

Information preferences of people living with fibromyalgia – a survey of their information needs and preferences

Lubna Daraz,¹ Joy C. MacDermid,¹
Seanne Wilkins,¹ Jane Gibson,²
Lynn Shaw³

¹School of Rehabilitation Science, Faculty of Health Sciences, McMaster University, Hamilton, ON; ²Knowledge Translation, Institute for Work & Health, Toronto, ON; ³Faculty of Health Sciences, School of Occupational Therapy, University of Western Ontario, London, ON, Canada

Abstract

A lack of understanding about fibromyalgia and how to live with it may undermine the foundations of self-management and may compromise quality of life. The purpose of this study was to determine the information needs and preferences pertinent to people living with fibromyalgia. A cross-sectional web-based survey was developed based on conceptual and qualitative work informing information needs. Recruitment took place through hospitals, clinics, physicians and fibromyalgia support groups across Canada. Descriptive statistics using SPSS and graphical representations were employed to summarize and represent data. A total of 442 respondents (93% female, mode age 51-65) participated in the survey. No statistical differences in information needs were found between males and females or education level. Respondents (74%) frequently searched for information about fibromyalgia using a variety of resources including Internet (91%), doctors (75%), support groups (76%), and people with same condition (87%). Respondents expressed a strong need for information about symptoms (81%), implications (79%), treatments (87%), resources (85%) and coping (79%). However, concerns were expressed about the reliability of information and majority (93%) wanted information to be available online that is provided by healthcare providers or from reputable sources. Internet (48%), people with similar condition (35%) and support groups (35%) were perceived as useful resources for people living with fibromyalgia. Information resources need to be developed on the basis of both content and knowledge of the information needs of the target end-user. Healthcare providers and the Internet are expected to be reliable resources of information.

Introduction

Fibromyalgia is a common, disabling and controversial chronic disease that has serious consequences on the health and life of people who are living with the illness.¹⁻⁴ In Canada as many as 1.1 to 3.3 percent people are affected by this disabling disease.^{5,6} Fibromyalgia is six times more common in women than in men.^{5,7} This prevalence of fibromyalgia is similar worldwide and the number is growing each year.² Increased awareness and reporting of the condition is at least partially responsible for this increase.⁸⁻¹⁰

One of the main symptoms of fibromyalgia is extensive and persistent pain.^{8,11,12} Fibromyalgia symptoms that are not sufficiently manageable lead to substantial disability.¹³⁻¹⁶ There is no specific diagnostic test that identifies fibromyalgia, but there are efforts to introduce new diagnostic guidelines.^{8,17,18} These guidelines can be used as a foundation for understanding the disease and forming recommendations for effective treatments or management strategies.

Many people diagnosed with fibromyalgia stop working due to limitations in work capacity. Researchers who studied work capability of people living with fibromyalgia found that better awareness and use of work adaptations would allow people to be more successful in the labor markets.^{12,19,20} Given the current rates of disability and work loss, efforts to make people with fibromyalgia better prepared to deal with their illness or work capacity might result in substantially lower health and social costs. Schmidt and colleagues reported that in 2003, the healthcare costs in Sweden for people with fibromyalgia and similar conditions were more than \$2 billion in US dollars annually.⁴ In the USA, the estimated healthcare cost for people living with fibromyalgia is also between \$12-14 billion dollars each year.²¹ A similar depiction can be observed in Canada where many Canadians are also affected by fibromyalgia.^{6,22} A study by White and colleagues in London, Ontario, Canada found that annual costs, medications, and health services use among people living with fibromyalgia were twice that of those without widespread pain.⁶ As a result, the challenges for managing fibromyalgia become a burden for both people living with the illness and the healthcare systems.^{6,23}

Qualitative studies that reported the experience of people living with fibromyalgia have identified the complex challenges of managing family life, work conditions, psychological problems and a lack of support from healthcare providers, family members and society.^{4,20,24-26} Unfortunately, much of the research relating to this condition focused on medical aspects of the disease while paying little attention to the information needs and preferences of people

Correspondence: Lubna Daraz, School of Rehabilitation Science, Faculty of Health Sciences, McMaster University, 1400 Main St. West. IAHS – 403, Hamilton, ON L8S4L8 Canada. Tel: +1.647.781.8536. E-mail: darazl@mcmaster.ca

Key words: fibromyalgia, information needs, Internet, survey, coping, quality of life.

Acknowledgements: this work was supported by a Doctoral Research Award (Frederick Banting and Charles Best Scholarship) from the CIHR; a Strategic Training Fellowship in Rehabilitation Research from the CIHR Musculoskeletal and Arthritis Institute; a S. Leonard Syme Training Fellowship from the Institute for Work & Health; and a MSK Training Fellowship from the Ontario Rehabilitation Research Advisory Network to Lubna Daraz.

Conflict of interest: the authors report no conflicts of interest.

Received for publication: 27 June 2011.

Accepted for publication: 12 August 2011.

This work is licensed under a Creative Commons Attribution 3.0 License (by-nc 3.0).

©Copyright L. Daraz et al., 2011
Licensee PAGEPress, Italy
Rheumatology Reports 2011; 3:e7
doi:10.4081/rr.2011.e7

living with fibromyalgia.^{14,27} Previous authors have suggested that a lack of understanding and knowledge of the disease are among the most important factors that contribute to a lower quality of life and inability to manage the illness.^{1,5, 18, 9,28-31} As Crooks stated, *an important element of negotiating life with a chronic illness, for many, is seeking out information which can be used to come to a greater understanding of one's changed/changing body and possible treatment options.*¹⁰ There is also evidence that interventions that increase people's knowledge, skills and confidence positively affect their well-being.³² The Chronic Care Model that was developed by Wagner and colleagues²⁷ to improve care of chronically ill patients, the developers of the model advocated for knowledge and information as critical components of chronic disease management.²⁷ Appropriate information can assist people in managing their illness and making informed decisions about their health.^{10,32,33}

Daraz and others studied the experience of information use by women living with fibromyalgia.³⁴ Their study findings reported that women received limited information from their healthcare providers and lacked access to quality information about their illness. Despite their fundamental information needs, women

struggled to find and access appropriate information. They used diverse strategies such as personal capacities, supports through connections with others and new research in overcoming some of the challenges in accessing information. In spite of the challenges, women reported that they were able to draw on accessed information to make changes and to begin to coordinate their lives to live with fibromyalgia. This qualitative study³⁴ suggested that information on fibromyalgia does support people living with this health disorder. However, it does not necessarily represent the broad audience of people who might potentially use this information due to the small sample size. Given the expressed importance, it is essential to explore a broader description of these needs before pursuing resource development. Since the suitability of information content and format should be matched to the majority of the target audience, it is worthwhile to define these. Therefore, the purposes of this study were to identify the: i) information needs of people living with fibromyalgia; ii) importance assigned to specific categories of information; iii) ways people find/use information about fibromyalgia; iv) information format preferred by people living with fibromyalgia.

Materials and Methods

Methodology

This study was a cross-sectional national survey targeting people living with fibromyalgia.

Survey development

The content for specific items of the survey were generated from multiple sources including the issues identified by the qualitative study on this topic by Daraz and others and studies of information needs of similar groups of people.^{8,13,23,34,35} The structure and scaling items were selected using established principles^{36,37} and consensus between two lead authors. The wording and structure of the overall survey questionnaire were independently evaluated by each of the authors and iteratively revised for both content and clarity.

The final draft of the survey was pilot tested among participants who were not part of the sampling frame (n=10). This process resulted in further modification /simplification by minor changes to the format of the survey and individual items, clarity of specific items and removal of redundant questions. The final version of the survey was launched using Survey Monkey [http://www.surveymonkey.com/] which is a web-based survey tool that allows participants to complete a survey easily and anonymously using the Internet.

The survey was preceded by an informed consent form and included the following components (in order): i) Information Need, ii) Access to Information, iii) Information Use, iv) Use of Online Information and v) Demographics. The response items were set as a 7 point scale where possible. For example, items regarding importance of content, responses were categorized as very important, important, somewhat important, neutral, somewhat unimportant, unimportant and very unimportant. During analysis, items were collapsed into fewer categories to analyze differences in information needs based on education and gender. We dichotomized the 7-point scale into a 2-point scale (important, not important) based on the response rate.

Survey population

The following inclusion criteria were used to recruit participants for the survey: i) people (male or female) living with fibromyalgia (employed or not), ii) diagnosed with fibromyalgia at least a year prior to the start of the study and iii) able to communicate in English.

The recruitment strategy used to identify people living with fibromyalgia was implemented by contacting gatekeepers of access points (hospitals, clinics, physicians and support groups) in Canada. Study introductory letters were sent to hospitals notice boards, clinics and physicians providing services to people living with fibromyalgia, chronic pain groups and fibromyalgia support groups to inform them about the study and request their cooperation in recruitment. An electronic link to the survey was then sent to the gatekeepers who expressed their interest in the study to distribute to their members/patients using their email lists. Both males and females were surveyed to examine whether information needs and preferences varied by gender. The survey was launched on Survey Monkey on February 5, 2010 and closed on March 31, 2010.

The Survey Monkey software generated random numbers that were used as identifiers to allow for confidential responses. The exact number of people who were approached for participation was difficult to estimate since it was done through intermediaries, the accuracy of their e-mail lists was not verifiable and members of support groups were not all registered. As a result, it was not possible to estimate response rate. Further, since responses were anonymized, the recruitment source/site was unknown to the researchers.

Survey analyses

Routine survey analysis can be performed by Survey Monkey. Data were imported directly into EXCEL spreadsheet and then into SPSS (SPSS – IBM. http://www.spss.com) for more detailed analysis. A coding of open-ended

responses (i.e. additional comments) was developed by categorizing responses based on responses received for closed-ended questions. This process continued until all of the responses were coded successfully. To evaluate the difference between two educational groups and genders a statistical test of difference (Chi-Square) was conducted.

Descriptive statistics and graphical representations were employed to summarize and represent data. A power calculation for estimation using 442 respondents assuming a worst case proportion (0.5) and a 95% confidence interval indicated a margin of error of 0.046. The power calculation for 442 respondents, $\alpha=.05$, assuming 50% as one proportion (worst case scenario) indicated that 10% difference would be detected with 80% power. In all statistical analyses, a $P<0.05$ was considered statistically significant.

Results

Table 1 displays significant demographic characteristics of the sample. About 93% of the participants were female and 7% were male. The majority of the participants were Caucasian (96%) with post-graduate education (87%) and a significant number (69%) did not have a job due to fibromyalgia. Most of the respondents (94%) spoke English fluently enough to participate. The median time since diagnosis was 9 years with a range of <1-35 years. About 74 % of the respondents frequently searched for information about fibromyalgia and reported a variety of information needs (Table 2). From the people who provided responses (26%) to the open-ended (category *other*) question, 23% of those reported that they searched for information to be knowledgeable about fibromyalgia, 11% wanted to

Table 1. Respondents demographic information (n=442).

Age Category (%)	
18-30 years	4.2
31-50 years	41.7
51-65 years	45.7
Over 65 years	8.4
Gender (n= 442) (%)	
Female	93.3
Male	6.8
Ethnic Background (n=442) (%)	
Caucasian	95.6
Others	4.3
Average time since diagnosis (yr)	9
Employment Status (n=442) (%)	
Working	30.8
Not-working	69.2
Education (n=442) (%)	
High School or less	12.8
Post-Graduate	87.2

know more about coping, 20% wanted to know about treatments, 28% were not happy with healthcare systems/ professionals and the remainder of the respondents wanted information for family/friends, or to improve their quality of life. A substantial portion (80% or higher) of the respondents felt that it was very important to obtain information about symptoms, management, treatment options and to find someone who can help with their disease (Table 3) at the time of diagnosis. In addition, comments reported in the open-ended (category 'other') responses (25%) included more information about fibromyalgia (25%), diagnosis (16%), and concerns about healthcare providers (18%) and the rest discussed information sources, support groups, medication and diet. There were no differences between those who had post secondary

education and those less well-educated with respect to this high level of endorsement (Table 4). Similarly, more than 60% of the respondents felt that it was important for them to find information about the impacts of the disease on health and life, treatment options, medications, exercise, food, supports and coping after their diagnosis (Table 5). From the people who provided responses (19%) to the open-ended (category *other*) question also discussed their frustration about the lack of information from healthcare providers (29%), the need for more information about fibromyalgia (8%) and the remainder discussed wanting more information on self-help, quality of life, resources and insurance. There were no differences between males and females with respect to this high level of endorsement (Table 6). People reported variable difficulty in

accessing the information they need. Approximately equal numbers reported that accessing information was not difficult (45%) versus those who had difficulty (43%). The majority of the respondents (99%) obtained information online. Furthermore, most (91%) of the respondents found it easy to access online information and did so frequently – with 84% doing so at least once per month. They also reported accessing from other sources including doctors (75%), rheumatologist (58%), health magazines (61%), scientific studies (67%), support groups (76%), and people with the same condition (87%). However, other sources that were infrequently accessed were nurses (16%), occupational therapists (21%), psychiatrists (31%) and dieticians/ nutritionists (25%). Table 7 reports the frequency of use of the sources.

Table 2. Reasons people with fibromyalgia search for information (n=442).

Information needs	Strongly agree (%)	Agree (%)	Somewhat agree (%)	Neutral (%)	Somewhat disagree (%)	Disagree (%)	Strongly disagree (%)	Total Respondents
Learn more about fibromyalgia	83.1	12.9	2.3	0.5	0.2	0.5	0.5	427
Help make decisions about health	82.2	14.5	1.9	0.9	0.0	0.2	0.2	428
Learn about new research	80.0	15.5	2.1	2.1	0.0	0.0	0.2	426
Self-manage of health	69.7	20.1	5.9	2.6	0.7	0.7	0.2	423
Information for family	47.5	26.1	13.3	8.8	1.7	1.2	1.4	421
Lack of information from healthcare providers	41.5	20.2	16.4	7.8	3.3	6.1	4.7	426
Lack of attention from healthcare providers	41.3	16.2	17.3	7.6	6.2	7.4	4.0	421
Indistinct information from healthcare providers	33.6	21.4	14.6	12.9	4.9	7.2	5.4	425
Embarrassed to ask healthcare providers	7.3	8.7	10.9	13.0	8.7	23.6	27.7	423

Categories exploring the most endorsed responses are bolded.

Table 3. Importance of specific categories of information at the time of diagnosis.

Categories of information	Very important (%)	Important (%)	Somewhat important (%)	Neutral (%)	Somewhat unimportant (%)	Unimportant (%)	Very unimportant (%)	Total Respondents (%)
Types of available treatments	87.1	8.9	1.2	1.6	0.2	0.2	0.7	425
Who can help me with my condition	84.5	10.7	2.9	1.2	0.2	0.0	0.5	413
Usual symptoms and how to manage them	81.0	13.4	3.1	1.6	0.5	0.0	0.5	426
Possible health outcomes in the future	79.1	15.3	2.8	1.9	0.0	0.0	0.9	425
Things that I should avoid	75.5	17.2	2.6	3.5	0.2	0.2	0.7	425
Causes of the symptoms	74.5	15.7	6.3	2.6	0.2	0.2	0.5	427
When can I go back to normal activities	67.5	20.1	5.2	5.2	0.5	0.7	0.7	422

Categories illustrating the majority of responses are bolded.

Table 4. Impact of education level on information need.

Information needs	High school or below		Post-secondary education		P
	Respondents n =	% Think important	Respondents n =	% Think important	
The usual symptoms and how to manage them	49	100	332	99	0.44
The causes of the symptoms	50	100	328	99	0.43
The possible health outcomes in the future	50	100	329	99	0.43
When can I go back to normal activities	46	100	318	98	0.31
Things that I should avoid	49	100	323	99	0.43
Types of available treatments	49	100	334	99	0.39
Who can help me with my condition	49	100	321	99	0.50

Table 5. Importance of specific categories of information after diagnosis.

Categories of information	Very important (%)	Important (%)	Somewhat important (%)	Neutral (%)	Somewhat unimportant (%)	Unimportant (%)	Very unimportant (%)	Total Respondents
Treatment options	82.7	13.5	1.9	0.9	0.2	0.2	0.2	426
Impacts on my daily life	81.9	14.6	1.4	1.4	0.5	0	0.2	426
How to cope with fibromyalgia	79.3	16.2	3.3	0.7	0.2	0.0	0.2	426
Impact on my ability to work	78.4	14.8	2.6	2.1	0.9	0.2	0.9	426
Changes in my health	71.5	24.1	3.3	0.9	0	0	0.2	424
Exercises that can help with my pain	67.7	22.4	6.1	2.4	0.5	0.5	0.5	424
Emotional impacts	67.5	22.7	7.3	1.7	0.2	0.0	0.2	422
Type of supports exists for people like me	64.5	22.5	8.5	2.8	0.9	0.2	0.5	422
Alternative therapies	64.3	22.8	8.0	3.1	0.5	0.2	1.2	426
Medications that are good for me	64.2	25.0	5.9	2.8	0.9	0.2	0.9	425
Foods that are suitable for me	61.3	22.3	9.5	4.5	1.2	0.7	0.5	421
Connect with people with fibromyalgia	39.4	24.3	19.6	11.3	3.5	0.9	0.9	424

Categories exploring the most endorsed responses are bolded.

Table 6. Impact of gender on information needs.

Information Need	Female		Male		P
	Respondents n =	% Think important	Respondents n =	% Think important	
Changes in my health	362	100	26	100	0.79
The impacts of the disease on my daily life	363	99	25	100	0.71
Impact of fibromyalgia on my ability to work	359	98	26	100	0.51
Treatment options	364	100	26	100	0.79
Alternative therapies	357	98	25	96	0.49
Medications that are good for me	357	99	25	96	0.31
Exercises that can help with my pain	360	99	24	100	0.60
Foods that are suitable for me	348	98	26	100	0.43
How to connect with people with similar health problems	326	94	22	100	0.24
How to cope with fibromyalgia	365	99	27	100	0.70
Emotional impacts	356	99	27	100	0.63
The type of supports that exist for people like me	353	98	26	100	0.50

Table 7. Frequency of use of information sources.

Information sources	Very frequently (%)	Frequently (%)	Occasionally (%)	Rarely (%)	Never (%)	Total Respondents
Online/Websites	48	30	19	2	1	379
Support Groups	21	26	28	11	14	331
People with same condition	17	27	38	10	8	345
Doctor (s)	13	26	36	20	6	362
Other healthcare providers	9	17	34	12	27	292
Library	7	14	36	14	29	292
Health Magazines	6	18	37	21	17	303
Scientific studies	6	16	42	21	16	317
Family/Friends	5	14	36	19	25	295
Physiotherapists	4	8	27	24	37	284
Psychiatrists	3	10	16	16	55	268
Other magazines	3	6	27	24	40	267
Nurses	3	5	11	22	59	257
Rheumatologists	2	9	18	45	26	317
Dieticians/Nutritionists	2	7	16	18	57	257
TV/Radio	2	6	30	28	34	278
Acupuncturists	1	8	21	25	45	274
Occupational therapists	1	1	11	19	68	247

Categories illustrating the majority of responses are bolded.

Respondents indicated substantial variability in how useful they perceived different information sources to be. The most useful information sources were websites (48%), people with same condition (35%) and support groups (35%). Only 29% felt doctors were useful to some extent to access fibromyalgia information. Other clinicians including those who would be expected to spend considerable time promoting self-management (dietitians/nutritionists, nurses, occupational therapists, psychiatrists and rheumatologists) were also commonly seen as not being useful sources (Table 8). In contrast, respondents indicated a preference for receiving information from healthcare providers (Table 9) with 52% wanting information from healthcare providers and

45% preferring information from the web. In general, there were few information sources that were not looked upon favorably. About 35% preferred not to receive fibromyalgia information from face-to-face discussion with their religious leaders. However, the majority (93%) of the respondents preferred to use online information that was provided by healthcare professionals or by reputable sources.

Respondents reported their use of information as represented in Figure 1. While responses varied, there was a strong endorsement of the need for information with only 1% of the respondents reporting they did not use information at all to understand their disease. Some (12%) of the respondents provided open-ended responses regarding the barriers to use

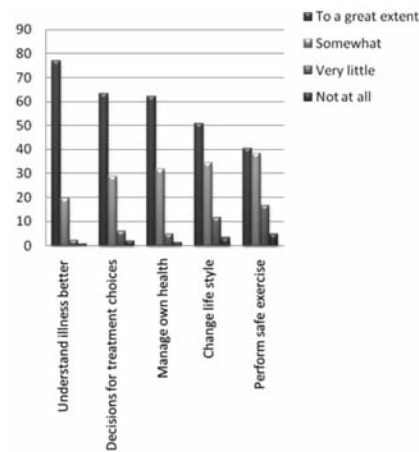


Figure 1. Frequency of use of information.

Table 8. Usefulness of different information sources.

	Information sources	Very useful	Useful	Somewhat useful	Neutral	Somewhat unuseful	Unuseful	Not useful at all	Total respondents
	%	%	%	%	%	%	%	%	%
Most useful	Online/Websites	48	33	15	3	1	0	1	398
	People with same condition	35	27	20	8	3	1	6	370
	Support groups	35	21	18	13	3	2	9	378
Somewhat useful	Doctor (s)	17	18	29	8	8	7	14	402
	Health Magazines	9	20	27	21	3	4	16	368
	Family/Friends	8	11	26	24	7	9	16	360
	Scientific studies	20	22	24	19	3	3	10	358
Not useful	Nurses	4	3	9	35	4	10	35	355
	Occupational Therapists	4	4	9	39	4	6	34	343
	Psychiatrists	5	9	13	29	4	8	33	353
	Dieticians/Nutritionists	5	8	13	35	2	7	31	345
	Acupuncturists	8	8	15	30	6	6	28	347
	Other Magazines	4	8	18	33	5	6	27	345
	TV/Radio	3	9	20	32	5	5	26	350
	Physiotherapists	8	13	16	28	6	6	23	360
	Rheumatologists	10	12	19	20	8	8	22	380
	Other healthcare providers	14	12	21	25	4	4	21	364
Library	10	20	19	24	4	3	20	353	

Categories illustrating the majority of responses are bolded.

Table 9. Preferred format of information sources.

Format of information sources	Strongly prefer	Prefer	Somewhat prefer	Neutral	Somewhat dislike	Dislike	Strongly dislike	Total respondents
	%	%	%	%	%	%	%	
Face-to-face with healthcare providers	52	27	11	7	1	1	1	400
Online/ Websites	45	35	17	3	0	0	0	399
Face-to-face with a person with fibromyalgia	36	27	19	15	2	1	1	400
Books	37	34	17	12	0	1	1	392
Email	33	33	20	10	1	1	2	393
Newsletters	29	32	21	13	3	1	1	392
Face-to-face with support groups	28	24	18	17	7	2	4	395
Videos (CD/DVD)	18	21	21	26	6	3	5	385
Magazines	18	25	24	25	3	2	3	386
Pamphlets /Brochures	13	23	30	24	5	2	2	394
Audios	11	14	18	35	8	7	8	368
Telephone	10	11	12	29	12	9	18	381
Face-to-face with religious leaders	4	4	8	34	6	9	35	385

Categories illustrating the majority of responses are bolded.

of information. They specifically mentioned about a lack of useful information (20%), and lack of access to care (8%) and the remainder discussed about the use of information for family/friends, to manage emotional impacts, and to help educate doctors about fibromyalgia. Finally, a substantial number of respondents (54%) provided spontaneous open-ended responses to the last question of the survey where participants were asked to share additional information regarding their information needs and preferences. They reported their frustration with healthcare providers (12%); the need for more education for physicians (15%); better availability of information for families (5%); coping strategies (12%); more information about fibromyalgia (12%); their struggle with unemployment insurance (2%); the need for awareness among government (10%), and the public (4%); concerns about the reliability of information (5%) and rest discussed about lack of access to treatment information that is available in other countries; funding for fibromyalgia research; specific treatment such as Guaifenesin Protocol; and struggles with physical and mental suffering for living with fibromyalgia.

Discussion

The survey results revealed that people living with fibromyalgia are active searchers and users of information and that they have broad information needs. They have continuous need for information that can help them understand their disease condition and its prognosis, treatment options, and coping strategies. People use information to make informed healthcare decisions and gain support from healthcare providers and others. Previous studies of people living with fibromyalgia or other chronic illnesses have also indicated strong need for condition specific information.^{5,10,19,20,34,38,39} This study builds on those findings by focusing on the specific types of information need and the sources that are used to locate it. Our findings suggest that there is a substantial gap between information needs and what people are able to access. About three out of five respondents strongly agree that due to a lack of information and support from healthcare providers, they frequently search for information about their illness from a variety of sources. It is also important to note that the need for specific information is equally important both for women and men with different levels of education. However, we acknowledge that our sample was preliminary female and well educated so the possibility for us to miss this effect is considerable.

Information needs do vary based on stage of

the disease. For example, on one hand, people indicate that it is important to them to know more about symptoms and future consequences of the disease before the final diagnosis with fibromyalgia. On the other hand, it is important to know more about treatments, impacts on life, coping, and alternative supports after they are diagnosed with fibromyalgia. This is a new finding and might suggest that information should be organized according to whether people are in the process of being diagnosed with fibromyalgia or have a confirmed diagnosis.

One of the other key findings of this study is that although people express a strong desire to seek information from their health care providers, their experiences have been unsatisfactory. A minority of respondents indicated that healthcare professionals are very helpful in terms of providing useful information. Of equal concern, up to one third of healthcare providers who spend considerable time with people and often use education for behavior modification (dietitians, occupational therapists, and psychiatrists) are perceived as inadequate sources. Conversely, the sources seen as most useful are the Internet, other people who are living with fibromyalgia and support groups. These findings are consistent with other studies that investigated the patterns of Internet use and health information seeking behavior of people with chronic illnesses (cancer, heart problems, diabetes, back pain and fibromyalgia).^{10,40} Berger and colleagues studied the associations between chronic illness and frequency of Internet use for - health information, communication with healthcare providers, changes in health care utilization, and satisfaction with the Internet.⁴⁰ Their findings suggested that people with chronic illnesses are more likely to use the Internet for health information, to improve communication with healthcare providers and to increase the use of health care based on information found on the Internet.⁴⁰ The authors also recommended the Internet as a valuable tool for health communication and education for people living with chronic illnesses.

Another new finding from our study is that many people living with fibromyalgia do not want to receive information about their health from religious leaders. This suggests that strategies that may use religious leaders to disseminate health knowledge or transfer this knowledge into practice should be approached with caution.

Self-management is achieved when healthcare providers confirm that *persons with chronic illness have the confidence and skills to manage their condition; the most appropriate treatments to assure optimal disease control and prevention of complications; a mutually understood care plan; and careful, continuous follow-up*²⁷ Given these principles of self-man-

agement with chronic conditions, there is a central gap between the theoretical foundations of self-management and people's experiences with acquiring the information they need to self manage.²⁷ Our data call into question whether chronic management strategies are being effectively implemented by clinicians when a substantial proportion of patients believe that they have not been provided with adequate information. However, it is notable that despite ranking the healthcare providers as low on being useful information sources, people prefer to receive information in-person from them. This suggests that there is a need for healthcare providers to play a vital role in providing valuable information to their patients and develop a more patient-centered interaction in order to empower people with fibromyalgia. Wagner and colleagues also advocate this notion; *High-quality chronic illness care is characterized by productive interactions between practice team and patients.*²⁷ Further studies are needed to develop knowledge exchange strategies and transfer tools that could facilitate better communication between healthcare providers and people living with fibromyalgia. More efforts are needed to develop easily accessible information sources in a format preferred by this group of people.

Our data do suggest that the concept of self-management²⁷ has value since people report that they use information largely to improve their knowledge of the disease and self-manage their health. However, this study was unable to test the effect of information on health outcomes or quality of life. The relationship between information use and health outcomes for people living with fibromyalgia has yet to be determined. Further research is needed to examine to what extent health information generates measurable health and quality of life outcomes for them.

Although we are unable to determine whether concerns about information quality contribute to differences between changing knowledge and behavior, the data do indicate that respondents have a substantial apprehension about the quality of information they are able to access. Concerns about the quality of information have also been reported by many researchers. For example, a study was conducted to evaluate the nature and quality of kidney transplant-related information available on the Internet and found that the information was of poor quality in terms of source, language, accessibility and quality/depth.⁴¹ People with other chronic conditions (social phobia, paediatrics neuro-oncology, depression, cancer) similarly expressed their frustration resulting from barriers to accessing reliable information.⁴²⁻⁴⁶ These findings suggest that if people do not have confidence in information- they might be less likely to act upon it. Therefore,

regardless of whether the information is or is not accurate, it is important to establish a variety of approaches that might be needed to ensure that people living with fibromyalgia are able to identify and access high-quality information and acquire the confidence they need to act upon that information. Self-management programs may need to enhance participants' skills in communicating with their healthcare providers, their ability to access high quality information sources, skills in assessing information quality, and specific strategies to deal with situations where they have not been provided with adequate information.

Implications for practice

This study has implications for people living with fibromyalgia and all those who attempt to empower them through the use of information including families, caregivers, resource developers, librarians, nonprofit agencies/support groups and clinicians. People living with fibromyalgia need adequate and accessible knowledge that supports their needs during both diagnosis and the subsequent living with chronic disease stages. Given the mismatch between people's preferences for attaining knowledge through healthcare providers and the extent to which this is currently operationalized, there is a need for enhanced communication between clinicians, care providers and people with fibromyalgia around their information needs. However, persons with fibromyalgia could play more active role as knowledge brokers to improve this communication as they have gained ample knowledge to be trained as knowledge brokers through self-management.

Healthcare providers may need additional training to take on the role as knowledge brokers as well for patients with fibromyalgia. In addition, awareness of how to teach patients generic skills assessing the quality of health information and specific tools/information sources for fibromyalgia would enhance clinicians' roles as knowledge brokers. At a minimum clinicians should be able to recommend generic and disease specific high-quality health information, assess their patients' ability to access and use information and have ongoing communication with their patients to understand their knowledge and information needs. These skills, while not a traditional focus in clinical training may be particularly important for the management of chronic diseases. In addition, it would be important when evaluating clinicians' skills in chronic disease management that the important aspect of empowering people to use health information optimally should be specifically evaluated and opportunities for skill enhancement provided if needed.

Similarly, the extent to which patients use

the Internet suggests a role for health librarians to facilitate people living in the community with fibromyalgia to access appropriate information sources. Health librarians might also develop sources to assist with improving chronic disease programs for hospital-based education programs. The sources may empower patients with fibromyalgia to access high-quality web information and communicate their information needs.

Patient support groups might also act as important knowledge brokers between clinicians and people living with fibromyalgia. Since such groups tend to be nonprofit organizations and organized by lay people living with the disease, one potential vehicle for improving both the process and content of information access and use would be through targeted training of leaders and information resource developers within these organizations. These groups might also serve as a vehicle for training patients on how to more effectively interact with healthcare providers to discuss issues around information access, validity, personal relevance and usability.

Study limitations

There are limitations to our study, some arise from the nature of the web-based survey and others are inherent to the population or to our sample. The majority of the respondents are female, which is consistent with the epidemiology of the disease, but resulted in a lack of power to differentiate gender differences. We also have a high prevalence of respondents who are highly educated. This sampling may have arisen given that educated (and likely more economically advantaged) individuals are more likely to have home computers or time to dedicate to the survey. This type of respondent may also be more likely to have repeat interactions with their healthcare provider and join social support groups. For this reason, people who are less well educated or more socially isolated may not have been adequately represented in our sample. It is possible that these groups have particular information needs. One way to address this problem may be to use sampling strategies that specifically recruit isolated or disenfranchised subgroups of the fibromyalgia population and use qualitative methods to address this potential gap in the future. Since the majority of the respondents are Caucasian the study results may not reflect the experience of people from different ethnic backgrounds or cultural contexts who are living with fibromyalgia. This study serves as a foundation for understanding the knowledge behaviours and needs of people living with fibromyalgia and indicates a need for future studies that focus on differential needs related to personal, environmental and disease factors.

References

1. Rodham K, Rance N, Blake D. A qualitative exploration of carers' and 'patients' experiences of fibromyalgia: one illness, different perspectives. *Musculos Care* 2010;868-77.
2. Neumann L, Buskila D. Epidemiology of fibromyalgia. *Current Pain Headache Repor* 2003;7:362-8.
3. Schaefer KM. The Lived Experience of Fibromyalgia in African American Women. *Holis Nurs Practice* 2005;19:17-25.
4. Schmidt A, Husberg M, Bernhardt L. Social costs for rheumatology diseases. Linkoping University Centre for Medical Technology Assessment (CMT). Report; no 5, 2003.
5. McNally JD, Matheson DA, Bakowsky VS. The epidemiology of self-reported fibromyalgia in Canada. *Chro Disea Canada* 2006;27:9-16.
6. White KP, Speechley M, Harth M, Ostbye T. The Lodon fibromyalgia epidemiology study: the prevalence of fibromyalgia syndrome in London, Ontario. *J Rheumatol* 1999;26:1570-6.
7. Weir PT, Harlan GA, Nkoy FL, et al. The incidence of fibromyalgia and its associated comorbidities: a population-based retrospective cohort study based on international classification of diseases, 9th revision codes. *J Clinic Rheum* 2006;12:124-8.
8. Bennett MR. Clinical Manifestations and Diagnosis of Fibromyalgia. *Rheum Dis Clin North Am* 2009;35:215-32.
9. Bennett MR, Jones J, Turk CD, et al. An internet survey of 2,596 people with fibromyalgia. *BMC Musculosk Dis* 2007;8:27.
10. Crooks VA. I go on the Internet; I always, you know, check to see what's new" chronically ill women's use of online health information to shape and inform doctor-patient interactions in the space of care provision. *ACME: An Intern E-Journal for Crit Geograp* 2006;5:50-69.
11. Arnold LM, Crofford LJ, Mease PJ, et al. Patient perspectives on the impact of fibromyalgia. *Patient Educ Couns* 2008;73:114-20.
12. Gunilla M, Liedberg, Cris M. Henriksson. Factors of Importance for work disability in women with fibromyalgia: an interview study. *Arthritis Care Res* 2002;47:266-74.
13. Henriksson CM. Long-term effects of fibromyalgia on every-day life: a study of 56 patients. *Scand J Rheumatol* 1994;3:35-41.
14. Furlong LV, Zautra A, Puente CP, et al. Cognitive-affective assets and vulnerabilities: two factors influencing adaptation to fibromyalgia. *Psychol Health* 2010;25:197-

- 212.
15. Kennedy M, Felson DT. A prospective long-term study of fibromyalgia syndrome. *Arthritis Rheum* 1996;39:682-5.
 16. Kool MB, Middendorp HV, Boeije HR, Geenen R. Understanding the lack of understanding: invalidation from the perspective of the patient with fibromyalgia. *Arthr Rheumat* 2009;61:1650-6.
 17. Rheumatology.org [Internet]. Atlanta: American College of Rheumatology. <http://www.rheumatology.org/> Accessed: 2011 Feb 18.
 18. Pongratz D, Sievers M. Fibromyalgia - symptom or diagnosis: A definition of the position. *Scand J Rheumatol Suppl* 2000; 113:3-7.
 19. Lofgren M, Ekholm J, Ohman A. 'A constant struggle': Successful strategies of women in work despite fibromyalgia. *Disab Rehab* 2006;28:447-55.
 20. Sallinen M, Kukkurainen ML, Peltokallio L, Mikkelsen M. Women's narratives on experiences of work ability and functioning in fibromyalgia. *Musculosk Care* 2010;8:18-26.
 21. Soderberg S, Lundman B, Norberg A. Living with fibromyalgia: sense of coherence, perception of well-being and stress in daily life. *Res Nurs Health* 1997;20:495-503.
 22. Jain AK, Carruthers BM. Canadian clinical working case definition, diagnostic and treatment protocols- a consensus document. *J Musculosk Pain* 2003;11:3107.
 23. White LA, Birnbaum HG, Kaltenboeck A, et al. Employees with fibromyalgia: Medical comorbidity, healthcare costs, and work loss. *J Occup Env Med* 2008;50:13-24.
 24. Paulson M, Norberg A, Danielson E. Men living with fibromyalgia-type pain: experiences as patients in the Swedish health care system. *J Adv Nurs* 2002; 40:87-95.
 25. Sim J, Madden S. Illness experience in fibromyalgia syndrome: a metasynthesis of qualitative studies. *Soc Sc Medic* 2008;67:57-67.
 26. Koullil SV, Kraaimaat FW, Lankveld WV, et al. A patient's perspective on multidisciplinary treatment gain for fibromyalgia: An indicator for pre-post treatment effects? *Arthr Rheumatol* 2009;61:1626-32.
 27. Wagner EH, Austin BT, Davis C, et al. Improving chronic illness care: Translating evidence into action interventions that encourage people to acquire self-management skills are essential in chronic illness care. *Heal Affair* 2001;20:64-78.
 28. Davison NS. End-of-Life Care Preferences and Needs: Perceptions of Patients with Chronic Kidney Disease. *Clin J Am Soc Nephrol* 2010;5:195-204.
 29. Madden S, Sim J. Creating meaning in fibromyalgia syndrome. *Soc Sci Med* 2006; 63:2962-73.
 30. Cunningham MM, Jillings C. Individuals' descriptions of living with fibromyalgia. *Clin Nurs Res* 2006;15:258-73.
 31. Lempp HK, Hatch SL, Carville S F, Choy EC. Patients' experiences of living with and receiving treatment for fibromyalgia syndrome: a qualitative study. *BMC Musculosk Dis* 2009;10:124.
 32. Warner D, Procaccino DJ. Toward wellness: women seeking health information. *J Am Soc Inform Sci Tech* 2004;55:709-73.
 33. Halpert A, Dalton CB, Palsson O, et al. Drossman Irritable Bowel Syndrome Patients' Ideal Expectations and Recent Experiences with Healthcare Providers: A National Survey. *Dig Dis Sci* 2010;55:375-83.
 34. Daraz L. Information needs and availability of people with Fibromyalgia [dissertation]. Chapter 2. Hamilton, ON, Canada: McMaster University; 2011.
 35. Raymond MC, Brown JB. Experience of fibromyalgia. Qualitative study. *Canad Family Phys* 2000;46:1100-6.
 36. Couper MP, Traught MW, Lamias MJ. Web survey design and administration. *Public Opin Quart* 2001;65:230-53.
 37. Andrews D, Nonnecke B, Preece J. Electronic survey methodology: a case study in reaching hard-to-involve internet users. *Intern J Human-Comp Inter* 2003;16:185-210.
 38. Hogan PT, Palmer LC. Finding and using medical information. "Information work" and chronic illness: interpreting results from a nationwide survey of people living with HIV/AIDS. *Proceed Am Soc Info Sci Tech* 2005;42.
 39. Arthritis.ca. [Internet]. Toronto: The Arthritis Society. <http://www.arthritis.ca> Accessed: 2011 Jan 30.
 40. Berger M, Wagner TH, Baker LC. Internet use and stigmatized illness. *Soc Sci Med* 2005;61:1821-7.
 41. Hanif F, Abayasekara K, Willcocks L, et al. The quality of information about kidney transplantation on the World Wide Web. *Clin Transplant* 2007;21:371-6.
 42. Khazaal Y, Fernandez MA, Cochand S, et al. Quality of web-based information on social phobia: a cross-sectional study. *Depress Anxiety* 2008;25:461-5.
 43. Hargrave DR, Hargrave UA, Bouffet E. Quality of health information on the Internet in pediatric neuro-oncology. *Neuro Oncol* 2006;8:175-82.
 44. Griffiths KM, Christensen H. The quality and accessibility of Australian depression sites on the World Wide Web. *Med J Aus* 2002;176:97-104.
 45. Al-Bahrani A, Plusa S. The quality of patient-oriented internet information on colorectal cancer. *Color Dis* 2004;6:323-6.
 46. Graydon, J, Galloway S, Palmer-Wickham S, et al. Information needs of women during early treatment for breast cancer, *J Advan Nurs* 1997;26:59-64.