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Original Paper

# Web Search Behavior and Information Needs of People With Multiple Sclerosis: Focus Group Study and Analysis of Online Postings

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## Abstract

**Background:** Multiple sclerosis (MS) patients and their family members increasingly seek health information on the Internet. There has been little exploration of how MS patients integrate health information with their needs, preferences, and values for decision making. The INtegrating and Deriving Evidence, Experiences, and Preferences (IN-DEEP) project is a collaboration between Italian and Australian researchers and MS patients, aimed to make high-quality evidence accessible and meaningful to MS patients and families, developing a Web-based resource of evidence-based information starting from their information needs.

**Objective:** The objective of this study was to analyze MS patients and their family members' experience about the Web-based health information, to evaluate how they assess this information, and how they integrate health information with personal values.

**Methods:** We organized 6 focus groups, 3 with MS patients and 3 with family members, in the Northern, Central, and Southern parts of Italy (April-June 2011). They included 40 MS patients aged between 18 and 60, diagnosed as having MS at least 3 months earlier, and 20 family members aged 18 and over, being relatives of a person with at least a 3-months MS diagnosis. The focus groups were audio-recorded and transcribed verbatim (Atlas software, V 6.0). Data were analyzed from a conceptual point of view through a coding system. An online forum was hosted by the Italian MS society on its Web platform to widen the collection of information. Nine questions were posted covering searching behavior, use of Web-based information, truthfulness of Web information. At the end, posts were downloaded and transcribed.

**Results:** Information needs covered a comprehensive communication of diagnosis, prognosis, and adverse events of treatments, MS causes or risk factors, new drugs, practical, and lifestyle-related information. The Internet is considered useful by MS patients, however, at the beginning or in a later stage of the disease a refusal to actively search for information could occur. Participants used to search on the Web before or after their neurologist's visit or when a new therapy was proposed. Social networks are widely used to read others' stories and retrieve information about daily management. A critical issue was the difficulty of recognizing reliable information on the Web. Many sources were used but the neurologist was mostly the final source of treatment decisions.

**Conclusions:** MS patients used the Internet as a tool to integrate information about the illness. Information needs covered a wide spectrum, the searched topics changed with progression of the disease. Criteria for evaluating Internet accuracy and credibility of information were often lacking or generic. This may limit the empowerment of patients in health care choices.

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## KEYWORDS

multiple sclerosis; evidence-based information; information needs; Web search behavior; Internet; patients' involvement

## Introduction

Providing health care information and tackling the right questions at the right time together with professional advice can improve people's knowledge of the disease, reduce anxiety, facilitate symptom management, and increase a sense of empowerment [1]. In multiple sclerosis (MS), giving newly-diagnosed people targeted information improves their knowledge of MS and satisfaction with care [2,3]. With the advent of disease-modifying drugs, MS patients increasingly seek information about new treatments, and earlier attitudes of hopelessness have changed [4]. In general, more and more people demand active roles in medical decision-making and asking for health and research information to share decisions with doctors about treatment and management options [5,6]. They want to know the evidence behind different treatments [7], how research relates to them [8], and the implications of research findings for their health care options and choices. This creates a challenge for providing health information based on research and connections between the research and individuals, to enable people to apply research findings to their own circumstances. There are two good reasons to catch patients' information needs. First, to make relevant information available to patients, a research governance strategy bringing together researchers and patients is needed [9]. Second, a definite judgment of treatment effect needs to incorporate patient's voice into the design of the therapeutic programs [10].

Research-based health information has become the topic of studies focusing on how to present it clearly and unambiguously [7,11]. The most accessible and usable formats to communicate research-based information have also been studied [12-14].

One of the main sources of health care information is the Internet. According to recent surveys in the United Kingdom and Canada, it is now placed second to health professionals as a source [7]. Approximately 70% of individuals in the European Union use the Internet and almost 40% of those aged 16 to 74 use it to seek health information [15]. In Italy, almost one-half of people use the Internet, and more than a one-quarter of those aged 16 to 74 use it to seek health information [15,16]. The strongest users are aged 11 to 34 years.

MS patients, like other people with chronic conditions, increasingly search for health information on the Internet [17,18], also using YouTube, Facebook, blogs, or forums. The use of Web 2.0 as a source of information on new controversial treatments raised debate about its role, both in personal decision-making and in public demand for health care services or interventions [19,20].

To assess the accuracy of health information and use it to exert greater control over life events and situations, critical appraisal skills are essential [21]. This is particularly true for Web-based information, where skill is needed to judge the degree to which the information merits trust accordingly with the evidence available [22]. Patients' associations have a critical role in giving information to MS patients and family members [23] and increasingly use websites and social networks to provide information and refer people to high-quality sources. This reflects the need to encourage skilled, confident information users and to promote a higher level of patients' and community engagement in health care.

Health care and service providers can take different roles in relation to Internet information-seeking behavior [24]: working in partnership to obtain and analyze information, guiding patients in finding reliable sites, or dismissing patients' information queries. The INtegrating and Deriving Evidence, Experiences and Preferences (IN-DEEP) project, aligns itself with the first two roles. It is a collaboration between research teams in Italy and Australia, developing two parallel projects following the same steps and a mixed-methods approach. The projects involve researchers in health communication, neurologists, MS patients, MS patients' associations (MS Australia and Italian Multiple Sclerosis Association [AISM]). This project is focused on Web-based health information with the aim to make high-quality evidence more accessible and meaningful to MS patients and their families, in particular, starting from their information needs, to develop a Web-based source of evidence-based health information. A four-stage process has been developed: first the assessment of health information needs through qualitative research, second the development of a Web template for presenting evidence-based health information, third the implementation of a pilot Internet template, and fourth a Web-based survey to evaluate if the IN-DEEP Web-based resource meets the information needs of MS patients and family members. [25]

The present article deals with the first qualitative stage, aimed at documenting and analyzing MS patients' and families' experience in finding, assessing, integrating Web-based health information with personal values.

## Methods

### Protocol

The IN-DEEP protocol was published [25] and the ethical approval has been granted by the Faculty of Health Sciences Human Research Ethics Committee of La Trobe University, Australia, and the Ethics Committee of the Fondazione Istituto di Ricovero e Cura a Carattere Scientifico Istituto Neurologico

“Carlo Besta,” Italy. Face-to-face focus groups were formed with MS patients and family members and a Web-based forum was also proposed as an additional method to involve more people using the Internet and widen the collection of information.

### Focus Groups

We organized 6 focus groups, 3 with MS patients and 3 with family members, in Milan (North), Macerata (Center), and Palermo (South) from April to June 2011. MS patients aged between 18 and 60, diagnosed as having MS at least 3 months earlier, according to the Poser et al [26] or McDonald diagnostic criteria [27,28], and using the Web to search for information on MS were included.

For family members, inclusion criteria were age 18 and over, being a relative of a person with at least a 3-months MS diagnosis and using the Web to seek information on MS. The period of 3-months was an arbitrary choice aimed to include new MS people but not so close to the diagnosis, leaving a certain period of time to experience Web searching about MS. Family members of MS patients who took part in focus groups were excluded to increase the variety of sources, and make people feel guaranteed in sharing their opinion with no fear to be contradicted. MS patients and family members were invited by a group of neurologists and by AISM local units.

A purposeful sampling approach was used to select the participants. A screening questionnaire (SQ) completed in the presence of neurologists was used to collect information about participants. SQ was adopted to keep the project team in control of the recruitment process, maximizing the internal variability among participants and assuring they meet the including criteria at the same time. The SQ items covered sociodemographic characteristics and information about MS (year of diagnosis, type, Expanded Disability Status Scale (EDSS; as a standardized method of quantifying disability in MS, and therapy; [Multimedia Appendix 1](#)). Some questions focused on the frequency of Internet use and the kind of information sought. Selection was designed to obtain the most balanced sample in terms of age, education, MS length and severity, and a female/male ratio of

3:1. The focus groups were led by an expert moderator and an assistant moderator, using an interview guide as an outline for the focus group ([Multimedia Appendix 2](#)).

### Online Forum

The AISM hosted the Web-based forum on its Web platform for 1 month. Nine questions, and four subquestions, were posted covering searching behavior, use of Web-based information, truthfulness of Web information ([Multimedia Appendix 3](#)). AISM invited MS patients and family members by email and through the website. Participants received an information sheet by email, signed a consent form, and completed the SQ, as described above. Once the consent and SQ were returned to the researchers, they gave each participant a predefined username and password. Researchers were given moderator rights to post comments, to stimulate discussion, and assist participants. At the end, they downloaded a transcript of the forum, AISM closed the forum, and deleted the data.

### Data Analysis

Focus groups were audio-recorded and transcribed verbatim. Atlas.ti software (V 6.0) was used [29,30]. Data were analyzed from a conceptual point of view through a coding system [31]. The moderator and the assistant moderator independently read several times the transcripts and agreed on a common set of codes (ie, labels corresponding to emerging concepts). The analysis was guided by the research questions (see the interview guide, [Multimedia Appendix 2](#)) and the results were summarized according to them. Findings from focus group were analyzed together with data collected through the online forum.

## Results

### Participant Characteristics

In total 40 MS patients and 20 family members (mother/father 6, wife/husband 9, sister/brother 1, daughter/son 4) participated in the focus groups and the online forum ([Table 1](#)). All the MS patients, except 1, used the Internet for gathering information, 37 of them declared that they used it for health purposes.

**Table 1.** Participants' main characteristics.<sup>a</sup>

	Focus groups			Online forum		
	All participants n=41	People with MS n=24	Family member <sup>b</sup> n=17	All participants n=19	People with MS n=16	Family member <sup>b</sup> n=3
<b>Gender, n (%)</b>						
Female	26 (63)	17 (71)	9 (53)	16 (84)	14 (88)	2 (67)
Male	15 (37)	7 (29)	8 (47)	3 (16)	2 (13)	1 (33)
<b>Age, years</b>						
Mean (SD)	41.6 (10.3)	40.5 (10.2)	43.3 (10.6)	46.2 (10.9)	44.9 (11.4)	53.3 (2.9)
Median	42.0	42.0	41.0	46.0	42.5	55.0
Range	24-66	27-57	31-66	27-67	27-67	50-55
<b>Internet use for health purposes, n (%)</b>						
Yes	37 (97)	24 (100)	14 (93)	19 (100)	16 (100)	3 (100)
No	1 (3)	0 (0.00)	1 (7)	0 (0)	0 (0)	0 (0)
<b>Education, n (%)</b>						
Primary school	8 (20)	4 (17)	4 (25)	1 (5)	1 (6)	0 (0)
Italian Middle school	4 (10)	2 (8)	2 (12)	2 (11)	2 (13)	0 (0)
Secondary school	18 (45)	9 (38)	9 (56)	9 (47)	7 (44)	2 (67)
University	10 (25)	9 (38)	1 (6)	7 (37)	6 (38)	1 (33)
<b>Years with MS<sup>c</sup></b>						
Mean (SD)	11.0 (9.4)	9.1 (7.6)	13.9 (11.4)	12.2 (9.9)	10.6 (8.8)	20.7 (13.4)
Median	9.5	9.0	9.5	10.0	9.5	15.0
Range	0-33	0-32	1-33	2-36	2-31	11-36
<b>EDSS<sup>d</sup></b>						
Median	2.5	2.5	4.0	3.0	3.0	5.0
Range	0-8	0-7	0-8	1-9	1-9	3-7

<sup>a</sup>Some discrepancies in the total are due to some missing values.

<sup>b</sup>Years with MS, and EDSS reported in family members columns is related to the MS patient cared by a family member

<sup>c</sup>Multiple sclerosis.

<sup>d</sup>Expanded Disability Status Scale.

## Information Needs

Main information needs of MS patients and family members were about treatments, symptoms' management, and causes of the illness:

*When I was first diagnosed, I trawled the Internet looking for information on the disease, its biological mechanisms, and how to reverse symptoms. I often used Wikipedia to have a rough idea of the nervous system functioning and how the disease changes it. [MS patient, focus group]*

Among main interests was information about drugs, those they are using or those suggested by the neurologist, and adverse effects, new drugs or treatments available or under trial also abroad, how and where to have access to tests and new treatments, alternative therapies and diet. One of the most widely searched topics was new treatments. An example cited by participants was chronic cerebrospinal venous insufficiency (CCSVI). This condition, brought to the forefront by television programs, was looked for by the participants, and a few of them acted independently from their neurologist's opinion by doing or booking the echo-color Doppler and the percutaneous transluminal angioplasty. As reported by a participant: "I



consulted the Internet and clarified my ideas, because the medical Professor, as you have probably seen on you tube, was very clear” [MS patients, focus group]; “For example, when there had been the congress in Goteborg, there were the abstracts of all the presentations ... so one could have read what had been actually said” [MS patient, focus group].

The online forum participants searched for suggestions and information on how to cope with everyday life, managing symptoms and problems due to MS or drugs, such as fatigue, bladder disturbances, how to have a satisfactory sex life despite disability, how to avoid unsightly bruising due to interferon injections. Participants in the online forum admitted: “Being protected by the anonymity of the Internet, it is easier to look for information/exchanges with other patients on sensitive topics, like bladder problems or related to sex” [MS patient, online forum]. Life habits, as smoking, alcohol use, attending gym, etc, and their relation with MS were topics of interest, especially among the recently diagnosed participants, and young people. Family members were also interested in pension rights, social security entitlements, way to enter job protected and disadvantaged categories, and devices to improve or maintain the independence of MS patients; MS patients did not mention them at all. However, other sources of information can be more useful in case the user did not know exactly what to search for: “I did not know that he was entitled to the disability check until the health care professionals from the Institute told me” [Mother of a MS patient]. Interpretation of diagnostic test results (eg, magnetic resonance imaging, cerebrospinal fluid results) were also searched for.

Participants complained about a certain amount of unsatisfied information needs on the Web. While some topics were actually covered but might not be found because of a lack of confidence in Web searching, as information on pregnancy for MS patients or hereditary tests, some were not really known and were therefore not available, for example, information on a definitive cure or on the causes of MS.

A lack of information on alternative therapies, diet, and lifestyle was highlighted; appreciation was expressed by 1 of the MS patients for the useful US MS society list of the drugs currently in trial in the world. MS patients would need information on how to cope with family members, their concerns, and their obsessive behavior, while family members would need information on how to cope with MS patients; however, it was unclear if they actually searched for it.

Websites that greet the user with a depressing definition of MS, presenting the worst outcomes, was mentioned by MS patients as having a negative impact *on emotional or psychological well-being*. Patients needed some optimism in the way information was presented.

### **Sources of Information and Criteria to Discern Accurate Information**

Neurologists were the most important source of information for many participants but, among the family members of severely disabled MS patients, the general practitioner became the primary referent. The network of friends was also an important source of information as well as organizations offering services

to disabled people. Participants were curious about Web-based information but they were also cautious about its quality and trustworthiness, saying they preferred to discuss drugs and therapies with neurologists. The lack of the necessary skills to distinguish between reliable and unreliable information was given as a reason for opting out of Internet use, especially by the less educated MS patients.

Some subjective criteria were indicated to assess information but they were not universally agreed; also instinct has been mentioned as a form of reliability of information assessment: “I trust my gut instinct” [MS patient, focus group]; “I try to avoid exactly that, not to follow my gut instinct” [MS patient, focus group]. The independence of the source from financial and commercial interests was a shared criterion of trustworthiness, although there was no full agreement on how to identify nonindependent sources. For example, advertisement banners were seen by some as a sign of dependence but not by others “as the banners are everywhere.” The presence of links to downloadable documents including bibliographies and laws was another criteria raised during the discussion; it was considered a valuable opportunity to easily access further details and check the sources of information.

MS associations were mainly considered independent, but not all agreed. The institutional source was often cited as a criterion of credibility, especially the official websites, for example AISM, the Italian Health Ministry, hospitals, and health trusts.

Often the trustworthiness was tested through some kind of overlap: “After reading for four times the same information to me it is the casting out nines” [Mother of a MS patient]. If an item was discussed or presented on several trusted websites, or reported by many sources of information such as newspapers or TV, it was likely to be reliable. If information matched what the neurologist said or was known to be true by the searcher it was considered reliable: “I do a statistic of what is said and if this statistic is comforted by doctor’s opinion I think it is reliable” [MS patient, focus group]. The long age of a website or comments from a neurologist were mentioned indicators of reliability, especially if the neurologist was clearly recognizable and affiliation was stated.

In general, it was taken for granted that the “Internet is always up to date” [Husband of a MS patient].

Participants in the online forum stated they only searched for and trusted reliable Web-based information, but they did not specify how they distinguished between reliable or unreliable information. Websites that were not easily accessible, not clear, and where the date of update was missing were rejected or looked at with suspect.

### **Web Search Behavior**

Often the aim of seeking information on the Web was to prepare for discussions with the neurologist. Sometimes it was used after the visit to better understand what had been said or to collect information on the options presented by the neurologist. In some cases Web-based information was immediately applied to solve practical problems or cope with symptoms. Sometimes the aim of the consultation was to try to relieve the emotional burden, though this was not always achieved.

As time went on, the Web-based searching became less and expectations dropped, and participants became more cautious. There were two types of Internet users, the ones that rely on few reliable websites, which they regularly consulted like a “habit, as well as you read a newspaper,” and the ones that started their search using search engines, especially for occasional needs.

There were people that stopped searching after an initial period of intensive searching and decided to rely solely on their neurologist for information and advice. On the other hand, people that did not accept their disease or were frightened preferred, almost from the beginning, not to read anything related to MS. Over the time some of them accepted their disease, and became less frightened, and began to search the Internet again:

*At the beginning, I tell you one thing, you don't want to know too much. Yes, you have it, stop. Over time you become aware and want to know more and more.*  
[MS patient, focus group]

The decision to opt out of Internet use was usually taken soon after the diagnosis but also in later stages when conditions deteriorated. The tendency of MS patients to opt out of Internet use was clearly raised by family members, who felt committed to search on behalf of the ill person, acting as an information filter even if MS patients complained about this type of behavior. Family members also searched for themselves to overcome their feelings of impotence in face of unpredictability and uncertainty of the disease: “Goodness knows what I would do, I cannot do anything so it seems to me I'm able to help her this way.” [Mother of a MS patients]

At the beginning, people searched for information on the disease, its causes, its mechanism of action, symptoms, and therapy. In the years after diagnosis, they looked for ongoing clinical studies, scientific research, news spread by mass media, and social networks.

In searching for information about new drugs and trials, English speaking people believed English-language websites were more up-to-date and useful than Italian ones. The lack of access to scientific articles, mostly written in English language, was considered a barrier to this kind of information. Medical jargon was another strong barrier to information.

### Social Networks

In some cases the participants rejected the use of social networks, as they preferred to share information face-to-face, and also because of privacy concerns. Social networks were more used to read others' stories and retrieve information, than to share personal information and experience. Social networks were also used to make decisions about the management of their life with MS.

People using social networks trusted them because they involved MS patients who were considered independent from commercial or other interests:

*Information are quite secure given the seriousness of the issues. I do not think that in a forum attended by*

*people who have the disease people say useless things or things that are not true.* [Husband of a MS patient]

Here again, some criteria were applied to assess the trustworthiness. Consistency of the information, consistency with information received from the neurologist, a competent moderator, a clear statement of the forum objectives, and lack of argumentativeness were all applied.

Those who did not use social networks, considered them unreliable since it was impossible to check the identity of people behind the nicknames, “All of these sites where there are threads posted... first of all I do not know who wrote that, because they have all a nickname, are not recognizable people, I do not know if it is true that they have the disease or if they are people who write just to write I mistrust these” [Husband of a MS patient], or because the participants was no scientific background: “If you go on a forum, it happened to me several times, that someone says that this medicine works this other works, but who are you to say it?” [Partner of a MS patient].

Selected forums could become important supportive tools for newly diagnosed young people or, less frequently, their family members. Facebook was sometimes used as a source of information (especially for new controversial intervention, as for examples CCSVI), or as a space for keeping in contact with friends, “where you did not present yourself as an ill person.”

## Discussion

### Principal Findings

The focus group and the online forum draw a new picture of the information needs of MS patients and family members, pointing to topics and issues to be considered to offer good information. As recently showed by a Cochrane review information, it is central to increase disease-related knowledge and it is in part correlated with the decision making process and quality of life [32]. There are two good reasons to catch patients' information needs. First, to make relevant information available to patients, a research governance strategy bringing together researchers and patients is needed [33]. Second, a definite judgment of treatment effect needs to incorporate patient's voice into the design of the therapeutic programs [34].

This study shows a wide spectrum of information needs, such as a comprehensive communication of diagnosis, prognosis, and adverse events of treatment, MS causes or risk factors, new drugs, practical and lifestyle-related information.

The use of the Web varied widely according to personal characteristics, health role (MS patient or family member), and time from the diagnosis. There were people who considered Internet useful for collecting information and learning about others' experiences, also using social networks, while others were cautious and preferred relying on information given by their neurologist. MS patients were mainly “on demand” users, searching on the Web before and/or after seeing the neurologist or when a new therapy or a new risk factor was proposed. MS patients reported changes in information-seeking over time. They searched Internet for information about the disease extensively, but without a planning, soon after diagnosis. Later, during the course of the disease, they changed their attitude and

adopted more focused strategies searching answers to specific questions. Some MS patients gave up Internet searches but were still interested in up-to-date news, particularly new treatments and research results. Family members continued to use Internet searching for information that could help, like exercises or diet, and information on legal rights for people with MS.

The use of the Web was also influenced by other media. The CCSVI was an example of the effect of interactions among different media about health care issues: many people started searching information on the Web about CCSVI after watching television programs on it; on the other side, the Web raised the attention to this topic among MS patients, driving also the attention of other media. This process amplified the messages conveyed and the demands about CCSVI. In this controversial case, the Web played an important role, giving the opportunity to access articles, conference presentations, interviews, and providing practical information, such as searching for hospitals that offered CCSVI diagnosis and treatment.

The use of social networks was also very variable. Some considered online forums reliable because they were written by people living with the disease, not driven by commercial or professional interests, and offered information not provided by neurologists or medical websites, such as matters related to practical and life-style-related information. Others did not use social networks, and considered them unreliable because they are written by lay people, preferring face-to-face interactions to share their experience with other people with MS or the neurologist.

Difficulty to recognize reliable information on the Web constituted a critical issue raised by both MS patients and family members, saying they got confused when information on websites they perceived as reliable collided with information given by the neurologists. MS patients and family members were also not confident about which criteria should be used to assess the quality of Web information and their descriptions were often generic.

Neurologists remained the most important source of information for many participants in our study. This finding agrees with the results of a survey on preferred sources of health information in MS patients in the United States [35], where the most trusted source was a physician. Internet use was more common among the respondents to this survey than in our sample: this could be tied to socioeconomic and educational differences and to the different contexts (United States, Italy). For example, in Italy the shares for individuals who used the Internet regularly were almost 50% in 2012 and strong gender, age, and territorial inequalities still persisted [15,16].

### Comparison With Other Studies

Even if the results presented here are related only to the Italian setting, the need to have a reliable source of information, the wide spectrum of information needs of patients and family, and how to navigate through the amount of information available in Internet are issues relevant regardless of the country and the culture. A strong wish to get reliable and independent information, particularly Web-based, was reported both by the Italian and Australian MS patients participating to the focus

groups and online forum (data submitted for publication). Distinguishing good quality information and deriving usefulness from it were difficult for many of the participants in both studies, mainly because of information overload and contradictory results they found on the Internet. Searching strategies changed over time in response to information needs but neurologists and MS Societies remained the most trusted information sources for decision making by MS patients in the two countries. A Web-based survey conducted among Italian parents of children with rare diseases described their Internet use profile, and explored how Internet use affected their health decisions [36]. Parents participating in the Web-based survey were more likely than MS patients participating in our study to access the Internet daily, and stated that Web information increased their comprehension of the disease and improved its management. However, there were some key differences between the two studies. First, different study designs. Second, a different health role of parents of children affected with rare diseases and adults patients with MS. Third, a likely high quality format of Web health information for children with rare diseases enabling their parents to make Web-based information applicable and meaningful for their personal circumstances.

### Study Limitations

Although the questionnaire used for participants' selection focused on Internet use, some family members in the focus groups only occasionally used the Web to find MS information. This limited some findings about their Web-searching behavior and about assessing the quality of websites.

People participating in the online forum tended to answer the questions without launching new topics and rarely sharing comments with others. It could be that inviting people to take part in a research project discussing predefined questions limited their interaction, moreover only 1 month of observation could be a too limited time period. In order to learn about people's behaviors in participating in a forum it could be better to observe their spontaneous posts and questions.

### Implications for Development of the IN-DEEP Web-Based Source of Information

This is a first qualitative step of a more complex research plan, results come out from a selected group of people, some selection bias are possible. Nevertheless the results show a wide spectrum of inputs to be considered in developing Web-based good information for MS patients and families. In the next stages, we will develop and evaluate a model for presenting health information on the Internet making high-quality evidence, primarily derived from the Cochrane reviews, more accessible and meaningful to MS patients and their families. Some points have been discussed, particularly what topics to include and which "research-based" sources. Other implications from these findings refer to the quality of communication that has to be clear, complete, transparent, and updated to enable people using the information and make it applicable and meaningful for their personal circumstances.

The difficulties in assessing and evaluating the quality of Web-based health information suggest also the need for



educational tools, as a glossary and sections with methodological information.

Considering that information needs gradually change along the course of the disease, the Web-based IN-DEEP model will be tailored on three levels of information with increasing level of details. The website format reflected preferences for layered

information complexity (ie, “the short answer,” “the detailed answer,” “the deep answer”) and a combination of words, numbers, and pictures to explain benefits and adverse events, with additional sections on practical information, research methodology, and personal histories. Personal experiences were considered useful to convey and reinforce the messages and translate them to daily life [37].

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## Conflicts of Interest

PC reports nonfinancial support from Biogen Dompe, nonfinancial support from Sanofi Aventis, outside the submitted work.

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## Multimedia Appendix 1

Screening questionnaire.

[PDF File (Adobe PDF File), 26KB - [ijmr\\_v3i3e12\\_app1.pdf](#)]

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## Multimedia Appendix 2

Interview guide.

[PDF File (Adobe PDF File), 24KB - [ijmr\\_v3i3e12\\_app2.pdf](#)]

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## Multimedia Appendix 3

Online forum questions.

[PDF File (Adobe PDF File), 29KB - [ijmr\\_v3i3e12\\_app3.pdf](#)]

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## Abbreviations

**AISM:** Italian Multiple Sclerosis Association

**CCSVI:** chronic cerebrospinal venous insufficiency

**EDSS:** expanded disability status scale

**IN-DEEP:** INtegrating and Deriving Evidence, Experiences and Preferences

**MS:** multiple sclerosis

**SQ:** screening questionnaire

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Original Paper

# The Impact of Different Surgical Modalities for Hysterectomy on Satisfaction and Patient Reported Outcomes

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## Abstract

**Background:** There is an ongoing debate regarding the cost-benefit of different surgical modalities for hysterectomy. Studies have relied primarily on evaluation of clinical outcomes and medical expenses. Thus, a paucity of information on patient-reported outcomes including satisfaction, recovery, and recommendations exists.

**Objective:** The objective of this study was to identify differences in patient satisfaction and recommendations by approach to a hysterectomy.

**Methods:** We recruited a large, geographically diverse group of women who were members of an online hysterectomy support community. US women who had undergone a benign hysterectomy formed this retrospective study cohort. Self-reported characteristics and experiences were compared by surgical modality using chi-square tests. Outcomes over time were assessed with the Jonkheere-Terpstra trend test. Logistic regression identified independent predictors of patient satisfaction and recommendations.

**Results:** There were 6262 women who met the study criteria; 41.74% (2614/6262) underwent an abdominal hysterectomy, 10.64% (666/6262) were vaginal, 27.42% (1717/6262) laparoscopic, 18.94% (1186/6262) robotic, and 1.26% (79/6262) single-incision laparoscopic. Most women were at least college educated (56.37%, 3530/6262), and identified as white, non-Hispanic (83.17%, 5208/6262). Abdominal hysterectomy rates decreased from 68.2% (152/223) to 24.4% (75/307), and minimally invasive surgeries increased from 31.8% (71/223) to 75.6% (232/307) between 2001 or prior years and 2013 ( $P < .001$  all trends). Trends in overall patient satisfaction and recommendations showed significant improvement over time ( $P < .001$ ). There were differences across the surgical modalities in all patient-reported experiences (ie, satisfaction, time to walking, driving and working, and whether patients would recommend or use the same technique again;  $P < .001$ ). Significantly better outcomes were evident among women who had vaginal, laparoscopic, and robotic procedures than among those who had an abdominal procedure. However, robotic surgery was the only approach that was an independent predictor of better patient experience; these patients were more satisfied overall (odds ratio [OR] 1.31, 95% CI 1.13-1.51) and on six other satisfaction measures, and more likely to recommend (OR 1.64, 95% CI 1.39-1.94) and choose the same modality again (OR 2.07, 95% CI 1.67-2.57). Abdominal hysterectomy patients were more dissatisfied with outcomes after surgery and less likely to recommend (OR 0.36, 95% CI 0.31-0.40) or choose the same technique again (OR 0.29, 95% CI 0.25-0.33). Quicker return to normal activities and surgery after 2007 also were independently associated with better overall satisfaction, willingness to recommend, and to choose the same surgery again.

**Conclusions:** Consistent with other US data, laparoscopic and robotic hysterectomy rates increased over time, with a concomitant decline in abdominal hysterectomy. While inherent shortcomings of this retrospective Web-based study exist, findings show that patient experience was better for each of the major minimally invasive approaches than for abdominal hysterectomy. However,

robotic-assisted hysterectomy was the only modality that independently predicted greater satisfaction and willingness to recommend and have the same procedure again.

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## KEYWORDS

hysterectomy; vaginal hysterectomy; robotics; laparoscopy; patient satisfaction; patient outcomes assessment; Internet

## Introduction

The growth of online support communities and patient engagement on the Internet has provided researchers with unique opportunities to study patient reported outcomes. Population groups can now be readily identified on the Web to study outcomes following disease diagnosis or treatment. Despite their potential limitations, Internet-based studies are able to gather data from a sizeable and geographically diverse patient group at relatively low cost. We used the advantages of this type of data collection to study patient reported experiences following different surgical modalities for hysterectomy.

There has been an ongoing debate regarding the benefits of different surgical techniques for hysterectomy. Many studies attempting to address this question have compared only clinical outcomes, while others have included direct in-hospital costs of the procedures [1-4]. Minimally invasive compared with open approaches for hysterectomy have often been shown to offer somewhat better clinical outcomes, but sometimes at a higher per patient cost [1-6].

More recently, a large study of health insurance claims data linked with workplace absenteeism showed that minimally invasive surgery compared with the open, standard approach for certain conditions resulted in significantly lower health plan spending and significantly fewer days of absence from work over a 1-year peri- and postoperative period [7]. These findings were evident specifically for uterine fibroid resection, the only gynecologic surgery studied. The authors suggest that the policy implications of their results indicate a need for a broader scope of outcomes in the evaluation of technologies, not limited to clinical findings or direct medical expenses.

The present study adds to this ongoing debate by suggesting that patient satisfaction and return to normal activities should also be considered in the equation regarding the cost-benefit of different surgical modalities. Our study describes the use of abdominal, vaginal, laparoscopic, robotic-assisted, and single-incision laparoscopic techniques for benign hysterectomy over time in a large online patient community seeking and providing information about hysterectomy and related aspects of women's health. Since benign hysterectomy has seen a significant change in treatment choice over the past decade, this study importantly compares time trends in the use of the different modalities as well as differences in self-reported patient recovery, satisfaction, and recommendations. The independent associations of surgical approach and recovery with overall patient satisfaction and recommendations are further explored.

## Methods

### Participants

Participants in this study were identified through HysterSisters.com, a large online community of women who give and receive support and resources for hysterectomy decisions, treatments, and recovery. HysterSisters.com has been certified by the Health on the Net Foundation to "promote and guide the deployment of useful and reliable online health information, and its appropriate and efficient use." The website was launched in 1998 and has registered close to 300,000 women since that time. The HysterSisters' privacy policy indicates that research related to women's health is sometimes conducted on the site "...to identify unmet needs of women through aggregate reporting of women's experiences, opinions and therapeutic treatments." HysterSisters' founder agreed to the plans and purpose of this study.

In early February 2013, all members who were still registered to receive the HysterSisters' Web-based newsletter and had valid email addresses were invited to participate in this study. All contact with the membership was done through HysterSisters so that no one on the study team had access to individual email addresses. Only women in the United States who linked to and completed the Web-based survey and indicated that they already had a hysterectomy for benign indications are included in this report.

### Data Collection

Data were collected with the assistance of HysterSisters.com and MarketTools software over the period February 4<sup>th</sup> to February 13<sup>th</sup> 2013. A link on the February HysterSisters' newsletter invited recipients to participate in the hysterectomy survey. A specific email went out from the HysterSisters' founder 2 days later inviting women who had a hysterectomy or were thinking about having one to provide their input in a short 5 to 7 minute survey. A follow-up email, identical to the previous one, was sent on February 11th. Women accessed the study questionnaire through a link on one of the communications. Cookies were used to track survey access so that all completed questionnaires were from unique respondents. This study received an exemption from the requirement of institutional review board (IRB) approval from Quorum Review IRB and this exemption is on file.

The data collection tool was developed to adequately address questions in the study protocol. Based on past experience, the Web-based survey was tested via the Internet to ensure proper function including the adaptive questions that created a skip pattern depending on an individual's responses. Each participant was shown four to five screens and answered up to 24 questions



with each screen containing two to six items. Respondents were able to go back to review and change answers.

All questions on the survey had categorical multiple-choice responses. They included whether the participant ever had surgery to remove the uterus (hysterectomy), the primary reason (benign/noncancerous or cancerous conditions with examples), the type of hysterectomy with explanations (abdominal, vaginal, laparoscopically-assisted vaginal hysterectomy, laparoscopic hysterectomy, robotic-assisted hysterectomy, single-incision laparoscopic hysterectomy, and not sure), and the year, beginning with 2001 or earlier up to 2013. Respondents also indicated if they had had specific abdominopelvic or gynecologic surgeries prior to their hysterectomy.

On a 5-point (Likert type) scale, participants rated how satisfied (extremely satisfied, very satisfied, somewhat satisfied, not satisfied, extremely dissatisfied) they were overall with the surgery and with specific aspects of hysterectomy (invasiveness, complications, length of hospital stay, pain and discomfort, recurrence of problem, and time until return to normal activities) and how likely they would be to recommend the same type of hysterectomy to someone else. In addition, women were asked what modality they would choose if they had to do the surgery all over again. Respondents also reported the amount of time it took them to return to normal activities including walking, driving, and getting back to work.

Self-reported sociodemographic information was collected on age group, education, family income, race/ethnicity, urban/suburban/rural residence, and type of health insurance (private, Medicare, Medicaid, other). No personal identifiers were obtained. These data were stored in a centralized database with password-protected access for study researchers only.

### Statistical Analysis

All analyses excluded the small number of women who were unsure of the surgical technique. Study categories included abdominal, vaginal, laparoscopic (combining laparoscopic and laparoscopically-assisted vaginal hysterectomy), robotic-assisted, and single-incision laparoscopic hysterectomy. For most analyses, year of hysterectomy was grouped into three periods (2007 or prior, 2008-2010, 2011-2013). It was important that all types of surgeries were performed in each time period to reduce possible confounding of time of surgery with approach. Thus, the first period was defined to include the newest robotic approach, first reported by this cohort in 2006. The years 2008 to 2013 were split evenly into two 3-year periods.

Chi-square tests were used to compare outcomes over the different surgical modalities. Trends over time were assessed with the Jonkheere-Terpstra test for trend. Logistic regression was used to describe the associations of surgical technique with patient experience, adjusted for age and time period. Multivariable, forward, stepwise logistic regression was employed to identify characteristics that were independently associated with important outcomes after surgery: (1) how satisfied the respondents were with the overall and specific results after surgery (time to return to normal activities, pain and discomfort, invasiveness, complications, length of hospital

stay, and recurrence), (2) how likely they would be to recommend their surgical approach to another person, and (3) whether they would choose the same technique again. The variables considered for entry into the logistic model were chosen a priori without considering results of univariate or bivariate analyses. These included patient age group (<40, 40-49, 50-59, 60+), education (high school or less, some college, college graduate, graduate school or higher), family income (<\$50,000, \$50,000-\$75,000, \$76,000-\$125,000, >\$125,000), race/ethnicity (white, non-Hispanic, African American, Hispanic, other), community type (urban, suburban, rural), type of hysterectomy, time periods of surgery ( $\leq$ 2007, 2008-2010, 2011-2013), and prior abdominopelvic surgery (yes/no). Recovery time regarding walking (within 1-2 days, yes/no), driving (within 1 week, yes/no), and returning to work (within 4 weeks, yes/no) was also allowed to enter for some outcomes. No imputed values were used in the regression analyses. Results are presented using the odds ratio (OR) and its 95% confidence limits (95% CI).

All analyses were performed using SAS version 9.2. Given the large data set analyzed, a two-sided  $P < .01$  was used to determine statistical significance.

## Results

### Online Recruitment

The HysterSisters' February newsletter was sent to 134,618 members of the online community. Two dedicated study invitation emails subsequently went out to those who had valid email addresses (114,116/134,618, 84.77%), as determined by the newsletter mailing. At least one of the mailings was opened by 55.29% (63,095/114,116) of women. Of those, 18.53% (11,694/63,095) clicked on the survey link and 17.80% (11,232/63,095) began to complete the questionnaire. There were 121 women screened out on the first question by responding that they never had and were not planning to have a hysterectomy and 1934 completed only part of the survey. The questionnaire was completed in full by 78.48% (9177/11,694) of those who clicked on the link or 14.54% (9177/63,095) of those who opened one of the emails. This paper describes the results of analysis of all US respondents who had undergone a benign hysterectomy and specified the surgical modality (6262). The techniques included 41.74% (2614/6262) abdominal, 10.64% (666/6262) vaginal, 27.42% (1717/6262) laparoscopic, 18.94% (1186/6262) robotic, and 1.26% (79/6262) single-incision laparoscopic hysterectomies.

### Patient Sociodemographic Characteristics

A majority of women, 77.34% (4843/6262), had their hysterectomies between the ages of 40 and 59 (Table 1). A college or graduate degree was obtained by 56.37% (3530/6262) and yearly family income was below \$50,000 in 22.34% (1399/6262). A little more than one-half of the participants, 52.59% (3293/6262), indicated that their family income was over \$75,000. The group was predominantly white non-Hispanic, as reported by 83.17% (5208/6262); 8.80% (551/6262) considered themselves African American, and 3.80% (238/6262) Hispanic. Most of the respondents, 53.75% (3366/6262), lived in suburban areas; 18.48% (1157/6262) came

from urban cities and 27.77% (1739/6262) were rural dwellers. Health insurance was private, either through an employer or through self-insurance, in 85.47% (5352/6262) of the total group.

**Table 1.** Patient sociodemographic characteristics by surgical approach.

Characteristics	Abdominal N=2614	Vaginal N=666	Laparoscopic N=1717	Robotic N=1186	Single-incision la- paroscopic N=79	<i>P</i> value <sup>a</sup>
	n (%)	n (%)	n (%)	n (%)	n (%)	
<b>Age, years</b>						<.001
<40	333 (12.74)	110 (16.52)	362 (21.08)	224 (18.89)	10 (12.66)	
40-49	1097 (41.97)	269 (40.39)	780 (45.43)	599 (50.51)	31 (39.24)	
50-59	1017 (38.91)	201 (30.18)	502 (29.24)	315 (26.56)	32 (40.51)	
≥60	167 (6.39)	86 (12.91)	73 (4.25)	48 (4.05)	6 (7.59)	
<b>Education</b>						.009
Middle or high school	362 (13.85)	94 (14.11)	231 (13.45)	119 (10.03)	10 (12.66)	
Some college	788 (30.15)	223 (33.48)	543 (31.62)	343 (28.92)	19 (24.05)	
College	954 (36.50)	237 (35.59)	642 (37.39)	478 (40.30)	34 (43.04)	
Graduate school or higher	510 (19.51)	112 (16.82)	301 (17.53)	246 (20.74)	16 (20.25)	
<b>Family income</b>						<.001
<\$50,000	644 (24.64)	139 (20.87)	369 (21.49)	223 (18.80)	24 (30.38)	
\$50,000-\$75,000	649 (24.83)	174 (26.13)	447 (26.03)	283 (23.86)	17 (21.52)	
\$76,000-\$125,000	817 (31.25)	237 (35.59)	589 (34.30)	427 (36.00)	17 (21.52)	
>\$125,000	504 (19.28)	116 (17.42)	312 (18.17)	253 (21.33)	21 (26.58)	
<b>Race</b>						<.001
White	2099 (80.30)	592 (88.89)	1462 (85.15)	991 (83.56)	64 (81.01)	
African American	298 (11.40)	30 (4.50)	120 (6.99)	98 (8.26)	5 (6.33)	
Hispanic	96 (3.67)	16 (2.40)	67 (3.90)	55 (4.64)	4 (5.06)	
Other	121 (4.63)	28 (4.20)	68 (3.96)	42 (3.54)	6 (7.59)	
<b>Community type</b>						.04
Urban	500 (19.13)	111 (16.67)	300 (17.47)	230 (19.39)	16 (20.25)	
Suburban	1408 (53.86)	341 (51.20)	912 (53.12)	664 (55.99)	41 (51.90)	
Rural	706 (27.01)	214 (32.13)	505 (29.41)	292 (24.62)	22 (27.85)	
<b>Insurance type</b>						.10
Private	2217 (84.81)	551 (82.73)	1470 (85.61)	1045 (88.11)	68 (86.08)	
Medicare	81 (3.10)	33 (4.95)	54 (3.15)	29 (2.45)	3 (3.80)	
Medicaid	60 (2.30)	19 (2.85)	35 (2.04)	16 (1.35)	1 (1.27)	
Other	256 (9.79)	63 (9.46)	158 (9.20)	96 (8.09)	7 (8.86)	

<sup>a</sup>*P* value based on the overall chi-square test of the characteristic by surgical modality.

Comparison of the different treatment approaches on sociodemographic characteristics showed that patients differed significantly ( $P<.01$ ) across techniques on age group, education, family income, and race/ethnicity (Table 1). Patients who had undergone laparoscopic or robotic hysterectomy were similar in age ( $P=.062$ ), but younger than women who had abdominal

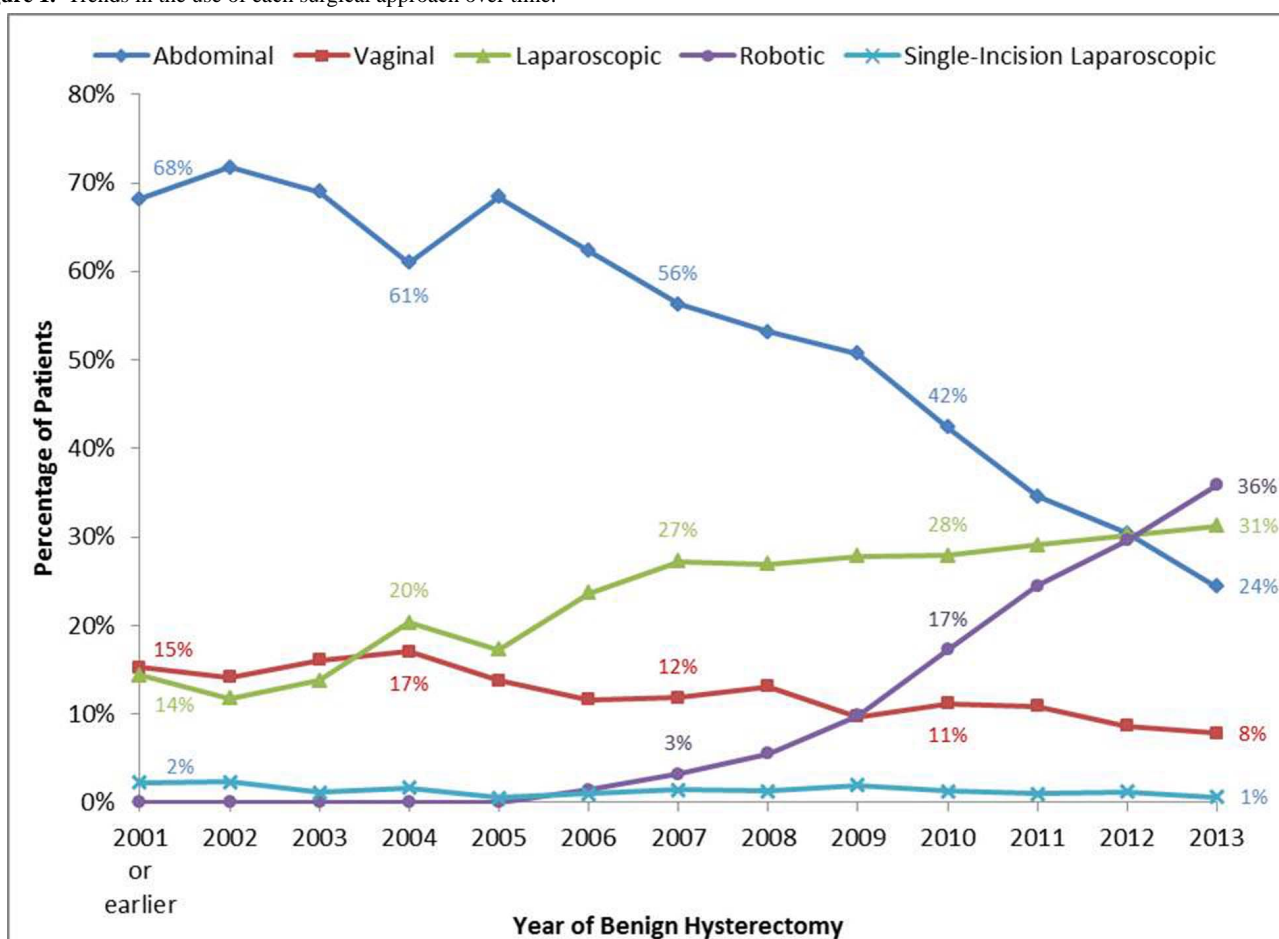
or vaginal surgeries ( $P<.001$ ). The group who had robotic surgery was also younger than those who had the single-incision laparoscopic approach ( $P=.01$ ). A higher percentage of patients who had single-site laparoscopies were greater than 50 years of age when compared with the other surgical groups.

The most consistent finding with regard to socioeconomic status was that patients who had a robotic hysterectomy were better educated ( $P=.003$ ) and had higher family income ( $P<.001$ ) than women who had the abdominal approach (Table 1). The lowest percentage of white women was found in the group who had abdominal surgery (80.30%, 2099/2614;  $P<.01$  for comparisons with each of the other modalities except single-incision laparoscopy where there was no difference).

### Time Trends in Modalities for Hysterectomy

Trends over time indicated that the use of abdominal and vaginal approaches significantly declined between 2001 or earlier years and 2013 ( $P<.001$  for both trends, Figure 1). Abdominal hysterectomy rates fell from 68.2% (152/223) to 24.4% (75/307) and vaginal rates from 15.2% (34/223) to 7.8% (24/307) over time. The use of laparoscopic surgery significantly increased from 14.3% (32/223) to 31.3% (96/307) and robotic surgery from 0% (0/223) (prior to its approval and introduction in 2005) to 35.8% (110/307) in 2013 ( $P<.001$  for both trends). Single-incision laparoscopic hysterectomy rates were very low and basically unchanged over time (5/223, 2.2% in 2001 or prior years to 2/307, 0.7% in 2013). Thus, in this study, minimally invasive hysterectomy increased from 31.8% (71/223) of procedures in 2001 or earlier to 75.6% (232/307) of surgeries in 2013.

Figure 1. Trends in the use of each surgical approach over time.



### Patient Reported Experience: Satisfaction, Recovery, and Recommendations After Hysterectomy

There were significant differences in each measured outcome across the surgical modalities as described in Table 2 ( $P<.001$ ). Logistic regression analysis, including three covariates (age group, time period, and approach to hysterectomy), was used to describe associations of procedure and time period with each outcome. Findings indicated that there was less overall satisfaction and more dissatisfaction in the abdominal hysterectomy group when compared with the vaginal ( $P=.009$ ),

laparoscopic ( $P<.001$ ), and robotic ( $P<.001$ ) surgical groups. Extreme satisfaction rates ranged from 41.35% (1081/2614) in the abdominal to 55.73% (661/1186) in the robotic hysterectomy group. These analyses also showed that overall satisfaction significantly increased between time periods 1 and 3 ( $P<.001$ ).

Less satisfaction and more dissatisfaction with time needed to return to normal activities was also evident among women who had an abdominal hysterectomy when compared with those who had vaginal, laparoscopic, and robotic minimally invasive surgery (all  $P<.001$ ). Rates of extreme satisfaction varied from

18.63% (487/2614) among those who had abdominal procedures to 39% (31/79) in the single-incision laparoscopic group.

Logistic regression results regarding satisfaction with pain and discomfort after hysterectomy again indicated that women who had the abdominal approach were less satisfied when compared with those in each of the other groups, except single-incision (all  $P < .001$ ). These analyses also showed that satisfaction was significantly less in time period 1 compared with period 3 and greater at older ages compared with younger (both  $P < .001$ ).

Similarly, significantly less satisfaction with invasiveness of the surgery, complications associated with the hysterectomy, and length of hospital stay were seen with abdominal hysterectomy compared to vaginal, laparoscopic, and robotic approaches (all  $P < .001$ ). More dissatisfaction was evident in time period 1 than in period 3 (all  $P < .002$ ).

Satisfaction with recurrence of the problem after hysterectomy was greater for those who had robotic surgery only ( $P < .001$ ), when comparing the abdominal approach to the other minimally invasive procedures. Less satisfaction was seen in the earliest time period and at younger than older ages.

The abdominal hysterectomy group also was less likely to return to walking within 2 days, to driving within 1 week and to working within 4 weeks than the vaginal ( $P = .008$ ), laparoscopic

( $P < .001$ ), and robotic groups ( $P < .001$ ). In addition, those who were younger ( $P = .001$ ) and had surgery most recently ( $P = .006$ ) returned to walking sooner. Rates of early return to driving and work were highest for those who had the single-incision laparoscopic hysterectomy, 39.7% (31/78) and 57.8% (37/64), respectively.

Recommendation of the surgical approach to another and choosing the same technique again followed similar trends by modality (Table 2). Patients who had an abdominal hysterectomy were significantly less likely to recommend that approach or choose it again than patients who had one of the minimally invasive procedures (all  $P < .001$ ). Those who had surgery in the earliest time period versus the most recent were less likely to recommend their approach ( $P < .001$ ). Women who had surgery in the most recent time period versus time periods 1 or 2 were significantly more likely to choose their procedure again (both  $P < .001$ ).

Rates of definitely recommending the same procedure ranged from 27.74% (725/2614) in the abdominal to 69.81% (828/1186) in the robotic hysterectomy group and rates for choosing the same hysterectomy procedure again varied from 39.02% (1020/2614) in the abdominal to 86.85% (1030/1186) in the robotic surgery group.

**Table 2.** Patient satisfaction, recovery, and recommendations by surgical technique.

Characteristics	Abdominal N=2614 n (%)	Vaginal N=666 n (%)	Laparoscopic N=1717 n (%)	Robotic N=1186 n (%)	Single-incision laparoscopic N=79 n (%)	P value <sup>a</sup>
<b>Overall hysterectomy results</b>						<.001
Extremely satisfied	1081 (41.35)	317 (47.60)	862 (50.20)	661 (55.73)	40 (50.63)	
Satisfied	1346 (51.49)	305 (45.80)	762 (44.38)	483 (40.73)	31 (39.24)	
Dissatisfied	187 (7.15)	44 (6.61)	93 (5.42)	42 (3.54)	8 (10.13)	
<b>Time to return to normal activities</b>						<.001
Extremely satisfied	487 (18.63)	185 (27.78)	497 (28.95)	400 (33.73)	31 (39.24)	
Satisfied	1640 (62.74)	395 (59.31)	989 (57.60)	635 (53.54)	40 (50.63)	
Dissatisfied	487 (18.63)	86 (12.91)	231 (13.45)	151 (12.73)	8 (10.13)	
<b>Pain and discomfort after hysterectomy</b>						<.001
Extremely satisfied	445 (17.02)	189 (28.38)	444 (25.86)	413 (34.82)	24 (30.38)	
Satisfied	1539 (58.88)	355 (53.30)	1015 (59.11)	616 (51.94)	45 (56.96)	
Dissatisfied	630 (24.10)	122 (18.32)	258 (15.03)	157 (13.24)	10 (12.66)	
<b>Invasiveness of hysterectomy</b>						<.001
Extremely satisfied	475 (18.17)	291 (43.69)	735 (42.81)	616 (51.94)	41 (51.90)	
Satisfied	1782 (68.17)	339 (50.90)	927 (53.99)	536 (45.19)	35 (44.30)	
Dissatisfied	357 (13.66)	36 (5.41)	55 (3.20)	34 (2.87)	3 (3.80)	
<b>Complications associated with hysterectomy</b>						<.001
Extremely satisfied	777 (29.72)	240 (36.04)	645 (37.57)	527 (44.44)	40 (50.63)	
Satisfied	1342 (51.34)	316 (47.45)	849 (49.45)	527 (44.44)	31 (39.24)	
Dissatisfied	495 (18.94)	110 (16.52)	223 (12.99)	132 (11.13)	8 (10.13)	
<b>Length of hospital stay</b>						<.001
Extremely satisfied	656 (25.10)	265 (39.79)	735 (42.81)	602 (50.76)	39 (49.37)	
Satisfied	1716 (65.65)	347 (52.10)	870 (50.67)	530 (44.69)	37 (46.84)	
Dissatisfied	242 (9.26)	54 (8.11)	112 (6.52)	54 (4.55)	3 (3.80)	
<b>Recurrence of problem after hysterectomy</b>						<.001
Extremely satisfied	1384 (52.95)	364 (54.65)	976 (56.84)	722 (60.88)	43 (54.43)	
Satisfied	1058 (40.47)	240 (36.04)	601 (35.00)	406 (34.23)	27 (34.18)	
Dissatisfied	172 (6.58)	62 (9.31)	140 (8.15)	58 (4.89)	9 (11.39)	
<b>Return to walking</b>						<.001
Within 2 days	1036 (39.74)	302 (45.62)	870 (50.97)	645 (54.94)	34 (43.04)	
After 2 days	1571 (60.26)	360 (54.38)	837 (49.03)	529 (45.06)	45 (56.96)	
N/A	7	4	10	12	0	
<b>Return to driving</b>						<.001
Within 1 week	307 (12.23)	196 (30.43)	561 (33.71)	398 (34.43)	31 (39.74)	
After 1 week	2204 (87.77)	448 (69.57)	1103 (66.29)	758 (65.57)	47 (60.26)	
N/A	103	22	53	30	1	
<b>Return to work</b>						<.001
Within 4 weeks	458 (20.70)	211 (40.81)	722 (50.10)	534 (53.67)	37 (57.81)	



Characteristics	Abdominal	Vaginal	Laparoscopic	Robotic	Single-incision laparoscopic	<i>P</i> value <sup>a</sup>
	N=2614 n (%)	N=666 n (%)	N=1717 n (%)	N=1186 n (%)	N=79 n (%)	
After 4 weeks	1755 (79.30)	306 (59.19)	719 (49.90)	461 (46.33)	27 (42.19)	
N/A	401	149	276	191	15	
<b>Would recommend the same type of hysterectomy</b>						<.001
Definitely	725 (27.74)	376 (56.46)	984 (57.31)	828 (69.81)	48 (60.76)	
Likely	1241 (47.48)	223 (33.48)	613 (35.70)	302 (25.46)	22 (27.85)	
Unlikely	648 (24.79)	67 (10.06)	120 (6.99)	56 (4.72)	9 (11.39)	
<b>Would choose the same type of hysterectomy again</b>						<.001
Yes	1020 (39.02)	482 (72.37)	1231 (71.7)	1030 (86.85)	55 (69.62)	
No/not sure	1594 (60.98)	184 (27.63)	486 (28.3)	156 (13.15)	24 (30.38)	

<sup>a</sup>*P* value based on the overall chi-square test of the characteristic by surgical modality.

### Independent Predictors of Patient Satisfaction and Recommendations After Hysterectomy

The multiple impacts of sociodemographic factors, time period of surgery, prior abdominopelvic surgery, patient-reported recovery time, and surgical modality on patient satisfaction and recommendations after hysterectomy were examined in forward, stepwise, multivariable logistic regression as described in the methods. Figure 2 presents the significant independent findings ( $P < .01$ ) for these outcomes: (1) satisfaction with results overall (extremely satisfied, satisfied, dissatisfied), (2) would recommend the procedure to another (definitely, likely, unlikely), (3) would choose the same procedure for oneself again (yes, no). Figure 3 shows findings for satisfaction with: time until return to normal activities, pain and discomfort, invasiveness, complications, length of hospital stay, and recurrence. Single-incision laparoscopic hysterectomy was not included in these analyses due to the small number of surgeries employing this technique.

Independent predictors of being more satisfied overall were African American race (OR 1.67, 95% CI 1.38-2.04;  $P < .001$ ), walking within 2 days after surgery (OR, 1.53, 95% CI 1.36-1.71;  $P < .001$ ), having had a robotic-assisted hysterectomy (OR 1.31, 95% CI 1.13-1.51;  $P < .001$ ), returning to work within 4 weeks after surgery (OR 1.29, 95% CI 1.14-1.46;  $P < .001$ ), driving within 1 week after surgery (OR 1.29, 95% CI 1.12-1.48;  $P < .001$ ) and higher income (OR 1.08 per income level, 95% CI 1.02-1.14;  $P = .005$ ). Having had a hysterectomy in the earliest time period (ie, 2007 or prior) was a predictor of being less satisfied with the overall results of hysterectomy (OR 0.70, 95% CI 0.61-0.81;  $P < .001$ ). Thus, after controlling for the effects of the other significant contributors to overall satisfaction, robotic-assisted hysterectomy was associated with a 31% greater odds of being: (1) extremely satisfied compared with less satisfied or dissatisfied (combined), and (2) extremely satisfied or satisfied (combined) compared with dissatisfied (Figure 2).

Characteristics that were independently and positively associated with a greater likelihood of recommending the same surgery to someone else included having had a robotic-assisted

hysterectomy (OR 1.64, 95% CI 1.39-1.94;  $P < .001$ ), walking within 2 days (OR 1.66, 95% CI 1.48-1.86;  $P < .001$ ), driving within 1 week (OR 1.30, 95% CI 1.13-1.51;  $P < .001$ ), returning to work within 4 weeks (OR 1.26; 95% CI 1.11-1.43;  $P < .001$ ), and higher income (OR 1.11, 95% CI 1.05-1.17;  $P < .001$ ). Having undergone an abdominal hysterectomy (OR 0.36, 95% CI 0.31-0.40;  $P < .001$ ) and having had surgery in the earliest time period (OR 0.58, 95% CI 0.51-0.67;  $P < .001$ ) were associated with being less likely to recommend the same surgery to someone else. Robotic-assisted hysterectomy was independently associated with a 64% greater odds and abdominal hysterectomy was associated with a 36% lower odds of definitely recommending the same procedure versus being likely or unlikely (combined) to recommend it, and definitely or likely (combined) versus unlikely to recommend it.

Predictors of patients choosing the same surgery again were having a robotic-assisted hysterectomy (OR 2.07, 95% CI 1.67-2.57;  $P < .001$ ), walking within 2 days (OR 1.57, 95% CI 1.38-1.78;  $P < .001$ ), having undergone surgery in the most recent time period, 2011-2013 (OR 1.49, 95% CI 1.29-1.73;  $P < .001$ ), and returning to work within 4 weeks (OR 1.23, 95% CI 1.07-1.41;  $P = .003$ ). Having undergone an abdominal hysterectomy (OR 0.29, 95% CI 0.25-0.33;  $P < .001$ ) and having had surgery in the earliest time period (OR 0.64, 95% CI 0.54-0.77;  $P < .001$ ) were associated with not choosing the same surgery for oneself again. The odds of abdominal hysterectomy patients choosing the same approach again were 29% of the odds associated with all other modalities. Robotic hysterectomy patients were more than twice as likely as others to choose the same approach again. There were no significant differences in these outcomes by age group, education, urban/rural status, and prior abdominopelvic surgery.

Results of multivariable stepwise logistic regression on components of patient satisfaction are shown in Figure 3. Greater satisfaction with time until return to normal activities was evident among African American women (OR 1.60, 95% CI 1.34-1.90;  $P < .001$ ), those who had a robotic-assisted hysterectomy (OR 1.23, 95% CI 1.07-1.41;  $P = .007$ ), and whose surgery was in the time period 2008-2010 (OR 1.16, 95% CI

1.04-1.30;  $P=.009$ ). Abdominal hysterectomy (OR 0.60, 95% CI 0.54-0.67;  $P<.001$ ) and prior abdominopelvic surgery (OR 0.79, 95% CI 0.71-0.87;  $P<.001$ ) were associated with less satisfaction and, thus, more dissatisfaction.

Being African American (OR 1.65, 95% CI 1.39-1.97;  $P<.001$ ), robotic surgery (OR 1.35, 95% CI 1.17-1.54;  $P<.001$ ), older age (OR 1.14, 95% CI 1.07-1.21;  $P<.001$ ), and higher income (OR 1.08, 95% CI 1.03-1.13;  $P<.001$ ) independently predicted greater satisfaction with pain and discomfort after surgery. Abdominal hysterectomy (OR 0.58, 95% CI 0.52-0.65;  $P<.001$ ), surgery in 2007 or earlier years (OR 0.75, 95% CI 0.65-0.85;  $P<.001$ ), and prior abdominopelvic surgery (OR 0.83, 95% CI 0.75-0.91;  $P<.001$ ) were associated with less satisfaction.

Greater satisfaction with invasiveness of surgery was also associated with being African American (OR 1.73, 95% CI 1.45-2.08;  $P<.001$ ) and having had robotic surgery (OR 1.36, 95% CI 1.18-1.56;  $P<.001$ ). Less satisfaction was evident among those who had an abdominal hysterectomy (OR 0.28, 95% CI 0.25-0.32;  $P<.001$ ), underwent surgery in the earliest time period (OR 0.77, 95% CI 0.68-0.89;  $P<.001$ ), and experienced a prior abdominopelvic procedure (OR 0.86, 95% CI 0.78-0.96;  $P=.007$ ).

Satisfaction with complications was significantly greater among African Americans (OR 1.38, 95% CI 1.17-1.64;  $P<.001$ ) and

those who had robotic surgery (OR 1.29, 95% CI 1.13-1.48;  $P<.001$ ) and higher income (OR 1.08, 95% CI 1.03-1.13;  $P=.001$ ). Women who had an abdominal hysterectomy (OR 0.72, 95% CI 0.65-0.80;  $P<.001$ ), prior abdominopelvic surgery (OR 0.79, 95% CI 0.72-0.87;  $P<.001$ ), and surgery in the earliest time period (OR 0.82, 95% CI 0.72-0.93;  $P=.002$ ) were significantly less satisfied.

Robotic surgery (OR 1.39, 95% CI 1.21-1.60;  $P<.001$ ) and being African American (OR 1.38, 95% CI 1.16-1.65;  $P<.001$ ) predicted greater satisfaction with length of hospital stay. Abdominal hysterectomy (OR 0.52, 95% CI 0.46-0.58;  $P<.001$ ), the earliest time period of surgery (OR 0.74, 95% CI 0.65-0.85;  $P<.001$ ), and prior abdominopelvic surgery (OR 0.81, 95% CI 0.74-0.90;  $P<.001$ ) predicted greater dissatisfaction.

Women who had robotic surgery (OR 1.26, 95% CI 1.10-1.43;  $P<.001$ ), who were older in age (OR 1.13, 95% CI 1.06-1.20;  $P<.001$ ), and had higher income (OR 1.10, 95% CI 1.05-1.16;  $P<.001$ ), and education (OR 1.07, 95% CI 1.02-1.14;  $P=.009$ ) were significantly more satisfied with recurrence of their problem after surgery. Those who had surgeries in the earliest time period (OR 0.77, 95% CI 0.67-0.88;  $P=.002$ ) and prior abdominopelvic surgery (OR 0.77, 95% CI 0.69-0.85;  $P<.001$ ) were less satisfied.

**Figure 2.** Independent predictors of overall patient satisfaction and recommendations after hysterectomy.

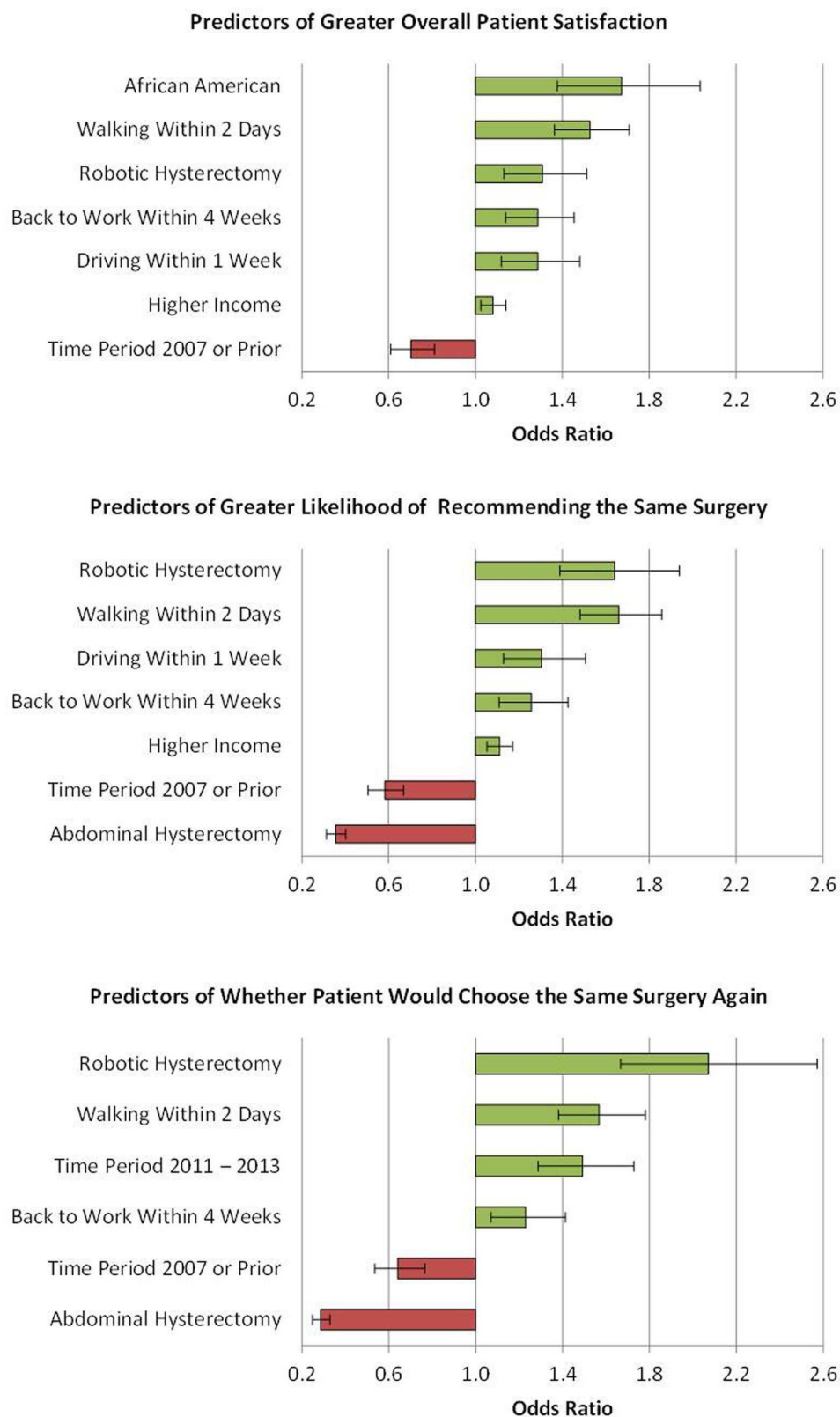
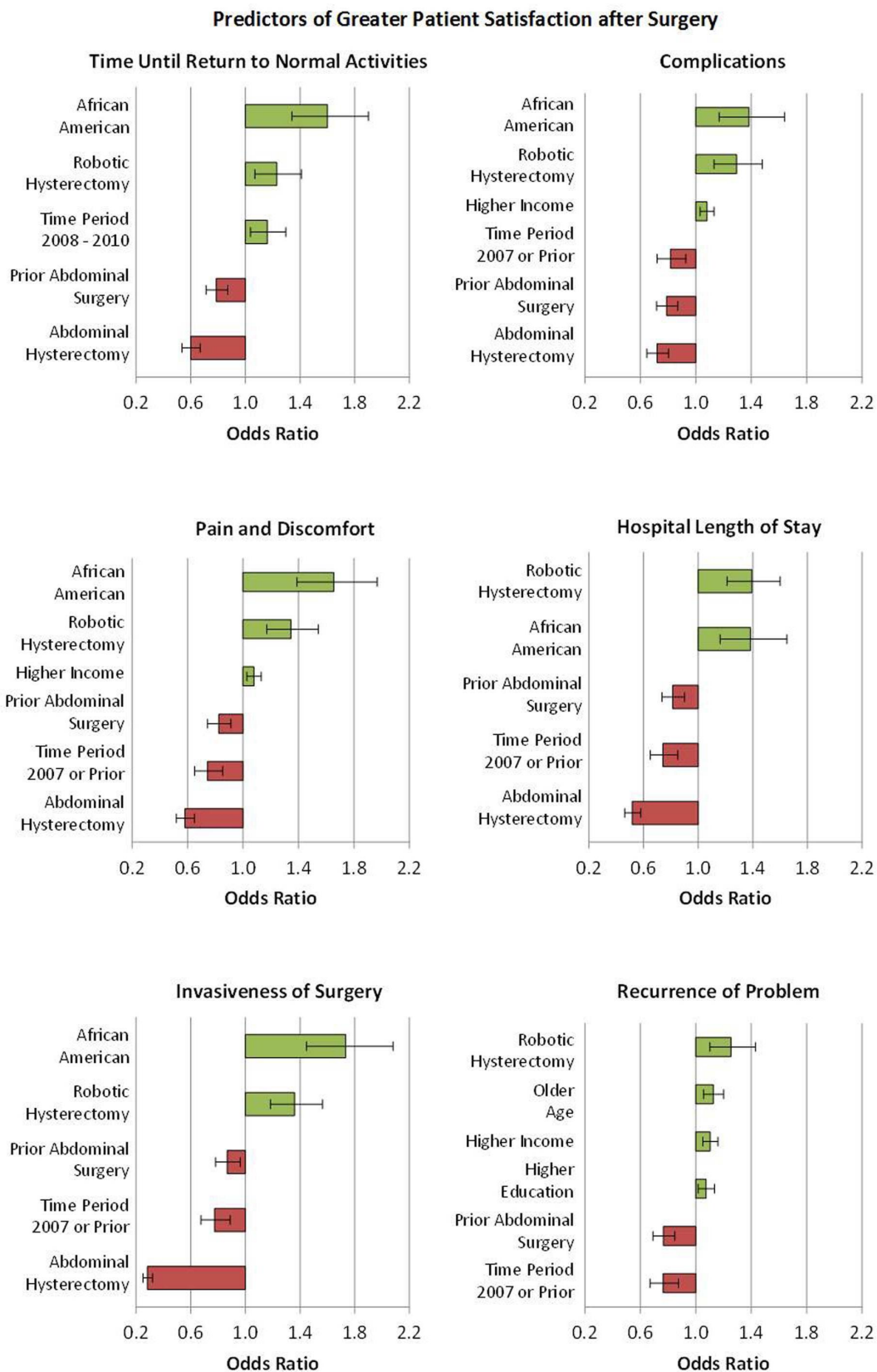


Figure 3. Independent predictors of greater patient satisfaction after hysterectomy.



## Discussion

### Principal Results

During the study period, the rates of abdominal and vaginal hysterectomy declined with a concomitant increase in laparoscopic and robotic hysterectomy. There was no change noted in the relative number of single-site laparoscopic hysterectomy procedures being performed. In fact, there was pivotal point in the year 2012 where usage of the three major modalities intersected. In the following and final year of the study, it appears that robotic-assisted laparoscopic hysterectomy was reported by more women (35.8%, 110/307) than open abdominal hysterectomy (24.4%, 75/307) and slightly more than laparoscopic hysterectomy (31.3%, 96/307). Improvements in all patient experiences over time as measured by satisfaction with results, timely return to work, quicker return to normal activities such as walking and driving may be partially attributed to the increasing rates of minimally invasive surgery.

Robotic-assisted laparoscopic hysterectomy is the only modality that was an independent predictor of better patient experience with better overall satisfaction, better satisfaction with specific outcomes, and greater willingness to recommend and choose the same technique again even after accounting for the effects of other important predictors. Abdominal hysterectomy was associated with a worse patient experience relative to the other types of procedures.

Analyses suggest that possible reasons for significantly better overall satisfaction with robotic than other hysterectomy procedures, despite similar invasiveness of the robotic and laparoscopic procedures and less invasiveness of the vaginal approach, include greater satisfaction with return to normal activities, pain and discomfort, perceived invasiveness, complications, length of hospital stay, and recurrence of problems among women who had the robotic approach.

Early return to activities including walking, driving, and work were also independent predictors of overall satisfaction and the likelihood of recommending the same procedure. African Americans reported greater overall satisfaction after hysterectomy due to greater satisfaction with time until return to normal activities, with pain and discomfort, perceived invasiveness of surgery, complications, and length of hospital stay. However, these findings did not translate into greater likelihood of their recommending the same approach or choosing it again.

### Limitations

As a retrospective study, the potential for unmeasured biases always exists. In the present study, some of these were balanced by the fact that the data were obtained from women who were part of a database and had surgery at many different hospitals, performed by many different surgeons across the United States. Thus, the limitations and biases from unique surgical programs were eliminated. Difficulties in recall may have played a role in answering certain survey questions, particularly about surgeries from the earliest years. However, it is unknown if specific recall biases occurred that would have affected study results. Participants were given the opportunity to indicate “not

sure” on any questions asking about type of procedure. Furthermore, patients who had procedures in the earlier years reported less satisfaction than those who had procedures in later periods, even in multivariable analysis. One might expect that recall of such issues in the earlier years would be diminished and make it more difficult to find such significant differences.

We did not collect data on the primary reason for the hysterectomy, severity of disease, whether ovaries or the cervix were removed, number of complications from surgery, patient characteristics like obesity or uterine size, comorbidity, functional status, contraindications for specific modalities, and employment or self-employment, any of which may be “unobserved” influences on choice of technique or patient experience over time. These aspects could not be considered or adjusted for in multivariable analysis. We had no way of ascertaining if, for example, women who had robotic surgery were more actively involved in the choice of the approach and, therefore, were more satisfied with the outcome. While differences observed in sociodemographic groups by modality could influence results of patient experience, these were controlled for as well as possible in multivariable logistic regression analysis using income and education as surrogates.

In terms of recruitment for an Web-based survey, this study had a good response rate. Among those who clicked on the link to the survey, 78.48% (9177/11,694) continued on to completion. We also recruited a large study population, a total of 9177, in a short time frame of 10 days. In a randomized study of the reliability of Internet versus mailed questionnaires for assessing health, activity level, disability, and health care utilization, Ritter et al [8] found that participation rates were at least as good, if not better, for those assigned to the Internet compared with those assigned to the mailed questionnaires with less recruitment effort.

However, these results may not be generalizable to the population of all hysterectomy patients since, for example, data suggest that Internet users may be younger, better educated, and have higher family income than the general population [9]. Nevertheless, any such selection bias would likely be the same across the surgical modalities so as not to impact results of comparisons by approach. In addition, influences of age and socioeconomic status were considered, and adjusted for when appropriate, in multivariable analysis of all outcomes. The positive aspects of using an online community for our research, ready availability, large size, geographic diversity, and low cost, could outweigh the aforementioned limitations.

This study survey was not measuring clinical outcomes that are sometimes inaccurately self-reported by patients. Participants did need to reliably report the type of hysterectomy they had undergone, but, as mentioned, were also given the option of choosing “not sure.” We had no means to validate this self-reported information. Research suggests that patients can reliably self-report many, especially chronic, medical conditions. For example, Cascade et al [10] compared patient reports of gout with medical record diagnosis and found a 97.4% confirmation rate. Studies of treatments for breast cancer in women have shown high reliability. In particular, Gupta et al [11] found a 94% concordance rate between self-report and



medical record for type of surgery conducted for breast cancer. Maunsell et al [12] showed very high agreement between self-report at 3-years post diagnosis and medical records for all aspects of breast cancer treatment including type of surgery. Kappa ranged from .89 (axillary dissection) to 1.0 (breast surgery). These self-report study issues are common to all kinds of survey research, whether Internet-based or not.

### Comparison With Prior Work

Our findings compare favorably with recent published data regarding rates of hysterectomy by modality. Wright et al [13] reported data from 2007-2010 in the national Premier Perspective Database and showed hysterectomy rates of 46.6% abdominal, 20.7% vaginal, 28.6% laparoscopic, and 4.1% robotic-assisted laparoscopic [13]. Our rates over the same time period (2007-2010) are 48.65% (958/1969) abdominal, 11.27% (222/1969) vaginal, 27.58% (543/1969) laparoscopic, 11.02% (217/1969) robotic, and 1.47% (29/1969) single-incision laparoscopic hysterectomy. Use of minimally invasive surgery was similar in the former and latter studies (53.43% [1052/1968] vs 51.35% [1011/1969], respectively).

Although prior studies of overall patient satisfaction after hysterectomy are scarce, and none include robotic surgeries, they have often reported greatest satisfaction with total laparoscopic minimally invasive surgery. McKenzie and Grant [14] prospectively compared total abdominal hysterectomy (TAH), laparoscopic-assisted vaginal (LAVH), and total laparoscopic hysterectomy (TLH) modalities on satisfaction scores (0-100) 3 months after the procedures and found no differences across these approaches. However, TLH patients indicated they were most satisfied (scores between 90 and 100: 79.6% TAH, 77.3% LAVH, 82.8% TLH). A study from Singapore showed that overall satisfaction (scale 1-10) was significantly higher for TLH compared with TAH patients (8.5 vs 7.2,  $P < .01$ ) [15]. In a prospective study, Abdelmonem et al [16] found no differences in satisfaction rates one to three months after surgery by TAH, TLH, and total vaginal hysterectomy (TVH) approaches, but a greater percentage reported being highly satisfied in the TLH group compared with others (highly satisfied - physical: TAH 58%, TVH 67%, TLH 72%; highly satisfied - psychologically: TAH 63%, TVH 75%, TLH 81%) [16].

More recently, Sarlos and colleagues [17] reported findings from a randomized study indicating that patients who underwent robotic hysterectomy had significantly greater improvement in quality of life ( $P < .001$ ) 6-weeks postoperatively than patients who had a conventional laparoscopic procedure. Investigators could not offer a good explanation for these results since most parameters such as incidence of complications, use of analgesics postoperatively, hospital length of stay, and return to activity and work were similar between the two surgical groups.

In a study following a group of premenopausal women for 8 years, some of whom eventually had a hysterectomy for benign pathology, Kuppermann et al [18] showed that multivariable predictors of greater satisfaction with hysterectomy included greater pelvic problem impact overall, higher scores before surgery on "benefits of not having a uterus," and greater symptom reduction afterward. Although our study was not able

to examine such factors related to satisfaction, these authors did not report the impact of surgical modality or return to normal activities on the outcome.

McKenzie and Grant [14] found that time to return to work was faster for patients who had LAVH and TVH than for TAH (no pain on movement took 3.4, 3.2, and 4.8 weeks, respectively; return to full activity without resting took 4.8, 5.5, and 6.6 weeks, respectively). Mean time to return to full activity was significantly shorter in TLH (mean 6.2 SD 6.3 weeks) versus TAH patients (mean 10.7 SD 6.3 weeks;  $P = .001$ ). Abdelmonem et al [16] showed that recovery milestones (full mobility and return to work) were met significantly sooner after TVH and TLH compared with TAH. Return to work was shortest for TLH and TVH compared with TAH (mean 21.1 SD 10, mean 28.5 SD 13.3, mean 53.6 SD 11.8 days, respectively). A randomized study by Sarlos and colleagues [17] showed no differences between robotic and conventional laparoscopic hysterectomy in time until return to work or other activity.

In a prospective study, Vonk Noordegraaf and colleagues [19] found that the strongest influence on the amount of sick leave taken before returning to work after different types of gynecological procedures was the invasiveness of the surgery. Those who took the most leave had undergone an abdominal hysterectomy. Other predictive factors included expectations before surgery on return to work and preoperative functional assessment. Other factors that can have an effect on both return to work and satisfaction are receipt of clear and reasonable instructions and counseling on returning to normal activities [19,20]. Although our study did not ascertain this information, multivariable logistic analyses showed that return to work within 4 weeks was significantly less likely among women who had an abdominal (OR 0.25; 95% CI 0.22-0.28;  $P < .001$ ) or a vaginal (OR 0.63; 95% CI 0.52-0.77;  $P < .001$ ) hysterectomy. Being white (OR 1.61; 95% CI 1.36-1.91;  $P < .001$ ) and earning a higher income (OR 1.12; 95% CI 1.06-1.19;  $P < .001$ ) predicted an early return to work. Our analyses further show that return to walking within 2 days and return to driving within 1 week were also significantly less likely among women who had an abdominal hysterectomy.

The impact of patient experiences on others' health care decisions has been explored in the literature, but studies are few. In an Internet study of factors involved in choosing between hospitals, investigators showed that the experience of other patients was considered at least as important in making a choice as information provided by the hospitals [21]. The patient-attributed "report card grade regarding physicians expertise" had the highest relative importance in making a choice. Overall, importance was highest for patient experience-based information on delivered care. The Pew research group has shown that other patients, family, and friends influence the choice of a treatment option, only second to the medical practitioner himself [22,23]. These US studies have found that when respondents were asked about who is more helpful when they need information about alternative treatment options, 63% indicated a medical professional, 24% indicated fellow patients, friends and family, and 4% indicated both equally. A more recent Pew study found that 70% of US adults got medical information, care, or support from a physician or

health care professional the last time they had a health problem; 60% got information or support from friends and family; 59% looked on the Internet for health care information, and 24% got information or support from other patients [24].

Certainly more research is warranted to assess the impact of specific treatment modalities on patient experience and the impact of patient experience and satisfaction on others' choices of medical and surgical treatments.

## Conclusions

Over the past decade, there have been several articles published on the topic of robotic surgery and its application to minimally invasive hysterectomy for the treatment of benign pathology. Those studies presented data from the perspective of noninferiority of robotic techniques compared with historically approved minimally invasive approaches and questioned the cost effectiveness of this technique. Other important considerations have been frequently omitted from the discourse

in the literature. These factors include the impact of this technology on the quality of life of patients in terms of overall satisfaction with the surgical procedures and how quickly patients return to normal activities including being productive again in the workplace.

This retrospective study examined these parameters and compared patients' responses by all the types of hysterectomy procedures currently being offered. It is acknowledged that in the population studied both laparoscopic and robotic hysterectomy rates increased while the rates of the abdominal and vaginal approaches decreased. From a clinical standpoint, any of the minimally invasive techniques would be preferable to an abdominal approach. It should be noted, however, that robotic hysterectomy was the only modality that was an independent predictor of better patient experience, greater satisfaction, and willingness to recommend and have the same procedure again.

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## Conflicts of Interest

Michael Pitter, MD is on the Speaker's Bureau and is a proctor at Intuitive Surgical, Inc. Christopher Simmonds was Senior Director of Marketing Services at Intuitive Surgical during the initiation and conduct of this study. Usha Kreaden, MS is Principal Biostatistician at Intuitive Surgical. Helen Hubert, MPH, PhD is a consultant in epidemiology to Intuitive Surgical.

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## Abbreviations

- IRB:** institutional review board  
**LAVH:** laparoscopic-assisted vaginal hysterectomy  
**OR:** odds ratio  
**TAH:** total abdominal hysterectomy  
**TLH:** total laparoscopic hysterectomy  
**TVH:** total vaginal hysterectomy

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Original Paper

# The Relation Between Caregivers' Multiliterate Reading Habits and Their Children's Oral Health Status

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## Abstract

**Background:** Caregivers' oral health literacy (OHL) assessment results have been found to be related to their children's oral health status. A further aspect of this relationship may be the role of caregivers' reading habits.

**Objective:** Our goal was to describe the relationship between caregivers' multimodal (digital and print) and multilingual (English and Chinese) reading habits, their OHL, and their child's oral health status in Hong Kong.

**Methods:** A random sample of 301 child-caregiver dyads was recruited from kindergartens in Hong Kong. Data included sociodemographic information and caregivers' self-reported digital print and reading habits across two languages (Chinese and English). Caregivers' OHL levels were assessed by two locally developed and validated oral health literacy assessment tasks: Hong Kong Rapid Estimate of Adult Literacy in Dentistry-30 (HKREALD-30) and the Hong Kong Oral Health Literacy Assessment Task for Pediatric Dentistry (HKOHLAT-P). Children's oral health status was assessed using two measures: dental caries experience (number of decayed, missing, and filled teeth) and oral hygiene status (Visible Plaque Index).

**Results:** Bivariate variations revealed significant differences in mean OHL scores between caregivers with different reading habits ( $P < .01$ ). Correlations revealed significant associations between caregivers' practices of reading multimodal (print/digital) and multilingual (English/Chinese) texts, their literacy levels, and their children's oral health status ( $P < .01$ ). Adjusting for sociodemographics and all other reading habits in the regression analysis, the caregivers' habit of reading digital and print texts was significantly retained in the final model. Regression analysis revealed significant associations between caregivers' reading habits (digital Chinese) and their OHL word recognition scores: OR 5.00, 95% CI 1.10-3.65,  $P = .027$ . Significant associations were also evident for their OHL comprehension scores (digital Chinese: OR 2.30, 95% CI 1.30-4.20,  $P = .004$ ; print Chinese: OR 2.50, 95% CI 1.40-4.30,  $P = .001$ ). However, no significant associations were found between caregivers' reading habits and child's oral health status ( $P > .05$ ).

**Conclusions:** Caregivers' habits of reading print and digital Chinese texts are significantly associated with their OHL scores. Their reading habits, however, do not affect their children's oral health status.



**KEYWORDS**

health literacy; multilingualism; multiliteracies; health informatics; medical consumerism; digital; caregiver; oral health status; paediatrics

## ***Introduction***

Health literacy is a concept that is both old and new [1]. One oft-cited definition from the World Health Organization (WHO) indicates it to be “a representation of the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health” [2]. Early studies to develop efficient, pre-consultation literacy assessment tools [3,4] and patient education programs in English [5] noted the focus on functionalist aspects of health literacy to be a major limitation. Analogous critique has been leveled against early definitions of a more recent but associated concept—oral health literacy (OHL) [6-9]. While the functionalist studies to date have documented clear connections between caregiver health literacy and child health outcomes [10], as well as between caregiver oral health literacy (OHL) and child oral health outcomes [11-13], more work needs to be done to understand the connection between caregiver literacy and child health status. A second consideration is the critical re-thinking of what constitutes literacy in the modern world. There has been a shift in literate practices in recent years from traditional print texts to digital texts and multimodal forms (eg, hypertextual, audio-visual, gestural spatial). The combination of these new and old literate practices in highly diverse modern communities has given rise to the multiliteracies movement [14], which has examined the future of literacy and literacy pedagogy. The original multiliteracies design framework indicated how individuals engage with varying semiotic codes to identify, read, and create new texts [15].

In terms of implications for health literacy, research has shown that people with better digital and health knowledge can be expected to consume more information in various forms (digital and print texts) [16]. The field of medical informatics has developed content-specific, multiliterate practices as more individuals are relying on the Internet to access their (oral) health care-related information. While recent studies have emphasized the need for research explaining the use of information accessed online [17], work to date has found that, in general, people who seek online health information are more educated, earn more, and are more likely to have high-speed Internet access at home and at work [18,19]. Online health information is being accessed from various sources actively exchanging health information, including websites run by organizations, homepages run by individuals, online support groups, and blogs. A 2009 survey by Pew Internet and American Life Project found that approximately 61% of adults in the United States looked online for health information [20], and approximately 66% of health information seekers started with search engines such as Google or Yahoo with approximately 27% starting with specific health-related websites [21]. Other surveys have indicated that approximately 65% of participants

searched for health information for at least half of the time they were online [22]. Together, these studies suggest that reading digital texts, especially via Internet searching, could reflect health information seeking behaviors.

The modern “multiliteracies” view, which rethinks the nature of texts, has also considered issues of diversity where individuals know or use more than one language system even if they do not live in a multilingual community [23,24]. Bilingual education and biliteracy research [25-27] indicate that bilinguals vary considerably in their command and usage of their two languages [28]. In addition to language usage, bilinguals may also vary in their cultural identity and various social variables. Hong Kong is a case in point. With Hong Kong’s policy of trilingualism and close relationship with China, Mandarin and English are learned and used in the territory; however, the vast majority of citizens are ethnic Chinese who speak Chinese (Cantonese dialect) as their native and dominant language. The longstanding practice of using English as a medium of instruction in secondary and tertiary education means that most educated Hong Kong citizens are fluent readers—even if not fluent speakers—of English.

English is an especially interesting example of a second or an additional language. Because the majority of advances in science and technology during the 20<sup>th</sup> century were published in English, it has therefore become the common language of science and technology. Studies exploring the relation between bilingualism or multilingualism, multimodality, and health outcomes are rare. Therefore, this study examines caregivers’ multilingual and multimodal literacy—especially involving English as their common language for medical and oral health knowledge—and its relation to their children’s oral health. Given that the field of OHL has begun developing instruments in non-English contexts, such as Spanish [29] and Chinese [30-32], further examination is warranted. Despite the documented links between (oral) health literacy and (oral) health outcomes, as well as those between parental OHL and child oral health status [11-13], little is known about whether caregivers’ OHL levels and their reading habits can make a difference to their children’s oral health. This study responded to this research gap by examining the relation between (1) caregivers’ multimodal and multilingual reading habits, (2) their OHL scores, and (3) the oral health status of their preschool children in Hong Kong.

## ***Methods***

### **Sample Recruitment**

A random sample of 301 preschool child-caregiver dyads living in Hong Kong participated. Among the 316 dyads recruited, 301 completed assessments; the response rate was 95.3%. The sample frame consisted of children from 10 kindergartens on Hong Kong Island (each with an enrollment of 70 children or

more). One in four kindergartens was randomly selected and within each kindergarten, children were randomly selected for recruitment. All Chinese children aged 5 years who attended grade three (K3) in these 10 kindergartens were chosen randomly (by random digit tables). Their parents were contacted through the kindergartens with an invitation letter explaining the objectives of the project, and the consent form was distributed. Participation was voluntary, and no additional efforts were made to enroll the subjects. Eligibility criteria included healthy children who (1) were 5 years of age, and (2) were accompanied by a primary caregiver who could speak Cantonese and read traditional Chinese script. Children with specific learning disabilities or requiring learning support, and caregivers who could not read and write Cantonese were excluded from the study.

Using SAS software version 9.3, sample power was calculated based on Fisher's Z test for Pearson correlation to have a 90% chance with two-sided test at a 5% significant level for detecting at least a 0.2 correlation; therefore 258 parent-child dyads would be sufficient. Allowing for potential non-response of about 15%, 316 dyads were recruited.

This study was approved by the by the Institutional Review Board of the University of Hong Kong/Hospital Authority Hong Kong West Cluster (HKU/HA HKW IRB) (Ref: UW 09-184).

### Data Collection

On arrival, dyads were assigned identifiers, and caregivers completed questionnaires (comprising pre-test background questions on family sociodemographics and caregiver self-reported reading habits) and underwent OHL assessments. Their children underwent clinical examinations of oral health status; assessments were conducted simultaneously and the assessors were kept blind of other assessors' data. OHL assessment began with a word-recognition test using the Hong Kong Rapid Estimate of Adult Literacy in Dentistry-30 (HKREALD-30). Each caregiver was asked to read aloud a list of Chinese words related to oral health (eg, labels of parts in the mouth, dental procedures). It was conducted as an interview by trained and calibrated examiners and took about 2 minutes [30]. Immediately afterwards, a comprehension literacy assessment using the Hong Kong Oral Health Literacy

Assessment Task-Pediatric Dentistry (HKOHLAT-P) was administered to the caregivers. This paper-and-pen assessment took about 45 minutes. It consists of 3 sections: (1) oral health knowledge section, (2) oral health-related numeracy, and (3) oral health-related reading comprehension. The scores of HKOHLAT-P range from 0-52 [31,32].

Children's oral health status was assessed by trained and calibrated examiners, using the methods and criteria as prescribed by the WHO basic oral health survey protocol [33]. This included an assessment of experience with dental caries—number of decayed, missing, and filled teeth (dmft). The Visible Plaque Index (VPI) [34] was used to assess oral hygiene status of the children by recording plaque deposits for various sites around the tooth to provide a summary score of oral hygiene—number of sites with dental plaque divided by number of sites examined.

### Statistical Analyses

The data analysis was carried out using the PASW (Predictive Analytics Software) statistics 18.0. Descriptive statistics were produced to examine the profile of the study group. Bivariate analyses examined variations between caregivers' reading habits and their literacy levels (Table 1). Correlation analysis (Spearman correlation) between the two literacy instruments was conducted and was also conducted between the caregiver's multilingual reading habits, caregiver's habit of reading multimodal, multilingual texts, and child's oral health status (Table 2).

Multiple logistic regression analysis was carried out with the two OHL assessment instruments as the dependent variables (Tables 5.1 and 5.2 in Multimedia Appendix 1) and the independent variables being caregiver, child sociodemographics and the caregiver's four main reading habits (print and digital Chinese; print and digital English) in 6 separate models (Models 1-5: unadjusted models—Model 1: Sociodemographics; Models 2-5: Sociodemographics, and one reading habit in each model respectively; Model 6: adjusted model with all independent variables). Similar analyses were also performed with two measures of the child's oral health status (dmft and VPI) as dependent variables (Tables 5.3 and 5.4 in Multimedia Appendix 1).

**Table 1.** Results (independent sample *t* test) showing bivariate variations between caregivers' reading habits and their OHL test scores (n=301 dyads).

Reading materials	HKREALD-30		HKOHLAT-P	
	Mean (SD)	<i>P</i> value	Mean (SD)	<i>P</i> value
<b>Print Chinese</b>				
None	16.1 (3.28)	<.001 <sup>a</sup>	33.0 (7.52)	<.001 <sup>a</sup>
<1 hour	22.13 (3.78)		41.3 (6.44)	
1-3 hours	23.3 (4.35)		43.5 (4.67)	
>3 hours	23.9 (3.02)		44.8 (3.96)	
<b>Print English</b>				
None	20.5 (3.92)	<.001 <sup>a</sup>	41.1 (6.65)	.005 <sup>b</sup>
< 1 hour	23.3 (3.74)		43.0 (5.86)	
1-3 hours	23.6 (4.36)		43.9 (4.36)	
>3 hours	24.4 (2.69)		44.4 (4.22)	
<b>Digital Chinese</b>				
None	20.1 (4.21)	<.001 <sup>a</sup>	38.9 (6.80)	<.001 <sup>a</sup>
< 1 hour	21.2 (3.92)		41.4 (6.28)	
1-3 hours	23.7 (4.35)		43.8 (5.01)	
>3 hours	23.9 (3.02)		44.2 (4.59)	
<b>Digital English</b>				
None	21.0 (3.87)	<.001 <sup>a</sup>	40.9 (6.22)	<.001 <sup>a</sup>
<1 hour	22.8 (4.32)		42.3 (6.42)	
1-3 hours	24.0 (3.67)		44.2 (4.18)	
>3 hours	24.1 (3.08)		44.8 (3.98)	
<b>Factual Chinese</b>				
None	17.1 (4.67)	.001 <sup>b</sup>	36.7 (10.7)	<.001 <sup>a</sup>
<1 hour	22.7 (3.93)		40.9 (5.84)	
1-3 hours	23.4 (3.59)		44.1 (4.97)	
>3 hours	22.9 (4.14)		43.5 (5.06)	
<b>Factual English</b>				
None	21.8 (4.42)	.191	42.6 (6.91)	.194
<1 hour	23.0 (3.89)		42.5 (5.68)	
1-3 hours	23.4 (3.46)		44.6 (5.02)	
>3 hours	22.6(4.53)		43.0 (5.12)	
<b>Creative Chinese</b>				
None	20.7 (5.56)	.193	40.6 (8.06)	.205
<1 hour	22.7 (3.92)		42.4 (5.65)	
1-3 hours	22.9 (4.11)		43.4 (5.54)	
>3 hours	23.5 (3.52)		43.7 (5.16)	
<b>Creative English</b>				
None	21.6 (4.34)	.041 <sup>c</sup>	42.6 (6.55)	.417
<1 hour	23.1 (3.72)		42.5 (5.58)	
1-3 hours	23.3 (4.05)		43.8 (5.08)	
>3 hours	23.6 (3.74)		43.3 (5.21)	

<sup>a</sup> $P < .001$ .<sup>b</sup> $P < .01$ .<sup>c</sup> $P < .05$ .**Table 2.** Correlations (Spearman correlation coefficient) between caregivers' reading habits (multimodal, multilingual) and their child's oral health status.

Reading habits	dmft		VPI	
	<i>r</i>	<i>P</i> value	<i>r</i>	<i>P</i> value
<b>Hours spent reading digital texts</b>				
<b>Multilingual texts</b>				
Digital Chinese texts	-.230	<.001 <sup>a</sup>	-.064	.270
Digital English texts	-.270	<.001 <sup>a</sup>	-.095	.102
<b>Reading habits scale</b>				
<b>Multilingual texts</b>				
Chinese texts	-.191	<.001 <sup>a</sup>	-.042	.464
English texts	-.234	<.001 <sup>a</sup>	-.085	.140

<sup>a</sup>Significant at  $P < .001$ .

## Results

The sociodemographic profile of the participants is presented in Table 3. Three quarters of the children (75.4%, 227/301) had a dental caries experience ((dmft>0) and mean dmft was 4.2 (SD 4.5; see Table 4). Most of the dental caries experience was related to untreated dental decay: the prevalence of decayed teeth (dt) was 68.8% (207/301) and the mean dt was 3.3 (SD 3.9). Almost all children had evidence of plaque deposits at one or more sites (99.3%, 299/301), and the mean VPI was 63.5 (SD 20.4).

The mean of caregivers' multilingual reading habits in Chinese and English were 8.00 (SD 2.81, range 0.00-12.00) and 5.73 (SD 3.34, range 0.00-12.00) respectively. The mean HKREALD-30 score was 23.0 (SD 3.97, range 9.00-30.00), and the mean HKOHLAT-P score was 43.6 (SD 5.59, range 21.00-52.00).

Bivariate variations performed between caregivers' reading habits and their literacy levels revealed systematic variations in their means (Table 1). Caregivers' practice of reading print Chinese and English, digital Chinese and English, and factual Chinese texts were significantly associated with their own OHL test scores ( $P < .001$ ). Associations were also found between reading factual English texts and their OHL word recognition scores ( $P = .041$ ).

Importantly, correlations indicated a significant although modest association between the children's dmft and the caregivers' reading habits in English ( $r = -.234$ ,  $P < .001$ ), as well as the caregivers' Chinese reading habits ( $r = -.191$ ,  $P = .001$ ) (Table 2). Correlations also indicated significant although modest associations between children's dmft and their caregivers' habit of reading digital texts in English ( $r = -.230$ ,  $P < .001$ ) and Chinese

( $r = -.270$ ,  $P < .001$ ). However, no analogous associations were found for the children's VPI ( $P > .05$ ) (Table 4).

To further understand these correlations, multiple logistic regression analyses were performed (see Multimedia Appendix 1). The analyses indicated that the caregivers who read more digital Chinese texts were more likely to score better in the OHL word recognition test: OR 2.00, CI 1.10-3.65,  $P = .027$  (see Table 5.1, Model 3, in Multimedia Appendix 1). After adjusting for sociodemographics and all other reading habits, caregivers' habit of reading digital texts was significantly retained in the final model: OR 2.00, CI 1.10-3.65,  $P = .027$  (see Table 5.1, Model 6, in Multimedia Appendix 1). Further analyses with HKOHLAT-P (Table 5.2 in Multimedia Appendix 1) also indicated that caregivers' habit of reading print Chinese (OR 2.50, CI 1.40-4.30,  $P = .001$ ) and digital Chinese texts (OR 2.30, CI 1.30-4.20,  $P = .004$ ) were associated with an increased likelihood of having a higher score in their comprehension test (see Table 5.2, Models 2 and 3, in Multimedia Appendix 1). After adjusting for sociodemographics and all the other reading habits, caregivers' habit of reading print Chinese texts was significantly retained in the final model: OR 2.50, CI 1.40-4.30,  $P = .001$  (see Table 5.1, Model 6, in Multimedia Appendix 1).

Multiple regression analysis with child's oral health status as a dependent variable, however, revealed that except for the education level of the caregiver (dmft model: OR 0.40, CI 0.20-0.65,  $P < .001$ ; Table 5.3 in Multimedia Appendix 1; VPI model: OR 0.60, CI 0.40-0.90,  $P = .028$ ; Table 5.4 in Multimedia Appendix 1), none of the reading habit variables were retained in the final caries and VPI models in both adjusted and unadjusted analyses (Table 5.3 in Multimedia Appendix 1), indicating that caregivers' education level is by far the strongest predictor of child's oral health status.

**Table 3.** Profile of the study population (caregivers and children) (n=301 dyads).

Characteristics	n (%)
<b>Caregiver</b>	
<b>Gender</b>	
Mother	223 (74.1)
Father/ other caregiver	78 (25.9)
<b>Educational level</b>	
Secondary school or lower	155 (51.5)
Above secondary school	146 (48.5)
<b>Age, years</b>	
<40	192 (63.8)
≥40	109 (36.2)
<b>Income level<sup>a</sup>, HKD</b>	
< 20,000	102 (33.9)
≥ 20,000	199 (66.1)
<b>Child</b>	
<b>Gender</b>	
Male	134 (44.5)
Female	167 (55.5)

<sup>a</sup>20,000 HKD=US \$2580

**Table 4.** Clinical oral health status of children: dental caries experience (dmft) and oral hygiene status (VPI) (n=301 dyads).

Clinical oral health status	%	n	Mean	SD	Minimum	Maximum
<b>Dental caries experience</b>						
dmft <sup>a</sup>	75.4	227 <sup>a</sup>	4.2	4.5	0.0	20.0
decayed teeth (dt)	68.8	207 <sup>a</sup>	3.3	3.9	0.0	18.0
missing teeth (mt)	30.2	91 <sup>a</sup>	0.7	1.3	0.0	6.0
filled teeth (ft)	7.6	23 <sup>a</sup>	0.2	0.9	0.0	9.0
<b>Oral hygiene status</b>						
VPI <sup>b</sup>	99.3	299 <sup>b</sup>	63.5	20.4	0.0	100

<sup>a</sup>dmft>0

<sup>b</sup>VPI>0

## Discussion

### Principal Results

This study indicates significant associations between caregivers' reading habits and their OHL. The main hypotheses tested were that an individual who spends more hours reading texts (both Chinese and English) should (1) perform better in a print-based OHL test, and (2) have children with better oral health.

### Strengths and Limitations

The results presented here should be considered in light of the study's limitations. First, the study used a cross-sectional design, making it difficult to draw causal inferences. Second, the data were collected from socioeconomic background neighborhoods

higher than that in Hong Kong as a whole (Table 3); this sample might not be representative of the entire population of preschool parent-child dyads living in other parts of the Hong Kong Special Administrative Region (HKSAR). Since correlations in the present study were weak but significant, further studies with much larger and diverse samples are required to produce stronger correlations. Finally, the developed instruments focus only on the functional OHL of the caregivers [35]; future research should also focus on other theoretically important dimensions such as communicative literacy to higher levels of critical health literacy [1,36]. Furthermore, since the instruments were developed in traditional Chinese script and Cantonese vocabulary, care should be taken in extrapolating these instruments to other Chinese dialects such as Mandarin. Future



studies should evaluate these instruments in more diverse populations.

Despite these limitations, the study has several strengths. First, this is multidisciplinary research involving investigators from literacy, psychology, dental public health, and pediatric dentistry collaborating together to address a multifaceted issue. The use of locally developed, validated instruments to measure OHL levels is another important strength. Third, dmft and VPI were used to assess the dental disease severity of each child. By contrast, all other known OHL studies have examined disease severity by using parental oral health status reports or chart reviews [8,37]. Fourth, trained calibrated examiners interviewed caregivers as well as performed the clinical examinations.

### Comparison With Prior Work

Currently, about 60% of Hong Kong adults find online health information to be useful [38]. Our study constitutes a first step in exploring factors such as caregivers' multimodal reading habits (print and digital texts) and their OHL scores in influencing their children's oral health status. The present findings are likely to draw more attention to the field of medical informatics in China. With more patients relying on the Internet as their information source prior to medical consultations [39], there has been a shift in traditional doctor-patient relationships [17]. Indeed, approximately 80% of physicians reported in a 2011 study that patients presented printed Internet-sourced health information during their clinic visits [40]. Interest in the Internet as a communication tool for health-related information is also on the rise [41].

People who seek online health information are typically patients or their friends/relatives [42], with various goals and levels of Internet search experience [43]. In general, women are more likely than men to search for health information [44]. Given that approximately 75% of caregivers in our study were female, our findings offer a valuable window on the possible relations between caregivers' reading habits and health-information seeking. Studies in general medicine have shown people's satisfaction in seeking health information online [41] and have shown that sicker patients approached their doctors with more information accessed online [45]. These indicate possible associations between patients' accessing of digital texts and their health status. The correlations uncovered by the present study found a significant, albeit modest, association between caregivers' reading habits (multimodal, multilingual) and their

OHL scores and their children's dmft (decayed, missing, or filled teeth status) status. However, the caregivers' self-reported reading habits in this study were not explicitly restricted to hours spent on reading online (oral) health information. Future studies would benefit from deeper investigation of this aspect.

The logistic regression analyses suggested that only sociodemographics such as education, income, and the multimodal reading habits (digital Chinese for word recognition scores and print Chinese and digital Chinese for reading comprehension) were predictors of caregivers' OHL test scores. Note that HKREALD-30, one of our OHL measures, was developed from a keyword corpus database of locally available public health materials, including materials from online sources such as government oral health promotion websites. Additionally, this word-recognition task presents words in isolation selected for their level of frequency and so are likely to occur across multiple modalities (print and Web-based). It makes sense that the caregivers' reading habits predicted their HKREALD-30 scores.

HKOHLAT-P, the other OHL measure, assesses reading skills and not just word recognition. It is language rich and was generated from both print and digital texts [32]. It therefore makes sense that reading print Chinese and digital Chinese were significantly retained in the final unadjusted models, and print Chinese was retained along with the income level of the caregiver in the final adjusted model (Table 5.2 in [Multimedia Appendix 1](#)). Associations between multilingual reading habits and OHL test scores and associations between multimodal, multilingual reading habits of caregivers and their children's oral health status were not evident in the final models in the present study, suggesting further research is needed to understand these issues better.

### Conclusions

This study suggested that caregivers' habits of reading print and digital text were significantly associated with their OHL scores, although no associations were found between caregivers' reading habits and their children's oral health status. The study in OHL among a Chinese-speaking community (Hong Kong) reported here supports a widening of the definition of health literacy by highlighting the importance of health informatics, especially for oral health promotion in a multilingual territory such as Hong Kong.

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### Conflicts of Interest

None declared.

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### Multimedia Appendix 1

Results of multiple regression analysis.

[PDF File (Adobe PDF File), 49KB - [ijmr\\_v3i3e13\\_app1.pdf](#) ]

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## Abbreviations

**dmft:** decayed, missing, filled teeth

**HKD:** Hong Kong Dollars

**HKSAR:** Hong Kong Special Administrative Region

**HKOHLAT-P:** Hong Kong Oral Health Literacy Assessment Task-Pediatric Dentistry

**HKREALD-30:** Hong Kong Rapid Estimate of Adult Literacy in Dentistry-30

**OHL:** oral health literacy

**PASW:** Predictive Analytical Software

**VPI:** Visible Plaque Index

**WHO:** World Health Organization

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