

PETTT TECHNICAL REPORT

PETTT-01-AS-01



Understanding Users of a Medical Information Website: A Phone Interview Study of Arthritis Source Users

Kristina Liu, Jennifer Turns, and Tracey Wagner
2001

Abstract:

We conducted a phone interview study of users of the Arthritis Source in order to accomplish two related goals: (a) to gain insight into the effectiveness of the arthritis source and (b) to learn about patient conceptions of arthritis. To do this, we focused on two arthritis conditions -- Rheumatoid Arthritis and OsteoArthritis, identified ten Arthritis Source users with each condition, and completed a structured interview over the phone. The transcriptions of these interviews constitute our data. The analysis of the data focuses on (1) an initial characterization of conceptions, (2) an evaluation of the success of our questions, and (3) an evaluation of whether we are sufficiently educated about arthritis and the two conditions for us to conduct the interviews.

To cite this document, use the format:

Turns, J. and Wagner, T. (2001). Continuing Medical Education: Observations of CME Course on Feb. 8 and 9, 2001. Technical Report PETTT-01-PT-01. Program for Educational Transformation Through Technology, University of Washington, Seattle, Washington.

Notice: PETTT has made its working papers, reports, and other documents available for your free use, but only if you (a) reference us in your bibliography and (b) tell us about it by emailing us at pettt@u.washington.edu.

Table of Contents

<u>Executive Summary:</u>	Error! Bookmark not defined.
<u>Table of Contents</u>	ii
<u>Summary of the Study</u>	7
<u>Goal: (From Human Subjects modification).</u>	7
<u>Procedure:</u>	7
<u>Questions on Usability</u>	7
<u>Arthritis Concept Questions</u>	7
<u>Patient Profile</u>	8
<u>Bone Cancer Scare MYRNA L. MANES (Tape#1)</u>	8
<u>Site Evaluation</u>	8
<u>Results</u>	8
<u>Patient/Physician Relationship</u>	8
<u>Knowledge</u>	8
<u>Highlight of the Interview</u>	9
<u>Suggestions</u>	9
<u>Patient Profile</u>	10
<u>Sharon the Technical Writer (Tape#2)</u>	10
<u>Site Evaluation</u>	10
<u>Results</u>	10
<u>Patient/Physician Relationship</u>	10
<u>Knowledge</u>	11
<u>Highlight of the Interview</u>	11
<u>Suggestions</u>	11
<u>Patient Profile</u>	12
<u>(Leo the Nuclear Submarine Caption, Tape #3)</u>	12
<u>Site Evaluation</u>	12
<u>Results</u>	12
<u>Patient/Physician Relationship</u>	12
<u>Knowledge</u>	13
<u>Highlight of the Interview</u>	13
<u>Suggestions</u>	13
<u>Patient Profile</u>	14
<u>The Myth of Osteoporosis (Tape#4)</u>	14
<u>Site Evaluation</u>	14

<u>Results</u>	14
<u>Patient/Physician Relationship</u>	14
<u>Knowledge</u>	14
<u>Highlight of the Interview</u>	15
<u>Suggestions</u>	15
<u>Patient Profile</u>	16
<u>Leo the foot solder (Tape#5)</u>	16
<u>Site Evaluation</u>	16
<u>Results</u>	16
<u>Patient/Physician Relationship</u>	16
<u>Knowledge</u>	16
<u>Highlight of the Interview</u>	17
<u>Suggestions</u>	17
<u>Patient Profile</u>	18
<u>Pampered Lily (Tape#6)</u>	18
<u>Site Evaluation</u>	18
<u>Results</u>	18
<u>Patient/Physician Relationship</u>	18
<u>Knowledge</u>	18
<u>Highlight of the Interview</u>	18
<u>Suggestions</u>	19
<u>Patient Profile</u>	20
<u>Mary In Pain (Tape#7)</u>	20
<u>Site Evaluation</u>	20
<u>Results</u>	20
<u>Patient/Physician Relationship</u>	20
<u>Knowledge</u>	20
<u>Highlight of the Interview</u>	21
<u>Suggestions</u>	21
<u>Patient Profile</u>	22
<u>Lupus PhD (Tape#8)</u>	22
<u>Site Evaluation</u>	22
<u>Results</u>	22
<u>Patient/Physician Relationship</u>	22
<u>Knowledge</u>	22
<u>Highlight of the Interview</u>	22
<u>Suggestions</u>	23
<u>Patient Profile</u>	24
<u>A female truck driver Sjorgren's Disease (Tape#9)</u>	24
<u>Site Evaluation</u>	24

Results 24

Patient/Physician Relationship 24

Knowledge 24

Highlight of the Interview 25

Suggestions 25

Patient Profile 26

Rubecca running out of time (Tape#10) 26

Site Evaluation 26

Reason 26

Results 26

Patient/Physician Relationship 26

Knowledge 26

Highlight of the Interview 27

Suggestions 27

Patient Profile 28

A distracted Mom (Tape#11) 28

Site Evaluation 28

I mean it has a lot of information... (to the extent that she did not remember any of it) 28

Results 28

Patient/Physician Relationship 28

Knowledge 28

Highlight of the Interview 28

I'm having a hard time right now? 28

Suggestions 28

Patient Profile 29

An anti-drug grandmom who may have cancer (Tape#12) 29

Site Evaluation 29

Results 29

Patient/Physician Relationship 29

Knowledge 29

Highlight of the Interview 29

Suggestions 29

Patient Profile 30

Able, I'll paint pigment on the spot if it helps... (Tape#13) 30

Site Evaluation 30

Results 30

Patient/Physician Relationship 30

Knowledge 31

Highlight of the Interview 31

<u>Suggestion</u>	32
<u>Patient Profile</u>	33
<u>Shanta, the young female RA patient (Tape#14)</u>	33
<u>Site Evaluation</u>	33
<u>Results</u>	33
<u>Patient/Physician Relationship</u>	33
<u>Knowledge</u>	34
<u>Highlight of the Interview</u>	34
<u>Suggestions</u>	34
<u>Patient Profile</u>	35
<u>The frustrated Marion (Tape #15)</u>	35
<u>Site Evaluation</u>	35
<u>Reason</u>	35
<u>Results</u>	35
<u>Patient/Physician Relationship</u>	35
<u>Knowledge</u>	35
<u>Highlight of the Interview</u>	36
<u>Suggestions</u>	36
<u>Patient Profile</u>	37
<u>The Hawaiian based military officer, Phil Navin (Tape#16)</u>	37
<u>Site Evaluation</u>	37
<u>Results</u>	37
<u>Patient/Physician Relationship</u>	37
<u>Knowledge</u>	37
<u>Highlight of the Interview</u>	38
<u>Suggestions</u>	38
<u>Patient Profile</u>	39
<u>Newman, the concerned father...(Tape #17)</u>	39
<u>Site Evaluation</u>	39
<u>Reason</u>	39
<u>Results</u>	39
<u>Patient/Physician Relationship</u>	39
<u>Knowledge</u>	39
<u>Highlight of the Interview</u>	40
<u>Suggestions</u>	40
<u>Patient Profile</u>	41
<u>Renee "What's the white stuff in the X-ray?" (Tape #18)</u>	41
<u>Site Evaluation</u>	41
<u>Results</u>	41
<u>Patient/Physician Relationship</u>	41

Knowledge..... 42

Highlight of the Interview..... 42

Suggestions 42

Patient Profile..... 44

4/2/01 Gregory the crisis center director (Tape #19) 44

Site Evaluation 44

Results 44

Patient/Physician Relationship 45

Knowledge..... 46

Highlight of the Interview..... 46

Suggestions 47

Patient Profile..... 48

Frank the volunteer (Tape #20) 48

Site Evaluation 48

Results 48

Patient/Physician Relationship 48

Knowledge..... 48

Highlight of the Interview..... 49

Suggestions 50

Summary of the Study

(From Activity plan): We will conduct a pilot study focused on characterizing conceptions of Arthritis, in general, and two specific conditions -- Rheumatoid Arthritis and OsteoArthritis. The goal of the pilot study will be two-fold: to learn about patient conceptions and also to evaluate our methodology. We will conduct the pilot study using structured interviewing techniques, with the design of the questions being a significant element of this effort. The interviewing will be over the phone (a modification to the already approved phone interviews for collecting usability information). We plan to collect information from a total of 10 subjects, 5 for each condition. The analysis of the data will focus on an initial characterization of conceptions, an evaluation of the success of our questions, and an evaluation of whether we are sufficiently educated about arthritis and the two conditions for us to conduct the interviews.

Goal: (From Human Subjects modification).

The purpose is to evaluate the effectiveness of the Arthritis Source website. However, we believe that patients' perspectives on arthritis will help us to better interpret their perceptions of the usefulness of the website.

Procedure:

The participants will be informed that the phone interview will include questions about their visits to the Arthritis Source website and their views on what they think arthritis is. Questions about their visits to the website are similar to those stated in the original proposal. Questions about their own arthritic condition start with the type of arthritis they have, followed by what they think that particular type of arthritis is.

Questions on Usability

Right now we are interviewing people diagnosed with either OA or RA. Do you have either of these conditions?

1. Could you tell me about your visit or visits to the Arthritis Source?
2. Could you tell me what you were trying to do when you visit the Arthritis Source?
If for specific information – Did you find what you were looking for?
3. Did you benefit from your visit or visits to the Arthritis Source? (In what way?)
4. What did you like about this site? (Can you tell me why)
5. What did you not like about this site? (Can you tell me why)
6. What do you think would improve the Arthritis Source?

Arthritis Concept Questions

----- (Name) in order to help us to improve the Arthritis Source to better serve the arthritis community, we need to know what people like yourself think about what arthritis is.

1. Could you tell me what you think arthritis is in general ?
2. Could you tell me how RA/OA affects the body?
3. Do you know what contribute to getting RA/OA?
4. Do you know how is RA/OA diagnosed?
If the answer is no – Do you remember what your doctor told you about your diagnosis?
5. What is the most difficult to understand about RA/OA

Patient Profile

Bone Cancer Scare MYRNA L. MANES (Tape#1)

Age: 51-60

Gender: Female

Arthritis Type: Osteoarthritis

Time Diagnosed: one week

Why Visited:

1. Recent diagnosis
2. information like new ways to treat arthritis
3. new things to do for arthritis
4. or places to go for help
5. pain management
6. Doctors or medicine

Site Evaluation

- This is very helpful information for me.
- I mean it has a lot of information... (to the extent that she did not remember any of it)

Results

- I'm more comfortable with it [her condition]. That I'm not going to just set down and let it all stiffen up.
- I'm more comfortable about the fact it's [having arthritis] not going to curtail my life to the degree that I was afraid it was.

Patient/Physician Relationship

- I don't think that they really did determine for sure what it was, but I'm going to go along with what they said because the other option is not very pleasant
- **I also know that they can't tell the difference in between bone cancer and arthritis if it's at a joint.**

Knowledge

- I assumed that arthritis was something that might affect me in my 80s rather than in my 50s.
- Degenerative arthritis is a condition when the bones start to deteriorate. I have got bone spurs and deterioration which leaves calcium deposits on my spine and on some of my joints, **so I would say that arthritis is probably caused by a lack of calcium.** I'm allergic to milk and a lot of milk products, so I probably haven't consumed enough calcium in my life.
- But I also believe it may be a generic thing because I understand that two of my sisters have it also.
- I'm retaining water extremely bad and in that [the Arthritis Source] it didn't tell me that was a part of this arthritis thing.

Highlight of the Interview

- Now before we get started, honey, let me explain something to you. I just found out that I have degenerative arthritis of the spine. But I really don't know a whole lot.
- I liked the idea that I can go in there and set down and find what I'm looking for on it.
- I have a backache at all times! It - it hurts. I don't know how else to put it.

Suggestions

I'd like to see something address the point of how they could tell for sure whether it is bone cancer or arthritis.

Patient Profile

Sharon the Technical Writer (Tape#2)

Age: 61-70

Gender: Female

Arthritis Type: rheumatoid

Why Visited:

1. I have two shoulder arthroplasties and have found that one shoulder has superior subluxation with possible cuff tear and the other was not corrected when the shoulder was replaced 1 year ago. I need to find out more about the course to take now.

Site Evaluation

- It was a source that I enjoyed reading because it seemed to be very comprehensive.
- It explained exactly how it should be done with rheumatoid arthritis... (I had a rotator cuff tear and a shoulder replacement. That is the main thing I was looking for)
- It was very good information, which I had not received from anywhere else.
- The femoral orthoplastic technique section was excellent.
- I liked the fact that they have an alpha listing number one for all kinds of subjects, every subject you can think of. And then even within that alpha listing, you have all kinds of sections and subsections.
- It just had a lot of information, a lot of sites is just you know one article someplace or something...(in this single site it has all the information that you are looking for)
- I will probably go to it every time I have surgery, which is quite often.
- I am fairly new at the computer at finding things and once I found it ...I thought that oh this is great. I can use this for everything.
- I love the way it has especially going through a sentence, it will have something underlined or highlighted so you can just look up what that is. It is really great that way.
- A lot of the terms are very technical but I like that. I prefer having something like that since I have tried to teach myself about all these terms rather ... it is not over simplified. That is what I like.
- You can find portions that are very understandable and some parts aren't and so it is good that they have all these ways of sending you know referring you someplace that will explain in more detail.
- It takes you back to the index or it will say at the end more information go to index and so forth. So it is excellent and it really doesn't leave anything up to the imagination which I like because being new to the PC a lot of sites I just get totally lost on.
-
-

Results

- Keep the listing of things that it had for future reference.
- Bookmarked the site as a favorite in the web browser.
- **I didn't realize that they have to do things differently if you do rheumatoid arthritis until I read that**

Patient/Physician Relationship

- I read several things that referred _(I'll have to fill this in myself)with rheumatoid arthritis that has to be done differently, to see whether my doctor had done that because my shoulder did not work out right.

- at one point I thought I might have to sue my doctor because it the rotator cuff was never repaired correctly and he knows that I have had rheumatoid arthritis for years and he had done several surgeries.
- My second doctor agreed with these things (rotator cuff surgery should be done differently with RA condition.) They probably don't appreciate that but...
- I don't know if I told him about the site, I just told him what I had read at the time.

Knowledge

- I am having cervical disc surgery C3 through C7... I guess most of the rheumatoid is C1 and 2
- RA is a systemic disease and it can affect every part of your body practically, the joints. I think it is an autoimmune disease.
- It is different from osteoarthritis. It can start at a young age and it can affect bones, joints. I guess it can even affect organs
- RA is diagnosed by some tests show that you have a rheumatoid factor or whatever and a sedimentation rate
- RA usually it is bilateral. If you have your left hand affected, your right hand is going to be affected. It is not caused by **over use** or whatever like osteoarthritis is caused by tennis elbow in baseball pitchers and just plain **elderly people**.
- OA tend to get from over use. It is more about **actual injury** to the joints where rheumatoid is the **immune system attacking itself**.
- I am going in to have a cervical disc surgery. And that is probably osteo, I think the spine is more osteo than it is rheumatoid because I am now 60, 61
- Taking Prednisone may result in spinal stenoses?
- osteoporosis may be caused by the Prednisone and the arthritis.
- because I have taken large doses of Premarin and Calcium and all that forever and I drink lots of milk and stuff. I shouldn't have it (Osteoporosis) based on what they say.
- **the doctor couldn't decide at first between lupus and rheumatoid** and then based on everything I told him, he checked out my joints and so forth he determined. He put me on medication at first to see for sure what it was and since the medication helped, he just knew it was rheumatoid. Most people I guess it is shown by blood test but mine didn't, I was one of those strange people that didn't show...

Highlight of the Interview

- **The one thing about it that a lot of doctors and surgeons don't understand is the fact that it, I have had to fight with surgeons sometimes they want to do something that I know I can't do as a rheumatoid arthritic patient.** They wanted to pin my hip which means you can't stay off that whole leg for three months. I said I couldn't do that. I said my hands and arms will not be able to support me and it will make them worse if anything. So, I told them I had to replace it so they did. And my rheumatologist agreed with me.

Suggestions

I think RA patients should know about all the different things, about surgeries. need to see a rheumatologist number one and I think many internal medicine doctors try to handle it and they really don't know all of the ramifications. I have known a lot of people that I have tried to refer rheumatologists but with health plans it is hard sometimes to get referrals to the specialists.

Patient Profile

(Leo the Nuclear Submarine Caption, Tape #3)

Age: 51-60

Gender: male

Arthritis Type: Osteo

Why Visiting: I had total shoulder replacement surgery on aug 23, 2000, and the results have been nothing less than fantastic. I am scheduled to have my other shoulder done on dec. 11, 2000, and am interested in following your post surgical rehabilitation format that

Site Evaluation

- The descriptions of the surgical procedures were very detailed and excellent. I was very excited about this website. I found it entertaining to read. Of course there were many medical terms that I did not understand at first. It was written for the surgeons.
- What I like about it is how the medical procedures were explained. It is written by a very knowledgeable person. I found information here where I couldn't elsewhere. It's very, very well written.
- It made me feel **comfortable** about getting my surgery because I know exactly what is going on.
- I found the information provided in your exercise section is very similar to the therapy program I received in the North Carolina ... therapy center. Apparently, there's a lot of information sharing in the field of physical therapy.

Is there anything you did NOT like about the site? N: Not one a bit! I would recommend anybody with arthritis to check out this site. ... Go there first!

•

Results

- I also benefited from the exercise section and got hold of a CD of the exercise through the link which has a 800 number to call. I received the CD in four days
- So, do you think your knowledge may help you follow the instructions better or may be it better motivate you? N: I am not sure. It might help. I have always been very curious about new knowledge. I think it has something to do with the kind of person I am. I wanted to restore my health and wanted to be active. Now after these successful surgeries and remarkable progress of rehabilitation, pains are all gone. I felt like 18 again. I should have done this a long time ago.

Patient/Physician Relationship

- No, I didn't. I was very excited about my progress and I don't want to intimidate her. I don't want to make her feel inadequate about her professional knowledge.

N: She was absolutely impressed by my progress and wanted me to demonstrate to other patients....Maybe I will share this information with her in the future.

- First I got the list of the top 50 hospitals. I wanted a very, very good reputation. I checked on the successful rates and how often they perform the procedures. I called hospitals from California to Florida and everywhere. I talked to the staff members, but not the doctors themselves. When I finally got down to the five physicians... I was told by Dr. xx's staff that if they need a surgery on their shoulders, he would be the one they let him touch them.... I spent a lot of time in making sure I got the best. I asked him a hundred questions and spent one and half hours talking to him. He answered my questions.

Knowledge

- I have Osteoarthritis and it was diagnosed in 1984. Through x-ray. I had pains on my shoulders and they got worse and worse.
- I had microscopic surgery earlier but my doctor told me that my bones deteriorated to such a condition that it would not help.
- Other than shoulder pains I don't see Osteoarthritis affect my body in other way.
- Honestly, I don't know (what contributed to getting OA). I've asked at least 50 professionals. They couldn't tell me. One thing they mentioned was genetics. I might have the genes that made my bones more vulnerable... But none of my siblings has osteoarthritis. It might have been injuries, my deep sea diving, or too close to the nuclear sources.. or how I've used my body. ... I am what they call an overachiever. I always give 110% ,whether it be footballs, marine duties, diving...

K: So... can it be due to overuse?

N: I don't know. It can be one reason.

Highlight of the Interview

Since you asked, I'd tell you what I told my surgeon. He looked at my conditions and was amazed that I put up with the pains for so long. I told him only I knew how the pains have affected me. I changed to a different person. I could not do things I used to do and I became not approachable. It affected my relationship with the family. When he asked me which side I want it done first. I told him I didn't care. Just cut off any one of my arms to alleviate my pains.

Suggestions

- I would like to see diagrams explaining how you do the exercises.... Of course, you can throw in warnings like, do not perform these at home without first check with your doctors or therapists
- With the advancement in the plastic surgery maybe people shouldn't put up with their pains so long before getting a surgery that can stop their pains. And have a good attitude towards the situation.

Patient Profile

The Myth of Osteoporosis (Tape#4)

Age: 51-60

Gender: Female

Arthritis Type: Osteoarthritis

Time Diagnosed: one week

Why Visited: To check on the definition of Sjogren's Syndrome for a friend, and then to check on some things about Arthritis for myself, since I have been an Arthritis sufferer since 1976.

Site Evaluation

- I definitely will visit it again.
- The main thing I like about the whole idea is that like you say that it is there, that I can go look up things and maybe find someone that understands what I am going through. (...Just the group that you know that has the site, the people behind it are caring about helping you.)
- **...on the Arthritis Source, I feel like there is someone that I can ask questions and they will take time to answer it.**
-

Results

- I printed something out. I have a folder I keep it in.

Patient/Physician Relationship

- maybe find someone that understands what I am going through.... Because sometimes the doctors don't seem to grasp the idea of where you are coming from or what you need.
- specialists sometimes don't take enough time to explain really what is going on. The specialist I had that gave me the shots, he was just in and out very quickly. I didn't have time to ask any questions and I had to go three times for injections. So, when I went back I said hey explain more to me about this. You know, I want to know what is going on here and what you think this will do and how you think this will help me and so I just had to kind of keep him in there long enough to talk to him. ...Like on the Arthritis Source, I feel like there is someone that I can ask questions and they will take time to answer it.
- I told him [the doctor who gave me the Senvisk injection] that I was taking it [Glucosamine Condroion] and he said well it wouldn't hurt anything. He said there weren't any research studies on that, so there is no proof that it really helps the joints but it wouldn't hurt to take it. So when they say that kind of thing what is the use of taking it.
- I say on the second time I went back, I said I need to ask you some things. He did but he was always in such a big hurry like he didn't have time to stay in there very long.
- It just seems like I want more information than.. ...than he could give me.... I don't know.
-
-
-

Knowledge

- the stress of the whole thing (taking care of mom who's very ill) seems to make my arthritis worse.
- I have to prop my legs with pillows and things to try to get relief from pain.

- I have a body pillow I use that , I stretch it along my body and between my legs and then **I have another pillow that has a rounded edge on and I put that under my right knee that hurts the worst.**
- I was in the hospital for my back, which probably was arthritis then and just didn't know it. They showed me how to put a pillow between my legs and sleep on my side
- Osteoarthritis is hereditary. My mother has it really bad.
- The only thing I have ever thought of [other than heredity] is maybe I had 4 kids and I have often wondered if during pregnancy where the nutrients and things come from the mother's body if that drains your bones or something too much at times and takes too much away from you that **it causes a lack of calcium** that you need. I don't know, that was just a thought. Maybe I had a lack of calcium growing up I don't know. I did take calcium a lot but when I started having calcium deposits in my knees, I quit taking it. I thought well I am getting too much here, I had better quit. I didn't drink much milk. I liked milk but I didn't drink a lot...I drank too much soda pop. You know how kids are.
- I didn't have a structured diet as far as you know regular times to eat. My dad worked from 6:00 in the morning til 9:00 at night and we did not have regular meal times. We just ate whenever. I kind of think diet had something to do with it. I ate a lot of snack foods, snack food junky. I still am. You know you kind of whatever you grow up doing that is what you do.

(I don't even know where I got that idea from. K: Could it be you got mail campaign? I: It could be, could be.) I: Just an unfounded thing probably. You know how people get ideas. There was someone that said I should take calcium but I told them that I had calcium deposits and I didn't want to take any more.

- The orthopedic surgeon told me that I could have those injections once a year if they helped. And they did help a lot. They helped the pain quite a bit.
- I know there is no cartilage left in either knee.
- It just bothers me that I am going to have to have knee replacements. I don't want to have it done but people tell me if I wait too long then it is worse.

Highlight of the Interview

Suggestions

Patient Profile

Leo the foot solder (Tape#5)

Age: 51-60

Gender: Male

Arthritis Type: RA

Time Diagnosed: 1985

Why Visited:

1. was looking for a site that had something to do with arthritis and rheumatoid or arthritis.
2. Looking for pain relief remedies due to recent flare up

Site Evaluation

- it was mostly self-explanatory.
- It would tell you where to go next, who to contact and whatever, where to go to.
- I had no problem finding what I was looking for
- whoever thought it up or whoever thought up the site, it seems it was pretty well thought out
- That statistics ...I really don't think that is really necessary

Results

- Received physical therapy that was difficult to get
- Received more attention from the doctor
The exercise program they told me about it and they even scheduled me for some exercise programs for physical therapy.

I think I'm getting to be a pain in his case you know, he said Brunson that is you. Yes, why don't you come on if you think that you have a problem come on in and I can see if I can fit you in or whatever. But I think that that one thing might have helped quite a bit.

Patient/Physician Relationship

- I had intended to get some information because I was thinking that maybe because it was a veterans hospital that they kind of dragging behind as far as medication and whatever was concerned. the information that I got from this I took along with me to the rheumatologist.
- he stated that because of red tape and restraints and budgets and whatever that certain medications were not going to be available.
- I took all that stuff over there and he told me they were aware of a lot of these treatments it was their budget wasn't allowing them to get into this at the present.
-

Knowledge

- It is the bone that, the cushion I call it the cushion between the bone and tissue. And it is a deteriorating type situation.
- I thought it was just age
- and body fluids and whatever like calcium, certain vitamins that were in your diet during the time that you were growing up or a deficiency of these things.
- Calcium is a bone builder, it strengthens the bone or whatever.

- Lack of calcium, lack of potassium, certain things that maybe your body is deficient in, like cold in the bones or whatever.
- Cramps in the legs, in the hands.
- That is mainly the problem because if I am driving and all of a sudden my fingers feel like they are locking in place. You know like cramping in the joints and I noticed that when I started having these arthritis I call it arthritis attacks
- Inflammation.
- Harsh conditions areas, life experiences I guess I don't know, it is like different climates, different countries, I don't know. I really couldn't tell you

Highlight of the Interview

We discussed that (the printout) for about 10 minutes and he took the folder and he looked through it. He asked me could he hold on to it and he told me he would give it back to me at the end of the clinic session. (He photocopied it). He was aware of where I got the information from because up on top of the page it was printed out.

Suggestions

It might benefit if it was a situation where it was like a therapy type situation like some type of a session where we contact each other and explain the problems or whatever.

That might be a good idea like if you did a website where you can contact these people and they can contact you and you talk to them like I am talking to you. That might be a good idea.

Patient Profile

Pampered Lily (Tape#6)

Age: 51-60

Gender: Female

Arthritis Type: r.a.; fibro; sjogren's

Time Diagnosed: 10 years ago

Why Visited:

1. Recent diagnosis
2. Information about Fibro
3. Information about RA
4. Second opinion
5. Just recommendation on diet, exercise, medication, the whole rounded part of it.

Site Evaluation

- No new information on the site that was not already explained by her doctor
- Informative

Well, it was informative. I think it would help a lot of people if they didn't go to a specialist. I know that a lot of insurances will not pay for specialists, especially if they are in an HMO or whatever. And I have been lucky enough with...I work for Proctor & Gamble.

Results

Patient/Physician Relationship

- I want to be...I take a full 100% participation in my care. I don't think that doctors are gods. They are just help.
- She is very open to discuss anything that I bring to her.

Knowledge

- Sjogren's disease affects the glands in your mouth that produce the moisture and the glands in your eyes that produce the moisture and in a lot of the other openings in your body. It dries those up.
- My shoulders, and my arms and my hand refused to work it is as much a mental as it is a physical disease.
- have deterioration of all the major joints even with the up to date medications and therapies and eating programs and exercise programs
- Well they have proven that it is partly hereditary. 80% of it happened in women.
- some inherited genes are more prone to have it than others
- maybe virus has something to do with it

Highlight of the Interview

K: Okay. If the doctor has already explained it to you, why are you still looking?

I: I just wanted to see if there was anything...

K: Anything more.

I: Yes. The clinic that I go to is an experimental clinic, they work with the drug companies and most of the time they are on top of the newest things. But I was just checking to make sure, looking for a second opinion.

Suggestions

Just to keep it up to date. There was a lot of information there but like I said just go in whenever and keep it as up to date as they can keep it.

Patient Profile

Mary In Pain (Tape#7)

Age: 51-60

Gender: Female

Arthritis Type: Osteoarthritis and Rheumatoid

Time Diagnosed: 10 years

Why Visited:

Why Visiting

1. to learn more about the problem that I have with fatigue and arthritis
2. to try to find out what more possibly that I could do to help myself.
3. understand more about what may happen to me in the future.

Site Evaluation

- I found everything that I needed
- The search feature is very helpful
- The site went provides detail information
- It is there for me day or night.

I: Right, yes. I mean if something if a question comes up all I have to do is go to that website and it answers my question for me you know. It is there for me day or night.

It was very, very informative. It, I mean it really went into detail. It just didn't tell you what arthritis was I mean it went into lengthy detail you know telling me that different parts of the body, different joints and everything that can be affected you know by the arthritis. It was just very, very informative for me. It made me understand a lot.

Results

Go see a Rheumatologist

it caused me to go to a rheumatologist rather than just my medical doctor here because I knew from reading the information on the web that I needed to see somebody else. I needed to get with someone that could help me with my arthritis.

Patient/Physician Relationship

- he thought I need to be as informed about my condition as I can be

Knowledge

1. it is inflammation you know around the joints
2. one thing is the fatigue
3. My joints began to hurt. My shoulders, across my shoulders would hurt, my back, my knees, you know just terrible, terrible pain.
4. rheumatoid affects your joints and osteo actually attacks more of the bone, deteriorates the bone.

With rheumatoid you find that there is more inflammation, swelling and with the osteo it is just the bone is deteriorating away.

5. Osteo was diagnosed through the blood work too.

Highlight of the Interview

There wasn't anything I didn't like. No, I mean I was very, very pleased. Like I said it answered a lot of questions that I had and prompted me to go ahead and get you know seek attention now. I knew I needed...I had a suspicion. You know, I mean they told me that I had arthritis. I thought arthritis okay big deal. But then so many other things started happening and that is when I went to the website and like I said that prompted me to go on to get help with this arthritis before I become so crippled you know that I could not get around.

Suggestions

So just the only thing I can think of is just trying to find you know medications that are going to help people, so many people say Viox is better for them than Celebrex and some people say no Niproxin is better and I know they have come out with yet another now it is called Mobic. So just you know **keep doing what you are doing.**

Patient Profile

Lupus PhD (*Tape#8*)

Age: 31-40

Gender: Female

Arthritis Type: Lupus like condition

Time Diagnosed: 6- 7 months

Why Visited: I am seeking diagnosis and have felt left out on my own as many of my doctors have been reluctant to offer treatment (I am pregnant) or even testing.

Site Evaluation

- the site seemed pretty easy to use for people who are not familiar with the Internet.
- I did appreciate that you did have information on there that is more medically complex or more up to date with research than some of the sites.

So the most up to date information on the current research is really valuable. You can bring that into your doctor and talk about it.

Results

- it was because of your site partially that I found my doctor.

Patient/Physician Relationship

- If my doctor had more time to discuss things with me, I think it would be a wonderful benefit because there is a lot of good information out there.

I would rather use it as sort of a jumping off point and discuss things with my physician but they really don't have time to sit and discuss all the current research and what not with you but it is a good supplement to a visit to a doctor.

Knowledge

6. Arthritis conditions: excess snovial joint fluid, swelling, joint pain, bursitis and tendonitis.
7. basically my autoimmune system is having difficulty distinguishing self and non-self and so the immune system is attacking my own body, my connective tissues.
8. I have several factors genetic predisposition to autoimmune illness,
9. I also have a shared, this is a controversial issue, but shared tissue type with my husband and my symptoms and things became worse upon pregnancy. In fact, I wasn't really sick until I got pregnant.
10. And then I am sure that there were environmental factors. One of the theories is the exposure to a virus, even a common childhood cold or something can bring some of these things on.
- 11.

Highlight of the Interview

K: So you do feel that some kind of bulletin board and discussion group would enhance the Arthritis Source?

I: I think that would be very valuable to patients.

Suggestions

Patient education I think should be the primary goal and it is also very helpful to have support boards, if they wanted to add that to improve the site. Some kind of bulletin board posting or something, people find that helpful frequently to connect with other people who have the same problems.

Patient Profile

A female truck driver Sjorgren's Disease (Tape#9)

Age: 51-60

Gender: Female

Arthritis Type: RA

Why Visited: looking for information about sjorgren's syndrome and its relations ship to arthritis and sle

Site Evaluation

- It lets me know well the information on the Sjorgrin's disease , it lets me know more of what the symptoms are for that part of it as well as what the arthritis does.
- they gave enough information but they didn't over do it and draw it out for someone that didn't understand a lot of the medical terms like other sites might have had. Your actual the only one I visited because it had the information I wanted on it.
- It was easy to access and beneficial with information.
- if you go into the search mode for arthritis, that is one of the first ones up there. So you don't have to go all the way to the very bottom of the list to find information.

Results

- I did print outs the different types of arthritis mainly the diseases the types of arthritis and like the affects of them
- I did discuss them with one of my sisters cause one of the types was her Sjorgrin's.

Patient/Physician Relationship

Knowledge

- Sjorgin's disease, rheumatoid arthritis associated with lupus
- It affects the joints, not spontaneous but the same joints on one, just a form of arthritis that I know that I've got.
- When it flares I know that it hurts. Basically it is a stiffening
- **Too much calcium** can get there and that will also help cause it. **Too much calcium buildup will cause it.**
- **Genes** I guess. Some people get it and some don't. No. Babies can get it, old people can get it, middle age people can get. You can be born with it.
- some doctors diagnose it through blood tests, others see the patient's movements, blood work.
- A lot of time when the barometric **pressure goes up**, you will feel your joints will hurt a little bit more than other times when it is nice and warm outside.
- Moving to different places is not going to help it.
- when it is nice and warm and sunny outside, I don't hurt half as bad when it is going to rain.
- Do you think the climate has something to do with? I: I would almost say yes but some people will say no.

Highlight of the Interview

Suggestions

Patient Profile

Rubecca running out of time (Tape#10)

Age: 41-50

Gender: Female

Arthritis Type: Osteo

Why Visited:

- Pain, stiffness and inflammation, alternative medicine
- To look up info on medications and other things.
- Just trying to find out a lot information about it what you can take like for the pain and not have to take so many prescription medications and just stuff like that. Yeah, about pain relief and inflammation.

Site Evaluation

- There is a lot on there about arthritis. Anything you want to know.

Reason

Results

- I read so much about it, I don't remember you know a lot of what I do read about it. There is not a lot I know you can do for it just take the medications and stuff for it.

I am going to ask about the natural supplements to take along with the prescription.

Patient/Physician Relationship

- I just have a regular medical doctor I go to for arthritis and I have also been to an orthopedic doctor for arthritis before too. I have had surgery on my right knee.

Knowledge

- I guess the osteoarthritis and the rheumatoid arthritis is the two mainly.
- And I think isn't Lupus a form of arthritis?
- I think certain foods worsen it. They say if you eat a lot of meat that that worsens arthritis.
- I: Most people have arthritis, not many people that don't have it from what I read about
- I think it is just inflammation of the joints and swelling of the joints. I don't think it is the crippling kind. I know rheumatoid is but I think the osteo is just the inflammation and pain of the joints.
- And it seems like when it is really cold weather or really rainy it is hard to get going sometimes. That makes the pain worse.
- I: It just makes like a swelling stuff on the knee joints and just pain and stiffness.
- : I don't know why it makes your knee pop, but it makes mine pop.
- No, I just figure people...some people are just prone to get arthritis and some aren't.
- I would saw overuse of the knee joints and injury could cause arthritis to set up in a joint. I have heard that,

Highlight of the Interview

Well, I am running out of time. I am going to have to go.

Suggestions

Patient Profile

A distracted Mom (Tape#11)

Age: 18-30

Gender: Female

Arthritis Type: Osteoarthritis

Time Diagnosed: today

Why Visited:

1. Recent diagnosis
2. *To see the causes of arthritis and what is about it*
3. Pain management

Site Evaluation

- This is very helpful information for me.

I mean it has a lot of information... (to the extent that she did not remember any of it)

Results

Patient/Physician Relationship

Knowledge

- Osteoarthritis can be caused by torn ligament.
- A weak muscle and damaged bone tissues can contribute to getting osteoarthritis
- It causes inflammation in the tissue on the joints.
- The affected areas become weak and sometimes require braces.
- Lots of pain!
- Bicycling can strengthen the muscles and is good for osteoarthritis in the knee.

Highlight of the Interview

I'm sorry, the kids... I don't know is there another time that I can be called because

I'm having a hard time right now?

Suggestions

Patient Profile

An anti-drug grandmom who may have cancer (Tape#12)

Age: 71-80

Gender: Female

Arthritis Type: Rheumatoid Arthritis / (may be osteo... not sure anymore...)

Time Diagnosed: 22 years ago

Why Visited:

Why Visiting

Looking for the most updated information on Sjogren's to keep myself, as well as my dentist & physicians, informed of the latest possible help.

1. Looking for updates on Sjogren's Syndrome.
2. Just to gain more information on what the newest on arthritis treatment. (exercises)

Site Evaluation

Grandmom did not remember much about her visit to the site. All she remembered was she did not find exercise as a treatment for arthritis.

No I mean as a treatment for [arthritis], I think it might have mentioned that exercise was good but that was about as specific as it get.

...

You know what I should do is go back on that site and be thinking about this and be able to answer it because it was quite awhile ago that I went on that site.

Results

- Grandmom will visit the site again and correspond by email. She does not answer phone calls without caller ID.

Patient/Physician Relationship

.

Knowledge

- Rheumatoid arthritis entails destruction of the connective tissue in my hands..
- **Arthritis in general is caused by wear and tear. It's a natural process of getting old.**

Highlight of the Interview

It is a site that you are just going to be giving information to patients or to interested people. You can't really recommend medical advice I'm sure. You would probably be stepping on somebody's toes.

Suggestions

Grandmom became interested when she heard Dr. Matsen is collecting questions from the patients...*Possibly an email addition to that would be...*

Patient Profile

Able, I'll paint pigment on the spot if it helps... (Tape#13)

Age: 51-60

Gender: male

Type: RA

Why Visiting

Have been taking viox with no results still suffering much pain. Hard to sleep, hard to come to work every day.

Site Evaluation

- It was easy. It was an easy site to map out, the way it is mapped out. It is easy to go from one subject and you know you are interested in something else and it takes you pretty much right to it. I've been to some websites of others that you can't find anything, very difficult to use. Very user friendly is the main thing.
- Yes the way it is structured, it is very easy to find what you need. Or like I say if you find one thing and you think well I need a little bit more information is there more and you know you were able to find it real fast.
- Links or everything else. It was very good. I liked that
- You find some like that everything seems to be just right and you have no problems with them and you don't get lost in them.
- I have been there like 2 or 3 times just to kind of follow up on some of the information that I found on there.
-

Results

- What I need to do now would probably be to talk to my physician about that and see if I can schedule some other tests.
- The different types of arthritis that there are and the symptoms that I am feeling or that I have and found a definition that meshed more to what I have than what I think the doctor says I have.

Patient/Physician Relationship

- I don't feel that my personal physician has actually defined what type of arthritis I have..
- The doctor has told me that I have rheumatoid arthritis but it doesn't feel like it to me from what I have read up on the subject. It feels a little different to me. It feels more of a muscle than a bone thing and I believe that is the type of symptom that that is.
- X-rays and they asked me to lift my arm up a little bit and I had a little trouble lifting it. He said well then you have rheumatoid arthritis.
- doctor in about two weeks and I am going to bring that up to him.
- I mean I realize some doctors probably don't like you to try to self-analyze yourself or self-diagnose yourself I mean.
- I think I need to do that. I have known the doctor for quite some time and I don't think I will have too much of a problem. I'm sure if I request additional testing to verify or whatever, I don't think he will deny it or anything like that. The doctor I have is an HMO type doctor and they are kind of hard to get tests from them sometimes.

- I haven't seen an arthritis specialist at all or a pain specialist or anything like that, although I have told my doctor for the past I guess year and a half that my pain has been increasing and the last time I saw him I told him the pain was definitely almost debilitating at times.
- I said dealing with a HMO doctor, he literally has to take you through all the cheapest stuff before he takes you to the better ones
- to find out as much information as they...The only danger of that is you start self-diagnosing and you go to the wrong end. You know like what I say what I feel and what I think I may have, I feel more comfortable going to my doctor and saying this is how I've been feeling. I have been on the Internet and been looking up you know arthritis and I think this is more like the symptoms I have are more in line with that and we would go from there with him. I'm sure you are not going to ignore me and say oh no you are crazy I know what you have, especially when I tell him that the medication I have been taking has not really being the job or anything like. Like I said I have known this doctor for quite a few years, so I don't think I will have too much of a problem with that.

Knowledge

- I don't recall doing any blood tests. (patient was diagnosed with RA)
- Could you describe what is happening inside your body with the rheumatoid arthritis condition?

I: I can tell you, I will describe it like from the beginning when I first started. Of all things, I was playing golf and I felt just a little twinge, just ever so slight just enough to throw my game off. I didn't worry too much about it. A few weeks later I noticed it was just a little bit more than a twinge and you know like anybody I put some BenGay on it took some pills and it seemed like it was okay. It seemed like for a couple of months there was really no problem and then all of a sudden I felt more than a twinge again, it came back a little stronger. From that point on, is when I noticed that I was really having problems with it. It wasn't a really strong pain or anything like that, it wasn't like a like a stabbing pain or anything but I could feel there was something not quite right.

- K: Okay could you tell me how the rheumatoid arthritis affects your body? I: It changed my golf swing that is the worst thing it did. Lost about 20 yards there but I can still play and enjoy it. So I mean it hasn't really killed it but...
- . It is possible that even playing golf could have caused it
- it does traumatize your shoulders and wrists and type of thing, the upper part of your body and your back also.
- I notice when I play it kind of relieves it. I guess doing the exercises and going through the motion it tends to relieve the pain somewhat. I feel better after I play. My wife doesn't believe that but it is true. She looks at me and goes you are a liar.
- No I don't recall him giving me a blood test for anything for arthritis. I will have to ask him the next time I see him if he did. But I don't remember.
-

Highlight of the Interview

I have tried all of the different ointments that you can think of you know. As I have often said I would put pigment around if I thought that would work but...people laugh at me. Well it is just that you get so desperate when you are in pain. You are almost willing to try anything. You know if somebody tells you that will work, put motor oil on your arm it will work you will do it. It is people that don't experience the pain that don't know what it is like.

Suggestion

Hmm. I don't know about the only thing you could probably have would be an online doctor that would talk to you. One that you could email and say this is what I am feeling, this is what is going on, these are my tests. That would be about the only way you could improve it really. But that would be asking too much there. They do it for Viagra, men that need Viagra they call up a doctor these are my symptoms and what I have and 99% of the time from what I hear they prescribe it for you. And that is a much more dangerous drug than for arthritis.

Patient Profile

Shanta, the young female RA patient (Tape#14)

Age: 25

Gender: female

Arthritis Type: Rheumatoid Arthritis

Why Visited:

Why Visiting: I am 25 yrs old. I have rheumatoid arthritis and am planning on getting pregnant.

Site Evaluation

Actually you know I don't think I really came across that I hadn't already...that I hadn't already read before.

Well I have rheumatoid arthritis but it is not to a point where I would consider surgery at this point. Okay, so you didn't look at the other? No, I didn't.

I: No I just looked under the rheumatoid.

Well it was good for me to know that that was out there. Not that I, really when I was on there I wasn't really taking my time to research too deeply but.

What did you like about, oh the benefit to your visit to the Arthritis Source is knowing that it is there, available and that you can find it whenever you need it.

I: Right.

K: What did you like about this site?

I: Well just knowing that it was there basically. Knowing that I could go there and see check on any information that I might have a question about or concern that I could find that site and go to it.

K: So I want to paraphrase you, basically what I understand what I heard you say was you didn't necessarily remember all of the information you looked up and you look at certain information that you have in mind and nothing was really new to you but you still liked this site because it is available, it is there and I can go back to it whenever you need.

I: Uh-huh yeah. That's right.
the way you benefit from it was again the knowledge that it is there.

I: Exactly.

: ...asking you to list questions that you have about your condition.

I: Oh wow.

And when we are done with this project, I will send you the questions other patients have and the answers the specialists give back...

I: Oh wow that would be really nice.

Results

Patient/Physician Relationship

- Well actually when I first found that I had arthritis, I had a rheumatologist and my husband is in the Navy. So when we moved here I have a totally different doctor and I just feel that he is more of a family practice type not too educated on the arthritis side. So there are a lot of times when I

don't feel that he really has the answers. He just gives me general answers. That is why I was going online to see if there was anything on there. But.

- K: Okay. Now how do you feel about discussing it with him?

I: I feel comfortable I just don't feel like...

K: There is a need yet?

I: Right.

- I guess for one instance, my rheumatologist would give me shots of Cortisone in my hands instead of prescribing me more medication. And I feel like when I go to this doctor, that is all he does. He just gives me more medication instead of other options and I don't like part. But so that was one reason I was going online just to see if there were any like exercise or diet as opposed to more medicine.

Knowledge

Could you tell me what you think rheumatoid arthritis is.

I: Well I can tell you how it makes me feel. It basically makes my joints well terribly, some days better than others and I get flare-ups and some part so my hands, my knees, my feet, any joints really. But all I know it can deteriorate your joints and then it attacks your joints and your bones. That is about it.

•

Could you describe what is happening inside your body?

I: No.

K: Okay.

I: No you think I would be to?

K: This is standard questions that we ask everybody.

Okay, it is kind of hard when you think about it because I am used to being told. It is hard to just say...

- Well my father has rheumatoid arthritis and I have been told that it is not hereditary but you know I can't help but think maybe there is some kind of hereditary part of it . But yeah he has it also, so I don't know. I would think maybe stress, I really don't know
- I: I know with myself it was diagnosed through blood work.
-

Highlight of the Interview

Well, I am running out of time. I am going to have to go.

Suggestions

Patient Profile

The frustrated Marion (Tape #15)

Age: 61-70
 Gender: male
 Arthritis Type: PMR

Why Visited: Well when you came down with this, I was desperate. So I just put in PMR arthritis and I got onto a site and I wandered from there to there. I found all the sites very inadequate. I felt like, I was in so much pain so angry. I would like to put my fist through the computer. And it would have been hard work to do that. Frustration was my feeling.

. It is not enough just take your Prednisone, go home, walk, garden which you can't do anyhow and carry on with your life but it is not enough. I wanted more.

. So what you were looking for was more than just information about PMR. You also want to know how people cope with it maybe?

I: Yes, yes. How other people have survived.

what is happening to your body? Why is it like this? What can you do? People like to know, well I like to know even if you have to hang upside down. I know I sound crazy.

Site Evaluation

I: It gave me the basics and that but that was it. (PMR)

Reason

Results

Patient/Physician Relationship

- Find out information, what other people had done to help this because I was so alone. Even my doctor said nothing.
- It is just a very painful condition. And the only...my medical doctor says that Prednisone is the only thing and I really feel that he had to go research it to find out what I had. Because it took him a month before he told me and put me on Prednisone.

Knowledge

- Does it just miraculously go away? Do I wake up one morning and I can bounce out of bed again? (PMR)
- Polimitus Rheumatica (sp?) Arthritis, I think that is what it is. My mind has gone in the last year. It is a form of arthritis that affects all the openings in the trunk of your body, your legs, your arms and your neck. It makes it difficult, you can't turn your...you can do it with excruciating pain turn your head, move your arms. It was hard work to comb my hair. But I am stubborn. Oh another thing, my hair is falling out

Highlight of the Interview

Suggestions

Well I think information and if there is anyone you could discuss it with or say I am doing this, what else can I do, it is not working. And just information really.

I would like to ask questions and get decent answers to them.

Patient Profile

The Hawaiian based military officer, Phil Navin (Tape#16)

Age: 41-50

Gender: Male

Arthritis Type: Osteoarthritis

Time Diagnosed: 1972

Why Visited:

1. To seek second opinion and information about the surgical procedure and post operation rehabilitation while waiting for a complete left shoulder arthroplasty.
2. To find out other patients' experiences.

Site Evaluation

- Very Informative
- Like the simple shoulder test
- Like the drawings
- Couldn't find anything about other patients' experiences on your website.

"Probably one of the best sources as far as information on shoulder pain and the actual surgery that was going to take place." (visited 5-10 other websites); love the simple shoulder test "which gave me some pretty good clues that this probably was my only course of action was the arthroplasty."

"more pictures more drawings that people can click on to kind of show them what may be going on within their ..and show them what is happening... your site was pretty good".

Results

- Better informed patient
- Reduced anxiety level

Patient/Physician Relationship

- When a patient became better informed, he did not threaten his physician
12. Doctors' don't understand patients' needs

The doctor can sit there and say you have this and this wrong with you and yes this is what you are going to need but the physician never experiences or rarely ever experiences the actual surgery he is performing.

Knowledge

13. Osteoarthritis entails degeneration of bony area and inflammation in the joints.
14. Bone spurs may develop due to the degeneration which may in turns flake off other parts of the cartilage.
15. It may be caused by earlier injury
16. Patients will experience pain, have limited range of motion. Certain activities will cause arthritis patients greater pain and inflammation.

Highlight of the Interview

P: So you are going to send me my airline tickets to go to Seattle and my \$1,000 per minute for talking right?

Suggestions

Provide a mean for patients to share information that is critical to them.

K: So you would be willing to be put on our mailing list or phone contact on the website for other patients to contact you? Is that what you are saying?

P: "Oh sure, sure, sure."

P: "some kind of patient surveys, descriptions, narratives, discussions, what they experienced prior to surgery and certain post-surgery as far as rehab treatment, pain those kinds of things. Those are really critical I think to any patient before they go into a major surgery. All those are important things that I think the patient needs to know but I couldn't find any of that stuff on your site."

Patient Profile

Newman, the concerned father...(Tape #17)

Age: 31-40

Gender: male

Arthritis Type: Rheuarthrospondylopathy

Why Visiting

I am HLA B27 positive and wanted to find additional information on ankylosing spondylitis

Site Evaluation

- Well it gives me a better understanding of the disease in general you know what causes it.
- Did not find what he was looking for
- it was written well. It was easy to understand. It wasn't in, you know it was in lay terms so I could understand it. It was you know easy to access the information.
- In terms of the lay out? I: Exactly, exactly. I didn't have any problems. I know that I have been on some sites where you know it is very difficult, it is not very user friendly. I found this to be user friendly.
- When you said user friendly you mean easy to follow? I: Easy to follow yeah not a difficult page. Doesn't have all those pop up windows. I hate pop up windows. I was very happy that it didn't have pop up windows.
- What did you not like about this site? I: Uh I can't think of anything off the top of my head. K: Other than it didn't answer your questions. I: Well yeah the specific information that I was looking for I was not able to find.
- if there was some kind of... K: Patient discussion. I: Right that was connected with the site that would be great. K: If it is not offered by this site but it has links to other bulletin board or sites that people discuss their conditions or sharing their experience, that can be helpful? I: Absolutely, absolutely. There are you know people that are experiencing the same thing are very helpful to learn from.
-

Reason

Results

Patient/Physician Relationship

Knowledge

- Well I know it is an autoimmune disease and then my particular case it is the HLAB27 is some kind of genetic marker and that makes me more likely to come down with ankolos (sp?) and spondolotis (sp?) or other different types of rheumatic diseases.
- basically just a joint deterioration in my spine caused by autoimmune
- I've never had an injury to my spine which would cause me to have arthritis.
- They have done bone density scans and found that you know my bone density is fine. So it is not like an osteo arthritis.

- Well yeah I know people that have had an osteo arthritis where they have had low bone density in their spine and that is caused, that is a contributing factor to them having arthritis in their spine
- Osteoarthritis I do believe yeah, or osteoporosis. K: Do you think they are the same? I: I think so.
- Well I've got degeneration in my spine that is quite painful. My spine gets quite stiff. Then I have got in my I think they are called sacroiliac joints, I get a lot of inflammation in there and that is quite painful. I also suffer from iritis and that is no picnic either. I found that in the last probably last couple of years I have had increased muscle pain you know just weird muscle pain like in the chest and in different spots in my back that I can't pin down that I was actually doing a physical activity that would have you know that would have actually caused that pain. That is pretty much how I am affected.
- Well what I have seen on the x-rays it just looks like I have got bone spurs and that is pretty much from the middle of my back all the way to about the base of my neck and so it just looks like on each side on the x-ray on each side there is little parts where they are not flattened square like in the base of my spine. from how I understand it, it is the inflammation around the vertebrae that causes it.
- (calcium deposit) That is kind of what I expected because from how I understand how arthritis works is you get the inflammation and then the body tries to heal or tries to fight that inflammation and then that is how you get the calcium deposits on the joints but that it not what I saw. But I could be wrong. I don't have the trained eye.
- I: Based on a blood test yeah.
-
-

Highlight of the Interview

Well, I am running out of time. I am going to have to go.

Suggestions

- I think that very helpful information would be you know suggested exercise plans.
- What kind of eating habits
- diet basically stressing diet and exercise and trying to stay mobile. I think that people should...again
- I think for some people support groups information about support groups are probably be very valuable. I mean me I have my family but a lot of people may not have that. It is not an easy thing psychologically.
- Maybe information on you know like with my particular condition they say it can affect the ribs and the expansion of the chest that you should not smoke if you have an_____sponditis.
- Say maybe a link to the American Heart Association or a link to a smoking cessation site or something like that.

Patient Profile

Renee "What's the white stuff in the X-ray?" (Tape #18)

Age: 18-36

Gender: female

Arthritis Type: anklosing spondilitis hypermobility joint syndrome

Why Visited:

- To see if there was any other anything, any other recommendations as far as exercises, vitamins or things that they recommended

Site Evaluation

- Did you find your answer? I: A few not all. Basically every website that I visited basically said that there was no treatment other than treating the symptoms, no preventative treatment.
- Okay, so when you said that you didn't get all your information you mean that they don't have a solution for you in terms of how to treat this disease.
- They had a pretty good kind of like an encyclopedia of medicine that in people with normal terms can understand.
- They had a pretty good kind of like an encyclopedia of medicine that in people with normal terms can understand.
- On the printable information when you go to print something out there was a lot of things, when you go to look it up from the main page and then you would go to print it out. I would end up getting the same thing more than once. And I don't know if that was my mistake or if that you know not just user friendly as being able to print things off. I don't know if it is more to just browse and read or the printable version and the readable version are different.
-

Results

- Being able to print off the information and read over it and then explain it to my husband and we sat down and read over it together. It kind of gave us an idea of the two different things that we were dealing with or possibilities.

Patient/Physician Relationship

- Just information on what the doctor had told me. Uh-huh the pamphlet that they give out at the doctor's office wasn't very descriptive and by looking it up on the Internet I did find more information on it.
- Yeah definitions, descriptions and other various outcomes.
- I had a clearer understanding of what the doctor had told me. When you go in and see the doctor, they go through everything so fast because you are in a time slot and with being able to look at it on the Internet I printed it off. I was able to sit down and read it at my own pace.
- when you go see the doctor they are basically telling you in their words and their words broke down to your words aren't the same.
- Basically when I went into the specialist he has told me that you know I have symptoms of ankylosing spondylitis, I have symptoms of sacralitis (sp?) and he won't put an actual name on it. So I just pulled information from the website for the things that he told me that I had the

symptoms of. It has been a 6-7 month process now but they won't actually give me an actual diagnosis.

- Did you have a chance to ask them or you were concerned that they didn't have time to explain things to you? I: No because I visit with his nurse quite a bit afterwards and she is able to answer most of my questions.
- It was after my first visit that you know he had told me that I have different symptoms of different things and that he wasn't comfortable with actually giving me a diagnosis yet and we were going to try a couple different medicines before. So I just went to the website and looked up some of the things that he had told me and talked to me about. And gave me the brochures on because he told me that the Internet had really good sites to look at and find you know better definitions than what the little leaflets or pamphlets they gave out at the doctor's office are.
- K: Oh so your doctor suggested you check, surf the Internet and look for definitions? I: Uh-hmm. And you didn't go back to him and tell him what you found? I: I really haven't had a chance to do that because the stuff that I printed off was for the ankylosing spondylitis and he is leaning more toward the sacriolitis. And I haven't done any looking on that one.
-

Knowledge

- Ankylosing spondylitis. Degenerative disc disease.
- They did a lot of blood work and a lot of x-rays and a lot of cat scans and things like that.
- My low back. K: Is it pain or stiffness? I: I have pain, I have stiffness, I have major fatigue. Pick one.
- Umm basically any overuse of any particular joint, I suffer 3, 4, 5 days afterwards my ankles, my wrists and my fingers and my low back hurt continually.
- Rheumatoid affects one certain joint at any particular time, not necessarily at the same time and osteoarthritis is the Calcium builds up in your joints I believe.
- I do know that I have benign joint hypermobility syndrome and which is where your elasticity deteriorates in your ligaments and tendons and so forth and that causes extra wear and tear on the joints. And I have it very bad in my fingers and the knuckles go the opposite direction than they are supposed to, they have a lot of bright white spots around them. They are the ones that tend to swell the most and my wrists pop real bad. the spot where they usually hurt or where they pop when I move my hand back and forth that is where these bright white spots are in the x-rays and I am curious what those are.
-

Highlight of the Interview

- Well there are millions of people in the world that have arthritis. If there was a way that they could say you know this helps for them or this helped for a different individual and be able to relay it onto to someone else. You know word of mouth...travel by Internet.
- The best thing that I have found in the whole entire world is to when you make really, really hot dish water to wash dishes and the lubricant that is in dishwashing detergent if you will put your hands in that just as hot as you can stand and run your fingers through the water and back and forth through the soap it is the most, it is basically the most I don't know it is a tremendous feeling when your hands hurt that bad.

Suggestions

- so you have some confusion about which page get print out? I: Exactly. Because in what you see as far as the version that you read and the version that you print you feel like you missed something in between and I went back and forth to try to get everything

- : Exercises that they use, I mean anything for relief of pain besides just medicine. You know anything that anybody finds works. I have heard anything from the paraffin bath to the heat to the ice and you know different things like that for people that have it real bad in their hands because my joints and my knuckles and my fingers swell tremendously. It is just extremely painful to where you can't pick anything up, you can't brush your hair,
- So anything for those wonderful moments when you are at your last resort and don't know what to do. Helpful hints I guess you would call it.
- Well there are millions of people in the world that have arthritis. If there was a way that they could say you know this helps for them or this helped for a different individual and be able to relay it onto to someone else. You know word of mouth...travel by Internet.
- The best thing that I have found in the whole entire world is to when you make really, really hot dish water to wash dishes and the lubricant that is in dishwashing detergent if you will put your hands in that just as hot as you can stand and run your fingers through the water and back and forth through the soap it is the most, it is basically the most I don't know it is a tremendous feeling when your hands hurt that bad. I don't know how to explain it. I really don't know how to explain it but that is the most comforting there is the word I am looking for. It is past my bedtime. . But any comforting help or hints you know that someone could pass on to someone else because it took me forever to figure out that just dishwashing soap and hot water was just such a... Who would ever think of it. Right. I: Exactly.

Patient Profile

4/2/01 Gregory the crisis center director (Tape #19)

Age: 51-60
 Gender: Female
 Arthritis Type: Sjogrens

Why Visited: To find information on Sjogrens

- What it was was we finally got a computer and I just sat down and looked things up that I wanted to look up. So that is how I found the Arthritis sites
- I was looking up information on Sjogren's syndrome.

Site Evaluation

: Since I am new on the computer probably yes.
 : Okay good. What did you like about this site?

I: I don't think I was looking to like anything at all. I was just looking for information.

K: Okay is there anything that you like about it?

I: I don't remember.

K: Okay is there anything that you did not like about it? Was there anything that bother you or something that?

I: I think that some of the information was of a higher tech that a doctor could read through better than as lay person. I am not a complete lay person. I am an EMT so I do have medical training. But I felt that if the information could be made in such a manner that it was regular people friendly as being one part and then the second part being doctor friendly. That would make it easier for people who have no medical background to understand.

K: So you are suggesting that to provide two tiers type of information one for more regular people and one for people with a medical background.

I: Correct.

So for you yourself it wasn't, the information was conveyed in clear enough manner for you then?

I: Right.

K: You were just concerned that people without any medical information would not be able to understand it thoroughly.

I: I think it would be harder for them yes.

Results

: I know that I copied off their stuff that I have kept to read and have kept copies to send to family members.

Patient/Physician Relationship

How about with your doctors, do you or health care provider did you talk about, did you discuss the information you find you find?

: Yes.

K: Did that help?

I: Help him or me?

K: Either way.

I: I know that he was also doing the same thing as I was and so just exchanged what websites we saw, we found things.

: Okay so he was not visiting the same site then?

I: He could have been but I don't know.

K: Okay, how did you feel about discussing information that got from the website with your doctor?

I: Fine.

K: It is okay?

I: Uh-huh.

K: And this discussion exchange of information did it help in any way? You asked whether to him or to you. Is it beneficial, is it helpful to you?

I: It was because it was a new disease thing and nothing of and so it gave me the ability to find information out and then to proceed to find more information out. I don't believe in being the last person to know what is going on.

: How about your doctor, do you think that it is beneficial to him that he know more?

I: I don't know.

K: You don't know.

I: I don't know because he is looking up stuff on it as well cause we both laughed about how much time we were spending on our computers trying to find more information about it.

K: So did he encourage you to continue to do that or what was his opinion about you as a patient finding, spending so much time finding out information on the website?

I: Oh, he had no problem at all. Matter of fact he gave me some new sites and he is a family physician and the rheumatologist that I was seeing also gave me different sites to look into.

K: So for both physicians and patients you all thought that visiting a website is helpful?

I: Correct.

The hardest thing with a disease like Sjogren's syndrome and Fibromyalgia is to get medical people who believe in what you are saying.

You go to the doctor and tell him these are my symptoms you know and they look at you and say oh honey you will be okay, you are just a little stressed out.

K: Okay.

I: I can remember saying to the doctor bullshit, I am not stressed out. That to me is the most important piece is finding a physician who understands and accepts these submedical problems that come from the essence of arthritis family. And that is real important because you do at times think you are going crazy. It is a real unfair, it is very hard on you mentally.

Knowledge

: I don't think that people know that there are many aspects of arthritis, that arthritis is arthritis. And that is how I felt too until suddenly other diseases that I am finding are in the arthritis family are becoming part of my life. So that you think when someone says that I have got arthritis you normally think of as crunching bones and joints and stuff like that. Whereas, there are actually other diseases within the arthritis family that someone can be suffering with on top of their arthritis.

Sjogren's is a disease that won't kill you but will make your life miserable. It is an autoimmune disease that causes lots of pain.

K: Could you tell me how Sjogren's disease affect your body?

I: Oh I can tell you lots because I just got out of the hospital on my way to Mayo Clinic. It dries out my whole system. It has caused pradeditis (sp?) where there is swelling in the pardited (sp?) gland area where I have developed pretty bad scar tissue where they might have to do surgery to remove some of the scar tissue. It makes it very hard for me to sleep. It causes severe fatigue. It dries out my mouth and my ears and my eyes.

K: How does, can you describe what is happening inside your body? Have you envisioned what is going on there?

I: Well when your eyes dry out, it causes your vision to change.

: It is diagnosed through blood tests, a lip biopsy and the fact of the dryness in the body are some of the ways that it is diagnosed. And also just the explanation from the patient as to what they are going through.

.

Highlight of the Interview

because he is looking up stuff on it as well cause we both laughed about how much time we were spending on our computers trying to find more information about it.

K: So did he encourage you to continue to do that or what was his opinion about you as a patient finding, spending so much time finding out information on the website?

I: Oh, he had no problem at all. Matter of fact he gave me some new sites and he is a family physician and the rheumatologist that I was seeing also gave me different sites to look into.

K: So for both physicians and patients you all thought that visiting a website is helpful?

I: Correct.

I can remember saying to the doctor bullshit, I am not stressed out. That to me is the most important piece is finding a physician who understands and accepts these submedical problems that come from the essence of arthritis family. And that is real important because you do at times think you are going crazy. It is a real unfair, it is very hard on you mentally.

How do I deal with it? You are going to laugh when I tell you what I do in life.

I am in charge of a crisis intervention. How I emotionally deal with it is that I have very good friends that I talk too. And since I am in the social work line of work, they are mostly social workers and therapists and counselors and stuff like that. So I always reach out. ... Support group in our community.

Suggestions

if you were drawing a chart and you would have the word arthritis on the top and then underneath it you would draw a connecting line and on that connecting line you would have the names of diseases that are directly tied to the arthritis. Like the Sjogren's syndrome I have goes back to arthritis. Fibromyalgia are the two that I can think of but I know there is more than that that go back to the arthritis family.

Patient Profile

Frank the volunteer (Tape #20)

Age: 71-80

Gender: male

Arthritis Type: Osteoarthritis

Information found: yes

Why Visited: Yeah I've made God it must be a dozen or so by now. Normally when I go to the Arthritis Source, I am looking for information to give to other people, people who call on the help line.

Site Evaluation

- And sometimes your information is almost the same as the Arthritis Foundation's information but on several occasions I have found things that were very valuable on your site that did not exist on our site, that is the arthritis.org.
- Do you remember in what instances where Arthritis Source provided more information than? I: Well the exercise videos I think are really good.
- K: Are there other things that you can think of? I: Well there was one or two technical types of arthritis or something that we found on your site that we did not have.
- Oh, I think the site itself is very well done technically, it is easy to navigate. It is very intuitive. it is easy to find what you want to find.
- Well there were a couple of times when we had questions about some rare type of arthritis that we used the search engine because we knew we weren't going to find it under types of arthritis. But normally I just click on types of arthritis and then whichever one I want is there.
- I think it (videotape) is very valuable for people with arthritis who have access to the Internet.
- I have the URL up above my desk at the Arthritis Foundation and almost every call I ask the person if they are online. And if they say yes, I give them your URL. And tell them that is a good source for information.
-

Results

Patient/Physician Relationship

I didn't access it hardly at all for myself, I am an old-fashioned guy and I don't want to want to know everything. I want my doctor and my nurse to know everything. When I was having my first hip joint after the doctor agreed we are going to do it in two weeks you know or whatever. He said now there are some things I have to warn you about and I said doc do you have to warn me about or do you have to offer. He said I have to offer. I said I don't want to know about any trouble. I said all I want to hear you say is everything is going to be all right Frank and Dr. ____ looked at me and smiled and said everything is going to be all right Frank. That was that. I don't like all these side affect warnings, they scare people. Okay there is a suggestion if you can get something strong on that site educating people that most of these side affects only occur to 3% or 6% or 8% of the people affected. Because there are so many people that read that list of side affects and then they don't want to take their medicine. And they call us and they say I am afraid to take the medicine that the doctor prescribed and I don't think that is good.

Knowledge

- osteoarthritis is when you have warn out or abused damaged your joints.

- Well it generally it is the loss of collagen in the joint and eventually the bone is touching bone, it makes you stiff, makes you pain and if it goes on unchecked or untreated why you can have a joint just freeze up, can't move it. Your fingers...I am starting to notice it now.
- : Could you describe what is happening inside your body then?

I: Describe what?

K: Describe what is happening inside your body.

I: Well no not really I guess but the joint has been injured or has been worn out and I think there are some people who are genetically disposed to it and other people who have collagen that is like iron. My father used his joints, his legs, his feet much more than I did in my life and he never had any arthritis. But I started having arthritis when I was fairly young.

- Yeah I don't mean like the hereditary diseases or anything I think some of us like teeth, I have soft teeth. My mother had soft teeth. My dad had very hard teeth. So I am not thinking of it as a genetic defect really but just some people are different you know.
- Of course we have like the carpal tunnel syndrome from the repetitive motion. As I sit here playing solitaire at my computer, I am contributing to that in my hands.

K: So repeated use, over use or worn out or damaged those are things will contribute to getting osteoarthritis?

I: That is what I read and hear.
How do I think it is diagnosed?

K: Yes.

I: Well I would say it is pretty obvious the person has pain perhaps swelling, inflammation and the question for the doctor is – is it osteo or it is rheumatoid or one of the other autoimmune problem diseases because that is the big trouble the autoimmune. If you have that why, that is you know much worse than osteo. Or I should say it can be much worse than osteo.

K: Okay what tests do they use to, are there any tests that they use to diagnose osteoarthritis?

I: I don't there are but I don't know. X-rays is the biggest way. There are tests for rheumatoid that are good indicators but I don't even think they are proof. The SID rate tests and such things.

•

Highlight of the Interview

If they are online your site is wonderful. But if they don't have a computer, then they need me... Human contact... to many people the human contact is very important you are right, especially if someone calls and says they are worried their doctor says they should have hip surgery and I say hey it is no big deal I've had both of mine done. You know and they say oh really. And I say yeah you know. For instance I tell them the same thing every time. It is not like going downtown for a chocolate sundae but when I had my done, I couldn't believe how little pain and anguish there was. And boy they all like to hear that and it is true.

K: And how often does that occur?

I: At least twice a week.

We have support groups. Around the state. But support groups are kind of dwindling and I am not sure why. I think it is because it is hard to get people who will sign up to lead them.

Suggestions

Well, I know what they all want, not all but many of them want alternative care or they want a diet to solve their problem. They want to be able to stop eating beets or start eating carrots to get rid of their arthritis and of course it isn't going to happen unless they have gout. If they have gout why they diet is very important.

K: Okay, so.

I: Many of them want to know exercises that will help. the most often questions we get are my doctor is diagnosed me with such and such type of arthritis and he said if I called you you could send me information about that problem. So then we send them information about Reiter's Syndrome or any of the various types of arthritis.

K: So basically what kind of information do you think other arthritis patients should know is to call you.

I: Well yes and no. I mean if you are asking an opinion, I think it is better maybe not to know too much about your problems. I think the doctors should know. You start learning it...you know what happens when students are studying medicine I trust. As they study each disease they develop the symptoms and stuff. You know that do you?

K: I heard about it.

I: Yeah you heard about it. Well I think the human brain is a very, very powerful thing and if you start really studying these diseases you are liable to bring them on yourself you know.

K: So maybe the less they know the better for themselves.

I: Yeah depending on just how far you go with it. I don't mean they should be ignorant of what they should do to help themselves to get treatment but we get calls every now and then from people who want to know everything they can possibly know about this disease and I don't think that is right. We send it to them you know. But I don't know that it is good for them.