

**Living with Chordoma Online: A Thematic Analysis of User's Experiences in an Online
Cancer
Support Group**

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Thesis submitted to the Faculty of the
Virginia Polytechnic Institute and State University
in partial fulfillment of the requirements for the degree of

**Master of Science
in
Business Administration**

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May 12, 2009
Blacksburg, VA

KEYWORDS: Online Health Forum, Chordoma, Cancer Support Group

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(ABSTRACT)

The internet has revolutionized the way people are able to seek information and express themselves. Many fields have been dramatically impacted by its occurrence and the health field is no exception. It is becoming increasingly popular to participate in online discussion forums centered on health-related topics. The goal of this research is to describe participants' experience of using an on-line forum focused on Chordoma, a rare form of cancer. Analysis of free-response questionnaires filled out by members of the forum, revealed four key themes: (a) the forum is a source of invaluable information, (b) the forum is a source for emotional support and hope, (c) members share a unique bond that often results in friendship, and (d) members' involvement changes over time. Benefits obtained by the users and implications for medical professionals are discussed.

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Introduction

The internet has revolutionized the way people are able to seek information and express themselves. Many fields have been dramatically impacted by its occurrence and the health field is no exception. People can use the internet to seek information about medical conditions, self-diagnose illnesses, or have on-line consultations with professionals. In addition to seeking professional advice and information, it is becoming increasingly popular to participate in online discussion forums centered on health-related topics. These forums (sometimes referred to as social support or self-help groups) are typically not ran or monitored by medical professionals, but are sustained by average people who are in some way connected to the health situation being discussed. These groups give participants an outlet to provide or ask for information, share stories, or seek advice from others who have some experience with the health issue at hand. Generally the inclusion criteria for a forum is widely open; participants could include those who are experiencing (or have experienced) the health issue, friends and family of someone who has the condition or someone who is curious about the topic. Participants may only post on forums once or they may use the forum on a weekly or even daily basis. By briefly scanning multiple health-related on-line forums, one is able to see the great variety in different forums. Each one truly is unique, as they are shaped by the unique individuals who participate in them.

The popularity and longevity of these forums indicates the significant role they play in the lives of the individuals who choose to use them. Since these forums can play such an

important role in their user's lives, it is important that health care providers have an informed understanding of the experience of participants in these forums. The goal of this research is to describe participants' experience of using an on-line forum focused on Chordoma, a rare form of cancer. The researcher intends to identify and describe various themes (or patterns) that emerge from interviews with participants about their experiences in order to provide a better understanding of what it is like to be an active member of the Chordoma forum. Benefits obtained by the users and implications for medical professionals are discussed.

A Brief Review of Relevant Literature and Information

Benefits From Using Online Health-Related Forums. There are many benefits associated with online support groups. Given that the group is established on the Internet, as opposed to a traditional face-to-face group, several barriers are eliminated and advantages are attained. Barriers created by geographic location or physical limitation are non-issues when groups are formed via the internet. Participants also have 24-hour instant access to information and emotional support (White & Dorman, 2001). In online forums, there is a feeling of communality (Wright & Bell, 2003). Members of online forums often communicate with each other with empathy (Preece & Ghazati, 2001). Since user's of an online health forum share a common bond, they are able to relate to each other. Members of the online community have perceived similiarity and are able to feel apart of a larger group, this can lead to reduced feelings of isolation (King & Moreggi, 1998). The internet is widely used for information searches on health topics; online health forums allow users access to health information and personal stories from other individuals who have a similar health issue. There are a number of benefits that are associated with using online health forums.

Motivations to Use Online Health-Related Forums and Their Effects. Tanis (2008) developed a list of six general motives for participating in an online health-related forum: (1) seeking information, (2) seeking emotional support, (3) inclusion, (4) supporting others, (5) pass time, and (6) convenience. He investigated whether one's motive for participating in a research forum had an effect on their ability to cope with the health situation they were facing. The results indicated that for those who used an online health-related forum for inclusion or information gathering, there was an overall positive effect of using the forum on the individual's degree to cope with their health situation.

Health Benefits from Writing. There is evidence that writing about traumatic or emotional events can lead to improved health. Pennebaker (Niederhoffer & Pennebaker, 2002) pioneered the expressive writing paradigm, in which one writes about their event or experience for 20 minutes on 3 consecutive days. In a study concerning prostate cancer patients, results indicated that individuals who participated in expressive writing showed improvements in physical symptoms and greater health care utilization compared to control group (Rosenberg et al., 2002). This process could be extended to writing about one's event on forums online.

Chordoma: General Information

Chordoma is a rare, generally malignant bone cancer that is thought to arise from remnants of the embryonic notochord in the spine and skull-base. Chordomas occur in both genders and all age groups. It appears to be a very sporadic cancer, with no confirmed causes or risk factors. Only 300 patients are diagnosed with Chordoma in the United States each year (McMaster et al., 2001). The mean survival rate in the United States is estimated to be 7 years; more specifically, there is a 68% survival rate at five years and a 40% survival

rate at ten years (McMaster et al., 2001). Given the average survival rate of 7 years and the incidence rate, the number of people currently living with Chordoma in the United States is approximately 2,100.

The two most common methods of treatment are surgery and radiotherapy. In order to completely remove the tumor, aggressive surgery is typically required, which often leads to significant side effects and complications (Sekhar et al., 2001). Post surgery, additional treatment is usually needed because complete resection is not always a possibility. Radiation therapy is generally the recommended treatment (Park et al., 2006). Because the tumor is slow growing, high doses of radiation are required; however, these tumors often develop near critical structures that can be damaged by the radiation, which limits the amount of radiation that can be safely applied. Proton beam radiation is generally the most effective radiotherapy option. In the United States, there are only 7 centers where this therapy is available, requiring most patients to temporarily relocate to receive treatment.

Post-treatment (surgical and/or radiation), it is very common for the tumor to return. Oftentimes, additional surgeries are required over several years to treat reoccurrence. The patient usually undergoes the maximum amount of radiation during initial treatment and it is no longer a treatment option for reoccurrences. Metastasis occurs more commonly in patients with Chordoma in the spine, with an incidence rate of 20-40% (Bergh, 2000). Given the rarity and sporadic nature of Chordoma, little research has been conducted and few conclusions have been reached.

The Chordoma Online Forum

The Chordoma online forum is an Internet-based support group for those diagnosed with Chordoma and their caregivers. The site provides links to reliable information sources

concerning Chordoma. The website also has a message board on which members communicate with each other regarding various aspects of living with the illness. When and why the site was started is somewhat unclear; however, it is suspected that it was originally created by a neurosurgeon primarily to serve as a research tool. In 2003, a group of Chordoma patients who met while receiving proton-beam radiation took over the site. Patients and caregivers now voluntarily run the site. Anyone is able to read the posts on the forum; however, in order to respond to or create posts you must be a member. All potential members are required to write a biography and send it to the manager so they can be approved to join the group. This prescreening process enables the manager to prevent individuals from abusing the site. In February 2009, the forum had 600 registrations; however, only 120 active members. Currently, the website is in transition. They are relocating from a free server (e.g. MSN) to a university-sponsored server.

Members discuss various topics on the forum; some examples include methods of treatment, doctors who specialize in Chordoma, lodging at treatment facilities, and logistics for having insurance pay for treatment. The forum is organized by 3 Chordoma types: clival, sacral, and spinal. Members are able to respond to and post threads. Below, is a fictionalized example of a post and its responses. An actual post is not included here to protect the privacy of the members.

From: Cindy

My 19 year old daughter was diagnosed 2 weeks ago with a Chordoma tumor (3cm) located at the brain stem. I am wanting to know if anyone can tell me who has the leading clinic and experience in this area? Dr. Learner wants to perform surgery, remove as much as possible and then treat with radiation. I'm sure he is highly qualified, but I am desperate for more information.

One other problem! My daughter moved to VA last year and planned on starting college there next fall. Our insurance dropped her and the day she was diagnosed, I received the

forms to complete for her new insurance...TOO LATE! She is uninsured! I called Medicaid and they said she does not qualify. Does anyone know resources out there to help? Karen, my daughter, is a beautiful young woman, inside and out. She is not only my daughter, she is my best girlfriend. Any advice or direction is MUCH appreciated!!! Thank you!

Response: Lauren

Dear Cindy

I am so sorry to hear of your daughter's illness. We have seen this problem within the group before.

Look at the threads:

[Need help understanding what to expect](#)

[Stanford denies surgery saying it is elective](#)

Barbara, who also had insurance problems, has now had her surgery. Love and prayers to you both!

Response: Rick

My daughter is 15 years old, and has a Chordoma, located at L4-L5. She was treated with radiotherapy, but also with chemotherapy. Chemotherapy does not work on adults but may succeed on young people. And it succeeded on my daughter. I know I am the only one who have tried this medicine, but I think you should speak your doctor about it. However, after the chemo, the others techniques are still possible.

If you want more information, or the coordinate of my doctor, ask me.

Response: Susan

My name is Susan and my husband has Chordoma of the brain and he has had two tumors since. One in 96 and the second one in 98 the second could not be remove and we went to Boston and saw a Dr. Graver and he was the best of all the doctors we have talk to i can give you his number and you can tell him that Susan from Ky. gave you this number. I stay in contact with him a lot and he is very warn and kind he is from Scotland my husband surgery was done in Louisville and I think you said you were from Tennessee, that is not to far from Louisville about four hours maybe. If you would like the number please let me know. I know what you are going through please let someone that knows what they are dealing with because this in not known very well around here. My number is 572-888-9547 I would like to hear back from you -- thank you!

Methodology

The goal of this research was to develop a better understanding of users' experience of the Chordoma online forum. To obtain accounts of users' experience, an online questionnaire was employed. An online, free-response questionnaire was chosen as the

method of data collection for several reasons. Given that the Internet is a medium that participants frequently use, specifically to share their experiences with Chordoma, I decided this would be the most comfortable means for the participant to share his/her experience of using the forum. Research often cites that one reason patients utilize online health forums is because of the anonymity; the online questionnaire allowed participants to maintain the same level of anonymity that they have when using the Chordoma forum.

The manager of the Chordoma forum was contacted during the early stages of the design of the research, to build rapport, get permission to conduct the research, and gain insights into her suggestions for the conduct of the research. After establishing good rapport with the manager and permission to conduct the research through the forum was obtained, a member was contacted to get suggestions on the methodology used for data collection. The member has a vast amount of experience with the users of the forum and was able to provide valuable insight into the best means of obtaining the desired information. The member and I discussed options for data collection and decided that the online questionnaire was the best method for the reasons stated before. The member, as well as the manager reviewed information given to the participant regarding the purpose of the research and the questionnaire. They both made suggestions for improvement and their suggested changes were made before the questionnaire was made available to participants.

Prior to data collection, the research protocol and data collection methods were reviewed and approved by the Institutional Review Board of Virginia Tech.

Method of Recruiting:

The manager of the Chordoma forum sent a personal email to members of the forum with information regarding the questionnaire. This email contained information regarding

the objectives of the research and a word of encouragement to complete the survey. The manager also included in this email that I was “already known” to them, as I am the daughter of a Chordoma patient and forum member. This email sent directly from the manager with some personal information about me allowed for the development of rapport and trust. At this point in time, there were an estimated 65 members who were currently active on the forum; emails containing the above mentioned information and the link to the survey online were sent directly to this population from the manager.

Participant Eligibility:

The only eligibility requirement to participate in the study was that the participant be an active member of the Chordoma forum. An active member was defined as someone who currently is a registered member of the forum, who currently reads and/or posts threads in the forum. The eligibility was also not limited to just those whom Chordoma affected directly (i.e. a patient), so that caregivers were also allowed to participate. One participant who partially filled out the online questionnaire was not included in the analysis because he stated that he did not use the forum.

Participants:

Thirty-two people responded to the online questionnaire; however, as mentioned above, one respondent said he did not use the forum and his answers were not included in the analysis. All of the participants were either the patient who has been diagnosed with Chordoma or a caregiver for a Chordoma patient (e.g., spouse, mother). Respondents ranged in age from 32 to 74 ($M = 55.7$ years, $SD = 11$ years). Regarding gender, the majority of participants were female (74%). Most of the responses were from citizens of the United States (83%). Of those who responded that were not from the US were from Canada, Italy,

India, or Australia. Although the forum welcomes anyone regardless of their residence, the majority of members are from the United States.

Data Analysis:

Responses were analyzed using the inductive thematic analysis procedures described by Braun and Clark (2006). First, the data were read and re-read and initial ideas about potential themes contained within the data were noted. Then, the data were read carefully to identify meaningful units of text relevant to the research questions – initial codes were developed. Next, the codes were collated into themes. A member check was performed to ensure the authenticity and credibility of the themes developed. The member check served as a check on the viability of the interpretation of the data. Two members (one who participated in answering the questionnaire and one who did not) read the report and provided feedback. Both members felt the report accurately reflected the experiences of members of the Chordoma online forum.

Free-Response Questions:

The goal of this research was to develop a better understanding of users' experience of the Chordoma online forum. In order to accomplish this, the questions asked were designed to be very broad and their exact meaning was open to interpretation. Several of the questions asked could have been considered to be asking the same question; however, to some participants these questions could have two very different meanings. The questions were designed to get a better understanding of the user's experience from when they first started to use the forum to current time. The following questions were asked in free-response format: (1) Describe the online Chordoma forum; (2) How were you first introduced to the forum?; (3) Describe your first experience of using the forum (your first experience does not

have to be a participatory/active experience, it could involve only reading posts). (4)

Describe your experiences of participating in this forum.; (5) What functions does the forum serve for you? (6) What benefits do you receive from using the forum? (7) Are there any consequences or negative aspects that you associate with using the forum? (8) Has your use of the forum changed over time? (9) Describe your role in the forum. (10) Describe your relationship with other members of the forum. (11) How often do you visit the Chordoma website?; (12) How often do you post and/or respond to threads on the Chordoma website?; (13) Do you participate in other health related online forums?; (14) What is your gender?; (15) How old are you?; (16) What is your ethnicity?; and (17) What is your place of residence?. The direction “please try to give specific examples and stories” was included on particular questions in an attempt to get the richest data possible.

Limitations:

There are several limitations faced when using free-response questionnaires as the data collection method. The respondents were limited to only answering the questions that were asked. Given this, there is the possibility that there are areas unexplored by the questions asked. To reduce this possibility, before the questionnaire was finalized, a long-standing member of the forum reviewed the preliminary questions. The member made suggestions for improvement and his suggested changes were made before the questionnaire was made available to participants. A second limitation that must be considered is the researchers inability to further clarify responses. Because this was a questionnaire and not an interview, the researcher was unable to ask any probing questions to illuminate and clarify responses. In an attempt to limit this, the participants were asked to give specific examples and detailed descriptions when responding to questions.

Results

Some members wrote at great length about their experience participating in the Chordoma online forum, others wrote very little. The most verbose responses were given to the fourth question: Describe your experiences of participating in this forum. Participants wrote an average of 103 words (SD = 146, range = 1-776). For the first question (describe the online Chordoma forum) participants wrote an average of 77 words (SD = 61.49, range 14-289). Many of the questions were very broad and open to individual interpretation. Often times, participants felt that their response to an earlier question also answered another question and wrote a message like “see above answer.”

The response means for the other nine questions are listed below. They are introduced in order of mean response length. In response to the third questions (Describe your first experience of using the forum [your first experience does not have to be a participatory/active experience, it could involve only reading posts]) participants wrote an average 55 words (SD = 33, range 16-139). Regarding the question concerning the functions of the forum serves, participants wrote an average of 45 words (SD = 38, range 6-159). In response to the eighth question (has your use of the forum changed over time) participants wrote an average of 38 words (SD = 36, range 1-133). When responding to the question about benefits of participating in the forum, participants wrote an average of 32 words (SD = 37, range = 2-178). In response to the second question (how were you first introduced to the forum), participants wrote an average of 30 words (SD = 28, range = 4-124). When describing their role in the forum, participants wrote an average of 28 words (SD = 36, range = 1-152). In response to the tenth question (describe your relationship with other members of the forum), participants wrote an average of 28 words (SD = 20, range = 1-82). Finally,

regarding negative aspects of participating in the forum, participants wrote an average of 26 words (SD = 30, range = 1-99).

Analysis of these responses revealed four key themes: (a) the forum is a source of invaluable information, (b) the forum is a source for emotional support and hope, (c) members share a unique bond that often results in friendship, and (d) members' involvement changes over time.

A Source of Invaluable Information

Given the rarity of Chordoma, sources of information that are patient-friendly are extremely hard to find. Much of the information available is from scientific journals and the intended audience is medical professionals. Members of the forum use each other as “expert” resources for information regarding the intricacies of living and dealing with the disease.

The folks that are members are searching for information regarding all aspects of Chordoma. These include, but are not limited to types of treatment, problems and aftermath related to treatment, logistics involved with travel for treatment, financial concerns such as insurance, etc. (John, male).

After learning of their diagnosis, many patients are left with unanswered questions. Often times, the doctor who originally diagnoses them with Chordoma, knows very little about the disease or treatment options.

It is such a lifeline of support for a rare condition. Even the dr's at Mayo said they only see 5 patients a year like my husband's – so they do not have as many answers as the survivors on the website (Amelia, female).

After reading about Chordoma through postings on the forum, members are able to develop an understanding of the disease they have been diagnosed with. Sometimes, members become more knowledgeable than their current oncologists:

I knew more in general what was necessary than some of my first drs and this info was from the board... The expertise on the website is maybe greater than any dr that we have had experience with thus far (Elizabeth, female).

Chordoma requires a high degree of specialization for treatment; there are only a few doctors who specialize in its treatment. There are also a very limited number of treatment options. One such option is proton-beam radiation, a treatment that is only offered in seven establishments in the USA. This information may not be readily available for patients. After learning of their diagnosis, patients or their caretakers turn to the forum to look for advice on what doctors to go to and where they can receive treatment.

I do see where patients are going for help. Since reading the posts I have found out where the other hospitals are who are treating Chordomas in the country. That's is very valuable information. I was lucky since I lived near Loma Linda (a treatment facility) but if I were an uninformed person I can see where the forum would be able to guide me to a hospital with experience. I think that would be the biggest benefit, INFORMATION is the key to everything (Andrew, male).

Many of the patients later experience a recurrence of their tumor after initial treatment. This recurrence may be several years after initial treatment and new medical advances could have been made. Members read and share information to stay up-to-date on the latest developments in Chordoma treatment.

The forum enables us to find out about any new treatments which may become available in the future. We hope we'll never them, but we are very interested in new research, just in case (Sarah, female).

Sarah explains that members can use the forum to “discuss any new scientific articles that a member may have read which might offer some new hope for the future for all.”

The information provided on the forum is invaluable for many members. For Elizabeth, the forum “has been a lifeline in many ways, literally. The medical information

obtained or discussed including off line, has been enormously important.” If Chordoma is treated incorrectly the likelihood of complete resection is limited and reoccurrence is heightened. Amelia, for example, feels her life would have been different if she had the forum as an information source when she was first diagnosed:

I only wish I had found the forum earlier. I think I would have known to get an experienced Chordoma doctor...when my Chordoma recurred, I found the names of experienced Chordoma surgeons [from the forum] that I could see. I only wish that I had had this information before my first surgery. I think my life would be a lot different.

A Source for Emotional Support and Hope

Being diagnosed with any illness can be an emotionally challenging event. Being diagnosed with a very rare illness adds an additional layer to the emotional challenge. The forum provides its members with the opportunity to give and receive emotional support as they go through their experience with Chordoma. Being able to share personal hardships with people who have a shared understanding of their experience is helpful for members.

[The forum] provides an opportunity . . . to support each other when we need it the most. As this is a rare disease it is sometimes hard to find others and this is a great place to do that, share experiences and get pointers. The support side is as important or even more so than the information as it makes you feel like you're not alone and you can, if you wish, express all the good and bad stuff going on.

For Lauren, the forum offered emotional support for both her and her husband and was able to act as a substitute for professional therapy:

[The forum] helped ease some of my stress. While I contemplated getting counseling help for myself, the resources available online were very helpful. I did not end up with outside counseling, as the website helped me deal . . . I have felt much more at ease after reading or posting on this forum. My husband is much more calm about the whole situation, for me it turned my world upside down so for me it was a lifeline. It helped calm me by reading how others were dealing with their situation . . . I know my husband got personal [phone] calls from people on the website which helps him

immensely . . . [The forum] serves as my counseling right from home. It is great!
(Lauren, female).

For many illnesses, there are group therapy sessions that patients can attend; given the rarity of Chordoma, this attending a local group meeting is not a likely option for those diagnosed. As Mary explained, members can use the forum to help deal with the questions that many of them are facing and assist each other in emotional healing:

The Chordoma forum online provides a means of support similar to group sessions where you can feel not alone and know that others share in your same situation. We discuss similar pains, concerns, and personal matters. There are lighthearted replies to lift spirits and genuine remarks to aide when times are tough. It is a healing place and it aids in the process of understanding the “why me” and how to live with this devastating diagnosis.

The opportunity to communicate with others who have also been diagnosed with Chordoma and have survived provides hope for those who are newly diagnosed.

I had so many questions and concerns and it just felt so good to have others answer my questions and comfort my fears. The number one thing I took away from the group back then was HOPE. Before I found the group, I couldn't find one good thing to think positive about. All the research showed little to no chance of fighting my husbands Chordoma. So, I had no hope, until I found the group (Katie, female).

Many of the long-time members expressed that they were motivated to respond to new members' posts to offer support. Alice posts “mainly to give encouragement to those who are experiencing what I've gone through...and to assure them that there is a ‘light at the end of the tunnel!’” Members understand what newly diagnosed Chordoma patients are experiencing and if sharing their experience can offer them any comfort they readily share. Nina “offer[s] aid for those who are newly diagnosed if it something which I personally have been through and might can allay their fears.”

A Unique Bond Resulting in Friendship

The members of the Chordoma online forum share a unique bond. Because of the cancer's rarity, each other's existence allows the members to feel as if they are not alone. Elizabeth described being diagnosed with Chordoma as "a profoundly lonely experience." After finding the online forum, many members acknowledged the comfort they found from finding others in their similar situation.

It was overwhelming to read and hear those who are as unfortunate as you are. Till then, I had thought I am the only creature of this type of the earth . . . connecting [with other Chordoma patients] is very important (Rachel, female).

For Nina, the Chordoma forum provides her with "a place where I feel as I am a part of a group of caring and interesting people." Many of the members wrote how the common denominator they shared led to friendship.

I have a good and pleasant relationship with each and all. They share a special bond with me and I consider each and all a good and close friend (Sarah, Female).

Because the treatment of Chordoma requires a specialist, many of the members have the same oncologists or are treated at the same facility. The limited resources available to treat Chordoma sometimes leads to members personally meeting each other at hospitals. Members also reach out to each other via personal emails if they have similar Chordomas. Friendships are formed through the Internet connection and also through personal encounters.

There are two other people we correspond with via email. One of them was kind enough to contact us because she had a cervical Chordoma, the same as my husband, and we have become very good friends with her. The other one is a man we met in Boston when he and my husband were undergoing Proton treatment, and formed a friendship with him (Sophie, female).

For some members, the friendships they have formed move beyond corresponding through the Internet or phone and they occasionally get together in person. Anna was able to connect with a fellow member who lives near her.

I have made a friend who is similar in age, education, and family circumstance to me. Our Chordoma experiences are very similar also. We meet, share stories, and have a good time (Anna, female).

Often times, long-standing, or “veteran” members try to connect with others who are in their geographic area to mentor them through the early stages of their diagnosis. Alana reached out to a member in her area and their friendship became so strong that they are now housemates.

I was living in Long Island at the time and she came on saying she was from Yonkers. I got on as soon as I saw her posting and told her where I was from, what I had and that she wasn't alone . . . She was only recently diagnosed so over the time before her surgery we not only talked about this but she expressed her worries and concerns. This contact was almost a daily occurrence until her surgery . . . From that contact, we have now become close friends and share a house . . . There are not many who know that the person they share a house with knows exactly how they are feeling because they have ‘been there done that’ (Alana, female).

Unfortunately, the members of the group sometimes experience the loss of one of their virtual or personal friends to Chordoma. The death of a member can serve as a reminder of one's mortality.

These are my friends. We share births, weddings, and deaths. I have cried several times over the recent deaths of several members who died of this illness. It can be a very personal thing when you have communicated with someone about a disease that you yourself have and know that this could happen to you. Having these friends strengthens your resolve, helps you through the rough patches and helps you stay focused (Mary, female).

Friendships between members often form in the early stages of one's diagnosis and sometimes continue up until their death:

I have held the virtual hands of people dying from Chordoma a number of times and it doesn't get any easier (Sherry, female).

Involvement Changes Over Time

Members expressed that their need for and participation in the forum changed over time. When they were new members they often were in high need of information and support. Later, they were able to shift from being the one in need to the one providing assistance to others.

In the beginning, I needed time to read stories of others and to be encouraged by those that were further into the experience of Chordoma. After I posted our story, I became more able to help encourage others in their situations . . . In the beginning I was the one being encouraged and given hope and as time has progressed, I have become someone that can give hope and encouragement (Felicia, female).

In the beginning, I asked a lot of questions for myself but as time went on and we started to climb our medical hurdles, I would read others stories and for once I could give back and answer their questions and concerns (Katie, female).

Members also wrote how their personal need for the forum changed over time along with their condition:

My personal need for support has seemed to dissipate over the years simply because there hasn't been any change in my condition. The concerns are just not that prevalent in my day-to-day life (John, male).

Members write that there is a diminished need for the forum once they have become comfortable with their condition. For Mary, once she "became more adapted to [her] condition and the 'fear' factor . . . [she has] taken more of a back seat." The frequency of participation in the forum often changes because members do not want their cancer to be such an integral part of their daily life. As Sarah explains, her participation:

Ebbs and flows depending on what is going on in my life. I have many issues in my life and I have resumed a more or less normal life. I would not want to let my 'illness' be the center of my existence. At first, as natural, you are consumed with

finding the doctor, having the surgery or treatment . . . then as life resumes more to a normal pace you change your focus. It is at this time you still need to forum but you may not participate at such an involved state.

Although some members' participation dissipates overtime because their personal needs change, they acknowledge the continual role the forum will play in their lives.

I did finally tire of all the Chordoma, all the time. More recently, I have been visiting the forum less frequently . . . There is a rhythm to life, and right now my rhythm does not involve the forum deeply. I will very likely come back to it sometime in the future, because I have very positive feelings for it (Mary, female).

As much as I hoped I would always be as involved as I once was, my participation is not on a regular basis anymore. It's been 7 years since my husband got the diagnosis and treatment . . . I still need them (the forum members) but not as much as I used to. I will always be a member because I know this will forever be a part of our lives . . . It has been 7 years but I remember how I felt like it was yesterday (Kate, female).

Conclusions

In an attempt to describe the experience of using an online health forum, this research has shed some light on what it is like to be a member of the Chordoma online forum. From questionnaire responses from members of the forum, four key themes were identified. The forum provides a vital function for both information and emotional support, especially for those who have been recently diagnosed with Chordoma. The forum is described as a literal lifeline because of the value of the information provided by other members who are experiential experts. Given the low prevalence and lack of a cohesive body of knowledge about Chordoma, the forum allows members to jump geographic barriers to come together and share individual stories of successful, or unsuccessful, treatment. With enough individual stories compiled, the forum becomes the cohesive body of knowledge and those affected by Chordoma are given access to the information they need. The knowledge

acquired from the forum is often described as greater than that of many of the doctors who treat them.

The members of the forum also provide each other with the emotional support that only someone who has gone through this experience can. The stories of success and words of encouragement from other members gives those affected by Chordoma emotional strength and much needed hope. Members who are farther along in their experience with Chordoma feel a sense of obligation, as well as satisfaction to mentor newer members and to provide them with knowledge about Chordoma and hope for the future. The bond between the members of this forum is deep and unique. They understand each other's struggles and triumphs better than any other person on the planet. This bond often results in the formation of friendships. These friendships are not tethered to the Internet, often members become "real life" friends who seek out each other's company. Unfortunately, these strong friendships sometimes end when a member falls victim to their illness and passes away.

Over time, members' use and need for the forum changes as their lives change. Chordoma cannot always be the center of their life, thus they cannot participate in the forum as actively as they may have during their initial diagnosis. For some, the forum is like an addiction in the beginning. They are waken up in the middle of the night and compelled to read and read until they develop some sense of understanding or find comfort and hope. As they become comfortable with their diagnosis or they are successful in treatment, their need for the forum dissipates. Although members may rely less on the forum over time, this does not change their appreciation for the important role the forum plays in the lives of newly diagnosed patients. Members often reply to posts, offering information and advice when

they come across a new member who has a similar case as theirs or when they feel they can offer hope to someone who is without.

This research reveals exactly how vital the forum is for its members. Because Chordoma is an uncommon illness and the effects of the numerous combinations of treatments is certainly not scientifically documented, the information on the forum may be of use to medical professionals. Just as participants condition match and suggest treatment options that were successful for similar others, oncologists could use the information on the forum to generate ideas for their patients. The forum is also a valuable resource for doctors who are those who originally diagnosis patients. The members frequently wrote about how little, or inaccurate information their doctors in the beginning had. These are no trivial issues because if the Chordoma is inappropriately treated, the patient's chance of proactively fighting the cancer can be reduced. The forum could serve as a crash course to Chordoma for doctors and medical professionals unfamiliar in this area so they are better able to assist their patients in taking the first successful step in their treatment. It is also important for medical professionals to have a deeper understanding of how valuable of a resource the forum is for those affected by Chordoma. The forum assists immensely in both information gathering and emotional support. Although online health forums have been recognized as important, they may be an under appreciated tool – especially for those with an uncommon condition.

Limitations

This study has several limitations due to the data collection method used. The objective of this research was to develop a deep understanding of what it is like to be a member of the Chordoma online forum. The data collection method limited the respondents to only answer the questions that were asked by the researcher. Because of this, there may be

areas of user experience that were not uncovered because of the questions asked. The researcher was also unable to ask any additional questions to clarify participant's responses. Although, one of the themes identified (involvement changes overtime) was talked about by all participants and a strong pattern was detected in the data, it is unclear whether this occurred because it is an integral part of user experience or because that was a question directly asked by the researcher.

Future Research

Given the limitations of the data collection method discussed above, to truly gain a deep understanding of the user's experience, in-depth interviews may be a more appropriate data collection method to utilize in future research. It may also be beneficial to create a fictionalized narrative as a means to present the experience of a forum user. Although the findings of this current research shed light on what it is like to be a user of the forum, a fictionalized account may be a more powerful way to present the user's experience. Chordoma is an uncommon cancer and many of the benefits members discussed were specifically related to its rarity. Future research should explore whether the benefits of participating in online health forums are greater for those with rare conditions. If this is the case, it is extremely important that health care providers encourage individuals with rare conditions to seek out an online community.

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Appendix A: Online Questionnaire Questions

Questionnaire – User Experience of an Online Cancer Support Group

1. Tell me about the Chordoma online forum
2. How did you hear about the forum
3. When did you first use the forum
4. Why did you use the forum
5. What functions does the forum serve for you
6. Why have you continued uses the forum
7. Could you describe your experience of using the forum
8. Has your use changed over time
9. What benefits do you receive from using the forum
10. What features attract you to using the forum
11. Are there any consequences of using the forum
12. How would you describe your role in the forum
13. What is your relationship like with other members

Appendix B : IRB Consent Form

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY

Informed Consent for Participants in Research Projects

Involving Human Subjects

Title of Research Project: Living with Chordoma Online: A Thematic Analysis of User Experience of an Online Cancer Support Group

Principal Investigator: Gina Xenakis, Marketing Department, Virginia Polytechnic Institute and State University

I. Purpose of this Research/Project

This study involves research and its purpose is to investigate participant's experiences of using the online Chordoma forum. The research will involve participants filling out questionnaires about their experiences of using the forum. I will be asked to describe my experiences on the above topic by filling out a questionnaire.

II. Procedures

My participation in the above-mentioned questionnaire will involve sharing my experiences of using the online Chordoma forum. It should take no more than one-hour in total to fill out the questionnaire.

III. Risks

The risks associated with participating in this study may include becoming emotional when writing about my experience.

IV. Benefits

No promise or guarantee of benefits has been made to encourage me to participate. The data collected from me during this study will be used for purposes of a master's thesis.

V. Extent of Anonymity and Confidentiality

My identity, and that of any individuals who I mention, will be kept confidential at all times and will be known only to the principal investigator. When the researcher receives the questionnaire, pseudonyms (i.e., false names) will be used for my name and for the names of any other individuals who I mention. Any details that could identify me or any individuals

who I mention will also be altered. This questionnaire will be destroyed after the interview has been transcribed.

It is possible that the Institutional Review Board (IRB) at Virginia Tech will view this study's collected data for auditing purposes. The IRB is responsible for overseeing the protection of human subjects who are involved in research

VI. Compensation

I will not receive any form of compensation for participating in this study.

VII. Freedom to Withdraw

My participation in this research is entirely voluntary and my refusal to participate will involve no penalty or loss of benefits to which I am otherwise entitled. Similarly, I am free to withdraw from this research at any time without penalty or loss of benefits to which I am otherwise entitled. If I choose to withdraw from the research, any information about me and any data that I have provided will be destroyed. I am also free to choose to not answer any question, or to not complete any activity, and this choice will involve no penalty or loss of benefits to which I am otherwise entitled.

VIII. Participant's Responsibilities

I voluntarily agree to participate in this study. I have the following responsibilities: to participate in an interview of no more than one hour, as described in Section II above.

IX. Participant's Permission

I have read and understand the *Informed Consent* and the conditions of this study. I have also had all of my questions answered. I hereby acknowledge the above and my consent is implied by my participation,

Should I have any pertinent questions about this study or its conduct, or participants' rights, I may contact:

| | |
|--------------------|-----------------------------------|
| Gina Xenakis | (540) 231-1909 gxenakis@vt.edu |
| | |
| Dr. David Brinberg | (540) 231-7639 dbrinber@vt.edu |

Appendix C : IRB Approval Letter



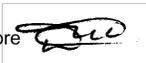
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FWA00000572(expires 1/20/2010)
 IRB # is IRB00000667

DATE: January 30, 2009

MEMORANDUM

TO: David L. Brinberg
 Gina Xenakis

FROM: David M. Moore 

Approval date: 1/26/2009
 Continuing Review Due Date: 1/11/2010
 Expiration Date: 1/25/2010

SUBJECT: **IRB Amendment 1 Approval:** "Living with Chordoma Online: A Thematic Analysis of User Experience of an Online Cancer Support Group", IRB # 09-063

This memo is regarding the above referenced protocol which was previously granted approval by the IRB on January 26, 2009. You subsequently requested permission to amend your IRB application. Since the requested amendment is nonsubstantive in nature, I, as Chair of the Virginia Tech Institutional Review Board, have granted approval for requested protocol amendment, effective as of January 30, 2009. The anniversary date will remain the same as the original approval date.

As an investigator of human subjects, your responsibilities include the following:

1. Report promptly proposed changes in previously approved human subject research activities to the IRB, including changes to your study forms, procedures and investigators, regardless of how minor. The proposed changes must not be initiated without IRB review and approval, except where necessary to eliminate apparent immediate hazards to the subjects.
2. Report promptly to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.
3. Report promptly to the IRB of the study's closing (i.e., data collecting and data analysis complete at Virginia Tech). If the study is to continue past the expiration date (listed above), investigators must submit a request for continuing review prior to the continuing review due date (listed above). It is the researcher's responsibility to obtain re-approval from the IRB before the study's expiration date.
4. If re-approval is not obtained (unless the study has been reported to the IRB as closed) prior to the expiration date, all activities involving human subjects and data analysis must cease immediately, except where necessary to eliminate apparent immediate hazards to the subjects.

cc: File

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