Information-seeking behavior of women in their path to an innovative alternate treatment for symptomatic uterine fibroids EC

Kalyani Ankem, PhD

See end of article for author's affiliation.

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Objectives: The purpose of the study was to discover how women found out about uterine fibroid embolization (UFE) for the treatment of symptomatic uterine fibroids.

Methods: The study retrospectively tracked women from the beginning of their illnesses and analyzed their information-seeking behaviors. Twenty-eight women who had the procedure at the Detroit Medical Center were interviewed using a standard script. Median values and frequencies were calculated to represent information needs, information sources, and perceived helpfulness. Spearman correlations were calculated to find relationships between demographics and information needs.

Results: Although the women expressed a great need for almost all types of information (median = 5), those with higher levels of education indicated a greater need to know the reasons that their doctors had for suggesting treatments (r = 0.55). The gathered frequencies indicated that friends, magazines, television, and the Internet were important information sources. A preliminary model of information seeking showed that while friends, magazines, and television made several of the women aware of the new procedure, the Internet was heavily utilized for learning about treatment options.

Conclusions: Health sciences librarians may inform women about their health and treatment options by guiding women to easily readable, authoritative, and reliable information sources, including Web information sites.

Highlights

- Women diagnosed with a non-life-threatening illness that required a surgical intervention wanted answers to many questions and were active information seekers.
- At the same time, many women did not care to know about the reasons behind their doctors' suggestions for treatment.
- Several women used the Internet to learn more about the illness and its treatment options.

Implications

- Popular magazines and television can be effective in generating awareness of women's health information.
- Health sciences and public librarians may assist patients in identifying useful information sources by providing guidance in accessing easy-to-read magazine articles and authoritative, reliable, and relevant Web information sites.
- Women's information-seeking behaviors in illness situations require further study.

INTRODUCTION

Although women's health is a major discipline, women's health information needs and seeking is still a developing area of study. Relatively little has been researched and written about how women seek information pertaining to their health. In particular, research on women's information seeking in illness situations is scant, though it has been pursued in medicine, nursing, and allied disciplines, such as psychology [1–17]. Most of the existing literature is focused on patients with breast or ovarian cancer [18, 19]. Two themes, the types of information women need and the sources they use, have generally been approached separately for the most part, thereby leaving a gap in the literature for a probe on types of information that is received or sought from the various information sources.

The few studies in library and information science literature have dealt with the research problem differently and investigated the needs and behaviors of women not diagnosed with any particular illness [20, 21]. Also, these studies tend to emphasize theoretical models [22, 23]. Although this emphasis is expected in the library and information science literature, a gap remains in the literature regarding women's information behavior after diagnosis.

The present study, which is intended to be an important contribution to research on women's information needs in real health situations, probes how women who were diagnosed with symptomatic uterine fibroids found information about an innovative, minimally invasive procedure known as uterine fibroid embolization (UFE).

Uterine fibroids are nonmalignant tumors that occur in women of reproductive age, with the prevalence of these tumors increasing with age. Of women age 35 and older, 20% to 40% have uterine fibroids that are considered significant in size [24]. The traditional

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treatment for symptomatic uterine fibroids has been hysterectomy, an extensive surgical procedure performed by obstetrician-gynecologists [25]. In hysterectomy, the uterus is entirely removed surgically and the disease is completely cured. However, the removal of the uterus also means irreversible infertility for the women [25]. As a result, uterine-sparing treatments have become preferred alternatives for women with the disease. UFE is one such uterine-sparing, minimally invasive procedure and is performed by interventional radiologists.

The major benefits of UFE for women with fibroid disease, in general, are avoiding surgical risks and lengthy hospitalization. For women of childbearing age, there is also the potential for preserving fertility [25]. Thus far, the reports of clinical trials conducted to study UFE indicate that it is safe and effective in shrinking uterine fibroids and treating the symptoms of the disease in select patients [26–33]. Also, its efficacy in comparison to hysterectomy is promising [34].

Ravina and others in France first published results noting the success of UFE in 1995 [35]. While using embolization as an adjunct procedure to control bleeding before hysterectomy and myomectomy, another surgical but uterine-sparing procedure for treating fibroids, Ravina noticed that the embolization itself was having an effect of shrinking the fibroids. This discovery sparked a significant innovation in interventional radiology. Since 1995, interventional radiologists have integrated the practice of UFE. This author's study of interventional radiologists conducted in Michigan in 2002, however, indicated that radiologists still considered UFE a new procedure because its diffusion had been slower than expected [36]. While discussing issues involved in adopting the procedure, several radiologists mentioned that gynecologists, who are the primary or secondary contact for women and perform hysterectomy and other procedures for symptomatic fibroids, might be reticent to refer suitable patients to the radiologists for the new procedure. A later article in *The Wall Street Journal* reiterated the radiologists' concern [37].

OBJECTIVES

To further explore such issues, this study was designed to examine the information needs of women with symptomatic uterine fibroids who had been treated by UFE and the sources from which they received and/or sought information. This study explored the path through which women found out about the less invasive new procedure, retrospectively tracking women from diagnosis to procedure in order to understand the information sources that provided much-needed information in their path to UFE. It examines women's information needs, the ways women moved through the process of identifying a treatment, the kinds of information sources they used, and their evaluation of utility.

METHODOLOGY

Patients who underwent UFE between January of 2000 and March of 2005 at the Detroit Medical Center (DMC), a hospital affiliated with Wayne State University in Michigan, were sent letters about the study and asked to participate. In the letter, the patient was given an opportunity to refuse participation by leaving a message for the researcher that she did not wish to be contacted any further regarding the study. The protocol, which was developed in collaboration with the interventional radiology department at Wayne State University, was approved by the university's human subjects committee. As the study is retrospective and analyzes the behavior of women who had the procedure between 2000 and 2005 and as the information search behaviors of some of these women had commenced before 2000, the embolization procedure is referred to as innovative in this article.

Of the forty-nine women who had the procedure at DMC during the aforementioned period and were sent letters, one patient left the researcher a message expressing her wish to not be contacted any further. A week after sending the initial letters, the researcher called the participants to conduct telephone interviews. At this time, the researcher discovered that one patient was deceased, one did not speak English, three had uterine artery embolization for indications other than uterine fibroids, and nine had moved or could not be reached for various reasons over the telephone for an interview.

Overall, of the thirty-five women who had the procedure at DMC and for whom the researcher had accurate contact information, twenty-eight women participated in telephone interviews. Therefore, the response rate (80%) was high. Also, a majority of the women who participated expressed great interest in the study and were enthusiastic about their participation. Upon completion of the interviews, one participant's responses were construed as unlikely because all of her responses to questions with a five-point Likert scale were the highest and all of her responses to questions about information received or sought from various sources were nondiscriminatory; that is, all sources were noted as providing information. The participant was determined to be an outlier and was removed from the analysis [38].

Interview guide

The interview guide designed for the study (Appendix and supplemental material available online) was based on an instrument employed by Galloway et al. [10] in their study of the information needs of breast cancer patients, which also explored reliability and validity of the original instrument. Permission was obtained from the publisher of the instrument for the adaptation. All of the questions from Galloway et al.'s instrument that could be applied in this study were listed and measured on the same five-point scale (ranging from ''not important'' to ''extremely important'') in the first section of the interview guide. For example, the questions on incision and possibility of death from Galloway et al.'s instrument were excluded because these questions are only relevant in more severe illnesses. Also, the first section of this interview guide was the foundation

Table 1
Frequency of use of information sources (n = 27)

Information need	Ob/Gyn	Radiologist	Other physician	Family	Friends	Television	Radio	Magazines	Newspapers	Internet
Feeling during tests	10	10	1					1		2
Meaning of test results	12	11	1					1		3
Treatments available	13	3	2	1	3			5		13
Reasons doctor suggested a treatment	13	1								
Treatment costs										1
Benefits of embolization	9	21			2	1		3		12
Risks of embolization	9	21			1	1		3		12
Benefits of alternate treatments	13	5	2		2			5		13
Risks of alternate treatments	13	5	2		2			5		13
Side effects and complications of embolization	8	21	1		1			3		12
Preparing for embolization	3	22	1							
Feeling after embolization	1	22	1							2
Length of time before resuming day-to-day activities after procedure	3	23	1			2		1		5
Effect of procedure on life in the future	3	10	1					1		4
Recurrence of symptomatic fibroids	9	12	1					1		7
Workings of the procedure	6	23				2		3		11
Caring for self after embolization		20	1					1		1

Note: Numbers represent frequencies of use of an information source in meeting an information need. Participants indicated use of more than one information source for a type of information that she needed.

for the entire interview. In the present study, the adapted interview guide was tested in mock interviews with non-patients to establish clarity and comprehension.

After the mock interviews, the interview guide adapted for the present study of women diagnosed with symptomatic uterine fibroids consisted of four parts: questions about (1) the interviewees' information needs, (2) information sources employed, (3) helpfulness of the information sources as viewed by the women, and (4) demographics.

The information needs segment of the interview guide asked the women about the importance that they attached to various types of information concerning their illness, treatment, care, and the new procedure. These information needs were closely aligned with the needs identified by Galloway et al. [10].

The second part of the interview guide listed the possible sources of information for the women in receiving and/or seeking the various types of information they needed, including physicians, personal contacts, popular media, and the Internet. These information sources were based on a broad review of the female cancer patients' information needs literature.

It is important to mention that the information needs were listed in the order in which the women were expected to need information based on a preconceived sequence of stages during illness. For the purposes of this study, these preconceived stages of progression during illness from a patient's perspective were awareness of options, knowledge of options, decision, and the procedure. The items in the questionnaire that were intended to glean responses in each stage were: awareness of options: questions 17 to 20, knowledge of options: questions 21 to 25, decision: questions 26 to 31, and procedure: questions 32 to 33.

The patients responded to the queries about information sources that provided each type of information women needed during the progressive stages of illness. In addition, the patients were forthcoming with several comments that complemented these responses. These comments were transcribed carefully with a reference number to the relevant query; for instance, comments related to question 17 were transcribed with a reference number Q17. When the responses about information sources were synthesized with these supplementary comments about receiving information, a preliminary model of information source use in learning about and undergoing embolization emerged.

In the process of building this preliminary model, the frequencies of information source use gathered in each stage were examined in light of the additional comments concerning information source, such as details of specific magazines and their use in meeting an information need at a stage of progression during illness, to determine the use of an information source exclusively at a certain temporal stage for embolization-related information. For example, information on benefits and risks of embolization were obtained by women throughout the illness. However, to determine the use of a source for this information at the knowledge stage, after awareness of the procedure and before a decision was reached, the raw frequencies of information source use were examined in the context of the women's additional comments. Also, when responding to the query on receiving information on available treatments, which might not include embolization, at the awareness stage of options, women did not select television; however, they mentioned in comments that they heard about embolization on a television show. In this case, although Table 1 does not show a frequency for receiving information on treatments available through television, the preliminary model notes television as a source for creating awareness of embolization specifically. The purpose of presenting frequencies in Table 1 was to provide data concerning information source for a type of information at anytime throughout the patient experience, from

awareness of options to undergoing embolization, whereas the preliminary model only constructs prevalence of use of an information source for embolization-related information specifically at each stage, from awareness to undergoing the procedure in the patient's experience.

The women's comments that were transcribed validated the preconceived stages of progression during illness, with a modification required in only one stage: the knowledge stage. The knowledge stage emerged as 2 phases: conscious exploration and self-education. This modification in the stage emerged because the women's comments while answering questions 21 to 23 indicated that they were uncertain and thus still exploring their options through interpersonal means, whereas their comments related to questions 24 and 25 indicated that they were educating themselves through various means by seeking information on aspects that they were aware of and had explored to improve clarity. Also, several additional comments from the patients while responding to questions about information sources led to the data concerning family practitioners, internists, and gynecologists reported in the online only tables.

Respondents were also asked to rate the helpfulness of information sources using a five-point Likert scale of helpfulness (ranging from ''not helpful'' to ''extremely helpful'') modeled after the measurement of helpfulness employed by Schapira et al. [39]. The last part of the interview guide, designed by this researcher, included questions on age, education, and race and/or ethnicity.

In addition, the women were free to provide any comments about their experiences from the time they first felt ill to the stage of having the procedure and its aftermath, including any comments on whether the embolization was a success or failure and how they were faring at the time of the interview.

The interview was designed to be fifteen minutes long; however, most participants chose to talk to the researcher about their experiences beyond the allocated time. The researcher employed a standard script to conduct the interviews to ensure consistency between respondents. The interview questions were read to the participant after a brief introduction to the study and a description of how the interview would be conducted.

Statistical analysis

Median values were calculated to find the degree of importance women attached to various types of information. The median was chosen as the statistic to express the level of information need because the importance women attached to the different types of information was measured on an ordinal five-point Likert scale. Next, Spearman correlation coefficients ($P < 0.05$) were used to explore whether the importance that the women attached to various types of information was associated with their age and/or education (both variables measured as ordinal data in the interview). Lastly, women's use of information sources in receiving and/or seeking information was represented in frequencies, and median values were used to summarize the ordinal data representing the helpfulness of each information source to women. In addition, the Wilcoxon test was applied to find if gynecologists differed from the radiologists in the helpfulness of information they provided to their patients. The threshold for statistical significance was set at $P < 0.05$.

Table 2
Participant demographics (n = 27)

Age	
Mean	45.3
Standard deviation	6.7
Range	20–58
Education	
Partial high school	1 (3.7%)
High school	3 (11.1%)
Some college	6 (22.2%)
College graduate	17 (63.0%)
Race or ethnicity	
White	5 (18.5%)
African American	21 (77.8%)
Other	1 (3.7%)

RESULTS

Demographics

The demographics of the women who participated in the study are shown in Table 2. The mean age of the women who participated in the study was 45.3 years (range 20–58 years). The youngest woman in the study was 20 years old, an uncommon age for this illness. Although 17 women had graduated from college, 10 women lacked college degrees, including 4 women who never attended college. Of the women, 21 were African American, 5 were white, and 1 was of mixed race/ethnicity that included Asian heritage.

Information needs of women diagnosed with symptomatic uterine fibroids

Among the twenty-eight women, almost all expressed a great need for information on diagnosis, treatment, and self-care. The median values of the importance that women attached to the various types of information are shown in Table 3. As can be seen, the majority of the information needs were rated as extremely high (median values = 5).

Deviating from this pattern, the women gave less importance to only three types of information: doctor's reasons for suggesting a treatment (median = 3), costs associated with treatments (median = 1), and details of how the procedure worked in treating symptomatic fibroids (median = 4). As can be seen, women attached relatively less importance to reasons their doctors, in this situation often gynecologists, gave for suggesting treatments (Table 3). The technique and the mode of action for the embolization procedure—that is, how the procedure is performed by radiologists and how it works to treat the problem—however, was only slightly less important compared to need for other types of

Table 3
Information needs of women diagnosed with symptomatic uterine fibroids (n = 27)

Information need	Median importance	Very or extremely important (%)	Slightly or moderately important (%)	Not important (%)
Feeling during tests	5	18 (66.7%)	1 (3.7%)	8 (29.6%)
Meaning of test results	5	18 (66.7%)	1 (3.7%)	8 (29.6%)
Treatments available	5	23 (85.2%)	1 (3.7%)	3 (11.1%)
Benefits of various treatments	5	23 (85.2%)	1 (3.7%)	3 (11.1%)
Risks of various treatments	5	23 (85.2%)	1 (3.7%)	3 (11.1%)
Reasons doctor suggested a treatment	3	12 (44.4%)	2 (7.4%)	13 (48.2%)
Treatment costs	1	5 (18.5%)	2 (7.4%)	20 (74.1%)
Side effects and complications of embolization	5	23 (85.2%)	1 (3.7%)	3 (11.1%)
Preparing for embolization	5	17 (63.0%)	5 (18.5%)	5 (18.5%)
Feeling after embolization	5	22 (81.5%)	2 (7.4%)	3 (11.1%)
Length of time before resuming day-to-day activities after procedure	5	22 (81.5%)	2 (7.4%)	3 (11.1%)
Effect of procedure on life in the future	5	16 (59.3%)	3 (11.1%)	8 (29.6%)
Recurrence of symptomatic fibroids	5	17 (63.0%)	6 (22.2%)	4 (14.8%)
Workings of the procedure	4	18 (66.7%)	4 (14.8%)	5 (18.5%)
Caring for self after embolization	5	19 (70.4%)	4 (14.8%)	4 (14.8%)

Note: Information needs were measured on a 5-point Likert scale of importance that women attached to the various types of information (ranging from 1 ''not important'' to 5 ''extremely important'').

information, which were rated extremely high by the women as represented by median values of 5.

Correlations were calculated for the women's need for each type of information, their ages, and their educational levels to find if these demographics affected the women's need for information. The Spearman correlation coefficients presented in Table 4 indicated that the women with higher levels of education did want more of certain types of information: different treatments available for symptomatic fibroids ($r = 0.55$), benefits of various treatments ($r = 0.55$), risks associated with various treatments ($r = 0.55$), physician's reasons for suggesting a particular treatment ($r = 0.55$), and costs associated with treatments ($r = 0.44$). These were all treatment-related information; thus, the significant positive correlations indicated that the women with higher levels of education wanted more information on many treatment-related issues, including the physician's reasons for suggesting a particular treatment ($P < 0.05$).

The reasons physicians provide for suggesting a treatment, in particular, is critical patient information in the illness process [40]. However, as noted earlier, it was found to be less important (median = 3) in this study. An examination of the percentages of women in Table 3 also shows that fewer women (n = 12) said they found the reasons physicians provided for selecting a treatment for them to be very or extremely important. The correlation between women with higher levels of education and their need to know about the reasons for physician treatment recommendations suggested women with higher levels of education found this information more valuable.

Most participants were in their mid-forties with little variance in age in the sample. As such, no significant correlations were observed between age and need for any information, except for the information on length of time required before normal day-to-day activities could be resumed after the procedure ($r = -0.44$). The significant negative correlation indicates

Table 4
Correlations between demographics—age and education—and women's information needs

Information need	Correlation	
	Age and level of information need	Education and level of information need
Feeling during tests	0.26	0.16
Meaning of test results	0.26	0.16
Treatments available	0.22	0.55*
Benefits of various treatments	0.22	0.55*
Risks of various treatments	0.22	0.55*
Reasons doctor suggested a treatment	0.32	0.49*
Treatment costs	0.37	0.44*
Side effects and complications of embolization	0.05	0.30
Preparing for embolization	−0.02	0.20
Feeling after embolization	0.04	0.37
Length of time before resuming day-to-day activities after procedure	−0.40*	0.21
Effect of procedure on life in the future	−0.18	0.32
Recurrence of symptomatic fibroids	−0.10	0.13
Workings of the procedure	−0.02	0.20
Caring for self after embolization	−0.31	0.16

* Significant correlation ($P < 0.05$).

Table 5
Helpfulness of the information source (n = 27)

Information source	Helpfulness median	Very or extremely helpful (%)	Slightly or moderately helpful (%)	Not helpful (%)	No information received from source (%)
Obstetrician/gynecologist	2	10 (37.0%)	10 (37.0%)	6 (22.2%)	1 (3.7%)
Primary care physician	1	3 (11.1%)	2 (7.4%)	13 (48.2%)	9 (33.3%)
Radiologist	5	20 (74.1%)	5 (18.5%)	2 (7.4%)	0
Family	0	1 (3.7%)	4 (14.8%)	5 (18.5%)	17 (63.0%)
Friends	0	4 (14.8%)	7 (25.9%)	2 (7.4%)	14 (51.9%)
Television	0	4 (14.8%)	1 (3.7%)	2 (7.4%)	20 (74.1%)
Radio	0	1 (3.7%)	1 (3.7%)	1 (3.7%)	24 (88.9%)
Magazines	0	7 (25.9%)	3 (11.1%)	1 (3.7%)	16 (59.3%)
Newspapers	0	2 (7.4%)	0	0	25 (92.6%)
Internet	4	15 (55.6%)	5 (18.5%)	0	7 (25.9%)

Note: Helpfulness was measured on a 5-point Likert scale (ranging from 1 "not helpful" to 5 "extremely helpful").

that as the women's age increased, they attached less importance to knowing about the length of time required before resuming day-to-day activities ($P < 0.05$); that is, older women found this type of information less important (Table 4).

Information sources used by women diagnosed with symptomatic uterine fibroids

In participant responses identifying information sources, frequencies indicated that most of the information participants needed was received primarily from radiologists. The Internet was a major source for information in addition to the gynecologists (Table 1). Popular magazines also were identified as an important source of information. Among lesser or rarely used information sources were other primary care physicians, family members, newspapers, and the radio (Table 1).

Women were also asked to rate the helpfulness of an information source in providing information that they needed. Table 5 shows that the radiologists were viewed as the most helpful in providing information (median = 5). The Internet with a median value of 4 ranked next after the radiologists as a helpful information source. Following the Internet in helpfulness were the gynecologists and other primary care physicians with median values of 2 and 1, respectively.

In addition, during analysis, radiologists were compared to gynecologists regarding their helpfulness as an information source. The results of the Wilcoxon test indicated that radiologists were viewed as significantly more helpful than gynecologists ($P < 0.05$). The women did not agree about the helpfulness of the other information sources.

Toward a model of information seeking in women's path to an innovative procedure

In terms of existing work on developing a theoretical basis for women's health information behavior, Warner and Procaccino [22] have applied Kuhlthau's information search process (ISP) model to analyze women's health information needs, search strategies, and use of information in everyday situations. According to Warner and Procaccino,

> results appeared to address the uncertainty stage of the ISP model, as there were conflicting responses regarding the facility of locating information, the usefulness of the information found, and whether or not the subjects' health questions were answered. [22]

The preliminary model in this study does not explore women's cognitive processes in information seeking; rather it focuses on women's information needs and their use of communication channels in information seeking in non-life-threatening health situations as they find their way to an innovative procedure. The frequencies gathered concerning types of information the women received from various information sources (Table 1), supplemented by women's comments during the interview, were the basis for the preliminary model. In tandem, the types of information in the second section of the interview guide follow a temporal sequence of need for information in the process of being diagnosed with symptomatic fibroids and having the embolization procedure.

The five stages through which the women moved as they became aware of the new procedure, sought information, and eventually had the procedure are: (1) awareness; (2) conscious exploration of options; (3) self-education; (4) probing, discussion, and decision; and (5) procedure (Table 6 and Figure 1). The stages are mutually exclusive only in a temporal sense; for instance, as self-education can occur at the procedure stage as well, the self education stage in the model refers specifically to self-education that occurs in a temporal sequence before a decision is reached concerning treatment in the process of a patient moving from diagnosis to procedure. The information sources used by women at each stage, either actively or passively sought, are discussed here.

At the awareness stage, women heard of the procedure through a mix of mass and interpersonal sources. Interpersonal sources predominated, including friends who were often also colleagues, rather than physicians. Few participants reported that they found out about embolization from their gynecologists and fewer from their family members. Mass media sources, such as television and magazines, also were instrumental at this stage for some women. Women described how

Table 6
Use of mass media versus interpersonal sources from awareness of embolization to undergoing embolization (n = 27)

	Mass	Interpersonal
Awareness	Popular magazines (6) Television (5) Newspapers (2)	Friend (9) (two of the friends were staff in primary care physicians' offices) Family member (2) Gynecologist (11)
Conscious exploration of options		Gynecologist (7)
Self-education	Internet (14) Popular magazines (3) Newspaper (1)	
Probe, discussion, and decision		Gynecologist (3) Radiologist (4) Friend (1)
Procedure	Internet (2)	Radiologist (7)

Note: Numbers represent frequencies of use of an information source in meeting embolization-related information needs at a particular stage in the process of information seeking. A patient may indicate, and often indicated, use of more than one information source.

they had stumbled on the procedure through a television show or a magazine article, mentioning specific shows—such as *20/20, Primetime Live, 48 Hours,* and *Today*—when they spoke about television. Among popular magazines, they often mentioned *Essence*, a magazine geared toward African American women. Other magazines in which the women had come across articles on the procedures for symptomatic uterine fibroids included *Prevention, Women's Day,* and *First*. Noteworthy here is that the women who did not become aware of UFE through their gynecologists had already consulted with a gynecologist but became aware of the procedure through other channels.

Once they became aware of the new procedure through a source other than their gynecologists, they often went back to their gynecologists to ask about it (Table 6 and Figure 1). No other source was mentioned at this stage of conscious exploration of options.

At the next stage, self-education, the women relied heavily on the Internet for active information seeking (Table 6 and Figure 1). They spoke in a compelling tone about the possibilities for information and communication allowed on the Internet. Some women also noted that they read articles in popular magazines that they came across in their everyday interactions at this stage. This form of information seeking was often passive in that the women did not make an effort to get the information, but they came across it in their everyday interactions. These women were educating themselves by reading the magazine articles because they were already aware of the procedure, an awareness that came about through any of the various means, when they came across the articles that they spoke of reading at the self-education stage.

Upon exploration and self-education, participants often returned to physicians for further confirmation and discussion before they reached a decision (Table 6 and Figure 1). A mix of interpersonal sources was evident at this point: gynecologists, radiologists contacted directly by the women, and, to a minimal extent, friends (Table 6). At the procedure stage, most of the information was obtained from radiologists as can be expected (Table 6 and Figure 1). A few respondents reported that they were still searching on the Internet around the time of the procedure (Table 6).

Obstacles faced by women in their path to the innovative procedure

Major obstacles faced by women—derived from open comments throughout the interview and, in particular, the second part of the interview guide—were that primary care physicians often only directed patients to gynecologists (Table 7), and gynecologists often suggested hysterectomy as the treatment to women (Table 8). Also of concern was the indication that among the cases who were readily referred to the radiologists by the gynecologists, some were unsuitable candidates for the procedure. Of the seven women who had an unsuccessful embolization resulting in complications and/or further surgery (Table 9), five were patients to whom the gynecologists had suggested embolization. These five patients were part of the group of only nine patients in the study to whom the gynecologists had suggested embolization without being prompted (Table 8), and, as can be seen in Table 8, the patients often received a referral to embolization after asking about alternatives. At times, however, the women who received a referral for embolization from gynecologists who were not prompted had contacted more than one gynecologist. Among the gynecologists of these nine women, four were the first gynecologists contacted, four were the second gynecologists approached, and one was the third gynecologist contacted by the patient.

DISCUSSION AND CONCLUSIONS

The percentage of African Americans in the sample was only slightly higher than expected, as the demographics of Detroit indicate that 81.6% are African American, 12.3% are white, and the remaining are of other race or ethnicity. Due to the demographics of Detroit as well the prevalence of the illness among African Americans [24], race must be given a consideration in any application of the findings of the present study.

Participants in this study—diagnosed with non-life-threatening, symptomatic uterine fibroids—indicated a great need for almost all types of information. This was a striking difference from patients of cancer, a se-

vere, chronic illness, who have been found to have a need for certain information but not a uniform need for all types of information related to their disease [10, 11, 13–17]. Most remarkable in this study was participants' heavy use of the Internet and positive perception of the helpfulness of information obtained over the Internet. Some cancer patients, in contrast, have shown a relative reluctance to exploit the Internet for information [8]. These varying levels of use of the Internet might be attributed to the differences in the nature of the illnesses, non-life threatening versus life threatening, in which the illness itself affects information use.

The findings, including the unexpected findings on the channels that made women aware of the new procedure (friends, magazines, and television) and the importance of education level in active and/or assertive information seeking by women for treatment-related information, have implications for health sciences librarians in hospitals as well as public libraries. Given the great need for information that participants indicated, it is incumbent upon health sciences librarians to create and establish women's health information systems that can educate women on a number of life-threatening as well as less severe health conditions. These systems must provide information on diseases, prevalence, demographics, and other concerns. In doing so, the importance of magazine articles, which often appear in a simple language, must not be ignored as a source for creating awareness. Most importantly, a concerted effort should be made to encourage women to ask their physicians about their health concerns. As the current study has revealed, some women, especially those with lower levels of education, do not probe their physicians about the treatment choices the physicians make for them.

It is also possible that some of these women would not approach an information professional or an organized information facility, such as a library. Therefore, proactive information dissemination efforts outside the library, such as introducing community-based information campaigns involving child-care facilities and salons, may be necessary. These initiatives are particularly critical in light of participants' perception of the lack of helpfulness of information provided by family physicians and internists.

Limitations of the present study include a small sample; hence, the study requires caution in formulating broad generalizations to populations beyond the hospital and treatment intervention chosen for analysis. The results of the study, however, are relevant to other women's health issues of comparable illness severity. Although individuals may recollect health-related experiences far more clearly than many others, the retrospective nature in querying women's experiences calls for caution in the interpretation of results. It may be worthwhile to note that, in this study, the women certainly did not hesitate and were clear in their descriptions as they spoke of their recollected experiences.

Additionally, as the majority of the patients at DMC who had the procedure by March 2005 were included in this study, a pilot study was impossible to conduct. This lack of a pilot study necessitates further testing of the instrument with similar populations. Also, the sample included only the women who had UFE. As such, the reader must be advised of limitations in validity because studies that include women who were informed about UFE but did not pursue it and women who were never informed about UFE and had hysterectomies might produce different responses to certain questions. In understanding the preliminary model of information seeking, the reader must be mindful of the small sample size and the temporal sequence of use based on a retrospective analysis of women's responses.

Future directions for study include an in-depth qualitative analysis of information seeking by the women. Also, a comparison of information-seeking behaviors of women in health situations of differing severity would be beneficial. The survey instrument can likely be applied in investigations of other women's health conditions.

In summary, potential implications for health sciences libraries and librarians include the following. First, the study indicates that many women in health situations of comparable severity may have a great need for information; therefore, health sciences librarians must actively engage in helping women find information. The study also suggests that some women may hesitate to probe certain questions concerning their treatment, which may require health sciences librarians to encourage all patients to be analytical in their interactions with mass media as well as interpersonal information sources. Most importantly, health sciences librarians are well situated to provide guidance in accessing easy-to-read and authoritative information sources, particularly reliable Web information sites, given the preference women have shown for this medium in seeking information.

REFERENCES

1. Stewart DE, Abbey SE, Shnek ZM, Irvine J, Grace SL. Gender differences in health information needs and decisional preferences in patients recovering from an acute ischemic coronary event. Psychosom Med 2004 Jan–Feb;66(1):42–8.
2. Jickling JL, Graydon JE. The information needs at time of hospital discharge of male and female patients who have undergone coronary artery bypass grafting: a pilot study. Heart Lung 1997 Sep–Oct;26(5):350–7.
3. Crawford P, Hudson S. Understanding the information needs of women with epilepsy at different lifestages: results of the ''Ideal World'' survey. Seizure 2003 Oct;12(7):502–7.
4. Rees CE, Bath PA. Information-seeking behaviors of women with breast cancer. Oncol Nurs Forum 2001 Jun;28(5):899–907.
5. Hopkins MB. Information-seeking and adaptational outcomes in women receiving chemotherapy for breast cancer. Cancer Nurs 1986 Oct;9(5):256–62.
6. Edgar L, Remmer J, Rosberger Z, Fournier MA. Resource use in women completing treatment for breast cancer. Psychooncology 2000 Sep–Oct;9(5):428–38.
7. Bosompra K, Ashikaga T, O'Brien PJ, Nelson L, Skelly J, Beatty DJ. Knowledge about preventing and managing lymphedema: a survey of recently diagnosed and treated

breast cancer patients. Patient Educ Couns 2002 Jun;47(2): 155–63.
8. Raupach JC, Hiller JE. Information and support for women following the primary treatment of breast cancer. Health Expect 2002 Dec;5(4):289–301.
9. Johnson JD, Meischke H. Women's preferences for cancer information from specific communication channels. Am Behav Sci 1991 Jul–Aug;34(6):742–55.
10. Galloway S, Graydon J, Harrison D, Evans-Boyden B, Palmer-Wickham S, Burlein-Hall S, Rich-van der ij L, West P, Blair A. Informational needs of women with a recent diagnosis of breast cancer: development and initial testing of a tool. J Adv Nurs 1997 Jun;25(6):1175–83.
11. Harrison DE, Galloway S, Graydon JE, Palmer-Wickham S, Rich-van der Bij L. Information needs and preference for information of women with breast cancer over a first course of radiation therapy. Patient Educ Couns 1999 Nov;38(3):217–25.
12. Stewart DE, Wong F, Cheung AM, Dancey J, Meana M, Cameron JI, McAndrews MP, Bunston T, Murphy J, Rosen B. Information needs and decisional preferences among women with ovarian cancer. Gynecol Oncol 2000 Jun;77(3):357–61.
13. Bilodeau BA, Degner LF. Information needs, sources of information, and decisional roles in women with breast cancer. Oncol Nurs Forum 1996 May;23(4):691–6.
14. Degner LF, Kristjanson LJ, Bowman D, Sloan JA, Carriere KC, O'Neil J, Bilodeau B, Watson P, Mueller B. Information needs and decisional preferences in women with breast cancer. JAMA 1997 May 14;277(18):1485–92.
15. Luker KA, Beaver K, Leinster SJ, Owens RG. Information needs and sources of information for women with breast cancer: a follow-up study. J Adv Nurs 1996 Mar;23(3):487–95.
16. Luker KA, Beaver K, Leinster SJ, Owens RG, Degner LF, Sloan JA. The information needs of women newly diagnosed with breast cancer. J Adv Nurs 1995 Jul;22(1):134–41.
17. Graydon J, Galloway S, Palmer-Wickham S, Harrison D, Rich-van der Bij L, West P, Burlein-Hall S, Evans-Boyden B. Information needs of women during early treatment for breast Cancer. J Adv Nurs 1997 Jul;26(1):59–64.
18. Ankem K. Types of information needs among cancer patients: a systematic review. LIBRES [serial online]. Sep 2005. [cited 8 Jun 2006]. <http://libres.curtin.edu.au/libres15n2/>.
19. Ankem K. Use of information sources among cancer patients: results of a systematic review of the research literature. Inform Res [serial online]. Apr 2006. [cited 9 Jun 2006]. <http://www.informationr.net/ir/11-3/paper254.html>.
20. Gollop CJ. Health information–seeking behavior and older African American women. Bull Med Libr Assoc 1997 Apr; 85(2):141–6.
21. Wathen CN, Harris RM. An examination of the health information seeking experiences of women in rural Ontario, Canada. Inform Res [serial online]. Jul 2006. [cited 25 Sep 2006]. <http://www.informationr.net/ir/11-4/paper267.html>.
22. Warner D, Procaccino JD. Toward wellness: women seeking health information. J Am Soc Inf Sci Technol 2004 Jun; 55(8):709–30.
23. Genuis SK. Exploring the role of medical and consumer literature in the diffusion of information related to hormone therapy for menopausal women. J Am Soc Inf Sci Technol 2006 May;57(7):974–88.
24. Society of Interventional Radiology. Uterine fibroid symptoms and diagnosis. [Web document]. Fairfax, VA: The Association, 2006. [cited 25 Sep 2006]. <http://www.sirWeb.org/patPub/uterine.shtml>.
25. Wong GCH, Goodwin SC. Uterine artery embolization for uterine fibroids. Appl Radiol 2001 Jan;30(1):26–31.
26. Goodwin SC, Vedantham S, McLucas B, Forno AE, Perrella R. Preliminary experience with uterine artery embolization for uterine fibroids. J Vasc Interv Radiol 1997 Jul–Aug; 8(4):517–26.
27. Goodwin SC, McLucas B, Lee M, Chen G, Perrella R, Vedantham S, Muir S, Lai A, Sayre JW, DeLeon M. Uterine artery embolization for the treatment of uterine leiomyomata: midterm results. J Vasc Interv Radiol 1999 Oct;10(9): 1159–65.
28. Spies JB, Scialli AR, Jha RC, Imaoka I, Ascher SM, Fraga VM, Barth KH. Initial results from uterine fibroid embolization for symptomatic leiomyomata. J Vasc Interv Radiol 1999 Oct;10(9):1149–57.
29. Spies JB, Ascher SA, Roth AR, Kim J, Levy EB, Gomez-Jorge J. Uterine artery embolization for leiomyomata. Obstet Gynecol 2001 Jul;98(1):29–34.
30. Worthington-Kirsch RL, Popky GL, Hutchins FL. Uterine arterial embolization for the management of leiomyomas: quality-of-life assessment and clinical response. Radiol 1998 Sep;208(3):625–9.
31. Pron G, Cohen M, Soucie J, Garvin G, Vanderburgh L, Bell S. The Ontario uterine fibroid embolization trial. part 1. baseline patient characteristics, fibroid burden, and impact on life. Fertil Steril 2003 Jan;79(1):112–9.
32. Pron G, Bennett J, Common A, Wall J, Asch M, Sniderman K. The Ontario uterine fibroid embolization trial. part 2. uterine fibroid reduction and symptom relief after uterine artery embolization for fibroids. Fertil Steril 2003 Jan;79(1): 120–7.
33. Walker WJ, Pelage JP. Uterine artery embolisation for symptomatic fibroids: clinical results in 400 women with imaging follow up. BJOG 2002 Nov;109(11):1262–72.
34. Spies JB, Cooper JM, Worthington-Kirsch R, Lipman JC, Mills BB, Benenati JF. Outcome of uterine embolization and hysterectomy for leiomyomas: results of a multicenter study. Am J Obstet Gynecol 2004 Jul;191(1):22–31.
35. Ravina JH, Herbreteau D, Ciraru-vigneron N, Bouret JM, Houdart E, Aymard A, Merland JJ. Arterial embolization to treat uterine myomata. Lancet 1995 Sep;346(8976):671–2.
36. Ankem K. Influence of information sources on the adoption of uterine fibroid embolization by interventional radiologists. J Med Libr Assoc 2003 Oct;91(4):450–9.
37. Helliker K, Etter L. Silent treatment: hysterectomy alternative goes unmentioned to many women: gynecologists often don't cite less-invasive procedure to treat fibroid tumors; bailiwick of other specialists. Wall St J (East Ed) 2004 Aug 24:A1.
38. Statistics Canada. Statistics: power from data! [Web document]. Toronto, ON, Canada: The Agency, 2006. [cited 15 Nov 2006]. <http://www.statcan.ca/english/edu/power/glossary/gloss.htm#O>.
39. Schapira MM, Meade CD, McAuliffe TL, Lawrence WF, Nattinger AB. Information sources and professional consultations sought by men newly diagnosed as having prostate cancer. J Cancer Educ 1999 Winter;14(4):243–7.
40. Hirshaut Y, Pressman PI. My online wellness: women's health: finally choosing your doctor. [Web document]. Albany, NY: Capital District Physicians' Health Plan, 2006. [cited 15 Nov 2006]. <http://www.myonlinewellness.com/topic/bconco3>.

AUTHOR'S AFFILIATION

Kalyani Ankem, PhD, kankem@nccu.edu, Associate Professor, School of Library and Information Sciences, North Carolina Central University, Durham, North Carolina 27707

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Table 7
Internist/family physicians' suggestions and/or treatments for women (n = 27)

	First internist or family physician	Second internist or family physician	Third internist or family physician
Not involved in discussion	4		
No clear decision		1	1
Directed to gynecologist without discussing options	12	1	
Discussed options that did not include embolization	2		
Treated and then directed to gynecologist after some time	1		

Table 8
Gynecologists' suggestions and/or treatment for women (n = 27)

	First gynecologist	Second gynecologist	Third gynecologist
No clear decision	6		1
Suggested hysterectomy or performed myomectomy or other treatment without discussing options	7	4	1
Suggested hysterectomy, myomectomy, or other treatment without discussing options first and suggested embolization after patient asked for options and/or directed to embolization after patient brought it up	7	1	
Suggested embolization when patient asked for options as soon as she approached the gynecologist	1		
Suggested embolization as an option without patient asking for options	4	4	1
Suggested hysterectomy or other treatment and rejected embolization when patient brought it up	1		1

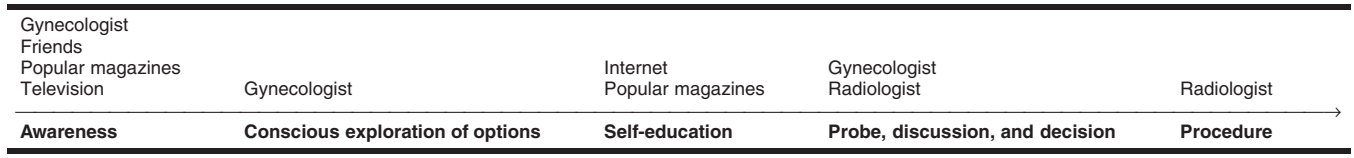
Note: Numbers represent frequencies of women who received a particular suggestion and/or treatment from their first, second, or third gynecologist.

Table 9
Success of the new procedure as viewed by women (n = 27)

	Successful embolization	Failed embolization	Not sure
Gynecologist suggested embolization without patient asking for options	2 (7.4%)	6 (22.2%)	1 (3.7%)
Gynecologist suggested embolization after patient asked for options	6 (22.2%)	1 (3.7%)	
Patient suggested embolization and gynecologist supported	1 (3.7%)		
Patient decided by herself to have embolization (some of these women consulted the radiologist directly)	7 (25.9%)		2 (7.4%)

Note: Numbers represent the frequencies of women who had a particular decision-making pattern prior to the procedure and a successful versus unsuccessful embolization later.

Figure 1
The role of information sources in creating awareness of the procedure and facilitating decision making about the procedure among the women at different stages of information seeking.



APPENDIX

Information needs of women with symptomatic uterine fibroids: where do women find the information they need?

A survey of women undergoing uterine fibroid embolization through the Library and Information Science Program, Wayne State University, Detroit, Michigan.

We are interested in knowing the types of information women with symptomatic uterine fibroids need and the sources from which they find answers.

In Section A, please read each of the statements, and place a mark in the appropriate box that best describes the importance of having this information.

Section A: Information you need

How important was it or is it for you to have this information?

	Not important	Slightly important	Moderately important	Very important	Extremely important
1. How I will feel during the tests (e.g., ultrasound).	☐	☐	☐	☐	☐
2. What the results of the tests mean.	☐	☐	☐	☐	☐
3. What types of treatment are available.	☐	☐	☐	☐	☐
4. Benefits of various treatments available.	☐	☐	☐	☐	☐
5. Risks involved in various treatments available.	☐	☐	☐	☐	☐
6. Why the doctor suggested a treatment plan for me.	☐	☐	☐	☐	☐
7. How much the treatment will cost.	☐	☐	☐	☐	☐
8. Side effects and complications of embolization.	☐	☐	☐	☐	☐
9. How to prepare for embolization.	☐	☐	☐	☐	☐
10. How I will feel after embolization.	☐	☐	☐	☐	☐
11. How long before I can resume normal activities.	☐	☐	☐	☐	☐
12. How this may affect my life in the future.	☐	☐	☐	☐	☐
13. If the fibroids will grow back and symptoms recur.	☐	☐	☐	☐	☐
14. How embolization works.	☐	☐	☐	☐	☐
15. How to care for myself after embolization.	☐	☐	☐	☐	☐
16. Other types of information you needed or still need (please specify): _____					

In Section B, please read the statements, and place a mark in the appropriate box that describes where or from whom answers to the information needed were found. You may check more than one box.

Section B: Source providing information

Where or from whom did you find answers?

	Ob/gyn	Radiologist	Other physician	Family/friends	Television/radio	Magazines/newspapers	Internet
17. How I will feel during the tests (e.g., ultrasound).	☐	☐	☐	☐	☐	☐	☐
18. What the results of the tests mean.	☐	☐	☐	☐	☐	☐	☐
19. What types of treatments are available.	☐	☐	☐	☐	☐	☐	☐
20. Why the doctor suggested a treatment plan for me.	☐	☐	☐	☐	☐	☐	☐
21. How much the treatment will cost.	☐	☐	☐	☐	☐	☐	☐
22. Benefits of embolization.	☐	☐	☐	☐	☐	☐	☐
23. Risks involved in embolization.	☐	☐	☐	☐	☐	☐	☐
24. Benefits of alternate treatments.	☐	☐	☐	☐	☐	☐	☐
25. Risks involved in alternate treatments.	☐	☐	☐	☐	☐	☐	☐
26. Side effects and complications of embolization.	☐	☐	☐	☐	☐	☐	☐
27. How to prepare for embolization.	☐	☐	☐	☐	☐	☐	☐
28. How I will feel after embolization.	☐	☐	☐	☐	☐	☐	☐
29. How long before I can resume normal activities.	☐	☐	☐	☐	☐	☐	☐
30. How this may affect my life in the future.	☐	☐	☐	☐	☐	☐	☐
31. If the fibroids will grow back and symptoms recur.	☐	☐	☐	☐	☐	☐	☐
32. How embolization works.	☐	☐	☐	☐	☐	☐	☐
33. How to care for myself after embolization.	☐	☐	☐	☐	☐	☐	☐

In Section C, read the statements, and place a mark in the box that best describes how helpful people or the media that provided the information needed were.

Section C: Helpfulness of the source

How helpful did you find the individual or media providing the information?

	Not helpful	Slightly helpful	Moderately helpful	Very helpful	Extremely helpful
34. Obstetrician/gynecologist	☐	☐	☐	☐	☐
35. Internist	☐	☐	☐	☐	☐
36. Family practitioner	☐	☐	☐	☐	☐
37. Radiologist	☐	☐	☐	☐	☐
38. Family/friends	☐	☐	☐	☐	☐
39. Television/radio	☐	☐	☐	☐	☐
40. Magazines/newspapers	☐	☐	☐	☐	☐
41. Internet	☐	☐	☐	☐	☐

42. Helpfulness of other sources that provided information (please specify): _____

In Section D, read the questions, and place a mark in the appropriate box that best describes demographics.

Section D: Demographics

43. What is your age?
Under 26 ☐
26–35 ☐
36–45 ☐
46–55 ☐
Over 55 ☐
44. What is your educational level?
Partial high school ☐
High school graduate ☐
Some college ☐
College graduate ☐
45. What is your race and ethnicity? _____

Have we overlooked anything? Please use this space for additional comments about the types of information women with symptomatic uterine fibroids need and the sources from which they receive or do not receive information.

_____

_____

Thank you. Your contribution to this effort is greatly appreciated.

Galloway S, Graydon J, Harrison D, Palmer-Wickham S, Burlein-Hall S, Rich-van der Bij L, West P, Evans-Boyden B. Toronto informational needs questionnaire—breast cancer. In: Redman BK, ed. Measurement tools in patient education. Adapted with the permission of Springer Publishing Company, New York, NY.