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What Arthritis Pain Practitioners and Patients Want in an Online Self Management Program

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Abstract

Objective—Self-management of pain is a critical component of arthritis care; however, limited mobility can restrict access to resources. Although the Internet has become a primary source of health information, few studies address what patients want and need from a self-management website.

Methods—Thirty-two people diagnosed with arthritis and 12 practitioners a) participated in individual one hour interviews and b) sorted and rated a list of 88 unique statements that were derived from the interviews. Qualitative data were analyzed using Concept Mapping procedures.

Results—The six cluster map provided the best discrimination between statements. Follow up analyses suggested that although patients with arthritis and practitioners generally agree on the categories of content on a self-management website about arthritis, they appear to disagree on the importance of each category.

Conclusions—These findings about patient and provider desired content and features can be used by health educators to develop curriculum for health education of patients with arthritis pain.

Keywords

arthritis; pain; self-management; Internet

INTRODUCTION

Arthritis is the leading cause of disability for individuals over the age of 15 in the United States (CDC, 2001). One of every five adults in the United States (46.4 million people) is affected by arthritis (CDC, 2006a). Activity limitation attributed to arthritis was experienced by 17.4 million people, or 8.3% of the population in the United States.

In addition to the traditional medication regimen, the Centers for Disease Control (CDC) Arthritis Program (CDC, 2006b) recommends the use of evidence-based self-management education programs (e.g., Arthritis Foundation Self-Help Program developed by Kate

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Lorig). Self-management programs encourage participants to engage in activities to improve their health and well-being, such as increasing their physical exercise, increasing their cognitive symptoms management (e.g., distraction techniques), and improving their interpersonal communication skills (e.g., how to enhance their communication with their doctors).

Systematic reviews indicate that disability (Newman et al., 2004; Warsi et al., 2003), as well as pain levels (Dixon et al., 2007), have been reduced in response to self-management programs conducted face to face, but they do not have long term effects on the outcomes of people with rheumatoid arthritis (see Cochrane review by Riesma et al., 2002). In addition, such programs are not widely available and less than 1% of arthritis patients participate in them (Arthritis Foundation, unpublished data). To increase the accessibility of self-management programs by arthritis patients, initially and over time, these programs are now being offered online (e.g., Lorig et al., 2006; Lorig et al., 2008).

While the younger generations still exceeds the older in Internet use, the use of the Internet by older generations expands (Jones & Fox, 2009) as Baby Boomers approach senior citizen status (i.e., “the silver tsunami,” Fox et al., 2001). Arthritis is among the many health topics being searched online: A patient information website for individuals with arthritis was visited, on average, almost 300 times a day, with repeat use by 21% (Wilson et al., 2001). Forty three percent of patients surveyed at a rheumatology clinic had Internet access (Gordon et al., 2002); topics of their online searches included arthritis (83%), drug treatment (54%), alternative therapies (31%), and diet and arthritis (46%). Unfortunately, the quality of current online arthritis information is inadequate (Asani et al., 2005; Culver & Chadwick, 2005; Suarez-Almazor et al., 2001). Therefore, researchers have begun to develop and test online interventions to help people with arthritis: specifically, use of the Internet-based self management programs have been associated with improved health status and self efficacy one year later (Lorig et al., 2006, Lorig et al., 2008).

The goal of this study was to identify from key stakeholders (i.e., patients and health practitioners) what types of information to include in a proposed online self management program for people with arthritis pain, *painACTION*. The *painACTION* program is unique in that it learns about the user through self assessments then suggests content on the site that will be personally relevant to that user.

METHODS

This study included gathering information from arthritis patients and health practitioners through phone interviews and Concept Mapping (CM). CM offers a quantitative process for structured analysis of qualitative data (Jackson & Trochim, 2002)and has been used in the area of online health curriculum development (Cousineau et al., 2008). CM consists of several sequential steps: 1) elicitation research, where individual interviews or phone interviews with the target audience generate specific ideas in response to a stimulus question; 2) consensus-building, where participants respond to the collection of statements by independently sorting them into logical thematic categories and then rating the relative importance of each statement; 3) analysis, whereby a specialized software program (i.e., Concept Systems™, 2007) is used to generate conceptual maps; and 4) interpretation of results and translation to the educational program. The New England Institutional Review Board, registered with the Department of Health and Human Services, approved this study.

Patient Participants

Thirty-two arthritis patients were recruited through recruitment flyers in health clinics and online (CraigsList.org). Inclusion criteria were: a) arthritis diagnosis from a doctor (self report), b) over the age of 18, and c) able to read and write English. All patients signed an informed consent form prior to participation. They were compensated $50.00 for their participation in two steps: an interview and Concept Mapping (CM) tasks (total compensation was $100). Eighty seven percent of those who participated in the phone interviews (*n* = 28) completed the CM tasks.

Expert Panel

The expert panel consisted of 12 health practitioners who worked directly with people with arthritis pain: specifically, five physicians (specialties: Anesthesiology; Internal Medicine; General Medical Practice; Physical [Sports] Medicine/Rehabilitation; Family Practice and Pain Management), two rheumatologists, two psychologists, one social worker, one nurse practitioner, and one pharmacist. They were recruited through an online newsletter from a continuing medical education website called *painedu.com*. They each received $100 for the interview and $100 for completing the CM tasks (i.e., $200 total). Ninety-one percent of the practitioners who were interviewed (*n* = 11) completed the CM tasks.

Interview Procedures -- Patients

Patients participated in a one hour interview. The patient interview questionnaire was developed by the research team through a review of the a) the project objectives, b) related interview questions from previous projects of the self management behaviors of other patient populations, and c) literature on arthritis self management. Interview questions included length of diagnosis, mobility and functionality, self management methods, Internet usage (i.e., arthritis sites visited), discussion of proposed program features, and patient-provider communication. Then they were asked to generate statements based on a focus prompt for the CM task: “On a website like *painACTION*, I would like to be able to learn, see or do…” Lastly, they answered demographic questions.

Interview Procedures -- Experts

Expert panel members also participated in a one hour telephone interview. The expert interview questionnaire was developed using the same methods as those used to develop the patient interview questionnaire. It included questions about self management recommendations, the educational needs of arthritis patients, proposed features of the website, and the top three things patients should know about self managing arthritis pain. They were then asked to elicit statements based on the same focus prompt as the patients.

Concept Mapping Procedures

First, the research team combined the statement lists generated from the phone interview CM prompt by both the participants and practitioners. Next the research team purged the list for redundant statements, as well as statements deemed overly general or specific. The final list included 88 unique statements related to arthritis and self-management. Participants were instructed to sort the statements into groups “in a way that makes sense to you.” After sorting, participants were asked to rate all statements on a seven point scale in regard to their perceived importance given the described purpose of the program (i.e., 1 = “Not important” through 7 = “Important”).

Data Analysis

Two methods of analysis were used to analyze these interview data: (1) Two of the researchers (KT and JA) conducted a content analysis of the self management strategies mentioned in the interviews; they achieved a Kappa of .70 + on 76% of the strategies. Data for the remaining strategies were reviewed for consensus. (2) The CM technique was used: The main statistical procedures (i.e., multidimensional scaling and cluster analysis) and their application to CM have been well-described (Davison, 1983; Everitt, 1980; Kruskal & Wish, 1978; Trochim, 1989). The mapping procedure (Concept Systems, 2007) located each statement as a separate point on a "map," with statements sorted together more frequently shown as closer on the map than those sorted together less frequently. In addition, a cluster analysis organized the statements into higher order conceptual groupings called "clusters."

RESULTS

Patient Participants

Half of these arthritis patients were over the age of 50 (66%), and more than half of them were diagnosed with OA (63%). The remaining participants were diagnosed with RA (21%) or another type of arthritis (16%). See additional demographic data in Table 1.

Interviews

A content analysis of the interview questions about self management strategies yielded the following results: Each person with arthritis pain mentioned between one and ten strategies (*M* = 3.6, *SD* = 2.0); 70% reported use of at least three strategies. The practitioners reported that they recommend between two and ten self management strategies (*M* = 5.3, *SD* = 2.2); 67% recommended at least five strategies. The strategies recommended by the greatest number of practitioners (i.e., between 41–67%) were: exercise, ice, medication, heat, rest, and physical therapy (i.e., meet with a health professional for non-pharmaceutical treatment including therapeutic exercise, massage, or hydrotherapy, etc.). The strategies that were reported by the greatest number of people with arthritis pain (i.e., 43–60%) were: walking, exercise, healthy diet, and medication. See Figure 1.

Concept Mapping

Using Concept Systems (2007), the research team created multiple maps that summarized how participants sorted the statements into groups. Each map represented the sorting data with a different numbers of clusters (i.e., four clusters, five clusters, six clusters, seven clusters, eight clusters). to identify the "best" map (i.e., most conceptually meaningful for the project). A map with fewer clusters (e.g., four) will divide into a map with more clusters (e.g., five) clusters because a single cluster is dividing into more conceptually distinct groups of statements. After reviewing each of these maps, the team determined that the six cluster map showed the most meaningful groupings of the 88 content statements (see Figure 2).

Each cluster has up to five layers, where the number of layers represents the average importance rating of items in the cluster, relative to others on the map. The six domains in the cluster were as follows (the highest rated item per cluster is in brackets): *Tools to Manage Pain* [How do I cope with the pain (*M* = 5.95)], *Future of Arthritis Pain* [Latest research findings (*M* = 5.51)], *Disease and Pain Education* [Information about things that can be done to stop the arthritis from getting worse (*M* = 6.33)], *Physical Activity and Diet* [How to maintain strength to support joints (*M* = 5.62)], *Daily Living* [What kind of things affect pain (*M* = 5.67)], and *Communication and Support* [Have the ability to email questions to practitioners (*M* = 5.31)]. See Table 2 for the top three items in each cluster, including cluster means.

In addition, the research team generated a pattern match map, which is a comparison of the practitioner and patient group on how they rated the particular content on the site on accordance of importance (*r* =.65) (see Figure 3). Results indicated that generally patients reported that *Disease and Pain Education* was the most important area while generally practitioners indicated that *Daily Living* was the most important. To further explore these differences, subsequent *t*-tests were conducted to test the means by group (patient versus practitioner) for each cluster. We found that patients (*M* = 4.93, *SD* = .57) rated the *Future of Arthritis Pain* cluster significantly higher than the members of the expert panel (*M* = 4.60, *SD* = .65; *t*(32)=3.6, *p* = .001). These findings suggest that people with arthritis are more concerned about receiving information on the future of their arthritis pain than health care professionals.

DISCUSSION

The prevalence of arthritis in America is expected to increase to 67 million adults by the year 2030 (Hootman & Helmick, 2006). For the majority of arthritis patients, pain leads to isolation and limited functioning (Katz & Yelin, 2001). Knowing how to self manage this pain is something that can help reduce pain (e.g. Dixon et al., 2007) and disability (e.g., Newman et al., 2004), but accessing outside resources is challenging; therefore, arthritis patients have begun to actively seek guidance for the management of symptoms online (Gordon et al., 2002; Wilson et al., 2001). The goal of this study was to obtain input from patients and practitioners about the content and features to include in a proposed CBT-based online self management program for people with arthritis pain.

The interview data suggested that self management strategies (e.g., exercise) are being recommended by practitioners and used by patients; however, participants had not incorporated other strategies that health providers believe have efficacy (e.g., heat, rest); this could be due to lack of compliance or a lack of communication with their health care provider. Because people with OA are older, they are usually coping with multiple conditions (e.g., obesity, heart disease – Kadam et al., 2004); hypertension, diabetes, respiratory disease – Breedveld, 2004); they are likely to spend their time with the doctor discussing other issues (Gignac et al., 2006).

Examination of the Concept Mapping results indicates that while the patients and the practitioners seem to have congruent ideas of what should be included on the website (i.e., what they want to know), they have different ideas of prioritization and importance of the topic areas. Patients wanted information about the progression of the disease while practitioners focused on medication compliance. For example, OA is seen by both patients and physicians as an inevitable part of the aging process (Gignac et al., 2006), which can inhibit patients from getting the help that they need to manage their symptoms. Results of this study suggest that there is an education gap around self management of arthritis pain.

Limitations

There are several limitations to this pilot study. Participants were recruited by advertisement and word of mouth and may not represent arthritis patients who are *not* interested or motivated to participate in a research study. In addition, arthritis diagnosis was not confirmed by medical record so people without arthritis may have participated; however, all participants reported the specific type of diagnosis of arthritis (e.g., osteoarthritis) that they had received from a doctor to qualify for participation in the study. Small samples of participants were involved thus reducing the generalizability of the results. Similarly, all participants were compensated for their input, which is a potential source of bias; however, such compensation was commensurate with traditional interview renumeration. In addition, there was no relationship between the patients and the practitioners in this study; it may be that the practitioners of the patients would have reported the same self management strategies that were reported by their patients. Despite these limitations, the results of the current study represent an initial step toward the development of a theory-based, interactive program that educates and supports arthritis patients experiencing pain.

CONCLUSION

In summary, the need for information and support for arthritis patients is paramount considering that one of every five adults in the United States (46.4 million people) is affected by arthritis (CDC, 2006a). This project helped to identify some specific and contextual needs of arthritis patients and health practitioners for an online health intervention program. Health educators can use these findings to develop curriculum about the specific areas for which arthritis patients desire health information. Ultimately, the intention is that programs like *painACTION* will contribute to public health efforts to educate and empower arthritis patients to take control of their health.

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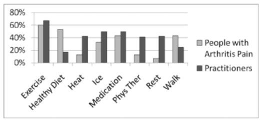

Figure 1.
Percentage of Reported Self Management Activities: Patients (*N* = 32) versus Practitioners (*N* = 12)

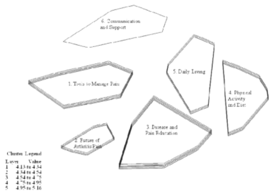

Figure 2.
Six Cluster Concept Map Generated with Data from Arthritis Patients (*N*= 28) and Practitioners (*N* = 11)

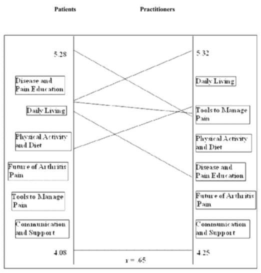

Figure 3.
Pattern Match of Cluster Importance Ratings by Arthritis Patients (*N* = 28) and Practitioners (*N* = 11)

Table 1

Demographics of Participants with Arthritis Pain (*N* = 32)

Demographic Characteristic	**Percentage**
Gender	
Female	50%
Male	50%
Race and Ethnicity	
White	75%
Black/African-American	19%
Hispanic	6%
Education	
Did not graduate from High School	3%
Graduated from High School/GED	6%
Some College	22%
2 years college/Associate’s Degree	13%
4 years college/Bachelor’s Degree	47%
Some Graduate education	3%
2 years of graduate education/Master’s Degree	6%
Household Income	
Under $25,000	13%
$25,000 – $49,999	31%
$50,000 – $74,999	22%
$75,000 – $99,999	19%
$100,000 – $124,999	9%
Over $125,000	6%
Relationship Status	
Single/Never married	13%
Married/Domestic partnership	58%
Separated/Divorced	26%
Age	
Under the age of 50	34%
Above the age of 50	66%
Self-reported Diagnosis	
Osteoarthritis	63%
Rheumatoid Arthritis	21%
Other (e.g., psoriatic arthritis)	16%

Table 2

The Three Highest Rated Concept Mapping Statements per Cluster with Mean Ratings by Arthritis Patients (*N*= 28) and Practitioners (*N* = 11)

Cluster 1: Tools to Manage Pain (*M* = 4.81, *SD* = 0.51), 11 statements total	
Statement	**Mean**
How do I cope with the pain	5.95
How to be proactive about taking pain medication prior to doing activities that cause pain	5.33
Provide links to other resources for additional arthritis information	5.31
Cluster 2: Future of Arthritis Pain (*M* = 4.83, *SD* = 0.53), 7 statements total	
Statement	**Mean**
Latest research findings	5.51
Information on what specialized doctors are available	5.41
Studies that are being done	4.97
Cluster 3: Disease and Pain Education (*M* = 5.16, *SD* = 0.48), 23 statements total	
Statement	**Mean**
Information about things that can be done to stop the arthritis from getting worse	6.33
Side effects of treatments	5.92
Information about the onset of flares what really triggers them	5.69
Cluster 4: Physical Activity and Diet (*M* = 4.98, *SD* = 0.35), 19 statements total	
Statement	**Mean**
How to maintain strength to support joints	5.62
Information on less painful exercise techniques with demonstrations	5.56
Information on better ways to prevent arthritis through exercise	5.41
Cluster 5: Daily Living (*M* = 5.06, *SD* = 0.37), 12 statements total	
Statement	**Mean**
What kind of things affect pain	5.67
How to protect joints	5.64
Learn how to manage a long term illness	5.44
Cluster 6: Communication and Support (*M* = 4.13, *SD* = 0.65), 16 statements total	
Have the ability to email questions to experts	5.31
How to talk with your health care provider	5.18
Read about what other people do to manage their pain	4.95