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## Redemption or contamination: reviewing the illness narratives of the chronically sick and their support systems

Allison R. Dearing

*The University of Tennessee at Chattanooga*, [hxt837@mocs.utc.edu](mailto:hxt837@mocs.utc.edu)

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**Redemption or Contamination: Reviewing the Illness Narratives of the Chronically Sick  
and their Support Systems**

Allison R. Dearing  
Departmental Honors Thesis  
The University of Tennessee at Chattanooga  
Department of Social, Cultural, and Justice Studies

Examination Date: April 1st, 2019

Dr. Shawn Trivette  
Professor of Sociology  
Thesis Director

Dr. Zibin Guo  
Professor of Anthropology  
Department Examiner

## HOW DO SUPPORT SYSTEMS INFLUENCE THE ILLNESS NARRATIVES' SEQUENCES OF THE CHRONICALLY SICK?

### ABSTRACT

Chronically sick individuals deal with pain on a daily basis, which can lower their quality of life and make it more difficult. Illness narratives or “sickness stories” have been known to help people place illness in their lives. Support systems are a factor that could influence individuals’ illness narratives to lead them towards a redemption or contamination sequence. In this study, I interviewed twenty-five women with endometriosis and asked them questions regarding their health status, illness narratives, and support systems. The interviews were reviewed and categorized between redemptive and contamination sequences. The support systems influence on the sequence were also reviewed to determine how helpful they are at helping the sick cope. I argue that support systems are necessary for reaching a redemptive sequence and that the quality of support is more beneficial than the quantity. The individuals that did not utilize their support systems led to contamination sequences. In order for an individual to reach a redemption sequence, they must have at least one form of quality support and utilize the support to benefit from it.

Keywords: chronic illness, illness narratives, redemption sequence, contamination sequence, endometriosis, support systems, invisible illness.

## INTRODUCTION

This study aims to review support systems and how they influence illness narratives of the chronically sick. Chronic pain affects individuals' lives and can be presented through many different forms and symptoms. The chronic illness being used for review in this study are women that experience chronic pain from endometriosis. Their illness narratives can help give insights to what individuals with chronic invisible pain experience and how they lead to a redemptive or contamination sequence outcome. Their support systems and health history were reviewed to determine if they have a direct influence on a chronically sick individual's life sequence, or in other words if they motivated them to live through the pain. The support systems that were reviewed are partner, family, friends, physicians, support groups, and religion. Support Systems are an important factor of coping with a chronic illness. In this review, illness narratives from the chronically sick will be evaluated as well as the quantity and quality of their support systems.

## CHRONIC ILLNESS

Chronic illness is defined as an illness or disorder that affects an individual's daily functioning for more than three months a year, requires hospitalization for a month per year, or requires the use of adaptive devices or assisted technology (Muscari 1998). Chronic illness is usually accompanied with chronic pain. The chronic pain individuals feel is associated with the symptoms of their chronic illness. People with chronic illnesses may deal with a vast array of personalized painful symptoms. Being diagnosed with a chronic illness is a life altering circumstance and dealing with the constant symptomatic pain daily can greatly change how an individual views and lives their life (DiVasta *et al.* 2016).

### *Endometriosis as a Chronic Illness*

Fifteen percent of the female population during reproductive age suffers with endometriosis symptoms(Flower *et al.* 2009). Endometriosis is a debilitating disease that occurs when the uterine lining grows outside the uterus. Although the exact cause for endometriosis is unknown, genetics and estrogen dominance have been known to play a role in its development( Flower *et al.* 2009). Endometriosis can cause chronic pain that affects the daily lives of women all over the world. The pain levels and pain cycles of endometriosis can vary with frequent symptoms such as chronic pelvic pain, Irritable Bowel syndrome, chronic fatigue, dysmenorrhea, fibromyalgia, anxiety, depression, nausea, lower back pain, headaches, migraines, and abdominal cramps. Endometriosis is the main cause of infertility in women (Fassbender *et al.* 2014) and can cause other autoimmune disorders and inflammation in the body to occur, which causes more illness and pain. Although endometriosis is treatable, it is not curable and is a long term chronic illness. Endometriosis is an invisible chronic illness, which means the disease itself is not visible to others.

## ILLNESS NARRATIVES

When someone is diagnosed with a chronic illness it can be hard for them to define their illness, so creating an illness narrative may be useful. Illness narratives are stories that explain how someone's illness started, what it evolved to, and how they are currently coping or dealing with it (in other words a story about their illness). Illness narratives allow for people to reflect back on their memories and create a narrative about their health condition and have the ability to reveal how people make sense of their illness. Studies have determined that illness narrative analysis is a valuable method for uncovering insights about the illness and experience (McMahon, Murray, and Simpson 2012). When people have chronic illnesses that are not

outwardly visible, hearing their stories can help people understand what they are going through and it shows the significance of the illness in that person's life (McMahon *et al.* 2012).

Illness narratives can have different genres that depend on how the narrator tells their narrative. Some genres include: epic or heroic, tragic, comic or ironic, disembodied, romantic, and didactic (Bury 2001). Illness narratives typically begin when the person was diagnosed with their illness, or events leading up to their diagnosis, and continue to show how the individual copes with their illness. Illness narratives have been proven to be important to individuals for helping them place illness in their life and distinguishing between a redemption or contamination sequence (Bradway 2005).

#### *Redemption & Contamination Sequences*

Individuals frame their illness narrative in a positive or negative sequence. A positive outcome is known as "Redemption sequence" and a negative outcome is known as a "Contamination sequence" (McAdams 2001). Redemption sequences are described as narratives that transition from negative emotion towards positive emotion, while contamination sequences are narratives that transition from positive emotion towards negative emotion (McAdams 2001). Getting diagnosed with an illness is not typically a positive experience, but that does not mean an illness narrative will end in a contamination sequence. Illness narratives may have multiple redemption and contamination sequences throughout.

Determining which sequence an individual's illness narrative originates from how the individual frames the illness in their life at that moment. People may frame their illness narrative in their mind however they desire and base it on how they perceive their current experience with their illness. Redemption stories help individuals grow and contamination stories have been

shown to stop them from growing (Murphy 2016). Redemption sequences show that the individual still has hope, while contamination sequences show a lack of hope. Hope is an effective tool at helping chronically ill individuals cope (Griggs and Walker 2016). Redemption and Contamination sequences are useful tools at uncovering if individuals' coping mechanisms are helping lead them to a happier life, or if they have lost hope.

## SUPPORT SYSTEMS

Multiple factors may influence the outcome of illness narratives' sequences, and one main possible influence is individuals' support systems. When suffering with a chronic illness, individuals need a support system to help them cope. Support systems are important for improving chronically ill individuals' quality of life. Research shows that the quality of a person's support systems plays a bigger role in their life satisfaction than the quantity of individuals (Hupcey 2001). There are multiple different kinds of support systems for someone who is chronically ill. Some examples of support systems are: family, friends, formal relationships (ex. doctor, nurse, therapist), support groups, and religion. Some individuals have one type of support system and others may have more. Support systems may also help restore hope in an individual's life when their life feels not worth living due to the chronic pain. People without social support have been shown to have higher unhealthy mental and physical states (Crotty *et al.* 2015).

There are two types of support that can be given: direct and indirect support. Direct support is getting instrumental help with direct action, such as helping make special dietary food or help driving an individual to the doctor. Indirect support is helping the individual indirectly with more emotional support, for example, helping comfort the individual or buying the

individual health food as a gift (Crotty *et al.* 2015). Individuals without support systems are more likely to feel lonely and socially isolated (Barnack and Chrisler 2007).

### *Family, Friends, & informal relationships*

Two major support systems are family and friends. A family support system can be made up of immediate family members, spouses, pets, and other close relatives. Family has been shown to be more likely to provide both direct and indirect support, specifically the spouse (Crotty *et al.* 2015). An individual's spouse or family is more likely to help out with the daily activities such as giving medication, transportation, and preparing meals. People with strong family support are also less likely to receive formal support. Friends are an important support system, but individuals with chronic illness may find it hard to relate to their friends and feel uncomfortable to ask them for instrumental help (Beatty 2004). Friends are more likely to provide indirect support and may be an important part of coping with a chronic illness.

### *Formal Relationships*

When chronically ill individuals do not have close family or friends, they are more likely to receive help from formal relationships. Formal relationships are people within the professional world that help provide support such as: doctors, nurses, therapists, or anyone who provides a form of support in a formal way. Formal relationships can include medical support, mental health support, and community-based agency support (Sit & Stermac 2017). Formal relationships can be either direct, indirect, or both. A doctor is more likely to administer direct support, and a therapist is more likely to give indirect support. However, a doctor could give an individual both direct and indirect support. Chronically ill individuals without family and friends lean on formal relationship support to help them cope with their lives (Sit & Stermac 2017).



### *Religion*

Religion may also play a significant support role in individual's lives by providing hope and faith. Throughout history, religion has been used to help treat the sick. One major example of this is in the Catholic church when the sacrament of healing is bestowed on a sick individual (Timm 2015). When people are chronically ill, they need something to believe in. Religion gives the individual purpose which helps them keep moving forward in their life. Religion is another outlet people can use to cope with their chronic pain. Religion provides people without family and friends an outlet to express their feelings through prayer with their Divine Creator. Religion is likely going to provide indirect support through spiritual emotional support.

### *Support Groups*

Support groups serve as an outlet where individuals can receive the support they need from people going through the same thing as them, providing emotional or indirect support. Support groups can be conducted online or in person. Being involved with a support group allows individuals to have a safe space for them to share their emotions about suffering with their chronic illness. It also gives individuals opportunities to receive advice from other people who have the same type of chronic illness.

## METHODS

### *Interest & Study population*

The study is a qualitative review of in-depth interviews of chronically sick women with endometriosis and their illness narratives. The population of interest is chronically sick

Running Head: Support Systems Influence on the Illness Narrative sequences of the Chronically Sick individuals, and the study population is women with endometriosis that experience chronic pain nationally and participate in online support groups.

### *Sample & Data collection*

Non-probability snowball sampling was used to select twenty-five women with endometriosis that experience chronic pain in the surrounding areas. People in endometriosis support groups online were contacted through various media including through phone calls, texts, video chatting, and email. If they responded, the IRB-approved research study was explained and they were asked to sign an electronic consent form which was sent to their email address. Interviews took place face-to-face at UTC or online through video calling.

The interviews followed an interview guide that asked questions regarding the individual's long-term health status, support systems, and illness narrative. The questions asked how their illness changed their perception of self, how their daily life changed, and examples of real experiences from living with endometriosis. Other general questions were asked regarding the severity of their symptoms and daily responsibilities they hold as individuals. The interviews conducted were over thirty minutes long. The audio recordings of the interviews were transcribed and saved under a pseudonym to preserve confidentiality.

### *Data analysis*

The interviews consisted of individuals' illness narratives and other related health and support questions. The transcriptions were analyzed for redemption or contamination sequences in the illness narratives. The illness narratives were categorized redemptive if they found a way to be positive or have positive emotion and were considered contamination if they were negative or had negative emotion, after an initial event. Illness narratives can have multiple different

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sequences involved and each sequence the participant experienced was reviewed. After the sequences were categorized, the participants' responses and opinions regarding their illness narratives and support systems were reviewed to see if there was any influence. The support systems being reviewed were family support, partner support, physician support, religion and spirituality, friend support, and support groups

## FINDINGS & ANALYSIS

### *Illness Narratives-Typical Experiences*

When reviewing the interviews, multiple common themes were discovered throughout the participants' illness narratives. These themes are experienced by most endometriosis sufferers throughout their illness journey. One experience was the lack of other people's understanding of their chronic pain. Most participants reported that majority of people are not understanding of their pain or chronic disease, and that they often feel misunderstood. People think that they are making their pain up because they do not know how they feel. One participant, Martha, became scared due to others never understanding her pain, so she began keeping quiet about her pain in order to reduce how much outsiders would pass judgement:

I was too shy and too scared to tell them [my] because a lot of times people don't understand. Even the people that are close to you think you're making it up, or anything. 'You're just being lazy' or you know a billion gazillion things they tell you and it hurts you so I wouldn't [talk about it].

Martha was used to people not understanding her pain and it made her stop feeling comfortable to tell other people about it. She eventually learned how to stand up for herself and tell others about her pain, and was able to get a diagnosis. Because some people are disbelieving of individual's chronic pain, it causes them to have to learn how to self-advocate for themselves,

especially in the medical world: “I don't really consider it a choice to find the answers, but it's also been motivating that every time I've pushed a doctor that didn't listen to me, I find I've been right. So you get a little bit of validation when you know when you're right. Like you feel like, okay i'm not insane.” The participant, Susan, had to use her voice to explain their pain because there symptoms cannot be seen and the endometriosis cannot be seen without surgery. When no doctor believed her pain, she still believed in herself and learned how to stand up for herself.

Another common experience that the participants shared in their illness narratives is how they feel about themselves now that they have been diagnosed with a chronic condition that has changed their life, and how they adapted to the change. Before they experienced endometriosis pain, the participants noted that they felt: happy, hopeful, and innocent. After being diagnosed and experiencing the chronic pain, they said they would explain themselves now post diagnosis as: hopeless, tired, and similar to an older person (specifically 75 years old). One participant, Mary, noted that she views her life with the endometriosis diagnosis as pre and post loss due to her miscarriages that were caused from the endometriosis. A lot of participants view there life as pre and post loss, but from the death of their “healthy” not limited selves. Whenever they became sick, a part of them died and another part was born. They no longer can be the fully capable person they once were, they now have to limit themselves.

Another common theme mentioned in the illness narratives were the lack of awareness about endometriosis in the world. Every participant mentioned how there is a lack of awareness of endometriosis. The participants think the social world and medical world are not well informed on endometriosis and that awareness needs to be raised. One participant stated that about half the women she talks to know what endometriosis is and other women do not. Men

usually are not informed on the subject because people may see it as “taboo” to talk about a woman’s period or reproductive condition. One participant noted how even though her symptoms matched endometriosis, she had visited gynecologists previously before her diagnosis and none of them mentioned endometriosis as a possibility, which is concerning considering how prevalent the condition is becoming. Another problem mentioned was how uninformed the public is about the condition itself and the amount of pain and loss of quality it can have on someone’s life. A lot of people misunderstand endometriosis as a condition that only causes painful periods, when it can be even more debilitating than one week of intense pain. The participants also mentioned how people are always trying to give them treatment advice, when they do not realize that most women have tried multiple forms of treatment. One participant, Helen, mentioned how people had suggested to her to start eating more vegetables and maybe she would stop experiencing pain and get better:

People always have an opinion. ‘Try this or you just need to do this’. Like I haven't tried everything in the world. ‘You just need to eat more green vegetables.’ It's like, Yeah, okay. Yeah, I’ve spent over \$10,000 on surgery and other treatment options, but yeah I hadn't thought of vegetables!

Helen expressed that she was tired of hearing people’s opinions on her illness that they know no information about. Society’s lack of awareness of endometriosis leads to people thinking false information about endometriosis and how to treat it. It is not taken very seriously as an illness and rarely gets covered under disability without other chronic conditions included.

### *Surgery vs No Surgery*

A majority of the sample had surgery as a treatment option for endometriosis. Half of them received ablation surgery and the others received excision. The women who did not have

surgery were not always contamination sequences, but they were more likely to be contamination than ones who had received surgery. One participant had an exploratory surgery done, but was unable to pay for the excision or ablation. Surgery provided pain relief for at least a few months after surgery for a majority of the patients who received it. It provided the participants with a redemptive sequence, but the pain typically returns which causes another contamination sequence, so the patient gets another surgery.

Surgery is considered the gold standard treatment option for endometriosis and can be helpful at reducing their pain, which can help lead them to a redemptive sequence. However, in some cases the surgery can cause their endometriosis pain to worsen or the surgery provides relief but the individual worries about the pain returning, which can lead to a contamination sequence. There was one participant, Hannah, who said the surgery had set everything off and was the reason her pain started becoming worse: “The ablation that he had done had, like ticked off everything. I was feeling like I was going into straight labor, and I had both of my kids without epidurals.” Hannah’s surgery had lead her to a contamination sequence due to the pain she was experiencing post operation. She later learned that the adhesions from her previous surgery were what was causing her intense pain, and that some of the endometriosis had grown back. Surgery is a viable option for people who suffer from endometriosis, but is depends on the surgery’s results on whether it provides a redemption or contamination sequence.

## SUPPORT SYSTEM INFLUENCE

### *Family Support*

Family support can be broken down into two categories: partner support and (extended) family support. The closest form of support in the sample was partner support. If the participant

did not have a partner, then their closest support system was their family. Participants with partners usually lived with them, and if the participants did not have a partner then they lived at home with their family. This was because most of the participants were unable to commute to work due to their chronic unpredictable pain, so now they are unable to work or choose to work from home. In a few participants' cases, they had already moved out of their family house to live on their own, and had to move back home due to being unable to work and pay for their own place after becoming progressively more sick.

Partner support was one of the most important and utilized form of support. When the participants with partners need support, their partner is their first choice. Partners also were most likely to provide the most physical and emotional support or direct and indirect support. Partners will help out around the home or with the children, will work overtime for financial loss of their partner being unable to work, and will provide consistent emotional support to their chronically sick partner. They also help provide their partner with other forms of physical support such as taking them to doctor appointments or to the ER/hospital. According to the sample, partners eventually take the main role of family support. When the participants had partners, their extended family became more distant and began providing more emotional support rather than physical: "My parents definitely provide a lot of emotional support. And as far as like, you know, taking care of me and making them food for me and things like that, my husband is the one that actually does all that together." Multiple participants credited their partner for their redemptive sequence and said that they would not be able to make it through daily life without them. People without partners tend to credit their family as their closest form of support.

The most supportive family members usually were ones who suffered with a similar chronic pain condition. Because endometriosis is genetic, participants had mothers and sisters suffering with the same condition. This creates a stronger bond between the family members and allows the person to trust their support and feel like they are understanding of their pain. Family members can be supportive without being able to relate to their pain, but it is up to the individual if they choose to accept their support:

My mom is constantly checking on me. I know she's worried about me, but it's kind of annoying. I get a daily text and it's like, 'how are you feeling today? How are you feeling today?' I've had to tell her a few times. Like just don't ask for the record. I'm feeling shitty. Like it's just always going to be shitty.

Helen's mom wanted to emotionally support her daughter from a distance, but the participant rejected her mother's support. Family support is one of the most common form of support, but it is not always one of the strongest. Some families may not be very understanding of chronic pain or illness and judge them for never being around. Martha's family accused her of only calling when she needs a favor:

Sometimes my family is not helpful. My family is Spanish, so it's hard sometimes to get a ride from them because they say 'oh, you only call when you need a favor' and they'll just throw it in your face. I think Spanish people do that sometimes and it's harmful. Because right now we only have one car and I have two kids [with a working husband who uses the car] and when my son and I have certain appointments I have to go to, they don't understand. I'm not asking them because I want to ask them it's because I need to.

The participant's family is not understanding of her pain and situation she is in because of her illness. They assume she does not spend time with her (extended) family because she does not care about them, when she actually struggles to make it through doing her daily responsibilities due to her pain. She needs their physical support to get a ride for her



appointment, but they are unwilling to be supportive and helpful. The participant has a supportive partner who takes on the physical support roles at home when he is not working overtime, and he also provides emotional support because her family is unable to understand the severity of her illness.

While some participants chose to disregard their family's support or did not have their family's support, a majority of the participants' family was a basic emotional or physical support system that they credit with helping them in their lives. Family and partner support is where the participants felt the most comfortable to utilize their support and receive both emotional and physical help.

#### *Physician Support*

The participants saw a mix of supportive and unsupportive doctors over the years according to their illness narratives. There were participants who had seen over ten doctors in the past seven years. Unsupportive doctors were likely to generalize their pain and disregard it as being dramatic: "Some doctors said that it was just like really bad cramps or I have like a low pain tolerance." The unsupportive doctors were detrimental to Ashley's health and quality of life because they made her feel like her pain was all in her head. This can cause individuals to second guess themselves which can defer treatment longer.

Unsupportive doctors were less likely to help with any pain and provide little treatment options. They usually referred their patient to another doctor or made them feel insecure about their pain:

I went to the ER because I could not stop throwing up and was experiencing the worst pain in my life, and I am not someone who goes to the ER, so this was scary for me but I needed help. Hours and an IV later, the doctor comes up to me and makes some remark

about how my tests came back negative and that I sound like I just need to cut back on the Taco Bell [which I had not eaten]. I was mortified and hurt.

Meg was experiencing extreme pain she was not used to and was vulnerable. The doctor she entrusted with her health dismissed her pain as a crude joke. Experiences like these are what cause people with chronic invisible pain to shy away from the medical field and risk not getting the treatment they are in need of. She was diagnosed over a year after that experience with endometriosis. She could have been diagnosed sooner if the doctor had taken her pain more seriously instead of dismissing it. Some participants speculate that their doctors in the past were unsupportive because they think the individuals were only trying to get pain medicine. Other unsupportive doctors that dismissed their pain were gynecologists that did not mention endometriosis as a possibility while treating their patients. Multiple patients were told that their period pain was normal and to “take a midol.” It was not until years passed and the pain began to increasingly worsen that these women realized something more was going on. Unsupportive doctors make it almost impossible for individuals to be properly diagnosed, because if they do not believe your pain then they will not waste their time trying to figure out the problem.

Supportive doctors were more likely to listen to their patients and try to understand their pain. What the participants considered a supportive doctor differed depending on the individual. There were multiple definitions for what a supportive doctor is including willingness to listen to them, believing their pain, and willing to prescribe pain medicine and other treatment options to their patient: “She knows when I can and can't handle the pain, and if I call her she will send me in something that helps me get through at least you know...the couple of days on my period. And I think that's the greatest thing ever. She's a big support to me.” Some participants cannot afford a lot of treatment options and are more interested in having a doctor's support by providing pain

medicine for relief. Other participants considered doctors who were willing to provide additional treatment options including surgery as supportive, and were not as interested in a doctor who covered the pain through pain medicine. They wanted to get rid of the pain through surgery.

Doctors that explained treatment options and their illness symptoms to their patients were more likely to be to be considered supportive:

Yeah, definitely I think she's [the doctor] supportive. I think especially my PA is, because she has more time to sort of sit down and talk with me about different things, like any sort of problem that I have. I just go to her even if it's not related to gynecology. If it's like, look, I'm constipated. She'll sit down with me and talk with me about those things.

Without a supportive doctor or PA, Lauren is not able to understand her illness or the possible treatment options that are out there. They are unable to find pain relief unless they have a supportive doctor who is willing to help treat them. A supportive doctor is necessary when being diagnosed with a chronic pain condition like endometriosis and can help lead their patients to a redemptive sequence if they choose to help treat them and manage their pain together as a team. The participants stated in the interviews that they know their body and pain more than anyone else does, including the doctor. If more doctors were open to listening to how people feel then more people would be able to be treated properly.

### *Support Groups*

All the participants involved in the research belonged to endometriosis support groups online through Facebook. The participants stated that they used their online support groups they were involved in to ask questions and get advice on things related to their condition. Joining online support groups was one of the first things the participants did after being formally

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diagnosed with endometriosis: “After being diagnosed, I started joining some of the Facebook groups and it was like, okay, that's what I need. And I joined that Nancy's Nooks Endometriosis group.” Hannah used online support groups to get advice on how to treat her condition and help find an excision specialist to perform her future laparoscopic surgery.

Some participants stated that they like to help give other women advice and support on the page just as much as receiving it:

I like mentorship, to mentor younger teen girls. One of the things I'll talk to them about every once in a while, is just recognizing, like, is this actually normal? Is it normal to feel pain with this? Or is it normal to have X, Y, and Z happening? Like just having a general understanding of how our bodies are supposed to feel.

Providing online support for other women suffering with endometriosis allows Amanda to find positive meaning in through her illness and come to a redemptive sequence. The participants liked to be involved in the support groups because it provides them the opportunity to give and receive support while getting involved with a new community that relates to them and their life.

Support groups are helpful at making people who suffer with an illness not feel alone. People with other forms of support may not utilize support systems to their full advantage and use it as a form of supplemental support instead. One participant stated that she did not like going on support group pages online because she was tired of seeing all the complaining and negativity on the page: “Because I feel like a lot of people just go and complain in these groups, but maybe that's okay. Maybe people don't have anyone to talk to and they just need to vent to someone.” During the interview she stated that although she doesn't like seeing the negativity on the page, she understands that this may be the only outlet of support for some women who do not

have other forms of support in their life. This shows that although the participants had multiple forms of support, some women may only have one such as online support groups.

### *Friend Support*

Most participants had friends as a form of social support, but not every participant did. Friends in most of the participants' lives were seen as basic support and fun, while others saw friends as an unnecessary stress they do not need or have time for in their life.

The types of support that friends offered were physical or emotional support. Participants that shared details about their illness with their friends were more likely to offered physical and emotional support. The participants expressed their appreciation that their friends were willing to offer physical support, however most of them feel uncomfortable to accept the help and would prefer to ask a family member instead. The most common form of physical support offered by friends was offering a ride to or from an appointment. Emotional support is a more accepted form of support by people who suffer with chronic pain. Some of the participants have friends, but they did not tell them about their condition and therefore their friends do not have the opportunity to provide adequate support. Some participants experienced losing friends as a result of their illness changing their lives and being unable to attend multiple social events due to their chronic pain.

Participants were most likely to utilize friends as a support form if they had a similar pain condition:

I think it's it's hard for someone that doesn't have this to understand exactly what it is (referring to endometriosis). Just because describing it doesn't really provide a big picture of what you go through. So I think it's really hard for someone to understand it if they don't have it, but actually one of my close friends actually has endometriosis so she fully understands exactly what it is and fully supports me.

Jonette's friend also suffers with endometriosis which made it easier for her to open up about her condition and accept her support.

Friends are a helpful form of support when utilized, but are usually not used to their fullest extent of support due to people feeling uncomfortable to bother their friends, or if they do not want to disclose their condition with them. Friends are seen more as a supplemental form of support rather than a main form.

### *Religion & Spirituality*

The participants in the study were either Christian, spiritual, or practiced nothing. Some of the participants expressed that even though they are Christian, they are not very active in their faith. The participants who practiced spirituality were most likely to use it to meditate and clear their minds. They stated that with their chronic pain comes anxiety and meditation can help calm them. They said it was beneficial for their health by lowering their stress levels. The participants who actively practiced Christianity were few, but they all stated that God was a large support system involved in their life and throughout their illness journey. They believe that God is their main support system and that they could not make it living through the pain without him.

One participant, Lois, suffered from infertility due to her endometriosis, and suffered multiple miscarriages. When she found out she was infertile due to the endometriosis, it caused her great pain. She found a redeeming quality of life through her belief in God because she believes that God's plan for her all along was adoption: "We need a lot of parents who are willing to take children that need a home. And so I feel like that is a huge purpose in my world is providing a home for the kids who need it, providing love for the kids who are in bad situations. So that's a huge driving force for me." She believes that God allowed her to be infertile so that

she could help other children in the world who need a mother to love them, because she is the strong person who is capable of providing that love.

Another woman, Macy, said that God supported her throughout her surgery and was the one to physically remove her pain afterwards. She said that while she was in mass one day, all the elders prayed for her while placing their hands on her. She believes that God began healing some of her pain while they were praying over her: “Everybody was placing their hand on me at that point, people had their hands on my back and I was, you know, screaming out before God, you know, and that was my encounter. After that for six whole weeks, I was pain free, in my back, which was amazing...I do lean on God to help me with my pain.” She believes that God helped her experience some pain relief when she needed it, and she leans on God to help her through her pain.

The participants that believed in God actively found that God was a major support system in their life and that they could not live without him. Every person who utilized religion, specifically Christianity in this sample, as a support group led to a redemption sequence showing that religion support may be an important aspect of getting to a redemptive sequence.

Participants with infertility problems were more likely to choose God as their main form of support. A few participants stated that God is the reason they have motivation to live through their pain, and they credit him and utilize him as their main source of emotional support:

“Without God I wouldn’t have been anything. I knew him way before this [pain], so he’s my rock. He’s there with my family’s not there he’s there with my husband is not there”. The women choose God as their main form of support over their family or partners.

*Redemption vs Contamination sequences*

The participants began with a contamination sequence when they were diagnosed with a chronic long term condition such as endometriosis after already living years in pain. How the participants redeem themselves or if they redeem themselves is what is being researched. People who suffer with chronic illnesses can go through multiple redemption and contamination sequences.

The participants' experiences and factors that typically lead to a redemption sequence was when the participant could find another positive meaning from their pain or illness. An example of this is the participant who used her illness journey to help mentor other girls who may be going through the same thing. Support systems are the building blocks that allow the chronically sick to live a life where they can find greater meaning and be positive, despite of their pain. Support systems such as partners and family allow for the sick to have a form of physical and emotional support for daily living. These support systems are important for a redemption sequence because they provide comfort and act as a "crutch" for the individual when they are unable to do things on their own. Physician support is a major key to finding a redemptive sequence because it allows the patients to understand what is wrong with them and allows them to have options to help treat them and their pain. Support groups were utilized as a form of receiving and giving advice to others and forming a sense of togetherness by communicating with other people going through similar pain. Having understanding friends can help lead to a redemption sequence because it provides the individual with comfort and allows them to live their life as normal as possible. Religious support is the mostly likely to lead directly to a redemptive sequence in the sample, but because there were few active religious participants more research may need to be conducted.



Participants with contamination sequences also had support systems. The difference between women with a contamination sequence and women who had a redemptive sequence were how much they utilize their support systems. The participants that relied mostly on themselves and did not use the support systems they have were most likely to lead to a contamination sequence. Women with endometriosis consider themselves strong and are more likely to fight through the pain in fear of guilt and also by not wanting their pain to limit them. They do not want their life to change so they would rather try to deal with all the pressures by themselves, but this is what ultimately sabotages them. They do not want to be reminded of their pain, and when people try to comfort them they are not accepting like Helen mentioned previously:

I kind of wish that I hadn't told people [about my diagnosis]. My mom is constantly checking on me. I know she's worried about me, but it's kind of annoying. I gets a daily text and it's like, how are you feeling today? How are you feeling today? I've had to tell her a few times. Like just don't ask for the record. I'm feeling shitty. It's just going to be shitty. So I started lying now. After surgery, because I don't feel 100% but everybody thinks I should. Because surgery just fixes things. So I sort of made the decision a couple of weeks ago that I was just going to tell everybody I'm doing great. Yeah, and then they finally leave me alone.

Helen decided that she would rather lie to her support systems than to receive the emotional support that they were giving. She prefers to pretend like nothing is wrong with her even though she suffers with daily pain. She complained of all the things she misses out on in life now and all the things she has to accomplish by herself. She chooses to accomplish everything alone because she had almost every support system and said that she is independent and does not need them. This participant was experiencing a contamination sequence because

she chose to lean on herself and not utilize the support systems she has, which caused her a lower quality of life from the stress.

Another factor that could inhibit growth to a redemption sequence is chronic pain. Women who suffered from chronic pain with little pain relief were more likely to lead to a contamination sequence. Surgeries caused participants to experience both redemptive and contamination sequences depending on their outcome.

The participants with a redemption sequence were most likely to have at least one quality form of support that they felt comfortable utilizing. The participants with contamination sequences were likely to have support systems, however they did not utilize them. When it comes to a redemptive sequence you only need one form of quality support, but you must utilize the support or it is useless.

## DISCUSSION

The common themes experienced by the participants are common themes that could be experienced by a vast array of chronic invisible illness. Multiple chronic conditions have a lack of understanding about their condition that forces them to learn how to advocate for themselves. People with chronic illness also go through a transition from their old “healthy” self to their new “sick” self. They have to learn how to adapt and be okay with their new normal. The final common theme is lack of awareness about the condition. Some chronic conditions are known more than others, however there are almost always misconceptions about the condition and its severity.

After reviewing the sequences and the influence of support systems influence multiple inferences can be made. Only one quality form of support is needed for a redemption sequence,

Running Head: Support Systems Influence on the Illness Narrative sequences of the Chronically Sick

but the forms of support that showed the most influence are partner support, physician support, and religious support. Support groups and friend support were seen as the most supplemental forms of support and were usually utilized the least.

The research shows that support systems have a direct influence on the chronically sick's sequence outcome. The participants in this study all had at least one form of support system. Results showed that the number of support systems is less important than the quality of the support (Hupcey 2001). The more comfortable the individual is with the support system, the more help and support they are willing to receive. This was especially true regarding partner and (extended) family support. The more comfortable the participant became with her partner rather than her family, the more support she was willing to receive from her partner and the less she asked of her family. Similar to previous research, her partner began becoming both the direct and indirect form of support, and the family became less direct and more indirect support (Crotty *et al.* 2015).

Doctors have the ability to provide emotional support and physical support, but they are more likely to provide physical support. Some supportive doctors provide emotional support, but the majority of doctors in general typically only perform physical support through treatment and surgery. Religion is usually left for emotional support, but two participants in the sample believe that their God healed their pain, which is physical support. The strong faith individuals have in religion and their belief of a life after helps motivate the individuals to keep living through the pain, so that one day they will be with their divine creator. Religion helps them remain more optimistic and gives their life additional meaning, which leads to redemption sequences.

Support groups provide advice and a sense of togetherness that can only be established when you share similar pain and experiences. Although most of the participants used the support group to receive advice only, other participants mentioned how for other women support groups online may be their only quality support system they have. Some people are not as fortunate as others to have people close to them who are willing to help them and understand their pain. This is why these women may reach out to support groups because they know the people in the group may be able to relate to them better and give them proper support.

Friend support may be the most supplemental form of support because multiple participants that experienced redemption sequences did not have any friends and only had family. Friends were seen as a benefit to have, but not needed to find motivation to live. This may be due to the fact that people would rather ask their family for support rather than ask a friend that they are more uncomfortable with for direct support (Beatty 2004).

## CONCLUSION

Individuals who experience chronic pain have a lower quality of life. Through their chronic pain, they have to figure out how to succeed and stay motivated in life as their new limited version of themselves. Chronic pain individuals, such as the women with endometriosis, experience similar illness narrative themes that help shape their illness journey. Every illness narrative can have multiple redemption and contamination sequences. Having a quality support system available only helps categorize the sequence outcome, depending on if they choose to utilize the support system. All support systems are viable options to help bring someone to a redemptive sequence, however partner/family support and doctor support were the most commonly utilized forms of support. Religion, partner/family support, and doctor support are the

three most important support groups to help bring someone to a redemption sequence. Support systems and friends can be beneficial at helping people cope and live with their illness, but are not necessary for having a redemption sequence and are seen as supplemental. When religion is utilized it is the most beneficial support system to lead to a redemption sequence.

If the participant chooses to lean on themselves as opposed to taking advantage of their support systems, they are more likely to lead to a contamination sequence. Individuals with endometriosis and other chronic conditions believe they are strong and do not want to appear as weak and want their lives to go back to how they were before the pain. If they do not learn how to accept others' help and support then they are more likely to be untrusting and negative about their future, ultimately leading to a contamination sequence

Support systems help provide people with chronic pain a higher quality of life and motivation to keep living through the pain. The limitations of this research are that every participant had at least one form of support and some support systems had little sample sizes to compare. Further research could be conducted regarding religious support and their influence on illness narrative sequence outcomes. The research showed that religion appears to have a high direct influence on redemption sequences throughout illness narratives, however the sample size of active religious participants was very small. Overall, support systems did have an influence on the sequence outcome of the chronically sick and how they viewed their lives.

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**APPENDIX A:**

**INFORMED CONSENT FORM**

**UNIVERSITY OF TENNESSEE AT CHATTANOOGA**

*How do Support Systems Influence the Illness Narratives' Sequences of the Chronically Sick?*

*Redemption or Contamination: The Illness Narratives of Women with Endometriosis*

Please read this consent document carefully before you decide to participate in this study.

- **Purpose of the research study:** This is a research study designed to contribute to general knowledge. The purpose of this research study is to examine how support systems may influence people with chronic illness' life in a negative or positive way after diagnosis, and the effects chronic pain has on individuals lives (specifically endometriosis). Around thirty women with endometriosis will be interviewed representing the chronically sick and will be recruited using snowball sampling.
- **What you will be asked to do in the study:** Your participation will involve being interviewed and answering questions about your health, life, and support systems.
- **Time required:** 15 minutes to 30 minutes (as needed)
- **Risks and Benefits:** The risks of the study are the possibility of private identifiable information being released (such as health status) and having to reflect on past health and life circumstances that may cause emotional distress. The potential benefits of the study include adding to academic knowledge about chronic illness and endometriosis. You will not benefit directly by participating in this interview. There are no incentives and you will not be paid for your participation.
- **Confidentiality:** Your identity will be kept confidential to the extent provided by law. The transcriptions and recordings will be saved under a pseudonym on a password protected flash drive. Your name will not be mentioned during the recorded interview and will not be used in any report or publication. After two years, the flash drive and transcripts will be terminated.
- **Voluntary participation:** You must be eighteen or older to participate. Your participation in this study is completely voluntary. Should you elect to discontinue participation, any information already collected will be discarded. There is no penalty or loss of benefit for choosing not to participate. You have the right to withdraw from the study at any time without consequence or penalty.

Whom to contact if you have questions about the study:

Student researcher: Allison Dearing 423-322-9757 [hxt837@mocs.utc.edu](mailto:hxt837@mocs.utc.edu)

Faculty advisor: Dr. Shawn A. Trivette 423-425-5461 [Shawn-Trivette@utc.edu](mailto:Shawn-Trivette@utc.edu)

If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you may contact Dr. Amy Doolittle, Chair of the UTC Institutional Review Board at (423) 425-5563. This research protocol has been approved by the UTC Institutional Review Board. Additional contact information is available at [www.utc.edu/irb](http://www.utc.edu/irb).

Agreement: If you wish to participate in this study, please sign the form below. A signature will indicate agreement to participate and to be audio recorded.

Participant's Name: (Print) \_\_\_\_\_

Signature \_\_\_\_\_ (Date) \_\_\_\_\_

Interviews will be recorded using audio recording to assist with the accuracy of your responses. The recordings will be transcribed and kept by the researcher in a locked flash drive. Only the researcher will have access to these recordings and they will be destroyed after they are transcribed. The transcriptions will have removed any personal identifiers from the interviews, and may be used in future studies without additional informed consent. The transcriptions and informed consent will be deleted/destroyed by December 2020. By signing this form you are consenting to audio recording of the interview.



**APPENDIX B: Interview Guide**

**RQ:** How do support systems influence the (redemption or contamination) sequence of illness narratives’ from the Chronically sick?

- When did you start getting sick? (Illness Narrative)
  - How did you know something was wrong? How long have you been sick?
- What are common symptoms you experience and how often?
- When were you properly diagnosed?
  - How long did it take to be diagnosed?
  - Did you receive other diagnosis before this?
- What types of treatment options have you tried?
- How do you see your life now vs before you got sick?
  - Describe your life before proper diagnosis vs after (did diagnosing make a difference?)
- Do you think the way people think of you has changed since being diagnosed with endometriosis(chronic (invisible) illness)? How has it affected your relationships?
  - Do you think there is a stigma (disgrace) with having endometriosis?
  - Because endometriosis is an invisible illness, do you think this has affected the way people treat you?
- What kinds of support systems are involved in your life?
  - Do you practice religion?
  - attend support groups?
  - have supportive friends/family?
  - have a good/qualified doctor or therapist?
  - Explain them (all that apply)
- How have support systems impacted you?
  - Have they been beneficial to your life with chronic illness/ healing? Not beneficial?
  - Could you succeed without them (support system)?

- Do you feel like your support systems understand you? Do you feel heard? Do you feel like they take your pain seriously?
- What is currently going on in your life (regarding your illness and just in general)?
  - what are your future plans?
- How would you say endometriosis affected or changed your life?