*, *health consciousness*, *gender*, *see others less than one time for week*, and *willingness to use* made positive effect to probability of acceptance. In comparison of WTP in different groups, age groups showed that WTP of the elderly group was higher than WTP of the middle age group and younger age group. However, WTP surveys need to be carefully conducted to minimize the sampling bias and allocate accurate structure of gender distribution.

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KEYWORDS

health services for the elderly; health information; remote consultation

Introduction

Aging Society

Japanese society has been known as an aging society. Coulmas defined the percentage of an aging society as follows: “There are three different types of societies based on the proportion of elderly. Aging society: 7-14% of the population are 65 years or older. Aged society: 14-21% of the population are 65 years or older. Hyper-aged society: 21% or more of the population are 65 years or older.” [1]. In 1970, the Japanese society was defined as an aging society, aged society in 1994, and in 2004, it became a hyper-aged society, and we expect this trend to continue [2]. Aging society comes with many social problems such as lack of medical resources and increase in social security expenses, and finding a solution to these problems has become an urgent task for Japan [3].

One of the biggest issues among aging societies is unnoticed isolated death. According to the Tokyo medical examiner’s office [4], unnoticed isolated death is defined as “death seen by no-one on their deathbed and mostly in home.” The reason for this social phenomenon is likely to be caused by the changing family structure, such as the nuclear family [5].

Although surveys about isolated elderly deaths in Japan have not been conducted, in Tokyo alone, 1973 males and 1143 elderly females were found after their death in their home, reported by Tokyo Medical Examiner’s Office. Moreover, 15,603 unnoticed isolated deaths were found in Japan more than 4 days after their death, reported by the Ministry of Internal Affairs and Communication [6]. The delay in finding of isolated death has become an increasing social cost [7]. The cost they need to pay is listed in Table 1.

Table 1. Social cost of unnoticed isolated death.

Payer	Price, JPY (US $)
Family or guardian of elder (guarantor)	
Removing fluids and filth of decayed body	20,000-350,000 (173-3040)
Elimination of pest	15,000-50,000 (129-434)
Deodorize and disinfect	20,000-100,000 (173-868)
Property value goes down	
If it’s a public residence and has no guarantor for the room, all expenses above become public expenditure	
Government	
Administrative autopsy	250,000-500,000 (2162-4325)
Police (increase of work load)	
Reregistration of individual record, cremation, cleaning out their belongings, etc	

Autopsy cost is mentioned as a public expenditure. However, this cost can be avoided if a death certificate is issued by the hospital, and thus, the early finding of disorder before death would save government expenses. The government [8,9] and several companies have offered methods to solve this problem [10-13].

Previous Research

In Iwamizawa City, Hokkaido, Japan, in cooperation with Hokkaido University; TV-Asahi Corporation; Hitachi, Ltd; Iwamizawa City; Hokkaido Television Broadcasting Co, Ltd; and Hamanasu Information Co, Ltd, have been conducting demonstration experiments of elderly telecare services using the Internet and digital terrestrial broadcasting to enhance health consciousness of the elderly and to improve elderly telecare [14].

About participation in this project, we connected the Internet to the television at the homes of participants who gave agreement. After issuing the participant’s user ID and password on the dedicated system, we made an Internet connection of the participant’s television and personal ID setting to their television. Registered TV in this study refers to a television that is ready to receive telecare services after personal ID setting is completed. The initial setting operation flow is shown in Figure 1. The person in charge of the city went for the equipment setting at the elderly home.

In this service, when a registered TV is not used for 3 days, the call center will make a confirmatory telephone call to the registered individual, and if the individual cannot be reached, then the neighborhood association and civil servant committee will visit the registered location to make sure the individual is not in any fatal situation. Other than the elderly telecare function, this service also offers information about health care, local events, and doctors on duty in local hospitals (Figures 2 and 3).

Although this system has been provided free of charge as a demonstration test, obtaining a certain level of return of economic investment is required for the sustainable operation of this service. The aim of this study was to quantify individual willingness to pay (WTP) measures of a digital terrestrial broadcasting service for elderly telecare.

Figure 1. Operational flow to start.

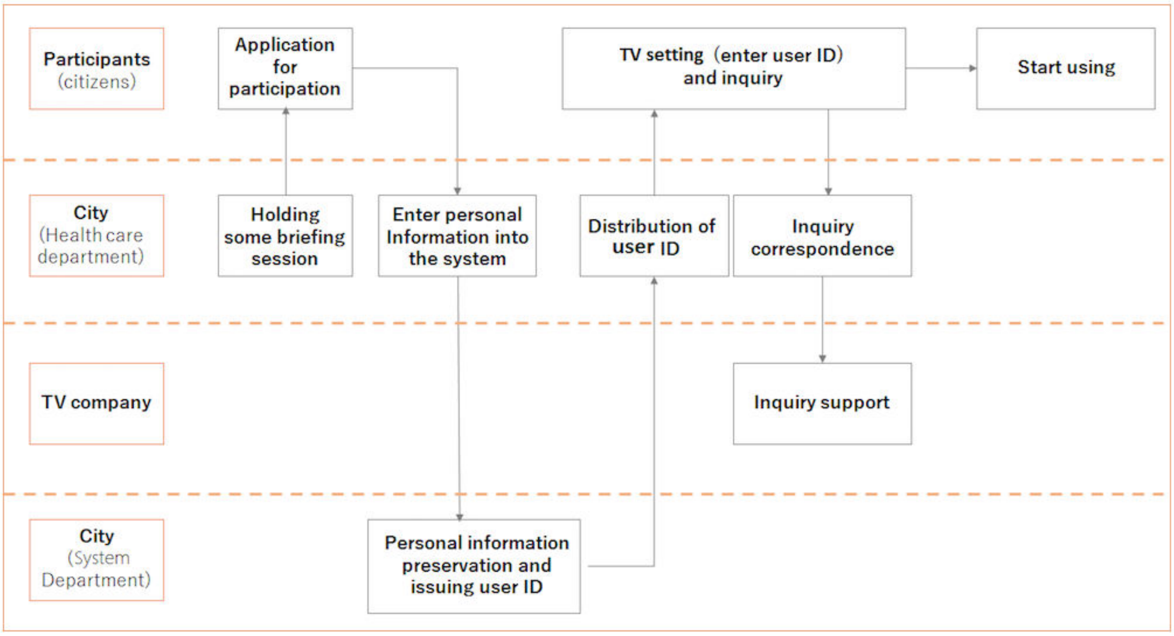
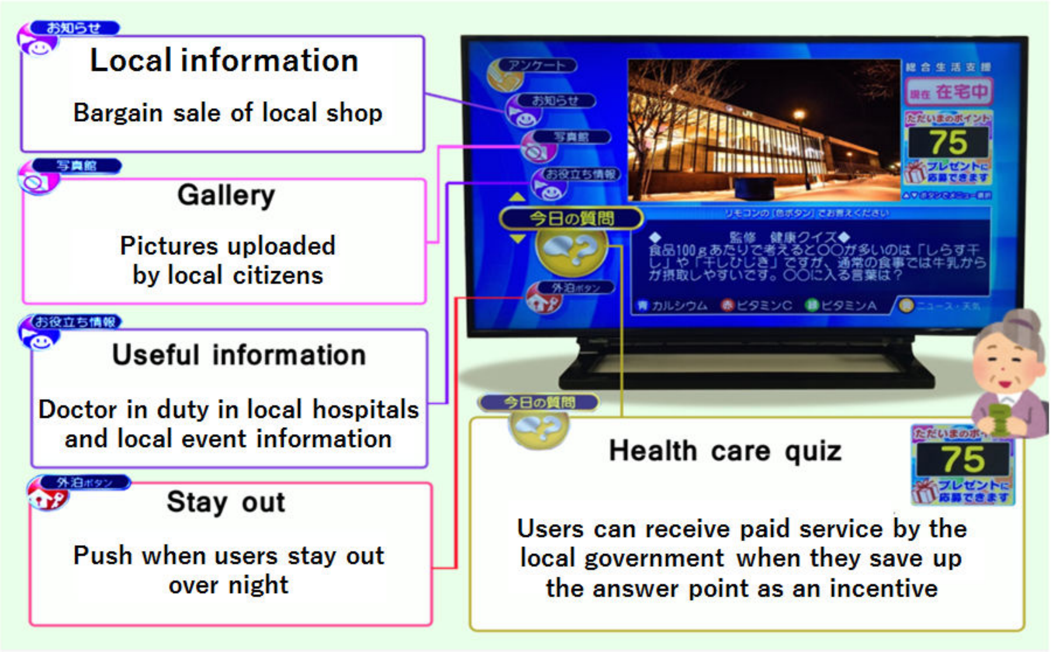
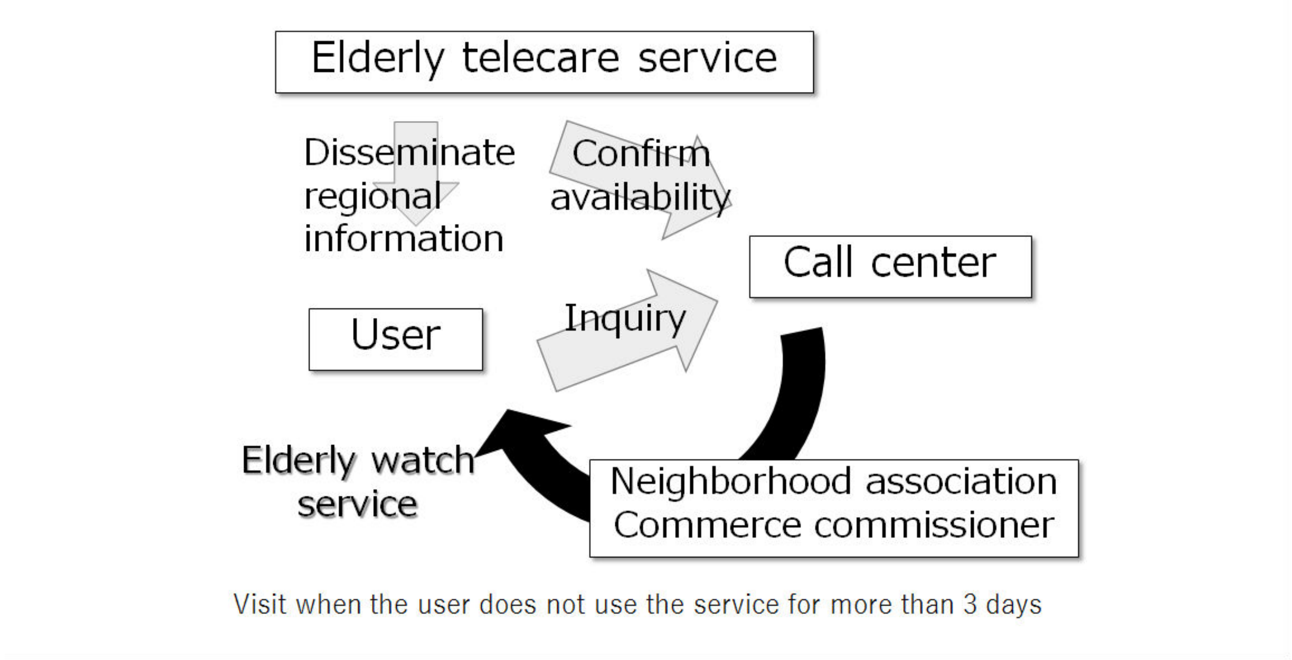


Figure 2. Contents of elderly telecare service.



食品100ｇあたりで考えると〇〇が多いのは「しらす干し」や「干しひじき」ですが、通常の食事では牛乳からが摂取しやすいです。〇〇に入る言葉は？

Figure 3. Elderly telecare service.



Methods

Contingent Valuation Method

In this study, we used the contingent valuation method (CVM) to quantify individual WTP, which is widely used in economic evaluations [15], for example, in the health, transportation, and environment sectors. The CVM survey is used to elicit WTP values for a hypothetical change in the availability of nonmarket goods or services. Individual WTP values are generally elicited through dichotomous choice. The procedure is to ask a random sample of individuals via an Internet survey if they would be willing to pay a certain amount for a hypothetical change in the availability of a particular service. The test samples will be given two yes or no questions regarding price (Table 2). The second price is lower for people answering *no* and higher for people answering *yes* [16].

Table 2. Question price patterns in JPY (US $).

Price-first question, JPY(US $)	Upper price-second question (first question: yes)	Lower price-second question (first question: no)
500 (4.3)	750 (6.5)	250 (2.1)
1000 (8.6)	1500 (13.0)	500 (4.3)
2000 (17.3)	2500 (21.7)	1500 (13.0)
3000 (25.9)	3500 (30.4)	2500 (21.7)

Data Collection

We decided to conduct an Internet survey because it is more cost-efficient and faster than mail or face-to-face interviews. A total of 400 Japanese citizens ranging from 18 to 100 years of age were chosen to participate in this survey. However, to reflect the Japanese population [17], the sample was strategically selected according to the Japanese population structure and then divided into 10 groups according to the subjects' age and residential area. We expected WTP of people living in urban cities to be higher than that of people in rural areas because unnoticed isolated death in urban cities is regarded as a problem reported by the Ministry of Internal Affairs and Communications [18], and age can also affect WTP. For a definition of age distribution, refer to Table 3. For a definition of population distribution in urban areas, refer to Table 4.

Table 3. Definitions of age distribution.

Definitions	Age (years)	Description
Younger	18-39	Low WTP[a] for service because they have no experience or need for this service
Middle	40-65	High WTP for service because this generation is mostly like to have parents older than 65 years, and so, they are willing to pay more
Elderly	Over 65	Potential users of this service who are older than 65 years can have a higher WTP because demand is relatively higher than the other age groups

[a] WTP: willingness to pay.

Table 4. Definition of population distribution in urban areas.

Urban area	City name	Population	Area (km^2)	Population density (people/km^2)
Sapporo area	Sapporo	2,584,880	4514	573
Sendai area	Sendai	2,169,757	5970	363
Kanto area	Saitama, Chiba, Tokyo, Yokohama, Kawasaki, and Sagamihara	36,923,193	14,034	2631
Niigata area	Niigata	1,421,694	5345	266
Shizuoka and Hamamatsu area	Shizuoka, Hamamatsu	2,741,028	4982	550
Chukyo area	Nagoya	9,107,414	7072	1288
Kinki area	Kyoto, Osaka, Sakai, Kobe	19,341,976	13,033	1484
Okayama area	Okayama	1,647,892	3637	453
Hiroshima area	Hiroshima	2,099,514	5048	416
Kita-Kyushu area, Fukuoka area	Kita-Kyushu, Fukuoka	5,515,427	5731	962
Utsunomiya area	Utsunomiya	1,086,898	5455	199
Matsuyama area	Matsuyama	717,687	2272	316
Kumamoto area	Kumamoto	1,476,435	4251	347
Kagoshima area	Kagoshima	1,152,748	3458	333

WTP Estimation

We used a double-bound dichotomous logit model; median WTP is estimated as a representative value. Median indicates that 50.0% of the respondents agree with the offered amount [19,20]. This is important because our project is a public project [21], and median is usually the deciding factor for many public decisions. For estimating the WTP parameter, we decided to use a logit model because we expect WTP to stagnate after the price reaches a certain amount [22,23]. First, we estimate WTP with a model including all variables (Figure 4). Next, we estimate WTP with a model including variables with significant influence, and finally, we compare the WTP between different age groups and area groups with the Krinsky and Robb credential interval [24].

Figure 4. The model includes all variables.

$$\Pr[Yes] = \frac{1}{1 + \exp\{-(\alpha + \beta_0\chi_0 + \cdots \beta_i\chi_i + -\beta_t logT)\}}$$

Table 5. Expected effects to willingness to pay (WTP).

Validation questions	Details
I agree to this project but I don't think it's worth paying.	Valid answer
I would like to use this service but I can't afford it.	Valid answer
I could not decide with this information.	Invalid answer
Even if it's free to use, I don't think it's worth paying.	Valid answer
Write your own reason if any ( ).	

Table 6. The questionnaire for excluding invalid answers.

Factor	Affect to WTP[a]
Age	Health risk goes up as people get older; therefore, WTP is likely to increase
Gender	
Male	Not significant
Female	
Family structures	
Living alone	If respondents live alone, they would feel necessary to use telecare service; therefore, WTP is likely to increase
Living with 2 or more people	
Family net income	
More than 8 million JPY	The more income they have, the more money they can consume
Less than 8 million JPY	
Personally knows people who live alone	
Yes	If respondents have an acquaintance who lives alone, they would feel the necessity of a telecare service; therefore, WTP is likely to increase
No	
Health consciousness	
Yes	If respondents are health conscious, they could give this system a good reputation; therefore, WTP is likely to increase
No	
Willingness to use	
Yes	If respondents have willingness to use, they would agree to pay
No	
Concern toward health	
Yes	If respondents have anxiety regarding their health, they would feel the necessity of a telecare service
No	
See others less than once a week	
Yes	If respondents go a week without seeing anyone, they could be in a state of social isolation in the local community and consider the risk of dying alone
No	

[a] WTP: willingness to pay.

Questionnaire Design

Regarding questionnaire design (Table 5), we prepared questions to ask about basic properties, such as "family structure," "family net income," "Do you have anyone who lives alone around you?," and questions related to factors affecting WTP such as "Do you habitually care about your health?," "Would you like to use this service?," "Are you concerned about your health?," "Do you have weekly meetings with anybody?," and "If this service costs JPY, would you be willing to pay? Think about the decrease in your income or saving," and "How about if this service costs ~JPY? Would you be willing to pay?" We also prepared questionnaires for excluding invalid answers (Table 6).

Results

Results of Questionnaire

The response rate of this questionnaire was 100%, but 95 answers were excluded because of invalid answers. Therefore, 305 (76%; Tables 7-9) answers were analyzed.

According to our initial calculation, the WTP average was calculated to be 1525 JPY (US $13.1). However, this figure is inaccurate, as it does not take into account the concern of overvaluation. As a general countermeasure, it is recommended to cut the hem with the maximum WTP [21]. In the second calculation, we decided to insert a maximum value of 3500 JPY (US $30.2), which gave us a new average of 809 JPY (US $6.9), and a median of 431 JPY (US $3.7; Figure 5, Table 10). In addition, we confirmed that multicollinearity between each variable does not occur, using the variance inflation factor (VIF; Table 11).

Table 7. Basic properties (305 valid responses).

Characteristics		Sample, n (%)
Gender		
	Male	191 (63)
	Female	114 (37)
Age in years		
	18-39	82 (27)
	40-64	123 (40)
	Over 65	100 (33)
Family structure		
	Living alone	67 (22)
	Living with spouse	97 (32)
	Living with spouse and child or children	106 (35)
	Single father or mother or living with a married child	3 (1)
	Three or more generations	21 (7)
	Others	11 (3)
Family net income in JPY		
	Lower than 2 million	51 (17)
	2-4 million	86 (28)
	4-6 million	71 (23)
	6-8 million	41 (13)
	8-10 million	33 (11)
	10+ million	23 (8)

Table 8. Factor summary.

Factors		Sample, n (%)
Age in years		
	18-39	82 (27)
	40-64	123(40)
	Over 65	100(33)
Gender		
	Male	191 (63)
	Female	114 (37)
Family structures		
	Living alone	67 (22)
	Living with someone	238 (78)
Family net income in JPY		
	More than 8 million	56 (18)
	Less than 8 million	249 (72)
Personally knows people who live alone		
	Yes	105 (34)
	No	200 (66)
Health consciousness		
	Yes	258 (84)
	No	47 (16)
Willingness to use		
	Yes	158 (51)
	No	147 (49)
Concern toward health		
	Yes	113 (37)
	No	192 (63)
See others less than once a week		
	Yes	19 (6)
	No	286 (94)

Table 9. Summary of price patterns.

Price in JPY (US $)	Yes-Yes	Yes-No	No-Yes	No-No
500 (4.3)	20	9	16	33
1000 (8.6)	16	13	17	35
2000 (17.3)	11	6	0	59
3000 (25.9)	10	5	4	51

Table 10. Estimated willingness to pay (WTP).

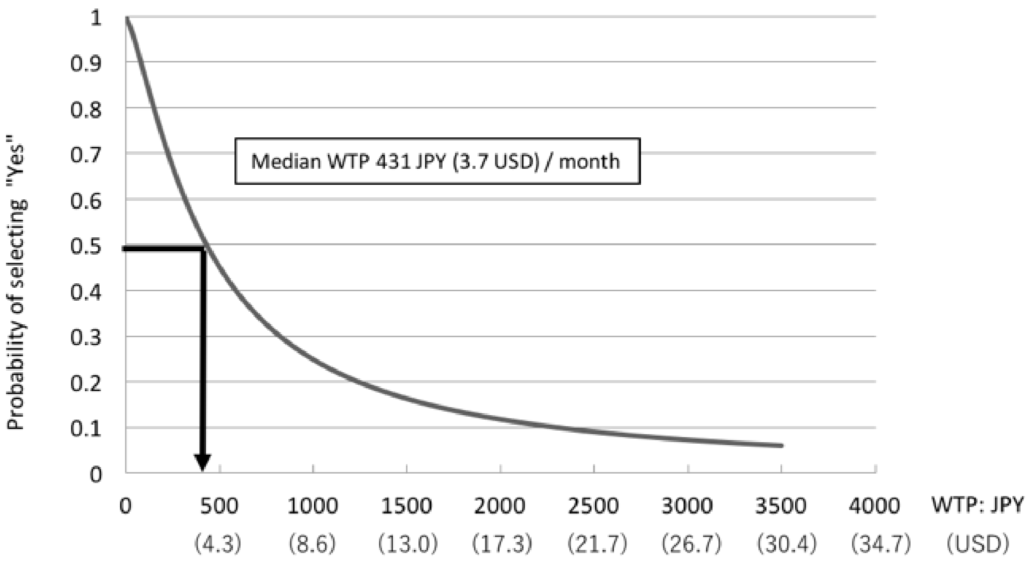
Willingness to pay	Price in JPY/month (US $)
Median	431 (3.7)
Average	1525 (13.1)
Average (truncated at the maximum bid)	809 (6.9)

Table 11. Estimated parameters of the willingness to pay (WTP) model.

Variables	Parameter (standard error)	*P* value	Variance inflation factor
Constant: alpha	5.312 (0.846)	<.001	
Log(bid)	−1.310 (0.121)	<.001	1.036
Health consciousness	1.086 (0.439)	.01	1.039
Gender	0.667 (0.272)	.01	1.004
Willingness to use	2.388 (0.303)	.001	1.036
See others less than once a week	1.003 (0.528)	.06	1.029

If we look at the comparison between different generations (Figure 6), we can see that younger generations (18-39 years) and middle generations (39-64 years) do not have significant differences. However, the older generation (over 65 years), who are potential users in the future, showed a much higher WTP and is significantly different from the other generations. Although we expected that people of different locations would make a significant difference in the WTP (Figure 7), the result shows that there are no significant differences for people living in urban and nonurban areas.

Figure 5. Estimated willingness to pay (WTP) model.



$$\Pr(Yes) = \frac{1}{1+\exp\{-(\alpha + consciousness\beta_i + willing\beta_w + lonely\beta_l + gender\beta_s - \beta_t \log(bid))\}}$$

Figure 6. CI of willingness to pay (WTP) for different generations.

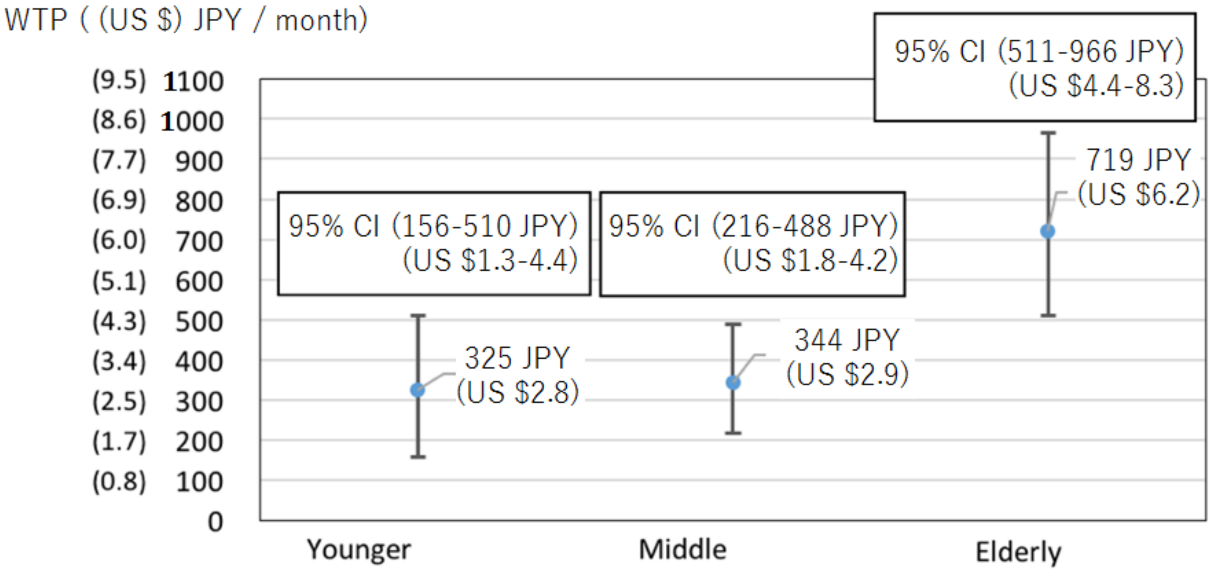
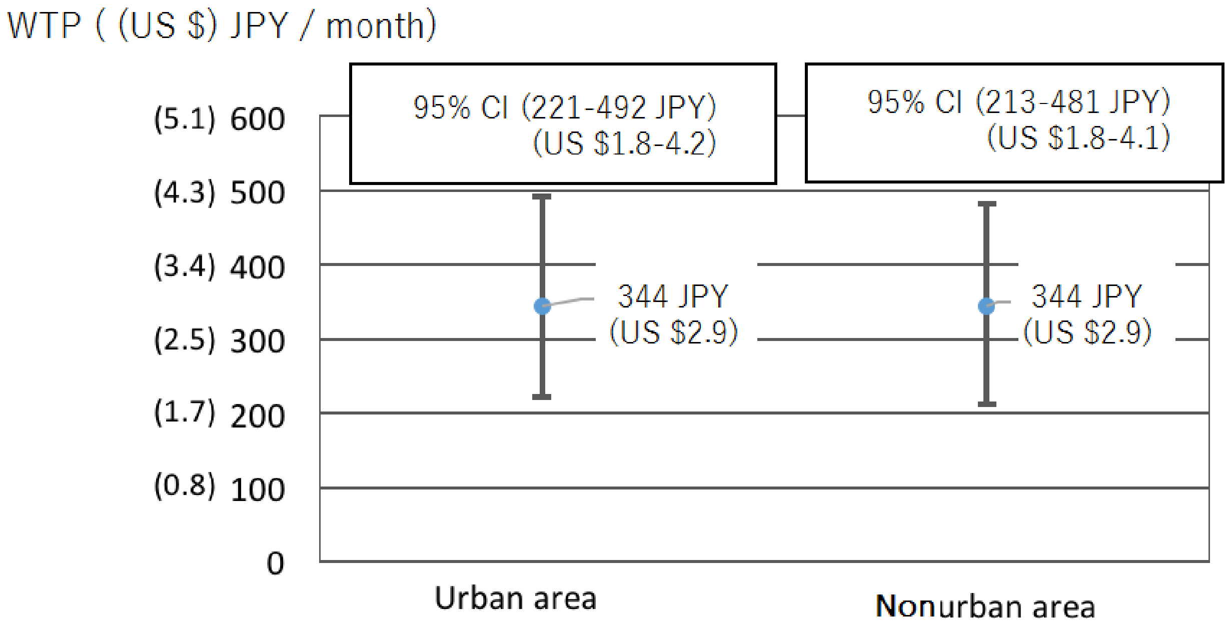


Figure 7. CI of willingness to pay (WTP) for urban and nonurban area.



Analysis of Factors Affecting WTP

In analysis of factors affecting WTP, variables with significant changes will be isolated and analyzed in more detail (Tables 12 and 13). We adopted a logistic linear model for the following isolated factors: *constant factors*, *log-bid*, *gender*, *health consciousness*, *willingness to use*, and *not seen for over a week*.

Table 12. Analysis of all factors that affect willingness to pay (WTP).

Variables	Parameters	*P* value
Constant	5.346	<.001
log(bid)	−1.326	<.001
Gender	0.669	.02
Age	−0.003	.67
Living alone	0.281	.40
High income	0.187	.57
Having an acquaintance who lives alone	0.199	.47
Health consciousness	1.011	.03
Willingness to use	2.422	<.001
Anxiety to health	0.354	.20
See others less than once a week	0.852	.12

Table 13. Analysis with only isolated factors that affect willingness to pay (WTP).

Variables	Parameters	*P* value
Constant	5.312	.001
ln (offer amount)	−1.310	.001
Gender	0.667	.01
Interest in health	1.086	.01
Willingness to pay to service	2.388	.001
See others less than once a week	1.003	.06

Discussion

WTP With Relation to Price

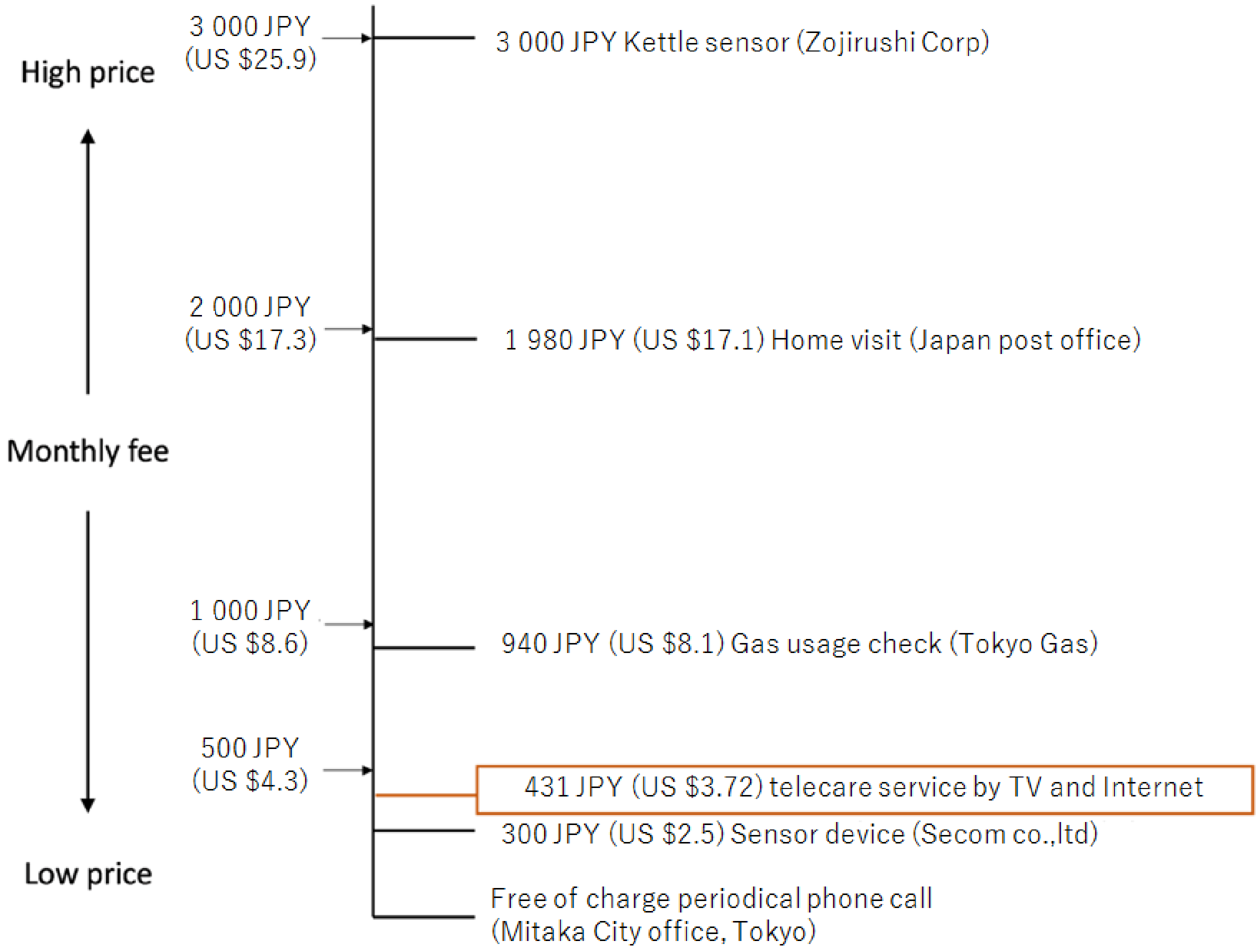
According to our research, the estimated median WTP is 431 JPY (US $3.7) per month, and the mean is 809 JPY (US $6.9) per month. It would be greatly beneficial if there were other similar research studies available for comparison. Unfortunately, WTP research for this service is first of its kind, which limited us from comparing with previous research. As the second best alternative, we decided to use figures of similar services to compare the practicality and validity of our research finding. Similar services (Figure 8) include a signaled kettle sensor for 3000 JPY (US $25.9) per month, a periodical home visit service by the post office for 1980 JPY (US $17.1) per month, and an add-on gas meter sensor service for 940 JPY (US $8.1) per month.

Compared with our finding, the prices listed above are more expensive. WTP only represents utility of consumers. However, services provided by privately owned enterprises need to retrieve costs and make a profit on top of the consumer utility. It is worth mentioning that care services are offered by the security company, Secom Ltd, for 300 JPY (US $2.5) per month. Although 300 JPY may seem less costly compared with any other services, this service is provided as an optional service of top of home security services for 5900 JPY (US $51.0) per month. If singled out, the service provided by Secom Ltd is likely to be higher than other services.

There is also a free periodic phone call service provided by Mitaka City in Tokyo but, although it is free of charge, it does not indicate that it is free to run and operate. The only reason this service can exist and continue existing is because of the direct financial support from the government in the form of taxes paid by the general public. In addition to government financial support, Mitaka City does not send any personnel to make home visits, which significantly cuts the cost on human resources.

In conclusion, the WTP figure of 431 JPY (US $3.7) per month is valid. We can make this conclusion because this figure is lower than all privately owned enterprises yet higher than public services provided by Mitaka City.

Figure 8. Price comparison with similar services.



Comparing Different Age Groups in WTP

Looking at different age groups, we notice a factor in significant difference in WTP comes from one of the three age groups. *Young generation from 18-39 years old* and *middle generation from 40-64 years old* do not make any significant difference. However, the WTP for *elderly generation (65+ years)* is substantially higher than the other two age groups. In the beginning of this research, we expected the middle age group to have the highest WTP because this group is expected to have the highest income. However, this group is also expected to have the longest working hours, and therefore, it is likely for this age group to pay to ensure the health of their parents. Another reason for this assumption is the marketing direction of privately owned enterprises. If we pay attention to the marketing direction of enterprises offering similar services, we can notice that all targets are set at the middle generation age group. This trend misleads us to think that the middle generation age group would have the highest WTP out of all three age groups. Thus, we misjudged the tendency, and the elderly generation age group has the highest WTP out of all. After this consideration, we believe the reason for the highest WTP for this age group is because of two reasons, the first of which is savings. In this research, we looked at net income but not savings. Although the middle generation age group may have the highest net income, the elderly generation age group has the highest savings out of all three age groups [25], which allows them to spend money on ensuring their own standard of living. The second reason is only an assumption; however, humans are likely to worry about one’s own health risk the most. Therefore, instead of spending money on others, it is more likely that one spends money on themselves, which for this service happens to be the elderly generation age group. As a reflection, we decided that if we were to conduct the same or similar research again, we would add *savings* as a new factor and pay more attention to the *spending pattern* of sampling subjects.

Comparing Urban and Nonurban Test Subjects in WTP

According to the research done by the Ministry of Internal Affairs and Communications, unnoticed solitary death is higher in urban than in nonurban areas [26]. We believe the reason for this trend is because people living in nonurban areas are not as busy as people living in urban areas, which allows them to have a closer relationship with one another. This close relationship naturally lowers the risk of unnoticed solitary death; therefore, the WTP in nonurban areas, because of direct relationship and closeness with neighbors, should be lower than WTP in urban areas. However, according to our research, the WTP for urban and nonurban does not make much of a difference in WTP. After careful consideration, we believe this is because excessively busy lifestyles in urban areas lower the public consciousness of solitary death in urban areas. Due to the lack of consciousness, the WTP in urban areas is roughly the same as in nonurban areas.

Analysis of Factor Affecting WTP

During research, we found six different variables that affect the final WTP estimation: *constant factors*, *log-bid*, *gender*, *health consciousness*, *willingness to use*, and *not seen for over a week*. We will look at four out of the six factors. With regard to gender, we expected that, given the same health consciousness, WTP would not change for either gender. However, the result shows that males have higher WTP than females. We believe the reason is because males have higher risks of solitary death compared with females (Tokyo Medical Examiners' Office). Health consciousness is an easy factor to understand. People with higher health consciousness naturally are more willing to pay to receive health care service and information, thus, their WTP is higher than that of people with lower health consciousness. Our previous study [27] indicated that willingness to use affects the WTP [27].

For the factor see others less than once a week, it is possible that they do not participate in the local society, so they found our project offering information about the local community and telecare service useful.

The technology acceptance model (TAM) is widely used as a model to analyze factors that people accept new technologies and services. In this model, four factors, *perceived usefulness*, *perceived ease of use*, *attitude toward using*, and *behavioral intention to use* are cited as factors leading to the use of new technologies and services by people [28].

Hirose et al are conducting research using TAM for responses to mHealth application on health behavior [29]. From the results, they suggest that it is possible to explain health behavior by TAM. For this service, we also need to consider the technological acceptability by TAM. Furthermore, we think that it is also necessary to consider availability of financial resources and elasticity of pricing to examine the possibility of more realistic service acceptance. We also believe that it is necessary to analyze what kind of causal relationship the new watchkeeping service used in this research can be accepted by using TAM. We will make future investigations to conduct surveys together with analysis by TAM and WTP.

In this research, we were conducting a questionnaire survey in temporary environments; hence, we cannot clarify what factors and performance are affecting the WTP. Analysis of customer satisfaction and physical satisfaction using a service quality model such as the Kano model is needed. On the basis of the analysis results, we believe that it is necessary to consider the acceptance price, taking the quality of service into account.

Sampling Bias on Internet Research

This research was conducted using an Internet survey; therefore, it is possible that there is bias [30,31]. The biggest bias is information technology (IT) literacy. For people with sufficient IT literacy, it is safe to assume that they are of a healthier group that is not in immediate need of this service, which thus lowers the WTP average. On the other hand, the people who need the service do not have enough IT literacy to answer the survey via the Internet. There is also gender bias to be considered. When we chose the survey sample, we made choices based on age and location, but we did not take gender into consideration, which may lower the accuracy of the final estimated WTP. To prove the existence of gender bias, we made the following table listing percentage of different sample groups (Table 14). The result shows that there is gender inequality in the research sample. If we look at the ratio of male and female in the survey participants, we can see that the male sample group is much greater than the female sample group. The ideal sampling group for male is 193, but the total number of males who took the test was 248, whereas the ideal female sample is 207, but the number of females who took the test was only 152. If we look at these figures using the chi-square test, the number of males in the age group of 50 to 64 years is greater than the expected value, whereas the number of females aged 50 to 64 years and 65+ years is less than the expected value. These numbers indicate that this bias may affect the final estimated WTP. If we were to conduct a similar research next time, it would be important to take the gender difference into account as well.

The double-bound dichotomous choice method used in this study may cause yes-saying bias. It also has the possibility of causing anchoring bias, in which the answer depends on the initial presentation amount. The point that it cannot fully cope with these tasks is considered to be one of the problems of CVM. On the basis of the theory of behavioral economics, we think that it is necessary to consider the WTP in a method not affected by the priming effect and the anchoring effect.

Table 14. Chi-square test for gender distribution. χ^2_{20}=104, *P*<.05.

Gender and values		18-29 years	30-39 years	40-49 years	50-64 years	Over 65 years	Total
Males							
	Observed value	22	20	41	66	99	248
	Predicted value	29	31	35	45	53	193
	Adjusted residual	−0.55	−0.79	0.49	1.71	4.20	
Females							
	Observed value	35	41	28	25	23	152
	Predicted value	28	30	34	46	70	207
	Adjusted residual	0.67	1.09	−0.59	−2.20	−5.48	

Conclusions

In this study, we conducted an Internet survey. Median WTP is estimated to be 431 JPY (US $3.7) per month, and mean WTP is estimated to be 809 JPY (US $6.9) per month. For comparison of WTP among age groups and differences between residential areas, the elderly group is estimated to be higher than other groups. In the analysis of factors that affect WTP, *constant factors*, *log-bid*, *gender*, *health consciousness*, *willingness to use*, and *not seen for over a week* had positive effects on WTP. With regard to *gender*, it was estimated that there was a significant effect only for men. In comparison of WTP in different groups, age groups showed that WTP of the elderly group was higher than WTP of the middle age group and younger age group. However, WTP surveys need to be carefully conducted to minimize the sampling bias and to allocate accurate structure of gender distribution.

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Conflicts of Interest

None declared.

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Abbreviations

CVM: contingent valuation method
IT: information technology
VIF: variance inflation factor
WTP: willingness to pay

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Original Paper

Shaping an Effective Health Information Website on Rare Diseases Using a Group Decision-Making Tool: Inclusion of the Perspectives of Patients, Their Family Members, and Physicians

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Abstract

Background: Despite diverging definitions on rare conditions, people suffering from rare diseases share similar difficulties. A lack of experience by health professionals, a long wait from first symptoms to diagnosis, scarce medical and scientific knowledge, and unsatisfactory treatment options all trigger the search for health information by patients, family members, and physicians. Examining and systematically integrating stakeholder needs can help design information platforms that effectively support this search.

Objective: The aim of this study was to innovate on the group decision-making process involving patients, family members, and physicians for the establishment of a national rare disease Internet platform. We determined differences in the relevance of health information—especially examining quantifiable preference weights—between these subgroups and elucidated the structure and distribution of these differences in people suffering from rare diseases, their family members, and physicians, thus providing information crucial to their collaboration.

Methods: The included items were identified using a systematic Internet research and verified through a qualitative interview study. The identified major information needs included *medical issues*, *research*, *social help offers*, and *current events*. These categories further comprised sublevels of *diagnosis*, *therapy*, *general disease pattern*, *current studies*, *study results*, *registers*, *psychosocial counseling*, *self-help*, and *sociolegal advice*. The analytic hierarchy process was selected as the group decision-making tool. A sensitivity analysis was used to determine the stability and distribution of results. *t* tests were utilized to examine the results' significance.

Results: A total of 176 questionnaires were collected; we excluded some questionnaires in line with our chosen consistency level of 0.2. Ultimately, 120 patients, 24 family members, and 32 physicians participated in the study (48 men and 128 women, mean age=48 years, age range=17-87 years). Rankings and preference weights were highly heterogeneous. Global ranking positions of patients, family members, and physicians are shown in parentheses, as follows: *medical issues* (3/4, 4, 4), *research* (3/4, 2/3, 3), *social help offers* (1, 2/3, 2), and *current events* (2, 1, 1); *diagnosis* (6, 8, 9), *therapy* (5, 9, 7), *general disease pattern* (9, 4/5/6, 6), *current studies* (7, 4/5/6, 3), *study results* (8, 7, 8), *registers* (4, 1, 5), *psychosocial counseling* (1, 2, 4), *self-help* (3, 3, 2), and *sociolegal advice* (2, 4/5/6, 1). Differences were verified for patients for 5 information categories *(P*=.03), physicians for 6 information categories (*P*=.03), and family members for 4 information categories (*P*=.04).

Conclusions: Our results offer a clear-cut information structure that can transparently translate group decisions into practice. Furthermore, we found different preference structures for rare disease information among patients, family members, and physicians. Some websites already address differences in comprehension between those subgroups. Similar to pharmaceutical companies, health information providers on rare diseases should also acknowledge different information needs to improve the accessibility of information.

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KEYWORDS

rare diseases; decision making; health information needs; preferences; patients; relatives; physicians

Introduction

Worldwide, approximately 350 million people are affected by rare disease [1]. Despite diverging definitions, people suffering from rare diseases share common difficulties. Particularly, health care professionals have little experience with this patient group, and patients typically wait a long time from the first symptoms to diagnosis. Moreover, medical and scientific knowledge concerning rare diseases is scarce, and low research efforts often result in, if available, unsatisfactory treatment options. When there is a treatment option available, patients still often need to consider financial aspects. Patients also frequently experience difficulties with the cost absorption of expensive treatments. Furthermore, rare diseases are very serious and chronic. Severe symptoms result in high disease burden and can have a significant negative impact on one’s quality of life. Above all, patients often face a shortened life expectancy [2]. Consequently, there is an urgent need for proper health information for this population.

The Internet offers a large pool of somewhat obscure information. In this context, this study examines how information on rare diseases can be presented in a more structured way. As a second step, we also examined whether stakeholder-specific websites presenting information in accordance with the information priorities of the targeted subgroups would be necessary. We hypothesized that the information structures of patients, family members, and physicians would be identical, as family members and physicians would generally search for information to fulfill patients’ needs. This would consequently lead to a single platform incorporating the overall group consensus on information priorities and therefore information presentation.

The literature, however, has not yet addressed the differing information needs between patients, family members, and physicians. Health information helps to empower patients, enabling them to understand, treat, cope, and effectively manage their disease [3-5]. Rare diseases’ patients are often called *experts* of their own illnesses because they gather health information consciously through Web searches or unconsciously through numerous consultations with different health care professionals [6]. Besides, doctors’ assessments of patients’ preferences appear to be critical for the outcome of health services [7]. In this regard, the dialogue between patients and physicians is critical. Therefore, health care professionals must be trained and prepared to listen to patients and discuss their experiences [8,9]. Furthermore, health information searches should be facilitated and encouraged, as they enable patients to be more effective in communicating with their physicians [5]. This study contributes and adds value to this existing literature and the underlying dialogue by eliciting the different perspectives of patients, family members, and physicians on the relevance of rare disease information.

Aside from the above points, little or no scientific knowledge exists for the 5000 to 6000 different indications summarized under the term rare diseases. Adding all diseases and all different information providers together creates a huge and obscure information pool. Indeed, information providers often fail to meet the information needs of patients and families searching social media and utilizing chat rooms to obtain information; however, they might be unaware of the low quality of this information [10]. On the other hand, obtaining knowledge of the many thousands of different rare diseases is well beyond the ability of physicians. Primary physicians are only familiar with approximately 400 different indications. Primary physicians can extend their knowledge through asking questions of colleagues and reviewing paper-based data sources [11]; however, even with the advent of electronic records, it remains highly time-consuming and difficult to search for the right terms and obtain appropriate evidence. Taken together, these facts suggest that effective health information presentation is exceedingly important. Collins et al suggest that information needs can be incorporated by capturing and embedding the relevance of information [12]. This study shows how this demand can be put into practice.

Literature shows that group decision-making tools are rarely applied when it comes to the establishment of health information portals. Health information needs are often met by retrieving information from historic user statistics or triggering retrospection. Stakeholders cannot actively participate [13,14]. However, by choosing the analytic hierarchy process as a group decision-making tool, we can actively involve patients, family members, and physicians to address their unmet informational needs. Furthermore, information categories that are underrated by stakeholders (ie, patients, relatives, or physicians) can be illuminated. A number of different models have already been applied during the establishment of effective cocreative business modeling [15,16]. However, until now, there have been no attempts to devise a similar model in a transparent manner for different stakeholders in relation to rare diseases.

The following study has been conducted against the backdrop of the conceptualization of a central website for rare disease information in Germany (ZIPSE, Zentrales Informationsportal über seltene Erkrankungen or central information portal about rare diseases) [17] connecting disease unspecific and specific information, as well as quality orientation for patients, their families, and health care professionals at a central platform [18]. As part of the German National Action Plan for Rare Diseases from 2013 (NAMSE, Nationales Aktionsbündnis für Seltene Erkrankungen) following the European council recommendations [19,20], knowledge transfer is improved through the development of Internet information systems. Already existing Internet information is collected and organized to increase the visibility of rare disease knowledge [18]. Physicians, family members, and patients are critical to this process; they are the major beneficiaries and should profit by effective health information provision.

In this paper, we describe how patients, family members, and physicians can contribute directly to this process of effectively gathering and presenting health information. More specifically, we describe an innovative group decision-making process involving these individuals aimed at establishing a national rare diseases Internet platform. This study also examined the information preferences of these stakeholders to enable health care systems, decision makers, and other national and international rare diseases portals to appropriately structure information that patients, families, and physicians strive for. The relevance of information is crucial for stakeholders' ability to relate to each other within a strong network approach. In this regard, the study provides unique insights into the quantitative structure and distribution of information preferences for these stakeholders, answering the question on how information provision in the context of rare diseases should be structured.

Methods

Ethical Considerations

The questionnaire was distributed both Web-based and as a paper-based version. Accordingly, consent was obtained in written form. The paper-based version was distributed after qualitative interviews with patients and their relatives. A positive ethics committee vote was obtained for the interview study from the ethics committee at Albert Ludwigs University of Freiburg (number 53/14). The Web-based version allowed for collecting opinions anonymously without having participants disclose personal details at any time. An information sheet was presented to all participants describing the aim and scope of the study. All participants were informed that they could withdraw from the study at any time.

Analytic Hierarchy Process (AHP)

An analytic hierarchy process (AHP) was implemented for the collection of individual preferences, as this study was devised to contribute the decision-making processes implemented in the ZIPSE project. Saaty gives detailed information on the AHP methodology [21]. Two authors also give a detailed overview of its application in health care [22,23]. Lately, the Institute for Quality and Efficiency in Health Care in Germany discussed the AHP as a method for the inclusion of preference structures into early benefit assessment. Similar to conjoint analysis, AHP raises quantifiable weights that can then be used to combine multiple endpoints into an efficiency boundary [24,25]. AHP offers a direct approach, whereas conjoint analysis compares different attributes in combination, thereby leading to an indirect calculation of weights. Furthermore, it is more intuitive and easier to understand for inexperienced participants compared with other techniques (eg, the analytic network process [26] but more informative than other techniques, eg, best-worst scaling, ranking) [27]). Quantitative preference distances make extensive evaluation of preference structures possible [20,28]. Therefore, the major benefit to AHP methodology is that it raises not only ranks but also measurable distances between criteria weights, leading to a visible preference structure. AHP does not only give a clear-cut ranking, it also indicates what categories are weighted similarly. Therefore, attributes that are weighted similarly, but ranked differently, do not need to be excluded. The AHP is able to appreciate individual judgments adequately to thereby derive an overall group consensus [29] and offers a clear-cut preference structure that can be easily applied to the presentation of health information.

AHP is particularly interesting for the field of rare diseases as it is applicable independent of the size of the indication. Even opinions of very small rare disease subgroups can be raised and evaluated [20,28]. Moreover, AHP appreciates the heterogeneity of rare diseases, which because of its definition, summarizes quite diverging disease patterns, as subgroup specific opinions can be evaluated separately. Consequently, this study recognizes the value of AHP when examining rare diseases.

Hierarchy Definition

A total of 300 information websites addressing rare diseases were searched and scanned concerning available information on their home pages. Litzkendorf et al also collected and verified the items through a qualitative interview study [30]. Similar information categories have also been found by the Genetic and Rare Disease Information Center [31] and for other indications such as multiple sclerosis [32]. Accordingly, information categories were drafted and prestructured. Four experts in public health research and one expert in health economics research were chosen from the Center for Health Economics Research Hannover (CHERH). The major criterion for choosing these experts was a research focus on either rare diseases or patient-reported outcomes. Participants were addressed personally. An invitation for participation was forwarded via email along with an attached Microsoft Excel 2010 sheet containing the included items. Afterwards, the final definition of the items was discussed in a workshop scenario. As a result, the different information category descriptions address biases because of different interpretations of information categories. Definitions were finalized if they seemed closed to interpretation and easily understandable (see Multimedia Appendix 1). Thirteen items were chosen, which resulted in 15 pairwise comparisons. The final hierarchy is presented in Table 1.

Questionnaire Development

Other studies used computer-based programs that immediately reflected the level of consistency generated by the answer [33]. Then, corrections are initiated. However, in our study, we did not use an intelligent computer-based fill-out system, instead implemented a paper-based questionnaire. A first draft of the questionnaire was designed and pretested. The pretest revealed insufficient consistency. Therefore, the questionnaire was redrafted. A graphic showing the hierarchy structure was removed to allow space for a graphic demonstrating the exemplary filling out of one question on the questionnaire. Furthermore, a ranking task was integrated, which visualized the intrinsic priorities during the fill-out process. A research question was specified for each visual scale.

Table 1. Hierarchy for information on rare diseases.

Hierarchy level 1 Research topic	Hierarchy level 2 Parameters	Hierarchy level 3 Elements
Importance of health information on rare diseases	Medical issues	Diagnosis
		Therapy
		General disease pattern
	Research	Current studies
		Study results
		Registers
	Social help offers	Psychosocial counseling
		Self-help counseling
		Sociolegal advice
	Current events	

The end of a paragraph containing items from one hierarchy arm was highlighted to emphasize the beginning of a new category. A subsequent pretest revealed improved consistency. Before fielding the questionnaire, the usability and technical functionality of its Web-based version were tested by the authors and a collaborating institution (see Multimedia Appendix 2).

Sample

Patients, physicians, and family members were identified as the main users of health information on rare diseases [34] and a central rare diseases information portal [20]. Participants were recruited using three different recruiting strategies to ensure the adequacy of the sample. The Freiburg Center for Rare Diseases located at the Department of Dermatology of the University Medical Center, University of Freiburg contacted patients and family members using rare diseases self-help groups. Overall, 39 individuals were asked to complete the questionnaire. To participate in the study, patients had to be aged 17 years and older; if they were younger than 18 years, a close relative was invited for answering the questions instead. Interviews were predominately conducted via telephone. To ensure a broad and balanced representation of patients suffering from rare diseases, eleven groups of rare diseases were formed when this study commenced; this was believed to represent considerable variety in rare diseases. Patients were recruited in accordance with these groups. Physicians were recruited by the CHERH. First, physicians with experience in rare diseases and working for specialized rare diseases centers were recruited. Later, the target group was extended to include physicians not imperatively familiar with rare diseases. This seems legitimate, as opinions of physicians unfamiliar with rare diseases but also searching for information were included. Furthermore, a Web-based version of the questionnaire was devised. The link to the open Web-based version was stored on a website offering Web surveys and forwarded by Alliance for chronic rare diseases (Allianz chronisch seltener Erkrankungen, ACHSE) using a mailing list of ACHSE members. A short description of the study was included. All data were collected and stored anonymously. ACHSE checked the avoidance of identification of rare diseases’ patients through disease characteristics. The study was initiated in August 2014, and data collection was finalized in August 2016. Overall, 112 questionnaires were answered online, and 64 paper-based questionnaires were completed.

Analysis

For each respondent, a consistency ratio (CR) was calculated. The CR was calculated in accordance with the following formula: $(\lambda_{max-}\ n)/(n-1)$. λ_{max}. The CR is a value which has been predefined by Saaty [21]. Following the threshold of Danner et al, we included all comparisons with a CR≤0.2; therefore, we assumed pairwise comparisons to be consistent up to this threshold [35]. Respondents with a higher CR were excluded. Individual priority vectors were calculated using the eigenvector method used in Saaty [21]. Afterwards, individual opinions were summarized using an aggregation of individual priorities method. As literature suggests that values must correspond to reciprocal values of individual participants, weights were aggregated choosing the geometric means calculation [27]. As priority values need to sum up to one, resulting local priorities were weighted accordingly. Then, local and global rankings were derived. The calculation was conducted using Microsoft Excel 2010 and R version 3.1.2 (R-project for statistical computing). Responses of patients, families, and physicians were compared. To compare differences between these three subgroups, a variance analysis should be conducted first. However, as we analyzed differences between each of the three groups, test statistics were calculated using a student *t* test. Only local weights were compared as global weights were derived from these. An analysis of sensitivity was conducted observing the stability of priority rankings. Typically, AHP studies conduct sensitivity analysis using expert choice and graphically altering the weights of decision criteria and observing how rankings of alternatives outcomes change. However, this study did not include a hierarchy level with alternative decision outcomes, only items. Therefore, we assessed the sensitivity by identifying outliers and excluding them. Thereafter, potential rank reversals were observed. The range of data was elicited by box plots.

Bootstrapping (N=1000) was conducted to assess the proximity of values in correspondence to the parameter of the population, especially acknowledging small samples in the groups of family members and physicians.

Results

Sample Characteristics

The mean CR was 0.22 (median: 0.14, standard deviation, SD=0.24) for all 176 participants. Questionnaires with a CR above 0.2 were excluded. A mean CR was calculated for each subgroup. CR for all people suffering from a rare disease was 0.25 (SD=0.27), CR for families was 0.17 (SD=0.11), and CR for physicians was 0.14 (SD=0.10). Accordingly, the proportion of consistent answers was 56% for patients, 67% for relatives, and 83% for physicians, showing that most of the inconsistencies occurred in the patient subgroup. Solely regarding consistent answers, average CR for all participants was 0.09 (SD=0.05). Characteristics of all participants are shown in Table 2, including participants who answered inconsistently. Physicians were not asked about their civil status or the number of household members because this did not seem to serve our research question. Furthermore, disease severity and age of diagnosis were not applicable for two subgroup.

Information Priorities

Tables 3-5 show both global and local priorities of level 2 and 3 items for all participants interviewed. Standard deviations of local priority weights are presented. Resulting ranks are also listed. As bootstrapping showed that calculated geometric means systematically underestimated the weights of information category, weighted geometric means were calculated. Results are presented separately for each subgroup.

Sensitivity Analysis

The results range is displayed in Figure 1 and shows the potential sensibility of local weights to outliers. The ranking results were calculated based on the geometric means because the literature suggests that this procedure is more precise [27]. However, the following box plots show the range of results in a more intuitive manner, displaying the average mean, as well as the maximum and minimum local weights.

To test for potential rank reversal, we excluded outliers and observed whether rank reversals were of consequence. Figure 1 identifies the outliers visually. The patient subgroup displays only one outlier that results in a rank reversal for the category *research*. *Research* is consequently ranked last with a priority weight of .19. Family members show outliers for categories *medical information* (.09), *therapy* (.21), *diagnosis* (.19), and *general disease pattern* (.60). The exclusion of outliers does not cause rank reversal. For the last group, *physicians*, outliers were identified for the following items: *medical information* (.11), *diagnosis* (.22), and *research* (.17). No rank reversals were observed.

Significance of Results

To examine differences between groups, we conducted a student *t* test, assuming opinions were aggregated following the normal distribution within the population. The results are displayed in Table 6. The null hypothesis states that the importance of items is perceived equally; the alternative hypothesis states that the importance of information on rare diseases is perceived differently. Significant differences are marked.

Furthermore, bootstrapping with a 95% CI was conducted to examine whether sample results lay within specific ranges of the population regarded. The results are presented in Figure 2.

Table 2. Sociodemographic characteristics of patients, family members, and physicians (N=176).

Parameters	Patients (n=120)		Family members (n=24)		Physicians (n=32)	
	Included (n=67)	Excluded (n=53)	Included (n=16)	Excluded (n=8)	Included (n=25)	Excluded (n=7)
Sex						
Male	11	18	2	1	13	3
Female	56	35	14	7	12	4
Age						
Average	51	50	46	49	42	49
Maximum	85	87	62	62	69	56
Minimum	17	17	23	33	28	29
Civil status						
Married or cohabiting	43	37	8	7	-[a]	-
Single	11	11	3	0	-	-
Divorced	9	3	2	1	-	-
Widowed	4	2	3	0	-	-
Educational qualification						
Technical college or university degree	28	16	10	3	25	7
Abitur	9	5	3	1	0	0
Advanced technical college degree	6	5	0	1	0	0
Secondary education	17	19	3	3	0	0
Secondary modern school qualification	7	8	0	0	0	0
Members of the household						
Average	2	5	3	3	-	-
Maximum	5	2	5	5	-	-
Minimum	0	0	0	0	-	-
Age at diagnosis, years						
Average	37	37	4	15	-	-
Maximum	74	79	37	47	-	-
Minimum	0	0	0	0	-	-
Disease severity						
No specification	0	0	1	0	-	-
Low	6	3	0	0	-	-
Medium	32	21	7	5	-	-
Severe	28	29	8	3	-	-
Profession						
Employed	27	25	16	5	25	7
Unemployable	14	10	0	0	0	0
Pensioner	20	14	0	2	0	0
Student or scholar	1	2	0	0	0	0
Homemaker	1	1	0	1	0	0
Special circumstances (further education or provision of work)	4	1	0	0	0	0

Parameters	Patients (n=120)		Family members (n=24)		Physicians (n=32)	
	Included (n=67)	Excluded (n=53)	Included (n=16)	Excluded (n=8)	Included (n=25)	Excluded (n=7)
Medical rare disease experience	-	-	-	-	24	3

[a] The symbol indicates that data are not available.

Table 3. Ranking results of patients.

Parameters	Patients (n=67)				
	Local weight	SD	Global weight	Local ranking	Global ranking
Medical issues	.21	0.21		3 or 4	
Diagnosis	.34	0.24	.070	2	6
Therapy	.37	0.21	.076	1	5
General disease pattern	.30	0.19	.062	3	9
Research	.21	0.17		3 or 4	
Current studies	.32	0.22	.069	2	7
Study results	.32	0.20	.068	3	8
Registers	.36	0.26	.077	1	4
Social help offers	.30	0.19		1	
Psychosocial counseling	.35	0.22	.103	1	1
Self-help	.32	0.24	.095	3	3
Sociolegal advice	.33	0.21	.098	2	2
Current events	.28	0.22		2	

Table 4. Ranking results of family members.

Parameters	Family members (n=16)				
	Local weight	SD	Global weight	Local ranking	Global ranking
Medical issues	.13	0.18		4	
Diagnosis	.24	0.21	.031	2	8
Therapy	.20	0.18	.025	3	9
General disease pattern	.56	0.20	.071	1	3/4/5
Research	.22	0.20		2/3	
Current studies	.31	0.21	.071	2	3/4/5
Study results	.16	0.10	.037	3	7
Registers	.52	0.23	.117	1	1
Social help offers	.22	0.16		2/3	
Psychosocial counseling	.35	0.23	.075	1	2
Self-help	.33	0.27	.071	2	3/4/5
Sociolegal advice	.33	0.22	.070	3	6
Current events	.43	0.18	-	1	-

Table 5. Ranking results of physicians.

Parameters	Physicians (n=25)				
	Local weight	SD	Global weight	Local ranking	Global ranking
Medical issues	.13	0.17		4	
Diagnosis	.23	0.16	.029	3	9
Therapy	.37	0.17	.046	2	7
General disease pattern	.40	0.19	.051	1	6
Research	.18	0.14		3	
Current studies	.44	0.22	.078	1	3
Study results	.25	0.18	.045	3	8
Registers	.32	0.22	.057	2	5
Social help offers	.26	0.17		2	
Psychosocial counseling	.29	0.11	.076	3	4
Self-help	.32	0.20	.083	2	2
Sociolegal advice	.40	0.20	.104	1	1
Current events	.42	0.17		1	

Figure 1. Range of results (local weights) of consistent answers by patients, family members, and physicians. CUS: current studies; DIG: diagnosis; GDP: general disease pattern; MED: medical issues; THE: therapy; PSY: psychosocial counseling; REG: registers; RES: research; SOC: social help offers; SHE: self-help; SOL: sociolegal advice; STR: study results.

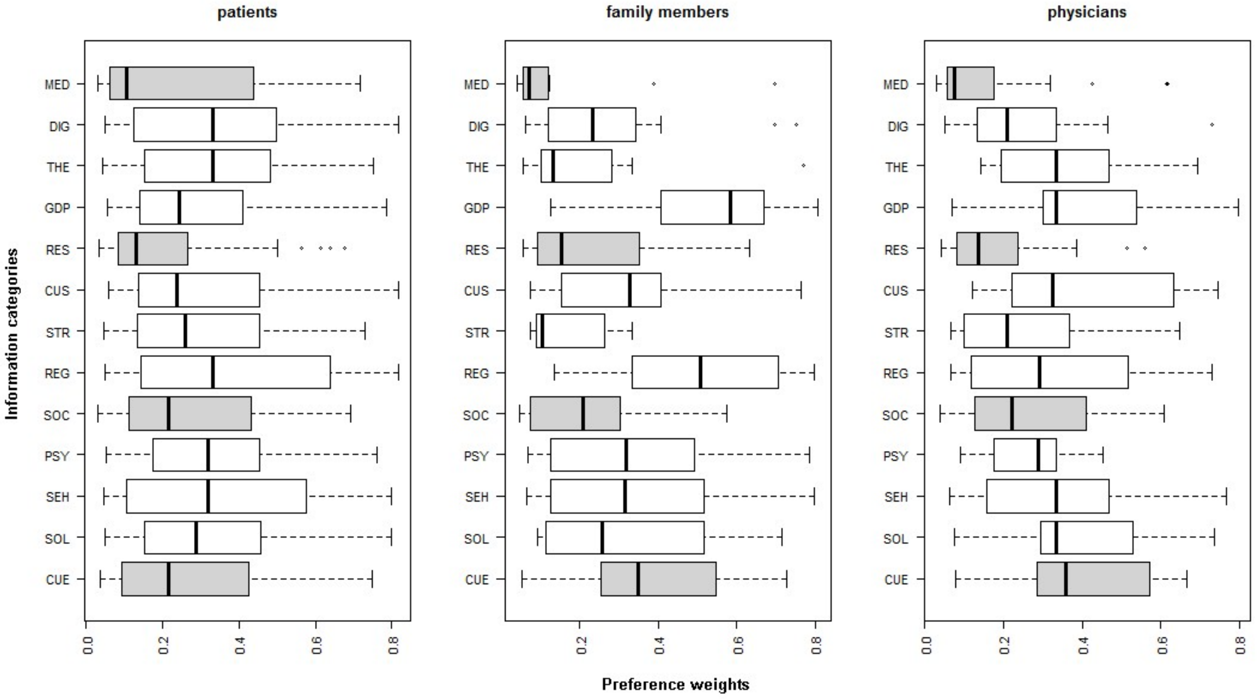

Table 6. Significance of differences between patients, family members, and physicians (n=108).

Parameters	Two-sample *t* test					
	Patients or families		Patients or physicians		Physicians or families	
	t statistic (degrees of freedom)	*P* value	*t* statistic (degrees of freedom)	*P* value	*t* statistic (degrees of freedom)	*P* value
Medical issues	1.60 (26)	.13	1.90 (55)	.06	0.04 (30)	.97
Diagnosis	1.43 (26)	.17	2.59 (62)	.01	−0.45 (26)	.66
Therapy	2.88 (26)	.01	0.07 (52)	.94	2.60 (31)	.01
General disease pattern	−4.26 (22)	<.001	−2.50 (39)	.02	−1.85 (32)	.07
Research	−0.65 (21)	.52	0.59 (54)	.56	−0.98 (24)	.34
Current studies	−0.26 (23)	.80	−1.98 (40)	.05	1.28 (34)	.21
Study results	3.99 (46)	<.001	1.20 (46)	.21	1.98 (38)	.06
Registers	−1.96 (25)	.06	0.87 (49)	.39	−2.44 (31)	.02
Social help offers	1.25 (27)	.28	0.19 (48)	.85	0.94 (34)	.35
Psychosocial counseling	0.01 (22)	.99	2.05 (78)	.04	−1.13 (20)	.27
Self-help	−0.12 (21)	.90	0.02 (48)	.98	−0.13 (26)	.90
Sociolegal advice	0.13 (22)	.90	−1.50 (44)	.14	1.17 (30)	.25
Current events	−1.98 (26)	.06	−2.52 (54)	.01	0.10 (31)	.92

Figure 2. The results of patients, family members, and physicians using bootstrapping and a 95% CI. CUS: current studies; DIG: diagnosis; GDP: general disease pattern; MED: medical issues; THE: therapy; PSY: psychosocial counseling; REG: registers; RES: research; SOC: social help offers; SHE: self-help; SOL: sociolegal advice; STR: study results.

Discussion

Principal Findings

This study shows that rare diseases information categories are weighted very differently, resulting in subgroup specific preference weight structures, distributions, and ranking results. Although *medical issues* were rated as least important by all subgroups, none of the other information categories showed an overall group consensus.

Significant differences between subgroups were confirmed by *t* tests comparing subgroup specific local weights for the following comparisons: the priority weight of patients and family members in the categories *therapy*, *general disease pattern*, and *study results* differed significantly. Moreover, patients and physicians showed significant differences within the categories of *diagnosis*, *general disease pattern*, *current studies*, *psychosocial counseling*, and *current events*. Comparing physicians' results against those of family members, *therapy* and *registers* showed statistical significance.

In quantifying these results, patients and family members showed diverging preference weights for 23% of the cases (3/13). On the other hand, patients and physicians showed different weights for 38% of the cases (5/13). Finally, physicians and family member's weights diverged only in two cases (15%, 2/13). These results indicate that patients and physicians show a comparably high percentage of diverging opinions on the importance of health information, weakening our initial hypothesis that physicians initiate their search strategy based on the patient-physician interaction. These results should be discussed very carefully because the potential implications are hard to grasp. The statistical significance test was based on the local preference weight. However, the final result of the AHP was expressed as an absolute rank. Therefore, the results should be situated in the overall context. The local weights revealed significant differences in health information with regard to *therapy*. Specifically, patients put this category first (1) on the local level, whereas physicians put it last (3). Regarding the health information on *general disease patterns*, ranks were assigned inversely. Similar rank switches at the local level can be observed when comparing patients' and physicians' perspectives on information relating to *general disease patterns* and *psychological counseling*. Interestingly, *general disease patterns* were perceived as least important by patients (3), whereas physicians regarded it as most important (1). On the other hand, patients considered *psychosocial counseling* as the most important subcategory, whereas physicians considered it the least important.

Checking all subgroups for the sensitivity of results, a rank change could only be observed once. Therefore, we conclude that the results were relatively stable. These results are consistent with Danner et al [35], who interviewed patients while they were completing AHP questionnaires. Extreme values, which could lead to very unstable results, often go along with high inconsistencies. Per these findings, some extreme opinions could have been excluded because of the set CR threshold.

Theoretical Contributions

Interestingly, all subgroups prioritized information on *social help offers* and *current events* over hard facts such as *medical issues* and *research*. This is perhaps because certain medical topics can be discussed directly with physicians following a diagnosis. Unfortunately, we cannot directly compare these findings with the findings of other studies, as the study participants, information categories, and indications vary greatly. However, patients receiving genomic results outlined that they preferred filtering information to avoid information overload and to avoid learning what their future might look like [36]. This anxiety about the future might explain why patients rated medical information as less important, despite the fact that it was named as a main search item in studies such as that of Morgan et al [31]. On the other hand, Anderson et al [37], as well as Schwarzer [38] reported consistent findings with Australian families suffering from genetic metabolic diseases and children with anorectal malformations, emphasizing the importance of self-help groups in the long run and psychosocial counseling when self-help reaches its limits. Dellve et al [39] also highlight the importance of psychosocial counseling for family members, especially parents with a child suffering from a rare disease. These findings also quantitatively support the importance of not only research networks, as advocated for by, for instance, Aymé and Schmidtke [40], but also social networks in the field of rare diseases and inclusion of these networks within national and international rare diseases information platforms, reflecting the unique importance of self-help initiatives in the field of rare diseases. Common diseases often do not need the support of self-help groups because research and political action have already been largely implemented. On the other hand, for rare diseases, many initiatives and knowledge extensions originate from these self-help groups [6]. However, patient initiatives continue to be put at the end of the line. Given that research- and patient-oriented websites still primarily offer either websites for physicians or for patients, even though information valuable to all stakeholders are presented, this makes cocreation and the exchange of opinions even more important.

The information category *registers* was the most important category for families (at rank 1); patients regarded it highly as well, ranking it in 4th place immediately after *social help offers*. Only physicians attributed a high relevance to *current studies*. This statement emphasizes the importance of providing information on rare diseases registers and appreciates the worldwide effort put into the development of such strategies [41], mirroring the importance of longitudinal data acquisition and analysis as numerous rare diseases are connected to a genetic predisposition [19]. These results emphasize the considerable involvement of family members, as they are potentially also affected.

Relatively little interest in study results can be explained through the communication of the results itself. Long et al [42] report that participants of studies receive results only in 33% of the cases. Only half of respondents saw an opportunity to even request the results. However, in this case, almost all respondents demanded researchers to at least sometimes offer the results. The strengthening of the communication of study results can be seen as an opportunity to improve the inclusion of health innovations in health care systems.

The present health information survey among physicians and senior patients reveals some major problems when comparing these results to those of other studies. Specifically, the results vary widely, especially because the health information categories were outlined differently [43]. This indicates that further subgroup analysis can be performed while controlling for influential factors such as age and indication. However, it should also be emphasized that our study forms the basis for an Internet platform for rare diseases and therefore focused on the major relevant stakeholders for this disease category.

Besides, research has often focused on topics such as information access [44] or barriers to information access [45], which leaves the question of how information needs are specified unanswered [46]. Further research is necessary to examine this topic in more detail. Nevertheless, the results have potential for further improving the basis of physician-patient communication.

Practical Implications for Web-Based Health Information Provision

What do these results mean for rare diseases–related information providers such as ZIPSE? The differences between subgroups suggest that subgroup specific information is necessary. First, the ranking structure of rare diseases information categories can be translated, one-by-one, into website design by positioning topics in accordance with stakeholder priorities.

Besides, it seems advisable to considered Miller's Law to avoid information overflow. It appreciated that the whole load of rare diseases Internet resources cannot be processed at once [47]. Limited perception capacities of human brains make it indispensable to only display the most important information at first glance. Miller's Law states that the short-term memory of an average human brain can only absorb approximately 7 items at once, thus, limiting the effectiveness of Internet data processing. Moreover, considering Miller's Law and potential information overflow, only the most important seven items should be included. Therefore, the findings suggest that information categories such as *general disease information* (9), *study results* (8), and *current studies* (7) do not need to be presented initially. In the case of a website especially designed for family members, *current events*, *registers*, *psychosocial counseling*, *self-help*, *sociolegal advice*, *current studies*, and *general disease pattern* should be presented first. On the other hand, physicians prioritized information on *current events*, *sociolegal advice*, *self-help*, *current studies*, *psychosocial counseling*, *registers*, and *general disease pattern*.

Nevertheless, another perspective should also be thought of at this point. From an educational point of view, this study also presents information categories that currently seem undervalued. For example, patients do not perceive *current studies* (7) or *study results* (8) as important, even though these results might hold crucial information for their disease treatment or maintenance. Family members do not perceive *diagnosis* (8) and *therapy* (9) as very valuable. Group representatives often advocate for their children or partners who are suffering from a rare disease to treat these information categories as more important. Moreover, even though approximately 60% of patients see physicians as the primary source of information [14], physicians do not perceive information on *diagnosis* (9), *therapy* (7), and *study results* (8) as important. Therefore, it seems advisable to discuss whether information should be located to improve its visibility and to reflect its importance for the major stakeholder, the patient. Consequently, whether physicians' priorities should reflect patients' interests as an *information lobbyist* also requires examination. First of all, it seems advisable to not only include the underlying results into the design of information platforms on rare diseases but also to discuss information placement with experts in the field and to fully disclose information placement strategies. However, we strive for a high involvement of patients, family members, and physicians to realize efficiency potentials for health care systems. This can only be accomplished by respecting the outcome of the decision-making process translating results one-to-one.

Study Limitations

Data interpretation was a limitation. The AHP research sample size is still a topic of discussion. It has been highlighted that AHP does not require a particularly large sample size [48]. Other authors emphasized that there is no recommendation at all for AHP sample size [23]. Both sources base their statements on the fact that AHP reflects the opinion of the specific group and is thus a group decision-making tool. However, in this study, we raise preference weights, which should be representative for groups when an adequate sample size is achieved.

The quantitative aggregation technique shapes a clear-cut implementation structure for information categories. However, it must be acknowledged that the results illustrate the average opinions of rare diseases' patients, physicians, and family members.

Another issue that should be recognized when interpreting study results is the exclusion of inconsistent answers as part of the AHP methodology. Dolan [49] found that of 20 patients, 90% were willing and capable of completing an AHP. Danner et al [34] argued that extreme values are often chosen to emphasize answers that are not willingly contributed to inconsistencies. In our study, patients delivered inconsistent answers 44% of the time, whereas family members and physicians did so in 34% and 22% of the cases, respectively. However, these results were excluded to follow theoretical AHP requirements.

During pretests of the questionnaire's paper-based version, low consistency values were generated. Ranking cards were included as first choice assistive tools to mirror ranking results immediately. During interviews with patients and family members, this tool was very helpful and led to improved CR values. However, during interviewer-led AHPs, physicians refused to use it. Nevertheless, interviewers noted the shown ranking orders verbally. Finally, a ranking task was placed before each block of comparisons in the Web- and paper-based version.

Comparing physicians with patients, low participation rates are observed. VanGeest et al [50] stated that low participation rates are very common in physicians' surveys. Postal and telephone approaches seem to be more effective than Web-based strategies. Monetary incentives were found to be an effective strategy to increase participation rates. Nonmonetary incentives reflected little changes. Unfortunately, no monetary funds were available for this study.

As already indicated, a change of medium was necessary. Initially, a paper-based version was implemented. After the first recruitment period, a Web-based questionnaire was also introduced to broaden the target group. Several studies such as those of Hirsch et al [51] and Coons et al [52] found differences between participation for paper-based and Web-based surveys. Therefore, it is beneficial to combine both approaches considering representativeness, thus capturing both infrequent and frequent Internet users.

Finally, sociodemographic data show a relatively large proportion of female participants. Literature and other rare diseases Internet providers disclaim that health information on rare diseases are more often searched for by women than by men. For instance, Morgan et al [13] determined that 95.7 % of all inquiries to the Genetic and Rare Disease Information Center came from women.

Conclusions

This study describes an innovation in the involvement of patients, family members, and physicians in effectively gathering, structuring, and presenting health information in a world struggling with an information paradox, namely, health information overflow on the one hand and a major lack of information on rare conditions on the other. This innovation comes in the form of the chosen group decision-making tool, the AHP, which has helped transform individual qualitative perceptions into a measurable scale. Accordingly, the strength of our study is its transparent quantitative demonstration of the information needs of physicians, patients, and family members, which makes direct comparisons and simple implementation possible. More specifically, this study provides unique insights into the quantitative structure and distribution of information preferences, as well as the validity of results. We were able to verify significant differences between preference weights of patients, family members, and physicians for some items, suggesting that the importance of rare diseases information is perceived differently in these subgroups. User-oriented information providers should seek to address these differences and provide stakeholder-specific websites in accordance with the relevance of health information. Furthermore, the importance of social help offers and current events as part of the information package might be underpinned, with a particular emphasis on the importance of social networks in the field of rare diseases. The finding that communication of study results is potentially undervalued can be seen as an opportunity to improve the inclusion of information on health innovations in health care systems. As we strive for a high involvement of patients, family members, and physicians to realize efficiency potentials for health care systems, the relevance of health information should be directly translated. Results must not only be considered when creating national rare diseases information platforms such as the ZIPSE but also when updating, redesigning, and implementing national and international rare diseases information platforms.

However, as part of the cocreation process, we solely focused on the subgroups interested in information on rare diseases as an explanatory variable for different information needs. We suggest that future studies examine other potential explanatory variables such as for instance gender, educational background, and civil status.

Finally, our findings might be helpful for improving communication between patients, legal guardians or partners, and health advocates, who are closely intertwined. This seems to have high potential because social and professional networks often remain separate within discussions of rare diseases. Promoting a discussion between stakeholders can help in combining forces within the backdrop of a networking approach, which has already been communicated and pursued through the implementation of national rare diseases plans. An understanding network that engages in successful collaboration can improve the quality of life of those affected by rare diseases, as well as lessen the perceived disease burden.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Description of rare diseases information categories.

[PDF File (Adobe PDF File), 22KB - ijmr_v6i2e23_app1.pdf]

Multimedia Appendix 2

Questionnaire.

[PDF File (Adobe PDF File), 155KB - ijmr_v6i2e23_app2.pdf]

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Abbreviations

ACHSE: Allianz Chronisch Seltener Erkrankungen
AHP: analytic hierarchy process
CHERH: Center for Health Economics Research
CR: consistency ratio
NAMSE: Nationales Aktionsbündnis für Seltene Erkrankungen
SD: standard deviation
ZIPSE: Zentrales Informationsportal über seltene Erkrankungen

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Original Paper

Health-Related Coping and Social Interaction in People with Multiple Sclerosis Supported by a Social Network: Pilot Study With a New Methodological Approach

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Abstract

Background: Social media are a vital link for people with health concerns who find in Web communities a valid and comforting source for information exchange, debate, and knowledge enrichment. This aspect is important for people affected by chronic diseases like multiple sclerosis (MS), who are very well informed about the disease but are vulnerable to hopes of being cured or saved by therapies whose efficacy is not always scientifically proven. To improve health-related coping and social interaction for people with MS, we created an MS social network (SMsocialnetwork.com) with a medical team constantly online to intervene promptly when false or inappropriate medical information are shared.

Objective: The goal of this study was to assess the impact of SMsocialnetwork.com on the health-related coping and social interaction of people with MS by analyzing areas of interest through a Web-based survey.

Methods: Referring to previous marketing studies analyzing the online platform’s role in targeted health care, we conducted a 39-item Web-based survey. We then performed a construct validation procedure using a factorial analysis, gathering together like items of the survey related to different areas of interest such as utility, proximity, sharing, interaction, solving uncertainty, suggestion attitude, and exploration.

Results: We collected 130 Web-based surveys. The areas of interest analysis demonstrated that the users positively evaluated SMsocialnetwork.com to obtain information, approach and solve problems, and to make decisions (utility: median 4.2); improve feeling of closeness (proximity: median 5); catalyze relationships and text general personal opinions (sharing: median 5.6); get in touch with other users to receive innovative, effective, and practical solutions (interaction, solving uncertainty, and suggestion attitude medians were respectively: 4.1, 3, and 3); and share information about innovative therapeutic approaches and treatment options (suggestion attitude: median: 3.3).

Conclusions: SMsocialnetwork.com was perceived by users 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.

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KEYWORDS

social media; eHealth; digital health; multiple sclerosis; social network; Web medicine

Introduction

Social media represent the most important virtual meeting places where users can get in touch with others, overcoming limitations of space and time [1,2] and may be considered a comforting space to share opinions and debate on disease-related concerns [3,4,5], especially for young people suffering from chronic diseases such as multiple sclerosis (MS) [6].

However, people with MS risk being exposed to inaccurate information on the Web [7] due to the assertive value of so-called patient-authored texts [8], which may be lacking in scientific and medically relevant evidence. To overcome this issue, in 2012 we created SMsocialnetwork.com, a social network to improve health-related coping and social interaction for people with MS **.**

The theoretical framework of this study has been suggested by the marketing approach proposed by Koh and Kim [9] in the work “Sense of Virtual Community,” implemented with both the theoretical model of Lazarus and Folkman [10], on psychological well-being during serious illness, and the transactional model of stress and coping [11].

We considered previous marketing studies to investigate SMsocialnetwork.com as a shoppable condition [12,13] (ie, a safe virtual space where one can find the sought-after health information [14-22]), evaluating the role of the online platform in targeted health care according to the clinical questions recommendations of evidence-based medicine (PICO: Problem/population, Intervention, Comparison, and Outcome) [23].

Our methodological approach assessed SMsocialnetwork.com using a Web-based survey in terms of the following areas of interest: utility (equivalent, in marketing research, to information need fulfillment [24]), proximity (measures and sources use of virtual co-presence [25]), sharing (use of self-presentation [23]), interaction (interpersonal communications [26]), solving uncertainty (perceived effectiveness [27]), suggestion attitude (knowledge contribution [26,28]), and exploration (personal innovativeness [29]). Analyzing items in the survey related to each of the 7 areas of interests, we performed a construct validation procedure. In other medical conditions, such HIV and heart disease, health-related Internet usage was associated with disease knowledge, information-seeking, coping, and using social supports as a stress buffer [30,31].

The aim of this study was to evaluate the impact of SMsocialnetwork.com on health-related coping and social interaction in people with MS by analyzing the above mentioned areas of interest through a Web-based survey.

Methods

SMsocialnetwork.com

SMsocialnetwork.com www.SMsocialnetwork.com is a Facebook-like social network dedicated to people with MS, created in 2012 by a group of neurologists and psychologists from the 1st Clinic of Neurology of the University of Campania “Luigi Vanvitelli” with vast experience in MS. It is based on Wordpress [32] and BuddyPress [33], two open source platforms for online communities. Several plug-ins are used to enhance and protect the online user experience.

In order to ensure proper use of the social network, we have guaranteed the constant online presence of neurologists amd psychologists from the medical team to oversee and participate on the public wall, intervening promptly in case of posts with false or inappropriate medical information. Neurologists and psychologists are not involved in technical aspects of the social network (graphic design, Web development, hosting services, and chat implementation were managed by the Web designer) but oversee the public activities of the users, post relevant information about MS, protect users from false rumors and fake news, answer questions via private or public message, and preserve users’ right to hope, in total respect of scientific rigor. Their intervention does not include banning users but does include explaining why that specific post is not scientifically correct. The SMsocialnetwork.com plug-ins were chosen in order to protect user privacy; at the subscription step, users had to agree with the privacy policy. Nonregistered users are able to view only the Welcome and About Us pages. Public wall, surveys, chat, and all other sections of the social network are restricted to registered users only.

SMsocialnetwork.com includes the following sections: (1) public wall and public posts, where users may read, write, post, comment, and get in touch with other users, which is continuously monitored by neurologists and psychologists; (2) streaming pages (oral communications at congresses, examples of outpatients visits, etc); (3) groups and forums on specific MS-related areas (pregnancy, pediatric demyelinating diseases, headache, sport, diet, etc); (4) links to scientific news or MS-related events; (5) private one-to-one and multiple chats; and (6) videos on specific topics uploaded by physicians on the SMsocialnetwork.com staff or external consultants with specific competence in MS. At the time of the investigation, SMsocialnetwork.com included 1020 active users (users who visited SMsocialnetwork.com and logged in over the 2 months prior to the study). The total number of pages viewed was 187,073, the average number of pages viewed per visit was 5, and the average duration of a session was 7 minutes 28 seconds.

Standard Protocol Approvals, Registrations, and Patient Consents

The study was performed in accordance with good clinical practice and the Declaration of Helsinki. All participants consented to the use of recorded surveys for scientific purposes on aggregate level. To protect the anonymity of the participants, the Internet protocol codes of the computers were not registered and no electronic cookies were embedded.

Web-Based Survey

We conducted a Web-based survey availing ourselves of a marketing approach generally used to learn how the system design and the social aspects of Web communities jointly influence members' behavior and participation [24,25,34-36]. We used a 39-item survey posted from April to June 2015 on the SMsocialnetwork.com public wall (displayed in a pop-up window when visitors accessed the website).

The survey was created with the collaboration of the Department of Business and Management of the Free International University for Social Studies "Guido Carli" (LUISS) in Rome and has been hosted on its server. SMsocialnetwork.com and all its data were hosted on an Italian server and MySQL database managed by Aruba Group. The full Italian version of the survey is available in Multimedia Appendix 1.

Measures and Procedures

The 7 main areas of interest on the survey were as follows:

1. Utility (5 items) measured how well the social network supports users in obtaining information, approaching and solving problems, making decisions, and attaining new insights about the disease. For each item, users gave a score on a Likert scale from 1 (not useful at all) to 7 (very useful).
2. Proximity (6 items) measured the user feeling of closeness with other social network users considering real-life relationships, dynamic chatting, and private messaging as well as interesting, supportive, or sympathetic comments on their own posts. Users gave a score on a Likert scale from 1 (do not agree at all) to 7 (strongly agree) (items 1 to 4) and on a Likert scale from 1 (not useful at all) to 7 (very useful) (items 5 and 6).
3. Sharing (6 items) measured how free the user felt to share private life information and general personal opinions in the social network activities (eg chat, posts, comments). Users gave a score on a Likert scale from 1 (do not agree at all) to 7 (strongly agree).
4. Interaction (8 items) measured the user ability to get in touch with other users in the community, playing an active role not only online but also in real life (eg, personal meeting, phone communications). Users gave a score on a Likert scale from 1 (do not agree at all) to 7 (strongly agree).
5. Solving uncertainty (4 items) measured the user's opinion on innovative, effective, and practical solutions regarding MS-related health conditions and management. User gave a score on a Likert scale from 1 (none) to 5 (a lot).
6. Suggestion attitude (5 items) measured user attitude on playing an active or passive role in proposing new suggestions about innovative therapeutic approaches and treatment options. Users gave a score on a Likert scale from 1 (completely passive attitude) to 5 (very active role).
7. Exploration (5 items) measured user tendency to explore other websites related to MS (eg, Web communities, thematic pages on general social networks, blogs, forum, chats). User gave a score on a Likert scale from 1 (not explorative at all) to 7 (very explorative).
8. At the end of the survey, users were asked to complete a satisfaction rating on SMsocialnetwork.com based on a Likert scale from 1 (not satisfied at all) to 7 (very satisfied) including items concerning degree of satisfaction regarding personal experience in the SMsocialnetwork.com community and degree of complexity regarding personal experience in the SMsocialnetwork.com community.

Statistical Analysis

Descriptive statistics are presented as relative frequencies, medians or means, and standard deviations, where applicable. Factorial analysis was performed to confirm the hypothesized domain structure and was implemented for each area of interest, considering only the first factor. Cronbach alpha was used to evaluate internal consistency reliability of each factor. Values above 0.70 for Cronbach alpha and above 0.8 for variance were considered acceptable. Items were excluded if they exhibited a low correlation with the construct, having a communality or item-rest correlation lower than 0.2. To evaluate consistency of items separately in each area of interest, we used factorial analysis to confirm that these items represent the same construct. Stata 13.0 (StataCorp LLC) was used for all analyses.

Results

From April to June 2015, surveys from 202 users were collected from a total of 1020 active users. We excluded 72 questionnaires because of incomplete answers; 130 questionnaires (males 19/62, 30.6%, and females 43/62, 69.4%) were considered for the analysis. The response rate, defined as the percentage of users who filled out the survey over the total number of active users, was 12.74%; 1.6% (1/63) of users were younger than 20 years, 44.4% (28/63) were between ages 20 and 39 years, 34.9% (22/63) were between ages 40 and 54 years, 14.3% (9/63) were between ages 55 and 59 years, and 4.8% (3/63) were older than 60 years (see Table 1 for further data).

Utility (5 items) median values were 4 or 5 for all items (see Multimedia Appendix 2 for details). The factorial analysis confirmed the consistency of utility: first factor accounted for 100% of variance and Cronbach alpha coefficient was 0.95. All items had a high communality and item-rest correlation. The mean utility was 4.2 (SD 1.8) and the median (Q1-Q3) value was 4.2 (2.8-5.6).

Table 1. Demographic and clinical data.

Characteristic	Response rate (%)	Totals
Gender, n (%)	47.7	
Female		43 (69.4)
Male		19 (30.6)
Age, n (%)	48.5	
<20 years		1 (1.6)
20-39 years		28 (44.4)
40-54 years		22 (34.9)
55-59 years		9 (14.3)
>60 years		3 (4.8)
Education, n (%)	49.2	
8 years		9 (14.1)
13 years (high school)		24 (37.5)
3-year degree		10 (15.6)
Master’s degree		15 (23.4)
PhD		3 (4.7)
Other		3 (4.7)
Disease duration, years, mean (SD)	90.0	7.7 (7.5)
Treatment/therapy duration, years, mean (SD)	86.9	6.7 (6.9)
Frequency of SMsocialnetwork.com access, n (%)	95.4	
≤1 time per month		43 (34.7)
1 time per week		18 (14.5)
>1 time per week		40 (32.3)
Daily		16 (12.9)
>1 time per day		7 (5.7)
Frequency of SMsocialnetwork.com access compared to total Internet access, n (%)	93.8	
All the time		15 (12.3)
>1 time		33 (27.1)
Sometimes		32 (26.2)
Few times		19 (15.6)
Rarely		23 (18.9)
Self-reported health status, n (%)	96.2	
Excellent		10 (8.0)
Good		35 (28.0)
Average		44 (35.2)
Not very good		29 (23.2)
I prefer not to answer		5 (4.0)
Other		2 (1.6)

Table 2. Analysis results summary of the areas of interest.

	Mean (SD)	Median	Q1-Q3	%	Maximum	Alpha
Utility	4.2 (1.8)	4.2	2.8-5.6	60	7	0.95
Proximity	4.5 (1.3)	5	3.7-5.5	71	7	0.85
Sharing	5.3 (1.4)	5.6	4.4-6.2	80	7	0.85
Interaction	3.9 (1.5)	4.1	2.9-5.3	59	7	0.9
Solving uncertainty	2.8 (0.8)	3	2-4	60	5	0.79
Suggestion attitude	3.3 (1.0)	3	3-4	60	5	0.76
Explore	4.7 (1.3)	5.3	4.6	76	7	0.85

Proximity (6 items) median values were 4 or 5 for all items (see Multimedia Appendix 2). The factorial analysis confirmed the consistency of proximity: first factor accounted for 82% of variance and Cronbach alpha coefficient was 0.85. All items had a high communality and item-rest correlation. The mean proximity was 4.5 (SD 1.3) and the median (Q1-Q3) value was 5 (3.7-5.5) (see Table 2).

Sharing (6 items) median values were 5 or 6 for all items except for item “I use a nickname to distinguish myself in this community” (see Multimedia Appendix 2) that also showed a poor communality (0.001) and item-rest correlation (0.05) and was not included in the final analysis. The factorial analysis confirmed the consistency of sharing: first factor on the residual 5 items accounted for 100% of variance and the Cronbach alpha coefficient was 0.85. All residual items had a high communality and item-rest correlation. The mean sharing was 5.2 (SD 1.4) and the median (Q1-Q3) value was 5.6 (4.4-6.2) (see Table 2).

Interaction (8 items) median values ranged from 3 to 6 (see Multimedia Appendix 2). The factorial analysis confirmed the consistency of interaction: first factor accounted for 80% of variance and Cronbach alpha coefficient was 0.90. All items had a high communality and item-rest correlation. The mean interaction was 3.9 (SD 1.5) and the median (Q1-Q3) value was 4.1 (2.9-5.3) (see Table 2).

Solving uncertainty (4 items) median value was 3 for all items (see Multimedia Appendix 2). The factorial analysis confirmed the consistency of solving uncertainty: first factor accounted for 100% of variance and Cronbach alpha coefficient was 0.79. All items had a high communality and item-rest correlation. The mean solving uncertainty was 2.8 (SD 0.8) and the median (Q1-Q3) value was 3 (2-4) (see Table 2).

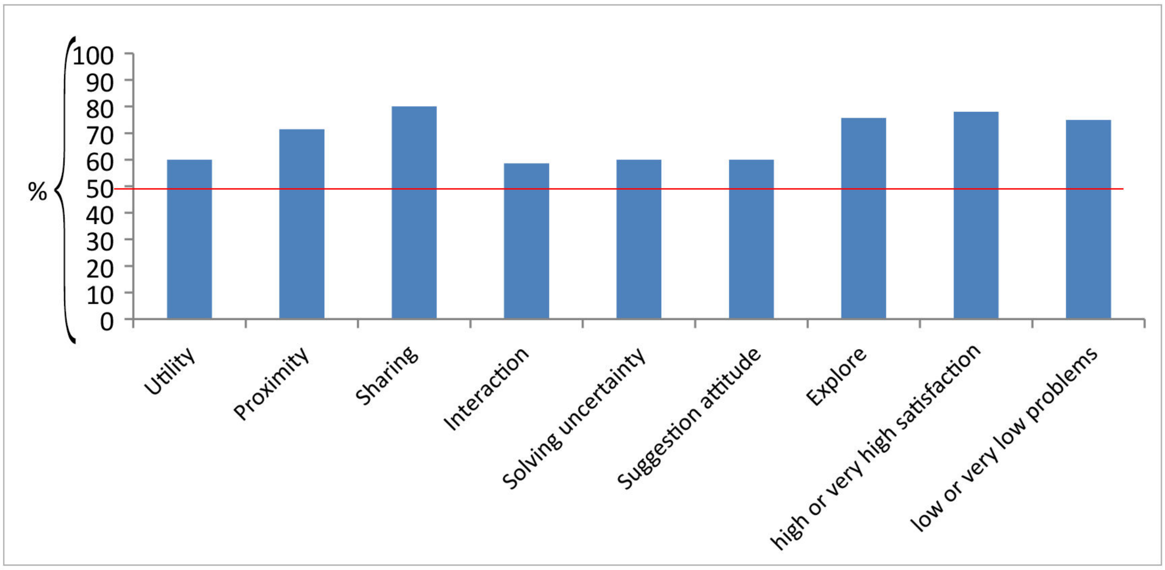
Suggestion attitude (5 items) median values ranged from 2 to 4 (see Multimedia Appendix 2). The meaning of the Likert scale in the item “In the discussions on treatments and drugs, you are more prone to listen/convince the other members of the contrary” (ie, high value meant low attitude to suggest and low value showed a high attitude to suggest) with respect to the other item scales and the relative values was reversed in the factorial analysis. This item and the item “In the discussion on treatment and drugs, you are more prone to listen or talk” showed a poor communality and item-rest correlation (0.0 and 0.17), and they were not included in the final analysis. The factorial analysis confirmed the consistency of suggestion attitude: first factor on the residual 3 items accounted for 100% of variance and the Cronbach alpha coefficient was 0.76. The residual 3 items had a high communality and item-rest correlation. The mean suggestion attitude was 3.3 (SD 1.0 and the median (Q1-Q3) value was 3 (3-4) (see Table 2).

Exploration (5 items) median values ranged from 3 to 6 (see Multimedia Appendix 2). The meaning of the Likert scale of the item “Usually I am not interested in visiting new websites” was contrary (ie, high value meant low attitude to explore and low value showed a high attitude to explore) with respect to the other item scales and the relative values were reversed. This item was removed because it showed a low communality and a low item-rest correlation. The factorial analysis confirmed the consistency of exploration: on the residual 4 items, Cronbach alpha coefficient was 0.85. The residual 4 items had a high communality and item-rest correlation. The mean explore was 4.7 (SD 1.3) and the median (Q1-Q3) value was 5.3 (4-6) (see Table 2).

Only solving uncertainty had low alpha (>0.8) and communality (0.2) scores. However, we considered the values ≥0.8 for variance and ≤0.2 for communality or item-rest correlation acceptable.

For each area of interest, the range and meaning of the Likert scale corresponded to the same range and meaning of each item used to identify it (ie, low value equals low degree of agreement and high value equals high degree of agreement). Finally, 78.2% of SMsocialnetwork.com users showed a high or very high degree of satisfaction regarding personal experience in the SMsocialnetwork.com community, and 75% of SMsocialnetwork.com users showed a low or very low degree of personal problematic experiences in the SMsocialnetwork.com community (see Figure 1).

Figure 1. Median scores of survey main areas and degree of satisfaction regarding personal and problematic experiences in SMsocialnetwork.com, reported as a percentage of the relative Likert scales (from 1 to 5 or 7).



Discussion

Principal Findings

In our analysis, the median scores of the areas of interest were above (utility, proximity, sharing, interaction, and exploration) or equal (solving uncertainty and suggestion attitude) to the intermediate value of the Likert scale. These data indicated, in line with the previous work of Oxman and Guyatt [37], a satisfaction with SMsocialnetwork.com (see Figure 1). Indeed, users positively evaluated SMsocialnetwork.com in the following areas:

1. Obtaining information, improving the approach to solve problems and making decisions, and providing new insights about MS
2. Improving the feeling of closeness toward other social network users
3. Catalyzing relationships, sharing private life information, and texting general personal opinions
4. Getting in touch with other users playing an active role especially online but also, to a lesser extent, in real life
5. Receiving innovative, effective, and practical solutions regarding MS-related issues and management
6. Delivering information about innovative treatment options

Furthermore, SMsocialnetwork.com users showed a tendency to explore other Web pages related to MS (eg, Web communities, thematic pages on general social networks, blogs, forum, chats) and exhibited both a high degree of satisfaction and a low degree of problematic experiences in the SMsocialnetwork.com community.

Social networking is one of the major players in the current era of transformational changes in how information is accessed and shared [38]. It is known that social networks transmit media such as video, blogs, ratings and reviews, podcasts, and audio among a group of people who are linked by a common characteristic, such as likes and dislikes [39]. Although social networks are considered primarily a recreational tool, they are becoming increasingly important to businesses and organizations [40]. Specifically, social networks hold considerable potential value for health care organizations because they can be used to reach stakeholders, aggregate information, and leverage collaboration [28,41]. In health-related areas, social networks users may find a way to track progress about the disease and access disease information, learn from real-world experiences of other people with the same medical condition, share their findings with other patients and with health care professional organizations, and create a virtual space where patients and caregivers give and receive support [42-45]. The high number of disease-related Internet pages is likely due to the ease of taking advantage of the Web's opportunities through the virtual environment. Recent research showed that a high number of Americans get information about therapies or diseases online [5] and a very high number of physicians and nurses are interested in using social networks for professional purposes. Because both patients and clinicians are using social networks, health care organizations have an opportunity to leverage multiple audiences. Recently, it has been recorded that more than 700 of the 5000 US hospitals count on social media and social networking to enhance their ability to communicate to stakeholders. Despite a high number of Web pages dedicated to MS, to the best of our knowledge, there are no social networks specifically dedicated to MS, and SMsocialnetwork.com is the first social network to share evidence-based information with the added value of the constant online presence of the medical experts. Using a Web-based survey, we investigated SMsocialnetwork.com as a shoppable condition [12,13,20] in which users may acquire information to support health-related coping and their social interaction.

We observed that MS patients interact on the Internet not only about MS-related issues but also on general personal opinions and private life information (sharing). Moreover, users showed a tendency to play an active role online by dynamic chatting and private messaging as well as posting interesting, supportive, or sympathetic comments (proximity). We observed a low user tendency to get in touch with other users in real life (interaction). While SMsocialnetwork.com users appreciate an intimate, close, and empathic community, they prefer an online relationship than face-to-face interaction compared to people in nonthematic Web communities. Indeed, the users of generalist social networks (eg, Facebook) seem to have close relationships in real life, and only a small percentage of social network users have never met or only met their Internet-based friends once [46], supporting that online social media are not a substitute for real-life interpersonal exchanges but offer a different experience that brings people together. We cannot exclude the role of MS disability on the reduced user real-life interpersonal relationships, as previously found in other chronic diseases [47-50].

Limitations

In this study, we collected 130 questionnaires, which may be considered a small number for a factorial analysis. However, we used the factorial analysis only to confirm the construct identified by items; on these premises our results should not have been affected by a larger sample size. Moreover, our response rate is in accordance with the mean response rate of social network–based studies, ranging from 2% to 27% with an average of 12%, generally considered as an indicator of reliable data quality for social network–based studies [51,52].

We excluded 35.6% of the surveys from the final analysis, which had more than 20% of the missing data. This is in line with the very high percentage of missing data generally observed in online surveys, where the anonymity allows inaccurate answers or early interruption of the questionnaire (missing data range from 15% to 20% in quantitative research) [53].

We cannot compare our data with those from other MS social networks without constant online presence of the medical team. Indeed, to the best of our knowledge, there are no social networks specifically dedicated to MS.

In our survey there were no items directly investigating the appreciation of MS experts’ contribution in SMsocialnetwork.com. However, in our factorial analysis, median scores of the areas of interest indicated, in any case, a general satisfaction [37] with the Web platform (see Figure 1). Obviously, we can only speculate about the advantage brought by the constant online presence of the SMsocialnetwork.com medical team. Finally, SMsocialnetwork.com did not provide an explanatory tutorial that would have been useful to facilitate users completing the survey [52].

Conclusion

In this study, we observed that an MS-dedicated social network (SMsocialnetwork.com) is perceived by users as a useful tool to receive information and solve problems in daily life, providing innovative and effective insights about MS health care. Moreover, users were prone not only to give information but also to hear and listen to others, and they did not try to convince and impose their opinions; they appeared to like discussing personal problems at the same level with others. We speculate that users were reassured by SMsocialnetwork.com experts’ constant online presence and competence. We also believe that an MS-dedicated social network may allow MS experts to reach a deeper comprehension of the needs of people with MS and may suggest how to improve both medical communications and clinical empathy, likely configuring a new kind of therapeutic alliance between physicians and patients.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Survey questionnaire in original language (Italian).

[PDF File (Adobe PDF File), 123KB - ijmr_v6i2e10_app1.pdf]

Multimedia Appendix 2

Survey items.

[XLSX File (Microsoft Excel File), 14KB - ijmr_v6i2e10_app2.xlsx]

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Abbreviations

LUISS: Free International University for Social Studies “Guido Carli”
MS: multiple sclerosis

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Original Paper

Short-Term Efficacy of an Innovative Mobile Phone Technology-Based Intervention for Weight Management for Overweight and Obese Adolescents: Pilot Study

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Abstract

Background: In the United States, approximately one-third of adolescents are now overweight or obese, and one in six is obese. This financial cost and the larger nonfinancial costs of obesity make obesity prevention and management for adolescents imperative for the health of the nation. However, primary care visits are typically brief, and primary care providers may lack adequate resources to help overweight or obese adolescents to manage weight issues. To augment the efficacy of primary care visits for adolescent weight management, mobile phone technology can be used as an adjunct treatment that provides additional opportunities for encouraging improvement in lifestyle, attainment, and maintenance of healthy weight.

Objective: The purposes of this study were to (1) measure effects of an innovative mobile phone technology-based intervention for overweight and obese adolescents and to (2) examine the intervention's feasibility for use in primary care clinics.

Methods: The mobile phone-based intervention had three components: use of the Fitbit Flex, participation in an online educational program, and receipt of biweekly text messages during the maintenance phase. A randomized controlled study design was utilized. Data regarding anthropometrics (body mass index [BMI] and waist-to-hip ratio), blood pressure, levels of physical and sedentary activity, diet, and self-efficacy regarding physical activity and diet were collected at baseline and at 3 and 6 months after the baseline assessment.

Results: A total of 40 adolescents participated in the study. At the 6-month follow-up visit, compared to participants in the control group, the mobile phone-based intervention participants had significant improvement in BMI ($z=-4.37$, $P=.001$), diastolic blood pressure ($z=-3.23$, $P=.001$), physical activity days per week ($z=2.58$, $P=.01$), TV and computer time ($z=-3.34$, $P=.001$), servings of fruits and vegetables per day ($z=2.74$, $P=.006$), servings of soda and sweetened drinks ($z=-3.19$, $P=.001$), physical activity self-efficacy ($z=2.75$, $P=.006$), and dietary self-efficacy ($z=5.05$, $P=.001$). Medium to large effect sizes were found in these outcome variables.

Conclusions: The use of mobile technologies may offer a practical, reliable adjunct to weight management for overweight and obese adolescents in busy primary care clinics serving adolescents.

Trial Registration: Clinicaltrials.gov NCT 01693250; https://clinicaltrials.gov/ct2/show/NCT01693250? term=Adolescent+obesity+AND+mhealth&rank=5 (Archived by WebCite at)

(Interact J Med Res 2017;6(2):e12) doi:10.2196/ijmr.7860

KEYWORDS

adolescent; obesity; mobile phone technology; website; randomized clinical trial

Introduction

During the last three decades, the prevalence of overweight and obesity in adolescents has increased in many parts of the world [1]. Chinese Americans are the largest group of Asian immigrants in the United States and approximately 20% to 25% of Chinese American adolescent are now overweight or obese [2]. At the same body mass index (BMI), Chinese Americans are at higher risk of developing hypertension and cardiovascular disease than are non-Hispanic whites [3,4]. Obesity during adolescent years is associated with many adverse health consequences, including type 2 diabetes mellitus, hypertension, hyperlipidemia, and psychosocial problems [5-8]. Moreover, approximately 70% of overweight adolescents and 80% to 90% of obese adolescents become obese as adults [9]. The direct medical cost of childhood obesity is estimated to be US $14 billion [10]. This financial cost and the larger nonfinancial costs of obesity make obesity prevention and management for adolescents imperative for the health of the nation, especially for high-risk and understudied adolescent populations. Important components in successful weight management for overweight or obese adolescents include increasing physical activity and decreasing sedentary activity and dietary intake [11,12]. Several strategies that promote self-monitoring and setting realistic goals have been found to improve obesity-related health behaviors (eg, physical activity, sedentary activity, and dietary intake) and prevention of obesity [13-15].

Because most adolescents receive their health care in primary care facilities, these settings are an appropriate venue for the development and promulgation of effective, feasible interventions to improve weight status and maintain healthy weight. A recent meta-analysis of 12 intervention studies has reported that a brief office-based primary care intervention to prevent obesity reduced BMI by a small but statistically significant degree (Cohen d=–0.04, P=.02); in comparison, control groups receiving no treatment, usual care, or active control treatments had no reduction or no substantial reduction of BMI [16]. However, primary care visits are typically brief, and primary care providers may lack adequate resources to help overweight or obese adolescents to manage weight issues. To augment the efficacy of primary care visits for adolescent weight management, mobile phone technology can be used as adjunct treatment that provides additional opportunities for encouraging improvement in lifestyle, attainment, and maintenance of healthy weight.

In the United States, approximately two-thirds of adolescents have a mobile phone, 91% of adolescents use the Internet via a mobile device, and most adolescents have Internet access at home [17]. In an era of advanced, affordable mobile phone technology, mobile phone interventions related to weight management can provide youths with immediate, tailored feedback [18]. The monitor device and apps can also increase adolescents’ ability to understand information, to self-monitor obesity-related behaviors, and to adhere to these clinical recommendations for successful weight management. However, few studies have examined the effects of mobile phone-based interventions used in primary care clinics for weight management in overweight and obese adolescents.

A systematic review of 14 randomized or nonrandomized clinical studies on the effect of technology-based interventions for obesity prevention in adolescents found that only six studies reported decreases in BMI or body fat percentage in the short term (less than 12 months). Results regarding physical activity, dietary behavior, and psychosocial outcomes, found that five of 11 studies did not find improved physical activity, six of 11 studies did not find improved dietary behavior, and two of seven studies did not find improvement in self-efficacy, self-competence, and peer support [19]. However, a second systematic review that examined two randomized clinical trials reported that overweight or obese children and adolescents participated in mobile phone-based interventions of 2 to 3 months’ duration substantially decreased the BMI-z scores compared with children and adolescents in control groups at 12 months after the intervention [20]. These two systematic reviews suggest that in this body of research, efficacy of technology-based interventions on weight management and behavior modification are inconclusive.

In this pilot study, using evidence from research on technology in clinical practice facilitated development of a hybrid intervention that combined lifestyle modification with routine clinical care. Chief among the benefits of this hybrid mobile phone technology-based intervention was the potential to improve health outcomes and reduce obesity in overweight and obese adolescents. This paper describes both phases of the study: phase 1 design and phase 2 pilot study. The aims of the pilot study were to (1) measure effects of an innovative mobile phone technology-based intervention for overweight and obese adolescents and to (2) examine the intervention’s feasibility for use in primary care clinics.

Methods

Phase 1: Designing the Intervention

Advisory Team and Stakeholders

The first step in the design phase was to establish an advisory team that could engage key stakeholders in this research project. Stakeholder engagement was necessary to ensure that the study would be not only clinically relevant but also feasible for adolescents in primary care settings. An advisory team consisting of two primary care providers and four adolescents was established to provide input on the design of both the study and the mobile phone-based intervention. The research team worked with the advisory team several times to review the study’s purpose and goals and to identify eight topics for an online educational program that we named “iStart Smart for Teens.” Each team meeting lasted approximately 90 minutes. The research team presented evidence-based content that the research team identified and potential ways to present this content to the advisory team. The advisory team worked with the research team to shape this content and also provided ideas on delivery modes that would be attractive to adolescents. The initial mobile phone-based intervention content was developed based on feedback from the advisory team.

Adolescent Focus Group Review

The initial version of the mobile phone-based intervention was reviewed by 10 adolescents in a focus group interview. The focus group, which met for 90 to 120 minutes, had two tasks. First, the group identified optimal procedures for using an activity-monitoring device (Fitbit Flex) to track adolescents' weight-related health behaviors (physical activity, sedentary activity, and food intake). Second, the focus group assessed the appropriateness of the mobile phone-based intervention's iStart Smart for Teens program. (Both Fitbit Flex and the iStart Smart for Teens program are described subsequently.) In leading the focus group discussions, the moderator used semistructured, open-ended guidelines. Overall, adolescents liked the mobile phone-based intervention. Minor suggestions regarding format of the online module and Fitbit apps were noted in the focus group. Subsequent to the focus group sessions, the research team used the group's input to refine the online modules. These focus group members did not participate in the intervention pilot study.

Structure of the Intervention

The mobile phone-based intervention had three components: use of the Fitbit Flex (6 months), participation in the iStart Smart for Teens online educational program (3 months), and receipt of biweekly text messages during the maintenance phase (3 months; see Figure 1). Both the Fitbit Flex app and the online program included tracking of physical activity, sedentary activity, and dietary intake progress; setting realistic individualized goals; monitoring progress related to reaching the goals; providing tips for everyday activities; and having interactive apps related to improving weight status and maintaining healthy weight.

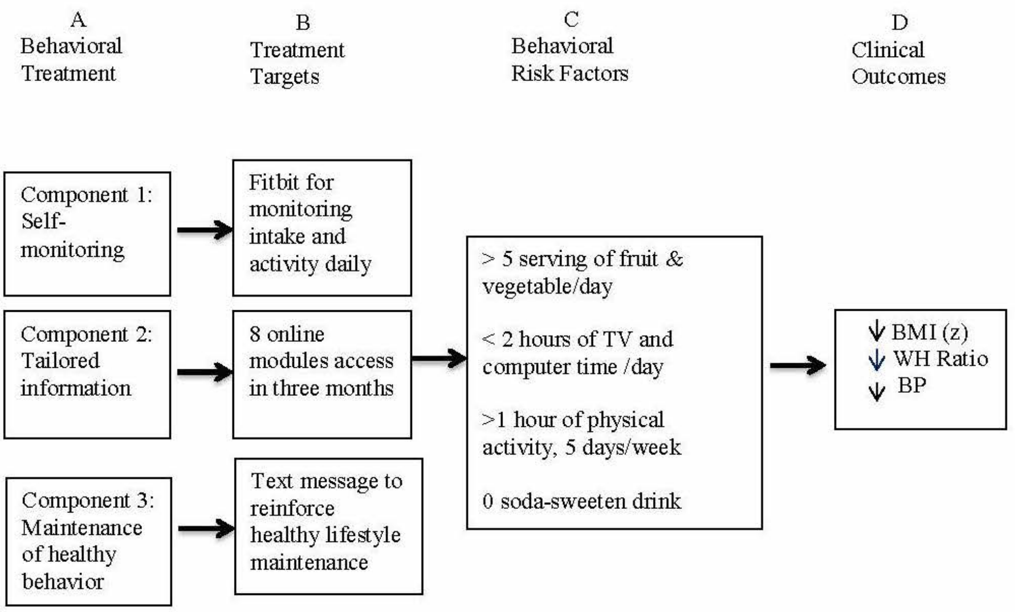
Fitbit Flex

A commercial monitoring device (Fitbit Flex) and its mobile phone app were selected as the technology for monitoring activity level and dietary intake. The Fitbit Flex is a wristband that tracks steps, distance (of running or walking), calories burned, minutes in activity, and minutes in sleep. Users could also record and track their dietary intake via the Fitbit mobile app. Individuals can check real-time statistics on their cellphone at any time with a quick glance at the Fitbit website or app. Individuals could also use a customized dashboard to analyze data on a daily basis and chart progress over time. Participants were given a study hotline telephone number to call if they encountered problems using the Fitbit Flex and the online program. Participants were asked to wear the Fitbit Flex device and were encouraged to use the app every day for the study's duration. A weekly message was sent to the adolescents to remind them to use the Fitbit device.

The iStart Smart for Teens Program

All information in the program was presented in English. The eight-module iStart Smart for Teens educational program used an online format consisting of short videos and animation narratives; the modules were accessible via both mobile phone and computer. In addition, the mobile phone-based intervention participants received instructions regarding topically relevant activities via mobile phone or computer; supplementary general information and tips were presented via app messages. Each of the program's modules (ie, classes) could be completed in 10 minutes or less. Participants in the mobile phone-based intervention group were asked to complete one module per week and the entire iStart Smart for Teens program within a 3-month period.

Figure 1. Pathway for Weight Management for Mobile phone-based intervention.



Module Structure

In design and style, the iStart Smart for Teens modules were patterned on popular online modules used by the Khan Academy. The Khan Academy online modules use integrated multimedia learning formats and variety of presentation strategies, including animation, short videos, and self-paced learning. The Khan Academy modules' design and style were suggested for use in the iStart Smart for Teens modules by the pilot study's advisory board members.

Topics

The iStart Smart for Teens program topics pertained to lifestyle modification, weight management, and stress management. The online modules' titles were (1) Introduction to the Eight Weekly Lessons and the 5-2-1-0 Message (ie, 5 servings of fruits and vegetables, 2 hours of screen time, 1 hour of physical activity, 0 sugary drinks) [21]; (2) Energize Your Health: Energy Balance and Nutrition; (3) Energy Balance: Nutrition; (4) Energy Balance: Physical Fitness; (5) Find Fun in Physical Activity: Energy Out; (6) Less Sit, More Fit: Decrease Screen Time; (7) Smart Problem Solving and Stress Management; and (8) Maintain a Healthy Weight for Life. The program also included activities to enhance adolescents' self-efficacy and facilitate their understanding and use of problem-solving skills related to physical activity, diet, and coping strategies.

Content Sources and References

The content of the iStart Smart for Teens modules was consistent with clinical guidelines for childhood obesity prevention [22]. The modules focused on the "5-2-1-0 message" (to ensure conformity with clinical guidelines, the program adapted information and tips from the We Can! 5-2-1-0 message [21]). The content of the text messages was based on information from several official sources (eg, American Academy of Pediatrics, Centers for Disease Control and Prevention [CDC], and World Health Organization). Text messages and information related to the 5-2-1-0 message included how to be a smart consumer, incorporate colorful and tasty vegetables and fruits in your meals, balanced nutrition for teens, ways to avoid sugary drinks, physical activity for every day, and limited screen time. Tips also included sharing meals with friends so you can enjoy small portions, mixing the colors in your meal by including different vegetables, and going jogging or walking with friends on a beautiful day.

Cultural Sensitivity and Appropriateness

Because the majority of patients in the partner primary care clinics were Chinese immigrants, the iStart Smart for Teens modules were tailored to both Chinese and Western cultures. To further ensure cultural concordance, sensitivity, and appropriateness, module materials were modified to reflect common beliefs and practices of Chinese American adolescents living in both Chinese and Western cultures in the United States. Accordingly, the modules discussed common Chinese and Western dietary practices, concepts, and beliefs with regard to promoting balance in health (including the Chinese concepts of *yin, yang,* and *chi*) and presented opportunities for participants to sample healthy Chinese and Western foods.

Maintenance Phase

Following completion of the iStart Smart for Teens online program, participants began the mobile phone-based intervention's 3-month maintenance phase. During this maintenance phase, participants received biweekly text messages that encouraged and stabilized positive behavior changes. The text messages included tips for lifestyle modifications, achievement of healthy weight status, and healthy weight maintenance. Sample messages included "The weather forecast indicates this week is going to be beautiful. Invite friends for a walk or best to catch some balls with friends" and "Got Vegs-add your favorite vegetables to the meal." Also, the mobile phone-based intervention group participants were encouraged to share their Fitbit data as a basis for weight management discussion and planning with their primary care provider at the clinics. Participants who did not use either Fitbit Flex or the app for more than 1 week received a text message to encourage consistent use. In addition, participants who did not use the Fitbit Flex for more than 2 weeks received a phone call from the research assistant.

Theoretical Underpinning: Social Cognitive Theory

The design and execution of the mobile phone-based intervention were informed by social cognitive theory (SCT), which holds that several key concepts such as self-efficacy, outcome expectation, skill mastery, and self-regulation capabilities are used to explain and predict behavior [23-25]. Specifically, the intervention's aim was to increase adolescents' self-efficacy by setting realistic and achievable goals and outcomes, providing necessary skills, and improving support to promote physical activity and healthy diet [23]. In accordance with SCT, the use of the Fitbit Flex and its apps promoted increased self-monitoring, and the use of the iStart Smart for Teens program provided necessary information and skills for weight-related behavior change (eg, recommendations for fruit and vegetable intake, physical activity, sedentary activity, and sugary drink consumption). The intervention's text message tips reinforced participants' adoption and maintenance of healthy lifestyles and weight management practices. Specifically, for overweight and obese adolescents, these tip messages helped to decrease excessive weight gain, waist-to-hip ratio, and blood pressure (see Figure 1).

Phase 2: Pilot Study of the Intervention

A randomized controlled study design with an active control group was used to estimate the effect size and assess the feasibility of the mobile phone-based intervention. The study was approved by the Committee on Human Research at the University of California, San Francisco (#12-09686).

Study Procedure

Participant Recruitment

To recruit eligible adolescents, the trained research assistant worked with primary care providers at two large community clinics whose patient populations were predominantly Chinese American in northern California. A study invitation letter was posted in the clinics. Pediatricians at the clinics were also given a study invitation letter to give to families of overweight or obese adolescents when they came to the clinics. A response letter and a self-addressed, stamped return envelope was included with the letter. To indicate whether they and their overweight adolescent wished to participate in the study, potentially eligible families were asked to mail the response letter within 2 weeks of receiving it.

Eligibility Criteria

To be eligible to participate in the study, an adolescent had to (1) be aged between 13 and 18 years, (2) have a BMI greater than or equal to 85th percentile (as indicated by the CDC growth chart), (3) own a mobile phone, (4) have access to a computer with Internet access, (5) be able to speak and read English, and (6) be a patient at one of the clinics participating in the study. Eligible adolescents also had to be in good health, be free of acute or life-threatening disease, and be able to engage in activities of daily living such as attending school.

Induction Into the Study

After receiving signed informed consent forms from both the adolescents and their parents, the adolescents completed online questionnaires regarding dietary intake, physical activity, and self-efficacy related to physical activity at baseline and at 3 months and 6 months after the baseline assessment. The adolescents' weight, height, waist and hip circumferences, and blood pressure were also measured by a trained research assistant at baseline, 3 months, and 6 months at the study sites. Parents provided demographic data regarding parental age, parental education level, and household income at baseline.

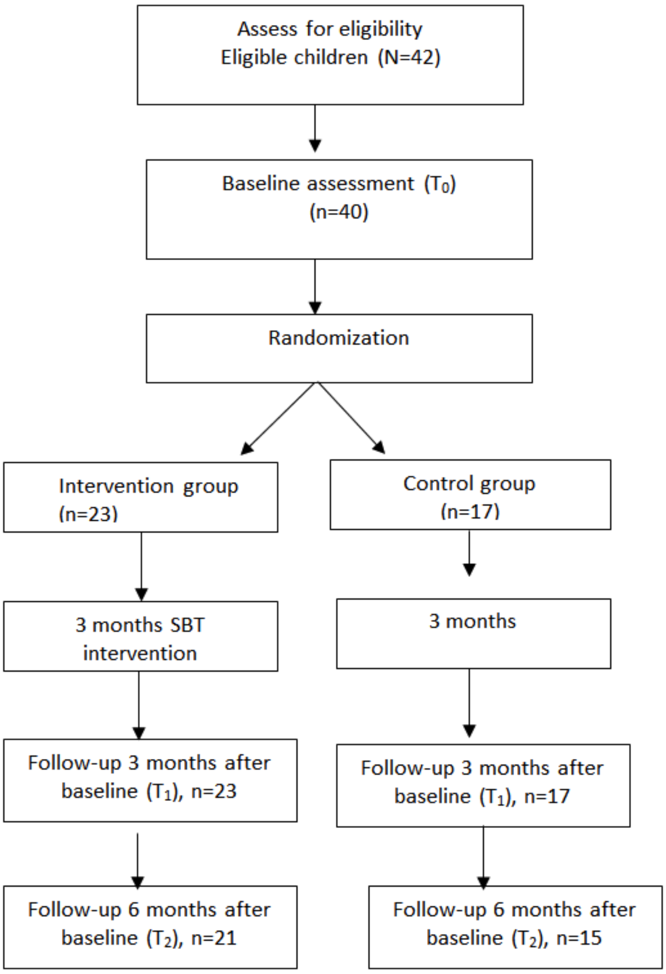
Assignment to Group

After the baseline assessment, the principal investigator randomly assigned eligible participants—40 overweight or obese adolescents—to either the mobile phone-based intervention group (n=23, 58%) or the control group (n=17, 42%) using a randomization table that was stratified by gender; the table was provided by an SPSS program (Figure 2).

The Mobile Phone-Based Intervention Group

After completion of the baseline assessments, adolescents in the mobile phone-based intervention group received a Fitbit Flex and downloaded an app and a link to the iStart Smart for Teens program to their mobile phone. Adolescents received in-person demonstrations and written instructions on how to access the Fitbit data and the iStart Smart for Teens program via cellphone and website.

Figure 2. Study CONSORT flow diagram.



The Control Group

After completion of the baseline assessments, control group participants were given an Omron HJ-105 pedometer and a blank food-and-activity diary and were asked to use the pedometer and diary for 3 months. Participants were asked to record and track physical activity, sedentary activity, and food intake in the diary. They also accessed an online program that consisted of eight modules related to general adolescent health issues, such as diet and nutrition, dental care, safety, common dermatology care, and risk-taking behaviors. The online program's content was based on information from the American Academy of Pediatrics; in the program's content and presentation, cultural concordance was not a consideration. Completion of each of the online program's modules required less than 10 minutes. All information was presented in English. All study participants received a US $20 gift card after completion of each data collection.

Measurement

To determine the effects of the mobile phone-based intervention, participants in both the mobile phone-based intervention group and the control group were measured with regard to anthropometrics (BMI and waist-to-hip ratio), blood pressure (systolic and diastolic), levels of activity (physical and sedentary), diet (fruits/vegetables and sodas/sweetened drinks), and self-efficacy (regarding physical activity and diet).

Anthropometry

Anthropometric measurements entailed calculation of BMI and waist-to-hip ratio. Participants' BMI was determined by dividing body mass by height squared (kg/m^2). The BMI-z score, which corresponds to the growth chart percentiles, was also calculated. For BMI, adequate sensitivity and specificity has been reported in children and adolescents, with sensitivity ranging from 29% to 88% and specificity ranging from 94% to 100% [26]. *Overweight* is defined as BMI percentile between 85th and 94th percentile; *obese* is defined as BMI percentile greater than the 95th percentile (percentiles are based on data in the CDC growth chart. Waist circumference was measured with a tape measure at the uppermost lateral border of the hip crest (ilium); hip circumference was measured at the maximal protrusion of the buttocks. Measurements were taken twice, and the circumferences were calculated as the mean of the two measurements to the nearest 0.1 cm [27]. The waist-to-hip ratio was derived from the waist and hip circumferences.

Blood Pressure

Systolic blood pressure and diastolic blood pressure were measured by using a mercury sphygmomanometer with specific cuff size appropriate for adolescents (Baumanometer, WA Baum Co, Copiague, NY, USA). After participants sat for 10 minutes, blood pressure was measured twice in the adolescent's right arm; blood pressures were measured to the nearest 2 mm Hg.

Physical-Sedentary Activity

To estimate participants' level of physical activity, they were asked a question from the California Health Interview Survey (CHIS): "Over a typical week, on how many days are you physically active for at least 60 minutes total per day?" [2]. A participant's stated number of days was used as the estimate for that participant. To estimate participants' level of sedentary activity, they were first asked to think about their free time during weekdays as well as weekends. They were then asked three CHIS questions: "On a typical day, about how many hours do you usually watch TV or play video games?" "About how many hours per day on Monday through Friday do you use a computer for fun, not schoolwork?" and "On a typical Saturday and Sunday, about how many hours per day do you usually watch TV or play video games?" [2]. The mean of the total number of hours spent daily in these sedentary activities was calculated as sedentary activity time.

Fruit/Vegetable and Soda/Sweetened Drinks Consumption

To assess participants' fruit and vegetable consumption, they were asked two CHIS questions: "Yesterday, how many servings of fruit, such as an apple or banana, did you eat?" Similarly, to assess sugary-sweetened drink consumption, participants were also asked, "Yesterday, how many glasses or cans of sweetened fruit drinks, sports, or energy drinks did you drink?" [2].

Physical Activity Self-Efficacy

The five-item subscale of the Health Behavior Questionnaire was used to measure the adolescents' degree of self-confidence in their ability to successfully participate in various age-appropriate physical activities [28]. Participants were asked if they could perform activities such as "keep[ing] up a steady pace without stopping for 15 to 20 minutes." Response options were (1) not sure, (2) a little sure, or (3) very sure; higher scores indicated greater self-efficacy.

Dietary Self-Efficacy

The self-report dietary self-efficacy questionnaire measured adolescent's self-confidence in their ability to choose foods low in fat and sugar [29]. The questionnaire contained 15 items, each of which began with the stem "How sure are you...?" Likert scale response options were (1) not sure, (2) a little sure, or (3) very sure; higher scores indicated greater self-efficacy.

Program Evaluation

After finishing the iStart Smart for Teens program, participants completed a six-item multiple-choice program evaluation questionnaire that asked questions such as "What do you think of the program?" "In what way was this program useful to you?" and "I will recommend this program to other adolescents."

Analysis

Demographic characteristics and all major study variables including feasibility data were calculated descriptive statistics. To compare differences between the mobile phone-based intervention group and the control group at baseline, *t* tests were used (when *t* data were normally distributed); nonparametric bootstrapped bias-corrected confidence intervals were used to calculate mean differences between nonnormally distributed variables. Multilevel linear regression models were used to examine between-group differences in outcome variables at baseline and at 3 and 6 months after the baseline assessment. Bootstrap using 5000 draws (to accommodate the small sample size and nonnormality of the outcomes) was used for estimation in the multilevel regression. These models were used to analyze outcomes over time and to ascertain between-group differences in linear change trajectories. Because pilot studies are not designed nor powered to assess the effect of the outcome, conventional *P* values or 95% confidence intervals may not be appropriate because pilot studies are often underpowered to achieve statistical significance at 5%. Alternatively, other *P* values and effect size estimates should be considered [30]. Given that this investigation was a pilot study, a *P* value of less than .10 was set as the statistical significance level.

With 23 participants in the intervention group and 17 participants in the intervention group, we had an 80% chance of detecting a larger effect size (.90) between the two groups as significant at the 5% level (two tailed). Given the purpose of this study was to examine the feasibility and estimate the effect size, analysis focused on the effect size estimate.

To calculate effect sizes, Cohen *d* was used to estimate between-group differences in outcomes at 6 months [31]. Effect sizes were calculated by dividing the difference between the means of the mobile phone-based intervention group and control group by the standard deviation of the baseline scores. Cohen *d* for small effect was 0.2 to 0.49; for medium effect, 0.5 to 0.79; and for large effect, greater than or equal to 0.8 [31]. Data analysis used Stata version 13 (StataCorp LP, College Station, TX, USA).

Results

Sample Characteristics

The sample of 40 participants had 23 boys (58%) and 17 girls (42%). Twenty-two adolescents were overweight; 18 adolescents were obese. The adolescents' mean age was 14.9 (SD 1.7) years. Participants' mean BMI was 28.3 (SD 4.7) kg/m^2, and the BMI percentile was 94.0 (SD 3.7). Approximately 90% of the adolescents identified themselves as Chinese American (Table 1). The annual income of approximately 58% of the families was less than US $20,000; the annual income of approximately 95% of the families was less than US $40,000. At baseline, the mobile phone-based intervention group and the control group did not differ in gender, weight status, family annual income, and any other variables (Table 2). The study retention rate at the 6-month follow-up visit was 90% (21/23) for the mobile phone-based intervention group and 87% (15/17) for the control group (Figure 2).

Table 1. Demographic characteristics of adolescent participants (N=40).

Variables	Intervention (n=23)	Control (n=17)
Child's age (years), mean (SD)	15 (1.69)	14.77 (1.60)
Mother's age (years), mean (SD)	44.32 (4.80)	44.20 (5.45)
Father's age (years), mean (SD)	46.76 (5.09)	46.43 (5.47)
Mother's education (years), mean (SD)	10.6 (2.9)	9.3 (3.8)
Father's education (years), mean (SD)	10.9 (3.3)	9.0 (2.7)
Child's gender (male), n (%)	14 (58)	9 (53)

Table 2. All outcome variables over the three time points (baseline and 3 and 6 months after baseline) by treatment and control groups (N=40).

Variable[a]	Intervention, mean (SD) (n=23)			Control, mean (SD) (n=17)		
	Baseline	3 months	6 months	Baseline	3 months	6 months
BMI	27.37 (3.26)	26.91 (3.25)	26.93 (3.43)	28.35 (4.36)	28.81 (4.43)	29.18 (3.88)
BMI-z	1.60 (0.50)		1.42 (.38)	1.54 (0.42)		1.80 (0.50)
Waist-hip ratio	0.96 (0.05)	0.96 (0.05)	0.96 (0.04)	0.96 (0.05)	0.97 (0.05)	0.97 (0.05)
SBP (mm Hg)	116.70 (9.06)	115.04 (6.96)	114.65 (8.14)	115.65 (18.87)	116.25 (14.88)	115.93 (14.50)
DBP (mm Hg)	72.74 (8.07)	69.39 (7.39)	70.15 (7.53)	69.94 (11.25)	71.63 (9.87)	72.14 (8.71)
Veg/Fruit (serving/day)	3.0 (0.95)	3.91 (1.04)	3.76 (.83)	3.17 (1.24)	3.25 (0.93)	3.08 (0.79)
Soda drink (cup/day)	1.43 (0.90)	0.48 (0.51)	0.35 (0.49)	1.24 (0.97)	1.03 (0.69)	1.07 (0.76)
TV/Computer (hr/day)	3.22 (0.74)	2.25 (0.69)	2.43 (0.60)	3.51 (1.39)	3.59 (1.46)	3.42 (1.57)
PA (day/week)	2.36 (0.99)	3.28 (1.01)	3.09 (1.26)	2.29 (1.57)	1.94 (1.06)	2.25 (1.71)
Nutrition SE	2.39 (0.39)	2.70 (0.40)	2.76 (0.34)	2.58 (0.33)	2.44 (0.30)	2.41 (0.25)
PA SE	2.14 (0.55)	2.75 (0.47)	2.62 (0.51)	2.27 (0.48)	2.28 (0.42)	2.23 (0.43)

[a] BMI: body mass index; DBP: diastolic blood pressure; PA: physical activity; SBP: systolic blood pressure; SE: self-efficacy.

Table 3. Multilevel regression: bootstrap.

Variable	Observation coefficient	SE	z	*P*	90% CI	Effect size *d*[a]
BMI						0.62
Time	0.28	0.10	2.78	.01	0.12, 0.45	
Group	–1.05	1.22	–0.86	.39	–3.09, 0.95	
Time×group	–0.58	0.13	–4.37	.001	–0.84, –0.40	
BMI-z						0.34
Time	0.06	0.02	2.4	.02	0.02, 0.09	
Group	–0.15	0.15	–1.02	.03	–0.40, 0.09	
Time×group	–0.12	0.03	–4.36	.001	–0.16, 0.07	
Waist-to-hip ratio						0.22
Time	0.01	0.01	0.15	.88	–0.01, 0.01	
Group	0.01	0.01	0.75	.46	–0.03, 0.01	
Time×group	0.01	0.01	0.72	.47	–0.01, 0.02	
SBP						0.06
Time	–0.98	0.84	–1.16	.24	–2.36, 0.42	
Group	0.82	4.71	0.17	.86	–6.93, 8.57	
Time×group	0.02	0.90	–0.03	.97	–1.45, 1.51	
DBP						0.21
Time	0.93	0.72	1.29	.20	–0.25, 2.12	
Group	2.21	3.17	0.70	.49	–3.00, 7.42	
Time×group	–2.66	0.84	–3.23	.001	–4.02, –1.31	
Fruit/Veg						0.63
Time	–0.11	0.17	–0.59	.55	–0.40, 0.19	
Group	–0.04	0.36	–0.12	.90	–0.63, 0.54	
Time×group	0.52	0.19	2.74	.006	0.21, 0.83	
Soda drink						0.78
Time	–0.12	0.09	–1.20	.23	–0.27, 0.04	
Group	0.09	0.27	0.31	.75	–0.37, 0.55	
Time×group	–0.44	0.13	–3.19	.001	–0.66, –.021	
TV/Computer time						0.93
Time	–0.04	0.09	–0.49	.62	–0.21, 0.11	
Group	–0.51	0.36	–1.43	.15	–1.10, 0.08	
Time×group	–0.37	0.11	–3.34	.001	–0.55, –0.19	
PA						0.67
Time	–0.05	0.11	–0.49	.62	–0.24, 0.13	
Group	0.41	0.38	1.05	.29	–0.23, 1.04	
Time×group	0.40	0.15	2.58	.01	0.15, 0.66	
Diet self-efficacy						0.96
Time	–0.08	0.04	–1.55	.10	–0.15, 0.00	
Group	–0.13	0.10	–1.22	.22	–0.32, 0.05	
Time×group	0.27	0.05	5.05	<.001	0.18, 0.36	
PA self-efficacy						0.74

Variable	Observation coefficient	SE	z	*P*	90% CI	Effect size *d*[a]
Time	–0.02	0.08	–0.23	.82	–0.16, 0.12	
Group	–0.03	0.14	–0.24	.81	–0.27, 0.20	
Time×group	0.28	0.10	2.75	.01	0.11, 0.45	

[a] Effect size: small (0.2-0.49), medium (0.5-0.79), and large (>0.8).

Efficacy of Mobile Phone-Based Intervention

Multilevel linear regression analysis revealed that, at the 6-month follow-up visit, compared to participants in the control group, mobile phone-based intervention participants had substantial improvement of BMI (z=–4.37, *P*=.001), BMI-z (z=–4.36, *P*=.001), diastolic blood pressure (z=–3.23, *P*=.001), physical activity day per week (z=2.58, *P*=.01), TV and computer time (z=–3.34, *P*=.001), servings of fruits and vegetables per day (z=2.74, *P*=.006), servings of sodas and sweetened drinks (z=–3.19, *P*=.001), physical activity self-efficacy (z=2.75, *P*=.006), and dietary self-efficacy (z=5.05, *P*=.001).

Large effect sizes were found in TV and computer time and in dietary self-efficacy; medium effect sizes were found in BMI, physical activity, fruit and vegetable consumption, soda and sweetened drink consumption, and self-efficacy regarding physical activity (see Table 3). A majority of mobile phone-based intervention participants reported using the Fitbit Flex tracking app several times per day and found the app to be helpful.

Feasibility and Perceived Usefulness of Mobile Phone-Based Program

Seventeen of 23 mobile phone-based intervention participants (75%) reported accessing the Fitbit program via the app or website several times a week, and five adolescents (20%) accessed the program once a week. All the adolescents (100%) who used the Fitbit Flex reported that the device was helpful in tracking physical activity level, and approximately 88% of adolescents found the device helpful in tracking physical activity food intake. All adolescents (100%) in the intervention group would recommend this program to others. The majority of adolescents (91%) shared their Fitbit data with their primary care providers.

Discussion

This pilot study's results suggest that the combined use of these tools by overweight and obese adolescents in primary care clinics can potentially improve weight management and the use of a tracking device, its app, and culturally appropriate self-paced online modules is acceptable to adolescents and feasible for use in primary care clinics. Our study's results substantiate the use of mobile phone technology to prevent excessive weight gain, promote healthy lifestyles, and improve self-efficacy in overweight and obese adolescents. Specifically, we found that overweight and obese adolescents in the mobile phone-based intervention group had (1) increased physical activity and consumption of fruits and vegetables; (2) decreased BMI, diastolic blood pressure, TV and computer viewing time, and soda and sweetened drink consumption; and (3) strengthened self-efficacy regarding both physical activity and diet.

The positive outcomes reported for the mobile phone-based program were due to several factors, three of which were essential. First, the program's technologies were appropriate for the nature and purposes of the intervention. The use of communication technologies has become an integral part of adolescent life [17], and the utility of these technologies (eg, mobile phones, apps, and monitoring devices) to promote positive health-related behavior changes is well established [20]. For example, the review of mobile phone intervention studies mentioned earlier noted the efficacy of this technology for adolescent weight management—both in increasing adolescents' engagement in weight management interventions and in decreasing adolescents' rate of dropout from these interventions [20]. Furthermore, these communication technologies have also proven useful for health information collection and transmission that facilitate patient-provider communication and decision making [32]—another important aspect of the mobile phone-based intervention. Also, with both the apps and the user-based iStart Smart for Teens online modules, simplicity of use contributed to accessibility and user acceptance.

A second major factor in the mobile phone-based program's success was the early involvement of key stakeholders: adolescents, research team members, and health care providers. The value of these stakeholders' contributions to our mobile phone-based program design corroborated the finding of a recent systematic review of research on adolescents' use of mobile phones to support chronic condition management. As with our pilot study, the review reported that the involvement of adolescents and clinical experts in program or prototype design increased adolescents' use of the interventions [33]. In addition, our involvement of health care providers also proved to be essential in the mobile phone-based program's implementation [34].

Third, the use of the Khan Academy modules as a model for the iStart Smart for Teens online module format and style resulted in the creation of an education program that was effective in presenting content, engaging participant interest, and promoting learning application and knowledge retention [35]. The education module's effectiveness was also augmented by the use of a variety of presentation strategies (eg, animation and short videos) that had been recommended by adolescents in our research team as being online learning methods preferred by most adolescents.

Traditional individual or group consultations for behavioral change and weight management are typically costly and time consuming. This mobile phone-based intervention can potentially support a large number of adolescents who, for logistical or other reasons, might not be able to participate in a traditional face-to-face weight management program. Results of our study suggest that implementing mobile technologies for weight management and maintenance of healthy weight may have great potential for decreasing the obesity epidemic while simultaneously improving the health behavior of adolescents who are overweight or obese. Moreover, because primary care clinics typically have limited time for consultation with adolescents regarding active lifestyle promotion and obesity prevention, mobile technologies can be used as valuable resources to assist both patients and providers.

Because this pilot study is one of the first investigations to examine the efficacy and feasibility of a mobile phone-based intervention for overweight and obese adolescents in a primary care setting, the study's results must be interpreted with caution. The results can only be generalized to similar populations (Chinese Americans). The pilot study's weaknesses included our use of convenience sampling and self-report measures and the brevity of the follow-up period. Because of the small sample size, we were not able to separately analyze data based on adolescent's weight status (overweight vs obese). Future studies may need to investigate whether specific subgroup of adolescents can benefit more on this type of program. Use of the Fitbit depended on self-report; therefore, bias and underestimation for the use of the Fitbit device may exist. Also, although we did not collect data on the program's impact on primary care providers' practice, brief discussions with adolescents in the mobile phone-based intervention group revealed that most adolescents shared their tracking data with their health care providers as a basis for discussion. We are currently conducting interviews with health care providers to explore the experiences of clinical weight management changes following the providers' use of mobile technology.

The importance of childhood obesity as an imperative among national health care issues is compelling for several avenues of future research in mobile phone-based interventions. Additional research should assess providers' perceptions of the utility of mobile phone-based interventions in facilitating weight management and should collect data on the effects of these interventions on primary care providers' practice. Researchers should also conduct comparative investigations to evaluate the relative efficacies of various technologies in application to behavior and weight change.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Website image.

[PDF File (Adobe PDF File), 609KB - ijmr_v6i2e12_app1.pdf]

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Abbreviations

BMI: body mass index
CHIS: California Health Interview Survey
SCT: social cognitive theory

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Original Paper

Internet Usage by Parents Prior to Seeking Care at a Pediatric Emergency Department: Observational Study

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Abstract

Background: Little is known about how parents utilize medical information on the Internet prior to an emergency department (ED) visit.

Objective: The objective of the study was to determine the proportion of parents who accessed the Internet for medical information related to their child’s illness in the 24 hours prior to an ED visit (IPED), to identify the websites used, and to understand how the content contributed to the decision to visit the ED.

Methods: A 40-question interview was conducted with parents presenting to an ED within a freestanding children’s hospital. If parents reported IPED, the number and names of websites were documented. Parents indicated the helpfulness of Web-based content using a 100-mm visual analog scale and the degree to which it contributed to the decision to visit the ED using 5-point Likert-type responses.

Results: About 11.8 % (31/262) reported IPED (95% CI 7.3-5.3). Parents who reported IPED were more likely to have at least some college education (P=.04), higher annual household income (P=.001), and older children (P=.04) than those who did not report IPED. About 35% (11/31) could not name any websites used. Mean level of helpfulness of Web-based content was 62 mm (standard deviation, SD=25 mm). After Internet use, some parents (29%, 9/31) were more certain they needed to visit the ED, whereas 19% (6/31) were less certain. A majority (87%, 195/224) of parents who used the Internet stated that they would be somewhat likely or very likely to visit a website recommended by a physician.

Conclusions: Nearly 1 out of 8 parents presenting to an urban pediatric ED reported using the Internet in the 24 hours prior to the ED visit. Among privately insured, at least one in 5 parents reported using the Internet prior to visiting the ED. Web-based medical information often influences decision making regarding ED utilization. Pediatric providers should provide parents with recommendations for high-quality sources of health information available on the Internet.

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KEYWORDS

Internet; emergency department; decision making

Introduction

Many parents seek advice from at least one source prior to presenting to a pediatric emergency department (ED) [1-5]. Parents commonly utilize the Internet to learn about pediatric health problems [1,2,5-16]. However, many websites do not present accurate evidence-based medical information or advice [6,9,17-20]. Deciphering health information and verifying accuracy can be a difficult task for parents [5,11,12,21-24]. Therefore, pediatric health care providers need to understand how families access and utilize medical information obtained on the Internet.

To our knowledge, only two studies have examined Internet use specific to parents who present to the pediatric ED; however, neither study was conducted in the United States [2,8]. Little is known about the websites that parents choose to visit or how this information contributes to the decision to visit the pediatric ED. The objective of this study was to determine the percentage of parents who search the Internet for medical information related to their child's presenting complaint in the 24 hours prior to the ED visit. Furthermore, we aimed to identify the websites accessed by parents and to study the degree to which the information found on the Internet contributes to the decision to visit the ED. We hypothesized that 20% of study participants would have searched the Internet in the 24 hours prior to their ED visit.

Methods

Conducting Structured Interviews

We conducted structured interviews from a convenience sample of parents in the ED from July 2010 to July 2011. This facility is a freestanding, urban, tertiary care children's hospital with approximately 54,000 annual visits. English-speaking parents or legal guardians of children presenting for care in either the main ED or the fast track area from 6:00 AM to 12:00 AM were eligible. Parents of children triaged at an emergency severity index (ESI) level of 1 [25], evaluated for abuse or neglect, transported by ambulance from the scene of a significant trauma, or transferred from a referring facility were excluded. Parents who had not been significantly involved in the decision to bring their child to the ED (eg, a child who presented directly from school), had registered more than one child to be seen, or had previously participated in the study were also excluded. If more than one parent was present, we asked for a volunteer and administered the interview only to that parent.

Eligible parents were interviewed in the exam rooms by either the primary investigator or a single research assistant trained by the primary investigator, within a window of time during which patient care would not be hindered. We utilized a 40-item paper questionnaire, which was developed by the research team and finalized after a short pilot study of 20 parents. After obtaining informed consent, the interviewer read the questions from the questionnaire and documented the parent's answers on the paper form. A combination of closed- and open-ended questions covered demographics, details of the ED visit, resources utilized (Internet and non-Internet), and accessibility to Internet. For all parents who identified themselves as Internet users, we were interested in their health information–seeking behavior. To understand this, we asked about the frequency of Internet use for any topic concerning their child's health, their awareness of certain pediatric health–focused websites, and their interest in visiting websites recommended to them by a physician. Parents who reported accessing the Internet for medical information related to their child's presenting complaint in the 24 hours preceding the ED visit (Internet use prior to the ED visit, or IPED) were asked the number and names of websites used, and the helpfulness of the content using a visual analog scale (VAS) [26], and how the information contributed to the decision to visit the ED using 5-point Likert-type response questions. For the question utilizing the VAS, the parents marked their answers on the paper questionnaire. One paper questionnaire was filled out per parent interviewed. The average amount of time for completion of the questionnaire was 10 min. We also conducted the same structured interview among a smaller sample of parents presenting to our suburban satellite facility, which opened after enrollment had begun at our main urban site. As the patient population at this location is different from the urban site, we enrolled a small sample of patients to determine whether a larger study at this separate facility with a different patient population would be worthwhile. Taking this into consideration, pertinent results and analysis from this sample are presented. This suburban facility is a 24-hour full-service pediatric ED, staffed by the same faculty as our main study site, with an approximate annual volume of 15,000 patients. The data showing the differences at the two sites are available to the reader upon request. We enrolled from August 2011 to September 2011, employing the same inclusion and exclusion criteria. The percentage of parents who reported IPED was calculated separately for this site.

Sample Size Derivation and Statistical Analysis

We estimated that there would be at least 20,000 potential participants during the study period. Using a CI of 95% with a margin of error of ±5%, we calculated a sample size ranging from 243 to 377 (using the hypothesis that 20% of parents would have IPED or a worst-case scenario of 50%). General descriptive statistics such as frequency, proportions, student *t* test (continuous variables), chi-square (categorical variables) test, and the Mann-Whitney *U* test were employed to analyze survey data using the Statistical Package for the Social Sciences (SPSS) Statistics version 19 (IBM Corp). A *P* value of <.05 was considered statistically significant. This study was reviewed and approved by our local institutional review board.

Results

Main Urban Site

Demographic Data

At the main urban hospital, we approached 326 parents, of whom 47 were determined to be ineligible (referred from another facility or not significantly involved in the decision to bring the child to ED); 17 declined to participate. Of the remaining 262 parents interviewed, 81% were mothers, and 96% of the study population reported that their child had a primary care physician. Descriptive data regarding all study participants at the urban site are presented in Table 1. The demographic distribution of our study population was consistent with the overall distribution of patients seen at this facility during the calendar year 2011 (data available upon request).

Non-Internet Resources Utilized

Over half of parents (56.1%, 147/262) had consulted at least one non-Internet resource prior to deciding to bring their child to the ED. The most frequently consulted resource was the patient's primary care doctor (45.6%, 67/147), followed by a family member (34.7%, 51/147).

Internet Accessibility

Of all participants at the urban site, 85.5% (224/262) identified themselves as Internet users, of whom 94.2% (211/224) reported having daily access to the Internet. The most frequently used device was a computer located in the parents' home. A majority (52.7%, 118/224) of Internet users reported that they used 2 or more devices for Internet access, and 55.8% (125/224) reported using a mobile phone.

Primary Objective: Internet Use Prior to ED Visit

Among all 262 parents interviewed, the percentage that reported IPED was 11.8% (31/262; 95% CI 8.5-16.3). Among only the parents with access to the Internet (n=224), 13.8% (31/224; 95% CI 9.9-18.9) reported IPED. Table 2 details the characteristics of all Internet users, grouped according to the presence or lack of IPED. Parents who reported IPED were significantly more likely to have at least some college education, had higher annual household income, had older children, and were slightly older themselves than those who did not report IPED. The most common chief complaints among those who reported IPED were abdominal pain, vomiting, cough, and fever.

Although insurance status was not significantly associated with IPED among only parents with access to the Internet (n=224), it was found that among all participants who had insurance status available (n=261), parents who had a child covered by private insurance showed a higher propensity (12/62, 19%) toward IPED compared with those covered by nonprivate insurance (19/199, 9.5%). This comparison was statistically significant using chi-square (*P*=.04).

Websites Used and Influence on Decision Making

We derived this analysis from the 31 parents who reported IPED. Within this group, 48% (15/31) reported using only one website. When asked to name the websites that they consulted, 35% (11/31) of parents were unable to name any of the websites used. Another 26% (8/31) were able to name only some of the websites used. When parents were able to recall the names, the most commonly named websites were WebMD (10/31) and Wikipedia (6/31).

Parents gave a mean score of 62 mm (SD 25 mm) on the VAS, favoring helpfulness of the Internet content. When asked to what degree the content contributed to their decision to visit the ED, 29% (9/31) of parents said that they were *more certain* they needed to bring their child to the ED after viewing the Internet content, and 19% (6/31) said they were *less certain*. For 16% (5/31), the Internet was the only resource that they consulted. The remainder 84% (26/31) had also consulted at least one non-Internet resource. Many of these parents (65%, 20/31) stated that they were already either somewhat certain or very certain that they needed to bring their child to the ED prior to consulting any resources.

IPED With Past ED Visit

Among all Internet users (n=224), 20 parents reported IPED in conjunction with an ED visit in the preceding 3 months. Within this group, 4 parents had decided to bring their child to the ED directly based on medical information found on the Internet, and 9 parents stated they had avoided an ED visit directly based on medical information found on the Internet.

General Health Information–Seeking Behavior

About 52.2% (117/224) of all Internet users reported at least one episode of Internet use for general pediatric health information in the preceding 3 months. Almost 14.7% (33/224) reported using the Internet more than 6 times for this purpose. Of these, the majority (135/224, 60.2%) were unable to recall specific names of websites used, but reported that they used a search engine such as Google to find information. When specific websites were named, they ranged from product websites (such as Gerber, Fisher Price, and Huggies), to medical establishment websites (such as Cleveland Clinic, Mayo Clinic, and Johns Hopkins), parenting lifestyle websites (such as BabyCenter), or national association websites (National Down Syndrome Society and Epilepsy Foundation), in addition to the commonly named WebMD and Wikipedia.

We were interested to know how often in the preceding 3 months Internet users utilized a short list of websites that we as a research team considered good sources for pediatric health information—healthychildren.org (sponsored by the American Academy of Pediatrics), CDC.gov (Centers for Disease Control and Prevention), kidshealth.org, and our local children's hospital website. Overall, 10.2% (23/224) reported visiting healthychildren.org, 15.6% (35/224) visited CDC.gov, 9.4% (21/224) visited kidshealth.org, and 15.6% (35/224) visited our local children's hospital website. Finally, when all Internet users were asked about their interest in utilizing websites recommended to them by a physician, the majority of users (195/224, 87.1%) stated that they would be somewhat likely or very likely to visit the physician-recommended website.

Table 1. Demographic data: all participants from urban site (N=262).

Demographic characteristic	n (%) or median (interquartile range)
Relationship to child, n (%)	
Mother or female guardian	220 (84)
Father or male guardian	42 (16)
Age of parent in years, median (interquartile range)	31 (25-37)
Age of child in years, median (interquartile range)	4 (1.3-11)
Race of parent, n (%)	
White	135 (52)
Nonwhite	126 (48)
Race of child, n (%)[a]	
White	124 (47)
Nonwhite	137 (52)
Education of parent, n (%)	
Some high school	34 (13)
Completed high school or General Educational Development (GED)	85 (32)
Some college	97 (37)
Completed college	32 (12)
Advanced degree or beyond	14 (5)
Gross household income in US dollars, n (%)	
Less than $25,000	125 (48)
$25,000-$50,000	74 (28)
$50,000-$75,000	21 (8)
$75,000-$100,000	11 (4)
Greater than $100,000	12 (5)
Insurance of child, n (%)[a]	
Private	62 (24)
Nonprivate[b]	199 (76)
Triage classification, n (%)	
ESI[c] 2	54 (21)
ESI 3	145 (55)
ESI 4	63 (24)
Day of enrollment, n (%)	
Weekend	17 (7)
Weekday	245 (94)
Time of enrollment, n (%)	
6 AM - 12 PM	15 (6)
12 PM - 6 PM	159 (61)
6 PM - 12 AM	88 (34)
Disposition, n (%)	
Discharge	207 (79)
Admit	55 (21)

[a] Some data were missing for a few participants (eg, child race and insurance).

[b] Nonprivate includes government insurance, self-pay, and no insurance.

[c] ESI: emergency severity index.

Table 2. Internet users (N=224).

Demographic characteristic	Used Internet in 24 hours prior to ED[a] (n=31), n (%)	Did not use Internet prior to ED (n=193), n (%)	*P* value
Relationship to child, n (%)			
Mother or female guardian	25 (13)	166 (87)	.43
Father or male guardian	6 (18)	27 (82)	
Median age of parent in years	35	31	.008
Median age of child in years	9	3	.04
Race of parent, n (%)			
White	20 (17)	95 (83)	.12
Nonwhite	11 (10)	97 (90)	
Race of child, n (%)			
White	18(17)	88 (83)	.21
Nonwhite	13 (11)	104 (89)	
Education of parent, n (%)			
High school grad or less	7 (8)	81 (92)	.04
Some college or more	24 (18)	112 (82)	
Gross household income in US dollars, n (%)			
Less than $25,000	11 (11)	92 (89)	.001
$25,000-$100,000	12 (13)	84 (87)	
Greater than $100,000	6 (55)	5 (46)	
Insurance of child, n (%)			
Private	12 (20)	47 (80)	.096
Nonprivate[b]	19 (12)	145 (88)	
Triage classification, n (%)			
ESI[c] 2	4 (9)	43 (91)	.46
ESI 3	19 (16)	100 (84)	
ESI 4	8 (14)	50 (86)	
Day of enrollment, n (%)			
Weekend	3 (20)	12 (80)	.47
Weekday	28 (13)	181 (87)	
Time of enrollment, n (%)			
6 AM - 12 PM	3 (21)	11 (79)	.56
12 PM - 6 PM	20 (15)	118 (85)	
6 PM - 12 AM	8 (11)	64 (89)	
Disposition, n (%)			
Discharge	23 (13)	152 (87)	.57
Admit	8 (16)	41 (84)	

[a] ED: emergency department.

[b] Nonprivate includes government insurance, self-pay, and no insurance.

[c] ESI: emergency severity index.

Table 3. Suburban site Internet users (N=49).

Demographic characteristic	Used Internet in 24 hours prior to ED[a] (n=14), n (%)	Did not use Internet prior to ED (n=35), n (%)	*P* value
Relationship to child, n (%)			
Mother or female guardian	12 (29)	30 (71)	>.99
Father or male guardian	2 (29)	5 (71)	
Median age of parent in years	36	33	.68
Median age of child in years	4.5	4	.82
Race of parent, n (%)			
White	10 (24)	31 (76)	.20
Nonwhite	4 (50)	4 (50)	
Race of child, n (%)			
White	10 (27)	27 (73)	.72
Nonwhite	4 (33)	8 (67)	
Education of parent, n (%)			
High school grad or less	2 (17)	10 (83)	.46
Some college or more	12 (32)	25 (68)	
Gross household income in US dollars, n (%)			
Less than $25,000	0 (0)	7 (100)	.18
$25,000-$100,000	8 (33)	16 (67)	
Greater than $100,000	5 (36)	9 (64)	
Insurance of child, n (%)			
Private	13 (37)	22 (63)	.04
Nonprivate[b]	1 (7)	13 (93)	
Triage classification, n (%)			
ESI[c] 2	0 (0)	1 (100)	.08
ESI 3	10 (48)	11 (52)	
ESI 4	3 (13)	20 (87)	
ESI 5	1 (25)	3 (75)	
Day of enrollment, n (%)			
Weekend	4 (22)	14 (78)	.53
Weekday	10 (32)	21 (68)	
Time of enrollment, n (%)			
6 AM - 12 PM	0 (0)	1 (100)	.73
12 PM - 6 PM	1 (20)	4 (80)	
6 PM - 12 AM	13 (30)	30 (70)	

[a] ED: emergency department.

[b] Nonprivate includes government insurance, self-pay, and no insurance.

[c] ESI: emergency severity index.

Suburban Site Results

Separately, we interviewed 49 parents from our suburban ED. With regard to the overall demographics, parents here reported higher income levels and education levels, and a larger percentage (35/49, 71%) of children was privately insured. All parents here identified themselves as Internet users. The percentage that reported IPED was 29% (14/49; 95% CI 17.9-42.4). A comparison of demographic characteristics between parents who reported and who did not report IPED revealed that children of parents reporting IPED were more likely to have private insurance (*P*=.04, Table 3). In total, 43%

(6/14) used only one website, and 29% (4/14) were unable to name any of the websites consulted. WebMD and Wikipedia were the most commonly named websites. When asked the degree to which the content contributed to their decision to visit the ED, 36% (5/14) of parents said that they were more certain they needed to bring their child to the ED, and 14% (2/14) said they were less certain. Almost all (48/49) Internet users reported that they would be very likely or somewhat likely to visit a website recommended to them by a physician.

Discussion

Principal Findings

We found that 1 in 8, or about 11.8% (31/262), of all parents who presented to an urban tertiary care ED had used the Internet for medical information in the 24 hours prior to the visit. To the best of our knowledge, this is the first such study performed in the United States. In 2006, Goldman and Macpherson [8] reported that 8.5% of parents presenting to a tertiary care pediatric ED in Toronto, Ontario, Canada, had searched the Internet for health-related information immediately prior to the ED visit. In 2008, Khoo et al [2] reported that 6% of parents presenting to a tertiary care pediatric ED in Melbourne, Australia, had searched the Internet immediately prior to the ED visit. From 2000 to 2010, Internet access in US homes doubled from 35% to 71% [27]. Moreover, almost half of all US mobile phone subscribers by February 2012 owned smartphones [28]. Data from both the Goldman and Khoo studies were collected in 2003 and 2007, respectively, and likely did not account for the rapid expansion of Internet access points (smartphones and electronic readers) since that time. As such, we expected the percentage of IPED from our study to be higher than that reported by Goldman and Khoo.

On the basis of statistically significant differences in education, income, and insurance status, our study findings suggest that parents from higher socioeconomic status (SES) are more likely to search the Internet prior to coming to the ED. Although our main study (not including the suburban site) yielded an IPED percentage that is higher than the previously reported estimates in the Goldman and Khoo studies, it is below our hypothesis of 20%. Interestingly, if the data are analyzed with respect to insurance status as a measure of SES, that is private insurance representing higher SES and nonprivate representing lower SES, 19% (12/62) of privately insured reported IPED, which very closely estimates our hypothesis. This finding at our main study site is further supported by the results from our suburban site, which sees a larger percentage of higher SES (eg, 71% privately insured), and yielded an IPED of 29% in a small sample.

In contrast, IPED among patients without private insurance at our main site was only 9.5% (19/199). Further research would be needed to clarify the factors that contribute to this difference in the lower SES group. According to our data, this finding is not entirely because of the lack of access to Internet; in fact, about 82.4% (103/125) of parents with an income level of less than $25,000 reported access to the Internet, 95% of whom had daily access to the Internet, with many accessing the Internet on computers in their own homes. Knapp et al [22] reported similar rates of Internet access among low-income parents in Florida. Across the United States, increases in broadband access from 2008 to 2009 were largely fueled by a 34% increase in access among US households with an annual income of less than $30,000 [29]. Parents in a comparable income bracket (annual income of less than $25,000) accounted for 47.7% (125/262) of our study participants at the main site. Within the nonprivate insurance group, 49% (98/199) had completed a high school education and had at least some college education. Prior studies have reported higher Internet use for general health information among more educated parents [16,22]. Further research is warranted to examine the role of education in IPED.

Our study also adds to the literature by reporting which websites parents access in their efforts to decide whether an ED visit is warranted. We found that when parents were able to recall the names of websites, WebMD and Wikipedia were the two most commonly named. Parents overwhelmingly reported using a search engine such as Google to generate a list of potential resources. It is not surprising that WebMD and Wikipedia were the most commonly recalled names, both with IPED, as well as for use with general health information. When search terms such as “vomiting,” “cough,” “belly pain in children,” and “meningitis” are entered into Google, WebMD and Wikipedia consistently appear in the top 5, if not the top 2, search results (search performed by author on November 21, 2016). This suggests that pediatric health–focused sites should aim at positioning their website at the top of a generated list of search results.

Although WebMD and Wikipedia were frequently mentioned, the more interesting and telling piece of information that we uncovered with regard to website identification is that a large number of parents (19/31, 61%) were unable to recall the specific names of websites used. This holds true not only in the group that reported IPED but also among parents who reported Internet utilization for general health concerns (60.2% could not name the websites used). This finding is important because it suggests that parents are not discerning information seekers when it comes to health information on the Internet, or do not know how to be. This is in contrast to the non-Internet resources utilized, where parents instinctively trusted their primary care provider or a family member for advice. There is little published data on how parents choose which websites to consult prior to seeking care for their child, although one recent Austrian study found that parents are most likely to visit a website run by doctors when seeking care in an outpatient clinic for an acute illness [15].

Similar to a recent Canadian study, our data suggest that parents often do not know where to look for good health information [21]. This is implied by the relatively low percentage of parents who visited websites that our study team believed had reliable pediatric health information, such as healthychildren.org or cdc.gov. Similar to other studies, our study also suggests that parents may be unaware of what constitutes good health information (eg, evidence-based information vs anecdotal reports) or how to identify reputable websites [21,22]. Further research is warranted to gain a better understanding of how parents decide what sources of information to trust on the Internet.

In keeping with prior studies, our study results also suggest that parents have some difficulty interpreting or putting into context information found on the Internet [11,12,23,24]. On average, parents found the information helpful to the understanding of their child's condition, but responses ranged from 0 to 100 on the VAS. In fact, several parents admitted that they were less certain that they needed to bring their child to the ED after consulting the Internet, yet they still did so. For ED providers, this indicates that they may encounter patients brought to the ED unnecessarily based on Internet guidance and, conversely, that patients who may need to come for evaluation may not actually come in. If parents have consulted the Internet, they may have certain preconceived expectations about the ED visit, and if this differs from the actuality, it could affect their perception of the quality of medical care received from the provider or the facility and their overall satisfaction with the ED visit. Thus, it is important for ED providers to recognize that many parents are using the Internet for guidance regarding ED visits.

Another important finding was the overwhelming interest from parents (87.1%) in receiving guidance from a physician about appropriate medical websites. Physicians should recognize this need among our patients' families and be prepared to offer guidance on websites that provide accurate evidence-based and helpful information. Professional medical organizations should assist providers through approval of their own sources of medical advice or endorsement of others.

Salo et al [30] reported high interest among adult ED patients in receiving website recommendations by physicians, along with discharge paperwork. Further study of the utility of interventions such as providing a list of condition-specific medical websites along with written discharge instructions is warranted in the pediatric ED population.

Limitations

Our study has several limitations. We enrolled a convenience sample of parents, and we relied on their ability to recall information over 3 months. Although our survey questions were not validated against actual Internet use by parents, the structured interview format allowed for collection of content data beyond search engine names. Only English-speaking parents were enrolled. Of note, at our facility, non-English-speaking parents comprise less than 5% of parents seen in the ED, and translator services are only available by phone. Due to the inherent study design, we were unable to sample parents who chose not to visit the ED. To address this limitation, we asked participants about past instances when they decided not to bring their child to the ED based directly on information they found on the Internet. As a research team, we chose certain websites for inclusion in the survey based upon our own experience and did not use any type of certification criteria such as the HONcode [31]. An in-depth quality review of all websites visited by parents was beyond the scope of this study. Finally, our study was performed at a single center where the majority of children are publicly insured. Thus, our findings may have limited application in other settings. Although we enrolled a sample of 49 parents at our satellite facility, it is a relatively small sample, and a larger study could provide more insight about this patient population. It would be beneficial to replicate our findings in other settings as handheld devices and broadband availability continues to rise.

Conclusions

Nearly one out of 8 parents used the Internet as a resource for medical information in the 24 hours prior to an ED visit. Among privately insured children, at least one in 5 parents used the Internet prior to the ED visit. For these parents, Web-based medical information appears to influence understanding and decision making with regard to ED utilization. Pediatric health care providers should facilitate access to high-quality electronic health care information because parents are interested in Web-based sources for pediatric health information recommended by physicians.

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Conflicts of Interest

None declared.

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Abbreviations

CDC: Centers for Disease Control and Prevention
ED: emergency department
ESI: emergency severity index
GED: General Educational Development
IPED: Internet use prior to an ED visit
SD: standard deviation
SES: socioeconomic status
SPSS: Statistical Package for the Social Sciences
VAS: visual analog scale

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Original Paper

A Strategy to Reduce Critical Cardiorespiratory Alarms due to Intermittent Enteral Feeding of Preterm Neonates in Intensive Care

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Abstract

Background: Many preterm infants require enteral feeding as they cannot coordinate sucking, swallowing, and breathing. In enteral feeding, milk feeds are delivered through a small feeding tube passed via the nose or mouth into the stomach. Intermittent milk feeds may either be administered using a syringe to gently push milk into the infant’s stomach (push feed) or milk can be poured into a syringe attached to the tube and allowed to drip in by gravity (gravity feed). This practice of enteral feeding is common in neonatal intensive care units. There is, however, no evidence in the literature to recommend the use of one method of feeding over the other.

Objective: The aim of this study was to investigate which of the two methods of feeding is physiologically better tolerated by infants, as measured by the incidence of critical cardiorespiratory alarms during and immediately after feeding.

Methods: We conducted a prospectively designed observational study with records of all feeding episodes in infants of gestational age less than 30 weeks at birth and with a minimum enteral intake of 100 mL/kg/day. In total, 2140 enteral feeding episodes were noted from 25 infants over 308 infant-days with records for several characteristics of the infants (eg, gestational age), feeding (eg, the position of infants), and of nursing-care events before feeding (eg, diapering). Logistic regression with mixed effects was used to model cardiorespiratory alarms for the push and gravity methods of feeding.

Results: After adjustments were made for all confounding variables, the position of infants was found to be statistically significant in changing the outcome of critical alarms for the two methods of feeding (*P*=.02). For infants in the lateral position, push feeds led to 40% more instances of one or more critical cardiorespiratory alarms in comparison with the gravity method. Both methods of feeding created a statistically comparable number of alarms for infants in the prone position.

Conclusions: This study provides objective data that may assist in optimizing enteral feeding protocols for premature infants. The incidence of critical cardiorespiratory alarms for infants in the lateral position can be lowered by the use of gravity instead of push feeding. No differences were observed between the two types of feeding when infants were in the prone position.

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KEYWORDS

preterm infants; enteral feeding; bradycardia; hypoxia; alarms

Introduction

Every year, approximately 15 million infants are born prematurely (before 37 weeks of gestation), and this number is increasing [1]. Many of these infants require extensive medical attention and need to be admitted to neonatal intensive care units (NICUs). As these infants may be unable to coordinate sucking, swallowing, and breathing, milk feeds (expressed breast milk or formula) are delivered into the stomach via a tube passed through the nose or the mouth. This is known as enteral feeding and is common across NICUs [2].

Typically, enteral feeding can be *continuous feeding* delivered through the course of the day via an infusion pump or *intermittent feeding* usually administered over 10 to 20 min multiple times daily, for example, at intervals of 2 or 3 hours [2]. A Cochrane review found no differences between these two methods of enteral feeding for infants to achieve full feeds, days to discharge, or the incidence of necrotizing enterocolitis in preterm infants weighing less than 1500 g [2]. Although the theoretical risks and benefits for both methods have been proposed, clinical evidence supporting one method over the other is limited, and the choice of feeding is likely dependent on unit preferences and tradition [2]. Notably, though in a study of 33 preterm infants, fed once by each method, intermittent feeding was associated with lower apnea and apnea-related hypoxia [3].

Intermittent feeding is typically of two types—the *push* type is where the liquid is gently pushed through a syringe into the infant’s stomach, and the *gravity* type is where the liquid in the syringe is allowed to drip in under the influence of gravity. In the push method of feeding, small volumes of milk might be pushed at multiple times for each feed, whereas in gravity, the height of the syringe determines the rate of milk flow. A Cochrane review comparing push and gravity methods of feeding in preterm and low-birth-weight infants could not find evidence to recommend one method over the other [4]. Therefore, the method of delivering feeds is largely dependent on the preference of individual nurses, parents, and unit traditions.

In a recent study of nearly 600 preterm infants, an analysis of approximately 300,000 critical desaturations (oxygen saturation, SpO_2 ≤80%) and 100,000 critical bradycardia (heart rate ≤80 beats per minute [bpm]) alarms showed a remarkable 2-hourly periodic increase in alarms [5]. This periodicity coincided with the timing and frequency of the enteral feeding routine in that unit. Some of the enteral feeding episodes were, as a matter of routine protocol, preceded by nursing care events, such as diapering, weighing, or nasopharyngeal suctioning, leading the authors to hypothesize that enteral feeding leads to cardiorespiratory instability resulting in critical patient monitor alarms around feeding [5]. However, the influence of nursing care itself cannot be definitively ruled out, as nursing care is also known to be a stressor [6-10].

This study is motivated by the hypothesis that enteral feeding leads to cardiorespiratory instability, by the prevalent clinical impression that cardiorespiratory events increase after feeding, and by the research recommendations of a Cochrane review to identify evidence-based strategies for the enteral feeding of preterm infants [4,5,11]. We used a data-driven approach to explore the relationship between feeding and cardiorespiratory alarms and to investigate which of the two methods of enteral feeding, push or gravity, is better tolerated by infants as measured by the prevalence of critical desaturation (SpO_2 ≤80%) and bradycardia (heart rate ≤80 bpm) alarms measured during and immediately after feeding. This analysis accounts for multiple confounding variables such as the duration of feeding, the quantity of milk, the position of the infant, and any nursing care events that might have occurred immediately before feeding.

Methods

Patient Population

This prospectively designed observational study was conducted in the NICU of the Máxima Medical Centre, the Netherlands (level III; tertiary care NICU; single-room design) between October 2015 and June 2016. Preterm infants born at less than 30 weeks of gestation were eligible for the study once they were receiving an enteral feeding intake of at least 100 mL/kg/day. Several characteristics of the study group are presented in Table 1. According to routine clinical protocol, all infants were fed at 2-hourly intervals (at even hours) via an orogastric (in the case of binasal continuous positive airway pressure) or a nasogastric tube, both of which could stay in place for up to 4 weeks. It should be noted that the enteral feeding tube was not repeatedly inserted and removed but instead stayed in place until it required replacement. During the study period (308 infant-days), infants received routine need-based medication (eg, all infants receive caffeine), respiratory support, and therapeutic repositioning. As this study was performed using deidentified data corresponding to routine patient monitoring, a waiver (registered as N 2016.125) was provided by the local ethical committee in accordance with the Dutch law on medical research with humans (wet medisch-weten- schappelijk onderzoek,WMO).

Table 1. Characteristics of the patient population.

Characteristics	Median (IQR[a])
Gestational age, weeks	27.5 (26.2-29.0)
Birth weight, g	965 (772-1116)
PMA[b] during feeding episodes, week	31.3 (29.8-32.6)
PMA at discharge, week	33.6 (32.1-36.2)
Length of stay, day	40 (22-70)
Number of feeding episodes	77 (55-114)

[a] IQR: interquartile range.

[b] PMA: postmenstrual age, which is gestational age plus postnatal age.

Enteral Feeding

For each feeding episode, nurses recorded the type of feeding (push or gravity), the type of milk (expressed breast milk or formula), the quantity of milk, the start and end time of feeding based on monitor time, the type of nursing care administered immediately before feeding, and the position of the infant (prone, lateral, or supine; 90% of lateral positions were additionally annotated as left or right lateral, whereas the remainder were merely annotated as lateral). According to the protocol, all nursing care events were performed before feeding, including changing the position of the infant. The types of nursing care records included diaper change, washing, weighing, airway suctioning, change of nasal mask or nasal prong, enteral administration of medication, miscellaneous care, and no care. After nursing care, enteral feeding was initiated. Gravity feeding was performed through a feeding tube (Vygon polyurethane Ch 6) connected to an open 10- to 20-mL syringe, placed approximately 15 cm above the patient to ensure forward flow. Push feeding was performed through the feeding tube connected to a closed 10- to 20-mL syringe by regularly pushing the milk through at a velocity of 1 to 2 mL/min.

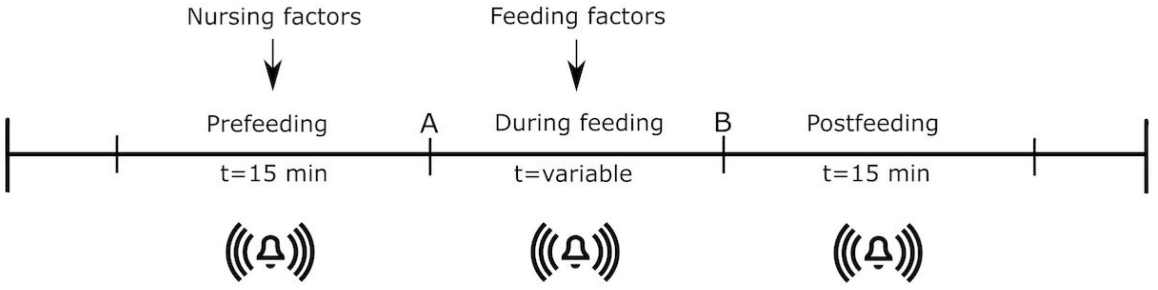
Patient Monitor Alarms

Cardiorespiratory events leading to patient monitoring alarms were automatically logged at the central monitors at the nursing station. These alarms were also displayed, in real time, on the patient monitors, the interbed communication system (which shows alarms originating from other beds at patient monitors), and the central monitors at the nursing station, in addition to being transmitted to handheld devices carried by the nurses.

For this analysis, all critical patient monitor alarms corresponding to desaturation ($SpO_2 \leq 80\%$) and bradycardia (heart rate ≤80 bpm) were measured. SpO_2 was monitored using disposable pulse oximetry sensors (LNOP Neo PT-L or LNOP Neo, Masimo SET) with an average setting of 10 s and alarms being generated after a 10-s delay if the SpO_2 fell to and remained below 80%. Bradycardia alarms occurred via heart rate measures using a 3-lead electrocardiogram (ECG) sensor (3M Red Dot or Ambu BlueSensor) with the heart rate being calculated as the average of the 12 most recent beat-to-beat intervals or the 4 most recent beat-to-beat intervals if the heart rate was less than 80 bpm. Alarms were generated as soon as the heart rate fell below 80 bpm. Other critical alarms were excluded, because they were found to constitute less than 15% of the total alarms [5]. In particular, apnea alarms based on chest impedance were excluded from the analysis, because recent research has indicated that apnea alarms are unreliable and are underdetected by monitors [12]. As shown in Figure 1, for every feeding episode, alarms in the 15 min before feeding (prefeeding period), the duration of feeding, and 15 min postfeeding were retained for analysis. These 15-min time windows were empirical choices based on unit experience.

To reaffirm the presence of the previously identified 2-hourly periodicity in alarms [5], alarm data from all infants present in the NICU during this study period were used to plot the average number of desaturation and bradycardia alarms through the course of the day. The number of alarms was normalized to represent the alarm pressure as would be generated by 100 infants for each consecutive 10-min interval of time [5].

Figure 1. Each feeding episode is of variable duration with A and B representing the start and end time of feeding, respectively. Nursing care takes place in the period immediately before feeding. Alarms are analyzed for periods of prefeeding, during feeding, and postfeeding.



Exclusion Criteria

Exclusion criteria included both specific participants and specific instances of feeding. To account for interinfant and intrainfant variability, only those infants with 25 or more records of enteral feeding were retained for the final analysis. Feeding episodes from days on which infants were mechanically ventilated were excluded because of the invasive nature of mechanical ventilation that requires an endotracheal tube as opposed to the continous positive airway pressure mode of ventilation. Furthermore, those episodes of feeding that occurred when the infant was supine or received feeding via a combination of push and gravity were excluded, because these events occurred infrequently. Although enteral feeding during kangaroo care is promoted in our unit, the proportion of feeding episodes associated with kangaroo care in comparison with the total number of feeding episodes were small and were also excluded from analysis. Upon applying these criteria, 6.22% of 2282 feeding episodes were excluded.

Statistical Modeling

The primary analysis, modeling the relationship between the dependent variable (alarms) and the independent variables (type of feeding, the position of an infant, etc.), was carried out using the generalized linear mixed model (GLMM), specifically logistic regression with mixed effects. With this model, 15 independent variables were investigated corresponding to the characteristics of the infants, such as feeding events and nursing care (Table 2). Details of this model are provided in Multimedia Appendix 1.

The *mixed* nature of the model arises from the presence of fixed and random effects. The fixed effects correspond to the regression terms that arise from independent variables and additionally due to any interaction between them (eg, type of feeding and position of infant). Random effects correspond to variable factors such as individual infants and each day within an infant and can, therefore, account for within-infant and within-day correlations. As an infant, in addition to exhibiting physiological patterns unique to oneself, may also have differences from one day to another; for example, a lasting physiological effect because of a recently performed medical procedure, random effects corresponding to the infant (RE-infant) and each day within an infant (RE-day) were incorporated. An interaction term was also included in the model to investigate the relationship between the position of the infant and the type of feeding. This decision was motivated by previous observations that position modulates physiology [13,14]

For the overall model, the statistical significance is reported. For each of the fixed effects and interaction terms, the regression coefficients were estimated along with the standard error, 95% CI, and statistical significance. For each random effect term, the standard deviation (SD) of its additive effect (by default, mean is zero) was estimated along with its 95% CI. For all statistically significant effects, the odds ratio (OR) and their 95% CI were reported. For the push and gravity methods of feeding, for both the prone and lateral positions of infants, the probability and SD of an alarm arising in response to feeding were estimated. These probabilities were calculated for the most representative values of our study population, that is, at median values.

In addition to the primary model that investigates the relationship between the variables listed in Table 2 and feeding-related alarms, subanalyses were carried out to specifically identify other relationships including the effect of left or right lateral position on feeding; whether feeding leads to desaturation alarms, bradycardia alarms, or both; and whether nursing care also leads to alarms. These subanalyses were carried out with the following combinations of dependent variables and fixed effects, while including RE-infant and RE-day: (1) presence or absence of desaturation and bradycardia alarms during and postfeeding for records corresponding to left and right lateral positions with all fixed effects, (2) individually testing for the presence or absence of desaturation and bradycardia alarms, one at a time, during and postfeeding with all fixed effects, and (3) presence or absence of desaturation and bradycardia alarms in the prefeeding period alone while including only nursing care events, postmenstrual age (PMA), and gender as fixed effects. All data were analyzed using Matlab R2015b Matlab (MathWorks). A *P* value of .05 was considered significant.

Table 2. The data types and distributions of all independent variables.

Independent variables	Data type	Distribution
PMA[a]	Categorical; ≤32 weeks or >32 weeks	1394 (65.14) ≤32 weeks
Gender	Categorical; male or female	976 (45.60) male
Type of feeding	Categorical; gravity or push	1251 (58.50) gravity
Nature of milk	Categorical; breast milk or formula	1636 (76.45) breast milk
Quantity of milk, mL per feed	Numerical[c]	15 (13-18)
Duration of enteral feeding, min	Numerical	10 (7-14)
Position of infant[b]	Categorical; lateral or prone	1078 (50.37) lateral
Diaper change	Categorical[d]; yes or no	618 (28.88)
Washing	Categorical; yes or no	98 (4.58)
Weighing	Categorical; yes or no	86 (4.02)
Airway suctioning	Categorical; yes or no	174 (8.13)
Change of nasal mask or nasal prong	Categorical; yes or no	487 (22.76)
Enteral administration of medication	Categorical; yes or no	222 (10.37)
Miscellaneous care	Categorical; yes or no	58 (2.71)
No nursing care	Categorical; yes or no	69 (3.22)

[a] PMA: postmenstrual age.

[b] All independent variables from *position of infant* until *no nursing care* were observed prefeeding.

[c] Numerical data are expressed as median (IQR).

[d] Categorical data are expressed as n (%) yes.

Results

We analyzed critical alarms in 2140 nurse-annotated episodes of enteral feeding. A total of 19.77% of these episodes (423 episodes) had at least one critical alarm during and immediately after feeding. The data were acquired from 25 preterm infants, each of whom contributed a median of 77 feeding episodes (interquartile range [IQR], 55-114) during a median length of stay of 40 days (IQR, 22-70).

The 2-hourly increase in alarms, associated with the enteral administration of feeding and nursing care, is illustrated in Figure 2. The use of a GLMM allows for the analysis of feeding alone, whereas other factors (eg, nursing care) are held constant at arbitrary levels. The regression coefficients for the primary model including their 95% CI and statistical significance are detailed in Multimedia Appendix 2. First, the primary analysis shows that the position of infants significantly modulates the number of critical alarms generated by the push and gravity methods of feeding (*P*=.02, Multimedia Appendix 2). In addition to the presence of a statistically significant interaction between position and the types of feeding, the odds of alarms increase with every increasing minute of feeding (OR 1.02; 95% CI 1.004-1.04; *P*=.01).

Figure 3 illustrates the interaction between the position of the infant and the type of feeding. It shows that in the lateral position, at median levels of all other variables and without contributions from random effects, the push method of feeding leads to a 40% increase in the probability of alarms in comparison with gravity (*P*=.02). There is no change in the probability of alarms between push and gravity methods of feeding if the infant is prone (*P*=.42).

Second, a subanalysis of those feeding episodes during which the infant was in the left or right shows that push, irrespective of the left or right lateral position, increases the OR of an alarm by 1.7 (95% CI 1.1-2.6; *P*=.009) and that all other variables are not statistically significant.

Third, a subanalysis of only desaturation alarms from the feeding and postfeeding period shows that infants generate significantly more alarms in the lateral position when fed by the push method of feeding (*P*=.01), whereas, in the prone position, both methods of feeding produce the same number of alarms. In the case of bradycardia alarms, however, the position does not modulate the number of alarms generated by the different methods of feeding.

Finally, the primary model used for assessing desaturation and bradycardia alarms during and postfeeding is statistically significant with fixed effects alone (*P*<.001). The addition of random effects accounts for dependencies in the data, and their inclusion improves the fit of the model to the data (*P*<.001). The 25 coefficients (number of infants) corresponding to RE-infant and 308 coefficients (number of infant-days) corresponding to RE-day contributed to 8% and 7% of the total variance, respectively.

Figure 2. The average number of all desaturations and bradycardia alarms measured during the study period is plotted through the 24 hours of the day. The 2-hourly increase in alarms (at even hours) occurs at times scheduled for nursing care and enteral feeding. The resolution of the x-axis is 10 min. The y-axis represents the alarm rate for 100 patients per 10 min.

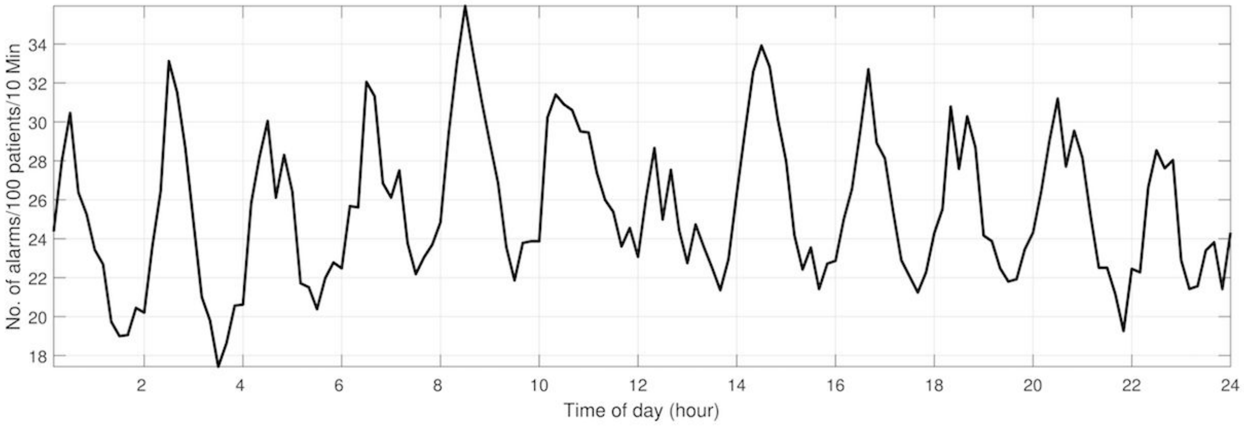
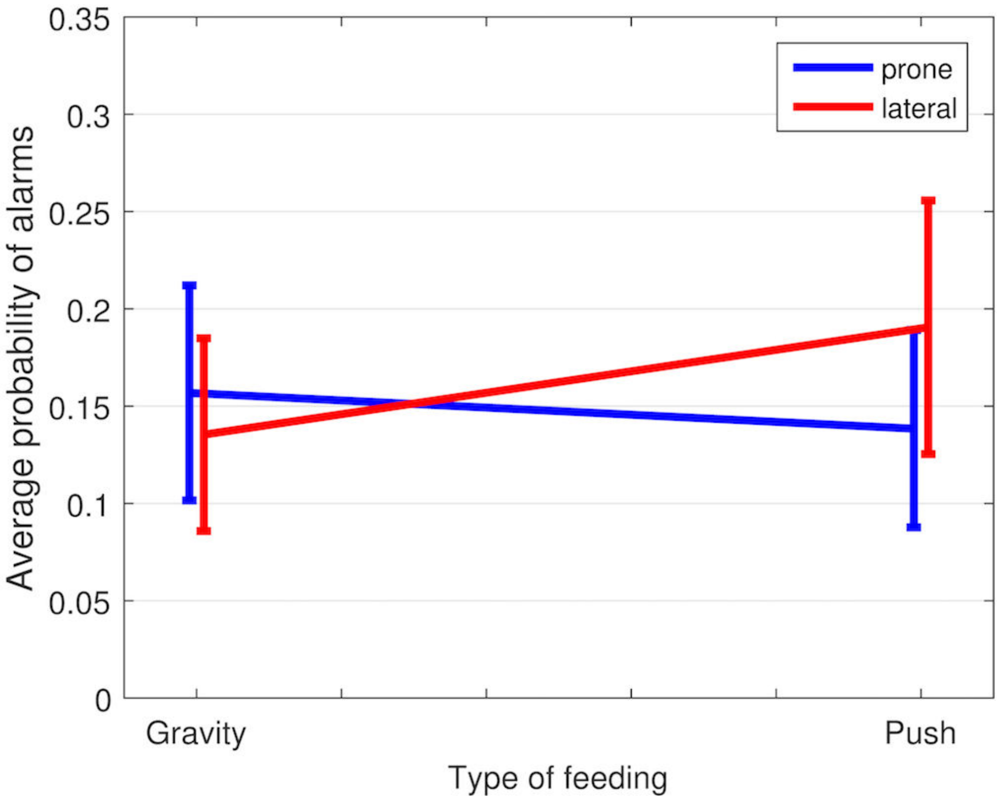


Figure 3. The probability of alarms in the prone (blue line) and lateral (red line) position for push and gravity types of feeding during and immediately after feeding. The intersection of the lines indicates an interaction between the position of the infant and the type of feeding. In the lateral position, the push method of feeding leads to a 40% increase in the probability of alarms in comparison with gravity (*P*=.02). The type of feeding does not affect the number of alarms when prone. The error bars indicate the standard deviation of the probability estimates.



The subanalysis of the prefeeding period with nursing care events, PMA and gender as fixed effects, and desaturation and bradycardia alarms in the prefeeding period as the dependent variables (both random effects included) shows that changing nasal mask or nasal prong increases the OR of an alarm by 1.7 (95% CI 1.1-2.8; *P*=.02), whereas other variables are not statistically significant.

Discussion

Principal Findings

We found that the position of infants significantly modulates the incidence of cardiorespiratory alarms generated by the two methods of feeding after accounting for all other variables. When infants are in the lateral position, the push method of feeding generates 40% more alarms than gravity, whereas if the infant is prone, both methods of feeding generate a statistically similar number of alarms. With regard to the lateral position, being left or right lateral is inconsequential.

These results suggest that the physiological stability of infants can be improved by using the gravity method of feeding when infants are in the lateral position. The need for such noninvasive strategies for optimizing feeding in preterm infants has also been highlighted elsewhere [15,16]. Although decreasing critical cardiorespiratory alarms is a desirable goal in its right, research on extremely preterm infants has also shown an association between hypoxemic episodes and increased risk of late death or disability at 18 months of age [17]. Additionally, this simple measure can have implications for reducing alarm fatigue in nurses, a notable safety hazard that compromises clinical workflow and patient safety [18-21]. A reduction in alarms also implies a reduction in the loud transient noises that alarms generate, a known cardiorespiratory stressor for preterm infants. Such iatrogenic environmental hazards in the NICU have been proven to impair development in multiple ways, including possibly neurodevelopmental outcomes [7,9,22-25].

As seen from the subanalyses of desaturation and bradycardia alarms, position modulates the prevalence of desaturation alarms for the two types of feeding but not bradycardia alarms. This result suggests that desaturations that occur as a result of interaction between position and type of feeding are not because of critical episodes of bradycardia but maybe related to other pathophysiologies, such as apnea triggered by gastroesophageal reflux. The fact that push feeding increases desaturation alarms in the lateral position but not in the prone position may suggest the activation of a peripheral mechanism, such as laryngeal stimulation, perhaps because of reduced abdominal pressure or in response to gastroesophageal reflux while lateral, resulting in central apnea via chemosignaling.

In addition to the interaction between the position and type of feeding, the duration of feeding also leads to a statistically significant increase in alarms after accounting for all other variables. As the duration of feeding (and not the volume of milk) is a significant factor, every increased minute of feeding increases the odds of an alarm occurring, and this suggests that the stimulation of peripheral receptors during feeding is continuous and not just precipitated by the first moments of feeding.

The addition of random effects—RE-infant and RE-day—significantly improves the model, although the results show that interinfant and intrainfant contribution to the total variance is small. Furthermore, the inclusion of random effects strengthens the assumption of independence between individual feeding episodes and allows for the quantification of interpatient and intrapatient variability that could not be explained by the fixed effects of the model.

To observe the immediate effect of nursing care, applying the model to the prefeeding period (after excluding feeding-based variables) shows that changing the nasal mask or prong increases the odds of an alarm. This suggests that the procedure for changing nasal mask or prong is particularly stressful for the infant (other nursing care events have no effect in this period), as similar findings have been noted in other literature as well [26-28].

Strengths and Limitations

A major limitation of the study is the observational nature of choice for push or gravity method of feeding based on the preference of nurses. This resulted in a quasi-random administration of feeds and was reflected in the balanced administration of push and gravity methods of feeding. Furthermore, the inclusion of random effects strengthens the assumption of independence between feeding episodes. Future studies attempting to reproduce this research will benefit from incorporating airflow sensors that can help determine whether desaturations in response to feeding occur because of apneas. The strengths of this study are the analysis of a large number of well-characterized feeding episodes of preterm infants in a NICU. The 2-hourly fluctuations in critical alarms support the earlier observation of feeding-associated instability [5]. The nature of the model employed here allows for the decomposition and quantification of every confounding factor that was incorporated into the model and to independently study their contribution, revealing that both nursing care (change of nasal mask or prong) and enteral feeding can lead to an increase in critical alarms.

Conclusions

We recommend a strategy for reducing critical alarms associated with enteral feeding by choosing to feed those infants who are in the lateral position by the gravity method of feeding. For infants in the prone position, we found no evidence to recommend one method of feeding over the other.

Acknowledgments

This research was performed within the framework of IMPULS perinatology.

Conflicts of Interest

No financial assistance was received in support of this study. Jan-Willem Bikker, an employee of Consultants in Quantitative Methods BV, consulted for Philips Research for this study. The remaining authors report no conflict of interest.

Multimedia Appendix 1

Details of the logistic regression model with mixed effects.

[PDF File (Adobe PDF File), 29KB - ijmr_v6i2e20_app1.pdf]

Multimedia Appendix 2

A table of regression coefficients corresponding to the primary analysis using the mixed-effects logistic regression model.

[PDF File (Adobe PDF File), 38KB - ijmr_v6i2e20_app2.pdf]

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Abbreviations

bpm: beats per minute
ECG: electrocardiogram
GLMM: generalized linear mixed models
IQR: interquartile range
NICU: neonatal intensive care units
OR: odds ratio
PMA: postmenstrual age
RE: random effect
SpO2: oxygen saturation
SD: standard deviation
WMO: wet medisch-weten- schappelijk onderzoek

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Original Paper

Internet Use and Access, Behavior, Cyberbullying, and Grooming: Results of an Investigative Whole City Survey of Adolescents

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Abstract

Background: According to the Digital Agenda for Europe, the way children use the Internet and mobile technologies has changed dramatically in the past years.

Objective: The aims of this study were to: (1) breakdown the modalities of access and use of the Internet by teenagers to assess risks and risky behaviors; and (2) provide scientific data to evaluate and counsel safe use of the Internet and new technologies by teenagers.

Methods: The study was conducted under the program “Strategies for a Better Internet for Children” started in May 2012 by the European Commission. It represents the main result of the project launched by Telecom Italia, “Anche io ho qualcosa da dire” (I too have something to say), thanks to which many contributions were collected and used to develop a survey. The questionnaire was structured in 45 questions, covering three macro areas of interest. It was approved by the Department Board at University of Magna Graecia's School of Medicine. After authorization from the regional high school authority, it was administered to all 1534 students (aged 13-19 years) in the city of Catanzaro, Italy.

Results: The data was broken down into three main groups: (1) describing education and access to the Internet; (2) methods of use and social networking; and (3) perception and evaluation of risk and risky behaviors. Among noteworthy results in the first group, we can mention that the average age of first contact with information technologies was around 9 years. Moreover, 78.87% (1210/1534) of the interviewed students reported having access to a smartphone or a tablet. Among the results of the second group, we found that the most used social networks were Facebook (85.78%, 1316/1534), YouTube (61.14%, 938/1534), and Google+ (51.56%, 791/1534). About 71.31% (1094/1534) of the interviewed teenagers use their name and surname on social networks, and 40.09% (615/1534) of them knew all their Facebook contacts personally. Among the results of the third group, we found that 7.69% (118/1534) of the interviewed teenagers have uploaded pictures or movies of which they felt ashamed; 27.05% (415/1534) have received invitations from people they met on the Internet to meet in real life; and 8.67% (133/1534) have accepted such invitations.

Conclusions: The results offer a breakdown of the teenagers' use of the Internet, focusing on how teenagers learn to use and access it while taking into account factors such as parental coaching, schooling, or self-education. It describes how they approach and interact with social networks and how they perceive risks and risky behaviors on the Internet. Information technology must be seen as an instrument and not as a hindrance. For this to happen, parental guidance, schooling, and medical counseling are needed for a sound development of the child in this critical stage.

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KEYWORDS

adolescent; Internet; social media; questionnaires; data collection

Introduction

> *...long ago, in the old days of the world before the Great War, with whose beginning so many things began whose beginnings, it seems, have not yet ceased...* [1]

The Rise of a New Media

The expression "digital natives" has been originally coined by the educator Mark Prensky [2] to highlight the lack of knowledge shown by the average American teacher in understanding and comprehending the needs of students who had grown up in the era of digital information. After 15 years, a full generation of digital natives exist. They can be considered the main actors of a contemporary world characterized by the proliferation and penetration of information technologies into the social fabric. This spread has indeed led to the formation of a new developmental environment somewhat parallel to the long-established ones (scholastic and domestic), which both educators and social and health operators or workers must take into account.

When the so-called "traditional media" (newspaper, radio, television) talk about adolescents and the Internet, they usually tend to focus on what comes through daily reports, such as cyberbullying, sharing of personal and often private information, shaming, stalking, and so on. Beyond that, however, there is a complex reality made of dynamic and carefully maintained social relations in which every subject is, at the same time, creator and user or consumer of contents [3,4]. The Internet was not created with youngsters in mind, but now it is a huge part of their life as they engage in a multitude of Web-based daily activities.

The pervasive nature of this new environment and the astonishing speed with which it has settled among adolescents has increased the natural gap existing between teenagers and their tutors [5].

The Role of Parents, Tutors, and Health Care Professionals

Parents and social or health operators tend only marginally to take part in these changes due to the often incorrect or poor understanding they have of the Internet and the many activities that adolescents carry out within it [6,7].

Posting contents, pictures, videos, attending online public debates on forums and communities with a simple click and creating customized personal profiles allows the weaving of increasingly wider social networks [8], and they are all elements that, beyond virtually extending the already existing face-to-face interactions managed in more traditional contexts (such as school and playgrounds), also carry out important elements of novelty (see "Discussion" section). These elements can have consequences [9] on the emotional, cognitive, and psychosocial development of children and teenagers that are still largely unexplored. Realizing the depth of the relations built through these new ways of communication represents an unavoidable step toward reaching a full understanding of the sometimes tragic events we already read about on the news [10]. According to several authors [11], youngsters are exposed to a vast array of risks in online that could be grouped in three main categories. The first one include Internet technology risks and refers to content-related (exposure to illegal or potentially harmful contents) and contact-related risks (cyber-grooming, forms of Web-based harassment such as cyberstalking and cyberbullying, exposure to illegal or hateful interactions) that are likely to arise in this particular kind of environment. A second one regards privacy and security risks and may be particularly evident in the use of social networks often carried without adequate understanding of potential short- and long-term consequences (ie, over sharing and sharing of problematic contents). Finally, consumer risks related to Web-based advertising and marketing that may exploit the lack of fully developed critical thinking skills leading to overspending and fraudulent transactions. Other concerns commonly regard abuse of Internet usage by teenagers and fear that it may substitute real-life interactions and therefore be noxious to the social and emotional development of subjects.

Several measures have been proposed to manage such issues and many initiatives from various stakeholders coexist at different and complementary levels [11]. However, a great deal remains to be done in order to better integrate these different efforts and evaluate their effectiveness in making the Internet safer. At the same time, such policies must keep in mind that the Internet represents not only a new and potentially dangerous environment, but also an opportunity as well as a widespread and useful tool in the hand of youngsters.

In order to reach these goals, a better assessment of how youngsters experience, use, and interact on the Internet is required. The primary scope of this study is, therefore, to define levels of involvement, levels of awareness of potential dangers and misconducts, and conditions of social network platforms and Internet usage displayed by a wide sample of adolescents. A deeper knowledge of the phenomenon based on a rich qualitative database is a primary requirement for any further interpretation and action related to the use of these kinds of technologies by adolescents. Moreover, since the classification of natural objects in science is unstable [12], we think that providing such qualitative data could be useful for future comparative studies and required to later evaluate the evolution and development of the phenomena.

Methods

Distribution and Coverage of the Survey

We conducted this study under the program “Strategy for a Better Internet for Children” [13] started in May 2012 by the European Commission. Its main goal is to create a database of information regarding Internet usage and behavior of adolescents on the Internet. Such data may be further used to identify a practical strategy to make the Internet a safer place for youngsters, and give them and their tutors the right tools and recommendations to live in this new environment without risks.

In order to achieve the goal, we developed a survey based on a rich preliminary exploratory groundwork, in collaboration with the European Union (EU) Commission, telecommunication corporation (Telecom Italia), and local educational authorities. The aim was to quantify the tendency of youngsters to adopt potentially risky actions on the Internet [14-17] and roughly map their behavior to gather useful data for future epidemiological, behavioral, social, and health-related researches on the issue. As suggested by the program “European Strategy for a Better Internet for Children” [13], it is important to collect data about Internet usage by adolescents in order to help them acquire the skills and tools they need to fully and safely benefit from using the Internet as well as unlocking a potential market for interactive, creative, and educational Web-based content. The data also represents a starting point of investigation to describe the effects that Web technologies have on the psychosocial and cognitive development of children and teens.

On June 3, 2013, broadcasting and telecommunication corporations were invited by the EU Commission to actively contribute and take part in the project. On June 26, 2013, Telecom Italia promptly gave life to the “Stati Generali della Tutela dei Minori” (Estates General for minors’ protection) and arranged a meeting, well-advertised and promoted by social media, which was attended by institutions, associations, and specialists of the field [18].

The main result of this meeting was the launch of “Anche io ho qualcosa da dire” (I too have something to say), a project directed by Umberto Rapetto. After a census of potential contributions and experts, we edited a syllabus, consisting of a list of key themes that were worth studying in relation to our main purpose. The chosen topics were then examined and debated during a series of events specifically conceived to captivate and involve the social fabric of some Italian regional centers with the intention of gathering ideas, point of views, and suggestions as much as possible. Through this exploratory work, we engaged with the public and identified some key themes that informed our survey questions.

The initiative was launched in Genoa on October 14, 2013 at the high school “Istituto Magistrale Pertini,” and it later reached the cities of Bari, Catanzaro, and Trento. It consisted in engaging the community of each city for 5 days with information campaigns, cultural spaces, and meetings dedicated to explore this issue. The next step was collecting the most significative contributions to draft, on the base of this experience, a pool of questions that underwent respondent validation. The questionnaire was then approved by the Board Commission of the Department of Medical Sciences of Magna Graecia University of Catanzaro and by the local educational authorities, which entitled its administration to all the students of public high schools of the regional center of Catanzaro. This study, therefore, consists of a descriptive statistical analysis, a census about Internet usage habits of all the teenagers (aged 14-18 years) that attended public high schools of an important Italian regional center, the city of Catanzaro, during school year 2013-2014.

The Questionnaire

We specifically drafted the questionnaire to investigate the frequency of access and Internet usage of the adolescent population of the city, which was the main target of our study. We structured the survey in three macro thematic areas: (1) learning and network access, (2) conditions of use and social networking, and (3) risk perception and behaviors. In the first one, we conducted a preliminary analysis on the Internet usage habits of the teenagers and the ways through which they came to acquire the practical competences required to surf the Internet. The focus of the second cluster was directed on the usage of social networking platforms and the managing of their personal identity on the Internet, whereas the last one analyze the adoption of potentially dangerous behaviors and their perception by the study subjects.

The overall questionnaire consists of 45 close-ended questions (available in Multimedia Appendix 1) covering the three macro areas of interest above mentioned. Each question was further designed to be clear, short, and precise to be easily understood and reduce fatigue among respondents. The answers were collected anonymously to minimize selective suppression of information by the subjects due to possible feelings of shame or social acceptance. The majority of questions were conceived to have a yes or no answer in order to simplify the analysis of responses; however, in many cases, we have decided to set more fixed options and allow the possibility to give multiple answers to avoid losing precious information and break any possible yes-or-no pattern effect among the subjects of the survey.

Results

Overview

The teaching staff delivered the survey over the academic year 2013-2014 to all secondary school students (aged 14-18 years) in the city of Catanzaro, except a single class (22 subjects). Both tutors and students have shown a great level of collaboration. A total number of 1534 students participated in the study (54.6% males; 43.3% females; 2.2% stated no gender). The cards were then collected and the response rates to each question (Yes or No or white) have been analyzed, divided by gender (Male or Female), and recorded in a data set (available in Multimedia Appendix 1). Results are reported according to the three macro areas, or clusters, described in the Methods section.

First Cluster: Access and Learning

This cluster aims to explore teenagers' Internet access routines: type, availability, and ownership of the devices with which the subjects access the Internet. It also aims to investigate from whom the teenagers get their first instructions on how to use the Internet, how they respond to the instructions given, as well as identifying the level of confidence shown to adults in terms of discussing their own activities on the Internet (Table 1).

Of the participants, 79.20% (1215/1534) possess a smartphone and/or a tablet for accessing the Internet. This fact agrees with several international research projects, according to which teenagers are becoming "cell-mostly," or even "cell-only" users, with the implementation (increasingly widespread) of devices such as smartphones or tablets. Conversely, a mere 20.73% (318/1534) accesses the Internet exclusively from their home PC.

We found that 96.87% (1486/1534) of teenagers in Catanzaro own or have access to a computer with an Internet connection. Among them, 72.68% (1115/1534) access the Internet by using their own PC, which is not shared with the rest of the family (Tables 2 and 3).

In 2013, in Catanzaro, teenagers started to use the Internet on average at the age of 9. We found that 53.0% (444/837) of the interviewed males and 41.0% (272/664) of the females were self-taught in the use of the Internet. For 29.85% (458/1534) of the interviewed subjects, Internet use had been taught at home (by parents or relatives) rather than in school. The most commonly given parental advice is about avoiding communication with strangers (81.02%, 1243/1534) and not spreading personal data (75.74%, 1162/1534).

Table 1. Internet access.

Question	Total yes	% yes	Male, % yes	Female, % yes	Gender not declared, % yes	Void forms
Do you own a computer?	1115	72.7	40.7	30.4	1.4	0.2
Does your PC have antivirus software?	1377	89.8	49.4	37.8	1.8	0.8
Do you have an Internet connection?	1486	96.9	52.6	42.2	2.0	0.1
Is your Internet connection fast enough?	1275	83.1	45.4	35.4	1.8	0.5
Do you own a tablet or mobile phone?	1215	79.2	44.0	33.2	1.6	0.3
Do you use a tablet or a mobile phone to go online?	1226	79.9	43.7	33.9	1.6	0.7
Do you use someone else's device, PC, tablet, mobile phone to go online?						
Parents	263	17.1	7.9	8.3	0.4	0.5
Friends	278	18.1	8.3	8.7	0.5	0.5
No	1021	66.6	37.7	27.1	1.2	0.5

Table 2. Learning.

Question	Total yes	% yes	Male, % yes	Female, % yes	Gender not declared, % yes	Void forms
Has someone taught you something about Internet use?	812	52.9	25.6	25.4	1.3	0.7
Who taught you to surf the Web?						
Parents	484	31.6	15.2	15.3	0.7	0.4
Teachers	63	4.1	1.7	2.0	0.1	0.4
Friends	280	18.3	9.3	8.2	0.4	0.4
Family	433	28.2	14.7	12.7	0.5	0.4
Myself	463	30.2	18.9	10.4	0.5	0.4

Table 3. Tutoring.

Question	Total yes	% yes	Male, % yes	Female, % yes	Gender not declared, % yes	Void forms
Do your parents surf the Web with you?						
Often	142	9.3	4.2	4.6	0.3	0.1
Sometimes	718	46.8	24.4	21.2	1.0	0.1
Never	675	44.0	25.7	17.5	0.7	0.1
Did your parents install filters to limit your Web surfing?						
Yes	112	7.3	3.4	3.3	0.4	0.3
No	962	62.7	35.8	25.5	1.1	0.3
Don’t know	463	30.2	14.8	14.4	0.7	0.3
Do you think that the practical experience of an adult would help you use the Internet?	1048	68.3	34.3	31.6	1.6	0.8
Did parents, teachers, or friends make suggestions about how you should use the Internet? If yes, what kinds of suggestions did they make?						
They told me never to give my personal data	1162	75.7	38.4	34.6	1.4	1.4
They gave me a maximum time to stay online	365	23.8	11.6	10.2	0.4	1.6
They told me not to communicate with strangers	1243	81.0	40.2	38.3	1.5	1.1
They told me which website I can connect to and what I should do	669	43.6	21.4	19.8	0.8	1.6
They told me to not send or post pictures that are of me or my family	635	41.4	21.4	17.7	0.8	1.5
They told me how to behave in case of complications, awkwardness, or fear	923	60.2	29.4	27.8	1.3	1.6
They explained to me how to use chats and instant messaging	547	35.7	17.6	15.6	0.8	1.6
They advised me to not use the Internet by myself	234	15.3	6.1	7.1	0.3	1.8
They advised me to tell them what I do online	523	34.1	15.3	16.5	0.6	1.7
Have you ever told to your parents/teachers/friends what you have seen or done online?	937	61.1	28.5	30.3	1.2	1.0

Table 4. Conditions of use.

Question	Total yes	% yes	Male, % yes	Female, % yes	Gender not declared, % yes	Void forms
Every day, how much time do you spend on the Internet?						
1 h or less	624	40.7	22.4	16.8	1.0	0.5
2-3 h	599	39.0	21.7	15.9	0.9	0.5
4-6 h	178	11.6	4.9	6.1	0.1	0.5
>6 h	144	9.4	4.7	4.0	0.1	0.5
Why do you connect to the Internet? You can give more than an answer.						
Do school homework	1225	79.9	41.6	36.2	1.6	0.5
Get sport, music and info news	1216	79.3	44.7	32.8	1.4	0.4
Play online	972	63.4	38.0	23.5	1.4	0.5
Music or video streaming or downloading	1359	88.6	47.5	38.9	1.6	0.6
Chat and instant messaging	1326	86.4	46.7	37.5	1.6	0.6
Email	504	32.9	19.4	12.1	0.6	0.7
Do you have any social network accounts? If yes, which?	1104	72.0	36.8	33.4	1.4	0.3
Facebook	1316	85.8	47.7	35.7	1.8	0.7
Twitter	547	35.7	19.4	13.0	0.6	2.7
MySpace	180	11.7	5.7	2.4	0.3	3.4
Google+	791	51.6	29.4	18.5	0.9	2.7
Pinterest	96	6.3	1.9	0.7	0.1	3.5
Flickr	118	7.7	2.9	1.3	0.1	3.4
YouTube	938	61.1	35.9	21.6	1.3	2.3
Instagram	606	39.5	17.7	18.5	0.7	2.7
Others	388	25.3	11.4	10.0	0.5	3.4
Do you use a webcam?	865	56.4	28.9	25.6	1.4	0.6
When do you use a webcam? You can give more than one answer.						
Video chat with schoolmates and friends	867	56.5	28.2	26.1	1.4	0.7
Video chat with friends met online	179	11.7	7.2	3.5	0.3	0.7
To learn more about the people you met online	56	3.7	2.2	0.7	0.1	0.7
Take pictures or make videos to post publicly online	230	15.0	7.0	6.8	0.5	0.7

Second Cluster: Conditions of Use and Social Networking

It consists of two areas of interest. First, we wanted to investigate the teenagers' social customs, their access to the most common social platforms, the average length of their Internet sessions, and the general purpose of their activity. The second part of the cluster focuses on the use of identities and pseudonyms while on the Internet, and on the usage of devices such as webcams (Tables 4 and 5).

Responses from this second cluster indicate that the majority of the teenagers in Catanzaro use the Internet to download music and movies (88.59%, 1359/1534), to chat and send messages (86.44%, 1326/1534), to search for news (79.26%, 1216/1534), or information for school projects (79.85%, 1225/1534). The most used social networks are Facebook (85.78%, 1316/1534), YouTube (61.14%, 938/1534), and Google+ (51.56%, 791/1534). Only 11.73% (180/1534) of the interviewed use MySpace, which dominated in this age group before the beginning of the "Web 2.0" era.

Of the teenagers in Catanzaro, 71.31% (1094/1534) use their real first and last name on social networks, the remaining 28.68% (440/1534) use pseudonyms, and 12.45% (191/1534) admit to using fake profiles. We find that 40.09% (615/1534) of the interviewed subjects know all of their Facebook contacts personally.

Table 5. Social networking.

Question	Total yes	% yes	Male, % yes	Female, % yes	Gender not declared, % yes	Void forms
When you are online, do you use a nickname or a fake identity?	440	28.7	16.9	9.6	0.5	1.6
Do you prefer to use a fake profile on the Internet?	191	12.5	6.2	4.5	0.2	1.6
When you are online, do you feel stronger than in real life?	210	13.7	5.9	5.9	0.3	1.6
Do you lie regularly when you are online?	197	12.8	7.9	3.2	0.2	1.6
Where do you have more friends?						
In real life	1136	74.1	40.4	30.1	1.6	2.0
On the Internet	384	25.0	10.9	11.9	0.3	2.0
How many friends do you have on Facebook or other social networks?						
<50	103	6.7	3.0	2.0	0.3	1.4
50-200	315	20.5	10.2	8.3	0.6	1.4
200-500	438	28.6	14.8	11.7	0.6	1.4
500-1000	321	20.9	11.3	7.9	0.3	1.4
>1000	252	16.4	8.3	6.5	0.2	1.4
How many social network friends do you know in real life?						
None	45	2.9	1.1	0.5	0.1	1.3
A few	54	3.5	1.1	0.8	0.3	1.3
20-50	100	6.5	2.5	2.6	0.1	1.3
50-100	178	11.6	5.1	5.1	0.1	1.3
>100	480	31.3	16.6	12.6	0.7	1.3
Everyone	615	40.1	22.4	15.6	0.8	1.3

Third Cluster: Risk Perception and Behaviors

We divided this cluster into three main areas. The first one focuses on Internet use for potentially dangerous behavior, such as bullying and shaming or requests to meet in person somebody known on the Internet. The second area analyzes publishing of compromising photos or videos, and how such photos or videos are exchanged in order to get favors or currency (often used in grooming). The section ends with a series of questions on risk perception about potentially illegal behaviors (Table 6).

We find that 27.05% (415/1534) of teenagers in Catanzaro admitted to having received requests from someone known to them on the Internet to meet in person, with a marginal gap between males and females (24.3%, 204/837 vs 26.0%, 173/664). Only 8.67% (133/1534) of the interviewed subjects have accepted invitations to meet up with strangers. Another potentially dangerous behavior, exchanging photos or videos for PostePay (an Italian debit card that can be recharged on the Internet) or cell phone credit top-ups or other presents, has been found in less than 10% (9.51%, 146/1534) of the cases (Table 7).

Nearly 62.12% (953/1534) of the interviewed subjects admit to uploading photos and videos online. Among them 40.35% (619/1534) report having uploaded more than 50 pictures of themselves, but less than 10% (7.69%, 118/1534) admit to having posted compromising photos or materials they might be ashamed of (Table 8).

The interviewed teenagers are mostly aware of the risks involved with this behavior: 84.35% (1294/1534) know that such behavior can bring legal consequences, and 77.90% (1195/1534) know that the police can gather personal information to investigate illegal behavior.

Table 6. Risk perception.

Question	Total yes	% yes	Male, % yes	Female, % yes	Gender not declared, % yes	Void forms
Have you ever been in trouble while you were online?	352	22.9	12.0	8.7	0.6	1.7
Have you ever used the Internet for revenge, to tease or be cruel to someone?	235	15.3	8.0	5.5	0.2	1.6
Are you afraid that someone can disparage you online?	537	35.0	15.6	17.1	0.6	1.7
When you chat, do you talk of things you find embarrassing in real life?	363	23.7	10.2	10.6	0.6	2.3
Have you ever received invitations to meet with people met online?	415	27.1	13.3	11.3	0.5	2.0
Have you ever accepted an invitation to meet with people you met online?	133	8.7	4.8	1.8	0.2	1.8

Table 7. Management of online self-image.

Question	Total yes	% yes	Male, % yes	Female, % yes	Gender not declared, % yes	Void forms
Do you post pictures or videos online?	953	62.1	31.5	27.3	1.4	1.9
How many pictures do you have on your profile?						
None	172	11.2	5.5	4.2	0.2	1.4
1	73	4.8	2.3	1.0	0.1	1.4
<20	294	19.2	12.8	4.6	0.3	1.4
20-50	345	22.5	12.1	8.5	0.5	1.4
>50	619	40.4	17.5	20.7	0.8	1.4
Have you ever sent or posted anything you feel embarrassed about?	118	7.7	4.3	1.4	0.1	1.8
Would you trade pictures of yourself for mobile credit or other things?	146	9.5	5.5	1.6	0.4	2.0

Table 8. Risky behavior and awareness.

Question	Total yes	% yes	Male, % yes	Female, % yes	Gender not declared, % yes	Void forms
Have you ever argued with someone online?	658	42.9	22.4	17.8	1.0	1.8
Do you like watching violent material on the net?	248	16.2	12.2	1.4	0.5	2.0
Do you know that you can be reported for your online behavior?	1294	84.4	43.9	36.9	1.8	1.7
Do you think that police could bust you if you do something wrong online?	1195	77.9	40.2	34.1	1.6	2.0

Discussion

Principal Findings

A child’s development does not run on completely fixed paths, but rather on possible and differentiated routes. Developmental trajectories are often irregular and unpredictable, and they heavily depend on the effect of environmental and sociocultural factors with which the subject interacts and relates to [8]. Adolescence is a transitory stage of life between childhood and adulthood, characterized by multiple shifts and adjustments, which are part of the acquisition of critical cognitive and social skills. Nowadays, we are witnessing a dramatic change in environmental conditions that are used to house—and, in a sense, drive—this important step, mainly due to the exponentially accelerating technological progress, a real hallmark of our time.

Such changes have several consequences. These concern both the development of the emotional, social, and cognitive skills of children, which may be shifted toward different paths than those with which we are familiar, thereby exposing children to certain risks and dangers. Parental figures and tutors who normally play a major role in child development have only partial knowledge of the new digital media- and Internet-related technologies. This reflects the poor understanding they have of the phenomenon and its dynamics [2], as well as the limited control they have over it. Research specifically oriented to assess the behavior of adolescents on the Internet and the risks associated with such activities seem particularly urgent. Most of the data collected in the past about Internet usage concerns mainly adults and young adults (college students) [19-21]. Only very recently, the focus has shifted toward younger population groups [22-26].

The presented research aims first and foremost to serve as an important fact-finding and investigative tool that could help fill the generational gap that has arisen as a result of the advent of the new digital technologies. We propose a descriptive and broadly representative study of the habits, motives, and styles of Internet access and social networking of adolescents. We believe that it could constitute an excellent database and a starting point for the development of intervention and risk prevention strategies. Some recent studies also specifically want to provide data on adolescent Internet access as well as give useful insight on the main consequences of new media [27,28]. However, because the majority of them are cross-sectional, our research differs in the methodology since we collected data from the entire teenage population of an Italian regional center.

Among the risks associated with Internet use, the growing phenomenon of cyberbullying has a great relevance [29-31]. This term refers to threatening or humiliating activities against others, as well as public shaming mechanisms, which occur through electronic devices [29]. The spread of this and other hazardous practices appears related to some characteristic attributes of communication mediated by new digital technologies: anonymity, synchronization, and accessibility [32]. Anonymity can be total [33] or it can be partial, involving just some aspects (ie, audio and/or visual). Thanks to anonymity the subject has greater control over the quality and quantity of personal information he or she wants to share publicly on the Internet. This can have both positive and negative effects on the development of adolescents. It can lead the subject to think that, once partially or not at all identifiable, he or she can act irresponsibly, impulsively, and, in extreme cases, in a way that can be harmful to himself or herself and to others without bearing responsibility. However, according to data obtained from our survey’s second cluster results, total anonymity is less and less common among young Internet users: 71.31% (1094/1534) of teenagers in Catanzaro use their real first and last name on social networks, 28.68% (440/1534) use pseudonyms, and only 12.45% (191/1534) admits to using fake profiles.

On the other hand, anonymity may also have a positive impact, encouraging self-disclosure leading to greater self-esteem and higher levels of socialization due to lower level of concern about one’s own physical appearance and judgment of peers [33,34]. A certain extent of anonymity can thus lead to higher self-exploration (or self-consciousness), particularly in the sexual sphere, which often suffers censorship or reproach in “real life” due to local cultural and religious habits and traditions. Our data reveal that 23.66% (363/1534) of adolescents in Catanzaro discuss online matters that they would otherwise be ashamed to talk about in person.

The widespread availability of current digital technologies results in higher accessibility for users, especially adolescents, who can be considered the main users of new social medias, and who have the opportunity to choose their social audience. They can stay in touch with people with similar interests, or with people whom they would never be able to meet in real life (ie, due to distance), or they can be introduced to different cultural practices. A greater level of Internet access obviously extends not only the number of opportunities, but also the number of risks. For instance, although traditional forms of bullying are limited in time and space, Internet-related ones do not have these constraints. This specific feature could potentially amplify the magnitude and persistence of the offence [31]. Indeed, 35.00% (537/1534) were afraid that someone could disparage them on the Internet. On the other hand, 15.31% (235/1534) of our teens admitted to having used the Internet for revenge, to tease, or be cruel. Asynchronicity is another characteristic of online communication, and it allows adolescents to have greater control over the information they decide to share due to the possibility of thinking and editing messages before sending them. It can be particularly beneficial for kids who are shy, emotional, or easily embarrassed in offline interactions [35].

Overall then, these opportunities can enrich and ease the identity formation process, but they can also make the subject vulnerable to the cyber-grooming phenomena, such as sexual harassment or unwanted solicitations from strangers [36]. We tried to assess risk perception and hazardous behavior on the Internet in the third cluster of the survey.

Data reveals that 22.94% (352/1534) of the interviewed adolescents claim to have had unpleasant experiences on the Internet, whereas 27.05% (415/1534) have received invitations to meet someone they got to know on the Internet in real life. Our data shows that teens are at least partially aware of the risks associated with such activities: only 8.67% (133/1534) of them have accepted these kinds of meetings. Although a high percentage of the adolescents surveyed admit to uploading photos and videos on the net (62.12%, 953/1534), less than 10%, 9.51% (146/1534) report a willingness to exchange photos or videos with phone cards or gifts. Only 7.69% (118/1534) of respondents say that they have published compromising or embarrassing material on the Internet.

Another main concern associated with Internet usage by adolescents is related to its abuse and compulsive usage. Results from first and second clusters regarding level of accessibility and conditions of Internet usage confirm that our teenagers become familiar with these technologies early in life, at around 9 years of age, and they seem to use them extensively. Of those we surveyed, 96.87% (1486/1534) have access to a computer and an Internet connection, and 79.20% (1215/1534) have a smartphone or a tablet. We found that 43.54% (668/1534) of respondents would rather have an up-to-date smart phone than a scooter, although for the majority (88.65%, 1360/1534: 47.06%, 722/1534 male and 38.39%, 589/1534 female), a day at the seaside remains a preferable option to chatting or playing videogames on the Internet. It therefore seems that Web-based reality is still far from being a substitute for the “real” one.

The learning process involved in properly using new digital devices is increasingly autonomous: although 52.93% (812/1534) of teens declare that someone has taught them to access and use the Internet, another 30.18% (463/1534) say that they have never been taught or informed by any adult. In our sample, a gender difference emerges: female children appear to be more protected. Girls receive more advice from parents and tutors, and are more willing to talk about what they do and how they behave on the Internet (30.24%, 464/1534 vs 28.48%, 437/1534 of males). Parental involvement and tutoring may therefore be strengthened in order to allow teens to better understand and manage their behavior on the Internet as well as be more aware of the risks to which they could be exposed. Nearly, 61.08% (937/1534) of our teens declared not to have told anyone what they have seen or done on the Internet. This is a point that should be further explored in order to disentangle the possible variables that could lead to such behavior and assess appropriate means of risk prevention.

One of the most intriguing possibilities of using social networking platforms (such as Facebook, Twitter, and so on) is amplifying and changing the social support network of the children. This becomes possible because new technologies lighten the cognitive and mnemonic load normally required for the construction and maintenance of social relationships, and also because they are able to overcome the limitations of time and space typical of more traditional forms of interaction. It is interesting to see if this really happens and, if so, to which extent. According to the social brain hypothesis [37-40] developed by anthropologist and evolutionary psychologist Robin Dunbar, the high degree of encephalization reached by the neocortex of social mammals, especially by Homo sapiens, may be a direct consequence of the cognitive demands required for the stable management of complex relationships that occur within social groups in response to different environmental pressures. Through statistical analysis and comparisons with other animal taxa and other kinds of primates, Dunbar has come to identify an approximate number of 150 friends or social relationships that the individual human subject is actually able to maintain.

The new generation of social platforms like MySpace, Facebook, and Twitter, however, seem to refute this conclusion since coming across profiles with more than 500 or 1000 "friends" is now the norm. Of the students who completed our questionnaire, 28.55% (438/1534) reported having 200-500 friends on Facebook, 20.92% (321/1534) more than 500 friends, whereas 16.42% (252/1534) reported having over 1000 friends. Dunbar analyzed this issue in a recent article [41,42], and according to him, the circle of friends on the social media is not qualitatively homogeneous as it tends to include a vast array of simple acquaintances that people do not foster in a stable (and therefore cognitively demanding) way. The Internet can bypass the biological and cognitive constraints imposed by stable social relationships and offer a new way to better maintain the already existing social networks of the subject, as well as allowing an extension to the layer of weaker, unstable, or indirect connections.

We are witnessing a paradigm shift in regards to the evaluation of social consequences when it comes to new digital technologies and their impact on the lives of adolescents [43]. Although in the 1990s an overall "pessimistic" conception supported by numerous studies [44] prevailed, the current picture appears to be more optimistic [21,2,8,42,9]. Today, both the portion of the population that has access to the Internet and the overall frequency of access have definitely increased. Although some years ago maintaining Web-based contact with people known in real life was very difficult as most of them did not use it, the situation has changed radically. This is confirmed by the results of our survey: 40.09% (615/1534) of respondents personally know all the contacts on their Facebook profile (only 2.93%, 45/1534 declare not to know anyone), and 72% (1094/1534) of the subjects use their own real name and surname on social networks. The principal reason for this change resides is that online communication in the 1990s was mainly based on blogs and chat rooms, and it used to occur among strangers with fictitious names. The new social platforms (ie, Facebook) and instant messaging services on cell phones tend instead to be closer to a non-physical place of meeting between real friends and acquaintances, to which are added layers of weaker and more volatile Web-based connections between strangers. Far from being necessarily bad, these accessory networks could have a positive impact on the psychosocial development of the teen, his or her self-esteem, and sense of social effectiveness [34].

Regarding the potential impact that new digital technologies have on the cognitive development of kids and teens, the debate is very open and the research is still in its early stages. Our teenagers live and grow in a world that increasingly resembles a "game room," among tools that guarantee access and are able to convey a lot of information at rates that were unimaginable until recently, forcing the receiver to process everything instantly and give quick answers. The frantic revision of information, the speed in processing responses, and switching from one task to another mark the times of a perhaps not harmonious, but faster psychomotor development. The high pervasiveness, accessibility, and frequency of use of these new technologies, now used daily and increasingly to accomplish a variety of tasks (from research and exchange of information, to gaming), appear to offer the possibility of enhancing, at least partially, our cognitive potential. As pointed out by Mark Prensky [45], digital tools (such as online databases, Google's search engine, computer simulation, and so on) help us overcome our memory constraints, enhancing our daily data gathering, decision-making processing, and access to alternative perspectives.

These observations are in line with some ground-breaking philosophical conceptions of the human mind according to which our cognitive processes are better understood from an externalist, theoretically driven point of view [46-59]. In short, these perspectives reject the classical internalist and neurocentric cognitive paradigm that confines our mental processing merely to the brain, stressing on the contrary the important role that the whole body system along with its constant interaction with both environmental and sociocultural factors play. Apart from the discussion concerning the practical criteria identified by proponents of this approach to delimit the range of environmental factors that could be considered genuine extensions of our cognitive processes [46,47,49-52], this new theoretical paradigm seems to be particularly well suited to achieving a better conceptual grasp of the massive role that the Internet and new digital technologies have come to play in our routine daily life [53-59]. It should, therefore, be further explored experimentally.

Understandably, these changes have triggered concerns related to the fact that such devices could eventually impoverish our sensory-motor, mnemonic, and cognitive skills, because of their partial integration in some external storage devices and the lack of focus associated with multitasking behaviors [60,61]. However, it seems that this kind of pessimistic conclusions suffer from the classic "fear of the novel" associated with the emergence of new technologies. They also ignore the fact that the Internet is certainly not the first technological innovation that has been able to change our behavior and our cognitive functions in some way.

As pointed out by Loh and Kanai in 2016 [61], "throughout our evolutionary history, our cognitive system had been reshaped by the advent of tool making and usage, language, writing, and arithmetic systems." These kinds of technological changes cannot be stopped and are not necessarily detrimental. As an instance, according to recent behavioral and neurophysiological studies, there is evidence that videogame training can induce neuroplastic changes associated with improvement of executive function, working memory, top-down attention, and visuospatial processing [62-65]. In light of these considerations, categorizing these changes as negative or positive per se seems naive, and future studies should focus on the analysis of causal relationships between the different variables involved in the many uses of such devices.

Conclusions and Limitations

Our survey provides an interesting snapshot of the frequency and methods of Internet usage of a highly representative sample of Italian adolescents allowing us to obtain also important information on possible risks and dangers, and the level of awareness of teens on the Internet. The extent and characteristics of the phenomena (the Internet usage and the behaviors of teenagers while using the Internet) have not been scientifically studied yet, leading to both a poor understanding and a general concern regarding its potentially dangerous social consequences. Building on these considerations, our study is essentially descriptive, and therefore, it mainly intends to contribute to a deeper understanding of the phenomenon in some of its many facets. The kind of information we were able to collect represents for these reasons a valuable starting point that could help in overcoming the huge generational gap which now exists between teens and their mentor figures due to the incredibly fast development of new digital technologies. This data allows us to assess many outcomes and risk factors to: (1) better comprehend the social consequences of the phenomenon; and (2) generate hypotheses about potential strategies of intervention. However, it cannot isolate causal relations between variables, so future experimental designs and longitudinal studies are required for the further development of the field. Another important goal we have pursued is to provide an effective instrument of investigation for future studies on the subject.

However, some limitations have to be taken into account. First of all, these kinds of technologies are in constant development, so we must be well aware that the situation described here may no longer have the same validity in a few years. We also need to keep in mind that the frequency and pattern of use of these technologies are strongly influenced by conditions of technological and cultural development of the population object of the study, and therefore, the results cannot have universal validity and some differences could be observed even at the regional level within the same country. However, overall this study gives us an accurate picture of the main features of this new reality in 2014, and the high representativity of the sample allows a good generalizability of data results.

We chose to use self-report surveys with close ended multiple questions due to technical reasons (large sample and data analysis). We are conscious that this format could be susceptible to various cognitive biases related to memory errors, underestimation of the real time spent on the Internet due to multitasking, and desire to appear more popular or hide information perceived as socially compromising. We tried to limit the latter problem by making the questionnaire totally anonymous (see "Methods" section). Finally, the currently available literature on the field rarely tends to consider the different activities associated with Internet usage separately (ie, information search, game, social network maintenance, work, and/or study) in relation to the possible impact that these could have on the psychosocial development of children and teens. This inevitably results in the tendency to draw vague and contradictory conclusions on the whole phenomenon [32]. Yet the use of the Internet cannot be conceived as a monolithic, unitary phenomenon, and its positive and negative effects should be better investigated by evaluating each time the type of activity in which the subject is involved [22]. Therefore, future studies should begin to pay more attention to this aspect in order to achieve a more detailed and specific understanding, rather than level it out into general and consequently unrealistic categories.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Original survey form (in Italian).

[PDF File (Adobe PDF File), 152KB - ijmr_v6i2e9_app1.pdf]

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Original Paper

How, When and Why People Seek Health Information Online: Qualitative Study in Hong Kong

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Abstract

Background: The Internet has become an established source for health information. The number of individuals using the Internet to search for health information, ranging from healthy lifestyle advice to treatment and diseases, continues to grow. Scholars have emphasized the need to give greater voice and influence to health consumers. Hong Kong, being one of the most technologically advanced and connected cities in the world, has one of the highest Internet penetration rates in the world. Given the dearth of research in an Asian context, Hong Kong is an excellent platform to study individuals' perceptions (eg, benefits and limitations on seeking health information online and how the information is used) on health information seeking.

Objective: The aim of this paper was to study individuals' perceptions on health information seeking and to document their Internet information–seeking behaviors.

Methods: Five focus groups (n=49) were conducted from November 2015 to January 2016 with individuals across different age groups (18 years or above). Focus group contents were audiotaped, transcribed, and analyzed using thematic analysis techniques.

Results: Older (55+ years) and less educated respondents were less likely to use the Internet to search for health information. Among individuals who obtained health information via the Internet, regardless of the severity of the health issue, the Internet was always the first source for information. Limited doctor consultation time and barriers to accessing professional health services were the main reasons for using the Internet. Convenience and coverage were regarded as the main advantages, whereas credibility and trustworthiness of health information were noted as limitations. The use of Web-based health information varied among individuals; hence, the implications on the doctor-patient relationship were mixed.

Conclusions: The prevalent and increasing use of the Internet for health information seeking suggests the need for health care professionals to understand how it can be optimally utilized to improve health outcomes. Strategies for communicating and disseminating credible health information in a form that users can understand and use are essential. Due to the rapid technological and related behavioral changes, online health information seeking and its effects need to be closely monitored.

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KEYWORDS

Internet; information seeking behavior; consumer health information; focus groups

Introduction

Hong Kong is one of the most technologically advanced and connected cities in the world. According to the Hong Kong Monthly Digest of Statistics (HKMDS), 2013, the estimated number of Internet users was 5.751 million in a population size of approximately 7.188 million. Internet access is available almost everywhere via broadband and Wi-Fi (39,796 public Wi-Fi hotspots in the city; Office of the Telecommunications Authority, 2015). According to the Census and Statistics Department (CSD) Hong Kong, 2014, more than 80% of households have personal computers connected to the Internet, with broadband penetration rates among the highest in the world. Ninety-six percent of mobile phone users access the Internet on a daily basis. The most commonly cited purpose of using the Internet is information searching (HKMDS, 2013). Acquiring health information from the Internet is also increasingly prevalent [1]. Individuals can obtain a wide range of information from healthy lifestyle advice to treatment and diseases [2,3].

Health information seeking relates to the ways in which individuals obtain information, including information about their health, health promotion activities, risks to one's health, and illness [4]. Health information accessed via the Internet has enabled individuals to become more active collaborators in their own health [5]. The breadth and nature of health information obtained influences individual's knowledge, beliefs, and attitudes toward a specific health behavior [6]. The Internet as a medium has the capacity to help change and promote health behaviors [7,8]; yet, the quality of the information varies widely [9-11]. The anonymity of content publishers and low rigor in monitoring and filtering Web-based content are some of the reported challenges from the abundance of inaccurate or misleading information [11,12]. Nonetheless, this shift toward individuals becoming more informed and empowered in managing their own health have implications on the ways they interact with professionals and the health care system [5].

Internationally, increasing studies have been conducted into understanding individuals' perceptions on Internet health information seeking [9,13-15]. Nonetheless, there is a dearth of research on users' perceptions on the benefits and limitations on seeking health information via the Internet and how the information is used in a Chinese context. There are likely to be differences among perceptions of health, telecommunication infrastructure, and patterns of inequalities in that of the West and East [16]. The increasing use of the Internet has raised important questions about the relationship between cultures and technologies.

Furthermore, scholars have repeatedly emphasized the need to give greater voice and influence to health consumers [3]. Much attention in the literature has focused on identifying who actively seeks or who does not seek health information, the frequency of use, and satisfaction with health information seeking [17-20]. There is a need for more qualitative research to examine how and why individuals obtain health information, where they go to retrieve such information, and how the health information is used. Qualitative research allows for greater exploration of reported behaviors in users. This allows for in-depth insights into the participants' experiences, underlying motivations, and thoughts and feelings associated with health-seeking behaviors that are often not captured through quantitative methods [21,22]. Focus groups are commonly used in qualitative research as this method encourages interaction among participants, as well as free and open disclosure in a group context. It enables the researchers to have direct contact with key informants and allows researchers to gain substantive information in an easy and efficient manner [23]. Group interaction offers valuable data on the extent of consensus and diversity among the participants and allows the researcher to ask the participants themselves for comparisons among their experiences and views [23]. Health information seeking is a common shared experience, and thus, the use of focus group provides an opportunity for participants to interact and share rich sources of information that would otherwise not be obtained through individual interviews. Given the dearth of research in an Asian context, Hong Kong thus provides an excellent platform to explore individuals' perceptions on health information seeking, where the use of the Internet and Web access devices is highly prevalent. This study, therefore, aimed to examine individuals' perception on health information seeking and their related behaviors. This paper also reports on user's perceptions of the advantages and disadvantages of seeking health information via the Internet and the application of the information obtained.

Methods

Study Design

Ethics approval was obtained from the institutional review board of the University of Hong Kong/Hospital Authority Hong Kong West Cluster. Five focus groups were conducted on Hong Kong adults from November 2015 to January 2016, with numbers in each group ranging from 9 to 11. Before recruitment, we proposed to conduct five focus groups based on recommendations from the literature on qualitative methods [24]—which allows flexibility in increasing or decreasing the number of focus groups after data collection has begun, and the focus group can stop when the point of data saturation is reached. Hence, we debriefed and reviewed the notes to reflect on each session before conducting the next session. By the fifth focus group, we were convinced that we had reached data saturation and stopped.

Data Collection

This study was part of a larger research project entitled the Hong Kong Family and Health Information Trends Survey (FHInTS) that examined the general public opinions and behaviors on family health, information use, and health communication under the FAMILY Project at the School of Public Health, the University of Hong Kong. Details of the survey design have been reported elsewhere [25]. To facilitate the next phase of the research project, which included a random telephone-based household survey, focus groups were conducted to (1) obtain input and refine the survey and (2) elicit insights and perspectives on health information seeking. This paper reports on individuals' perception on health information seeking and their related behaviors.

Recruitment of participants was conducted by the Public Opinion Programme (POP), a renowned survey agency in Hong Kong. Eligible participants were individuals residing in Hong Kong, aged 18 years or above, and fluent in Cantonese. A total of 3443 invitations were sent out to POP panel members either by email or phone (panel members were recruited through a consent question at the end of random telephone surveys. All members within a selected household were invited to enroll into the panel). Of the 82 participants who expressed interest, 49 participants participated.

Participation was voluntary, and written informed consent was obtained from the participants before the start of the focus group. Each focus group lasted for approximately 90 minutes and was managed by a panel of two members, specifically one moderator and one notetaker. An interview guide with prompts was developed to cover a range of key issues related to the research questions. Initially, five questions were asked:

1. What is your general perception on seeking health information online?
2. What are the benefits on seeking health information online?
3. What are the limitations on seeking health information online?
4. How do you search for information?
5. How is the information used?

After conducting the first focus group, transcripts and notes taken were reflected on before conducting the next one (including listening to audio record, reading notes, and debriefing with the research team); this resulted in an additional question for the subsequent sessions: (6) How do you use the health information obtained with your health professional?

The moderator was free to word and sequence questions in the most appropriate manner and to pursue areas in greater depth. Participants also completed a questionnaire on demographic characteristics. Participants who attended the focus group sessions were given HK $150 (US $1=HK $7.8) cash for their travel expenses and as a token of appreciation. Refreshments were made available.

Data Analysis

All focus groups were conducted in Cantonese, audiotaped, and transcribed verbatim into Chinese by experienced researchers at POP. Reviewing the entire transcripts would represent a significant increase in costs and time. As recommended by Poland [26], a random small sample of transcript from each focus group was reviewed. This determined the extent to whether a full review of the rest of the transcripts was needed. A research assistant who was not involved in conducting the focus groups checked 10% of the transcripts of each focus group. No major errors were noted, and therefore, we were confident that the transcripts were of high quality. Thematic analysis [27] was used to identify, analyze, and report patterns (themes). First, the transcripts were read in detail, and broad themes were noted. Then an in-depth analysis was conducted using a process of constant comparisons in which differences and similarities were analyzed to identify main themes and subthemes. Another member of the research team and the first author (JTWC) cross-checked, discussed, and agreed on the coding of the data and confirmed that the themes identified reflected the data. In the event that researchers differed in their coding decisions, themes were reanalyzed and checked against other coded data until a consensus was reached. The transcriptions were in Chinese, and the analysis was conducted based on the Chinese transcript. Themes that emerged were later translated into English by the researcher who was bilingual and near-native in English and native in Chinese. Back translation was used for quality control check by an independent research assistant. This involved translating the English themes and quotes into the Chinese language. This ensured that the translated version reflects the item content of the original version. The quotes in the paper were from the English translation of the original Chinese transcripts.

Results

Participant Characteristics

The characteristics of the sample are shown in Table 1. The majority of participants were male (53.1%, 26/49) and married (51.1%, 25/49). A similar proportion was spread among the age groups. About half (51%, 25/49) had a tertiary education and were currently working, with 63.3% (31/49) earning more than the average household income of HK $20,200 (CSD, 2013).

Main themes and subthemes were identified and grouped into five categories. These include (1) Perceptions on seeking health information via the Internet, (2) Perceived benefits of the Internet, (3) Perceived limitations of the Internet, (4) Strategy to navigate the Internet for health information, and (5) Implications of seeking health information via the Internet. These are described below with translated quotations that attempted to preserve the intent of the speaker. The quotations were taken from a number of respondents and were identified based on groups (G1, G2, and so on), and participants (A, B, C, and so on). Multimedia Appendix 1 details the themes and subthemes identified.

Perceptions on Seeking Health Information via the Internet

A majority (92%, 45/49) of respondents indicated that they did seek Web-based information and that they had sought health information via the Internet within the last 12 months. The main type of information that was sought includes healthy lifestyle advice (healthy eating and physical exercise) and prevention of chronic or infectious diseases. A majority (97%, 47/49) of these respondents agreed that the Internet was often the first medium they used to seek health information. As one respondent noted:

> *I think unless you are not familiar with the Internet, otherwise, it's always the first place to go.* [Group 3, Participant G]

In regards to why they used the Internet, all respondents agreed that it was for the desire for greater understanding, clarity, and confirmation of the health issue. This was the case regardless of whether they were seeking information for themselves or for someone else.

Table 1. Demographic characteristics of the participants.

Characteristics	n (%)
Sex (N=49)	
Men	26 (53)
Women	23 (47)
Age group, years (N=47) [a]	
18-24	9 (19)
25-34	8 (17)
35-44	8 (17)
45-54	6 (13)
55-64	8 (17)
65+	8 (17)
Education attainment (N=47)[a]	
Primary or below	2 (4)
Secondary	14 (30)
Tertiary or above	31 (66)
Marital status (N=47) [a]	
Single	19 (40)
Married	24 (51)
Divorced or widowed	4 (9)
Employment status (N=48)[b]	
Full-time	16 (33)
Part-time	5 (10)
Self-employed	5 (10)
Unemployed	22 (46)
Monthly household income (N=38) [c]	
<10,000	7 (18)
10,000-19,999	7 (18)
20,000-29,999	8 (21)
30,000-39,999	4 (11)
40,000+	12 (32)

[a] Missing n=2.

[b] Missing n=1.

[c] Missing n=11.

As noted by a male respondent:

> *My family members are elderly, I need to have some information first before persuading them to go see a doctor.* [Group 2, Participant D]

However, for a minority of respondents (8%, 4/49), particularly for those older than 55 years, traditional health services (eg, doctors and professionals) was a first point of call if they had a health problem. Only when traditional health services *failed* would they turn to the Internet to seek alternative treatment methods. Regardless of the severity of the health topic, older respondents preferred more traditional resources (eg, doctors and professionals, family and friends, printed newspapers, and radio or television) than the Internet. For example, a woman (aged 55+ years) noted that:

> *Amongst my friends, around our age, for us to actually seek online, it really has to be an illness that even the doctor or you have had it for a long time, sought help from a lot of places but still have not found a way to cure it. Then (you) may then search online and see if there is anything that might help.* [Group 5, Participant I]

One of the reasons for not seeking health information via the Internet was that it was difficult for respondents. Some (50%) of the older respondents claimed that they feel overwhelmed and nervous with using the Internet and that it was difficult to find information. Whereas some (50%) needed assistance to access Web-based information, others felt that a lot of effort was required to seek health information via the Internet:

> *I feel that [searching on the Internet] is bothersome. Sometimes when you search...I, myself, am not very good at searching. So going about it more directly (asking family/friends/professional) is faster.* [Group 5, Participant I]

Perceived Benefits of the Internet

When asked about the benefits of seeking Web-based information, four common themes emerged. These included convenience, coverage of vast information, self-awareness, and being able to share experience and form support groups. Convenience was noted as the main benefit of seeking health information via the Internet and was agreed by all respondents. The convenience of Web-based health information encompassed the ease and speed of access, at any time, and from any location. This was contrasted with accessing traditional health services. For example, a female respondent noted that:

> *The Internet is really easy to use, you can use it anytime. Unlike doctors or health clinics, I can’t call them and ask them at work, and after work, they are all closed. But with the Internet, you can search the information during work, and even after work, you can use your mobile phone to go on the Internet to search. I think this is really convenient and because it’s the Internet, it offers you more sources and opinions.* [Group 3, Participant G]

Many (78%, 38/49) of the respondents (including those that do not seek information via the Internet) stressed their limited time in doctor consultations and the often lack of time to discuss or elaborate on certain issues. The Internet was thus perceived to be particularly useful for expanding on the information received from the doctor. An example was provided by a male respondent:

> *Often, doctors don’t have the time to speak with you at length, because if he/she gives you 15 minutes, it is already a lot. For example, with cancer, lymphoma, even if he/she has a report after you have been tested, I think if you make him/her explain for 5 minutes, it will be a painful process for him/her, right? Typically, professionals, they will usually tell you a few things, but not a detailed explanation, so it is necessary for me to rely on the Internet for however many hours (I need to understand the issue).* [Group 3, Participant D]

With the convenience of the Internet, respondents were also able to obtain a vast amount of information, and they often obtained more information than their initial search topic, thus allowing them to expand their knowledge. The ability to access a vast amount of information was noted by a majority (71%, 35/49) of the respondents as a perceived benefit. For example, a male participant noted:

> *When you search (on the Internet) you get a lot of related information. For example, if I was initially just searching for the cause of diabetes, there would also be links to diets for diabetes and other related issues. I probably never thought about these (related information) prior to searching the Internet.* [Group 3, Participant F]

For some (44%, 21/49), the Internet raised their awareness on certain health issues and allowed them to attend to their health problems early. Respondents, particularly younger participants (aged 18-35 years), felt that the Internet allowed them to become more active seekers for their own health. This was expressed by a female participant:

> *I think the best advantage of going online to look for information is that I take the initiative to go online to look for information. For example if I go to listen to a health lecture on health information, it is actually led by one speaker, the things he speaks about, are the things I absorb. But the Internet is as big as the world, I can pick and choose what I want, this is the advantage I feel, but of course it also has its disadvantages.* [Group 4, Participant H]

Female respondents (20%, 10/49), in particular, spoke of the Internet as a medium that allows individuals with similar health concern or background to share and support one another:

> *It is actually psychological support on some level, I feel, I am getting some support, and also I can actually see that [their condition] and [my condition] are similar, so “Oh, they are okay, so I should be okay too”, it is this kind of feeling.* [Group 2, Participant K]

Perceived Limitations of the Internet

Despite the benefits, several limitations were noted by respondents about seeking Web-based health information. Specifically, trustworthiness, frustration and fear, and nontailored information were recurring themes that ran through all the focus groups. The quality and trustworthiness of the information on the Internet was a main concern for all of our respondents, particularly for those that did not seek information via the Internet (8%, 4/49). Even for young participants, finding credible health information via the Internet was not straight forward. As a male respondent noted:

> *I think there is too much information on the Internet, and sometimes you do not know if the information is right or wrong, so you need to read and know everything yourself, maybe it is easier to trust if you go to some more professional websites, right? With forums, maybe even believing 10% of it is problematic, so there is too much information, but it is very easy to search, but you need to filter it yourself. That means you still have to use some time to filter.* [Group 4, Participant C]

Respondents with lower education level attainment were more likely to report frustration during Web-based health information seeking. For example, the sheer volume of information was sometimes perceived as “daunting” and might cause confusion. A majority (71%, 35/49) of the respondents felt that the health information obtained could be misleading and may exaggerate the health problem, intensify anxious feelings, and delay seeking professional services. This frustration and fear from the sheer volume of health information applies to a range of health issues, including lifestyle information to life-threatening diseases:

> *There is so much information. For example, if I wanted information on healthy diet and how to lose weight, when you search, heaps and heaps of information comes up. So it’s really difficult to decide which to use, let alone whether it’s actually suitable for me or not, or even whether it’s trustworthy.* [Group 2, Participant H]
>
> *I think for some, if they need to have an operation and want to know more about it, they search the Internet. But some of the information regardless of it being true or not, may freak them out. They may delay having the operation and instead seek alternative non-traditional health services.* [Group 3, Participant B]

Furthermore, a couple of the respondents (31%, 15/49) felt that any advice provided over the Internet was limited by the fact that it was not based on the individual’s condition and knowledge of their past history:

> *Health information online is not tailored, so what works for one may not work for another, and I really don’t know whether it works for me.* [Group 2, Participant J]

Strategy to Navigate the Internet for Health Information

A recurring theme that was identified through all the focus groups was the strategies employed in navigating Web-based health information. Almost all (97%) of the health information seekers began their search process with search engines. Google was the most common search engine used; however, most (51%) did not go beyond the first two pages of citations following the search:

> *For the search results from a Google search engine search, if you compare the first three to five results and they are mostly similar with few differences, then you will not want to go through the effort of reading the sixth.* [Group 2, Participant J]

A part of navigating the Internet involved how to determine what information or websites to use and trust. Choosing a credible website was regarded as a common sense activity; however, when asked about the details, respondents had trouble in articulating their selection process. Nevertheless, some respondents (31%, 15/49) were able to express sources of health information that they would not select. For example, respondents agreed that they tended not to trust corporate websites, specifically those of pharmaceutical companies or those that clearly advertise products. Respondents also reported looking for the country of origin of the information and had more confidence in websites from Taiwan or abroad than websites from China Mainland. They preferred information that originated from what they considered to be impartial and reputable sources such as government, professional, or disease-focused organizations, or university websites. Whereas all respondents agreed that the Hong Kong government websites were credible, all of them felt that it provided very little information:

> *You will have a look at where the site comes from, you will have a look at if its layout has a lot of games, you can feel that it is commercial...I tend to believe sites from Taiwan or abroad, and I do not really believe those from China, Mainland.* [Group 2, Participant K]

Respondents also noted that to further determine which health information is credible, information would be compared across several websites, and only when they appeared similar would respondents perceive it to be trustworthy:

> *I rarely search using Mainland Chinese websites, and also, I usually go to at least 4 or 5 sites, I usually do this, I only trust it if “Oh, they are similar”. I will not focus on one site, and completely trust it, I definitely will not.* [Group 2, Participant B]

Implications of Seeking Health Information via the Internet

Respondents provided insights into using the health information obtained via the Internet for decision making. A number of respondents used the health information to understand a subject or topic better and/or to decide whether they needed to see a doctor and to determine what questions to ask their doctors. Specifically, 31% (15/49) respondents felt that the Internet allowed them to become informed users and be able to share decisions with their health professionals. For a majority (92%, 45/49) of the respondents, the doctor’s authority remains crucial and sometimes becomes even more important, as they sought clarification or understanding on the information gained from the Internet:

> *At least after reading [it online] yourself you know how to ask the doctor about it, if you do not read, then you will not know how to even begin asking.* [Group 1, Participant A]
>
> *For example as we said just now, if my arm is numb, I would not have known why before, but maybe now after going on the Internet and reading more, maybe whichever side of the brain has had a stroke, so I will immediately go to the doctor, and I will find out. Yes, you can say that [the Internet’s] preventive nature may actually increase the chances of me going to the doctor.* [Group 5, Participant D]

On the other hand, a minority (4%, 2/49) of the respondents expressed that they could use the information obtained to challenge the advice given by their health service providers. This challenge was an explicit response to not believing the health professionals:

> *The doctor isn't always right, so you need to use the information (obtained from the Internet) to keep questioning them.* [Group 5, Participant I]

Regardless of the severity of the health issue, for respondents that did seek Web-based information, they agreed that the Internet was always the first source for information. In cases where the health concern was not perceived as severe, respondents preferred to self-manage based on the information obtained from the Internet. In cases where the concern was severe, traditional health service was still preferred. However, traditional service was often accessed after respondents had searched the Internet for information:

> *I feel that you need to have a look at the question of how important it is. For example, I might be very fat, need to lose weight, and need to maybe look at the calories in food, so I might go online, because these things are relatively not so harmful to myself, so it might be worth trusting. But if my kidney is really painful, my stomach is really painful, or such, I might go online and have a look at what the reasons are for these things, and then I will still go and consult a doctor.* [Group 5, Participant D]

Overall, information from the Internet was generally perceived to be supplementary material and that the Internet is not a replacement to accessing traditional health services:

> *Going on the Internet to look for health information, to me, is supplementary and auxiliary. Sometimes the doctor might not explain in enough detail, so [you] find some supplementary information on the Internet, it mainly performs an assisting function.* [Group 3, G]

Discussion

Principal Findings

The aim of this study was to gain a better understanding on individuals' perceptions on health information seeking on the Internet and their related behaviors. The findings from a Chinese population highlight several important issues that could inform other rapidly developing regions with increasing Internet use.

Mirroring Western studies [28,29], younger respondents (18-45 years old) were more likely to use the Internet as a source for health information. Consistent with the literature, the Internet was valued for its convenience, breadth of information, and the capacity to provide peer support and social interaction [3]. Along with the reported advantages of the Internet, respondents also noted the inherent disadvantages (eg, credibility and sheer volume of information). The difficulty with navigating the Internet acted as a barrier for older respondents to seek Web-based health information.

Our findings align with the theory of planned behavior, which posits that intentions predict behavior, and intentions are in turn predicted by attitude. Generally, all of our respondents expressed the intention in knowing more about health issues. However, younger respondents tended to consult the Internet before seeking medical consultation. In this study, this was the case regardless of the severity of the health issue. Respondents attributed this tendency to seek Web-based information to the limited time of consultations they received from their doctors. On the contrary, doctor consultation remained as the first point of contact for older respondents. This behavior was mainly attributed to the paternalistic view that "doctors know best" and the distrust of the health information on the Internet. It's also important to note that the Internet was viewed as a supplement to health care rather than a replacement for professional care by all of our respondents. Understanding individuals' intentions and health information seeking behavior is important as it can assist in the development of recommendations and policies to guide more effective help seeking and self-management among individuals, leading to improve health outcomes. Our findings shed light on the critical belief that guided individuals, particularly the elderly, in the decision to engage in Web-based health-information seeking.

For some female respondents, the Internet further provided social support and reassurance on health issues. Previous studies have reported that patients' feelings, psychological problems, families, social problems, expectations of their doctors, ideas about their illnesses, and fears are rarely discussed between the doctor and the patient [30]. Our findings suggest the potential of the Internet to offer support to a large group of health consumers where they can share their personal health and illness experiences; they can offer special insights and reflections from the lived experiences of their specific health conditions that doctors may not be able to provide.

It is worthy to note that the initial research questions did not focus on health information seeking and its related impact on the doctor-patient relationship. However, following the first focus group, it was apparent to us that this was an important aspect to consider, and we then added a new question. Previous studies in Hong Kong noted that doctors were more powerful in terms of medical treatment and advice, in which during consultation, patient autonomy and self-management of illness are not usually advocated [31]. Our findings, however, suggest a shift toward a more balanced relationship between the doctor and the patient. Young respondents, in particular, noted that health information obtained from the Internet allowed them to be more informed and able to share decisions with and question their health professionals. This is consistent with studies that have observed a more powerful and autonomous patient when one is equipped with more medical and health information [19,20]. This is particularly salient in a Chinese culture where there is often a hierarchy and power-imbalance between the doctor and patient. As individuals are feeling more empowered, and are more inclined toward being involved in their health and health decision making, it may impact and change the way in which individuals interact with their health professionals. Future research into the role of health information and the impact on doctor-patient relationship will be important as technology and patient demand continues to evolve.

All of our respondents were conscious that there was an abundance of poor-quality Web-based health information. Indeed, previous studies have raised concerns for the quality of health information on the Internet and noted that the potential harm from inaccurate health information sources may be significant [12,32]. Health information from unqualified sources may lead to inappropriate treatments or delays in seeking necessary health services [12]. It is therefore important to devise ways to help individuals to choose information that is informative, credible, and useful. Health professionals may also consider ways to introduce and discuss Web-based health information with their patients. This may alleviate concern about the quality and overwhelming information and could have a positive impact on the patient's health care decisions and outcomes.

Our findings also suggest that although the Internet is an easily available source of health information, it may also create inequalities in health information accessibility, especially among the elderly, those with low income, and those with low educational attainment. It is important to note that the rapid advancement of technology can create a digital divide, where there are many individuals who do not possess the necessary skills or the devices needed to navigate the Internet and search for credible health information. We also observed that this group of individuals relied on traditional mode of health information delivery (ie, doctors). This is of concern, as these groups are those that are more likely to have health problems but are less likely to access health care services. This group may further be disadvantaged as health care providers are increasingly transitioning to digital and Internet technologies for disseminating health information. There is a need to consider how health information can be disseminated to this group of individuals.

Limitations

Transferability of these findings is limited to populations similar to participants in this study. Although every effort was made to recruit a diverse sample, our sample was of higher socioeconomic status. Future studies are needed to examine the perceptions of those with lower socioeconomic status. Individuals younger than 18 years were not included in our sample. Given that children and adolescents are growing up fast in the digital age, understanding their perceptions may further our knowledge on their health information–seeking behaviors. Finally, certain behaviors appeared to be intuitive and were therefore difficult to articulate. For example, some of our respondents were not able to describe their search and appraisal processes. Observational strategies may need to be employed in future studies to examine how health information via the Internet is obtained and used.

Conclusions

The rapid development of information technology (IT) has increased the importance and relevance of questions related to health information seeking via the Internet. Our study has revealed that older and less educated individuals were less likely to use the Internet to look for health information and had more challenges in benefiting from Web-based health information. We have also identified that the most predisposed to searching for health information on the Internet were motivated by limited doctor consultation time and barriers to accessing professional health services. Strategies for communicating and disseminating credible health information in a form that all users can understand and use are urgently needed. These include taking into account the variety of individual skills in both searching and critically evaluating information, as well as the skills to use digital devices and should reach those who prefer not to use the Internet for health information. Understanding how these skills—often referred to as digital health literacy—are related to adoption and usage of IT is necessary and should be useful for exploring health information needs in various socioeconomic groups. Studies on how seeking health information affect behaviors are also needed so that targeted interventions can be developed to improve health outcomes. The findings from the focus groups were used to fine-tune our FHInTS survey, which had since been developed, and data collection has been ongoing. Questions regarding the medium to access Web-based health information, credibility of information sources, possession of devices, access to health services, and demographics have all been refined or incorporated to provide a better understanding on health information–seeking behaviors among adults in Hong Kong. Due to the rapid technological and related behavioral changes, Web-based health information seeking and its effects need to be closely monitored.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Themes and subthemes from the focus groups (N=49).

[PDF File (Adobe PDF File), 51KB - ijmr_v6i2e24_app1.pdf]

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Abbreviations

CSD: Census and Statistics Department
FHInTS: Family and Health Information Trends Survey
HKMDS: Hong Kong Monthly Digest of Statistics
IT: information technology
POP: Public Opinion Programme

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Original Paper

Activity Trackers Implement Different Behavior Change Techniques for Activity, Sleep, and Sedentary Behaviors

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Abstract

Background: Several studies have examined how the implementation of behavior change techniques (BCTs) varies between different activity trackers. However, activity trackers frequently allow tracking of activity, sleep, and sedentary behaviors; yet, it is unknown how the implementation of BCTs differs between these behaviors.

Objective: The aim of this study was to assess the number and type of BCTs that are implemented by wearable activity trackers (self-monitoring systems) in relation to activity, sleep, and sedentary behaviors and to determine whether the number and type of BCTs differ between behaviors.

Methods: Three self-monitoring systems (Fitbit [Charge HR], Garmin [Vivosmart], and Jawbone [UP3]) were each used for a 1-week period in August 2015. Each self-monitoring system was used by two of the authors (MJD and BM) concurrently. The Coventry, Aberdeen, and London-Refined (CALO-RE) taxonomy was used to assess the implementation of 40 BCTs in relation to activity, sleep, and sedentary behaviors. Discrepancies in ratings were resolved by discussion, and interrater agreement in the number of BCTs implemented was assessed using kappa statistics.

Results: Interrater agreement ranged from 0.64 to 1.00. From a possible range of 40 BCTs, the number of BCTs present for activity ranged from 19 (Garmin) to 33 (Jawbone), from 4 (Garmin) to 29 (Jawbone) for sleep, and 0 (Fitbit) to 10 (Garmin) for sedentary behavior. The average number of BCTs implemented was greatest for activity (n=26) and smaller for sleep (n=14) and sedentary behavior (n=6).

Conclusions: The number and type of BCTs implemented varied between each of the systems and between activity, sleep, and sedentary behaviors. This provides an indication of the potential of these systems to change these behaviors, but the long-term effectiveness of these systems to change activity, sleep, and sedentary behaviors remains unknown.

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KEYWORDS

health behavior; public health; exercise; sleep; behavior change; fitness trackers; adult, mobile applications

Introduction

Higher levels of moderate-to-vigorous intensity activity, lower levels of sedentary behavior, and sufficient sleep on a daily basis are key components of maintaining a healthy lifestyle that is associated with improved quality of life, reduced risk of cardiovascular disease, and diabetes [1-3]. Yet, many adults are not sufficiently active for health benefits, spend considerable amounts of time in sedentary activities, and do not obtain sleep that is of a sufficient duration or quality [4-7]. There are numerous published intervention studies that aim to improve physical activity, sedentary, and sleep behaviors [8-11], and although many are effective, few are disseminated to the broader public [12].

Burgeoning technological innovations mean that mobile devices (smartphone or tablets) and wearable technology such as wrist worn activity trackers, now have increasingly sophisticated capabilities to capture, analyze, and provide feedback to users on their daily physical activity, sleep, and sedentary behaviors. Public interest in this technology is substantial, and adoption of this technology exceeds that of many interventions. Mobile device ownership is increasing, with nearly 80% of people owning a smartphone and 47% owning a tablet [13] and 10% of US adults owning an activity tracker [14]. Studies that critique the potential effectiveness of apps and websites to change behavior conclude that the majority of apps and websites do not contain features or functionality, which are thought to be effective in changing behaviors [15-18]. These critiques have been guided by the availability of behavior change techniques (BCTs) that are potentially effective in changing health behaviors such as goal-setting and self-monitoring [18-21].

The combination of apps, websites, and wearable trackers which synchronize data between them provides a “self-monitoring system,” allowing users to self-monitor their physical activity, sleep, and sedentary behaviors. Despite existing self-monitoring systems providing information on all three behaviors, previous reviews of self-monitoring systems have focused on a single behavior, in most cases physical activity [15,16,18,21-23]. As a result, it is unknown if the approaches implemented by self-monitoring systems to change behavior differ between physical activity, sleep, and sedentary behaviors. In addition, although there is emerging evidence regarding the potential of BCTs to promote behavior change, there is also debate concerning how the number of BCTs and the cooccurrence of BCTs can influence behavior change [20,24-27]. Therefore, examining differences in the number or type of BCTs included in self-monitoring systems for physical activity, sleep, and sedentary behaviors is a first step toward describing the differences in the potential effectiveness of the systems to change these behaviors. Therefore, the purpose of this study was to examine how the number and type of BCTs implemented in self-monitoring systems targeting activity, sleep, and sedentary behaviors differs for each behavior.

Methods

Self-Monitoring System Inclusion Criteria and Descriptions

Self-monitoring systems included in this review were the Fitbit Charge HR, Garmin Vivosmart2, and Jawbone UP3 and their respective mobile phone apps and websites. The Fitbit and Jawbone systems were selected for inclusion based on a 2014 review, which indicated that these systems included the highest number of BCTs in relation to physical activity of the 13 systems evaluated [18]. The Garmin system was not included in the prior review but was included in this review as the system includes a “vibration alert.” This feature is also included in the Jawbone and can be used to alert wearers to the fact that they have not taken any steps in the previous hour, which may be useful in assisting wearers to reduce their sedentary behavior. Inclusion criteria were that the self-monitoring systems include a wearable activity tracker that measured physical activity levels, sedentary behavior, and sleep; and an app and/or website that provided the user with information on their behaviors. The activity tracker in all three systems was worn on the wrist. This represents a comprehensive monitoring system. The Jawbone system included an activity tracker and app only and did not include a website that provided feedback to users on their behaviors, whereas the Fitbit and Garmin systems included all three components. This study did not require ethics committee approval, and no informed consent was required as it did not involve participants.

Coding and Data Extraction

Two trackers for each system were available, so two authors (MJD and BM) could concurrently use each system for a 1-week period. This included wearing the activity tracker and using the app and website (if available). Each author wore the same model of activity tracker, used the same version—the most recent version available at the time of wearing—of the app software on an Apple-based device (mobile phone and tablet), over the same 1-week period. Each activity tracker was worn during all daytime and sleep periods, except for when engaged in water-based activities, if the units were not water proof. At the end of each wear period, the features and content of the systems were independently coded using the Coventry, Aberdeen, and London-Refined (CALO-RE) taxonomy that contains a list of 40 BCTs [19]. The presence or absence of each BCT was coded specifically for the behavior of interest. For coding purposes, physical activity was defined as steps and/or moderate-to-vigorous intensity physical activity; sleep was defined as sleep quality, sleep duration, and/or sleep timing; and sedentary behavior was defined as sitting or standing stationary. This definition of sedentary behavior differs to other definitions which would not classify standing stationary as sedentary [28]; however, this operational definition was necessary as previous experience using the systems showed that standing stationary is classified as sedentary by the systems. For instance, to be coded as allowing users to set goals for sedentary behavior, the system had to allow the user to specifically set goals for that behavior (eg, maximum amount of sedentary behavior performed each day or hour). Agreement between coders on the number of BCTs present for each behavior within each system was calculated using Kappa statistics, and the magnitude of agreement was interpreted using the following criteria: 0.00=poor, 0.01-0.20=slight, 0.21-0.40=fair, 0.41-0.60=moderate, 0.61-0.80=substantial, and 0.81-1.00=almost perfect [29]. The coders then met to discuss any discrepancies in coding, and all discrepancies were resolved to produce a coding summary that is presented in Tables 1 and 2. All use of the systems and coding was conducted in August 2015.

Results

Summary of Behavior Change Techniques (BCTs) Implemented

Table 1 summarizes the number of BCTs coded as present for each behavior within each system. The version of the software used for each system is detailed in Table 1 footnotes. Between-rater agreement ranged from 0.64 to 1.00, representing substantial to almost perfect agreement. From a possible range of 40 BCTs, the number of BCTs present for physical activity ranged from 19 (Garmin) to 33 (Jawbone), from 4 (Garmin) to 29 (Jawbone) for sleep, and 0 (Fitbit) to 10 (Garmin) for sedentary behavior. When averaged across systems, self-monitoring systems implemented the highest number of BCTs for physical activity (n=26), a smaller number of BCTs were implemented for sleep (n=14), and the fewest BCTs were implemented for sedentary behavior (n=6). The total number of BCTs included within a system also varied (Table 1). The system that included the highest number of BCTs (n=69) across the three behaviors was Jawbone, followed by Fitbit (n=35), and then Garmin (n=33).

Table 1. Summary of the number of behavior change techniques (BCTs) implemented in relation to physical activity, sleep, and sedentary behaviors.

System and behavior	CALO-RE[a]			
	Rater 1 No. BCT[b]	Rater 2 No. BCT	Kappa	Summary No. BCT
Fitbit Charge HR[c]				
Activity	23	27	0.68	25
Sleep	10	12	0.75	10
Sedentary	0	0	1.00	0
Garmin Vivosmart2[d]				
Activity	18	19	0.95	19
Sleep	2	4	0.64	4
Sedentary	10	10	1.00	10
Jawbone Up3[e]				
Activity	33	33	1.00	33
Sleep	29	28	0.82	29
Sedentary	7	7	1.00	7

[a] CALO-RE: Coventry, Aberdeen, and London-Refined.

[b] BCT: behavior change technique.

[c] Fitbit app version 84.

[d] Garmin app version 2.13.1.

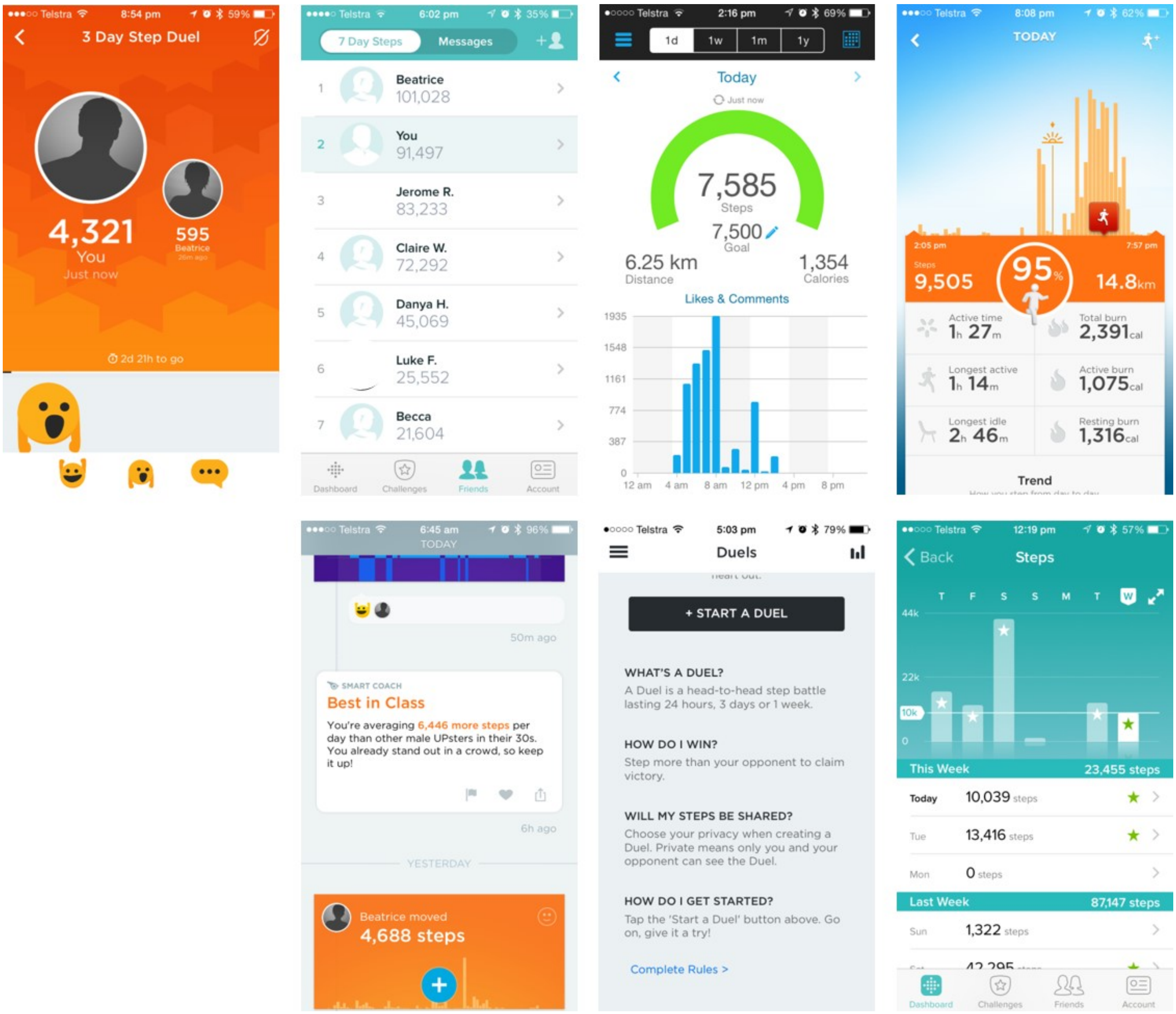
[e] Jawbone Up3 app version 4.7.0.121.

Activity

Table 2 displays which of the 40 BCTs were present within each system for monitoring physical activity. All three systems implemented the following 18 BCTs: providing information about others' approval, providing normative information about others behavior, goal setting (behavioral and outcome), goal review (behavioral and outcome), prompt rewards contingent on progress toward goal, prompt rewards contingent on successful behavior, shaping, self-monitoring (behavior and outcome), prompting focus on past success, providing feedback on performance, agreeing to behavioral contracts, facilitate social comparison, plan social support, prompt identification of role model, and relapse prevention. Table 2 also details the 6 BCTs that were not implemented in any of the three self-monitoring systems. These were model or demonstrate the behavior, prompt anticipated regret, prompt self-talk, fear arousal, prompt use of imagery, and general communication skills training.

The activity tracker for all three systems measured physical activity, which was then integrated into the app and/or website to provide users with additional feedback on activity levels. For example, self-monitoring systems frequently implemented BCTs related to social support and social comparisons by allowing peers to offer each other social support through the use of app messaging systems and emoji (Figure 1), peer leader boards (Figure 1), and/or challenges which displayed to users a history (amount or pattern) of their peer's physical activity (Figure 1). Challenges may offer users a "behavioral contract"; this can be used to prevent relapse, as physical activity is required to be performed over multiple days and plan necessary actions to achieve this (Figure 1). Self-monitoring, goal setting, evaluating activity in relation to goals, providing rewards on past success, progress toward goals (Figure 1), and providing feedback were typically delivered by graphical display of the volume of physical activity performed on a daily basis in comparison to a specified physical activity goal (Figures 1). Feedback to users on achieving a goal was typically highlighted by changing the color or pattern of a progress bar or adding a unique identifying feature to the progress bar (eg, a "star" or textured bar graph). In addition, the activity trackers of all systems vibrated and provided visual feedback to users' when the daily activity goal was achieved. The Garmin system automatically generated a goal for the user, whereas the Fitbit and Jawbone systems allowed users to set their own goal. The Garmin and Jawbone systems also automatically (Garmin) prompted a user (Jawbone) to increase their activity goal if they reached it consistently.

Figure 1. Screenshots of the app or website displaying how various behavior change techniques (BCTs) related to physical activity were implemented.



SMART COACH

Best in Class

You're averaging 6,446 more steps per day than other male UPsters in their 30s. You already stand out in a crowd, so keep it up!

Beatrice moved 4,688 steps

+ START A DUEL

WHAT'S A DUEL?

A Duel is a head-to-head step battle lasting 24 hours, 3 days or 1 week.

HOW DO I WIN?

Step more than your opponent to claim victory.

WILL MY STEPS BE SHARED?

Choose your privacy when creating a Duel. Private means only you and your opponent can see the Duel.

HOW DO I GET STARTED?

Tap the 'Start a Duel' button above. Go on, give it a try!

Complete Rules >

Table 2. Presence of specific behavior change techniques (BCTs) in relation to activity, sleep, and sedentary behavior.

Behavior change technique	Fitbit Charge HR			Garmin Vivosmart			Jawbone UP3			Total		
	Activity	Sleep	Sedentry	Activity	Sleep	Sedentry	Activity	Sleep	Sedentry	Activity	Sleep	Sedentry
Provide information on consequences of behavior in general	0	0	0	0	0	0	1	1	0	1	1	0
Provide information on consequences of behavior to the individual	0	0	0	0	0	0	1	1	0	1	1	0
Provide information about others' approval	1	0	0	1	0	0	1	1	0	3	1	0
Provide normative information about others' behavior	1	0	0	1	0	0	1	1	0	3	1	0
Goal-setting (behavior)	1	1	0	1	0	0	1	1	1	3	2	1
Goal-setting (outcome)	1	1	0	1	0	0	1	1	1	3	2	1
Action Planning	1	0	0	0	0	0	1	1	0	2	1	0
Barrier identification or problem solving	0	0	0	0	0	0	1	1	0	1	1	0
Set graded tasks	1	0	0	0	0	0	1	1	0	2	1	0
Prompt review of behavioral goals	1	1	0	1	0	1	1	1	0	3	2	1
Prompt review of outcome goals	1	1	0	1	0	1	1	1	0	3	2	1
Prompt rewards contingent on effort or progress toward behavior	1	0	0	1	0	1	1	1	0	3	1	1
Provide rewards contingent on successful behavior	1	1	0	1	0	1	1	1	0	3	2	1
Shaping	1	0	0	1	0	0	1	0	0	3	0	0
Prompting generalization of a target behavior	0	0	0	0	0	0	1	0	0	1	0	0
Prompt self-monitoring of behavior	1	1	0	1	1	1	1	1	1	3	3	2
Prompt self-monitoring of behavioral outcome	1	1	0	1	1	1	1	1	1	3	3	2
Prompting focus on past success	1	1	0	1	1	1	1	1	0	3	3	1
Provide feedback on performance	1	1	0	1	1	1	1	1	1	3	3	2
Provide information on where and when to perform the behavior	1	0	0	0	0	0	1	1	0	2	1	0
Provide instruction on how to perform the behavior	1	0	0	0	0	0	1	1	0	2	1	0
Model or demonstrate the behavior	0	0	0	0	0	0	0	0	0	0	0	0
Teach to use prompts or cues	1	0	0	0	0	1	1	1	1	2	1	2
Environmental restructuring	0	0	0	0	0	0	0	1	0	0	1	0
Agree behavioral contract	1	0	0	1	0	0	1	0	0	3	0	0
Prompt practice	1	0	0	0	0	1	1	1	1	2	1	2
Use of follow-up prompts	0	0	0	0	0	0	1	1	0	1	1	0
Facilitate social comparison	1	0	0	1	0	0	1	1	0	3	1	0
Plan social support or social change	1	0	0	1	0	0	1	1	0	3	1	0
Prompt identification as role model or position advocate	1	0	0	1	0	0	1	0	0	3	0	0
Prompt anticipated regret	1	0	0	0	0	0	0	0	0	0	0	0
Fear arousal	0	0	0	0	0	0	0	0	0	0	0	0

Behavior change technique	Fitbit Charge HR			Garmin Vivosmart			Jawbone UP3			Total		
	Activity	Sleep	Sedentry	Activity	Sleep	Sedentry	Activity	Sleep	Sedentry	Activity	Sleep	Sedentry
Prompt self talk	0	0	0	0	0	0	0	0	0	0	0	0
Prompt use of imagery	0	0	0	0	0	0	0	0	0	0	0	0
Relapse prevention or coping planning	1	0	0	1	0	0	1	1	0	3	1	0
Stress management or emotional control training	0	0	0	0	0	0	1	1	0	1	1	0
Motivational interviewing	0	0	0	0	0	0	1	0	0	1	0	0
Time management	0	0	0	0	0	0	1	1	0	1	1	0
General communication skills training	0	0	0	0	0	0	0	0	0	0	0	0
Stimulate anticipation of future rewards	0	1	0	1	0	0	1	1	0	2	2	0
Total	25	10	0	19	4	10	33	29	7	77	43	17

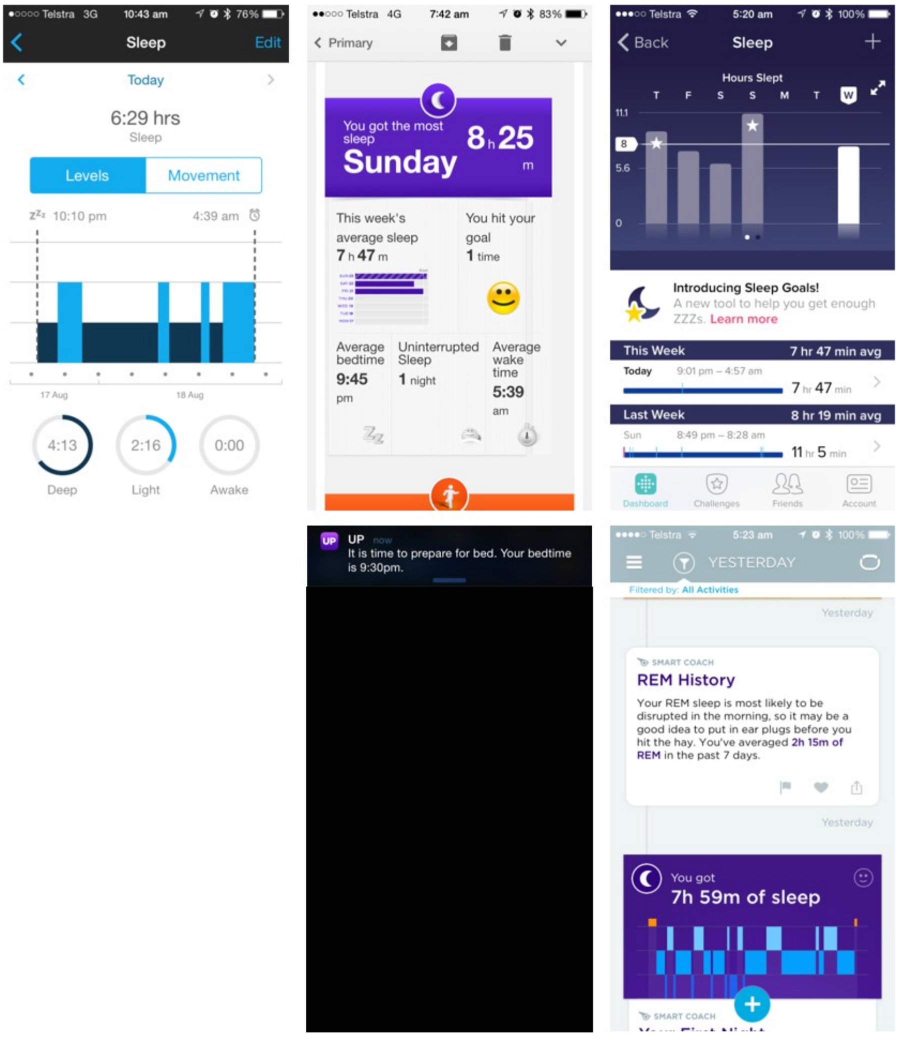
Sleep

All three systems implemented the following four BCTs: prompt self-monitoring (behavior and outcome), prompt focus on past success, and provide feedback on performance (Table 2). In terms of how these BCTs were implemented in each system, the activity tracker component of all systems provided a measure of sleep volume and quality. This information was then used to generate feedback to users, focus on past success, and providing feedback were implemented by providing graphical display on the volume and quality of sleep (Figure 2). In addition, Fibit and Jawbone systems also implemented the following 6 BCTs: goal setting (behavior and outcome), prompting review of goals (behavior and outcome), providing rewards contingent on successful behavior, and stimulate anticipation of future rewards. These were operationalized by identifying whether the volume and/or quality of sleep (Figure 2) met a user's goal or not (Figure 2) and by altering the graphical feedback provided by changing the color or pattern of a progress bar or adding a unique identifying feature to the progress bar (eg, a "star" or textured bar graph). The Jawbone system also implemented action planning, prompting, relapse prevention, time management (Figure 2), and environmental restructuring (Figure 2). Table 2 details the 11 BCTs that were not implemented by any of the self-monitoring systems.

Sedentary Behavior

The Fitbit system did not implement any BCT in relation to sedentary behavior. The Garmin and Jawbone systems both applied the following five BCTs: prompt self-monitoring (behavior and outcome), provide feedback on performance, teach prompts, and prompt practice. These BCTs were implemented by the activity tracker monitoring periods of no physical activity or steps and then displaying this information to users in terms of the volume of sedentary behavior (Figure 3) and specifically identifying periods of "long" sedentary behavior (Figure 3). Both Garmin and Jawbone units provided feedback to users via the activity tracker, vibrating to indicate if they had been sedentary for a "long" period of time. The Garmin system had a default setting of 1 hour of sedentary activity, which could not be altered by users, whereas the Jawbone system allowed this to be defined by the user. This difference resulted in the Garmin being coded as absent for goal setting (behavioral and outcome) in relation to sedentary behavior, whereas the Jawbone was coded as present. Table 2 displays the 28 BCTs that were not implemented by any of the systems in relation to sedentary behavior.

Figure 2. Screenshots of the app or website displaying how various behavior change techniques (BCTs) related to sleep were implemented.



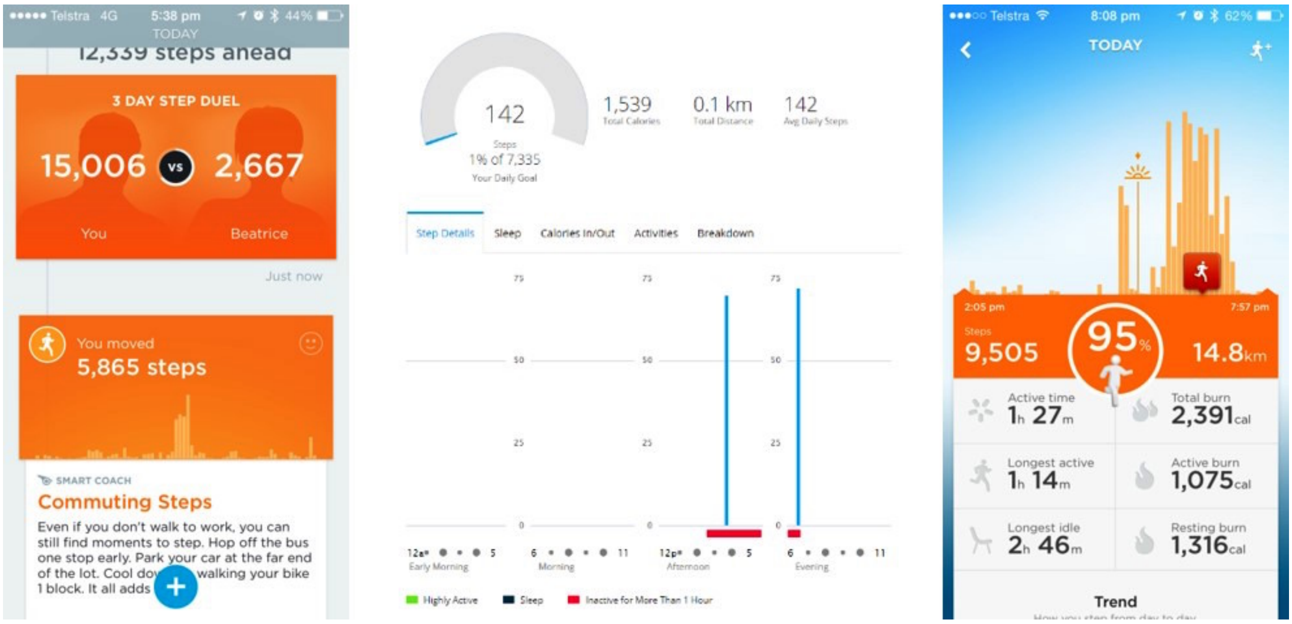
Introducing Sleep Goals! A new tool to help you get enough ZZZs. Learn more

It is time to prepare for bed. Your bedtime is 9:30pm.

REM History

Your REM sleep is most likely to be disrupted in the morning, so it may be a good idea to put in ear plugs before you hit the hay. You've averaged 2h 15m of REM in the past 7 days.

Figure 3. Screenshots of the app or website displaying how various behavior change techniques (BCTs) related to sedentary behaviour were implemented.



Commuting Steps

Even if you don't walk to work, you can still find moments to step. Hop off the bus one stop early. Park your car at the far end of the lot. Cool do walking your bike 1 block. It all adds

Discussion

Principal Findings

This study assessed the number and type of BCT that three self-monitoring systems implemented to support users in changing their physical activity, sleep, and sedentary behaviors and summarized how the most prevalent BCTs were implemented. The number of BCTs implemented varied between these behaviors. On average, the greatest number of BCTs were implemented in relation to physical activity, followed by sleep and sedentary behavior. All three systems provided self-monitoring of physical activity and sleep and provided feedback to allow the user to focus on their previous success with changing the behavior.

The type of BCT implemented in each system for monitoring physical activity was similar to that observed in other studies [18]. A major difference in the BCT implemented between physical activity, sleep, and sedentary behaviors was the use of challenges, leader boards, and peer to peer “messaging” for physical activity and not for sleep or sedentary behavior. These features operationalize BCTs related to action planning, providing information about others behaviors, social support, shaping, peer approval, and relapse prevention, which may be useful in changing behaviors [19]. These differences may reflect the inherent differences between behaviors and approaches to changing them. For example, the more physical activity people perform, the greater their health benefits [30], and this lends itself to the concept of leader boards and challenges, which can involve frequent peer-to-peer interactions. Yet, for sleep duration, more is not always better as sleep duration has a U-shaped curve in relation to health [31,32], and the concept of “good” sleep is highly individualistic resulting from a complex interaction between the duration, timing, and quality of sleep [1]. As such, whereas goal setting and feedback can be implemented in relation to sleep duration and quality as observed in the systems evaluated (see Figure 2), if leader board and challenge concepts are implemented in relation to sleep, they likely need to be configured around parameters of sleep that are more under the control of the individual, such as sleep hygiene behaviors. For example, the number of days or nights a person went to sleep and woke up at times that “matched” their goals for these behaviors. Alternatively, the concept of leader boards may not be appropriate for sleep. Furthermore, it is important to implement any BCT that seek to improve sleep behaviors in ways which do not increase worry and anxiousness regarding sleep, as this may be detrimental to improving sleep [33].

For sedentary behavior, in light of growing evidence that regular activity breaks are beneficial in comparison with continuous sitting, it may be useful to configure the concept of leader boards and challenges around this premise [34,35]. Leader boards and challenges were implemented in all three systems evaluated in this study in relation to physical activity and are also increasingly implemented in physical activity promotion websites [16]. These features were coded as BCT related to social support, shaping, and relapse prevention; yet, it is unknown how this type of electronic social support compares with in-person peer support and how this influences the efficacy of these strategies. A review of “online social networks” concluded that there was only modest evidence regarding their efficacy to increase physical activity, and continued research is required to clarify their efficacy [36]. Similarly, the evaluated systems implemented “badges” to reward users on their accomplishments, as do many physical activity promotion websites [16]. To date, little is known about how users perceive these features and their effectiveness to change behaviors.

Sleep hygiene education is an effective strategy to improve sleep behaviors in populations with clinical sleep disorders and is also thought to be useful in a public health context to improve the sleep for those people who have sleep complaints but do not have a clinical sleep disorder [37,38]. The Jawbone system implemented the greatest number of BCTs in relation to sleep and did so in a way that was broadly consistent with sleep hygiene guidelines on the timing of sleep, stress reduction, and restructuring the sleep environment to promote sleep [37,38]. It achieved this by measuring sleep and providing feedback on goals using the mobile device notification system to prompt the user to begin getting ready for bed and that their goal time to sleep was approaching. When combined with further education and strategies, these features could help users initiate prebed routines including relaxation techniques to reduce stress and also achieve regularity in the timing of sleep. There is some evidence of the efficacy of these approaches in the literature [37-39], yet, their effectiveness when implemented as part of self-monitoring systems is unknown. These are examples of the BCTs implemented within the Jawbone system that were not implemented within the other systems and highlight how the number and type of BCT implemented vary between the evaluated self-monitoring systems for given behaviors.

Two of the three systems (Jawbone and Garmin) included a vibration alert in the wrist worn activity to alert the user that they had been sedentary for a period of time. This may be a useful prompt to engage in physical activity and reduce sitting time and similar strategies have been implemented as part of ongoing interventions [40]. Although this is an example of a behavioral prompt, it is was not coded as present for goal-setting in the Garmin unit as the user could not set the timing of this feature and therefore adjust their goal. It must also be acknowledged that the two systems that provided feedback on sedentary behavior did so from the perspective of a lack of stepping or movement behavior which does not align with recommended definitions of sedentary behavior [41] and is a function of the technical limitations associated with the activity trackers being worn on the wrist and may have influenced the implementation of BCT for this behavior. Goal-setting is a BCT that is frequently implemented in interventions and is associated with behavior change [8,19,24-26,42]. The Garmin system automatically created a step-based goal for individuals based on the activity level (low, medium, and high) entered when creating a user profile and adjusts the goal based on activity levels the previous day. The Garmin system also used a default 1 hour goal for sedentary behavior, which could not be adjusted by the user, and the inability to adjust this goal was why it was coded as absent for this behavior in the Garmin system. It is unclear how the activity level specified when creating a user profile is translated into a step goal, as is how this automatically created goal relates to existing step-based recommendations [43,44]. The Fitbit and Jawbone systems allowed users to specify their own goals. However, a more useful approach to goal setting for self-monitoring systems may be to provide users with information on the level of behavior for optimum health, information on the goal setting process (eg, promote attainable goals and prompt revision of goals in light of performance), and engage them in the goal setting process (eg, personalized goals) to facilitate users setting goals that move them toward improved health, are attainable, and meaningful to the individual. This approach could be translated to activity, sedentary, and sedentary behaviors in efforts to enhance the way in which goal-setting strategies are implemented.

A total of 18 BCTs were implemented by all three systems in relation to physical activity (Table 2), including those previously associated with increased physical activity, such as providing information on the consequences of the behavior (individual and general), goal setting (behavior and outcome), prompt self-monitoring (behavior and outcome), facilitate social support, prompt practice, and prompt rewards contingent on effort or progress [25,42]. Setting behavioral goals, providing unspecified forms of social support, and adding objects to the environment have been identified as promising BCTs for reducing sedentary time [8]. BCTs related to social support were not present in any of the systems in relation to sedentary behavior and provides an opportunity to expand the capability of the systems to include BCTs that are promising to reduce sedentary time. We are unaware of any previous studies examining BCTs in relation to changes in sleep in either self-monitoring systems or intervention studies; therefore, the insights provided in this study are novel. Although the systems included a number of BCTs which are associated with improved behaviors, to date, there is limited effectiveness surrounding the use of self-monitoring systems to improve these target behaviors [45,46].

A number of BCTs were not implemented in any of the evaluated systems for any of the behaviors (Table 2), and many of these same BCTs are also absent from interventions on other lifestyle behaviors [20,24,26]. Several possibilities may explain this. Designers of self-monitoring systems may simply be unaware of the BCTs literature and implement features guided by the functionality of the system (eg, activity trackers measure amount of movement so systems focus on provided feedback on this), features based on app or website design principles, or features desired by users. Alternatively, omissions of certain BCTs may reflect decisions to implement fewer BCTs as effectively as possible rather than to implement as many as possible in a less effective manner. Furthermore, there is a debate concerning dose-response relationships between the number of BCTs and behavior change and if specific clusters of BCTs are more efficacious than other clusters or if certain BCTs are required to cooccur to maximize potential behavior change [20,24-26]. In light of this, decisions on BCT inclusion and implementation in interventions or self-monitoring systems should be based on addressing the specific behavioral determinants of a behavior. Furthermore, it is unknown how the different combinations of BCTs present in the self-monitoring systems for a specific behavior are related to behavior change. This may also explain differences in the number of BCTs implemented between behaviors, as there is a richer literature on the determinants of physical activity compared with sedentary behavior and sleep [8,47-49]. Furthermore, the mere presence of a BCT does not indicate the way in which it is implemented, which has important implications for behavior change.

Limitations

Limitations of this study include using a behavior change taxonomy that is directed toward changing physical activity and dietary behaviors to assess sleep and sedentary behaviors. Although this was offset by coding the presence or absence of a BCT specifically to the behavior in question. Furthermore, this study did not assess the features and functionality of the systems in relation to sleep hygiene recommendations which are useful in changing sleep behaviors [37,38]. There are many systems currently available, and it is unknown how systems not included in this study compare on their use and implementation of BCTs. All systems were only used over a 1-week period, which is consistent with previous evaluations [18], and a longer period of use may have resulted in a different user experience resulted in additional BCTs being coded as present. However, there are currently no recommendations regarding how long an intervention or self-monitoring system should be used for before coding.

Conclusions

In conclusion, the number and type of BCT implemented varied between the evaluated self-monitoring systems and the number and type of BCT varied between activity, sleep, and sedentary behaviors. The greatest number of BCTs was implemented in relation to physical activity, followed by sleep and sedentary behavior. However, the number of BCTs does not reflect how a BCT is implemented and presented to users, or the cooccurrence of a particular BCT with other BCT, which may influence the potential effectiveness of the self-monitoring system to actually change behavior [27]. It is important to note that this study was evaluating the “potential” of these self-monitoring systems to change activity, sleep, and sedentary behaviors and further research is required to establish their effectiveness to change these behaviors. Such evaluations could also examine the actual usage patterns of these devices and the different types of BCTs that users make use of.

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Authors' Contributions

All authors provided critical review of the manuscript. MJD, CV, and MK conceptualized the study, MJD and BM undertook data collection.

Conflicts of Interest

None declared.

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Abbreviations

BCTs: behavior change techniques
CALO-RE: Coventry, Aberdeen, and London-Refined

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Original Paper

Perceptions of Health-Related Information on Facebook: Cross-Sectional Study Among Vietnamese Youths

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Abstract

Background: While health information websites may have previously been the core source of information about health-related conditions on the Internet, social networking sites are increasingly replacing those websites as a source of health-related information. The increasingly popularity of social networking sites among the general population has consequential impact on health policies as well as health-related interventions. To date, there remains a paucity of research conducted in developing countries like Vietnam looking at the influence of social networking sites.

Objective: Our goal is to establish the baseline use of Facebook among Vietnamese youths and establish their perception of the reliability and usefulness of health-related information that they previously encountered while using the social networking site.

Methods: An online cross-sectional study was conducted from August 2015 to October 2015. Respondent-driven sampling (RDS) technique was used in the recruitment of participants. Sociodemographic, health status, behaviors, Facebook use and belief of information on Facebook, and interpersonal influence of social network sites were collected via an online structured questionnaire.

Results: Among 1080 participants, 72.87% (787/1080) reported being interested in health information on Facebook, and 50.74% (548/1080) and 17.50% (189/1080) perceived the information to be reliable and useful, respectively. A total of 10.93% (118/1080) of the participants also reported that they would follow the health advice they obtained from Facebook. Of significance, 7.13% (77/1080) of the participants also reported peer influences on their behavior. Factors that mediate Vietnamese perceptions of the information online include gender, level of perceived stress, age, educational level, and interpersonal influences from Facebook.

Conclusions: Our study is perhaps one of the first conducted in Vietnam that looks at the relationship between health information on Facebook and factors that might influence young Vietnamese perceptions of the information and the consequential use of that information.

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KEYWORDS

health information; social media; Facebook; beliefs

Introduction

Over the past decade, there have been rapid advances in Internet as well as mobile technologies. Such rapid advances in technology have revolutionized health care. Aside from the introduction and implementation of electronic medical records in the health care setting, the availability of the Internet has allowed individuals to seek out information about various medical disorders more readily [1]. It is pertinent to note that the influence of such technological advances is not limited to developed countries. Developing countries such as Vietnam are also becoming increasingly more connected to the Internet [2]. Prior studies conducted have reported that the penetration rate of the Internet in Vietnam has increased approximately threefold since 2005 [2].

More recent research has reported that youths in Vietnam tend to use the Internet, especially using their mobile devices, and those who are younger are also more likely to use social networking sites as well as messaging apps [3].

While technology has transformed how health care professionals function in their day to day activities, it has also affected the general public. There are myriad studies highlighting how technology has empowered individuals and transformed the way they seek out health-related information on the Internet. While health information websites may have previously been the core source of information about health-related conditions on the Internet, social networking sites are increasingly replacing those websites as a source of health-related information. Prior studies have reported there has been a paradigm shift in terms of information-seeking from the health information websites to social media of late [4]. A recent study has looked into how young adults sought information about diabetes and mental health online [5]. Based on the semistructured interviews conducted, it was noted that while young adults do use search engines to look for health-related information, they are increasingly using social media to seek health-related information as well [5]. The increasing popularity of social networking sites among the general population has consequential impact on health policies as well as health-related interventions. Huesch et al [6] have examined how social networking sites such as Facebook could potentially be used for public health interventions. Other research has highlighted the potential utility of social networking sites in reaching out to individuals in the general population who have experienced auditory hallucinations [7]. The research also reported how social networking sites such as Facebook could potentially be used as a form of support and a therapeutic tool for participants who are distressed by their hallucinations [7]. Aside from the use of Facebook for hallucinations, other researchers have proposed that Facebook could also be used to help reduce the incidence of problem drinking among university students through modification of social norms about drinking [8]. Facebook has also been used previously in the analysis of beliefs about common disorders such as attention-deficit hyperactivity disorder [9]. Clearly, there is a huge amount of potential for social networking sites to not only disseminate health-related information but also potentially be used as an intervention.

Granted, prior studies have documented the utility of Facebook as an intervention as well as a resource for health-related information. More recently, a study was conducted to determine the factors associated with how college students seek out health-related information using social networking sites [10]. Another study reported that various sociodemographic variables as well as the sources of the information are influential in participant receptiveness and preferences. Other research has demonstrated how Facebook could help augment tobacco prevention strategies taught in the classroom setting [11]. Notably, that study reported that a good proportion of students posted antitobacco messages on their social media account days after being exposed to tobacco prevention strategies in a classroom setting. Clearly, it is evident that Facebook is being used and perceived as a good tool to communicate health-related information [11].

In a developing country like Vietnam, with the rapid proliferation and increasing affordability of the Internet, it is thus pertinent for us to understand how youths perceive the health-related information on social networking sites. An understanding of this is pertinent prior to the conceptualization and implementation of interventions to deal with public health problems, modeling against research that has been done in the west. To our knowledge, there have not been any prior studies looking into how youths seek out health-related information on social networking sites in Vietnam. Here, thus far, the most common methodology of disseminating health-related information is via school-based campaigns [12].

The aim of this study is to establish the baseline use of Facebook among Vietnamese youths and establish their perception of the reliability and usefulness of health-related information that they previously encountered while using the social networking site. This study also seeks to determine how Vietnamese youths use the information they have obtained from online social networking sites. In addition, this study seeks to determine if there are other variables that might affect youth perceptions and receptiveness, such as their baseline health status. Understanding this information will help guide future public health interventions that use social networking sites as an interventional tool.

Methods

Study Setting and Population

In order to achieve the study’s objectives, an online cross-sectional study was conducted from August 2015 to October 2015 in Vietnam. The inclusion criteria for participation in the study include the following: aged 15 to 25 years, currently residing in Vietnam, and having access to an email or social network site account. There are no specific exclusion criteria for this study.

Respondent-Driven Sampling and Sample Size

For this cross-sectional study, the investigators made use of the respondent-driven sampling (RDS) technique in the recruitment of the participants. The sampling technique is as described elsewhere [13-15]. First, several core participants were recruited from high schools (Hung Yen high school and Phan Boi Chau high school) and universities (Hanoi Medical University and Vietnam National University) in Vietnam. The core participants were carefully selected to reflect the diversity of the Vietnamese population, taking into consideration age, gender, and level of education. Participants in the core groups were required to give their informed consent for the study and were told they would be required to make use of their email or social network site accounts to recruit other students to participate in the study. All participants in the core group were required to complete the Web-based study questionnaire prior to recruiting other participants. The invited participants were provided with the Web link of the survey form for them to complete the same questionnaire. There was no predefined end date of recruitment. The network was allowed to expand until it was deemed to be not able to expand any further. The survey was then deemed complete.

All the participants in the core group as well as the participants whom they invited were included in the final sample. Duplicate participants were identified through email, and amounted to a total of 7 cases, while 3 cases did not meet the inclusion criteria. Participants who did not complete at least 60% of the questions in the survey questionnaire were also excluded from the analysis. The resultant cumulative total sample size amounted to 1080 participants.

Web Survey Design

The cross-sectional survey was implemented and deployed using Google Forms. All the data acquired from the Web-based study was stored on Google's Health Insurance Portability and Accountability Act–compliant server. Prior to the commencement of the survey, all participants were provided with information about the study's purposes and methodology as well as information about the principal and coinvestigators. The questionnaire survey comprised 40 questions, and participants were required to answer 23 questions. The Web survey was piloted among a group of 20 youths of different ages and genders prior to the actual implementation. The participants in the pilot group assisted in the assessment of the usability and reliability of the Web-based survey across a variety of devices and operating system platforms. For the questionnaire, a logic check was implemented in order to ensure that the answers provided corresponded to the theme of the questions.

The Web-based survey included the following questionnaires:

- Baseline demographics questionnaire: Baseline demographic information such as age, gender, educational level, occupational status, marital status, ethnicity, and religion beliefs were acquired from the participants.
- Health-related quality of life (HRQOL): HRQOL was measured by using the EuroQol 5 dimension 5 level (EQ-5D-5L) instrument. The HRQOL questionnaire included 5 domains: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression, with 5 levels of response: no problems, slight problems, moderate problems, severe problems, and extreme problems, giving 3125 health states with respective single indexes. To compute those indexes, the interim scoring for the EQ-5D-5L from the cross-walk value set of Thailand was used due to the unavailability of the Vietnamese population's reference [16]. Additionally, the EQ-VAS (visual analog scale) assessed the self-rated health of respondents on a 20-cm vertical scale with the endpoint range from 0 to 100 points, labeled "the best health you can imagine" and "the worst health you can imagine." The validated Vietnamese version of the EQ-5D-5L has been used elsewhere [13,14,17-22].
- Stress measurement: The short-form Perceived Stress Scale (PSS) was used to measure the stress of participants in the last 30 days. This instrument included 4 items with a 5-point scale: never (0), almost never (1), sometimes (2), fairly often (3), very often (4). Two items were negatively coded (''In the last month, how often have you felt that you were unable to control the important things in your life?'' and ''In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?'') and 2 items are positively coded (''In the last month, how often have you felt confident about your ability to handle your personal problems?'' and ''How often have you felt that things were going your way?''). In scoring the stress measure, positive items are reverse scored, and then all items are summed (scores ranging from 0 to 16 for the 4-item scale). Higher scores indicate greater stress [23].
- Risk behaviors: Questions were asked as to whether participants have had other risk behaviors such as smoking tobacco products or use of alcohol. To quantify the severity of the alcohol use disorder, we used the Alcohol Use Disorders Identification Test–Consumption (AUDIT-C) instrument, which is a short version of the Alcohol Use Disorders Identification Test. This tool consisted of 3 questions with scoring from 0 to 12, with a higher score indicative of a higher risk of alcohol dependence. If male respondents scored ≥4 or female respondents scored ≥3, they were determined as AUDIT+ [21,24-30].
- Facebook use and belief of information on Facebook: We asked questions relating to the amount of time individuals spent using Facebook on a daily basis, as well as their primary activity on Facebook. In addition, we asked how participants usually obtained information about medical conditions and health-related conditions. Subsequently, participants were asked whether they had any interest in the health information on Facebook, and they were tasked to estimate the amount of time they spent reading health-related information on Facebook. Participants were asked to rate the perceived level of reliability of the health information, as well as the perceived level of usefulness. Participants were also asked how often they had shared health-related information using the social networking site.
- Interpersonal influence of social network sites: Questions were asked to investigate online peer influence. These included talking with new friends on the Internet, going to places introduced by online friends, effect of online friends

on behavior and lifestyle, and trying to do something introduced by online friends.

Statistical Analysis

Chi-square, *t* test, and analysis of variance were used to explore the differences among characteristics. Multivariate logistic regressions were employed to identify the associated factors. In this study, we applied a stepwise forward model strategy that uses a log-likelihood ratio test at a *P* value of .10 to select variables for the reduced models [31]. A *P* value of less than .05 was set as the level of statistical significance.

Ethical Approval

The Institutional Review Board of the Vietnam Authority of HIV/AIDS Control provided the ethical approval for this study. All participants were asked to provide an electronic informed consent. Participants were briefed and informed that they could withdraw anytime they wanted. Information obtained from the participants was coded and kept confidential.

Results

A total of 1080 participants took part in the questionnaire survey, out of which 41.94% (453/1080) were males; 54.26% (586/1080) of the individuals were in the 18 to 22 year age group. The vast majority (849/1080, 78.61%) were undergraduate students, 95.83% (1035/1080) were of Kinh ethnicity, and 72.59% (784/1080) were single. A total of 47.59% (514/1080) of the participants resided in rented accommodations. A total of 9.63% (104/1080) of the participants reported having had acute illnesses in the preceding month, and 18.88% (204/1080) of the participants reported that they have had chronic illnesses in the last 3 months. Among those sampled, 9.26% (100/1080) were overweight. In terms of their HRQOL, the vast majority of the participants reported having experienced mood symptoms (806/1080, 74.63%) as well as pain-related symptoms (548/1080, 50.74%). About 10.74% (116/1080) of the participants were currently smoking, and twice that (235/1080, 21.76%) were using alcohol. A total of 5.19% (56/1080) of the participants had also been smoking shisha. The mean scores for all participants on the EQ-5D and EQ-5D VAS were 0.73 and 80.59, respectively. The mean score for all participants on the PSS was 6.58.

Table 1 provides an overview of the baseline use of Facebook by the participants as well as their perceptions about health-related information on Facebook. The average amount of time participants spent on Facebook was 3.05 hours. The mean hours for females and males were 2.98 and 3.14 hours, respectively, and there were no significance differences between the means. The vast majority of the participants (713/1080, 66.02%) used Facebook primarily to keep themselves updated with the latest news. For most participants, friends are regarded as the primary source of their health information. At least 72.9% (787/1080) of the participants reported that they were interested in the health information shared on Facebook. A total of 65.74% (710/1080) of the participants spent less than 30% of the total time they spent on Facebook engaging in and reading health-related information.

Table 1. Use of Facebook for seeking health information among respondents.

Characteristics	Female	Male	Total	*P* value
Primary purpose for using Facebook, n (%)				
Chatting with friends	143 (22.77)	144 (31.86)	287 (26.57)	.011
Update news	436 (69.43)	277 (61.28)	713 (66.02)	
Counseling	6 (0.96)	4 (0.88)	10 (0.93)	
Playing games	43 (6.85)	27 (5.97)	70 (6.48)	
Health information sources, n (%)				
Friends	267 (42.52)	239 (52.88)	506 (46.85)	.006
Health page/groups	220 (35.03)	130 (28.76)	350 (32.41)	
Talk with consultants	2 (0.32)	0 (0)	2 (0.19)	
Others	139 (22.13)	83 (18.36)	222 (20.56)	
Interest in health information shared on Facebook, n (%)				
Highly interested	149 (23.73)	83 (18.36)	232 (21.48)	<.001
Interested	346 (55.10)	209 (46.24)	555 (51.39)	
Low interest or not interested	133 (21.18)	160 (35.40)	293 (27.13)	
Time spent reading health information on Facebook, n (%)				
<10%	164 (26.11)	178 (39.38)	342 (31.67)	<.001
10%-<30%	224 (35.67)	144 (31.86)	368 (34.07)	
30%-50%	118 (18.79)	64 (14.16)	182 (16.85)	
50%-70%	62 (9.87)	25 (5.53)	87 (8.06)	
>70%	6 (0.96)	4 (0.88)	10 (0.93)	
Unknown	54 (8.60)	37 (8.19)	91 (8.43)	
Time spent using Facebook per day (hours), mean (SD)	2.98 (2.562)	3.14 (2.901)	3.05 (2.713)	.351

There were, however, statistically significant differences between the genders in terms of their primary purposes of using Facebook (*P*=.011), their health information sources (*P*=.006), their level of interest in health information (*P*<.001), and the amount of time they spent reading health-related information (*P*<.001).

Table 2 provides a detailed analysis of the participant perceptions of the usefulness and reliability of health-related information on Facebook. A total of 50.65% (547/1080) of the participants reported that they felt that the information was moderately reliable, and 17.50% (189/1080) reported that the information was highly reliable. Only 4.91% (53/1080) of the participants perceived the information to be useful. The vast majority of the participants (629/1080, 58.24%) felt that the information was neither useful nor useless. Only 31.20% (337/1080) of the sampled participants reported that they would not share the health information on Facebook. A cumulative total of 10.93% (118/1080) of participants reported that they would follow the health advisory shared on Facebook. There are significant differences between the genders in all the domains discussed.

Table 3 highlights the interpersonal influence of Facebook and social media sites on respondents. Among the participants, 8.17% (79/967) reported that social media encourages them to either talk to or meet new friends online. In addition, 7.07% (68/962) reported that their behaviors, lifestyle, and perceptions are highly affected by others whom they have met online. Of significance, approximately 13.40% (129/963) of participants reported that they ventured to a new place that was introduced by their online friends. In addition, 8.58% (83/967) of participants also reported that they often would try out new activities introduced by their online peers. There was no noted significant difference among the genders and the interpersonal influence, as the *P* values obtained were all not significant.

Table 2. The belief of respondents in health information on Facebook.

Characteristics	Female n (%)	Male n (%)	Total n (%)	*P* value
Reliability of health information shared on Facebook				
Low	134 (21.34)	160 (35.40)	294 (27.22)	<.001
Moderate	364 (57.96)	183 (40.49)	547 (50.65)	
High	106 (16.88)	83 (18.36)	189 (17.50)	
Unknown	24 (3.82)	26 (5.75)	50 (4.63)	
Usefulness of health information shared on Facebook				
Not useful	242 (38.54)	156 (34.51)	398 (36.85)	<.001
Normal	370 (58.92)	259 (57.30)	629 (58.24)	
Useful	16 (2.55)	37 (8.19)	53 (4.91)	
Frequency of sharing health information on Facebook				
Always	23 (3.66)	34 (7.52)	57 (5.28)	.002
Often	35 (5.57)	30 (6.64)	65 (6.02)	
Occasionally	388 (61.78)	233 (51.55)	621 (57.50)	
Never	182 (28.98)	155 (34.29)	337 (31.20)	
Practice health information on Facebook				
Always	18 (2.87)	20 (4.42)	38 (3.52)	<.001
Often	49 (7.80)	31 (6.86)	80 (7.41)	
Occasionally	508 (80.89)	320 (70.80)	828 (76.67)	
Never	53 (8.44)	81 (17.92)	134 (12.41)	

Table 3. Interpersonal influence on Internet among respondents.

Characteristics	Female n (%)	Male n (%)	Total n (%)	*P* value
Talk and meet new online friends				
Often	30 (5.39)	49 (11.95)	79 (8.17)	<.001
Frequently	101 (18.13)	140 (34.15)	241 (24.92)	
Rarely or never	426 (76.48)	221 (53.90)	647 (66.91)	
Effects of online relationships on behaviors, lifestyle, and perceptions				
High influence	36 (6.46)	32 (7.90)	68 (7.07)	.466
Normal influence	138 (24.78)	89 (21.98)	227 (23.60)	
Low influence or no influence	383 (68.76)	284 (70.12)	667 (69.33)	
Go to places introduced by online friends				
Often	79 (14.21)	50 (12.29)	129 (13.40)	.685
Frequently	294 (52.88)	221 (54.30)	515 (53.48)	
Rarely or never	183 (32.91)	136 (33.42)	319 (33.13)	
Try to do something introduced by online friends				
Often	47 (8.44)	36 (8.78)	83 (8.58)	.671
Frequently	274 (49.19)	212 (51.71)	486 (50.26)	
Rarely or never	236 (42.37)	162 (39.51)	398 (41.16)	

Multimedia Appendix 1 provides an overview of the multivariate regression analysis to determine factors that are associated with health-related information-seeking using Facebook. Males (odds ratio [OR] 0.42, 95% CI 0.31-0.58) are less likely to be concerned about health-related information on Facebook. Those participants who have reported increased levels of perceived stress, as determined by their scores on the PSS, are also less likely to be interested in and concerned about health information (OR 0.89, 95% CI 0.83-0.95). Factors that mediate whether participants believe the health information they have acquired from Facebook are affected by sociodemographic variables such as age and education. Participants who are older are less likely to believe in the health information provided on Facebook (OR 0.87, 95% CI 0.80-0.95). Participants with vocational training education status are more likely to belief in the health information on Facebook as compared to those with university or postgraduate education. The analysis of interpersonal influences was conducted as we need to determine whether it is one of the associated factors that might mediate the sharing of health-related information by participants. Participants who tend to make use of social media like Facebook to form new relationships (OR 2.65, 95% CI 1.26-5.56) and participants who are easily influenced by their online peers (OR 2.20, 95% CI 1.05-4.60) are more likely to share health-related information using their social networking accounts. With regard to whether participants would adhere to the health information provided on the social network, being of male gender has been found to be negatively associated with adherence (OR 0.84, 95% CI 0.76-0.93). However, interpersonal factors like using the social network to find new friends and following the advice of online peers are associated with a heightened incidence of adhering to the health information provided. Of significance, health information is commonly perceived to be useful among those individuals who are overweight.

Discussion

Principal Findings

This is one of the first studies conducted in Vietnam that looks into the relationship between health information on Facebook and associated factors that might influence Vietnamese perceptions of the information and their use of the information that they have obtained from social networking sites. In our study, a total of 1080 participants took part and the vast majority were undergraduate students. A total of 18.88% (204/1080) of the participants reported that they have had health issues over the past 3 months, 9.26% (100/1080) of them were overweight, and a significant proportion have had pain or mood-related symptoms. Among the participants, 72.90% (787/1080) of them reported that they were interested in the health information on Facebook, and 50.65% (547/1080) and 17.50% (189/1080) perceived the information to be reliable and useful, respectively. A total of 10.93% (108/1080) of the participants also reported that they would follow the health advice they obtained from Facebook. Of significance, 7.07% (68/1080) of the participants also reported peer influences on their behaviors. Factors that mediate Vietnamese perceptions of the information online include gender, level of perceived stress, age, educational level, and interpersonal influences of Facebook. These factors moderated and affected how Vietnamese perceive the usefulness and reliability of the health information, as well as the likelihood that they would share the information with their peers.

There have been prior studies conducted in China looking at the equivalents of social networking sites like Facebook and determining factors that might affect how their cohort used social networks [32]. One study reported that Internet self-efficacy is a mediating factor influencing use [32]. Other studies have looked into specific ethnicity and how ethnicity in itself might be a mediating factor affecting use [33]. Lee [33] reported that as many as 98% of African American college students had a Facebook account and were actively using Facebook. In addition, younger users reported spending more time online. A study also reported how cultural factors could influence use [33]. Cultural factors do have a significant influence on the motivation to use Facebook as well as the amount of time devoted to using it. Underwood et al [34] reported that there are fundamentally 3 different types of users—broadcasters, communicators, and high interactors—and the use of Facebook differs among these groups. Other comparative studies have reported on how women from different cultures use Facebook differently [35]. For example, Americans tend to seek out Facebook for entertainment, whereas Koreans tend to seek social support and information online [34-36]. These previous studies highlight the prevalent usage of Facebook across various countries and that the usage might be mediated and influenced highly by cultural variable. Our study has reported that among our sampled cohort of Vietnamese, a good number of individuals were using Facebook and that the mean duration of use was 3.05 hours. In our study, we found that the vast majority of the participants have used Facebook to keep themselves updated about the latest news. The findings from our study are much in line with that of Kim et al [36], and this was expected as ours is an Asian cohort.

Our study, which looks into the acceptability and receptiveness of youths toward health information available on Facebook, is crucial, as a prior study has examined how social media could be used by community-based organizations who are conducting health promotion [37]. That study has examined social networking sites such as Facebook, Twitter, and YouTube and found that these social media networks helped in the dissemination of health information to participants [37]. Our study finds that Facebook could potentially be a good medium for the dissemination of health-related information, given that a good number of our sampled participants believe in the reliability of the information and are keen to share the information.

In our study, we found that males are less likely comparatively to be concerned about health-related information on Facebook. The fact that males are less likely to be concerned about health-related information might be accounted for by gender differences in the usage of Facebook. Raacke and Bonds-Raccke [38] reported that males tend to have a larger social network on Facebook and tend to make use of Facebook for dating-related purposes. In addition, we found that educational level would mediate whether participants believe the health-related information they have obtained online. Of significance, those with only a vocational level of education are more likely to believe the information online as compared to those with higher levels of education. We postulate that this might be related to how participants process the information by determining the accuracy and source of the information. Those with higher levels of education are more likely to consider the accuracy as well as the original source of the health-related information.

In addition, in our study we have determined that Facebook is associated with significant interpersonal influence. A prior study by Hormes [39] has suggested that the excessive use of Facebook is similar to that of a behavioral form of addiction and demonstrated that those who met the criteria for disordered social networking usage were more likely to use alcohol. While Hormes' study demonstrated the negative impact of Facebook, it has demonstrated that Facebook could potentially shape one's perceptions. In our study, it is likely that Facebook might have caused changes in perceptions toward health-related information, whereas in Hormes' study, Facebook normalized alcohol use and provided opportunities for increased use of alcohol. While there remains to date limited literature on interpersonal influences of Facebook, a previous study examining Internet addiction has demonstrated that those with Internet addiction are more susceptible to interpersonal influences due to their reduced cognitive abilities [15]. We postulate that this might be similar for Facebook users, especially for those who are using Facebook excessively.

There are several clinical implications that arise from our study. Given the results, clinicians should be aware that youths and young adults are increasingly exposed to health-related information on social media. Hence, there is a good potential for the use of social media to augment the conventional mechanism of delivery of health-related information. Clinicians should know that information gotten from Facebook might not be entirely factually correct and should provide evidence-based information and recommendations about the various diseases to their patients. It is important to tale gender and educational influences into consideration and for there to be tailored and customizable messages. Clinicians should recognize the role of social media in their outreach efforts because we have found in this study that social media has interpersonal influences and messages that are disseminated could have potentially positive or negative outcomes. Hence, in using Facebook as a medium for health information dissemination, there needs to be some moderation of the content that is posted online. There has been recent research demonstrating how social media use could help in public health campaigning, especially in a low-resource setting [40]. The authors have reported how effective such media are, given that they have inherent potential for rapid transfer of information to the masses [40].

Strengths and Limitations

Our study aimed to determine the use rates of social networking sites among young Vietnamese. Our study is perhaps one of the first studies examining the rates of social media use to be conducted in a developing country like Vietnam. We recruited a sizeable number of participants who, at the baseline, had knowledge of how to use the Internet (because they were required to make use of the Internet to take part in our survey). In addition, we were able to determine their perceptions and beliefs about health-related information shared on social networking sites as well as the interpersonal influences of social networking sites. We identified their baseline health status and other demographic variables and the influence of these variables on their perceptions of the health-related information shared online. Despite the clear strengths of our study, we do acknowledge several inherent limitations. Our sampled cohort might not be entirely representative of the general Vietnamese population. However, Internet-based sampling is the most effective low-cost way to reach out to individuals in a developing country like Vietnam. Also, our sampling is dependent on RDS and hence our participants needed to have social networking accounts to recruit other participants. We have only examined individual perceptions toward health-related information in general. Ideally, it would be of importance to determine their perceptions toward particular health-related information such as particular diseases, and this will help guide our future interventions.

Conclusion

This study is perhaps one of the pioneering studies conducted in Vietnam looking at the relationship between health information on Facebook and factors that might influence young Vietnamese perceptions of the information and the consequential use of that information. Clearly, from our study, a good proportion of young Vietnamese use social media to check out health-related information and share this information with their peers. Factors that mediate Vietnamese perceptions of the information online include gender, level of perceived stress, age, educational level, and interpersonal influences of Facebook. The above findings have clinical implications for clinicians who might wish to consider social sites for health-related interventions.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Associated factors with health information seeking behaviors and belief on Facebook among respondents.

[PDF File (Adobe PDF File), 22KB - ijmr_v6i2e16_app1.pdf]

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Abbreviations

AUDIT-C: Alcohol Use Disorders Identification Test–Consumption
EQ-5D-5L: EuroQol 5 dimension 5 level questionnaire
HRQOL: health-related quality of life
OR: odds ratio
PSS: Perceived Stress Scale
RDS: respondent-driven sampling
VAS: visual analog scale

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Original Paper

Quality of Patient Information Websites About Congenital Heart Defects: Mixed-Methods Study of Perspectives Among Individuals With Experience of a Prenatal Diagnosis

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Abstract

Background: When a heart defect is prenatally diagnosed in the fetus, expectant parents experience a great need for information about various topics. After the diagnosis, the Web is used for supplemental information, and the scarcity of research calls attention to the need to explore patient information websites from the perspectives of the intended consumers.

Objective: The overarching aim of this study was to explore the quality of Swedish patient information websites about congenital heart defects, from the perspectives of individuals with experience of a prenatal diagnosis of congenital heart defect in the fetus.

Methods: This was a mixed-methods study of websites identified through systematic searches in the two most used Web-based search engines. Of the total 80 screened hits, 10 hits led to patient information websites about congenital heart defects. A quality assessment tool inspired by a previous study was used to evaluate each website’s appearance, details, relevance, suitability, information about treatment choices, and overall quality. Answers were given on a 5-point Likert scale, ranging from 1, representing the lowest score, to 5, representing the highest score. Each website was assessed individually by persons with experience of continued (n=4) and terminated (n=5) pregnancy following a prenatal diagnosis. Assessments were analyzed with Kendall’s coefficient of concordance W, Mann-Whitney *U* test, Friedman’s test, and a Wilcoxon-Nemenyi-McDonald-Thompson test. In addition, each assessor submitted written responses to open-ended questions in the quality assessment tool, and two joint focus group discussions were conducted with each group of assessors. The qualitative data were analyzed with inductive manifest content analysis.

Results: Assessments represented a low score (median=2.0) for treatment choices and moderate scores (median=3.0) for appearance, details, relevance, suitability, and overall quality. No website had a median of the highest achievable score for any of the questions in the quality assessment tool. Medians of the lowest achievable score were found in questions about treatment choices (n=4 websites), details (n=2 websites), suitability (n=1 website), and overall quality (n=1 website). Websites had significantly different scores for appearance (*P*=.01), details (*P*<.001), relevance (*P*<.001), suitability (*P*<.001), treatment choices (*P*=.04), and overall quality (*P*<.001). The content analysis of the qualitative data generated six categories: (1) advertisements, (2) comprehensiveness, (3) design, (4) illustrations and pictures, (5) language, and (6) trustworthiness. Various issues with the included websites were highlighted, including the use of inappropriate advertisements, biased information, poor illustrations, complex language, and poor trustworthiness.

Conclusions: From the perspectives of the intended consumers, patient information websites about congenital heart defects are, to a large extent, inadequate tools for supplemental information following a prenatal diagnosis. Health professionals should initiate discussions with patients about their intentions to use the Web, inform them about the varied quality in the Web-based landscape, and offer recommendations for appropriate Web-based sources.

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KEYWORDS

congenital heart defects; consumer health information; information literacy; Internet; popular works; pregnancy; prenatal diagnosis

Introduction

Background

Many countries around the world include obstetric ultrasound examinations as part of routine maternity care. One of the investigations possible with the ultrasound examination involves assessment of the anatomy of fetuses, with the purpose to detect or rule out fetal anomalies [1]. The most common types of fetal anomalies are congenital heart defects, defined as malformations of the heart and great vessels [2]. The incidence of congenital heart defects is approximately 8 in 1000 live births [2], with an incidence of 2.5 to 3.0 for the most severe, which require specialist cardiologic care [3]. Between the years 2000 and 2005, roughly 1 in 5 cases of all congenital heart defects were detected before birth [4]. However, the rates of prenatal diagnoses have increased in recent years [5-7], and studies report that over 40% of the most severe defects are prenatally diagnosed today [2,4,7].

Expectant parents view the obstetric ultrasound examination as an important step toward parenthood [8-10] but are often unprepared for adverse news [11-13] and experience an emotional crisis when faced with a prenatal diagnosis [11,14]. Depending on legislation and availability of induced abortion, the diagnosis may require a decision to continue or terminate the pregnancy. Expectant parents faced with the diagnosis experience this decision as difficult [11,15]. The decision involves various informational [11,16,17] considerations such as the process of induced abortion and what to expect of the postnatal situation if the pregnancy is continued [17]. Consequently, these persons experience a great need for information and highly value that which is offered during consultations with specialist health professionals [17,18]. However, the psychological distress experienced in connection to the diagnosis negatively influences comprehension and retention of the information offered [12,17], and research suggests that these individuals use the Web for supplemental information [16,17,19].

Patients view the Web as an important source of health-related information [20] and commonly use it for such purposes [20,21]. During pregnancy, women frequently use it to search for information about a variety of topics such as fetal development, pregnancy complications, and antenatal care [22]. As a large source of potentially highly accessible information [23,24], it holds promise to promote patient equity and empowerment [23,25-27]. However, studies indicate that consumers experience various difficulties when using the Web for health-related information [28,29]. Further complicating the situation, there is a lack of overarching systematic activities that aim to assess and control the quality of the available Web-based information [23], resulting in a risk of contact with information of poor quality. Combined, these issues call attention to the disorganized state of the Web [24]. The informational difficulties [11,15-17] and ethical dilemmas [30] related to decision making regarding whether to continue or terminate the pregnancy highlight the need to explore the relevance, level of details, suitability, and information about treatment choices in patient information websites. Moreover, research indicates that users of Web-based information place high importance on website appearance [31-33], raising questions concerning whether the design of these websites correspond to the preferences of the intended consumers.

As a step toward ensuring high-quality patient information materials, research suggests a need for developers to involve the intended consumers in the stages of production [34]. However, studies investigating the quality of Web-based information often use researchers or health professionals as assessors, raising questions about its applicability in clinical settings. In light of the identified differences in perspectives between researchers, health professionals, and patients [35,36], more research that employs new methods to investigate the perspectives of the actual consumers of the information is needed. No study has yet been published that explores consumers’ perspectives on websites about congenital heart defects.

Objectives

The overall aim of this study was to explore the quality of patient information websites about congenital heart defects, from the perspectives of individuals with personal experience of a prenatal diagnosis of congenital heart defect in the fetus. Specifically, we set out to address the following research questions:

- How do individuals with personal experience of a prenatal diagnosis of congenital heart defect in the fetus assess patient information websites about congenital heart defects with regard to appearance, details, relevance, suitability, information about treatment choices, and overall quality?
- Are there any differences in the aforementioned assessments between (1) assessors with continued and terminated pregnancy, and (2) websites about congenital heart defects?
- What perspectives do individuals with experience of a prenatal diagnosis bring up when accessing these websites?

Methods

Study Context

In Sweden, all expectant parents are offered a routine ultrasound examination at approximately 18 weeks of gestation. One of the purposes of the examination is to assess the fetal anatomy, to detect or rule out possible fetal anomalies. Swedish law permits termination of pregnancy up to 18 completed weeks of gestation. At later gestations, approval must be granted by the National Board of Health and Welfare. Few pregnancies are terminated after 22 completed weeks.

Study Design

Through mixed-methods design with quantitative and qualitative approaches, we aspired to utilize the strengths and to offset the weaknesses of each approach [37]. Mixed-methods designs are presented as promising strategies to optimize assessments of Web-based health-related information [38].

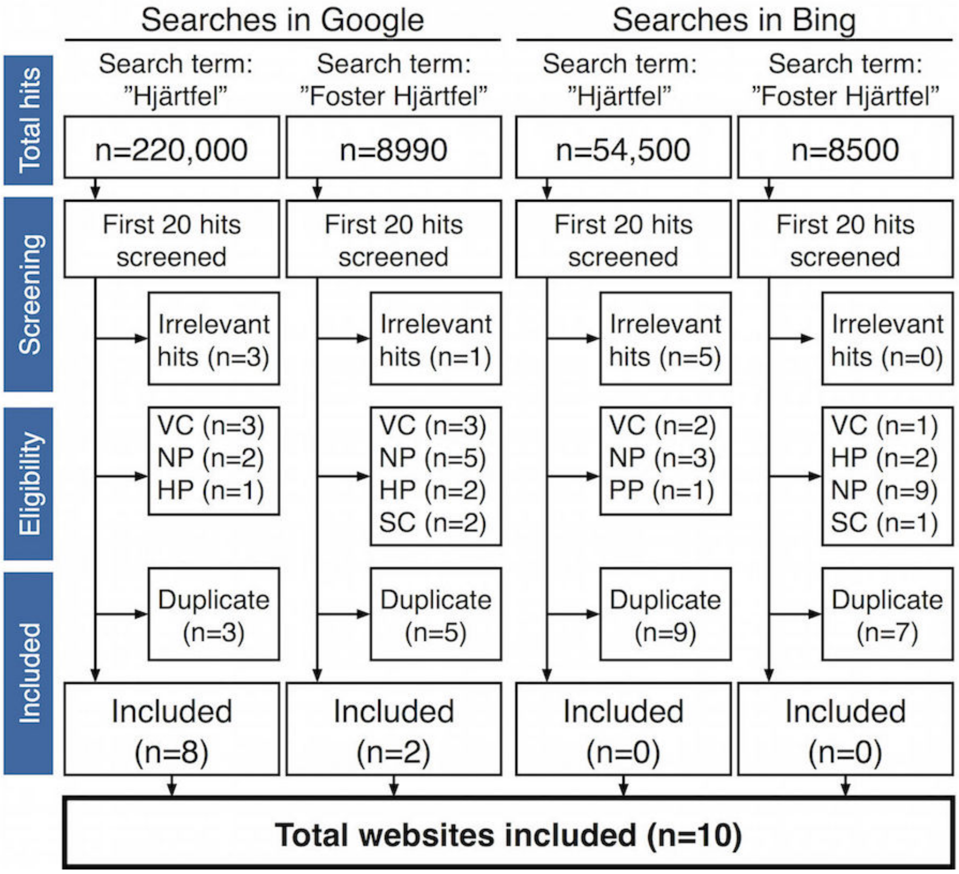
Patient Information Websites

The two most popular search engines on the Web, Google and Bing [39], were used to search for Swedish patient information websites about congenital heart defects. Swedish search terms for *heart defect* (*hjärtfel*) and *fetus heart defect* (*foster hjärtfel*) were used in searches during May 2015. In total, this resulted in 291,990 hits. We performed the searches in the incognito mode of our Web browser, to minimize influence from previous search patterns. The first 20 hits of each search were screened for inclusion by the first author. In total, 80 hits were screened; nine hits were deemed irrelevant, as they did not include any information about congenital heart defects. Relevant hits that included information about congenital heart defects leading to newspaper websites (n=19), communities or blogs (n=9), websites specifically produced for health professionals (n=5), scientific papers (n=3), and password-protected websites (n=1) were excluded. After correcting for duplicate hits (n=24), 10 Swedish patient information websites about congenital heart defects were included (Figure 1).

The first author decided which search terms to use. After the assessments, we asked the assessors, with experience of a prenatal diagnosis, which search terms they preferred to use when searching for patient information websites about congenital heart defects in connection to the diagnosis. The most commonly reported words in these search terms were *heart defect* (n=29 times mentioned) and *fetus* (n=11 times mentioned) (Multimedia Appendix 1).

The included websites were affiliated with charities and private organizations (n=3); government, hospitals, and clinics (n=3); independent information websites (n=2); and pharmaceutical companies (n=2). Of the included websites, 9 appeared in the first 10 hits of the searches, and 8 were identified in more than one of the searches (Multimedia Appendices 2 and 3).

Figure 1. Search procedure to identify Swedish patient information websites about congenital heart defects. VC=virtual community or blog; HP=website specifically produced for health professionals; NP=newspaper website; PP=password-protected website; SC=scientific paper.



Assessors

Assessors were purposefully recruited [40] to strive for variation with regard to country of birth, educational level, and age. They were recruited from 2 units for fetal cardiology in Sweden. Through her clinical network, the last author was responsible for the recruitment of assessors with continued pregnancy. In total, 8 potential assessors were asked to participate; 2 declined because of fear of rekindled painful memories. When contacted for further information, 2 females declined because (1) she felt like it was enough with her partner participating in the study (n=1 potential assessor) and (2) lack of time (n=1 potential assessor). Thus, 2 females and 2 males with continued pregnancy, assessed the websites. The first author was responsible for the recruitment of persons with terminated pregnancy. Potential assessors were identified when they took part in a previous interview study that used consecutive clinical recruitment [17]. In total, 8 potential assessors were asked to participate; 1 male declined because of lack of interest. When contacted for further information, 1 female and 1 male declined because of lack of time. Thus, 3 females and 2 males with terminated pregnancy assessed the websites.

Assessors with continued pregnancy were parents of children with congenital heart defects who were 2 (n=2 assessors) and 3 (n=2 assessors) years old. Assessors' ages ranged between 23 and 43 years. Regarding country of birth, 3 assessors with continued pregnancy were born outside Sweden, and all with terminated pregnancy were born in Sweden. Of the assessors, 2 had senior high school and 7 had university/college as highest educational level (Multimedia Appendix 4). Assessors with terminated pregnancy had undergone the procedure 20 (n=1 assessor), 24 (n=2 assessors), 27 (n=1 assessor), and 38 (n=1 assessor) weeks before assessments. Of the assessors, 4 with continued (n=2 assessors) and terminated (n=2 assessors) pregnancy were couples, and so experienced the same prenatal diagnosis. Assessors with continued pregnancy had experience of ventricular septal defect (n=2 assessors) or a combination of transposition of the great arteries, ventricular septal defect, and pulmonary stenosis (n=2 assessors). Assessors with terminated pregnancy had experience of atrioventricular septal defect with associated trisomy 21 (n=2 assessors), aortic stenosis (n=2 assessors), or a combination of Ebstein's anomaly and multiple structural malformations (n=1 assessor).

Data Collection

Quantitative Data Collection

During 2015, individual written assessments were performed by the assessors for each of the included website. A quality assessment tool was developed (Table 1), inspired by a previous study within fetal cardiology [41]. The tool included 6 questions regarding each website's appearance, details, relevance, suitability, information about treatment choices, and overall quality. Answers were given on a 5-point Likert scale, ranging from 1, representing lowest score, to 5, representing the highest score. A score of 3 represented quality criterion partly fulfilled, neither unsuitable nor suitable, and moderate overall quality. With 9 assessments for each of the 10 websites, we received a total of 90 assessments for each question in the quality assessment tool. In total, 8 assessors completed the assessments during a 4-hour workshop and 1 assessor at his home. Assessors were instructed to assess each included website separately and to access the sections that they found relevant to the subject of congenital heart defects when faced with a prenatal diagnosis (irrespective of which heart defect they had experienced). Because we aimed to collect assessments grounded in the perspectives of the intended consumers of the included websites, we did not provide further specific instructions to the assessors.

Qualitative Data Collection

Each question in the quality assessment tool was supplemented by a written open-ended question asking whether the assessors had any opinions related to the specific question. Additionally, assessors were asked to leave written comments regarding their perspectives on the positive and negative aspects of each website. Two focus group discussions were held regarding perspectives on the included websites, one with assessors who continued (n=4 assessors) and one with assessors who terminated (n=5 assessors) the pregnancy. The discussions were performed with the aid of a computer connected to a projector and were digitally recorded with audiovisual screen recordings. The first author moderated the discussions, and the second author attended the sessions as an observer. The websites were accessed one at a time, and assessors were encouraged to freely discuss aspects perceived as relevant to them. The discussions lasted 55 min for the assessors with continued pregnancy and 46 min for the assessors with terminated pregnancy. The first author transcribed the recordings verbatim.

Table 1. Quality assessment tool.

Question	Scale
Is the appearance appropriate for the target audience?	1 (no); 2; 3 (partly); 4; 5 (yes)
Is the level of detail appropriate for the target audience?	1 (no); 2; 3 (partly); 4; 5 (yes)
Is the content of the website relevant?	1 (no); 2; 3 (partly); 4; 5 (yes)
How suitable is the website as a source of information following a detection of congenital heart defect in the fetus?	1 (very unsuitable); 2; 3 (neither unsuitable nor suitable); 4; 5 (very suitable)
Is it clear that more than one treatment choice exists?	1 (no); 2; 3 (partly); 4; 5 (yes)
How is the overall quality of the website as a source of information following a detection of congenital heart defect in the fetus?	1 (low); 2; 3 (moderate); 4; 5 (high)

Data Analysis

Quantitative Data Analysis

Quantitative data were analyzed with R version 3.2.2. (R Foundation for Statistical Computing, Austria). Kendall's coefficient of concordance W was used to determine interrater reliability, with W ≥.21 representing fair, W ≥.41 moderate, W ≥.61 substantial, and W ≥.81 almost perfect concordance [42]. The median scores of all 10 included websites were calculated for each assessor, and the Mann-Whitney *U* test was used to compare these with the groups of assessors who continued and terminated the pregnancy. Friedman's test was used to compare the scores of the websites, and the Wilcoxon-Nemenyi-McDonald-Thompson test was used as a posthoc test to investigate possible differences between the scores of specific websites. *P* values of <.05 were considered statistically significant.

Qualitative Data Analysis

Qualitative data were analyzed with Nvivo for Mac version 11.4.0. (QRS International Pty Ltd., Australia). The written responses to the open-ended questions and the transcripts of the focus group discussions were analyzed with inductive qualitative manifest content analysis, inspired by the outline presented by Graneheim and Lundman [43]. The materials were read repeatedly to gain an overall understanding. Meaning units were identified, defined as words, sentences or paragraphs containing aspects related to each other through a common content and context. Meaning units were condensed, that is, shortened without losing content and context. Condensed meaning units were each assigned descriptive codes, functioning as labels of the content. Codes were structured into categories, defined as collections of codes that shared a similar commonality with internally homogenous and externally heterogeneous manifest content, that is, the visible content described with as little interpretation as possible [43].

Results

Quantitative Results

Inspecting all of the assessments (n=90), the highest proportion of the lowest score (1) was found for treatment choices (n=35, 39% of total assessment scores). By contrast, the highest proportion of the highest score (5) was found for relevance (n=16, 18% of total assessment scores); see Figure 2.

For all assessors, the interrater reliability ranged between 0.18 and 0.40 for the 6 questions in the quality assessment tool. Interrater reliability ranged between 0.36 and 0.66 for assessors with continued pregnancy and between 0.29 and 0.42 for assessors with terminated pregnancy. With the exception of treatment choices (median=2.0), all questions had a median total score of 3.0, representing moderate quality (Table 2). There were no significant differences between median scores of the assessments from assessors with continued and terminated pregnancy. Figure 3 presents the distributions of the assessment scores among the assessors with continued and terminated pregnancy.

Figure 4 presents the distributions of the assessment scores for each of the included websites. No website had a median score of 5.0, representing high quality, for any of the questions in the quality assessment tool. Median scores of 1.0, representing low quality, were found in questions about treatment choices (n=4 websites), details (n=2 websites), suitability (n=1 website), and overall quality (n=1 website). Website 10 had median scores of 1.0 for 4 of the 6 questions.

Table 2. Interrater reliability assessment scores for the questions in the quality assessment tool, with distributions of the assessment from assessors with continued pregnancy (n=40 assessments) and terminated pregnancy (n=50 assessments).

Questions	Continued pregnancy			Terminated pregnancy			Total		
	Interrater reliability[a]	Median	Interquartile range	Interrater reliability[a]	Median	Interquartile range	Interrater reliability[a]	Median	Interquartile range
Appearance	0.36	3.0	2	0.34	3.0	2	0.23	3.0	2
Details	0.60	3.0	3	0.42	3.0	2	0.38	3.0	3
Relevance	0.54	3.0	1	0.32	3.0	1	0.31	3.0	1
Suitability	0.66	3.0	2	0.42	3.0	1	0.40	3.0	2
Treatment choices	0.43	3.0	2	0.32	2.0	2	0.18	2.0	2
Overall quality	0.57	3.0	2	0.29	2.5	1	0.31	3.0	1

[a] Kendall's coefficient of concordance W.

Figure 2. Distribution (percentage) of all assessment scores (n=90) for each question in the quality assessment tool. 1=low quality, 5=high quality.

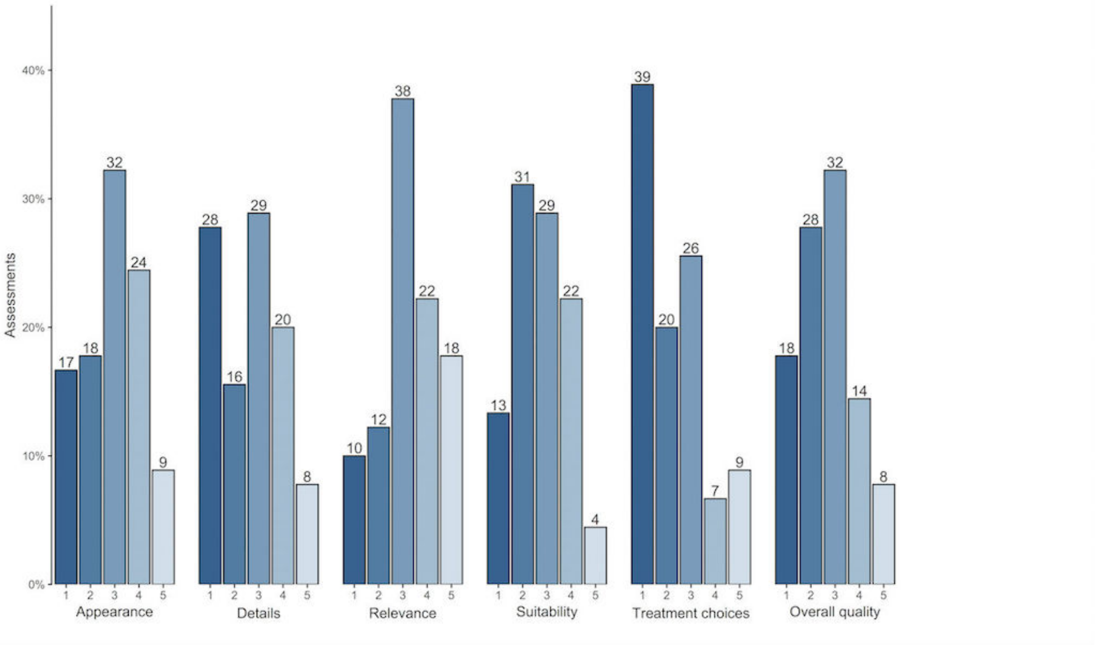


Figure 3. Distributions and medians (horizontal lines in dotplots) of the assessment scores from each of the assessors with continued (n=4) and terminated (n=5) pregnancy. 1=low quality; 5=high quality; C=continued pregnancy; T=terminated pregnancy.

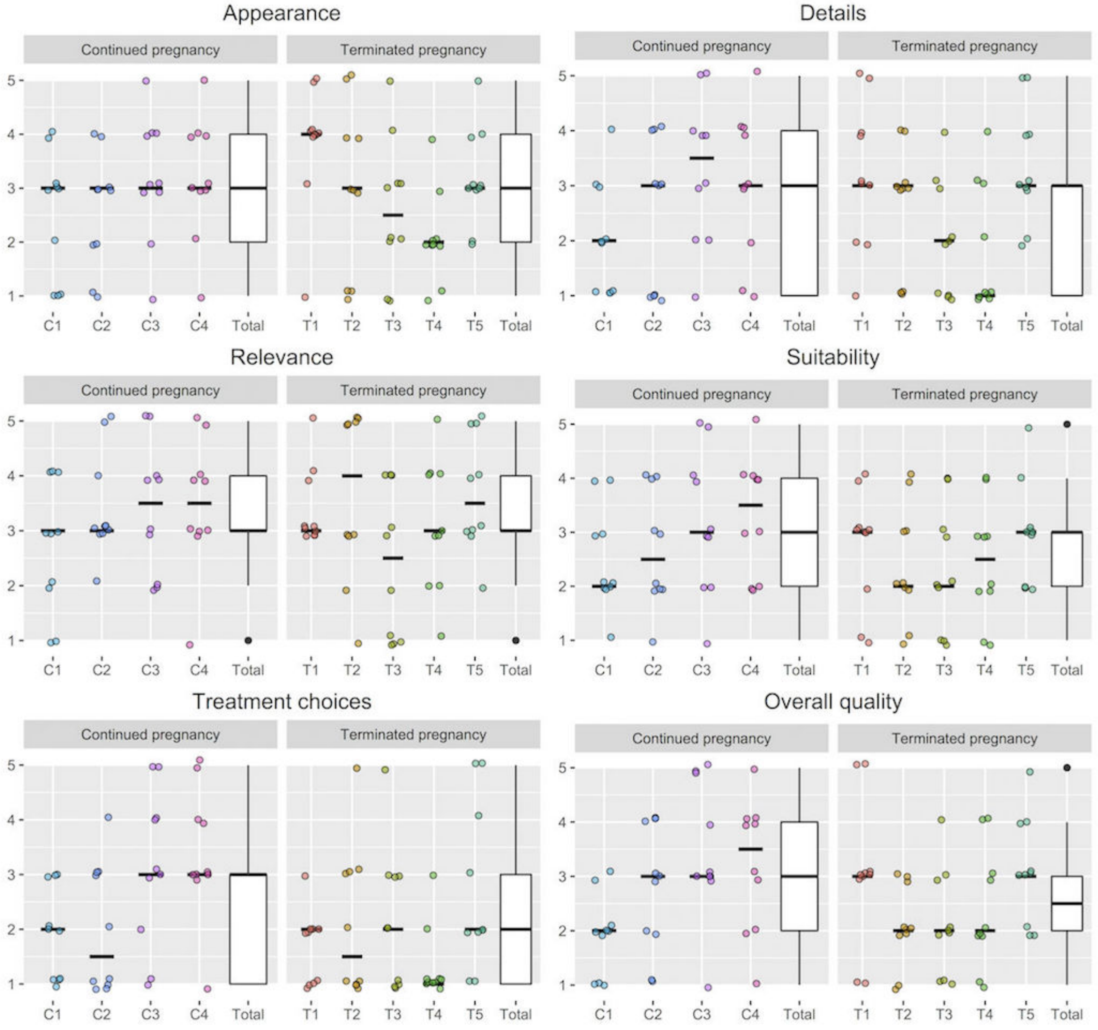
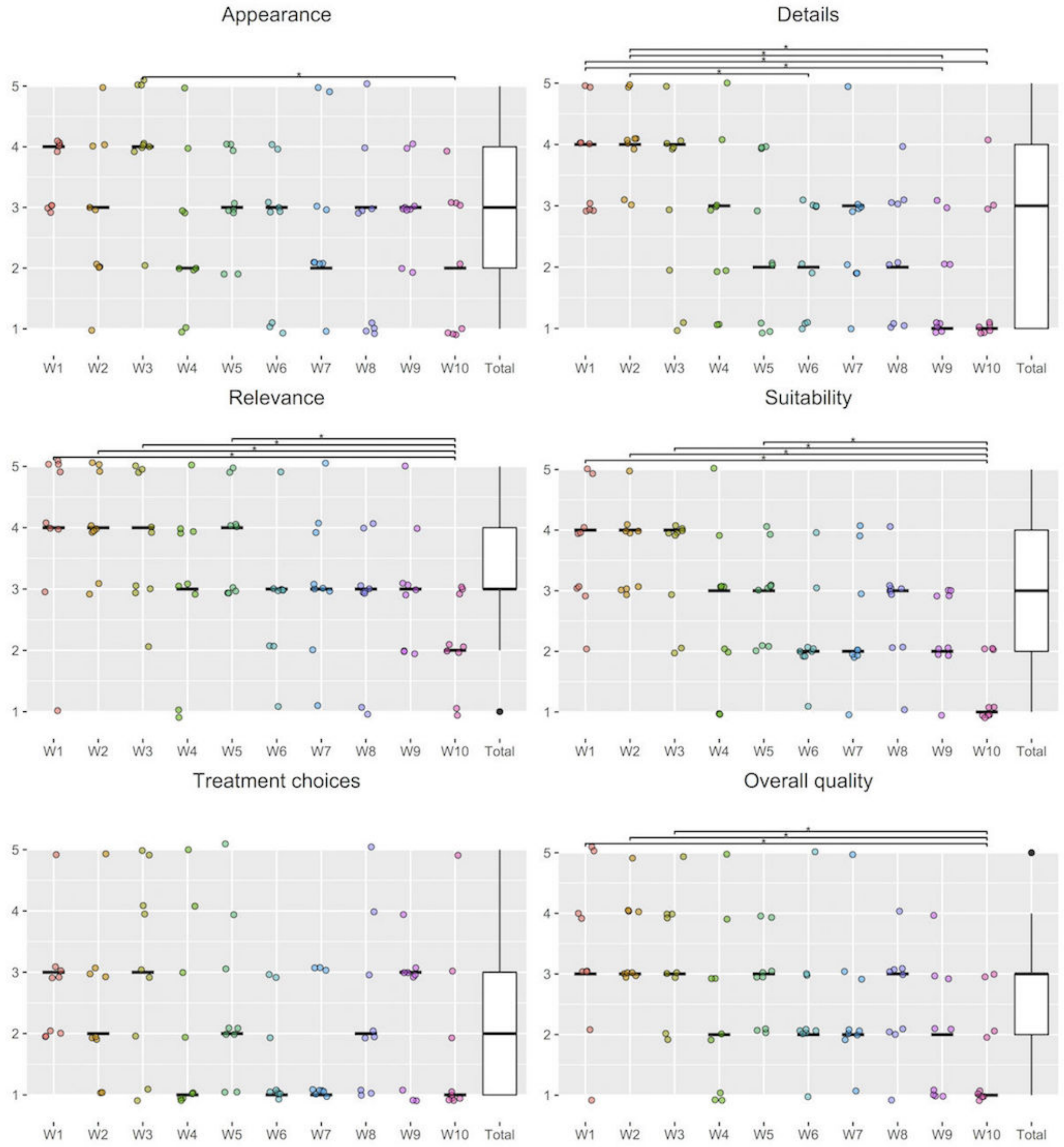


Figure 4. Distributions and medians (horizontal lines in dotplots) of the assessment scores for each of the websites included (n=10), with significant differences between websites indicated with brackets above plots. 1=low quality; 5=high quality; W=website; *$P<.05$.



Appearance

Friedman's test revealed significant differences between websites (χ^2_9=20.9, P=.01). Post hoc revealed significantly lower score for website 10 than website 3 (R=43.5, P=.008).

Details

Friedman's test revealed significant differences between websites (χ^2_9=33.7, P<.001). Post hoc revealed a significantly lower score for website 6 than websites 1 (R=38.0, P=.05) and 2 (R=39.0, P=.04), for website 9 than websites 1 (R=45.5, P<.001) and 2 (R=46.5, P=.002), and for website 10 than websites 1 (R=45.0, P=.005) and 2 (R=46, P=.003).

Relevance

Friedman's test revealed significant differences between websites (χ^2_9=28.9, P<.001). Post hoc revealed a significantly lower score for website 10 than websites 1 (R=44.5, P=.004), 2 (R=47.5, P=.002), 3 (R=39.5, P=.02), and 5 (R=37.5, P=.045).

Suitability

Friedman's test revealed significant differences between websites (χ^2_9=35.7, P<.001). Post hoc revealed significantly lower score for website 10 than websites 1 (R=54.5, P<.001), 3 (R=51.5, P<.001), and 5 (R=39.5, P<.04).

Treatment Choices

Friedman's test revealed significant differences between websites (χ^2_9=17.7, P=.04). Post hoc revealed no significant differences.

Overall Quality

Friedman's test revealed significant differences between websites (χ^2_9=28.1, P<.001). Post hoc revealed significantly lower score for website 10 than websites 1 (*R*=39.5, *P*=.03), 2 (*R*=47.0, *P*<.002), and 3 (*R*=42.0, *P*<.01).

Qualitative Results

Qualitative analysis generated six categories: (1) advertisements, (2) comprehensiveness, (3) design, (4) illustrations and pictures, (5) language, and (6) trustworthiness.

Advertisements

Advertisements made it difficult to recognize relevant information and were considered inappropriate in the context of prenatal diagnosis. When advertisements were used, the assessors regarded websites as less serious.

> *Children's party [in an advertisement]! Not really the first thing that comes to mind…It was more like that disturbed me.* [Male 3, continued pregnancy]

Comprehensiveness

Overall, medical information about the normal cardiovascular system and specific heart defects were regarded as sufficient and of good quality. Statistics, as well as information about postnatal care and quality of life, were appreciated. However, assessors pointed out a lack of information about the postnatal situation for families and inclusion of irrelevant topics. Assessors in both groups appreciated stories of previous cases, considered these to provide realistic insights into postnatal situation. However, those with terminated pregnancy pointed out a lack of stories about previous cases that terminated the pregnancy.

> *It doesn't say anything about how you would perform the surgery and nothing about other types of knowledge necessary about related subjects, how it is for the family...How will the child feel, how will it affect the parents.* [Female 5, continued pregnancy]

Information was considered belittling regarding the consequences of living with a severe heart defect, portraying an overly optimistic view of treatment and prognosis of severe defects. Balanced information about the alternatives to continue or terminate the pregnancy was considered lacking, and assessors with terminated pregnancy pointed out that there was insufficient information about induced abortions. The assessors observed that only 2 websites mentioned the possibility of terminating the pregnancy, but these were considered too simplistic and to lack relevant information about the actual process associated with induced abortion.

> *Doesn't include anything about pregnancy termination. They kind of direct the reader toward "it's just to keep going..."* [Male 2, terminated pregnancy]

Design

Clean interfaces were appreciated, with easy navigation between different subjects covered in the information. However, disorganized structures resulted in many unnecessary clicks required to continue reading, which hindered information uptake.

> *I didn't even see the information on that website because wherever you clicked you got to a new window and were transferred to another [website]. So for me, I did not even get as far as you did because I got so annoyed with the website.* [Female 1, terminated pregnancy]

Illustrations and Pictures

Clear and easy-to-read illustrations of the anatomy of the normal cardiovascular system and specific heart defects were appreciated and considered to promote information comprehension, and website quality was regarded as lower when websites lacked these tools. Assessors described other illustrations as irrelevant, unsuitable, and complex. Those with terminated pregnancy mentioned that use of pictures portraying children were inappropriate for the context of prenatal diagnosis. In contrast, those with continued pregnancy appreciated pictures of hospitalized children, as this was considered to promote realistic expectations of the postnatal situation.

> *One thing that I just don't appreciate is when you go into these [websites], and you see a picture of [a child]...Because that becomes, how would our child have looked like [...] You don't want that picture in the back of your head.* [Male 2, terminated pregnancy]

Language

Assessors appreciated websites that used understandable, easy-to-read language with comprehensible explanations and the option to read more by clicking on complex words. However, they described that websites used complex language with unnecessary medical terminology, which for them made it seem like the information was produced for health professionals rather than for laypersons.

> *Maybe a little too complicated in the text.* [Male 3, continued pregnancy]

Trustworthiness

Websites were considered trustworthy when information was updated, included references, and had specialist health professionals as authors of medical content. When one or more of these criteria were lacking, assessors raised suspicions about the information's accuracy. Websites from pharmaceutical companies were considered to be less trustworthy because of the possibility that they were profit driven. One website contained a disclaimer that the content had not been professionally reviewed, which made assessors frustrated as they considered themselves incapable of judging the accuracy. Another website had not been updated in more than a decade, which was considered a serious shortcoming.

> *One thing I reacted upon when I sat and read, when you accessed certain websites, you saw last time updated in 2002, and then it didn't feel very current.* [Male 2, terminated pregnancy]

Discussion

Principal Findings

This study aimed to explore the quality of patient information websites about congenital heart defects and to provide new insights into these sources from the perspectives of the intended consumers. To the extent of our knowledge, this study is the first to use individuals with experience of a prenatal diagnosis as assessors to explore the quality of information websites about congenital heart defects. Overall, the investigated quality criteria were quantitatively assessed as either partially or not fulfilled. Various issues were described during discussions, indicating a need for further improvement of Web-based information about congenital heart defects. The suitability was assessed as neither unsuitable nor suitable, and the assessors raised issues regarding untrustworthy information belittling regarding the consequences of living with a severe heart defect. All of these aspects are known risks with Web-based information [23].

Parents of children with congenital heart defects want information about appropriate websites in connection to a prenatal diagnosis [17,44], but a previous study suggests that few cardiologists provide these recommendations [45]. According to the assessments in this study, some websites are particularly poor choices as sources for supplemental Web-based information. For example, one website affiliated with a clinic, identified in three searches and placed high in the search rank, had significantly lower assessments across five of the six quality criteria. Combined, the quantitative and qualitative findings indicate a need for health professionals to acknowledge the existing quality deficits and varied quality of available websites and bring this subject up for discussion during consultations with individuals who plan to use it for supplemental information. These efforts are even more important in light of the reports that consumers of health information use suboptimal search strategies [28], are unsuccessful at finding satisfactory Web-based information about health-related topics [46], and rarely discuss Web-based information with health professionals [22]. However, we acknowledge that health professionals may lack the time needed to feel adequately updated about available Web-based sources [24,47] and experience challenges when consulting patients who read Web-based information [47,48]. To adequately meet these issues, there seems to be a need for systematic efforts from overarching institutions in charge of publishing such recommendations.

Our findings indicate a lack of Web-based information about pregnancy termination and a bias of information toward pregnancy continuation in websites about congenital heart defects. It is crucial that individuals faced with a prenatal diagnosis reach informed decisions on whether to continue or terminate the pregnancy. Research suggests that persons faced with a prenatal diagnosis need information about the option to terminate the pregnancy and use the Web for supplemental information [17]. However, few English websites about congenital heart defects contain this type of information, which the findings of this study also confirm for Swedish settings [41]. Preparatory information is a key aspect to quality abortion care [49], and previous studies report that patients have unanswered questions and feel unprepared for the abortion process [50-52]. It is of great concern that patients experience information about pregnancy termination as insufficient and high-blown, both from health professionals and from Web-based sources [17,50]. Moreover, previous studies indicate that websites about induced abortions contain inaccurate, misleading [53,54], unsuitable, and low-quality information [55], calling attention to the need for patients to cautiously use and interpret Web-based information about these topics. In light of our findings, health professionals must consider these aspects when consulting individuals who decide on pregnancy termination and must make efforts to ensure that patients come into contact with sufficient and relevant high-quality Web-based information. The findings illustrate the importance of coordinated informational approaches between units for fetal cardiology and fetal medicine.

The complex language and unnecessary medical terminology described by the assessors raises concerns regarding the readability of these sources. Readability levels above that recommended to the general, nonmedical audience have been observed among websites about noninvasive prenatal testing [56] and other pregnancy-related topics [57,58], echoing our findings. Illustrations are possible pedagogic tools to overcome readability issues and are especially important when offering information to individuals with low health literacy [59], that is, the degree to which individuals have the capacity to obtain, process, and understand health information [60]. Assessors appreciated clear and easy-to-read illustrations, described as beneficial to promote comprehension. However, they also pointed toward the use of complex and irrelevant illustrations, further illustrating the problems related to poor readability. In light of these findings, we recommend the use of supplemental high-quality illustrations when offering information about congenital heart defects, but efforts need to be made to ensure that they are understandable to the intended consumers and have a clear purpose. Moreover, website developers need to take steps to improve the readability of their Web-based information about congenital heart defects.

Strengths and Limitations

The strength of this study is that we used mixed-methods design [38] to quantitatively investigate a set of variables while still remaining open to other perspectives with an inductive qualitative approach [61]. Assessors with personal experience assessed the websites, with experience of both continued and terminated pregnancy following a prenatal diagnosis. Typically, studies investigating the quality of information websites about reproductive health issues use a limited number of researchers or health professionals as assessors, frequently between 1 and 4 assessors [41,53,56,62-64]. In light of the identified differences in perspectives between researchers, health professionals, and patients [35,36], we argue that by using 9 laypersons with personal experience as assessors, our study provides insight that may more closely correspond to the views and preferences of the intended consumers of the patient information.

We used both female and male assessors with experience of either continuation or termination of pregnancy, which implies that the assessments include views and preferences of laypersons with various backgrounds and experiences. However, considering the variations in severity, prognosis, and treatment of the possible heart defects that can be prenatally diagnosed today [65,66], we acknowledge that the assessment of our assessors may differ from laypersons with experiences of other prenatal diagnoses. The interrater reliability ranged between

0.18 and 0.66, with higher coefficients of concordance for assessors who shared similar pregnancy outcome. This indicates at least fair to moderate concordance between the assessors used in this study [42]. Moreover, we did not use any validated instruments to assess the websites, as these include an extensive number of items [38]. We urge a need for development of less extensive alternatives, suitable for the purpose of quality assessment that uses laypersons as assessors.

We did not collect any information concerning the literacy levels of the assessors. It is possible that their levels were above or below the population norms among the intended consumers. Consequently, we cannot make any claims regarding their literacy levels and their representativeness. The results need to be interpreted with this in mind.

We wanted the focus group discussions to reflect the topics of importance for the assessors and not be colored by our preconceptions as researchers. Thus, no discussion guide was used to guide the discussions, and the assessors were encouraged to freely discuss aspects perceived as relevant to them. We argue that this approach was an appropriate way to stay close to the perspectives of the assessors.

Swedish websites were included, an important aspect to consider in the context of prenatal diagnosis, which differs in routines and legislation between countries. However, previous assessments of English websites with a health professional or researcher as an assessor indicate that the identified problems in this study transcend various settings and are similarly perceived by professionals and laypersons [41]. It is important to bear in mind that consumers rarely search beyond the first 10 hits in searches performed in search engines [28]. Consequently, we argue that strengths of this study are that we screened the first 20 hits and performed the searches in the most commonly used search engines [39]. Moreover, 24 of the 80 screened hits were duplicates, indicating that we achieved saturation in the inclusion of available websites. The first author chose the search terms. Consequently, it is possible that these do not fully correspond to those used by the intended consumers. However, after the data collection, we asked the assessors which search terms they preferred to use when searching for patient information websites about congenital heart defects in connection to the diagnosis. The answers confirmed the used search terms (Multimedia Appendix 1), indicating adequate representativeness in relation to those search terms that are used among the intended consumers. Moreover, the first author screened the hits and decided which hits to include as patient information websites. It is possible that laypersons would include other hits.

Suggestions for Future Research

We encourage researchers to conduct studies that investigate how to improve the quality of Web-based information about congenital heart defects. Additionally, more research is needed to explore how individuals with low educational levels, individuals with low health literacy, and immigrants experience these websites.

Recommendations for Website Developers

The results indicate that website developers must ensure that sufficient information about treatment choices are included, with balanced information concerning pregnancy termination and possible consequences of living with a severe heart defect. Efforts should be taken to include statistics, as well as information about postnatal care and quality of life. If previous cases of persons faced with prenatal diagnosis are presented, make sure to include examples of cases with continued and terminated pregnancies. Clean and easily navigated designs, without advertisements, are important aspects when developing and maintaining websites. Clear and easy-to-read illustrations of the anatomy of the normal cardiovascular system and specific heart defects are desired among the intended consumers and should be included in Web-based patient information. Details should always be provided concerning references, authorship, and date of production. Website developers should strive toward continuous updates of the website and clearly state when it has been updated.

Conclusions

From the perspectives of the intended consumers, patient information websites about congenital heart defects do not fulfill quality criteria concerning information about treatment choices and only partly fulfill quality criteria concerning appearance, details, relevance, suitability, and overall quality. There are differences between existing websites, indicating variations in the Web-based landscape. The findings indicate that these websites include inappropriate advertisements, biased information, poor illustrations, complex language, and have issues with trustworthiness. Improvement is needed to meet the needs among the intended consumers for unbiased, complete, and trustworthy high-quality patient information websites. Combined, the findings suggest that existing patient information websites about congenital heart defects are, to a large extent, inadequate tools for supplemental information following a prenatal diagnosis.

When counseling expectant parents faced with a prenatal diagnosis of congenital heart defect in the fetus, we encourage health professionals to initiate discussions about their intentions to use the Web. Professionals should inform these persons about the varied quality in the Web-based landscape and offer recommendations for appropriate websites that include unbiased high-quality supplemental information. We encourage website developers to avoid (1) using inappropriate advertisements and pictures, (2) publishing information that the intended consumers may consider belittling regarding the impact of living with a severe heart defect, and (3) using complex illustrations without a clear purpose. Furthermore, we encourage them to (1) include information about pregnancy termination, (2) write information in a readable and understandable language, without the use of unnecessary medical terminology, (3) include stories from persons with lived experience of continuation and termination of pregnancy, (4) continuously update their websites with accurate information written by specialist health professionals, and (4) include a list of references.

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Authors' Contributions

TC, UMM, and EM conceived and designed the study. TC and UMM collected the data. TC analyzed the data and wrote the first draft of the manuscript. UMM, BW, GB, OA, and EM read the draft and provided comments for purposes of revision. All authors approved the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Number of words reported more than one time in search terms preferred by the assessors.

[PDF File (Adobe PDF File), 31KB - ijmr_v6i2e15_app1.pdf]

Multimedia Appendix 2

Search rank order and outcome of the screened hits.

[JPG File, 1MB - ijmr_v6i2e15_app2.jpg]

Multimedia Appendix 3

Affiliation, number of searches where identified, and search ranks for each included website.

[PDF File (Adobe PDF File), 34KB - ijmr_v6i2e15_app3.pdf]

Multimedia Appendix 4

Characteristics of the assessors with continued (n=4) and terminated (n=5) pregnancy.

[PDF File (Adobe PDF File), 48KB - ijmr_v6i2e15_app4.pdf]

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Viewpoint

Social Media and Multiple Sclerosis in the Posttruth Age

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Abstract

Over the last few decades, patients have increasingly been searching for health information on the Internet. This aspect of information seeking is really important, especially for people affected by chronic pathologies and require lifelong treatment and management. These people are usually very well informed about the disease, but are nonetheless vulnerable to hopes of being cured or saved, often amplified by misinformation, myths, legends, and therapies that are not always scientifically proven. Many studies suggest that some individuals prefer to rely on the Internet as their main source of information, often hindering the patient-doctor relationship. This is why a professional approach is imperative in this posttruth age, in order to maintain confidentiality, honesty, and trust in the medical profession.

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KEYWORDS

social media; multiple sclerosis; social network; digital health; eHealth; Web medicine

Background

Many patients with multiple sclerosis (MS) have expressed a need for more information and support [1,2]. The Internet is now an important source of health and medical information and its accessibility often makes it the first step in obtaining information about diseases and their treatment. Patients with MS, their families, and/or caregivers use the Web in everyday life as a source of medical information and to interact with others who are living with the same condition [3-5]. The Web can also be a source of comfort and support through the exchange of experiences, opinions, and emotions [6]. Patients and caregivers can find a wide range of opportunities for peer interactions and learning online. However, we need to differentiate between the various levels of validity and objectivity of the information that they might find online.

A group of neurologists, psychologists, anthropologists, science journalists, and legal authorities met in Naples, Italy, in November 2016 during the *Social Media and Multiple Sclerosis (SMMS): Communities of Practice* meeting. They discussed Internet usage by MS patients seeking health- and disease-related information for self-care and self-management purposes in the "posttruth" age. In this paper, we stress the need to provide patients and their caregivers with tools for prudent and productive Web navigating [7] and ensure that they can find and share valid information through their social media interactions.

Entering a few keywords into a search engine returns a huge number of hits; however, it is critical that patients and caregivers be able to recognize information that is potentially incorrect or only partially correct. The ranking that a search engine assigns to search results is determined by algorithms inherent to the program and may be based on the number of site interactions or the number of times that a site is linked or referenced. Thus, the choice of a Web search engine also influences the retrieved results [8].

Internet users should know that there are people or groups interested in spreading information that is not based on scientific evidence. Users should also be able to recognize links to sponsored content. Moreover, they should understand that queries made through a search engine are not as "independent" as they might think: results are influenced by stored information about previous searches performed on the computer. Authoritative information sources are preferred, such as scientific foundations and national and international scientific societies.

An early assessment of the quality of online medical information conducted in 1997 on pediatric fever revealed that only one in 10 websites provided complete and completely accurate information [9]. Subsequently, criteria were proposed to standardize the assessment of websites. Two types of criteria were considered: direct and surrogate. Direct criteria, the gold standard for assessing quality, include determining the accuracy and completeness of the information by experts. However, this type of verification is difficult to obtain because it involves expert intervention. Surrogate criteria are characteristics that tend to be associated with high-quality information. These include identifying the website owners and sponsors, providing dates for when the information was updated, supporting the information with bibliographic references to literature published in peer-reviewed medical journals, identifying the authors as medical professionals and indicating their affiliations, disclosing any conflicts of interest, and providing links to the websites of disease-related medical or scientific associations [10]; for example, websites could apply the publishing benchmarks from the Journal of the American Medical Association, which consider authorship, date of most recent update, references, and disclosure of conflicts of interest [11].

Meanwhile, several organizations provide website logos, badges, or "seals of approval" to be displayed only on websites that meet specific criteria [12]. The first organization to provide such a service was the nonprofit Health On the Net (HON) Foundation, established in 1995 to promote reliable online health information and to protect citizens from misleading health information [13]. The HON criteria are summarized in their code of conduct (see Textbox 1). Their website provides information and services that are tailored to patients, caregivers, medical professionals, or website developers.

In addition, the HON website provides an Internet search portal—HON Search—through which it is possible to focus search results on medical information that meets quality criteria. This can significantly improve search effectiveness by excluding advertisements and nonrelated websites from the search results. Results can be further filtered for interest to patients and caregivers or to medical professionals. Such guidance may help information seekers avoid some of the pitfalls of searches.

Another important initiative in this area is the DISCERN Project, which is based at the University of Oxford, Division of Public Health and Primary Health Care, Institute of Health Sciences [14]. Project members developed the DISCERN tool [15], which comprises guidelines for analyzing information on treatment choices that are applicable to a wide range of topics by users at many levels (see Textbox 2). The tool provides an index of the quality of medical information that is useful for patients and caregivers, as well as providing guidance to website content developers. The DISCERN website contains a reference guide that should only be used once one is acquainted with the full DISCERN instrument.

We have summarized the minimal requirements of a medical/scientific website into the following schema (see Textbox 3) and suggest that this information should be provided to MS patients and their caregivers.

We also suggest that the patient or caregiver be informed about the existence of HON and the DISCERN initiatives and be encouraged to use these services.

Textbox 1. Summary of the eight components of the Health On the Net Code of Conduct: criteria for obtaining website certification.

1. Authority: indicate the qualification of the authors.
2. Complementarity: information should support, not replace, the doctor-patient relationship.
3. Confidentiality: respect the privacy and confidentiality of personal data submitted to the site by the visitor.
4. Attribution: cite the source(s) of published information, date, and medical and health pages.
5. Justification: site must back up claims relating to benefits and performance.
6. Professionalism: accessible presentation and accurate email contact.
7. Transparency of financing: identify funding resources.
8. Advertising: clearly distinguish advertising from editorial content.

Textbox 2. DISCERN Project: summary of characteristics associated with good-quality information about treatment choices.

A good-quality publication about treatment choices will do the following:

- Have explicit aims
- Achieve its aims
- Be relevant to consumers
- Make sources of information explicit
- Make date of information explicit
- Be balanced and unbiased
- List additional sources of information
- Refer to areas of uncertainty
- Describe how treatment works
- Describe the benefits of treatment
- Describe the risks of treatment
- Describe what would happen without treatment
- Describe the effects of treatment choices on overall quality of life
- Make it clear there may be more than one possible treatment choice
- Provide support for shared decision-making

Textbox 3. Minimal requirements of a medical/scientific website.

A medical/scientific website must do the following:

- Use the correct vocabulary, be clear, and be easily understandable
- Clearly identify its managers and sponsors
- Have an editorial board responsible for scientific content
- Provide bibliographic support for all news published so that personal opinion—even from an expert—is clearly discernible from peer-reviewed scientific literature
- Clearly distinguish sponsored content
- Indicate when its content was last updated so the visitor knows if it is outdated
- Clearly state their privacy policy

Social Media as a Support Tool for People With Multiple Sclerosis and Their Caregivers

An online community or support group allows exchange of experiences and information among group members that may be helpful to patients and caregivers [16-18]. Online communities are characterized by communication that can be synchronous (eg, instant message, chat, and video chat) or asynchronous (eg, forums and blogs). Both forms of communication can be used to give and receive support and to interact with people who are sharing the same life experiences. Social media can also serve as a research tool to collect anonymous information for studying many aspects of the MS patient's journey [19,20].

We have collected some of the features found in online communities that can be instrumental for meeting the need for support and interaction that a person living with MS may be experiencing:

1. Public profiles. Communities with open profiles that are visible to everyone help users to find each other easily and to share personal information and experiences related to MS.
2. Messages. Communities that allow exchange of different types of messages meet the diverse needs of people with MS:
    a. Connections among individual users (ie, chat)
    b. Messages among established contacts (ie, contact lists, friend requests, and private messages)
    c. Peer counseling (ie, people with MS who volunteer their time to help others with MS)
3. Forum. These are forms of asynchronous interaction and communication that must be moderated to prevent abuses; moderation also serves to avoid the spread of incorrect information. Patients should be encouraged to frequent forums that are moderated by health care professionals.

The following are suggestions for critical reading of content and participation in online discussions in a community, blog, or forum:

The community website must have clear rules of conduct. Each member must carefully read and follow the rules of the community, blog, or forum. To protect the interests of the community members, administrators must deny access to users with interests different from those of the group (ie, spam, advertising, misinformation, or irrelevant information). The presence of moderators in a community should ensure that all members follow the rules. Channels should exist for reporting inappropriate behavior.

Privacy must be protected. Members of the community, blog, or forum should have the option to remain anonymous or share only the personal information they deem appropriate; it is important to remind patients that many threads and posts are open.

The website must share only validated content. Confirm that the content is supported by bibliographic references to scientific evidence that was produced under expert supervision and that the content is updated regularly.

Comments and posts by individuals can provide useful impetus, but it is important that users realize that the personal experiences of others may not apply to their specific situations. They must be able to confirm the information with authoritative sources and discuss it with their physician. Information about MS treatment discussed online may refer to solutions that have not been approved by the regulatory agencies in a patient’s homeland. Patients and caregivers should be encouraged to consult the website of the national MS organization for official information on drugs approved for MS in their country. In addition, they should ask their physician when questions arise. Moreover, it is important to stress at the outset that the relationship between the patient and the clinician is essential for all aspects of diagnosis and clinical management. Online support groups are not a substitute for direct interaction with the clinician. A survey of 8586 patients with MS revealed that, whereas the first source of information for most patients is the Internet, the vast majority of patients with MS still consider their physician to be the most trusted source for medical information [21]. Given the risks associated with improper treatment of MS, health professionals should take measures to ensure that their patients are prepared and equipped to navigate the eHealth world safely.

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Conflicts of Interest

None declared.

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Abbreviations

HON: Health On the Net
MS: multiple sclerosis
SMMS: Social Media and Multiple Sclerosis

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Original Paper

Alzheimer's Disease in Social Media: Content Analysis of YouTube Videos

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Abstract

Background: Approximately 5.5 million Americans are living with Alzheimer's disease (AD) in 2017. YouTube is a popular platform for disseminating health information; however, little is known about messages specifically regarding AD that are being communicated through YouTube.

Objective: This study aims to examine video characteristics, content, speaker characteristics, and mobilizing information (cues to action) of YouTube videos focused on AD.

Methods: Videos uploaded to YouTube from 2013 to 2015 were searched with the term "Alzheimer's disease" on April 30th, 2016. Two coders viewed the videos and coded video characteristics (the date when a video was posted, Uniform Resource Locator, video length, audience engagement, format, author), content, speaker characteristics (sex, race, age), and mobilizing information. Descriptive statistics were used to examine video characteristics, content, audience engagement (number of views), speaker appearances in the video, and mobilizing information. Associations between variables were examined using Chi-square and Fisher's exact tests.

Results: Among the 271 videos retrieved, 25.5% (69/271) were posted by nonprofit organizations or universities. Informal presentations comprised 25.8% (70/271) of all videos. Although AD symptoms (83/271, 30.6%), causes of AD (80/271, 29.5%), and treatment (76/271, 28.0%) were commonly addressed, quality of life of people with AD (34/271, 12.5%) had more views than those more commonly-covered content areas. Most videos featured white speakers (168/187, 89.8%) who were adults aged 20 years to their early 60s (164/187, 87.7%). Only 36.9% (100/271) of videos included mobilizing information. Videos about AD symptoms were significantly less likely to include mobilizing information compared to videos without AD symptoms (23/83, 27.7% vs 77/188, 41.0% respectively; P=.03).

Conclusions: This study contributes new knowledge regarding AD messages delivered through YouTube. Findings of the current study highlight a potential gap between available information and viewers' interests. YouTube videos on AD could be beneficial if the messages delivered meet users' needs and provide mobilizing information for further resources. Study findings will be useful to government agencies, researchers, nonprofit organizations that promote information about AD, and those responsible for social media to provide useful and accurate health information for the public.

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KEYWORDS

Alzheimer's disease; YouTube; videos; content analysis

Introduction

In 2017, approximately 5.5 million Americans are living with Alzheimer's disease (AD) and nearly 16 million family members and friends provide over 18 billion hours of unpaid care to those with AD and related dementias [1]. AD is a degenerative brain disease and the most common form of dementia [1,2]. Symptoms of AD can include: difficulty remembering, speaking, swallowing, or walking; apathy; depression; impaired communication; disorientation; confusion; poor judgment; and behavior changes [1]. The common risk factors for AD are older age, having a family history of the disease, and carrying the APOE- 4 gene [3-5]. Projections suggest that as baby boomers continue to age, by 2050 the incidence of AD, economic costs, and caregiver demands related to AD will increase exponentially [1].

Research on messages related to aging, cognitive health, and AD initially focused on traditional media, such as magazines, television news, and newspapers [6-8]. Although media coverage of cognitive health appears to have increased over time, the rise is not commensurate with growing scientific evidence that certain health behaviors can help maintain cognitive health [6]. For example, there is strong evidence that regular physical activity, management of cardiovascular risk factors, a healthy diet, and lifelong learning/cognitive training may reduce the risk of cognitive decline [1,9-10]; however, coverage of physical activity and cardiovascular risk factors in popular media is limited [6]. The recent rise of social media usage creates a new platform for the dissemination of this type of health information to large audiences. Emerging research has examined the impact of social media (specifically Facebook and Twitter) on health issues such as AD, diabetes, hypertension, and cancer [11-17]. YouTube, one of the most popular social media platforms on the Web with over one billion users, allows both individuals and organizations to distribute, search for, watch, share, and comment on user-generated video content [18]. Previous studies have examined messages communicated through YouTube on topics including diabetes, myocardial infarction, Ebola, prostate cancer, anorexia, and organ donation [19-24]; however, less is known about the messages related to AD delivered on the platform. While analyses of AD content in traditional media and on more static websites have been conducted [6-8], this study is the first to examine AD information specifically on YouTube. The following three research questions (RQs) were proposed to explore the characteristics and content of YouTube videos related to AD:

> RQ1: What are the characteristics (ie, format, source) of YouTube videos about AD?
>
> RQ2: What content about AD is presented in YouTube videos?
>
> RQ3: What types of YouTube videos about AD are viewed most often by audiences?

In 2013, the Alzheimer's Association and Centers for Disease Control and Prevention (CDC) published *The Healthy Brain Initiative: The Public Health Road Map for State and National Partners* (hereafter referred to as the Public Health Road Map) [25]. This Road Map provides guidance for state and local public health agencies and partners in several public health domains: monitor and evaluate, educate and empower, develop policy and mobilize partnerships, and assure a competent workforce [25]. This document also serves as a directive for researchers as they strive to connect their work to the public sphere. RQs 4 and 5 below are guided by two Road Map action items of the *educate and empower* domain: identify culturally appropriate strategies (E01) and provide links to accurate websites about AD (E03). AD prevalence varies by race. Older African Americans and Hispanics have a higher incidence of AD compared with older whites [1]; however, less is known about whether YouTube provides culturally appropriate AD messages for different ethnic groups.

> RQ4: What are the characteristics of speakers appearing in YouTube videos about AD?
>
> RQ5: Do YouTube videos about AD include mobilizing information (ie, website Uniform Resource Locators [URLs], physical addresses, and phone numbers)?

Methods

Sample

This content analysis focused on videos posted on YouTube after the release of the Public Health Road Map [25]. We searched YouTube using the term "Alzheimer's Disease" on April 30th, 2016. We included all videos uploaded between January 1st, 2013 and December 31st, 2015. If a video with the same title or a slightly different title with identical content appeared multiple times, the video was counted as one case and only the earliest video was included. Once duplicates were removed, a total of 478 videos remained. Videos were excluded if they were not in English, lacked an audio component, were longer than 10 minutes, were portions of major motion pictures, or had technical problems (eg, interrupted audio, unclear sound). A total of 271 videos were included for coding and analysis.

Variable Coding

The codebook for this analysis was adapted from a previous analysis of YouTube videos on organ donation [26]. Variables included in the codebook were also guided by the RQs and action items from the Public Health Road Map [25].

Video Characteristics

To answer RQs 1 and 3, the date when a video was posted, URL, video length, and number of views, likes, and dislikes were coded first at the time of capture. After viewing the videos, variables were coded as having a specific characteristic if it was mentioned or appeared at least once. The format of a video may influence whether people view it, like it, and how messages are delivered through it [27]. We categorized video formats into *public service announcement* (PSA), *testimonial*, *news story and interview*, *nonnews interview*, *formal presentation*, *informal presentation*, and *others*. Videos recording a caregiver's experience or care recipient's life were coded as a *testimonial*. *News story and interview* refers to videos that are journalistic-style or broadcast on a news program. Interviews conducted in a studio like "Good Morning America" were also coded as *news story and interview.Nonnews interviews* were videos made professionally, but not journalistic in nature, regardless of the appearance of interviewers. Videos in which researchers presented their research findings or informed knowledge about AD formally with slides or at an event (eg, conference, forum, webinar) were coded as a *formal presentation*. Other presentations or informative speeches made by laypersons, students, or those with a computerized voice were coded as an *informal presentation*.

Authorship was defined by "Who posted the video," which was determined by the user name under the video, and was categorized into individual researcher/health professional, government agency, layperson, nonprofit organization or university, for-profit company or organization, news source (eg, CNN or Fox News), and others that could not be categorized. The type of author was examined by the authors' profile pages on YouTube. If needed, we searched online for the organization/company name.

Video Content

To answer RQ2, video content was categorized into AD awareness, causes of AD, AD symptoms, protective and risk factors, treatment, screening/diagnosis, quality of life of people with AD, caregiving experience, resources of support, clinical trial research, and others.

Speaker Characteristics

To answer RQ4, characteristics of speakers that appeared in the videos were coded. A speaker was defined as a person who was shown onscreen and who spoke at least once. Characteristics of each speaker included sex (male, female), race (white, African American, Asian/Pacific Islander, Hispanic, other), age group (adult, aged 20 years to early 60s; older adult, aged 65 years or older), and role. The role of each speaker was identified by his/her title and self-introduction, including people with AD, informal caregivers (eg, family members, friends), journalists or interviewers (eg, reporters, talk show hosts), organization representatives (eg, volunteers, staff), healthcare professionals (eg, physicians, nurses, specialists), actors, researchers, and others (including those unknown/unclear from the video). When a person's voice was heard in the video, but he/she was not seen, the person was considered a voiceover instead of a speaker.

Mobilizing Information

Mobilizing information is defined as a particular type of information that permits citizen action [28]. Mobilizing information includes: names, addresses, and phone numbers of sources; titles of documents; specific dates; places of meetings; and website links that can direct the audience to additional resources. To answer RQ5, we examined whether a video included website URLs, physical addresses, or phone numbers for more information.

Interrater Reliability

Two authors (WT, KO) independently viewed and coded the same 20% random sample of the videos (56/271) to determine interrater reliability. The Cohen's kappa statistic, which measures interrater agreement of categorical variables between two coders [29], was calculated for all variables. Interrater reliability for all variables ranged from .736 to .964, indicating *almost perfect* coder agreement [30]. One of the coders (WT) finished coding the remainder of the videos.

Analysis

We analyzed data using SPSS 19.0 (IBM Statistics for Windows, Armonk, New York). Nonparametric frequencies and percentages were calculated for all variables. Associations between video characteristics and content, and between video characteristics and mobilizing information, were examined with Chi-square tests or Fisher's exact tests. The level of significance was set to $P<.05$.

Results

Of the 271 videos included in the study, 249 videos were uploaded in 2015, 17 were uploaded in 2014, and 5 were uploaded in 2013. The number of views at the time of data collection ranged from 2 to 431,079, with a mean of 9,876.9 and a median of 166.0. Both mean and median length of videos were approximately 3 minutes.

RQ1: Video Characteristics

Video Format

Informal presentations comprised 25.8% (70/271) of all videos, followed by nonnews interviews (52/271, 19.2%), news stories and interviews (50/271, 18.5%), formal presentations (26/271, 9.6%), testimonials (20/271, 7.4%), and PSAs (15/271, 5.5%). Other types of videos were mostly cartoon episodes (Table 1).

Table 1. Video characteristics, content, and speaker's characteristics of videos related to Alzheimer's disease on YouTube.

Variables	n (%)
Video Characteristics[a]	
Video Format	
Informal presentation	70 (25.8)
Nonnews interview	52 (19.2)
News story and interview	50 (18.5)
Formal presentation	26 (9.6)
Testimonial	20 (7.4)
Public service announcement	15 (5.5)
Other	38 (14.0)
Video Authorship	
Nonprofit organization/university	69 (25.5)
Layperson	57 (21.0)
For-profit organization/company	51 (18.8)
News source	39 (14.4)
Researcher	9 (3.3)
Government agency	5 (1.8)
Others	41 (15.1)
Video Content[a,b]	
AD symptoms	83 (30.6)
Causes of AD	80 (29.5)
Treatment	76 (28.0)
Protective and risk factors	50 (18.5)
AD awareness	45 (16.6)
Resources of support	41 (15.1)
Caregiving experience	35 (12.9)
Quality of life of people with AD	34 (12.5)
Screening/diagnosis	33 (12.2)
Clinical trials	32 (11.8)
Others	41 (15.1)
Speaker Characteristics[c]	
Sex	
Female	124 (66.3)
Male	126 (67.4)
Age Group	
Adult (aged 20 years to early 60s)	164 (87.7)
Older adult (aged 65 years or older)	55 (29.4)
Race	
White	168 (89.8)
African American	11 (5.9)
Asian/Pacific Islander	10 (5.3)
Other	12 (6.4)

Variables			n (%)
	Speaker Role		
		Researcher	72 (38.5)
		Informal caregiver	43 (23.0)
		Journalist/interviewer	43 (23.0)
		Healthcare professional	42 (22.5)
		Organization representative	39 (20.9)
		Individual with AD	23 (12.3)
		Actor	7 (3.7)
		Other	24 (12.8)

[a] Percentage was calculated for 271 videos

[b] Sum may not be 100%, because more than one content area was often covered in a video

[c] One video may include more than one speaker; each speaker was coded separately for his/her sex, race, age group, and role; percentage was calculated for 187 videos with speakers

Video Authorship

Approximately 25% of videos (69/271) were posted by nonprofit organizations or universities such as Emory University (11/69), the Alzheimer's Association (National: 5/69; Chapters: 3/69), and Alzheimer's Disease International (6/69). Laypersons posted 21.0% of videos (57/271). Fewer videos were posted by for-profit organizations or companies (51/271, 18.8%,), news sources (39/271, 14.4%), individual researchers (9/271, 3.3%), government agencies (5/271, 1.8%), and others (41/271, 15.1%; Table 1). Video format differed according to video authorship. News sources mainly posted news stories and interviews (33/39, 84.6%); 60.0% (3/5) of videos posted by government agencies were formal presentations; and 46.4% (32/69) of videos that nonprofit organizations or universities posted were nonnews interviews (*P*<.001, Fisher's exact test).

RQ2: Video Content

The most common focus of the videos was AD symptoms (83/271, 30.6%). Changes in behavior, thinking, personality, and mood were presented as common symptoms of AD. Almost one third of videos (80/271, 29.5%) presented causes of AD such as beta amyloid accumulation, plaque formation, and tangles. AD treatment, including therapies and programs aimed at helping people with AD stay physically, mentally, and socially active, were introduced in 28.0% of videos (76/271). Approximately 18.5% of videos (50/271) presented protective (eg, regular physical activity, healthy diets) or risk (eg, high level of stress, low level of vitamin D) factors (Table 1). Approximately 26.6% (72/271) of the videos presented caregiving-related information. Among those videos about caregiving, 66.7% (48/72) included challenges that caregivers may face (future plan, financial burden, searching for missing care recipients) and 43.1% (31/72) included available resources for caregivers (organizations that provides information, caregiver support groups and programs). Half of the videos about caregiving provided information on instrumental support, including financial resources and caregiving skills (36/72, 50.0%); 29 videos (29/72, 40.3%) described psychological perspectives (distress facing care recipients' symptoms, worry about genetic predisposition to AD) and 27 videos (27/72, 37.5%) were about social support (help and support from organizations, friends, family members, and other caregivers; social activities). Only 4 caregiving videos (4/72, 5.6%) presented physical needs of caregivers. Table 2 provides detailed information on video content with specific examples.

We examined the association between video content and format. Significantly higher percentages of formal presentations (13/26, 50.0%) and informal presentations (34/70, 48.6%) included causes of AD, compared with news stories and interviews (13/50, 26.0%), nonnews interviews (13/52, 25.0%), and other formats (7/38, 18.4%; χ^2=35.2, degrees of freedom [df]=6; *P*<.001). Similarly, AD symptoms were addressed significantly more often in informal presentations (31/70, 44.3%) and formal presentations (10/26, 38.5%) compared with other video formats (χ^2=16.1, df=6; *P*=.01). PSAs were significantly more likely to include resources of support (6/15, 40.0%) compared with testimonials (5/20, 25.0%), news stories and interviews (12/50, 24.0%), formal presentations (4/26, 15.4%), nonnews interviews (6/52, 11.5%), and other formats (7/38, 18.4%; *P*<.001, Fisher's exact test).

Table 2. Content of videos related AD on YouTube.

Content	Examples
AD awareness	Facts about AD (prevalence, cost of caring annually), support for AD-related research, fundraising, dignity in mental health, stigma about AD
Cause of AD	Proteins in brain, beta amyloid accumulation, tau protein accumulation, tangles, plaque formation, genetic risk factors (APOE- 4)
AD symptoms	10 early signs and symptoms of Alzheimer's by Alzheimer's Association; changes in thinking, behavior, personality, and mood; decline in the sense of smell
Protective factors	Regular physical activity, heart health, healthy diets
Risk factors	High level of stress, low level of vitamin D
Screening/diagnosis	Importance of early identification, memory test, cognitive test, magnetic resonance imaging scan of brain, positron emission tomography–computed tomography blood test, biomarkers
Treatment	Programs aimed at helping people with AD communicate with partners; stay active physically, mentally, and socially; new and promising drugs with positive testing results; treatments available for symptoms
Quality of life of people with AD	Personal stories about early symptoms, diagnosis, and experience of AD; simulation of AD experience
Caregiving experience	Daily tasks, emotions, and feelings (scared, sad, cry) of caregivers
Resources of support	Introduction of support programs and research centers, resources for caregivers, social activity, and campaigns such as "Walk to End Alzheimer's"
Clinical trials	Research studies with mice models investigating causes of AD, risk factors, treatment, and comparison of the brain of AD to the one without AD
Other	Graduate students' introduction about their research topics and why they entered the field, faith related (bible code, deliverance), history of discovering AD, evaluating accuracy of information in a movie
Caregiving-related information	
Challenges	Future plan, financial burden, searching for missing care recipients
Available resources	Organizations that provide information, caregiver support groups and programs
Support	Instrumental support (financial resources, caregiving skills); psychological support (distress facing care recipients' symptoms, worry about genetic predisposition to AD); social support (help and support from organizations, friends, family members, and other caregivers; social activities)

We also examined the association between video content and authorship. Videos from news sources (9/39, 23.1%) and laypersons (12/57, 21.1%) were significantly more likely to discuss the quality of life of people with AD than for-profit companies (7/51, 13.7%), nonprofit organizations or universities (5/69, 7.2%), or other sources (1/41, 2.4%; *P*=.02, Fisher's exact test). Other video content was not significantly associated with authorship (data not shown).

RQ3: Audience Engagement

Videos posted earlier on YouTube had more views than those posted later; however, the majority of videos analyzed were posted in 2015 (249/271, 91.9%). There were no significant differences regarding video characteristics or content across the three years examined. YouTube users viewed testimonials most often compared to other format types, with a mean number of 41,916 views. Quality of life of people with AD, caregiving experience, causes of AD, treatment, and AD symptoms were the main content areas that ranked highly in mean number of views. In terms of authorship, videos posted by news sources (mean number of views per video=11,774.7) were viewed the most, followed by nonprofit organizations or universities (mean=10,100.5) and laypersons (mean=7239.0; Table 3). Most YouTube viewers of the videos analyzed did not click on *like* or *dislike*. For most of the videos, the number of likes was less than 5% of the total number of views (266/271, 98.2%; data not shown). Over half of the videos did not have any dislikes (201/271, 74.2%). In an ad hoc analysis, the number of comments for each video was coded in August 2017. There were 3020 comments left by users for a total of 239 videos (range=0-716, mean=12.6; comments were disabled for 12 videos; 20 videos were not available for viewing at the time of coding). Videos posted by others (authors could not be categorized) received the highest number of comments (mean=47.6), followed by laypersons (mean=17.6), researchers/health professionals (mean=6.4), nonprofit organizations (mean=6.4), and news sources (mean=4.7). Videos with content regarding quality of life of individuals with AD received the highest number of comments (mean=31.0).

Table 3. Audience engagement by video characteristics.

Video Characteristics	Views		Range	
	Mean	Total	Minimum	Maximum
Video format				
Testimonial (n=20)	41,916.2	838,324	31	431,079
Public service announcement (n=15)	28,306.5	424,597	9	170,984
Formal presentation (n=26)	8286.6	215,451	12	118,245
Informal presentation (n=70)	4840.2	338,815	12	271,076
Nonnews interview (n=52)	3468.1	180,343	8	37,920
News story and interview (n=50)	989.3	49,465	8	17,514
Other (n=38)	16,569.4	629,637	2	399,971
Video content				
Quality of life of people with AD (n=34)	29,739.2	1,011,134	8	431,079
Caregiving (n=35)	18,121.3	634,245	8	431,079
Causes of AD (n=80)	13,845.8	1,107,662	12	399,971
Treatment (n=76)	8715.4	662,372	12	399,971
AD symptoms (n=83)	8321.6	690,691	8	399,971
Resources of support (n=41)	7606.6	311,870	2	123,340
AD awareness (n=45)	6639.1	298,760	8	123,340
Protective and risk factor (n=50)	1782.1	89,106	13	15,155
Screening/diagnosis (n=33)	985.6	32,526	12	13,696
Clinical trials (n=32)	857.2	27,431	17	17,514
Others (n=41)	12,073.1	494,998	2	271,076
Authorship				
News source (n=39)	11,774.7	459,213	8	431,079
Nonprofit organization/university (n=69)	10,100.5	696,933	8	170,984
Layperson (n=57)	7239.0	412,622	12	382,509
Profit organization (n=51)	3200.9	163,245	15	38,962
Researcher/health professional (n=9)	1886.1	16,975	12	15,155
Government agency (n=5)	1065.0	5325	21	1912
Others (n=41)	22,495.6	922,319	2	399,971

RQ4: Speaker Characteristics

There were 84 videos (84/271, 31.0%) without a speaker, which only had voiceovers. Among the videos with at least one speaker (187/271), male and female speakers were equally likely to appear in the videos (126/187, 67.4% male; 124/187, 66.3% female, respectively). Most videos featured white speakers (168/187, 89.8%) who were adults aged 20 years to their early 60s (164/187, 87.7%). Researchers appeared in the videos most often (72/187, 38.5%), followed by informal caregivers (43/187, 23.0%), journalists or interviewers (43/187, 23.0%), healthcare professionals (42/187, 22.5%), organization representatives (39/187, 20.9%), people with AD (23/187, 12.3%), and actors (7/187, 3.7%). Other speaker roles (24/187, 12.8%) included students, celebrities, congressmen, and those who did not introduce themselves (Table 1).

RQ5: Mobilizing Information

All videos failed to include a physical address (271/271, 100.0%) and 91.9% (249/271) of videos did not include phone number for viewers to locate additional information. Approximately 36.9% (100/271) of videos included a website URL. These links were often to *.com* (45/100) and *.org* (38/100) websites. Only 4 videos had a *.gov* URL. Video authorship was significantly associated with the presence of mobilizing information. More videos posted by nonprofit organization or university (35/69, 50.7%), for-profit organization or company (25/51, 49.0%), researcher/health professional (4/9, 44.4%), and government agencies (2/5, 40.0%) included a website URL compared with those posted by news sources (9/39, 23.1%), laypersons (11/57, 19.3%), and others (14/41, 34.1%; *P*=.002, Fisher's exact test; Table 4).

Table 4. Mobilizing information by authorship and video content (AD symptoms, resources of support).

	Videos with mobilizing information, n=100 n (%)	Videos without mobilizing information, n=171 n (%)	χ^2	Degrees of freedom	P-value
Authorship[a]			-	-	.002
Nonprofit organization/university	35 (50.7)	34 (49.3)			
For-profit organization/company	25 (49.0)	26 (51.0)			
Layperson	11 (19.3)	46 (80.7)			
News source	9 (23.1)	30 (76.9)			
Researcher/health professional	4 (44.4)	5 (55.6)			
Government agency	2 (40.0)	3 (60.0)			
Others	14 (34.2)	27 (65.8)			
Video content[b]					
AD Symptoms			4.3	1	.03
Yes	23 (27.7)	60 (72.3)			
No	77 (41.0)	111 (59.0)			
Resources of Support			23.7	1	<.001
Yes	29 (70.7)	12 (29.3)			
No	71 (30.9)	159 (69.1)			

[a] Fisher's exact test

[b] Associations between presence of mobilizing information and all other video content topics not presented here were not significant

We examined the relationship between mobilizing information and video content and found that videos focusing on providing resources of support were significantly more likely to include a website URL than videos that did not focus on resources of support (29/41, 70.7% vs 71/230, 30.9% respectively; χ^2=23.7, df=1; *P*<.001). Videos about AD symptoms were significantly less likely to include mobilizing information compared to videos without AD symptoms (23/83, 27.7% vs 77/188, 41.0% respectively; χ^2=4.3, df=1; *P*=.03). Videos focusing on other content categories were not associated with the presence of mobilizing information.

Discussion

Guided by action items from the Public Health Road Map [25], the current study examined the characteristics and content of messages about AD delivered through social media based on 271 videos uploaded to YouTube between 2013 and 2015. Findings of this study demonstrated that most videos included multiple content areas, with AD symptoms, causes of AD, and treatment being commonly addressed. However, videos with these frequently covered contents had fewer mean numbers of views than those videos focusing on quality of life and caregiving. Speakers featured in these videos were mostly white adults from the ages of 20 years to their early 60s. Less than half of the videos included mobilizing information.

The majority of videos analyzed were posted in 2015. Several reasons are possible for this result. First, much attention was paid to AD and dementia between late 2014 and 2015. For example, the 2015 government spending package, known as the *cromnibus*, included an increase of US $25 million for the National Institute on Aging, with an expectation that much of the funding would support additional research on AD and dementia. This funding may have influenced media coverage about AD and encouraged others to post videos online about AD. Another reason for more video postings in 2015 may be that older videos (published prior to 2015) may have become unavailable due to a terminated account associated with that video, copyright infringement, and uploader's removal. Since the data was collected in early 2016, those videos posted in 2015 are more likely to remain available than videos posted in 2014 and earlier.

Results demonstrated that most videos addressed multiple content areas. The primary foci of the videos were AD symptoms, causes of AD, treatment, and protective and risk factors. Fewer videos were focused on diagnosis and early screening. This finding is consistent with previous studies on cognitive health messages in television news, magazines, and newspapers [6-8]. This result also indicates that the information on early diagnosis and screening did not receive much attention by the individuals or organizations who created the videos, even though this information would be important for the general public [31-33].

The videos with frequently covered content such as AD treatment, symptoms, and protective and risk factors had fewer mean numbers of views than those focused on quality of life and caregiving. Videos regarding quality of life of individuals with AD also received the most comments. The number of views and comments metric can reflect viewers' interests. Therefore, fewer views of videos containing the most commonly featured content highlight a potential gap between available information and viewers' interests. Although we do not have the profile of viewers, people seeking AD information on YouTube are possibly caregivers of people with AD, based on the focus of videos that ranked high in number of views. Our results also showed that testimonial videos have the highest views among all formats. This finding indicates that YouTube users preferred to view testimonial videos that presented experiences of AD patients and their families. Previous research indicates that people prefer receiving health information through testimonials, thus the use of testimonials to distribute health information can be beneficial for health decision-making and behavior change [34,35]. However, AD videos using testimonials were less available on YouTube in this study. Future videos need to consider providing AD information in a testimonial format to increase viewership of this content. Understanding the viewers and their needs will be important for nonprofit organizations, researchers, and government agencies who plan to provide information and resources on YouTube. Creating content that people need will be beneficial to both the viewers and the uploaders in terms of marketing and health promotion strategies. Further research is needed to understand people using YouTube for AD information and messages that can reach different target audiences (caregivers, people with AD, and the general public), and to provide appropriate information that meets viewers' needs.

Speakers shown in YouTube videos related to AD were mostly white adults, despite the high usage of video-sharing sites among African Americans and Hispanics [36]. Considering the high incidence of AD among African Americans and Hispanics [37-41], the current AD messages on YouTube may not address specific information for, and cultural aspects of, these high-risk populations. Health messages tailored to match individual characteristics or targeted to specific group characteristics are beneficial to enhance people's attention and involvement in health issues [42,43]. In addition, most speakers portrayed in videos were adults from the ages of 20 years to their early 60s, and few speakers were individuals with AD or informal caregivers. Most people living with AD are aged 75 years or older, and approximately one in three informal caregivers who need information and support are aged 65 years or older [1]. People who create and upload YouTube videos may not be similar in demographics to those who are viewers of YouTube content, thus the videos may not reflect unique needs of the users, especially aging-related needs. Action items within the Public Health Road Map support the importance of identifying and promoting culturally appropriate strategies to increase public awareness about AD. Future research is needed to develop culturally appropriate messages for diverse populations and to understand the effectiveness of those messages delivered through YouTube and other social media.

Only 36.9% (100/271) of AD videos on YouTube included a website URL and most videos did not include a physical address or phone number. Providing mobilizing information is an important strategy that helps connect populations to additional resources [44]. AD videos focused on providing resources of support were more likely to include a website URL, which is an expected finding given the purpose of those videos. Videos focused on AD symptoms were less likely to include a website URL, although viewers may need contact information of organizations and health professionals for further screening and diagnosis when they have similar symptoms to those presented in the video. Providing mobilizing information also helps to promote organizations, including news sources and nonprofit organizations, for directing users to further health information and engaging them in advocacy activities [44,45]. All types of organizations (ie, nonprofit, for-profit, and government agencies) are increasingly turning toward social media to spread organizational news [46]. Using YouTube can be a wise marketing and public relations strategy for organizations who create videos to reinforce awareness of their programs and services, promote their fundraising efforts, and shape their organizational brand and identity [46,47].

Action items of the Public Health Road Map suggest the importance of disseminating evidence-based messages about risk reduction for preserving cognitive health [25]. Although we did not assess accuracy of information that AD-related YouTube videos provide, we noticed in an ad hoc analysis that 22 videos (either title or content) presented seemingly inaccurate or misleading information. The inaccurate or misleading information included the following: AD is contagious, anti-anxiety drugs cause AD, particular foods/drinks can be used to treat AD, and that certain vaccines can slow down the progression of AD. Those videos were mostly posted by laypersons or other authors who could not be categorized. As with most online information, the content on YouTube may not be peer-reviewed; therefore, registered users can post any content. Studies on other health topics presented on YouTube showed that videos often have inaccurate or misleading information [20-24,48]. Future research is needed to evaluate the quality of information provided by videos related to AD using in-depth methods, and to develop measures that can help audiences evaluate the information presented on YouTube and other social media platforms.

Limitations

This study had some limitations. First, we only used the single search term "Alzheimer's disease", thus we might have missed some videos focused on AD using other search terms such as "Alzheimer". Second, we only analyzed videos in English and videos about AD in other languages would have been missed. Finally, we also excluded videos over 10 minutes in length, based on other similar studies [22,26]. Previous research showed that most YouTube videos are less than 10 minutes long, and people are mainly interested in viewing these types of shorter videos [49,50].

Conclusions

This is the first study to analyze YouTube videos about AD, and it contributes new knowledge regarding AD messages delivered through this popular platform. Findings of this study also respond to action items in the Public Health Road Map [25] by attempting to understand whether AD messages on YouTube are culturally appropriate and include website URLs for further resources. The Public Health Road Map provides guidance for state and local public health agencies and partners in several public health domains to monitor and evaluate the status of cognitive health, including AD and related programs, and educate and empower the public and relevant agencies [25]. This study identified a lack of mobilizing information, as well as a potential gap between information available and viewers' interests, which will be useful for government agencies, researchers, and nonprofit organizations that promote information about AD (and those responsible for social media) to provide useful and accurate AD information for the public.

Future research is needed to assess whether messages disseminated on YouTube are evidence-based and to understand viewers' attitudes toward this information based on their comments. YouTube can be a useful platform to deliver AD information to reach high-risk populations; however, videos need to be improved in terms of cultural appropriateness of the information, users' characteristics and interests, and accuracy. AD videos could be more beneficial if they deliver messages that meet users' needs and include mobilizing information that can direct people to relevant and credible resources.

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Conflicts of Interest

None declared.

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Abbreviations

AD: Alzheimer’s disease
CDC: Centers for Disease Control and Prevention
df: degrees of freedom
PSA: public service announcement
RQ: research question
URL: Uniform Resource Locator

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Original Paper

“A Phenomenal Person and Doctor”: Thank You Letters to Medical Care Providers

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Abstract

Background: Thank you letters to physicians and medical facilities are an untapped resource, providing an invaluable glimpse into what patients notice and appreciate in their care.

Objective: The aim of this study was to analyze such thank you letters as posted on the Web by medical institutions to find what patients and families consider to be good care. In an age of patient-centered care, it is pivotal to see what metrics patients and families apply when assessing their care and whether they grasp specific versus general qualities in their care.

Methods: Our exploratory inquiry covered 100 thank you letters posted on the Web by 26 medical facilities in the United States and the United Kingdom. We systematically coded and descriptively presented the aspects of care that patients and their families thanked doctors and medical facilities for. We relied on previous work outlining patient priorities and satisfaction (Anderson et al, 2007), to which we added a distinction between global and specific evaluations for each of the already existing categories with two additional categories: general praise and other, and several subcategories, such as treatment outcome, to the category of medical care.

Results: In 73% of the letters (73/100), physicians were primarily thanked for their medical treatment. In 71% (71/100) of the letters, they were thanked for their personality and demeanor. In 52% cases (52/100), these two aspects were mentioned together, suggesting that from the perspective of patient as well as the family member, both are deemed necessary in positive evaluation of medical care. Only 8% (8/100) of the letters lacked reference to medical care, personality or demeanor, or communication. No statistically significant differences were observed in the number of letters that expressed gratitude for the personality or demeanor of medical care providers versus the quality of medical care (χ21, N=200=0.1, not statistically significant). Letters tended to express more specific praise for personality or demeanor, such as being supportive, understanding, humane and caring (48/71, 68%) but more general praise for medical care (χ21, N=424=63.9, P<.01). The most often mentioned specific quality of medical care were treatment outcomes (30/73, 41%), followed by technical competence (15/73, 21%) and treatment approach (14/73, 19%). A limitation of this inquiry is that we analyzed the letters that medical centers chose to post on the Web. These are not necessarily a representative sample of all thank you letters as are sent to health care institutions but are still indicative of what centers choose to showcase on the Web.

Conclusions: Physician demeanor and quality of interaction with patients are pivotal in how laymen perceive good care, no less so than medical care per se. This inquiry can inform care providers and medical curricula, leading to an improvement in the perceived quality of care.

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KEYWORDS

quality of health care; doctor-patient relationship; content analysis; decision making; doctor-patient communication; clinical encounter; patient satisfaction; online reviews; patient-centered care

Introduction

Patient satisfaction is imperative to the practice of medicine. Indeed, some elements of the therapeutic process, such as patients' adherence to medication, are related not only to the medical aspects of care but also to whether the patient feels acknowledged and appreciates that the doctor sees him as a person [1]. Patient-centeredness is now deemed as central to good medical care, such that we now view the process as a therapeutic dyad [2]. This study aims to answer the question of what patients value in the medical care they receive by the analysis of thank you letters to physicians and medical centers, as posted on the Web.

The act of writing these letters should not be taken for granted, as "less than 3% of those who have visited a hospital Facebook page or even liked the hospital Facebook page care to comment on a hospital post or share thoughts or express emotions..." [3], and patients' thank you notes constituted only 7% of the comments on US hospitals' Facebook pages. We interpret this as signifying that thank you notes are fairly rare and nontrivial, thus highlighting the reason to explore them in depth.

Previous Work

Anderson and colleagues performed content analysis of 2917 patients' comments on their health care experiences with a rated doctor or a clinic, as submitted to the patient satisfaction survey at DrScore website [4]. In their taxonomy of the main elements of patients' experiences with health care providers, Anderson and colleagues identified 25 categories of health care quality valued by patients that mapped onto the following seven broad thematic categories:

- Access to physician or health care services
- Communication with and by provider
- Personality and demeanor of provider, such as the extent to which the physician was supportive, caring, and compassionate
- Quality of medical care processes such as diagnosis and treatment
- Continuity of care as related to follow-up on health care issues or concerns, making referrals, and discussing test results
- Quality of health care facilities
- Office staff

Choice of Anderson Taxonomy

This taxonomy offers categories that are suitable for capturing and distinguishing among a wide range of both positive and negative patient feedback relating to their health care experiences. By comparison, there are other existing surveys that are commonly used in both the United States and the United Kingdom, such as the Medical Interview Satisfaction Scale (MISS) [5,6] that examines patients' satisfaction with their medical interview and the Consultation Satisfaction Questionnaire (CSQ) [7]. These examine the clinical encounter and assess patient satisfaction with individual doctor-patient consultations. Both those surveys assess more narrowly defined scopes of patient perceptions of health care [8]. Therefore, we chose to use the Anderson taxonomy [4] with various modifications, as listed in the Methods section.

Research Questions

Patient evaluations and the measures capturing them can be narrow or broad. This determines how indicative they are of merit or flaw. As noted by Cleary and McNeil, "global measures of satisfaction are affected by many factors, and unless a study is conducted in extremely well-controlled circumstances, it is difficult to interpret global measures" [9]. This implies that measurement of specific care domains is to be preferred over the measurement of broader ones.

The shared decision-making paradigm has been an emerging priority in medical parlance and practice [10,11]. The category of communication as included in our study allows for examination of aspects of the doctor-patient interaction, and the degree to which the patient receives information, is listened to, and—as a culmination of shared decision making—is considered a partner.

In the spirit of a call for exercising neutrality when examining and assessing medical quality [12], we posed two questions. Our main research question for this exploratory, small-scale investigation was as follows: what categories and aspects do patients mention in their thank you letters? The premise—which we cannot experimentally validate—is that patients mention the things they appreciate. Another research question was whether the patients were referring to general or specific aspects within categories [9,12,13].

Methods

Selection of Letters

The sample consisted of thank you letters and brief testimonials from patients or their friends and family (for the sake of brevity, we will continue with "patients") to various medical centers located throughout the United States and the United Kingdom and posted on the Web by the centers. These letters and testimonials were obtained using Google's search engine by entering the following combination of terms: "medical center patient thank-you letters" and "medical center patient testimonials." These search terms retrieved 89,800,000 results and 7,950,000 results, respectively. This search was performed in early December 2015.

As this was designed as an exploratory investigation, we planned to only analyze 100 letters. Therefore, we limited our content sample to postings from 26 US or UK medical facilities that, taken together, provided a wide range of medical services to their patients and that appeared in the first 10 pages of search results. We did not include sources that only posted brief letter excerpts or quotes from patients. As the main research question was—what aspects of care do patients thank doctors and medical facilities for—we sought to collect complete letters and testimonials.

On the basis of the order of appearance in search results, we chose medical facilities subject to the constraint that they represented the different types of medical institutions (university medical centers, community or regional hospitals, or specialty clinics) and locations (the United States or the United Kingdom) in equal proportion to the total number of Internet postings retrieved in our Internet search corresponding to the various types of medical institutions and locations. We then retrieved 100 letters in order of appearance from the medical facilities' Internet sites for coding and content analysis.

The study only analyzed publicly available materials that had already been posted on the Web by medical facilities. This is akin to analyzing newspaper articles. We neither contacted the letter writers nor did we have identifying information about them. Therefore, we did not require approval from the institutional review board.

Table 1 summarizes the characteristics of thank you letters in the content analysis. The final sample of 100 letters included 572 sentences and 773 utterances (ie, a bit of spoken, or in the case of letters, written language, which conveys a message). For example, the following sentence consists of two utterances: I arrived at the clinic in the morning (1) and found it very clean. (2). The letters and testimonials included in the study were posted by the medical centers themselves, suggesting the possibility of a selection bias in what they chose to present. That said, this study illuminates the content of letters that were posted on the Web but not all types of thank you letters ever sent to physicians and medical centers.

Table 1. Characteristics of thank you letters in content analysis (N=100).

Characteristic	n (%)
Author	
Patient	
Male	14 (14)
Female	38 (38)
Unspecified	28 (28)
Relative	
Male	2 (2)
Female	4 (4)
Unspecified	13 (13)
Other	
Male	1[a] (1)
Type of institution, unspecified	
University hospital or medical center	12 (12)
Regional or community hospitals	55 (55)
Clinic or specialty center	33 (33)
Location, unspecified	
United States	84 (84)
United Kingdom	16 (16)

[a] This letter was from a military commander thanking a neurosurgeon for his work to advance treatment and asking for advice to help take care of wounded soldiers under his command.

Coding Content

Patient evaluations and the measures capturing them can be narrow or broad. This determines how indicative they are of merit or flaw. As noted by Cleary and McNeil, “global measures of satisfaction are affected by many factors, and unless a study is conducted in extremely well controlled circumstances, it is difficult to interpret global measures” [9]. This implies that measurement of specific care domains is to be preferred over the measurement of broader ones. Therefore, not to lose information from letters in our study, we searched both for broad global-category evaluations (eg, access) and for narrow subcategory-specific evaluations (eg, within access: “responsiveness to phone calls”).

Each sentence or utterance within a sentence was marked as a thank you for one or more of the aspects of interactions between patients and their medical care providers. To do this, we used a coding rubric that was adapted from the Anderson taxonomy [4].

Our initial attempt to code the thank you letters further identified statements that did not clearly correspond to the operational definitions and examples originally proposed by Anderson and colleagues [4] for rating physician visits and required some adjustments. For example, a statement such as your gentle staff were great” does not fall into the office staff or coordination as defined by Anderson [4], with a bureaucratic emphasis. In these cases, we analyzed the sentence according to content, not according to the object of praise. So, with the example above, we would code “your gentle staff were great” as praise for personality or demeanor.

To encompass all the sentences included in the thank you letters, we broadened the scope of several main categories and added several new subcategories to the Anderson [4] coding scheme. Within medical care, we added the subcategory treatment outcome, which gives the long-term perspective of treatment. To illustrate: (about a baby who had liver transplant), “Now Dean truly is...a good size and growing fast, a typical toddler.” We also added the subcategory “friendliness to the personality or demeanor category and the subcategory availability to the access category. Furthermore, as some utterances did not fall within any of Anderson’s, we added two categories to the classification. These were general praise (eg, “Both of my parents are lucky to be patients of Dr. Tendler”) and other for statements that lacked any form of praise (eg, “I recently had Mohs surgery with Dr. Makkar”).

Additionally, whereas Anderson [4] had a subcategory of general in the access, communication and personality or demeanor categories, we added general to all other categories. For example, a statement such as “Tammy (Sachowsky) was great on my first mammogram” was coded as general under medical care, as this does not clearly correspond to any of its specific subcategories. See Multimedia Appendix 1 for a final list of the categories and subcategories, along with operational definitions and examples.

Each sentence or utterance within a sentence was coded to indicate the presence (1) or absence (0) of content corresponding to each of the categories and subcategories represented in final coding scheme. Two coders independently coded the content of the first 63 letters that contained 415 sentences in total. Discrepancies were discussed and resolved through dialogue between the 2 coders; because interrater reliability was very high, as indicated in the Results section, the remaining 37 letters were then coded by one coder, and the coder’s ratings for the complete sample of 100 letters were retained for content analysis.

Results

Interrater Agreement

Several measures of interrater agreement were calculated to verify the coding scheme. For each category, the percent agreement in scores between the raters—that is, the total number of matches in ratings between the raters, indicating either the presence or absence of content in each utterance, divided by the total number of ratings for the content category—was very high, ranging between 90% and 100%. Interrater reliability (.84) was measured using the index of reliability [14]. Interrater reliability, as measured by Cohen kappa [15], was also substantial (.67), albeit lower, because of the extremely low prevalence of content for the categories of continuity, which was indicated for only four and seven utterances by the 2 raters, respectively, and administrative coordination, which was indicated for only one and two utterances by the 2 raters, respectively. Indeed, one limitation of kappa is that when the prevalence of a phenomenon in question is quite low, discrepancies between observed agreement and kappa can be very high [16,17]. By contrast, the index of reliability also provides a measure of interrater precision that takes expected levels of chance agreement into account without depending upon the marginal frequencies (ie, prevalence) of the content categories, and as such, it is arguably more appropriate for this analysis.

Content Analysis

The content analysis sample consisted of 100 letters in total selected from 26 Web-based sources, corresponding to 26 medical facilities. On average, there were six sentences per letter, and 22 sentences were coded per source. Whereas the vast majority of sentences (76%, or 435 sentences) received a rating for only one content category, 22% (or 126 sentences) were coded in two to three content categories, and the remaining sentences received ratings across four to seven different content categories. Thus, sentences received 1.4 ratings, on average, across the content categories.

Figure 1 shows the percentage of letters that express at least one utterance for each of the major content categories. Letters tended to express the most gratitude for the medical care provided, followed by gratitude for personality and demeanor and nonspecific general praise. Most patients expressed praise for these three categories, with 73%, 71%, and 70% expressing gratitude for medical care, personality, and nonspecific general praise, respectively. Other was the next most frequent category mentioned, with 52% of letters with many factual statements, for example, “I recently had surgery with Dr. Smith.” Patients tended to express less gratitude for the communication skills of their medical care providers, with only 31% of letters. Finally, patients seldom expressed gratitude for facilities (6 letters), access, (12 letters), continuity (4 letters), and administrative coordination (3 letters). Indeed, a chi-square test of goodness-of-fit confirmed that the number of letters varied with respect to the type of content expressed, $\chi^2_{8, N=900}=331.6$, $P<.01$. This analysis was based on constructing a 9 (content category) x 2 (expression of gratitude: yes vs no) contingency table with all 100 letters represented in each column, totaling 900 observations.

Offering a more detailed view, Table 2 reports total number of utterances, the percentage of letters with content in that category, and the proportion of letters with general or specific utterances within each major content category. Letters differed in their tendency to express gratitude for general versus specific aspects of interactions with medical care providers. When praising the personality or demeanor of their medical care providers, patients referred mostly to specific qualities such as being supportive and understanding, 71.8% (51% of letters/71% of letters within category), humane and caring, 68% (48/71), or friendly, 28% (20/71). Fewer letters gave general praise to medical care providers’ personality or demeanor, 25% (18/71). By contrast, when referring to medical care, letters referred more to general qualities, 71% (52/73). The specific quality of medical care that was mentioned the most was treatment outcomes, 41% (30/73). This was followed by technical competence, 20.5% (15/73) and treatment approach 19% (14/73). In view of supportive being the most highly endorsed subcategory within personality and medical outcomes being the most highly rated medical care subcategory, it appears that people are most thankful for tangible outcomes—and processes—of their treatment. Chi-square tests of independence were performed to examine the relationship between these two types of content (personality and medical care) and the specificity of utterances in thank you letters. Although no significant differences were observed in the number of letters that expressed gratitude for the personality or demeanor of medical care providers as compared with the quality of their medical care ($\chi^2_{1,N=200}=0.1$, not significant), letters tended to express more specific praise for personality or demeanor but more general praise for medical care ($\chi^2_{1,N=424}=63.9$, $P<.01$). The chi-square analyses were based on constructing a 2 (content category: personality or demeanor vs quality of medical care) x 2 (expression of gratitude: yes vs no) contingency table with all 100 letters represented in both columns and rows, totaling 200 observations, and based on constructing a 2 (content category: personality or demeanor vs quality of medical care) x 2 (specificity of praise: general vs specific) contingency table representing the number of utterances expressed across letters for each content category and level of specificity, totaling 424 observations.

Figure 2 examines the juxtaposition of categories included per letter. People tended to simultaneously express praise for both personality or demeanor and medical care (33%) or for the personality, communication skills, and medical care aspects of their experience (19%). A large proportion of letter writers expressed thanks for the medical team’s medical care (73%), of which many expressed thanks for medical care and communication with them (20% of all letters). A similar proportion of letter writers (71%) expressed thanks for personality or demeanor, of which many expressed thanks for personality or demeanor and communication (29% of all letters). The surprisingly similar proportions of references to personality or demeanor and to medical care help validate the point that, to patients, these two are equally important. Interestingly, a relatively small percentage of letters (29%) only referred to a single major aspect, such as personality or medical care. A few (8%) of the letters did not refer to medical care, personality or demeanor, or communication.

Figure 1. Percentage of thank you letters with content indicating various aspects of interactions with medical care providers.

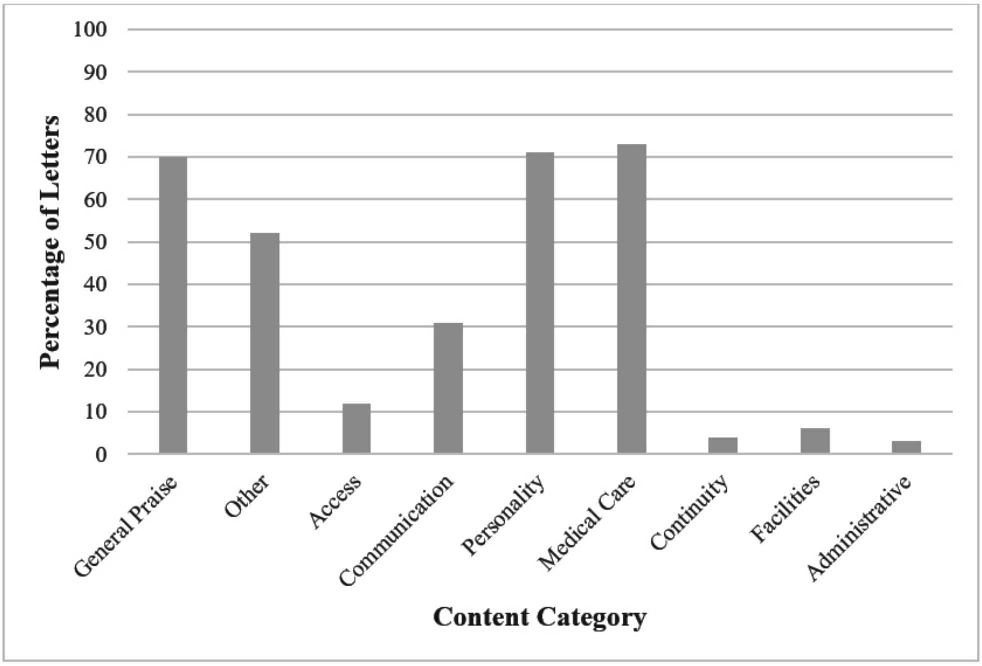
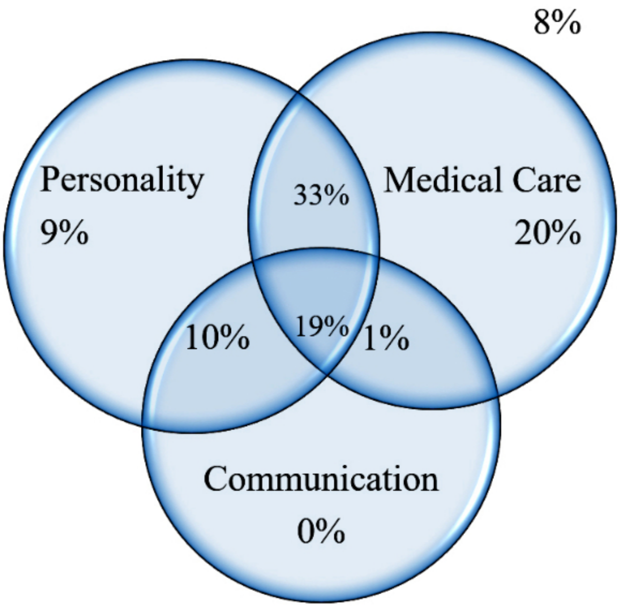


Table 2. Total number of utterances, the number of letters with content in that category, and the proportion of letters with general or specific utterances within each major content category.

Content category	Total number of utterances (percentage of utterances within category)	Number of all letters (percentage of letters within category)
Personality		
General	28 (12.1)	18 (25)
Specific		
Friendliness	29 (12.6)	20 (28)
Humaneness and caring	67 (29.0)	48 (68)
Supportive and understanding	89 (38.5)	51 (72)
Trust	7 (3.0)	6 (9)
Family or child	11 (4.8)	7 (10)
Total	231 (100)	71 (100)
Medical care		
General	91 (47.2)	52 (71)
Specific		
Patient advocacy	0 (0.0)	0 (0)
Technical competence	22 (11.4)	15 (21)
Time spent with patient	4 (2.1)	3 (4)
Diagnostic skills	5 (2.6)	5 (7)
Treatment approach	18 (9.3)	14 (19)
Thoroughness	1 (0.5)	1 (1)
Treatment options	1 (0.5)	1 (1)
Treatment outcomes	51 (26.4)	30 (41)
Providing medications	0 (0.0)	0 (0)
Total	193 (100.0)	73 (100)
General praise	143 (100.0)	70 (100)
Other	130 (100.0)	52 (100)
Communication		
General	3 (7)	3 (10)
Specific		
Listening skills	11 (24)	11 (36)
Patient as partner	6 (13)	6 (19)
Giving information	26 (57)	22 (71)
Total	46 (100)	31 (100)
Access		
General	0 (0)	0 (0)
Specific		
Waiting times	1 (8)	1 (8)
Responsive to phone calls	2 (17)	2 (17)
Availability	9 (75)	9 (75)
Total	12 (100)	12 (100)
Facilities		
General	3 (33)	2 (33)
Specific	6 (67)	5 (83)

Content category	Total number of utterances (percentage of utterances within category)	Number of all letters (percentage of letters within category)
Total	9 (100)	6 (100)
Continuity		
General	0 (0)	0 (0)
Specific		
Follow-up care	4 (80)	4 (100)
Test results	1 (20)	1 (25)
Referrals	0 (0)	0 (0)
Total	5 (100)	4 (100)
Administrative		
General	2 (50)	2 (67)
Specific	2 (50)	2 (67)
Total	4 (100)	3 (100)

Figure 2. Proportion of letters that mentioned each topic. Percentages are out of 100% (N=100) letters and testimonials analyzed.



Patients expressed gratitude for personality and medical care together in 52% of the letters analyzed, and they expressed gratitude for personality, medical care, and communication in 19% of the letters analyzed. Only eight of the letters (ie, 8%) lacked reference to medical care, personality or demeanor, or communication. Six letters mentioned nonspecific general praise or statements that did not indicate any form of praise (eg, other), and 2 letters expressed praise for the medical facilities.

Discussion

Principal Findings

The primary objective of this study was to address the question—what aspects of care do patients thank doctors and medical facilities for? Our main finding is that, first and foremost, patients and family members are thankful for their providers' medical care. Second, and very closely related, they are thankful for personality and demeanor.

Thus far, physician ratings, patient forums, and other Web-based resources provide insights to people's opinions of, and points of dissatisfaction with, their medical care. For example, a recent comparison of women's posts on pregnancy in general versus on vaginal birth after cesarean (VBAC) unveiled women's greater need for information and emotional support in the case of VBAC [18]. Our findings correspond with those of Lagu et al, who analyzed 33 physician-rating websites. Patients were asked to provide feedback on what the authors labeled as clinical aspects, which included physician's knowledge (49%), bedside manner (39%), and communication skills (30%). Nonclinical aspects involved punctuality (49%) and staff friendliness (36%) [19].

The analysis of thank you letters to physicians and medical centers offers additional resource relating to how patients view health care, which has thus far not been investigated. When it comes to the topic of medical care, letters are more likely to include general words of praise than any other category. Whereas some general praise is also awarded for physician personality, an overwhelming majority of the letters in this category mentioned the physician's supportiveness. This is one element of care that is both tangible to patients and appreciated by them.

Patients' abilities to point to specifics in their doctors' personalities or demeanors and then secondarily point to good medical care in general is reflected in the paper's title, which comes from a patient's letter, the full citation being, "She is just a phenomenal person and doctor," in this order. In more than half of the cases, these two aspects are mentioned together in the same letter, suggesting that from the perspective of the patient and family member, both are deemed necessary to evaluate care positively. The centrality of the emotional aspects of care dovetails with previous findings [13].

This somewhat mirrors the proportion of these aspects in patients' free form writing about physicians, indicating mainly that medical care per se, alongside bedside manners and communication, are what patients consider the bedrock of good treatment.

We looked at patients' and family members' responses to mostly successful outcomes, finding that patients deem providers' personality and behavior highly important, considering them more than the technical aspect of their professional actions. Similar principles, albeit in a mirror image, apply when observing malpractice claims. A survey of patients and relatives who took legal action against doctors found that the decision of patients and relatives to take legal action against their providers was determined not only by the original injury but also by what they perceived as insensitive handling and poor communication after the original incident [20]. Indeed, several studies suggest that doctors with better communication skills or even a tone of voice that is considered kinder, are less likely to be involved in malpractice claims [21,22]. This suggests that negative sentiment toward the medical staff is a major component in patients' overall dissatisfaction, rather than an adverse outcome per se. All these highlight the role of the interpersonal connection in medicine.

Most medical schools have implemented courses for training clinical communication skills. Indeed, data support improved communication behaviors among providers following such educational interventions [23]. However, it seems that postgraduate communication training for doctors is lacking [24].

Limitations

Several limitations exist in our investigation. For the purposes of our investigation, it is important to acknowledge the influence of selection bias in our content sample—not because of any of our practices but rather in accordance with the centers' interests. The letters and testimonials were posted by the medical centers themselves, and so they likely only posted letters and excerpts in which the content was consistent with the way the centers wished to be portrayed to the general public. As a result, the medical centers may have refrained from posting any letters that included negative statements about their staff or facilities or may have censored negative statements from posted material. On the other hand, as the focus of this work is the thank you letter, we were less concerned with letters of complaint. We also could not verify the authenticity of the letters themselves and relied on the assumption that the medical centers exercised professionalism by only posting authentic letters or testimonials. In this respect, the letters might be representative not only of how patients evaluate their care but also of how doctors and medical centers wish to be perceived by prospective patients and perhaps of what they feel such patients can comprehend and appreciate. This is a form of selection bias—of what is displayed on the Web.

There may also be a degree of selection bias in the types of letters that patients themselves send to medical centers and agree to have publicized on the Internet. When writing personal thank you letters to physicians, patients may prefer to write and deliver a letter by hand to make the gesture of appreciation more direct and personal. Such letters may also be accompanied by physical gifts (eg, box of chocolates and alcohol). By contrast, letters that patients send to medical centers may be more intended to give wider recognition to their physicians and other medical staff involved in their treatment.

Another limitation is the way the sample was created—albeit this was done based on the most prominent search results, wishing to cover as many specialties as possible and to only analyze several letters from each center so that no particular center's results are overrepresented. A more extensive inquiry, following this exploratory investigation, would perhaps include all the letters posted on the Web by all the centers from a specific specialty, in a specific geographical region.

The data analysis in this pilot work on thank you letters was strictly descriptive. We chose not to use significance testing, as the coding scheme involved seven categories, some of which resulted in few observations. Thus, a pairwise comparison between medical and personality or demeanor praise would prove problematic because of the Bonferroni corrections required. An analysis of variance, on the other hand, would merely show that differences exist. Future investigations of a larger scale can proceed with significance testing and planned comparisons.

Conclusions

Despite these limitations in selection and analysis, the texts provide a useful dataset for characterizing which aspects of medical treatment are considered important to patients and their families. It is possible that the letters also provide a glimpse into what matters to medical care providers, which is important for them to convey to future patients who might be reading these letters on the Web. This would be in line with the concern that social media is viewed as a marketing tool or as a means of engaging in a meaningful conversation with patients [3]. Future projects should in more depth analyze larger samples of letters, also taking into account nonpublished notes. As new ways of care evolve in a digital age, this information may help to better address communication needs of patients. In addition, to prove the validity of our method, a comparison with existing methods and surveys (MISS and CSQ) should be undertaken.

Limitations notwithstanding, these letters demonstrate the strong emphasis that hospitals, clinics, and medical educators should place on ensuring personable care, which is so crucial for patients’ experiences. If letters are not just posted for display but also read and learned, they can be a powerful beacon guiding medical care providers toward patient satisfaction.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Coding scheme adapted from Anderson et al (2007).

[PDF File (Adobe PDF File), 46KB - ijmr_v6i2e22_app1.pdf]

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Abbreviations

CSQ: Consultation Satisfaction Questionnaire
MISS: Medical Interview Satisfaction Scale
VBAC: vaginal birth after cesarean

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Original Paper

Promoting Engagement With a Digital Health Intervention (HeLP-Diabetes) Using Email and Text Message Prompts: Mixed-Methods Study

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Abstract

Background: Engagement with digital health interventions (DHIs) may be regarded as a prerequisite for the intervention to achieve positive health or behavior change outcomes. One method employed to promote engagement is the use of prompts such as emails and text messages. However, little is known about the characteristics of prompts that promote engagement. This study explored the association between the content and delivery mode of prompts and the users' engagement with HeLP-Diabetes (Healthy Living for People with type 2 Diabetes), a DHI that aimed to promote self-management in adults with type 2 diabetes.

Objective: The objective of this study was to identify the characteristics of prompts, specifically the content and delivery mode, which were associated with increased engagement.

Methods: This was a mixed-methods study. Email and text message prompts were sent to the registered users of HeLP-Diabetes. Use of the intervention was recorded and examined to identify which email and text message prompts were associated with subsequent visits to the DHI. Characteristics of prompts that were identified as particularly effective or ineffective were explored through think-aloud interviews with the participants.

Results: Of a total of 39 email prompts, 49% (19/39) prompts showed a significant association with subsequent visits to the DHI. However, none of the text message prompts were associated with subsequent visits to the DHI. Furthermore, think-aloud interviews were carried out with 6 experienced participants with type 2 diabetes. The findings suggest that these participants preferred email prompts that were clear, relatively short, and empowering; used nondirective advice; included health professional references; were visually appealing; and contained news and updates.

Conclusions: The findings of this study contribute to the existing evidence supporting the role of email prompts in promoting and maintaining engagement with DHIs. This study described the content of prompts that may be engaging. However, the results should be interpreted with caution, as prompts may be context-specific interventions and the results may not be generalizable across other DHIs or other types of interventions targeting self-management of type 2 diabetes.

(Interact J Med Res 2017;6(2):e14) doi:10.2196/ijmr.6952

KEYWORDS

mHealth; eHealth; email; text messages

Introduction

Importance of Digital Health Interventions

Digital health interventions (DHIs) are programs that provide emotional, decision, or behavior information and/or support for physical or mental health problems via digital platforms such as computers, mobile phones, or websites [1,2]. Lately, there has been a proliferation of evidence suggesting that DHIs may be effective in promoting self-care for chronic diseases, mental health, and health behavior change [1,3,4]. However, the effect sizes demonstrated in the systematic reviews of DHIs are often small [4-6], and this may be related to low engagement, or in some cases, lack of engagement with these DHIs [7-9].

Importance of Engagement

It has been suggested that engagement, defined here as users' regular interaction with part or all of the DHI [10], is positively associated with the effectiveness of DHIs, with a tendency toward a dose-response relationship [11-13]. Although the study of engagement is still in its infancy, there is a shared view that the promotion of engagement needs to be explored further [14].

Importance of Prompts and Their Characteristics

One suggested method of promoting engagement is the use of technology-based prompts such as emails and text messages [8,15-17]. Several systematic reviews have shown that prompts are associated with positive engagement with DHIs [10,15,16], and one meta-analysis comparing the use of prompts against not using prompts showed that prompts have a small to moderate significant positive outcome (relative risk [RR] 1.27, 95% CI 1.01-1.60, I^2=71%) [10]. However, the meta-analysis concluded that more research is needed to explore the differential effectiveness of the characteristics of various prompts, specifically their content and delivery modes [10].

There is relatively little work exploring whether the features of content and delivery are associated with enhancing engagement, and if so, identifying which features promote engagement. One study suggested that prompts with new content (eg, updated content on the DHI) were potentially associated with enhanced engagement [18]. A meta-regression that looked at the effect of text message and email prompts found both of these delivery modes to be effective in changing behavior [19].

HeLP-Diabetes

HeLP-Diabetes (Healthy Living for People with type 2 Diabetes) is a DHI targeting self-management of type 2 diabetes developed by a research team from University College London (UCL). It was developed with a strong theoretical underpinning and following the principles of participatory design, where users were defined as patients with type 2 diabetes and health professionals' caring for such patients. Focus groups conducted during the development process explored users' views on engagement and the potential of prompts delivered via emails and text messages to promote engagement. In response to the focus group data [20] and the results of a systematic review that showed the potential of prompts in promoting engagement [10], emails and text messages were used to promote users' engagement with HeLP-Diabetes. Prompts were sent to all the registered users 2 to 3 times per month.

HeLP-Diabetes was the subject of a research program that included two major studies undertaken in parallel: an individually randomized controlled trial (RCT) in primary care to determine effectiveness and cost-effectiveness [21] and an implementation study that aimed to explore how best to implement HeLP-Diabetes in National Health Service primary care practices [22]. The trial involved 20 primary care practices drawn from across England, with a mix of urban, suburban, and rural practices. The implementation study took place within one English clinical commissioning group (CCG) in London, the United Kingdom. Primary care practices in this area were excluded from the trial to avoid contamination. Participants were recruited to the trial between September 2013 and December 2014 and followed up for 12 months [21]. The implementation study took place between March 2013 and August 2015. The trial followed the standard "opt-in" recruitment procedures of adults aged 18 years or older who were registered with participating practices and had been diagnosed with type 2 diabetes. Participants were excluded if they were terminally ill, unable to use the intervention because of physical or mental impairment, or unable to provide informed consent. In the implementation study, the main outcomes were uptake and usage at the level of individual practices in the participating CCG. Practices were told that the intervention was available for use by any patient with type 2 diabetes and encouraged to refer all suitable patients to the program. In the implementation study, patients could use HeLP-Diabetes without participating in any research and were offered to use it as part of their routine diabetes care. Hence, the demographics of the user population differed between the two studies; in the implementation study, the demographics of users reflected the local population in that more than 50% came from black or minority ethnic backgrounds, one-third had only basic computer skills, and one-third had no formal education after minimum school leaving age. In contrast, the trial participants tended to be white (80%), and more than half of the participants rated themselves as experienced computer users. The study involved all the registered users of HeLP-Diabetes, that is, the trial participants who had been randomized to the intervention arm and all the patients registered through the implementation study.

Aim and Objectives

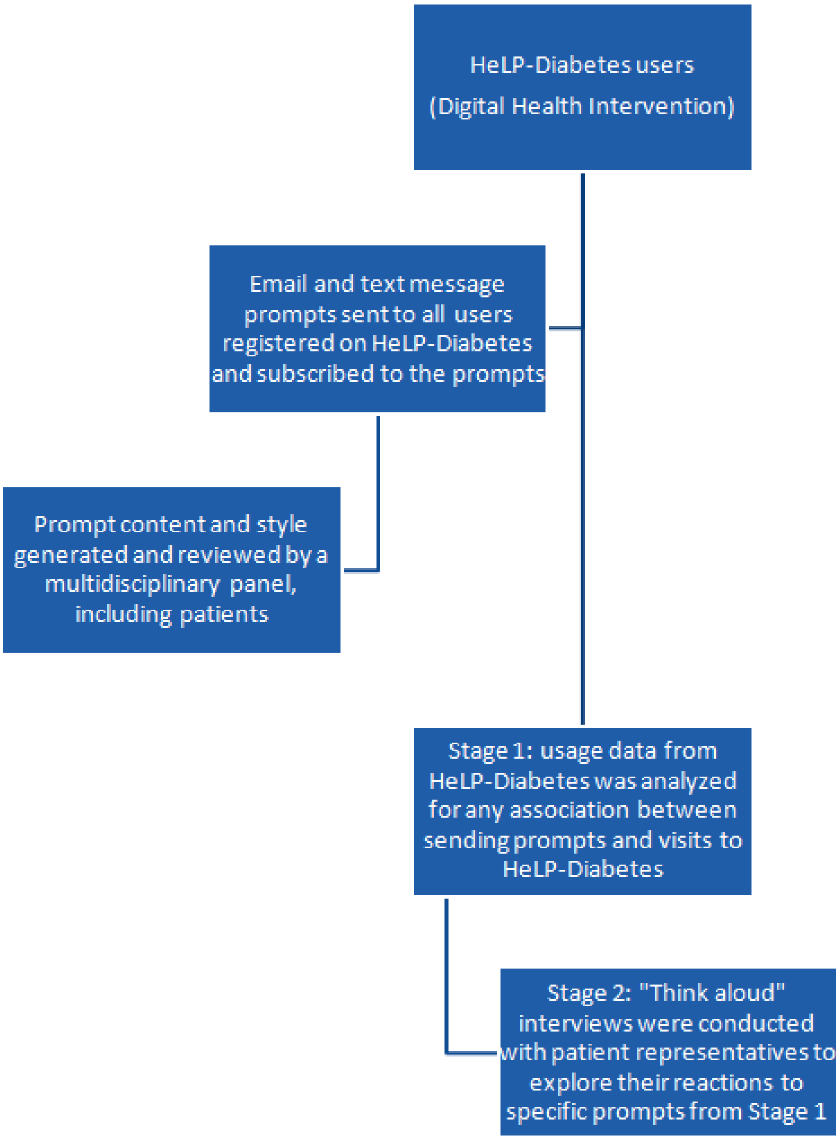
In the eHealth (electronic health) and mHealth (mobile health) field, there has been a call to accelerate the pace of health research to correlate with the speed of technology development. One suggestion to accelerate eHealth research is to use studies with smaller samples that answer discrete, specific questions, as we aimed to do in this study, rather than conducting one major randomized controlled study [23]. Thus, this study was conducted with an overall aim to identify the characteristics of prompts, specifically the content and delivery mode, that had the potential to promote user engagement with HeLP-Diabetes. Specific objectives were as follows: (1) to identify prompts associated with increased numbers of subsequent visits to HeLP-Diabetes, (2) to identify prompts that appeared to have no association with numbers of subsequent visits to HeLP-Diabetes, and (3) to explore features of these selected prompts to understand why they did or did not appear to lead to subsequent visits to HeLP-Diabetes.

Methods

Study Design

This was a mixed-methods study. It consisted of two components (see Figure 1): a quantitative component that analyzed usage data from the DHI to assess the association between sending email and text message prompts with subsequent visits to HeLP-Diabetes; and a qualitative component that comprised think-aloud interviews to explore user reactions to specific prompts that were selected based on the results of the quantitative component of the study. Ethical approval for the interviews was granted from UCL Ethics Committee (Project Identification number: 7263/001).

Figure 1. Flow diagram of study steps.



Stage 1: Quantitative Component

Objective 1 was to identify prompts that were associated with increased numbers of subsequent visits to HeLP-Diabetes, whereas objective 2 was to identity prompts that appeared to have no association with the number of visits.

Participants

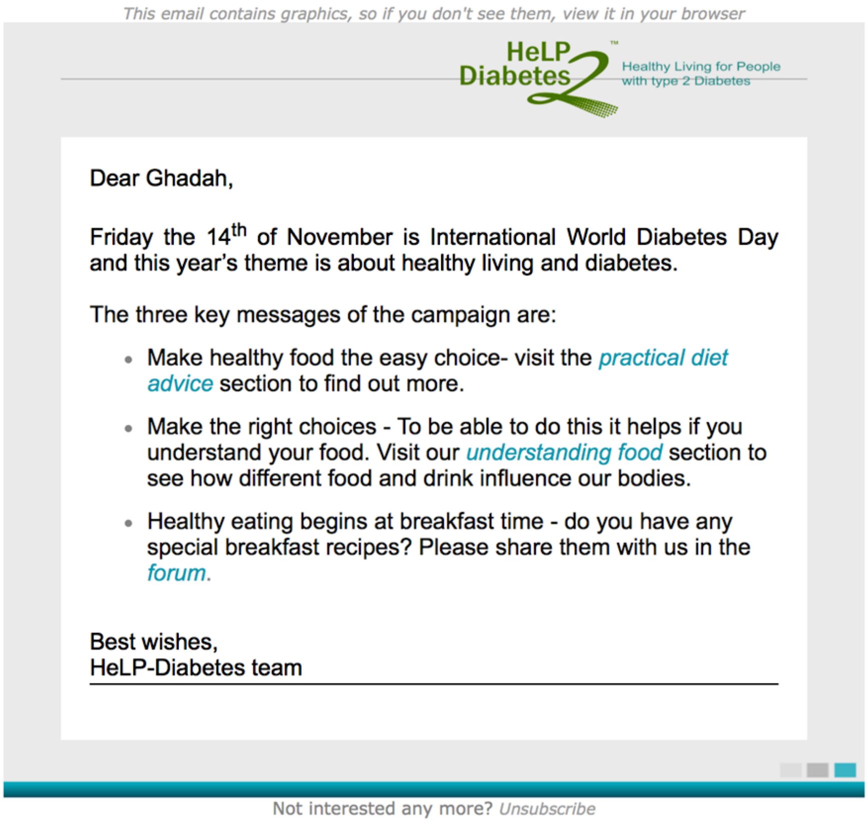
Participants included all the users registered on HeLP-Diabetes between March 2013 and May 2015 who had not specifically “unsubscribed” from receiving emails from the HeLP-Diabetes team. Hence, users were people with type 2 diabetes aged 18 years or older who were living in England, the United Kingdom. They had either volunteered to be a part of the RCT evaluating the clinical effectiveness and cost-effectiveness of HeLP-Diabetes or had been offered HeLP-Diabetes as a part of their routine care.

Design and Procedure

The primary goal of the email and text message prompts was to encourage users to visit the HeLP-Diabetes program; the prompts were not intended to have a direct impact on recipients’ self-care behaviors. Our proposed mechanism of action was that the prompts would bring key areas of the HeLP-Diabetes program to the attention of users and hence encourage visits. The HeLP-Diabetes program was considered the “active ingredient” in terms of promoting self-management. Content for prompts was developed through discussions with a multidisciplinary panel that included patient representatives, general practitioners, diabetes nurses, psychologists, dietitians, and project managers. Prompts were written by the lead author (GA) every month, with content selected to reflect recent diabetes-related news or research, HeLP-Diabetes updates, seasonal events, and other contemporary topics. In general, prompts opened by greeting the users with their username, followed by an introduction to the topics covered in the prompt and links to the relevant parts of HeLP-Diabetes. They ended with the HeLP-Diabetes contact email and the option of unsubscribing from future emails. Due to word count limits, text messages were usually limited to an introduction to the topic of the prompts and the relevant link (see Multimedia Appendices 1 and 2 for prompts content and examples, and Figure 2 for an example of an email prompt). The draft prompts were circulated to the multidisciplinary panel for feedback on content and tone and proofread before being sent to HeLP-Diabetes users. Email prompts were sent using the program “Acymail,” which enabled tracking which emails were opened and by how many users (“email open” rates).

The initial frequency of prompts was based on the advice from the participatory design panel and revised in line with subsequent feedback from patients’ representatives. Initially, the frequency for the prompts was 1 prompt per week; it was subsequently changed to 3 prompts per month. The prompts were not automated, hence a researcher was assigned to send them when they were finalized as per the abovementioned procedure; this resulted in differences in time periods between prompts. Any new user registering would only receive the prompts sent after their registration date. When users registered on HeLP-Diabetes, they were automatically subscribed to emails and given the option to subscribe to text messages. Email prompts were first sent in November 2013, whereas text message prompts started from October 2014. Recipients could unsubscribe from emails and/or text messages at any time.

Figure 2. Example of email prompt “World Diabetes Day.”.



This email contains graphics, so if you don't see them, view it in your browser

Dear Ghadah,

Friday the 14th of November is International World Diabetes Day and this year's theme is about healthy living and diabetes.

The three key messages of the campaign are:

- Make healthy food the easy choice- visit the *practical diet advice* section to find out more.
- Make the right choices - To be able to do this it helps if you understand your food. Visit our *understanding food* section to see how different food and drink influence our bodies.
- Healthy eating begins at breakfast time - do you have any special breakfast recipes? Please share them with us in the *forum.*

Best wishes,
HeLP-Diabetes team

Not interested any more? *Unsubscribe*

Outcome Measures

Usage data (website metrics) refer to parameters that are constructed from digital traces left by users of digital interventions [24]. The usage data for this study included the number, date, and time of visits to HeLP-Diabetes, number of users to whom prompts were sent, users’ identification numbers, dates and numbers of emails and text messages sent, and dates and number of email opens. Usage data were collected for both types of prompts; for email prompts, data were collected between February 2014 and May 2015, and for text messages, between October 2014 and May 2015 (see Multimedia Appendix 1 for list of prompts content). The usage data used in this stage were downloaded from HeLP-Diabetes. Usage data were recorded on HeLP-Diabetes and calculated from server logs that recorded pages viewed by user identification numbers for the duration of the study period. We planned to use Google Analytics for collecting usage data initially, but pilot work showed that the data quality was poor and not all user activity was being appropriately recorded.

Primary Outcome Measure

HeLP-Diabetes User Visits

"HeLP-Diabetes user visits" referred to the user logging into HeLP-Diabetes in the period between prompts. The HeLP-Diabetes user visits measure was used for both email and text message prompts. This was a binary outcome and not a continuous measure—people either visited or they did not in each period, and multiple logins were not counted as multiple visits. For example, if a user visited HeLP-Diabetes after receiving an email prompt twice before the next prompt was sent, only 1 visit was counted for that user.

Secondary Outcome Measure

Email Opens

The "email opens" measure was used for email prompts only. An email was counted as opened if the user's email client (eg, Yahoo Mail, Gmail, Outlook) downloaded the images embedded in the email, as this is the industry standard [25]. However, it is not a completely accurate measure because if images were blocked by email clients, users may be able to read text content without being counted as opening the email. Therefore, the reported email opens numbers may be an underestimate of the actual ones. Additionally, this measure only stored the details of the last time the email was opened; for example, if a user opened an email on the day he/she received it and subsequently reopened it, only the latter open was recorded.

Analysis

Email Prompt Analysis

Statistical analysis was conducted using the Statistical Package for the Social Sciences (SPSS) version 22. To describe the time over which prompts appeared to be associated with subsequent visits, we analyzed the data to identify the median and interquartile range (IQR) for the number of days between sending an email prompt and subsequent visits. This analysis suggested that any association of the prompts was limited to N days, and all subsequent analyses were limited to the visits that occurred within N days of an email prompt being sent. Thereafter, the association between opening an email prompt and visiting HeLP-Diabetes for each prompt within N days was analyzed with the chi-square test, using an alpha of <.05 to indicate statistical significance. A group of email prompts that showed a significant association between opening a prompt and visiting HeLP-Diabetes had a mixture of low and high number of visits, and those that did not show an association were selected visually to be explored in the think-aloud interviews in stage 2.

Text Message Prompt Analysis

Chi-square test was used to find any significant association between sending a text message prompt and visiting HeLP-Diabetes before the next prompt was sent (whether an email or a text message prompt). An alpha of <.05 was used to indicate statistical significance

Stage 2: Qualitative Component

Objective 3 was to explore the features of specific prompts to understand why they did or did not appear to lead to subsequent visits to HeLP-Diabetes.

Participants and Procedure

The sample was a convenience sample, as participants were 6 patient representatives who had been involved in the development of HeLP-Diabetes and the prompts. They were invited to participate in the think-aloud interviews via email. The interviews took place at a time convenient to the participant and at the UCL eHealth unit. During the interview, participants were introduced to think-aloud interviews, and they were encouraged to say all their thoughts and opinions about each prompt, irrespective of whether their thoughts or opinions were negative or considered by them to be insignificant. A short practice was performed at the beginning of the interview to familiarize the participants with the think-aloud techniques (eg, speaking their first thoughts loudly). They were then asked to choose one of the email prompts that had not shown a significant association between opening it and visiting HeLP-Diabetes in stage 1 of the study to practice on. They viewed the prompts on a computer screen. After that, participants were randomly shown the email prompts that the stage 1 of the study had found to be significantly associated with visiting HeLP-Diabetes. They were asked to vocalize their thoughts and opinions while opening each email and describe what they liked or disliked about the content of each prompt and their first impressions or thoughts. After viewing all the email prompts, they were asked some questions based on what they expressed while viewing the emails, and what other participants had expressed in previous interviews (the interview guide evolved throughout the interviews). The interviewer (GA) took notes while the participants viewed the emails and prompted them when they forgot to vocalize their thoughts aloud. At the end of the interview, GA asked the participants for some basic demographic information, namely their age, sex, highest level of education achieved, how long they had had diabetes for, and how they rated their expertise with computers (basic, intermediate, or advanced), as these characteristics may influence participants' perceptions of email prompts [26-28]. Once the participants finished their session, they were thanked and provided with a £20 voucher in appreciation for their help and reimbursed for any travel expenses. This stage of the study took place between July and September 2015 (see Multimedia Appendices 2 and 3 for the email prompts used in the think-aloud interviews and the interview schedule guide, respectively).

Analysis

Interviews were recorded and anonymized. They were transcribed verbatim by a professional and discreet transcriber who had signed a confidentiality agreement. Each participant had an identification number to ensure their anonymity (eg, P1). NVivo 10 was used for data management and analysis. An inductive thematic analysis approach was used. This started with familiarization with the transcripts and any notes taken during the interviews, followed by identification of themes that were strongly linked to the data rather than using preconceptions or a preexisting coding frame. An open coding process was applied where the transcripts were coded line-by-line and paragraph-by-paragraph. In addition, an “in vivo” coding (ie, coding using participants’ words) and constant comparative method, where we constantly compared the data across all the interviews by moving back and forth between them, were used. Emerging codes and themes were discussed and presented within the HeLP-Diabetes team meetings to ensure rigor and thoroughness of the analysis and to include expert and multidisciplinary input in the interpretation of findings.

Patient Involvement

Patients with type 2 diabetes who were involved in the development of HeLP-Diabetes were also involved in the development of the prompts. These patient representatives provided feedback and suggestions on topics, content, and the frequency of prompts. They also participated in the think-aloud interviews.

Results

Overview

The results are divided into two sections. The first section presents the results of the analysis of the email and text message prompts, whereas the second section presents the results of the think-aloud interviews with participants exploring the content of email prompts.

Stage 1

Objective 1 was to identify prompts that were associated with increased numbers of subsequent visits to HeLP-Diabetes, whereas objective 2 was to identify prompts that appeared to have no association with the numbers of visits.

Email and Text Message Prompts’ Characteristics

Between February 2014 and May 2015, 49 prompts were sent to all registered HeLP-Diabetes users; of these, 42 were email prompts and 7 were text message prompts. The number of users who received the prompts ranged between 69 (for prompts sent early in the study) and 432 (for later prompts). The period between each prompt and the next ranged from 3 to 24 days (see Multimedia Appendix 1 for prompts’ date, delivery mode, content, number of recipients).

Participants’ Characteristics

The number of patients registered to use HeLP-Diabetes increased steadily throughout the study period. Each of the prompt recipients had different percentages of characteristics. For example, of the 411 users with available characteristics information who were sent “HeLP Diabetes Newsletter 20-What can you eat?,” 60% (247/411) were male, 41.3% (170/411) were aged between 41 and 60 years, and 51.3% (211/411) were aged 61 years or older. Furthermore, 18% (74/411) participants had had diabetes for less than a year, 33.8% (139/411) for 1 to 5 years, 19.7% (81/411) for 5 to 10 years, 21.6% (89/411) for 10 to 20 years, and the rest for over 20 years 5.8% (24/411) or not stated 0.9% (4/411). Of the 200 people who answered the question about previous computer experience, 38% (76/200) described it as “basic,” 37% (74/200) as “intermediate,” and 25% (50/200) as “advanced.”

Association Between Email Prompts and Visits to HeLP-Diabetes

Examining all the user visits (N=918) that were recorded following the sending of each email prompt, from the first one in February 2014 until the last in May 2015, the time taken for users to visit HeLP-Diabetes after an email prompt was sent ranged from the same day to 23 days. The median time taken to visit HeLP-diabetes was 1 day after receiving an email prompt, with an IQR of 0 to 5 days (ie, 25% visited HeLP-diabetes on the same day of receiving an email prompt, and 75% did so up to 5 days of receiving a prompt). The percentage of users who opened or did not open an email and visited HeLP-Diabetes up to 5 days after a prompt was sent is shown in Figure 3. No user visited HeLP-Diabetes within 5 days after the email prompts “How do I lose weight and feel better?,” “Designing your care plan,” and “Shopping for food” were sent.

Data for 3 email prompts (“Keeping your bones healthy,” “HeLP-Diabetes Newsletter 9-Anxiety,” and “HeLP-Diabetes Newsletter 10-Break a sweat this summer!”) were excluded because the time between sending the prompt and the next email prompt was less than 5 days.

The chi-square test identified 19 email prompts (out of the 39 analyzed ones) that showed a statistically significant association ($P<.05$) between opening an email and visiting HeLP-Diabetes up to 5 days after an email prompt was sent (see Table 1). Out of those 19 email prompts, “World Diabetes Day” had the highest percentage of users who opened an email prompt and visited HeLP-Diabetes: the prompt was sent to 308 users, 43.2% (133/308) opened the email and of these 28.6% (38/133) then visited the website. The next most successful prompt was “HeLP-Diabetes Newsletter 12-Your diabetes is in your hands,” which was sent to 233 users and 27% (25/92) of users opened and then visited HeLP-Diabetes. The email prompt “Making HeLP-Diabetes easier” was sent to a larger number of users than the previous 2 prompts (N=428), but it had the lowest response rate; although 40.2% (172/428) opened the email prompt, only 8.1% (14/172) of users then visited HeLP-Diabetes. Starting from the email prompt “HeLP-Diabetes Newsletter 11-Holiday preparations,” the sample was bigger and the email prompts showed a significant association between opening the email prompt and visiting HeLP-Diabetes, with the exception of “HeLP-Diabetes Newsletter 13-Get rid of your medication worries!” and “Autumn health reminder.” These 2 email prompts were sent to a relatively larger number of users compared with earlier email prompts, but they did not have a high percentage of users who opened an email prompt and visited HeLP-Diabetes.

Table 1.

Email prompt title	Users who visited HeLP-Diabetes % (n/N)	Users who opened an email prompt % (n/N)	Users who opened an email prompt and visited HeLP-Diabetes % (n/N)	Chi-square result X^2(df[a], N), P value
How are your New Year's resolutions going?[b]	1 (1/71)	38 (27/71)	0 (0/27)	0.6 (1, 71), .43
HeLP-Diabetes Newsletter 6-Medication[b]	1 (1/69)	27 (19/69)	5 (1/19)	2.7 (1, 69), .10
Boosting your health during winter[b]	3 (3/79)	40 (32/79)	6 (2/32)	0.9 (1, 79), .35
Best diet advice![b]	2 (2/81)	44 (36/81)	2 (1/36)	0.02 (1, 81), .87
Share your personal experience with us![b]	2 (2/69)	36 (25/69)	8 (2/25)	3.6 (1, 69), .06
How do I lose weight and feel better?[b]	0 (0/83)	38 (32/83)	0 (0/32)	No user visited HeLP-Diabetes
Designing your care plan[b]	0 (0/90)	38 (35/90)	0 (0/35)	No user visited HeLP-Diabetes
HeLP-Diabetes Newsletter 7-Making changes[b]	5 (5/98)	31 (31/98)	9 (3/31)	2 (1, 98), .16
It's Springtime[b]	3 (3/99)	39 (39/99)	5 (2/39)	1 (1, 99), .32
Happy Easter	2 (2/102)	37 (38/102)	5 (2/38)	3.4 (1, 102), .06
Shopping for food	0 (0/103)	22 (23/103)	0 (0/23)	No user visited HeLP-Diabetes
Achieving your goals[b]	.9 (1/106)	30.2 (32/106)	3 (1/32)	2.3 (1, 106), .13
HeLP-Diabetes Newsletter 8-Personal experiences[b]	2.8 (3/108)	30.6 (33/108)	6 (2/33)	1.9 (1, 108), .17
How many meals do you eat per day?[c]	10.7 (12/112)	41.1 (46/112)	21 (10/46)	9.9 (1, 112), <.001
What you need to know about hypoglycemia![c]	8.5 (11/130)	40.8 (53/130)	18 (10/53)	12.5 (1, 130), <.001
Are you a complementary therapy user?[c]	6.6 (9/136)	31.6 (43/136)	18 (8/43)	14.6 (1, 136), <.001
Sexual health-let's talk about it![c]	4.8 (7/145)	27.6 (40/145)	5 (2/40)	0.004 (1,145), .95
Fasting during Ramadan[c]	8.4 (14/167)	28.7 (48/167)	16 (8/48)	6 (1, 167), .01
HeLP-Diabetes Newsletter 11-Holiday preparations	8.8 (16/182)	35.7 (65/182)	18 (12/65)	11.8 (1, 182), .001
How to handle the summer heat?	10.8 (23/213)	36.6 (78/213)	23 (18/78)	19.3 (1, 213), <.001
HeLP-Diabetes Newsletter 12-Your diabetes is in your hands	12.4 (29/233)	39.5 (92/233)	27 (25/92)	30.3 (1, 233), <.001
HeLP-Diabetes Newsletter 13-Get rid of your medication worries![c]	5.4 (13/242)	36 (87/242)	10 (9/87)	6.6 (1, 242), .01
Smile - You're on Camera!	6.8 (17/249)	35.7 (89/249)	14 (13/89)	13.2 (1, 249), <.001
Autumn health reminder[c]	4.5 (12/268)	35.4 (95/268)	5 (5/95)	0.2 (1, 268), .64
HeLP-Diabetes Newsletter 14-What's happening this October?	11.5 (33/286)	38.8 (111/286)	21.6 (24/111)	18.1 (1, 286), <.001
World Diabetes Day	14.6 (45/308)	43.2 (133/308)	28.6 (38/133)	36.6 (1, 308), <.001
HeLP-Diabetes Newsletter 15-Shopping done the right way	10.5 (35/333)	38.1 (127/333)	22.8 (29/127)	33.2 (1, 333), <.001

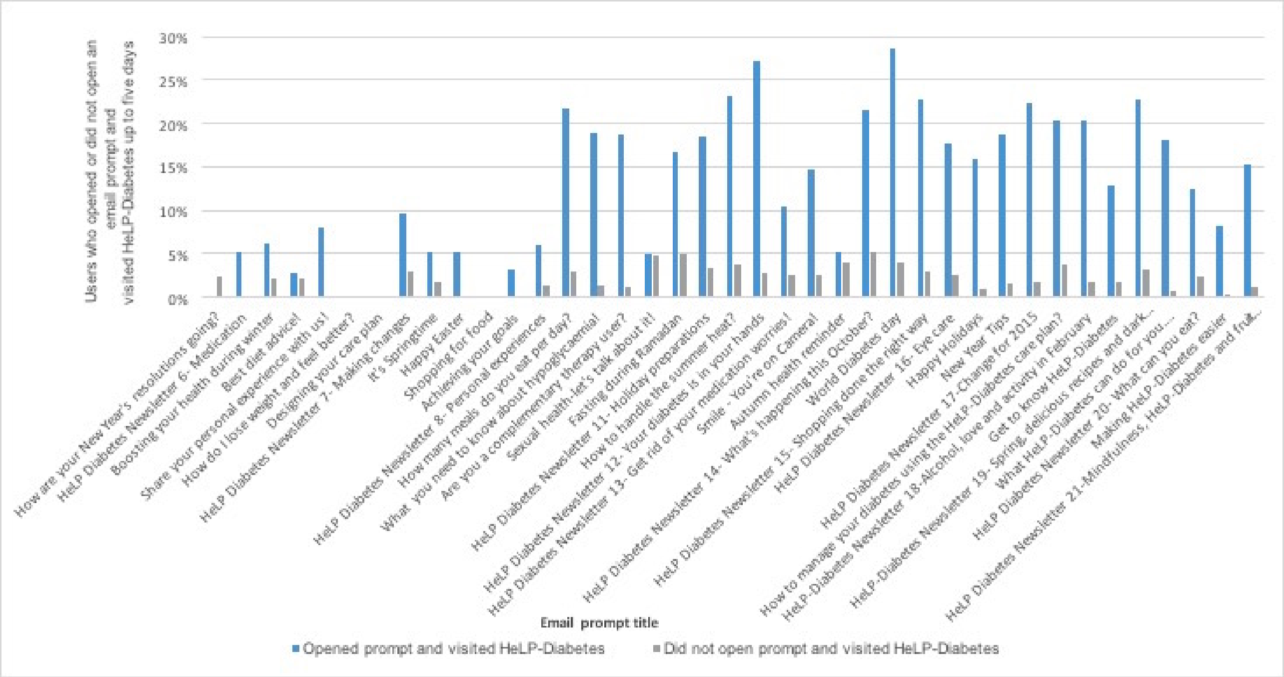
Email prompt title	Users who visited HeLP-Diabetes % (n/N)	Users who opened an email prompt % (n/N)	Users who opened an email prompt and visited HeLP-Diabetes % (n/N)	Chi-square result X^2(df[a], N), P value
HeLP-Diabetes Newsletter 16-Eye care	8.9 (30/338)	42.0 (142/338)	17.6 (25/142)	23.1 (1, 338), <.001
Happy Holidays	6.9 (24/346)	39.9 (138/346)	15.9 (22/138)	28.8 (1, 346), <.001
New Year Tips	8.9 (31/348)	43.1 (150/348)	18.7 (28/150)	30.9 (1, 348), <.001
HeLP-Diabetes Newsletter 17-Change for 2015	8.9 (32/358)	34.9 (125/358)	22.4 (28/125)	42.8 (1, 358), <.001
How to manage your diabetes using the HeLP-Diabetes care plan?	10.6 (40/376)	42 (158/376)	20.3 (32/158)	26.5 (1, 376), <.001
HeLP-Diabetes Newsletter 18-Alcohol, love and activity in February	9.5 (37/390)	41.8 (163/390)	20.2 (33/163)	37.7 (1, 390), <.001
Get to know HeLP-Diabetes	6.7 (27/404)	44.1 (178/404)	12.9 (23/178)	19.9 (1, 404), <.001
HeLP-Diabetes Newsletter 19-Spring, delicious recipes and dark chocolate	10.3 (42/407)	36.9 (150/407)	22.7 (34/150)	39.1 (1, 407), <.001
What HeLP-Diabetes can do for you….	7.5 (31/416)	38.5 (160/416)	18.1 (29/160)	42.9 (1, 416), <.001
HeLP-Diabetes Newsletter 20-What can you eat?	6.3 (26/416)	38.9 (162/416)	12.3 (20/162)	16.8 (1, 416), <.001
Making HeLP-Diabetes easier	3.5 (15/428)	40.2 (172/428)	8.1 (14/172)	18.3 (1, 428), <.001
HeLP-Diabetes Newsletter 21-Mindfulness, HeLP-Diabetes and fruit sugar	6.7 (29/432)	39.4 (170/432)	15.3 (26/170)	33 (1, 432), <.001

[a] df: degrees of freedom.

[b] 2 cells (50.0%) have expected count less than 5.

[c] 1 cell (25.0%) has expected count less than 5.

Figure 3. Percentage of users who opened or did not open an email prompt and visited HeLP-Diabetes up to 5 days after sending one.



Association Between Text Message Prompts and Visits to HeLP-Diabetes

There were 7 text message prompts sent between October 2014 and May 2015. None of these 7 text message prompts showed a statistically significant association between subscribing to receive text message prompts and visiting HeLP-Diabetes (see Table 2).

Stage 2

Objective 3 was to explore features of specific prompts to understand why they did or did not appear to lead to subsequent visits to HeLP-Diabetes.

Participants' Characteristics

There were 6 patient representatives who agreed to participate. Five out of the 6 representatives had worked with us previously, and they provided regular feedback about prompts' frequency, content, and timing from early 2014. The sixth participant started working with us in mid-2015 and only provided feedback on 1 prompt. All the participants were over the age of 50 years. Two of them were males, and 4 participants had degree-level qualifications. Most of the participants rated their computer experience as medium to high. The length of diabetes diagnosis ranged between 5 and 40 years (see Table 3).

Preference of Email Prompt Content

The main findings from the interviews related to participants' likes and dislikes of the prompts are presented below, accompanied with illustrative quotes.

Likes

Participants preferred short and clear email prompt content with an overview at the beginning of an email summarizing the content. Participants suggested including as many links to HeLP-Diabetes pages and section as possible without overwhelming users. One participant liked it when a clear description of what the links included in a prompt would direct the users to what was provided:

> *So, someone might say, I haven't got time to watch a video, and they look at their watch, and next the computer says, watch the 3-minute video, so that would be good, because 3 minutes is nothing, isn't it? I like that.* [P4; email prompt title: HeLP-Diabetes Newsletter 12-Your diabetes is in your hands.]

Some participants liked it when the emails started by greeting them with their usernames, whereas others felt that personalizing emails in such a way should only be done in short emails and that newsletters should not include their usernames. One user felt that personalizing emails did not make a big difference to the content and how engaging it was.

Table 2.

Text message prompt topics	Subscribed users who visited HeLP-Diabetes % (n/N)	Unsubscribed users who visited HeLP-Diabetes % (n/N)	Chi-square result X^2(df[a], N), *P* value
Flu jab reminder	5.8 (10/172)	10.9 (14/129)	2.6 (1, 301), .11
Home exercises	6.5 (12/185)	2.1 (3/142)	3.5 (1, 327), .06
Eating and drinking on holidays	4.0 (8/199)	5.3 (8/151)	0.3 (1, 350), .57
January blues	5.3 (10/190)	4.8 (8/167)	0.04 (1, 357), .83
Sharing problems and advices	4.8 (10/209)	5.6 (9/161)	0.1 (1, 370), .72
National Health Service medical exemption certificate	4.7 (11/234)	3.5 (6/173)	0.4 (1, 407), .53
Specialist and technical support	2.8 (7/246)	2.8 (5/180)	0.002 (1, 426), .96

[a] df: degrees of freedom.

Table 3.

ID	Sex	Age, in years	Education level	Length of diabetes diagnosis, in years	Computer experience	When user joined the team, number of prompts the user provided feedback on
P1	Female	55	Degree	15	High	From mid-2014, 8 prompts
P2	Male	50	Postgraduate	5	High	From mid-2015, 1 prompt
P3	Female	60	Degree	20	Medium-high	From early 2014, 10 prompts
P4	Male	58	Grammar school	12	Medium	From early 2014, 9 prompts
P5	Female	68	Postgraduate	40	Medium-high	From early 2014, 12 prompts
P6	Female	69	A level	10	Medium	From early 2014, 12 prompts

Popular content included the use of empowering statements in the titles or in the body of the email such as in the email prompt “HeLP-Diabetes Newsletter 12-Your diabetes is in your hands,” statements referencing health professionals or linking to their recommendations, email titles written as questions (eg, “How to handle the summer heat?” and “HeLP-Diabetes Newsletter 20-What can you eat?”), and including news or HeLP-Diabetes-related updates were seen as the most attention-grabbing type of content:

> *Well, obviously new developments and things like that, and research and obviously this October stuff. Things like that, topical things. Topical things to keep people engaged. Just anything new that’s coming out, and keeping people up to date with research and stuff like* [P6]

As for the visual appeal of email prompts, all the participants favored bold colors for the text, bullet point use, short emails (specifically newsletters) not exceeding A4 in length, and the use of pictures.

Dislikes

The majority of participants did not like wordy email prompts with lots of information; they felt that prompts should have information written succinctly and concisely:

> *I don't like a big sheet where it’s all mangled up together.* [P1]
>
> *Too much info. Too much info. I wouldn’t really be reading that.* [P2; email prompt title: HeLP-Diabetes Newsletter 20-What can you eat?]

Participants felt prompts should be easily understood and disliked the use of complicated medical terminology or language that was hard to understand.

Most of the participants disapproved of directive advice. They felt, as people living with a chronic condition, that they were told on a daily basis what they should or should not be doing when it comes to any aspect of their type 2 diabetes self-management. They preferred the use of the word “try” rather than “orders” when advice was given:

> *This is very directive - stay optimistic, stay happy. Rather than, try to stay optimistic is more of an empowering sort of thing.* [P2; email prompt title: HeLP-Diabetes Newsletter 12-Your diabetes is in your hands]

Perceived irrelevancy of email prompt content was a major reason behind not clicking the links embedded in the prompt. Irrelevant content included specific content targeting small subgroups of participants (eg, content targeting only smokers). Participants preferred more general content that applied to the needs of different patients.

When it came to the visual aspects of email prompts, participants disliked faint colors for text or pictures and particularly disliked it when color of the included links was indistinguishable from the rest of the written content.

Discussion

This mixed-method study provides an insight into the potential components or characteristics (specifically delivery modes and content) that can promote engagement with a DHI targeting self-management of type 2 diabetes (HeLP-Diabetes) and the factors that may influence their effectiveness.

Summary of Findings

Just under half of email prompts showed a significant association with visits to HeLP-Diabetes. Nineteen out of the 39 email prompts (49%) showed a significant association with visits to HeLP-Diabetes up to 5 days after an email prompt was sent, whereas none of the text message prompts showed a significant association. Furthermore, 75% of HeLP-Diabetes visits occurred in the 5 days after an email prompt was sent.

The think-aloud interviews suggested that an email prompt should be relevant to recipients, short and concise, easy to understand, with simple language and short sentences, contain links to the intervention, contain nondirective advice and aim for an empowering approach, and contain news and updates. Preferred visual aspects included the use of bullet points, pictures, and bold colors.

Fit With Literature

The email prompts’ results are consistent with the literature regarding engagement prompts; prompts may promote engagement but have a small to moderate effect as shown in a published meta-analysis [10]. However, text message results were unexpected, as the literature shows that text message prompts are better than emails [19]. This result might be because of an older sample not owning smartphones to click the links, the text messages not being detailed enough to be attention-grabbing or not tailored to a degree that facilitates behavior change.

The results of the study showed that, unlike other published studies [29,30], later prompts were not associated with reduced visits to the DHI. There was no downward trend but rather visits were fluctuating; this fluctuation might be because of the prompt content, frequency, timing, and other possible variables.

Some of the preferred email content identified in the interviews was consistent with what is recommended in the literature; the use of nondirective language in face-to-face health or behavior change-related settings has an influence on behavior change [31]. This type of language was also recommended to be used in DHI content [32]. Another feature is the inclusion of news articles or updates to HeLP-Diabetes sections and pages; one study that examined the effect of email prompt content on engagement showed that the inclusion of links to news items on a DHI showed a positive trend toward engagement [18]. Finally, inclusion of health professional references has been reported to be preferred by patients using a service [33]. Personalizing the content of DHIs is also recommended in the literature; however, it is still unclear what level of tailoring prompts should have [32,34].

Strengths and Limitations of the Study's Methodology

There were a number of key strengths of this study, including the use of both quantitative and qualitative methods to achieve the research aim, as the combination of methods complemented and provided a clearer picture of the results. Quantitative data cleaning and validating was conducted and reviewed by 2 authors, along with reviewing the interview transcripts and coding to ensure rigor and transparency. The quantitative outcome measure (ie, HeLP-Diabetes user visits) used in this study was objective, meaningful, highly sensitive, and responsive to change, as opposed to subjective measures such as questionnaires. A final key strength was that this research was conducted in a real-life setting rather than a controlled setting where variables that might influence causation are removed.

The study had some limitations, which is to be expected in the emerging field of DHI engagement prompt research. The first main limitation concerned the prompts; the number of users who received the earlier email prompts was small and underpowered to detect an association between receiving a prompt and visiting HeLP-Diabetes; some email prompts' opens might have not been accounted for if the embedded images were not downloaded; and only a small number of text messages were sent because of technical reasons. The second limitation concerned the think-aloud participants; 6 participants may not have been enough to identify a larger variety of HeLP-Diabetes users' possible preference for prompt content, however, in the field of human-computer interaction, using 5 users in a usability study is enough to show 85% of design problems that need to be fixed [35]. In addition, being experienced patient representatives who have helped with developing HeLP-Diabetes and prompts, they might not reflect the type of users who use HeLP-Diabetes. In particular, their demographic characteristics were dissimilar to those of many of the registered users in terms of educational qualifications and computer expertise. Another issue related to patient representatives was the fact that it was not possible to analyze whether they visited HeLP-Diabetes following the prompts that were shown to them. The interviews only provided data about the features they liked or not rather than whether the feature would lead to a visit to HeLP-Diabetes or not. Hence, the data did not allow for exploration of engagement behavior. However, it was not possible to recruit HeLP-Diabetes registered users, so patient representatives were asked to be interviewed. The final limitation was that prompts are context-specific interventions, which is why the results may not be generalizable across other DHI or other types of interventions targeting type 2 diabetes self-management. These limitations show that this study was good for hypothesis generation rather than effectiveness determination.

Research Implications

This mixed-method study provides a means to explore and optimize the effect of different prompt characteristics on engagement with any DHI before conducting an RCT to determine the effectiveness of the prompts. This type of study can be conducted within any research evaluating a DHI that uses prompts to explore their characteristics. By mostly selecting prompts that showed a significant association with visiting HeLP-Diabetes for the think-aloud interviews, the study results identified characteristics of email prompts that could be tested in a pilot RCT by the research team. Also, the quantitative stage of the study showed that some emails were associated with visits to HeLP-Diabetes, whereas none of the text messages showed any association. This led to a pilot RCT to assess the effect of different modalities.

One important characteristic that needs to be researched further in future studies is the frequency of prompts. For example, one systematic review that looked at frequency of prompts for DHIs targeting different health behaviors found that high-intensity and low-intensity prompts or irregular prompts both yielded positive engagement [36]. In addition, another study showed that text message prompts were more effective at changing health behaviors if they were sent daily compared with if they were sent less frequently [37]. In this study, the frequency of the prompts was based on the feedback given by patient representatives, because participants were registering over time and no fixed sample was available to test different frequencies. Hence, future studies can explore the frequency of engagement prompts.

Usage data analysis is a challenging area of research, as it involves considering and balancing advantages and disadvantages of using specific measures. In this study, "email opens" was used instead of links clicked because users might be triggered to visit HeLP-Diabetes without clicking the links in the email. Visits to HeLP-Diabetes were used instead of Web page visited, which would have shown users' interests and whether they visited the pages in the prompts or not. However, as with the earlier measure (ie, links clicked and email opens), visits to HeLP-Diabetes are more general and better able to catch users' activity than a specific measure. Future studies can compare the results of different measures and investigate which ones can capture engagement with DHI because of receiving prompts accurately.

The relationship between engagement with DHI and health outcome improvement was not the focus of this study. The HeLP-Diabetes RCT [21] conducted a subgroup analysis to assess the association between engagement and improvement in diabetes-related clinical outcome; the results were positive. However, it was not possible to determine whether engagement led to health improvement or vice versa; this issue can be explored in future studies, which can also look at the level of engagement that can lead to health improvement (ie, effective engagement) [14].

The data from stage 2 was not rich enough to facilitate deeper interpretation of how the reactions to the prompts led to subsequent behaviors. This may have been because of the method of data collection—"think-aloud interviews" are a method emanating from human-computer interaction science, mostly used to test usability issues rather than look for deeper meaning. Alternatively, it may be that our participants in stage 2, who had all worked with the HeLP-Diabetes team and were used to contributing feedback and ideas for the program, had become used to providing actionable feedback rather than deeper reflections. It would be useful to recruit naïve users in future studies and perhaps undertake additional interviews after the "think-aloud" data collection to obtain richer data.

Conclusions

This study showed that specific email prompts were associated with greater engagement with a DHI targeting type 2 diabetes self-management (HeLP-Diabetes), but that was not the case for text messages. Participants tended to open an email prompt and visit the DHI up to 5 days of receiving the prompt. The prompts explored in think-aloud interviews led to the identification of the prompt content features that users liked (eg, new content) or disliked (eg, directive advice). The study results can be explored further in future RCTs evaluating characteristics of engagement prompts.

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Conflicts of Interest

EM is the managing director of a not-for-profit community interest company, which aims to disseminate HeLP-Diabetes across the English NHS. She does not, and will not, take any remuneration for this role.

Multimedia Appendix 1

Prompts date, delivery mode, content, number of recipients.

[PDF File (Adobe PDF File), 44KB - ijmr_v6i2e14_app1.pdf]

Multimedia Appendix 2

List of prompts used in the think aloud interviews.

[PDF File (Adobe PDF File), 2MB - ijmr_v6i2e14_app2.pdf]

Multimedia Appendix 3

Interview schedule guide.

[PDF File (Adobe PDF File), 32KB - ijmr_v6i2e14_app3.pdf]

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Abbreviations

CCG: clinical commissioning group
DF: degrees of freedom
DHI: digital health intervention
HeLP-Diabetes: Healthy Living for People with type 2 Diabetes
IQR: interquartile range
RCT: randomized controlled trial
RR: relative risk
UCL: University College London

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Original Paper

Toward a New Kind of Vaccine: A Logical Extension of the Symmetrical Immune Network Theory

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Abstract

Background: The symmetrical immune network theory, developed in 1975, is based on the existence of specific T cell factors and hypothesizes that normal IgG immune responses comprise the production of 2 kinds of antibodies, namely antigen-specific antibodies and anti-idiotypic antibodies.

Objective: The aim of this study was to confirm the existence of specific T cells factors and to show that immunization of C3H mice with BL/6 skin or using nominal antigen for immunization (Tetanus Toxoid) induced production of antigen-specific (anti-BL/6 or antitetanus) antibodies plus anti-idiotypic antibodies (C3H anti-anti-C3H). Subsequently, we investigated the role of combinations of antigen-specific and anti-idiotype antibodies in a variety of animal models of clinical diseases.

Methods: Antigen-specific antibodies were produced by conventional immunization of mice (eg, with tetanus toxoid or by skin allografting). Subsequent anti-idiotypic antibodies were derived by exhaustive absorption of antigen-specific antibody, with confirmation of anti-idiotypic specificity by binding to relevant target antigen-specific antibodies in an enzyme-linked immunosorbent assay (ELISA). Antigen-specific plus anti-idiotypic antibodies were then used to modulate skin allograft survival, dextran sulfate sodium (DSS)-induced colitis, *ovalbumin* (OVA)-induced IgE production, and breast cancer growth in mice.

Results: Infusions of anti-BL/6 antibodies together with BL/6 anti-anti-BL/6 antibodies specifically suppressed (>85%) an immune response to BL/6 lymphocytes in C3H mice. The two kinds of antibodies with complementary specificity are hypothesized to stimulate 2 populations of T lymphocytes. Coselection of these 2 populations leads to a new stable steady state of the system with diminished reactivity to BL/6 tissue. A combination of anti-C3H and C3H anti-anti-C3H IgG antibodies down-regulated inflammation in a mouse model of inflammatory bowel disease (>75%) and attenuated anti-IgE production and sensitization to produce IL4 cytokines (>70%) in an OVA-allergy model. Combination of C3H anti-BL/6 and BL/6 anti-anti-BL/6 antibodies decreased tumor growth and metastases (>705) in an EMT6 transplantable breast cancer model.

Conclusions: Use of a combination of antigen-specific and anti-idiotypic antibodies has potential as a new class of vaccines.

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KEYWORDS

immunity; anti-idiotype antibodies immune system concepts; information networks

Introduction

Much research on anti-idiotypic antibodies has been focused on such antibodies mimicking the shape of the antigen, and therefore, being able to substitute for the antigen [1-3]. An antibody specific for an antigen X has a V region that is anti-X, which we refer to as an anti-X idiotype. If we immunize a rabbit with an anti-X antibody, together with an adjuvant, the rabbit may make anti-anti-X anti-idiotypic antibodies. However, such anti-idiotypic antibodies play no role in the immune network theory that has been developed in a series of papers and a monograph published from 1975 till date [4-7]. The theory is called the symmetrical immune network theory. The anti-idiotypes that play a role in immune network theory are of two types, namely coselection anti-idiotypes [5] and second symmetry anti-idiotypes [4]. Coselection anti-idiotypes are expressed by lymphocytes that are coselected (mutually selected) with antigen-specific lymphocytes, whereas second symmetry anti-idiotypes are anti-idiotypes present in an A anti-B or A anti-X serum that are specific for antigen-specific antibodies present in a B anti-A serum and where X is again an antigen.

The symmetrical immune network theory involves symmetrical stimulatory, inhibitory, and killing interactions. A simple symmetrical network model that includes antigen (Ag), antigen-specific lymphocytes (T+ and B+), anti-idiotypic lymphocytes (T− and B−), and nonspecific accessory (A) cells is shown in Figure 1. A cells include monocytes, macrophages, and dendritic cells. This model will be described below in the sections on the roles of specific T cell factors. In this model, an immune response involves an immunogenic form of an antigen stimulating T and B cells, specific T cell factors from the T cells binding to a receptor on the surface of A cells, and the antigen activating the A cell by cross-linking a receptor on the A cell via the specific T cell factors. The antigen also stimulates antigen-specific B cells by cross-linking their receptors, and they proliferate and express a receptor for the differentiation factor produced by the activated A cells. When the antigen-specific B cells receive the second signal differentiation factor, they switch to being antibody-secreting plasma cells.

Controversially, the symmetrical immune network theory involves a role for antigen-specific T cell factors. Many papers published in the 1970s and 1980s demonstrated the existence of such factors [8-18], including a paper by Takemori and Tada that rigorously demonstrated that carrier-specific T cell factors can specifically suppress IgG responses [10]. In 1991, GWH pointed out that the reproducibility of the Takemori-Tada result was a suitable test for the existence of these factors [18]. If that experiment could not be reproduced, it would call into question the fundamental ideas contained within the symmetrical immune network theory. On the other hand, if the experiment was reproduced, such factors presumably do indeed exist and their existence is thus currently erroneously being widely ignored. To our knowledge, in the 25 years since 1991, no one has claimed to be unable to reproduce the Takemori-Tada result, nor has anyone published confirmation that the experiment is reproducible. As a starting point for our further analysis of the importance of a symmetrical immune network theory to offer new insight into how to control various immune reactivities of clinical significance, we first attempted to confirm the reproducibility of this key experiment (see Figure 1).

In the studies described below, we have moved beyond this important confirmation of the existence of T cell derived antigen-specific suppressive factors to provide evidence that application of symmetrical immune network theory provides an invaluable means to alter, in separate mouse model systems, transplant rejection, inflammatory bowel disease, allergic responses, and tumor growth.

Figure 1. A simple idiotypic network model that includes antigen (Ag), antigen-specific T cells and B cells (T+ and B+), anti-idiotypic T cells and B cells (T- and B-) and non-specific accessory cells (A cells; see left hand panel). For explanation, see the sections in the text on the role of specific T cell factors in an immune response and the role of specific T cell factors in the induction of tolerance by an antigen.Repeat of Takemori and Tada study (right hand panel-see text for details). *P<.05 compared with no extract control (MANOVA).

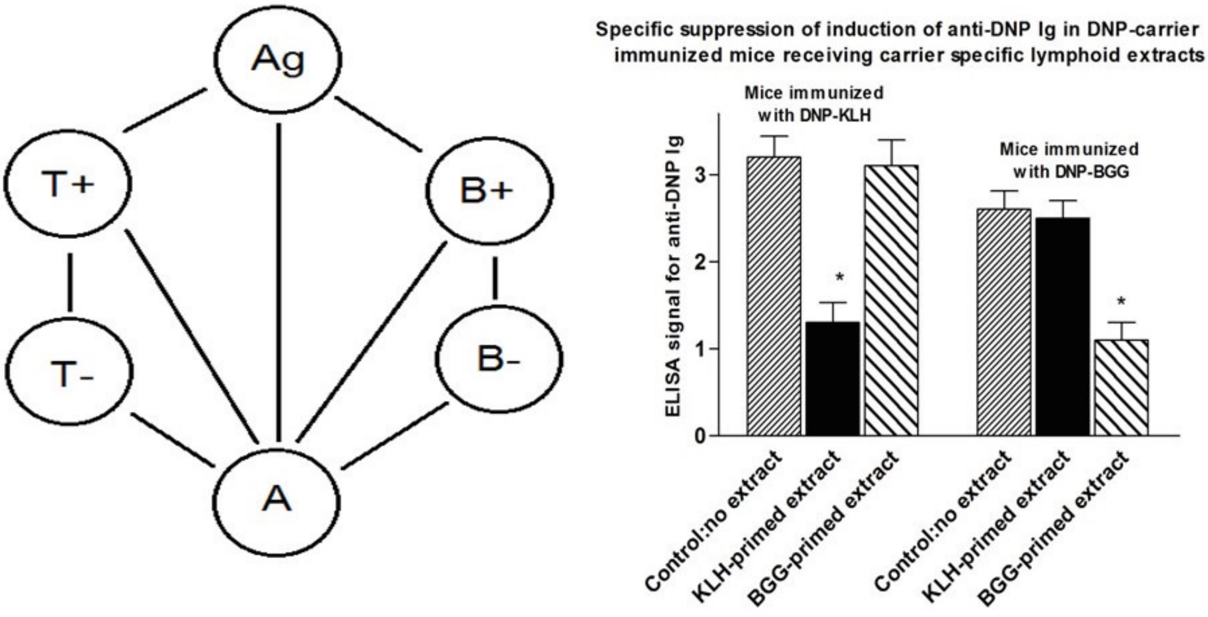
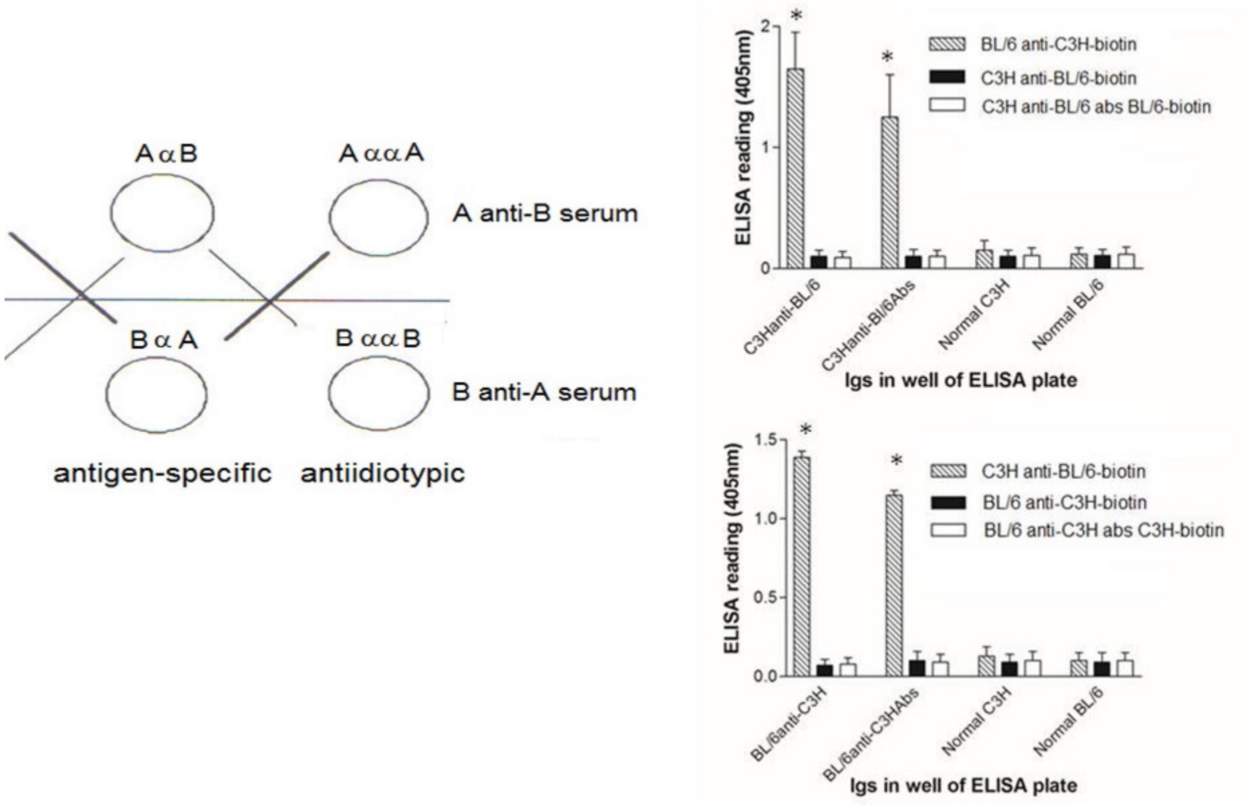


Figure 2. Left hand panel shows the antibodies in an A anti-B serum, where A and B are two strains of mice, including A anti-B and A anti-anti-A antibodies (shown as AαB and AααA, respectively). These are complementary to the B anti-A and B anti-anti-B antibodies that are present in a B anti-A serum.Right hand panel shows binding of complementary antibodies assayed by ELISA. Biotinylated BL/6 anti-C3H IgG binds to C3H anti-BL/6 IgG and to C3H anti-BL/6 IgG absorbed with BL/6 lymphocytes (upper panel), while C3H anti-BL/6 IgG binds to BL/6 anti-C3H IgG and BL/6 anti-C3H IgG absorbed with C3H lymphocytes (lower panel). ELISA plates were coated with10ng IgG. Biotinylated IgGs were used at 1:2500 concentration (with streptavidin-HRP at 1:2000). *P<.02 MANOVA.



Methods

Mice

Female C57BL/6, C3H/HEJ and BALB/c mice were purchased from Jax Labs, Bar Harbour Maine. All mice were housed 5 per cage and maintained at the University Health Network (UHN) animal facility (animal protocol: RMG: AUP1.18). Mice were used at 8 weeks of age.

Reproduction of Takemori and Tada Study

To prepare T cell extracts, 5 BALB/c mice per group were immunized x2 with 100µg/mouse keyhole limpet hemocyanin (KLH) or *bovine gamma globulin* (BGG) (both purchased from Sigma Biochemicals, Canada) at 14d intervals. Mice were sacrificed 14d after the last immunization, spleen+ thymus cells pooled within groups, and cells resuspended at 3x10^{8}/ml. Suspensions were sonicated at 4°C for 4 min and subjected to ultracentrifugation for 60 min at 4°C. Additionally, 0.3ml of sonicate per mouse was infused into groups of 10 BALB/c. However, 10 control mice received no extract.

A total of 5 mice of each group of 10 mice were subsequently immunized with either dinitrophenol (DNP)-KLH of DNP-BGG (100µg/mouse) in complete Freund's adjuvant (Sigma Biochemicals, Canada). Mice were sacrificed 12d later and serum collected from all individuals. Sera were assayed in ELISA plates that were precoated with DNP-coupled albumin (100ng/well) and with horseradish *peroxidase* (HRP)-anti-mouse Ig (Cedarlane Labs, Burlington, Canada) as developing Ig. Test sera were tested at 1:5, 1:20, and 1:100 dilution-only; data for 1:20 dilutions are shown in the Results section (see Figure 1, pooled from 2 studies).

Skin Grafting

C3H or BL/6 mice received allogeneic or syngeneic skin grafts transplanted to the flank as described previously [19]. Graft survival was monitored daily by an observer blinded to any previous treatment of the graft recipients.

In some cases, grafted mice were used as sources of antigraft specific Ig (or anti-anti-self Ig). In these instances, 15 mice per group were grafted twice (at 21d intervals), with donor skin (same donor haplotype) and blood obtained by cardiac puncture 10d after the second graft. Pooled serum was obtained by centrifugation (5000g at 4°C for 20 min), heat inactivated, aliquoted (0.3ml aliquots), and stored at −80°C. Where serum was absorbed (anti-anti-donor Ig), aliquots (0.3ml) were absorbed 3x for 60 min at room temperature with a fresh pellet of 3x10^{8} spleen and thymus, prepared from the described donors (20 mice/group used as donors for absorption). Following 3 serial absorptions, depletion of cytotoxic activity in serum was confirmed using spleen cell blasts and serial dilutions of antibody with rabbit complement (1:10 final dilution), incubated at 37°C for 60 min before addition of trypan blue to assess cell death. Routinely titres dropped from 50% lysis at ~1:2000 to ~1:2 following this absorption (Figures 2 and 3).

In other studies, mice were pretreated before transplantation with A anti-B sera and anti-anti-self Ig. In these cases, 8 mice per group received weekly injections (intravenous [IV] and/or intraperitoneal [IP]) of serum Ig at the concentration described, diluted in 0.3ml Phosphate buffered saline (PBS). Control serum in these studies (referred to as "normal IgG" in the text and Figures) represented serum pooled from a minimum of 15 equivalent nonimmunized naive mice.

Mixed Leukocyte Culture Assays (MLCs) and Chromium-51 Lysis Assays for Cytotoxic T Lymphocytes (CTL)

Graft recipients were sacrificed at the times described in the text and figure legends, and single cell spleen suspensions prepared for individual mice. 6x10^{6} responder cells were incubated in triplicate with 3x10^{6} irradiated spleen stimulator cells in flat bottomed culture wells (24-well culture plates) in 3.0 ml αMinimal Essential Medium (αMEM: Gibco, USA), supplemented with 10% of fetal calf serum and 10^{-6}M 2-mercaptoethanol (αF10). In some cultures, an aliquot (200µl) of medium was removed at 40 h to assess cytokine production, using commercial ELISA kits (BioLegend, USA). After 5d, cells were harvested, washed, and used at different effector:target ratios (from 50:1 to 5:1) in triplicate for lysis over 5 h of 5x10^{351}Cr-labeled 72 h ConA spleen cell blasts homologous with the cells used as stimulator in MLCs. Data shown in Figures 4 and 5 represent mean lysis at a 20:1 E:T ratio.

Figure 3. In the symmetrical immune network theory (left hand panel), self antigens of a vertebrate C stimulate Th1 and Ts1 lymphocytes (anti-C), which are co-selected with Th2, Ts2 and B2 lymphocytes (anti-anti-C), which in turn co-select Ts3 and B1 lymphocytes (anti-anti-anti-C). B2 cells are IgG-secreting B lymphocytes, and B1 cells are IgM-secreting B lymphocytes. Anti-foreign and anti-anti-self antibodies are produced in BL/6 and C3H mice immunized with tetanus toxoid (Td)-right hand panels. All IgGs were coated on ELISA plates at 50ng/well. All developing sera were used at 1:400 concentration, with streptavidin HRP used at 1:2000. In the upper panel, biotinylated BL/6 anti-C3H IgG binds to C3H anti-Td IgG and to C3H anti-Td IgG absorbed with Td. The lower panel shows the converse, with biotinylated C3H anti-BL/6 IgG binding to BL/6 anti-Td IgG. All data are from a total of 10 mice/group; *P<.05, MANOVA.

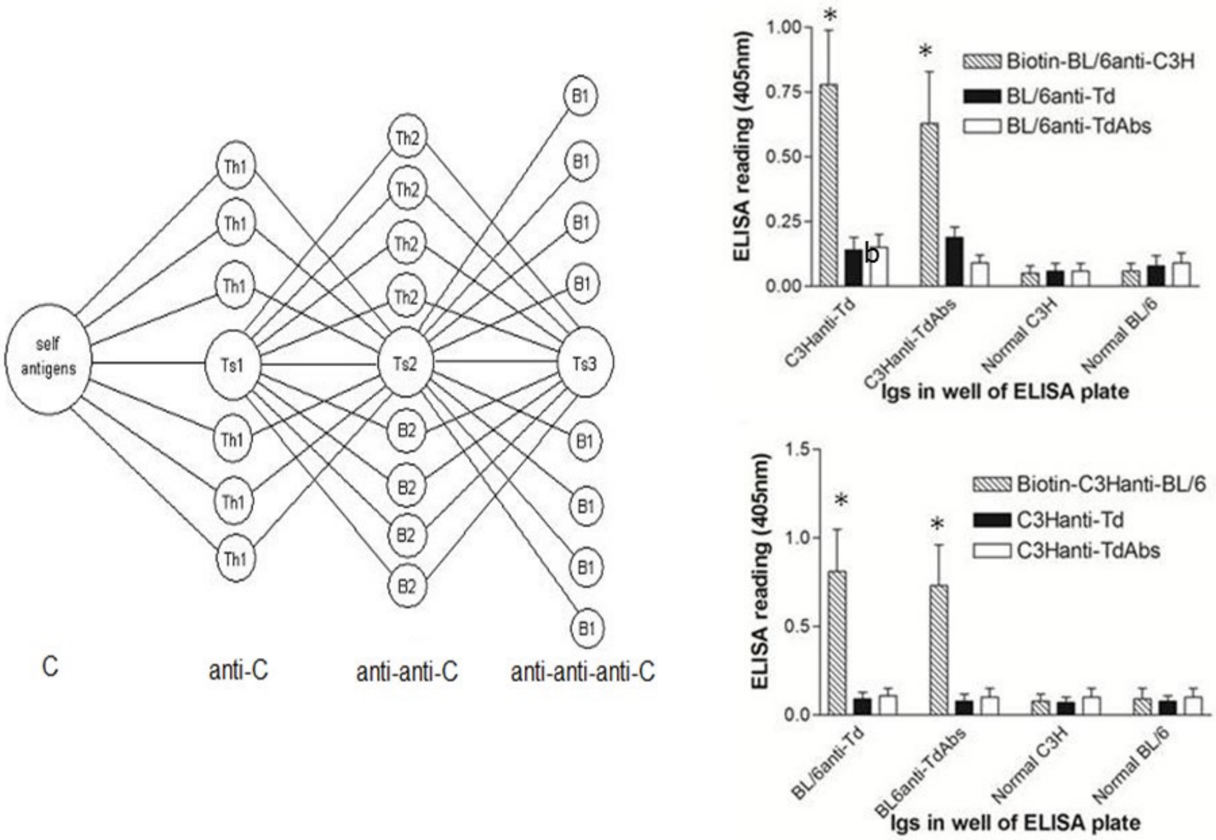
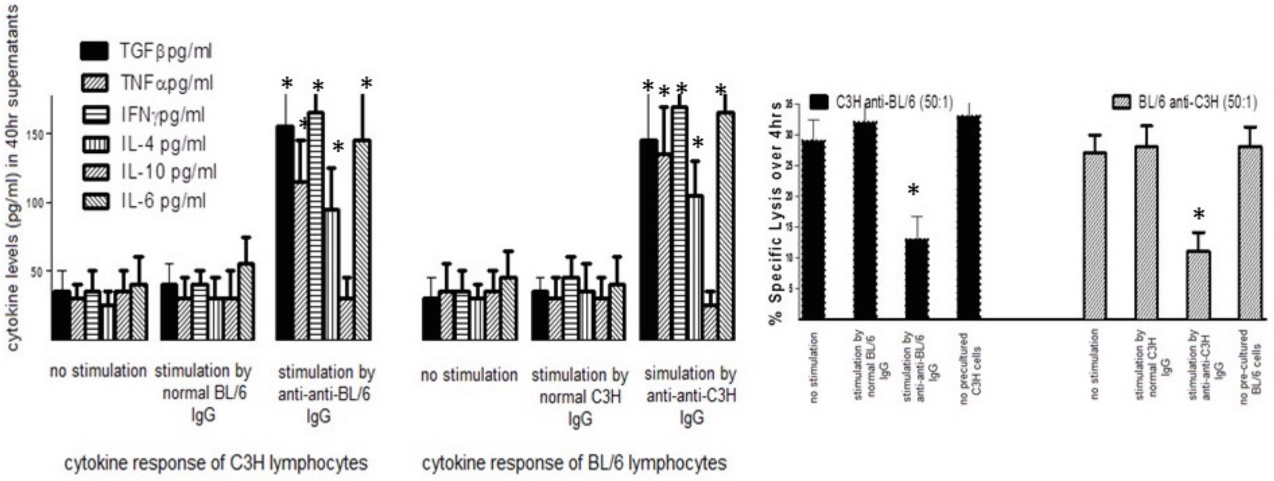


Figure 4. The 2 left hand panels show cytokine levels (measured in ELISA)from cultures of C3H splenocytes with no stimulation or stimulated with 20µg/ml of normal BL/6 IgG or BL/6 anti-anti-BL/6 IgG-far left- or cytokines from BL/6 splenocytes with no stimulation, or stimulated by normal C3H IgG or C3H anti-anti-C3H IgG. *P<.05 compared with corresponding no stimulation controls (MANOVA)The right hand panel shows antigen-specific Tregs in cultures of C3H (left) or BL/6 (right) splenocytes induced by anti-idiotypic antibodies from mice with cytokine production shown. Control cells received stimulation with 20µg/ml of either normal BL/6 IgG or no stimulation. Tregs were harvested at 96hr and added to mixtures of C3H (or BL/6) cells stimulated with irradiated BL/6 (or C3H) cells. CTL were assayed at 5d in 51Cr release assays. *P<.05 compared with corresponding controls not receiving Tregs (far right in each panel) by MANOVA.



Inflammatory Bowel Disease after Intravenous (IV) Ig Treatment

C57BL/6 female mice, with high susceptibility to dextran sulfate sodium (DSS)-induced colitis [20], purchased from the Jackson laboratories (Bar Harbor, ME) were used throughout. All mice were housed five per cage under specific pathogen-free conditions, allowed standard diet (or high fat) and water ad libitum, and used at 6-8 weeks of age. Where shown, mice received 10µg BL/6 anti-C3H (IP) and 10µg C3H anti-BL/6, absorbed with BL/6 (C3H anti-anti-C3H) IV weekly, beginning 14d before the first DSS treatment.

Animal experimentation was performed following guidelines of an accredited animal care committee (protocol no. AUP.1.18). Humane endpoints were used in all studies, with mice monitored daily. Animals were euthanized (overdose with pentobarbital) when they were exhibiting signs of distress (weight loss≥25%, hunched posture, diarrhea, and loss of active movements)—no mortality was seen in this chronic *inflammatory bowel disease* (IBD) protocol. Animals with diarrhea (but weight loss<25%) received daily IP injections of saline (1ml x3 at 8 h intervals) to avoid dehydration.

Induction of Colitis

Chronic DSS colitis was induced by giving mice (5/group) distilled drinking water containing 3% (wt/vol) DSS (m.w.=40 kDa; ICN Biochemicals, Aurora, OH) for 5 d, followed by 7 d of normal drinking water for a total of 3 cycles. Controls received normal drinking water throughout the study. Body weight was measured 3 times a week throughout the experiment. No significant mortality was seen in any groups in the chronic colitis model. As shown in relevant Figure 6, the maximum weight loss observed with animals weighed daily was ~25%, with all mice recovering weight loss within 7-10 d post cessation of DSS exposure. All studies consisted of 5 mice/group receiving either normal water or DSS to drink. Groups treated with normal water or DSS also received treatment with control Ig or a combination of anti-anti-C3H and anti-C3H IgG antibodies as shown.

Figure 5. The left hand upper panel shows a co-selection mechanism for induction of transplantation tolerance in vertebrate C based on the interactions of Figure 2. Anti-B antibodies stimulate anti-anti-BT cells and the anti-anti-B antibodies stimulate anti-B T cells. There is co-selection of the anti-anti-B T cells and the anti-B T cells, taking the immune system of C to a state in which there are elevated levels of these two T cell populations. This is a state of the vertebrate C that is specifically suppressed with respect to making an immune response to B.The lower panel shows a polyclonal version of this vaccination. Immunization of strain A with strain B tissue causes production of anti-B plus anti-anti-A IgG, while the converse immunization produces anti-A plus anti-anti-B IgG. The anti-A antibodies in the latter IgG are removed by absorption with A tissue (lymphocytes) yielding anti-anti-B IgG without anti-A antibodies. A vertebrate of phenotype C receives infusions of anti-anti-B plus anti-B IgG. C also receives anti-anti-A IgG, but in the absence of anti-A IgG there is no A-specific positive feedback loop.The right hand panels show the anti-BL/6 CTL response following treatment of 20C3H mice with weekly infusions of 1µg anti-BL/6 IgG plus 1µg anti-anti-BL/6 IgG, given either IV or IP. Sequential panels show the CTL responses after 2, 3, 4, 5 or 6 infusions respectively. CTL were measured in individual spleen samples after stimulation with BL/6 or third-party control (BALB/c) cells. Data show % lysis (20:1 effector target) in groups of 4 mice. * *P*<.05, MANOVA.

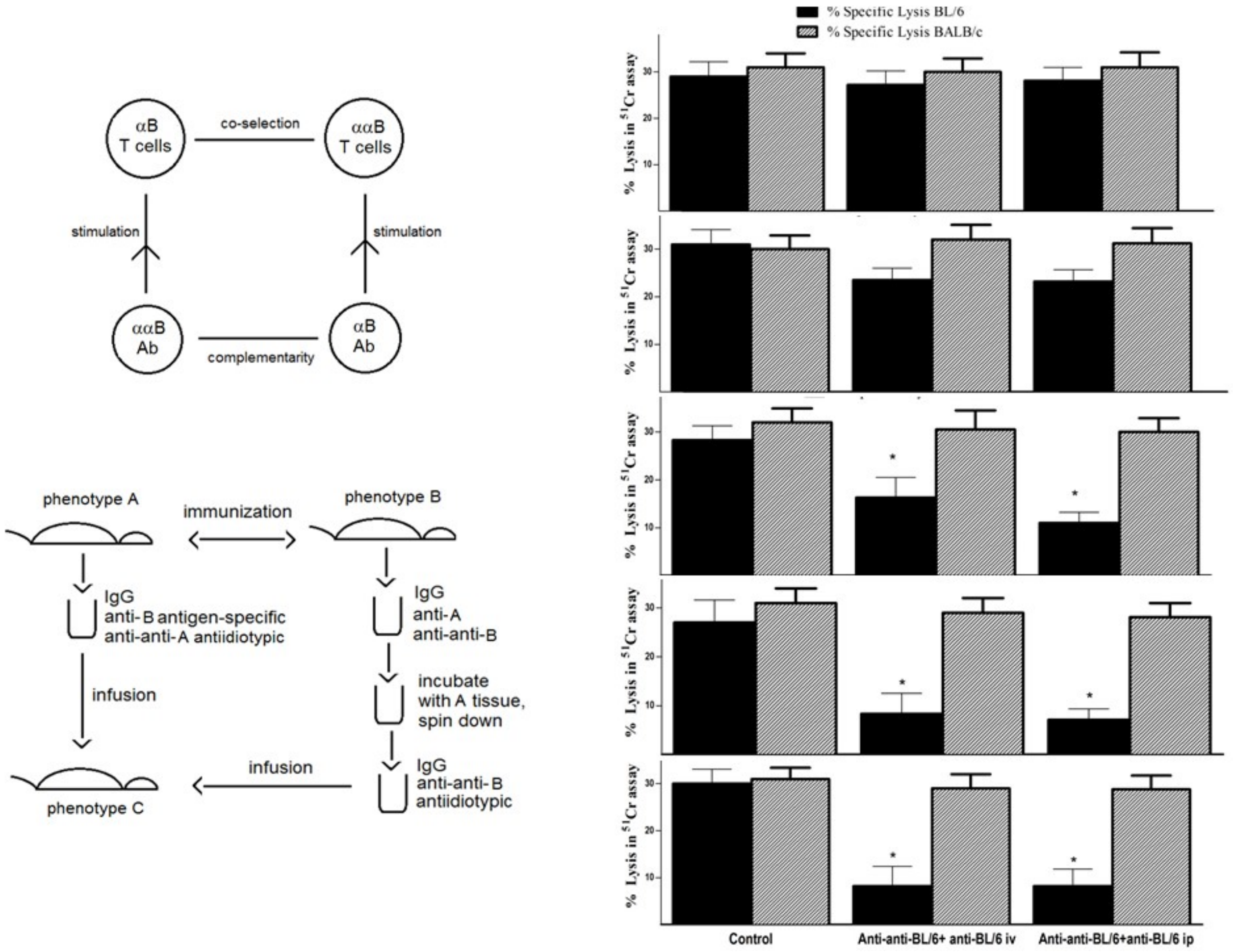
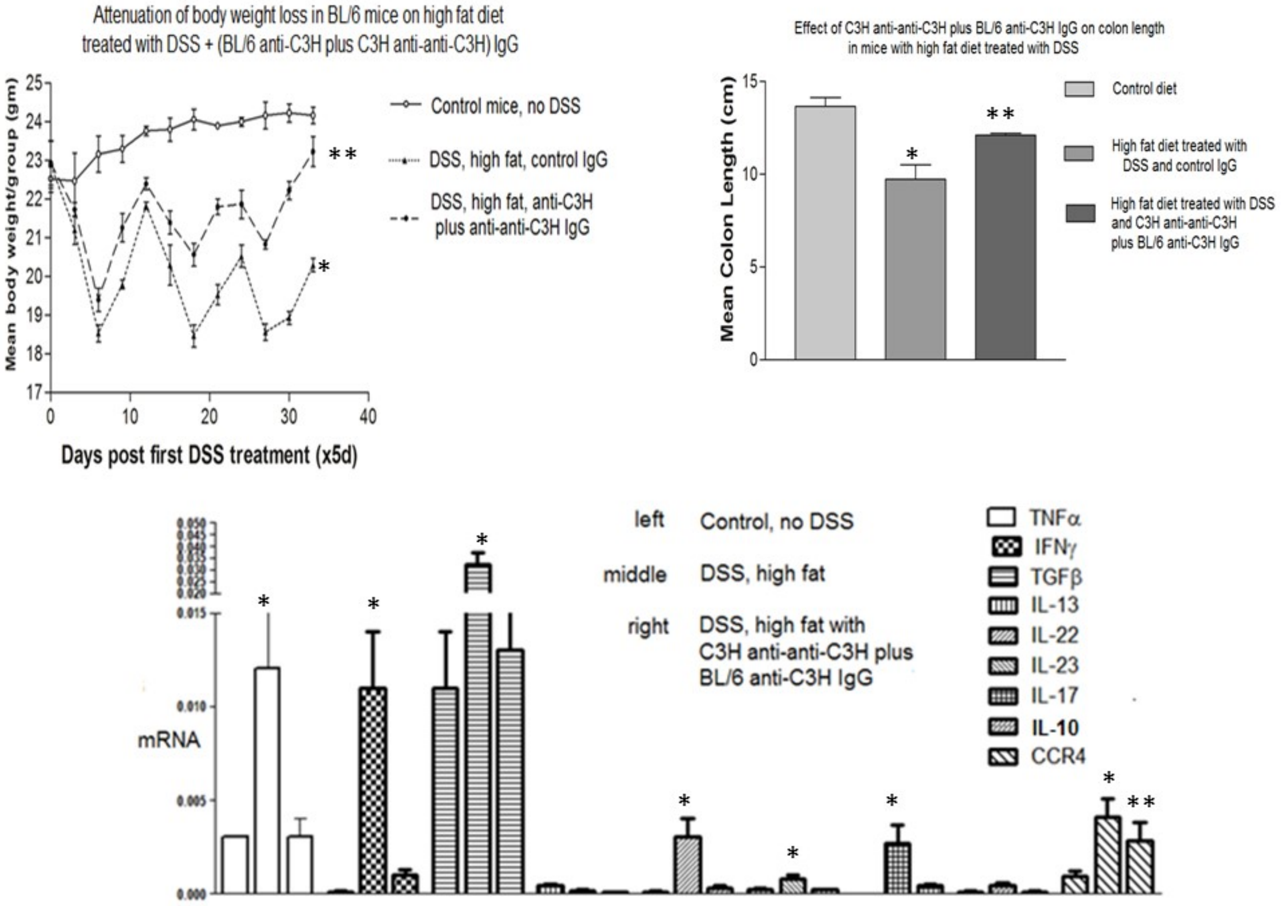


Figure 6. Inflammatory colitis in mice receiving C3H anti-anti-C3H antibodies plus BL/6 anti-C3H IgG antibodies. The upper left panel shows attenuation of weight loss in C57BL/6mice receiving antibody treatment. * *P*<.05 compared with control diet; ** *P*<.05 compared with high fat diet and control Ig (Mann-Whitney U test). The upper right panel shows diminished changes in colon length caused by DSS and high fat diet in mice receiving antibody treatment. * *P*<.05 compared with control diet; ** *P*<.05 compared with DSS/high fat diet and control Ig (Man Whitney U test). Finally, data in the lower panel shows attenuation of cytokine mRNA expression in DSS colitis after antibody infusion. Mice received 10µg of each of the antibodies intravenously on days -14 and -7 prior to the commencement of DSS and high fat diet on day 0. * *P*<.05 compared with control diet; ** *P*<.05 compared with high fat diet and control Ig (Mann-Whitney U test).



Ribonucleic Acid (RNA) Isolation and Real-Time Reverse Transcription Polymerase Chain Reaction (RT-PCR)

Total ribonucleic acid (RNA) was isolated from colonic tissue using TRIzol reagent (Invitrogen Canada, Burlington, ON). Total RNA (1 µg) was treated with DNase I and then reverse transcribed using High Capacity cDNA Reverse Transcription Kit (Applied Biosystems, Foster city, CA) following the manufacturer's instruction. First strand complementary deoxyribonucleic acid (cDNA) was diluted 1:20 and used for quantitative polymerase chain reaction (PCR) on an ABI 7900HT sequence detection system with SYBR green master mix (Applied Biosystems). Messenger RNA levels were normalized to a composite of glyceraldehyde 3-phosphate dehydrogenase (GAPDH) and hypoxanthine-guanine phosphoribosyltransferase (HPRT) expression levels. Experiments were repeated 3 times with 3 independent cDNA syntheses. The primers used for real-time reverse transcription polymerase chain reaction (RT-PCR) are shown in Table 1 below.

Table 1. Primers used for real-time PCR.

Cytokine or chemokine	Forward	Reverse
IFN-γ	5'-TATTGCCAAGTTTGAGGTCAACA-3	5'-GCTGGATTCCGGCAACAG-3'
TNF-α	5'-AGACCCTCACACTCAGATCATCTTC-3’	5’-CCACTTGGTGGTTTGCTACGA- 3’
IL-1β	5’-TCGTGCTGTCGGACCCATAT-3’	5’-GGTTCTCCTTGTACAAAGCTCATG-3’
IL-4	5’-TCATCGGCATTTTGAACGAG-3’	5’-TTTGGCACATCCATCTCCG-3’
IL-6	5’-CTCTGGGAAATCGTGGAAATG-3’	5’-CAGATTGTTTTCTGCAAGTGCAT-3’
IL-10	5’-AAGGCAGTGGAGCAGGTGAA-3’	5’-TTCTATGCAGTTGATGAAGATGTCAA-3’
IL-12	5’-CCCAAGGTCAGCGTTCCA-3’	5’-GGCAAGGGTGGCCAAAA-3’
IL-17	5’-CTCAGACTACCTCAACCGTTCCA-3’	5’-CCAGATCACAGAGGGATATCTATCAG-3’
IL-22	5’-GTGCCTTTCCTGACCAAA-3’	5’-TCTCCTTCAGCCTTCTGA-3’
IL-23	5’-GACAACAGCCAGTTCTGCTT-3’	5’-AGGGAGGTGTGAAGTTGCTC-3’
IL-23R	5’-AATTTGACGCCAATTTCACA-3’	5’-ACCAGTTTCTTGACATCGCA-3’
TGF-β	5’-CGAAGCGGACTACTATGCTAAAGA-3’	5’-GTTTTCTCATAGATGGCGTTGTTG-3’
Foxp3	5’-AGTCTGCAAGTGGCCTGGTT-3’	5’-GGGCCTTGCCTTTCTCATC-3’
CCR4	5’-AGACTGTCCTCAGGATCACTTTCA-3’	5’-CCGGGTACCAGCAGGAGAA-3’
CCL-17	5’-ATGCCATCGTGTTTCTGACTGT-3’	5’-GCCTTGGGTTTTTCACCAATC-3’
CCL-22	5’-AAGCCTGGCGTTGTTTTGAT-3’	5’-AAGCCGAGTTCAGCAAAGTT-3’

Induction of IgE after Ovalbumin (OVA) Immunization and Attenuation by IVIg

The protocol used to immunize BALB/c mice to produce IgE against OVA was essentially that described elsewhere [21]. A total of 8 mice per group received 10µg OVA emulsified in alum at day 0 and day 10. A control group received no OVA immunization. Beginning on day 7, groups of mice received normal saline IV, BL/6 anti-C3H Ig (10µg) IP weekly for 5 doses, C3H anti-anti-C3H Ig (10µg) IV weekly for 5 doses, or a combination of these latter 2 treatments. All 4 groups and the no OVA control received ongoing exposure to egg white solution in the drinking water until 42 d. At this time, all mice received a booster injection of OVA in alum, with sacrifice 7 d later.

On sacrifice, serum IgE to OVA was measured by ELISA using plates coated with 100ng/well of OVA and developed with HRP-anti-mouse IgE and appropriate substrate (Figure 7).

In addition, $5x10^6$ splenocytes from individual animals were challenged in vitro in 2ml medium, with 100µg/ml OVA for 72 h and IL-4 in culture supernatants assayed by ELISA (Figure 7).

EMT6 Breast Cancer Model

6 BALB/c mice per group received $5x10^5$ EMT6 tumor cells injected into the mammary fat pad, as described previously [22]. In experimental groups, the animals received weekly pretreatment with control Ig or a combination of anti-anti-C3H and anti-C3H IgG antibodies, beginning 14d before tumor injection. Tumor growth was monitored daily (Figure 8).

Figure 7. Attenuation of immune responses in 8/group OVA-immunized mice receiving combination treatment with anti-C3H and anti-anti-C3H Ig. Mice received OVA-in alum on days 0, 10, and 42, with some groups also receiving egg white solution (EWS) in the drinking water from days 14-42. Ig was infused weekly iv from day 7-35. Mice were sacrificed at day 49. Left hand panel shows IgE serum responses, while right hand panels shows attenuation of IL-4 production (ELISA) at 72hr from OVA-stimulated splenocytes of the same mice. *indicates significantly greater than controls receiving only OVA-in alum (far left), P<.05 (MANOVA); ** indicates significantly reduced relative to all other groups receiving OVA-alum and EWS, P<.05 (MANOVA).

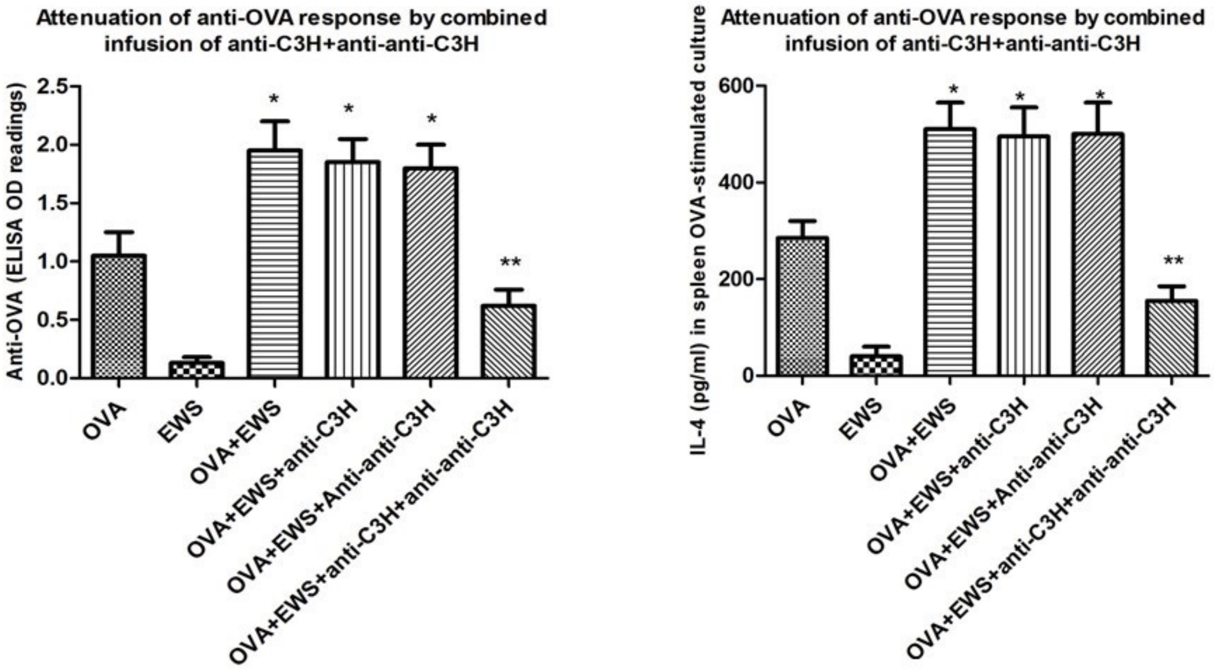
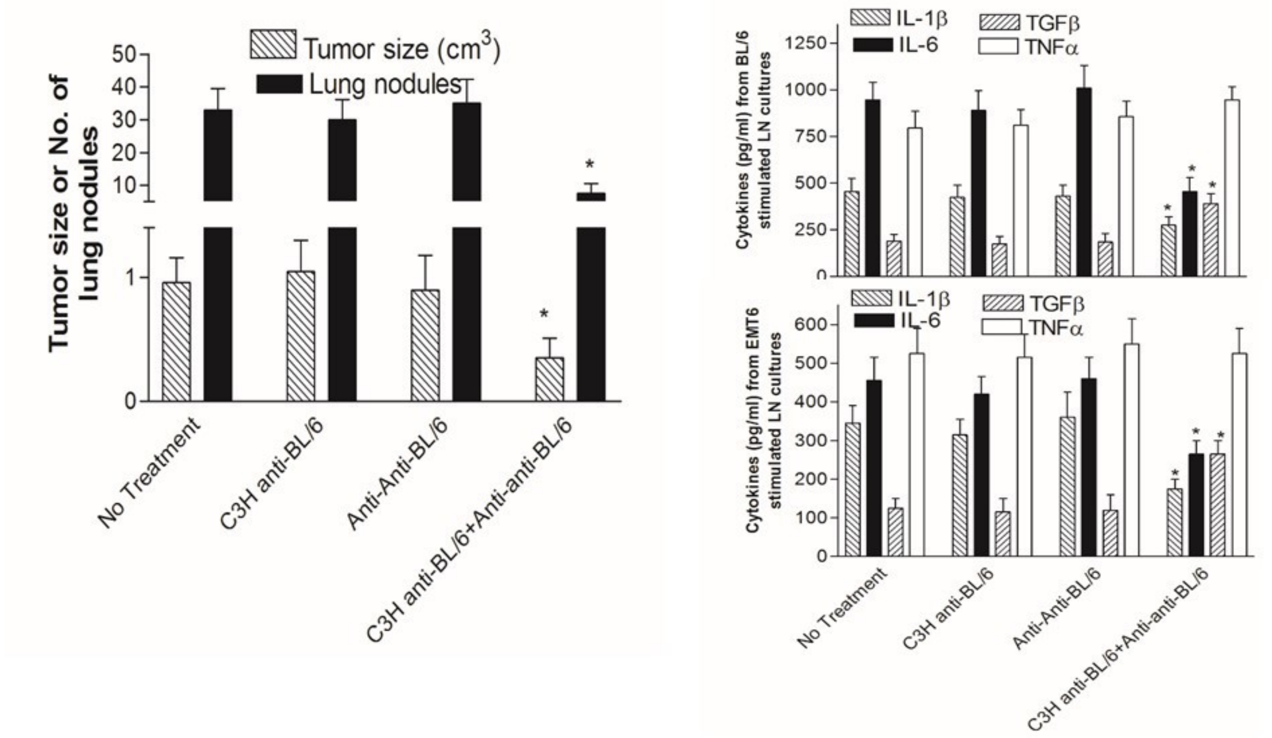


Figure 8. Decrease in tumor growth and metastases in BALB/c mice receiving anti-BL/6 and/or anti-anti-BL/6 Ig 14 and 7d before the transplantable breast cancer EMT6 (left hand panel). Injections of antibody were continued at 7d intervals until sacrifice. 14d after EMT6 injection tumors were resected and mice returned to their cages. Lung tumor nodules were measured 14d later. *P<.05 (MANOVA) compared with all other groups.The right hand panels show cytokine production (ELISA) from tumor-draining lymph nodes stimulated with either irradiated BL/6 splenocytes (upper panel) or EMT6 tumor cells (lower panel). *indicates P<.05 (MANOVA) compared with all other groups.



Statistics

All data from experiments reported below are summed over at least two studies, with a minimum of 10 mice or combined groups for all experiments. In general, for studies with multiple groups, a multivariate analysis of variance (MANOVA) test was first applied to assess for any significant differences between groups, and subsequently, where indicated, paired *t*-tests were used to compare individual groups with the documented control. In some instances (noted in the Figure legends), a Mann-Whitney non parametric tests was used to compare groups.

Results

Confirmation of Evidence for Specific T Cell-Derived Suppressive Factors

As shown in Figure 1, in an experimental design closely following the original Takemori and Tada design (see Methods), BALB/c mice received a cell free extract derived from sonicated (spleen + thymocyte) cell preparations of mice primed twice on days 0 and 14 with 100µg of BGG or KLH. The extract was infused into 5 mice per group that subsequently received DNP coupled to BGG or DNP coupled to KLH. IgG responses to DNP were measured by ELISA.

The data show clearly that mice receiving KLH derived cell extract showed a suppressed response to DNP-KLH but not DNP-BGG and vice versa, implying, as initially suggested by Takemori and Tada, the existence of antigen-specific (T) lymphocyte derived factors [10,11]. As per the original hypothesis from Takemori and Tada, specific tolerance induction results from (1) a non-immunogenic form of an antigen stimulating T+ cells, (2) specific T cell factors from T+ cells binding to the surface of the A cells and stimulating T− cells, and (3) the T− cells secreting specific factors and stimulating the proliferation of T+ cells. The positive feedback loop involving antigen-specific T (T+) and anti-idiotypic (T−) cells takes the system to a suppressed stable steady state with elevated levels of the T+ and T− cell populations. There is coselection (mutual selection) of the idiotypic T cells and the anti-idiotypic T cells. The specific T cell factors have a molecular weight of about 50,000 Daltons and are therefore believed to be monovalent, in contrast to an IgG antibody that, with a molecular weight of 150,000, is divalent. The elevated levels of T+ and T− populations with their specific monovalent factors inhibit the stimulation of B+ and B− cells by the cross-linking of the B cell receptors. An immune response involves the antigen cross-linking a receptor on the A cell via adsorbed T+ factors, the A cell secreting a nonspecific differentiation factor, B cells being stimulated by antigen and expressing a receptor for the nonspecific factor, and on receipt of the differentiation factor switching from proliferation to antibody-secreting cells.

Production and Testing of Anti-Idiotypic Antibodies

We showed previously that allo-immunization with lymphocytes could induce the production of anti-idiotypic antibodies, and small doses of these antibodies could subsequently enhance survival of allogeneic skin grafts [4]. The anti-idiotypic antibodies were produced by the strain of mice that was the donor of the skin grafts and were donor anti-anti-donor antibodies. Figure 2 shows the relationships of the antibodies in an A anti-B serum to the antibodies in a B anti-A serum according to the symmetrical immune network theory [4,23]. The antigen-specific antibodies include anti-MHC class I antibodies and anti-I-J antibodies. The antigen-specific antibodies in an A anti-B serum are also specific for the anti-idiotypic antibodies (B anti-anti-B) in a B anti-A serum. Similarly, the antigen-specific antibodies in a B anti-A serum are specific for the anti-idiotypic antibodies (A anti-anti-A) in an A anti-B serum. This set of relationships is known as “second symmetry” [6,24]. (“First symmetry” in the symmetrical immune network theory is the concept that if an idiotype A is anti-idiotypic to an idiotype B, the idiotype B is anti-idiotypic to the idiotype A; reviewed in [6]).

In our previous work on second symmetry in mice, we generated A anti-anti-A antibodies (anti-idiotypic antibodies) by immunizing mice of strain A with strain B lymphocytes. The A anti-anti-A antibodies were assumed to be produced in response to the anti-A receptors of the strain B lymphocytes. We have extended these studies to show that there is no need to immunize strain A with lymphocytes per se to generate the A anti-anti-A immune response. Rather, 2 rounds of B strain skin grafts on A strain mice also induce the production of A anti-anti-A antibodies in the A strain mice. This is shown explicitly in the data of ELISA assays in Figure 2

In these ELISA assays, normal IgG, alloimmune IgG, or IgG from alloimmune mice that had been absorbed using lymphocytes of the strain used in the skin grafting, were coated on ELISA plates at the dilutions shown in the caption of Figure 2. In all cases IgG was pooled from a total of 15 mice of each group. After incubation with biotinylated allo-antiserum, the bound antibodies were detected with streptavidin-alkaline phosphatase and substrate. The resulting signal is interpreted as resulting from the binding of biotinylated antigen-specific antibodies to complementary anti-idiotypic antibodies on the plate. Figure 2 (upper panel) shows that biotinylated BL/6 anti-C3H IgG binds to C3H anti-BL/6 IgG and to C3H anti-BL/6 IgG absorbed with BL/6 lymphocytes, but not to normal C3H IgG, nor to normal BL/6 IgG. This is ascribed to the presence of C3H anti-anti-C3H antibodies in the C3H anti-BL/6 IgG and in the C3H anti-BL/6 IgG absorbed with BL/6 lymphocytes. Absorption with BL/6 lymphocytes removes antigen-specific (anti-BL/6) antibodies without removing the anti-idiotypic antibodies. Additional controls are BL/6 anti-C3H and BL/6 anti-C3H absorbed with C3H lymphocytes. Conversely, the lower panel in Figure 2 shows biotinylated C3H anti-BL/6 IgG binds to BL/6 anti-C3H IgG and to BL/6 anti-C3H IgG absorbed with C3H lymphocytes, but not to normal BL/6 IgG, nor to normal C3H IgG. Additional controls used were C3H anti-BL/6 and C3H anti-BL/6 absorbed with BL/6 lymphocytes.

Figure 3 highlights a symmetrical immune network model that shows how the V regions of helper T cells, suppressor T cells, IgG secreting B cells, and IgM secreting B cells may be related to each other [6]. This figure purports to show the relationships between the various populations independently of any perturbation by an antigen. T suppressor (Ts) 1 cells express CD4 and are postulated to be regulator T (Treg) cells. Ts2 cells are at the center of the network. They express CD8 and include classic suppressor T cells. When there is a significant change in B cells secreting IgG specific for an antigen such as foreign MHC class I as the result of skin grafting, this impacts on all the populations shown including Ts2 and IgG secreting cells (B2) that as a class are believed to be anti-idiotypic to Ts1 and Ts3 lymphocytes, and in this respect are anti-anti-self.

When there is a significant change in the B2 lymphocyte population following exposure to an antigen, with the production of antigen-specific antibodies, there are plausibly changes in the other populations due to the couplings shown in Figure 3. Our findings are most simply explained in terms of the hypothesis that new immune responses with the production of IgG generally include the production of both new antigen-specific antibodies and new anti-idiotypic antibodies (anti-anti-self).

Antigen-Specific and Anti-Idiotypic Antibodies in Mice Immunized With Conventional Ag

In our first tests of the explanatory value of the symmetrical immune network model, we measured the production of antigen-specific and anti-idiotypic antibodies in BL/6 and C3H mice immunized with tetanus toxoid (Td) in the adjuvant monophosphoryl lipid A adjuvant (MPLA). Six BL/6 mice and 6 C3H mice were immunized on day 0 and day 14 and bled on day 21. Normal IgG, IgG purified from the immunized mice, or IgG from the immunized mice that had been absorbed with Td were coated on ELISA plates at the dilutions shown in Figure 3. Data in the panels of this Figure are pooled from 2 similar studies (total of 10 mice/group). Figure 3 shows that biotinylated BL/6 anti-C3H IgG (prepared from a pool of 15 mice immunized as described earlier by repeated skin grafts) binds to C3H anti-Td IgG and to C3H anti-Td IgG absorbed with Td but not to normal C3H IgG, nor to normal BL/6 IgG. This is ascribed to the presence of C3H anti-anti-C3H antibodies in the C3H anti-Td IgG and in the C3H anti-Td IgG absorbed with Td. Additional controls are C3H anti-Td and BL/6 anti-Td absorbed with Td. Figure 3 also shows that biotinylated C3H anti-BL/6 IgG (again pooled from 15 grafted donors) binds to BL/6 anti-Td IgG and to BL/6 anti-Td IgG absorbed with Td but not to normal BL/6 IgG, nor to normal C3H IgG. Additional controls are C3H anti-Td and C3H anti-Td absorbed with Td. This confirms that the IgG immune response of C3H and of BL/6 mice to Td includes the production of C3H anti-anti-C3H and BL/6 anti-anti-BL/6 antibodies, respectively.

Induction of Cytokines and Regulatory T Cells (Tregs) or Suppressor T Cells by Anti-Idiotypic Antibody

Further analysis of the functional properties of anti-idiotypic IgG is shown in Figure 4 where we indicate that anti-idiotypic antibodies can stimulate the production of cytokines and induce regulatory T cells. Figure 4 shows cytokine levels induced in cultures of C3H splenocytes (pooled from 5 naïve mice) at 40 h with no stimulation, and with stimulation by 20µg/ml of either normal BL/6 IgG or BL/6 anti-anti-BL/6 IgG (left hand of panel), whereas the right hand side of the same panel shows the cytokine levels induced in cultures of BL/6 splenocytes with no stimulation, and with stimulation by either normal C3H IgG or C3H anti-anti-C3H IgG. The cytokine levels were measured in duplicate by ELISA. All data are pooled from 2 similar studies. Stimulation by the anti-anti-self antibodies induced secretion of the inflammatory cytokines IFNγ, TNFα, and IL-6, with no measurable secretion of the anti-inflammatory cytokine IL-10. Interestingly, IL-4 and TGFβ production were also stimulated. The former is often used as a marker of Th2 stimulation and augments B-cell Ig production, whereas TGFβ is a key cytokine implicated in development and/or expansion of Tregs (Ts1 cells).

In many cases, when T cells from a mouse that has been primed with an antigen are combined with naïve cells in a recipient mouse, the mouse is specifically suppressed for responses to that antigen. This is the classic suppressor T cell phenomenon [25,26], in which the suppressor T cells express the CD8 marker and should not be confused with the CD4+, CD25+ Treg cells described elsewhere [27]. The CD8 suppressor T cell phenomenon can be understood in terms of coselection of antigen-specific cells and anti-idiotypic T cells. In the context of the model in Figure 3, Treg cells are interpreted as being Ts1 cells (CD4) and classic suppressor T cells are Ts2 cells (CD8).

From the study shown in the left panels of Figure 4, the cells stimulated to produce cytokines were harvested following incubation with anti-idiotypic antibody and tested for their ability to suppress the induction of cytotoxic T cells in a subsequent culture. The results are shown in Figure 4 (right hand panel), again pooled from the 2 independent studies. Lymphocytes pooled from triplicate C3H cultures that had received BL/6 anti-anti-BL/6 IgG antibodies suppressed the cytotoxic T lymphocytes (CTL) response of C3H lymphocytes to BL/6 lymphocytes, and lymphocytes pooled from triplicate BL/6 cultures that had been treated with C3H anti-anti-C3H suppressed the CTL response of BL/6 lymphocytes to C3H. Antigen-specific suppression is a known property of both CD8 suppressor T cells and of so-called inducible CD4+ Tregs (iTregs [CD4$^+$])—importantly, we acknowledge that the phenotype of the Tregs measured here remains to be determined. Taken in combination, the anti-anti-self-Ig mediated induction of cytokine production and Tregs is taken to reflect a role for such antibodies in activating a “network” of immunoregulation through complementary cell surface receptors.

Synergy Between Antigen-Specific Plus Anti-Idiotypic Antibodies in Inducing Graft Tolerance

The second symmetry relationships shown in Figure 3 is also postulated to provide a mechanism of inducing transplantation tolerance using coselection. A vertebrate A can be treated with a combination of A anti-B antibodies (antigen-specific) and B anti-anti-B antibodies (anti-idiotypic) to induce a state in which there is transplantation tolerance in A that is specific for B. The envisaged mechanism is shown in Figure 5. The anti-B antibodies stimulate anti-anti-B T cells and the anti-anti-B antibodies stimulate anti-B T cells. There is coselection of the anti-anti-B T cells and the anti-B T cells, taking the immune system of A to a state in which there are elevated levels of these 2 T cell populations. In the case of this tissue transplant model, this state is predicted to be one in which A is specifically unresponsive to B. A more detailed methodology for producing complementary pairs of antibodies for use in protocols designed to vaccinate animals to augment immunoregulatory circuits is shown in the lower left hand panel in Figure 5.

In an experiment designed to test the validity of this concept, A is represented by C3H mice and B by BL/6 mice. Groups of 20 C3H mice were infused with a combination of C3H anti-BL/6 antibodies and BL/6 anti-anti-BL/6 antibodies. We then sacrificed mice and tested for induction of anti-BL/6 CTL following stimulation with irradiated BL/6 splenocytes in vitro. The C3H anti-BL/6 IgG antibodies were contained in serum obtained from a pool of 15 C3H mice that had undergone 2 rounds of skin grafting with BL/6 skin. The BL/6 anti-anti-BL/6 antibodies were obtained from a pool of 15 BL/6 mice that had undergone 2 rounds of skin grafting with C3H skin. The IgG from the latter mice was absorbed with C3H spleen cells and thymocytes until all anti-C3H antibodies had been removed (see Methods).

Spleen cells from the treated C3H mice were tested for tolerance by exploring the attenuation of the induction of BL/6-specific CTL in response to stimulation by irradiated BL/6 spleen cells as the assay system. There were 2 groups of 20 C3H mice each, with group 1 being infused with anti-BL/6 plus BL/6 anti-anti-BL/6 antibodies given IV, whereas in group 2, the antibodies were given IP.

All C3H mice received weekly infusions of 1µg of BL/6 anti-anti-BL/6 antibodies plus 1µg C3H anti-BL/6 antibodies beginning on day 0. Mixed lymphocyte cultures using cells from 4 mice per group were set up at days 14, 21, 28, 35, and 42, with BL/6 spleen cells as the stimulators. The results are shown in the serial panels to the right in Figure 5. The negative control is the result for stimulation of cells from untreated C3H mice by BL/6 spleen cells, and the positive control is the result for induction of a BALB/c-specific CTL in response to stimulation by BALB/c lymphocytes. A highly significant reduction in the BL/6-specific CTL response was observed for the cultures set up after 4, 5, and 6 infusions of the antibodies. There was no significant difference between intraperitoneal and intravenous administration of the antibodies. Similar data were observed in a repeat study of the same type.

We conclude that stimulation of an immune system by antigen-specific (for example anti-B) plus complementary anti-idiotypic antibodies (anti-anti-B) can induce a new stable steady state in which the immune response to B is specifically suppressed.

Therapeutic Effect of Anti-Anti-Self Plus Complementary Antiforeign Antibodies in an Inflammatory Bowel Disease (IBD) Model

IBD is a category of autoimmune diseases that includes colitis and Crohn disease. BL/6 mice fed DSS develop IBD [20]. We tested the efficacy of prevention of IBD by antigen-specific plus anti-idiotypic antibodies in an experiment with 3 groups of 8 BL/6 mice. The first group was given normal drinking water and a normal diet, the second was given a diet that included DSS and high fat, and the third was given DSS and high fat plus 2 infusions of antigen-specific (BL/6 anti-C3H), plus anti-idiotypic (C3H anti-anti-C3H) antibodies for 2 weeks at days −14 and −7 before commencement of the diet of the DSS plus high fat diet at day 0. The mice were successfully treated by the combination of antibodies as measured in 3 assays, namely reduction of weight loss reduction in the change of colon length, and inhibition of the production of mRNA for 7 of 9 inflammatory cytokines (see respective panels in Figure 6). We attribute this therapeutic effect to changing the phenotype of the treated mice to have similarity to that of C3H mice, while not losing tolerance to the BL/6 phenotype, meaning self-tolerance to BL/6 is not lost. The treated BL/6 mice have the benefit of tolerance to both BL/6 and C3H, while the ability to respond to other antigens is fully retained. In a control experiment (not shown), the mice were treated with only C3H anti-anti-C3H antibodies. The suppression of inflammation was not observed. We conclude that treatment with antigen-specific plus anti-idiotypic antibodies as described here is effective in the prevention of inflammatory bowel disease.

Therapeutic Effect of Antigen-Specific Plus Anti-Idiotypic Antibodies in an Allergy Model

To assess whether this same strategy could be used to attenuate allergic diseases, we performed a study in 8 per group BALB/c mice immunized with OVA in alum and subsequently exposed to egg white solution in the drinking water—see Methods and [21]. After 7 d following a first immunization with OVA, subgroups of mice were given infusions of antigen-specific (BL/6 anti-C3H) or anti-idiotypic (C3H anti-anti-C3H) Ig alone, or in combination, along with egg white solution. A total of 5 immunizations was given at weekly intervals. Following 7 d after the last infusion, all mice were returned to normal drinking water, boosted with a final dose of OVA in alum, and sacrificed 7d later for measurement of serum IgE, and induction of IL-4 by OVA-stimulated splenocytes in vitro (see Figure 7).

It is apparent from these data that indeed, combination Ig treatment does indeed markedly attenuate IgE production. In accord with this finding, such treated mice showed a marked reduction in IL-4 release following OVA-restimulation.

Therapeutic Effect of Antigen-Specific Plus Anti-Idiotypic Antibodies in a Cancer Model

EMT6 is a transplantable breast cancer tumor [22]. A total of 6 mice per group received $5x10^5$ EMT6 cells 14d after 2 intravenous injections of C3H anti-BL/6 and/or BL/6 anti-anti-BL/6 IgG (10µg/mouse). Injections were continued at 7 d intervals thereafter until the final sacrifice. After 14 d from receiving the EMT6 injection, mice were anesthetized and tumors resected and weighed. Mice were returned to their cages for a further 16 d when all were sacrificed and lung nodules evaluated. The results for tumor size and the number of metastases in the lungs are shown in Figure 8 (upper left hand panel). The tumor size and the number of metastases was significantly less in the mice that received C3H anti-BL/6 plus BL/6 anti-anti-BL/6 IgG.

Cytokine data for this experiment is shown in the right hand panels in this Figure. Lymph nodes draining the tumor were harvested at sacrifice, and $1x10^6$ cells were cultured in duplicate in 1ml medium with either $1x10^6$ irradiated (2500Rads) BL/6 splenocytes or $1x10^5$ irradiated EMT6 tumor cells. Supernatants were harvested at 48 h and assayed in commercial ELISAs (BioLegend) for the cytokines shown. The results for stimulation of BL/6 spleen cells (H-2^b) and of EMT6 (H-2^d) were the same. IL-1β and IL-6 were significantly down-regulated, whereas TGFβ was significantly up-regulated. IL-1β and IL-6 are proinflammatory cytokines, whereas TGFβ regulates inflammation. There was no change in the level of TNFα. Hence, for three of the four cytokines, there was a significant therapeutic effect resulting from the infusions of the antigen-specific plus anti-idiotypic antibodies

Discussion

Principal Findings

The data described above have focused on documenting evidence that infusion of a combination of A anti-B and anti-anti-A antibodies can lead to development of an altered immune state in recipient animals in which attenuation of immunity to an antigen simultaneously administered can be achieved. We have investigated evidence for this hypothesis in models of nominal antigen immunization, of graft specific allo-tolerance, of IBD, of OVA-induced IgE production, and finally of breast cancer metastasis. In all scenarios, we observed a significantly altered immune state in antigen-challenged individuals.

A great deal of research on anti-idiotypic antibodies has been based on the idea that anti-idiotypic antibodies can mimic the antigen. There was optimism that such antibodies could be effective as vaccines, but this line of research has not led to the commercialization of any vaccines over the last 40 years. The symmetrical immune network theory has been developed over the same 40 years and is able to account for many aspects of the adaptive immune system [4-7]. An important aspect of the theory is that it is based on the well-established; nonetheless, controversial presumed existence of specific T cell factors [8-17]. As a first important step in documenting the validity of the underlying concept of symmetrical immune network theory, we confirmed in this paper (see Figure1b) that such factors do indeed exist, as initially postulated by Takemori and Tada [10].

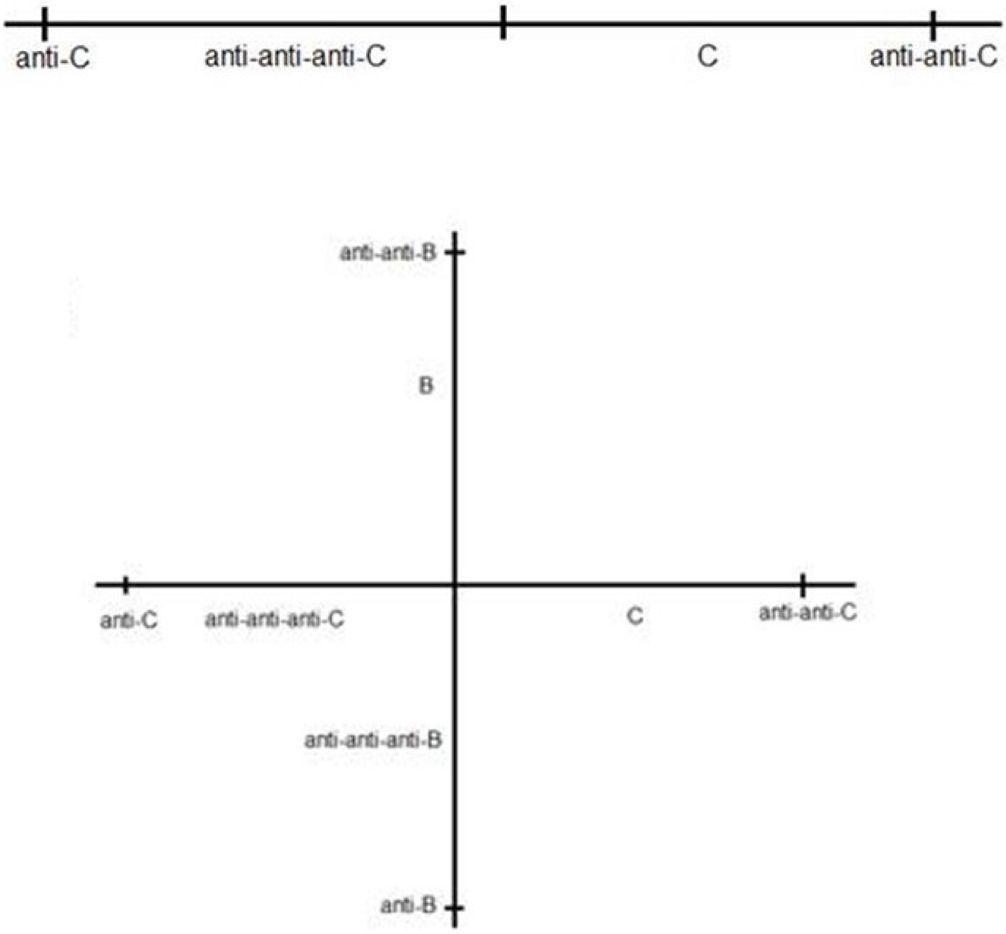
We find that normal IgG immune responses in a vertebrate against an antigen consist of 2 components, namely antigen-specific, and second symmetry anti-idiotypic antibodies. The second symmetry anti-idiotypic antibodies in an immune response of a vertebrate A to skin grafts from a vertebrate B bind to antigen-specific antibodies present in a B anti-A immune response. The IgG of a vertebrate A immune to the protein antigen tetanus toxoid likewise includes anti-idiotypic antibodies (A anti-anti-A) that are specific for antigen-specific antibodies (B anti-A) present in a B anti-A immune response—again data in Figures 2 and 3 support these concepts.

A combination of antigen-specific plus second symmetry anti-idiotypic antibodies is effective in inducing allograft tolerance. The proposed mechanism for this is that there is coselection of antigen-specific and complementary anti-idiotypic T cells. Data in a skin allograft model, shown in Figures 4 and 5, are in accord with these hypotheses also. Induction of anti-idiotypic regulatory cells is postulated to underlie the mechanism whereby this same approach could be used to down-regulate inflammation in a murine model of IBD (Figure 6) as measured in each of 3 assays, namely by monitoring weight loss (Figure 6), colon length (Figure 6), or mRNA expression of chemokines or cytokines (Figure 6). We also report that the same antibody combinations can be used successfully to attenuate allergic responses (IgE production after immunization of mice with OVA in alum, and production of IL-4 cytokines in these same mice—see Figure 7), and of inhibiting tumor growth and preventing metastases in the EMT6 mouse breast cancer model (Figure 8). In this latter case, two of three proinflammatory cytokines measured were down-regulated (IL1β, IL-6) and an immunoregulatory cytokine (TGFβ) was up-regulated (Figure 8). These data are consistent with the growing interest in altering immunosurveillance as a tool in regulating cancer metastasis [28]. It is worthwhile noting at this stage that all of the model systems described to test our hypotheses use acute perturbations of the immune system (transplantation, DSS exposure, tumor growth after transplant of tumor cells, and IgE response to acute allergen exposure). To date, we have little information on whether, and for how long, these altered immunregulatory states are maintained in the absence of ongoing antigen exposure, and whether unexpected side-effects (eg, altered autoantibody production) are incurred following antibody infusion, an important issue to answer before application of this therapy in clinical situations. Studies addressing these issues are in progress.

Our experiments indicate that the immune systems of 2 healthy vertebrates called A and B can be combined with the immune system of a third healthy vertebrate C to make C's immune system resistant to degenerative diseases. A, B, and C may be three strains of mice, and in the case of the application to the immunotherapy to humans, A and B may be mouse strains and C may be a healthy human. Anti-B antibodies may be obtained from immunization of A with B tissue, and anti-anti-B antibodies may be obtained from immunization of B with A tissue. C is then treated with a combination of anti-B and anti-anti-B antibodies. Note, however, that where the vertebrates used to produce the IgGs (A and B above) are of a different species (mouse) from those (C above) receiving the combined antibodies, we would anticipate a need for "humanizing" the IgGs infused to avoid a confounding human antimouse antibody (HAMA) response [29].

Why has evolution not led to normal immune systems being similarly resistant to degenerative diseases? In order to address this question, we would like to first explain that according to the symmetrical immune network theory [6], normal immune systems include self antigens C, lymphocytes that are anti-C and are coselected with anti-anti-C lymphocytes, and lymphocytes that are anti-anti-anti-C and are also coselected with anti-anti-C lymphocytes. The antigens C include especially MHC class II antigens that stimulate the anti-C Th1 lymphocytes and Ts1 lymphocytes. The anti-anti-C lymphocytes include Th2, Ts2, and B2 lymphocytes, whereby B2 lymphocytes are predominantly follicular (FO) B cells or marginal zone (MZ) B cells that secrete IgG following T-dependent activation [30]. The anti-anti-anti-C lymphocytes include Ts3 and B1 lymphocytes. B1 lymphocytes arise from a developmental pathway different from that of FO B cells and MZ B cells, are primarily activated through T-independent mechanisms, and in mice, populate mainly the peritoneal and pleural cavity where they generate so-called IgM (antibodies produced without infection), which defend against mucosal pathogens [31]. There is therefore a principle "shape space axis" comprising C, anti-C, anti-anti-C, and anti-anti-anti-C. Each of the members in this sequence has shapes that are complementary to the neighboring members in the sequence. We can also depict the shape space axis in a way such that neighboring members are similar to each other and members with complementary shapes are on opposite sides of the diagram. This is shown in Figure 9 (upper panel), in which the axis is defined by anti-C and anti-anti-C. C is complementary to anti-C, so it is on the same side as anti-anti-C, and anti-anti-anti-C is complementary to anti-anti-C, so it is on the same side as anti-C. The system is stabilized by anti-C being stimulated by anti-anti-C and vice versa. At any given time point, there would be a mixture of anti-C and anti-anti-C factors on the A cell surface, and we could expect random fluctuations in which of the two is present to a greater degree. Such fluctuations would result in fluctuations in the number of anti-C and anti-anti-C lymphocytes. There may then be a random walk in one dimension for the relative amounts of anti-C and anti-anti-C lymphocytes. At some stage this random walk could lead to the 2 populations no longer being mutually stabilizing. This idea is supported by the fact that autoimmune mice make anti-anti-C antibodies [20], which could be due to T cells no longer dominating the anti-anti-C region of shape space. In addition, we have found that old BL/6 mice make anti-anti-BL/6 (or "anti-anti-C") antibodies [21].

Figure 9. A one-dimensional shape space for the vertebrate C in which complementary shapes map to opposite sides of the origin (upper panel).A two-dimensional shape space results when the vertebrate C is treated with anti-B plus anti-anti-B antibodies. Anti-anti-C and anti-anti-B lymphocytes are co-selected with anti-C and anti-B lymphocytes respectively (lower panel).



When we treat C with anti-B plus anti-anti-B antibodies, we induce a new stable steady state with elevated levels of anti-anti-B and anti-B T cells. This amounts to creating a second shape space axis for the T cells of C that is plausibly orthogonally to the anti-C or anti-anti-C shape space axis because neither anti-B nor anti-anti-B has any relation to anti-C or anti-anti-C—see Figure 9 (lower panel). In this case, fluctuations in all of anti-C, anti-anti-C, anti-B, and anti-anti-B specific T cell factors would mean there is a random walk in two dimensions rather than one dimension. An immune system with a single shape space axis as shown in Figure 9 may be intrinsically less stable that a system with a second shape space axis. In the case of the former, the steady state involves primarily just anti-C and anti-anti-C T cell factors on the A cell surface, whereas there are four specificities of specific T cell factors for a system with 2 shape space axes. This difference in the number of shape space dimensions may be the basis for an immune system constructed using three immune systems (A, B, and C), and having 2 shape space axes, being intrinsically stronger than an immune system based on a single shape space axis.

Conclusions

We conclude that the symmetrical immune network theory leads to a possible preventive immunotherapy that does not involve the production of antibodies and can reasonably be called a new class of vaccine. Combinations of antigen-specific antibodies and second symmetry anti-idiotypic antibodies as described here comprise an immunotherapy for the prevention of IBD, for attenuation of allergic responses, and the prevention of breast cancer. The same therapy may prove to be effective in preventing also other autoimmune diseases and cancers, and as such, likely represents an important new addition to our clinical armamentarium.

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Conflicts of Interest

Both authors disclose an association with Network Immunology Inc.: RMG is the chief scientific officer and GWH is the chairman of Network Immunology Inc.

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Abbreviations

BGG: bovine gamma globulin
CTL: cytotoxic T lymphocytes
DNP: dinitrophenol
DSS: dextran sulfate sodium
ELISA: enzyme-linked immunosorbent assay
GAPDH: glyceraldehyde 3-phosphate dehydrogenase
HAMA: human antimouse antibody
HPRT: hypoxanthine-guanine phosphoribosyltransferase
HRP: horseradish peroxidase
IBD: inflammatory bowel disease
KLH: keyhole limpet hemocyanin
MPLA: monophosphoryl lipid A adjuvant
OVA: ovalbumin
PBS: phosphate buffered saline
RNA: ribonucleic acid
RT-PCR: reverse transcription polymerase chain reaction
Ts: T suppressor cells
Treg: regulatory T cells
Td: tetanus toxoid
UHN: University Health Network

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