Stories of Scleroderma: Losing, Learning and Living with the Chronic Illness

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Stories of Scleroderma:

Losing, Learning and Living with the Chronic Illness

Senior Honors Thesis

Boston College Sociology Department

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This project is dedicated to my Aunt, Maureen Brannigan
She was a true inspiration and I (literally) could not have completed this project without her
Rest in peace, beautiful
8/29/61 – 7/17/10

Special thanks to my advisor, David Karp, for his guidance and feedback
Introduction

One night when I was home with my parents in March 2012, my dad handed me a thick stack of papers that he wanted me to read. It was a document written by his sister, my Aunt Maureen, who passed away in July of 2010. She died from complications of an autoimmune disease called scleroderma. It is a cruel disease and not something you would ever want someone you love to go through. Maureen’s symptoms started in the beginning of 2003 and quickly progressed. This piece that she wrote was written in 2006 when her scleroderma subsided a bit and was in somewhat of a remission stage. She started the document by admitting, “I never thought about being a writer or ever writing a book, but I have a story to tell and by sharing it I hope I could help or inspire someone who is going through any type of illness or rough time in their life.” From what I gathered, she intended for her writing to be published as a book or featured in some sort of women’s health magazine. Her story goal was for her piece to raise awareness about the rare, little known disease called scleroderma and give one narrative of what it is like for people living with it. Unfortunately, she was never able to accomplish this in her life, as the scleroderma flared up again and she ultimately lost her battle with the disease.

I started reading the document late one night and could not stop. I stayed up until three in the morning finishing it. It was about fifty pages of single-spaced text. I was overcome by the account of how much she had been through. While I saw her fairly often and witnessed the way the disease debilitated her, she did a great job of hiding just how much she was really suffering. There were things I never knew she went through until reading her story. I was also overcome by her optimism and will to fight. I think that mindset played a huge part in her ability to fight the disease for so long. I was thinking about this as I was falling asleep one night later that week and it hit me that her writing could potentially be a great starting for a thesis project.
The sociological study of any illness is important and worthwhile, but scleroderma even more so because it is so poorly understood. People with chronic illnesses suffer physically and mentally and must navigate their changing role in society. I primarily saw my study as a tool for educating others with scleroderma, their caretakers and medical providers, and the general public. I saw myself furthering my aunt’s original objective by telling her story and supplementing it with the narratives of others with the disease and bringing a sociological explanation to their experiences. While I am do not expect to change any policies, I would be ecstatic if my work results in more people knowing what scleroderma is all about and maybe providing more money towards research.

People with scleroderma are worth studying because of the rarity and unique aspects of the disease. This study is sociologically useful because I am giving a voice to people that oftentimes feel as if those around them do not understand what they are going through. Focusing my thesis on the experiences of women with scleroderma may also be a way of raising awareness about the disease and circulating useful information to fellow scleroderma sufferers. I chose to focus on women with scleroderma, as the population was more accessible and the sociological implications of a disease can vary by gender.

I have found that my aunt’s case was kind of the “worst case scenario” and a manifestation of the fears of those with a less progressive case of the disease. By comparing and contrasting Maureen’s story with those of others diagnosed with scleroderma, I will highlight the variations in the disease and the way severity of symptoms and degree of visibility relate to sociological concepts in the field of health and illness and social psychological experiences. After highlighting what exactly scleroderma entails for different people, I will delve into their experience with concepts like stigmatization, identity, health within illness, and spirituality.
Because of the complicated nature of a rare, poorly understood illness, I also find it valuable to touch on the financial burdens and struggles within our health care system. Additionally, I explored the way one’s religious fervor, faith, and/or spirituality strengthened, weakened, or simply evolved as a result of the struggle with scleroderma. Each of these aspects will be explored through the different methodological techniques I used, namely a detailed case study of my aunt’s experiences, interviews with other women with scleroderma, and analysis of women’s anonymous postings on an online scleroderma support forum.
Theoretical Framework

In terms of a theoretical position to apply to this research, micro-level, social psychological theories fit best. Symbolic Interactionism analyzes happenings in the world in a way that is most in line with my beliefs about society. This theory focuses on the subjective meanings involved in social interactions. Symbolic Interactionism applies best to micro-level situations, including this research on social interactions for those with a chronic illness like scleroderma.

Erving Goffman’s work on symbolic interactionism and dramaturgical analysis is applicable to the forced identity transformation of scleroderma sufferers. In Goffman’s books, he writes about what happens when someone is robbed of his or her identity and the different ways in which they could react. This focus on social interactions and the appearances we seek to present in those situations is the crux of his (1959) book *The Presentation of Self in Everyday Life*. That book applies to the way scleroderma sufferers present themselves on the “front stage” and “back stage” and helps me isolate the aspects of their identities they feel comfortable sharing publicly and those that are mostly confined to their homes. Goffman’s work also talks about the metaphor of life as a stage and a series of human interactions where we are cognizant of and monitoring our performances. He mentions the fact that certain things are at stake when we engage in interactions, namely honor, intimacy, power, and information (Goffman, 1959). I explored how the dangers of interactions are heightened for those with an illness like scleroderma and what they worry about the most when engaging with others. I noticed a disconnect between what scleroderma sufferers allow others to know and see and how much they are really dealing with behind closed doors.
Goffman’s book, (1963) entitled Stigma, has been the most helpful and applicable to my research problem. Goffman’s notion of stigma is one of the central concepts of my study. For people with diffuse scleroderma, the disease will quickly progress to the point of visibility and the symptoms cannot really be hidden. It is most definitely an example of stigma, specifically a body stigma. "Persons who have a particular stigma tend to have similar learning experiences regarding their plight, and similar changes in conception of self - a similar 'moral career' that is both cause and effect of commitment to a similar sequence of personal adjustments" (Goffman, 1963, p. 32). The notion of similar experiences was an assumption I made going into my study. I assumed that those with the stigma of scleroderma would have some similar learning experiences and processes of adapting. While the similarities are there to an extent, the non-uniform nature of the disease and the extremely large spectrum of severity make for a more complicated application of Goffman’s stigma research.

I think the rarity of scleroderma and the lack of awareness/understanding of the disease may contribute to the associated feeling of stigma. For well-known diseases like cancer, I believe our society has created a way of recognizing that someone is a cancer patient and responding to them appropriately. For example, we generally would not criticize them for wearing a wig or headscarf. However, it is unlikely that many people will know what scleroderma is. I explored this idea most thoroughly in my semi-structured interviews. I was interested in hearing about how the rarity of the disease affects interpersonal relationships and the feeling of stigma associated with the illness. For example, my Aunt Maureen would sometimes get hurtful comments from ignorant people. While they typically were not intended to be mean, things were said like when a woman at a store once told her, “I give you credit for
having the nerve to come out looking like that.” I am arguing that that is not the type of comment that would be said to someone with cancer or some other well-known disease.

Goffman categorizes people as the stigmatized, the normal, and the wise. "The first set of sympathetic others is of course those who share his stigma. Knowing from their own experience what it is like to have this particular stigma, some of them can provide the individual with instruction in the tricks of the trade..." (Goffman, 1963, p. 19). In my study, those who share the stigma are other people with scleroderma. The wise are “persons who are normal but whose special situation has made them privy to the secret life of the stigmatized individual and sympathetic with it, and who find themselves accorded a measure of acceptance, a measure of courtesy membership in the clan” (Goffman, 1963, p. 28). These are the few people who are part of the normal population but accepted by the stigmatized person because of their special knowledge and sensitivity to their plight. As expected, it seems that many scleroderma sufferers have a small circle of wise people, namely family, close friends, and those medical professionals around whom they feel comfortable. I will argue that the extent to which a person is “wise” is along a continuum. For my aunt, her mother and her fiancé were supremely wise to the complexities of her struggles, whereas the rest of our family only had varying degrees of knowledge because there were things she was embarrassed for us to know.

As I approached my research from the lens of symbolic-interactionism, I paid attention to stigma symbols. "Prestige symbols can be contrasted to stigma symbols, namely, signs which are especially effective in drawing attention to a debasing identity discrepancy, breaking up what would otherwise be a coherent overall picture, with a consequent reduction in our valuation of the individual" (Goffman, 1963, p. 43). Stigma symbols might apply more to those in the early stages of scleroderma or those with more mild cases. When the disease is more severe, the
individual progresses from “discreditable” to “discredited” (Goffman, 1963, p. 41). Whether they are discredited relates to the "...'visibility' of a particular stigma, that is, how well or how badly the stigma is adapted to provide means of communicating that the individual possesses it" (Goffman, 1963, p. 47). If it is difficult to tell the individual possesses the stigma, much of her identity may remain in tact. However, when the disease is extremely visible the “normal” might be quicker to devalue the scleroderma sufferer.

Goffman’s discussion of stigma management relates to the way patients present themselves in different social situations. "The area of stigma management, then, might be seen as something that pertains mainly to public life, to contact between strangers or mere acquaintances, to one end of a continuum whose other pole is intimacy" (Goffman, 1963, p. 51). It is implied, and I have found it to be true, that those with the stigma do not need to manage it when they are just in the company of their few “wise” intimates who they trust. "Control of identity formation has a special bearing on relationships (Goffman, 1963, p. 85)...Further, as already suggested, every relationship obliges the related persons to exchange an appropriate amount of intimate facts about self as evidence of trust and mutual commitment" (Goffman, 1963, p. 86). Those close contacts will be privy to much of the intimate facts of the disease even though the sufferer might perceive the facts as shameful or embarrassing. When in the presence of strangers or those they feel less comfortable around, scleroderma sufferers may take special care to manage the stigma. "In [stigma management], special timing may be required. Thus, there is the practice of 'living on a leash' - the Cinderella syndrome - whereby the discreditable person stays close to the place where he can refurbish his disguise, and where he can rest up from having to wear it" (Goffman, 1963, p. 90). The time commitment associated with stigma management connects nicely with the idea of illness as career, as explored by David Karp.
David Karp’s *Speaking of Sadness* (1997) can be used as a model or inspiration for my research. The similarities include the fact that it focused on the narratives of people with a particular illness (in this case, depression) and primarily used in-depth interviews for data. I anticipate applying Karp’s theory/metaphor of illness as a career. For patients with a severe case of diffuse scleroderma, it becomes almost impossible to continue working their pre-diagnosis job. Rather, their time is spent going to various doctors’ appointments and physical therapy. For Maureen, the disease’s attack on her internal organs also resulted in kidney failure and the necessity of dialysis. She described her schedule:

I went to PT three times a week for a couple of hours (11:00-1:00) and then I would go straight to dialysis, which I was able to get on the same day as PT (M-W-F). I usually arrived at dialysis around 1:30 and left about 5:30. That was really my whole day – three times a week. After dialysis I was usually tired and drained and almost always had a severe headache. I was left with no choice most times but to come home and lay down. Tuesdays and Thursdays usually consisted of several doctor appointments, bloods tests, other tests or same day hospital procedures.

That description really shows the way in which being a scleroderma patient becomes like a career. Additionally, the way Karp weaves general information about depression with personal narratives with sociological theory in his book is a model I looked to while doing my own writing.
Literature Review

A. What is scleroderma?

The very early stages of my research focused on fact-finding about scleroderma. While I already had knowledge of the disease because of my Aunt’s struggle with it, I utilized the Scleroderma Foundation’s website to confirm and expand my knowledge.

Scleroderma is a rare autoimmune disease. The name comes from the Greek works “sclerosis” (hardness) and “derma” (skin) and a hardening of the skin is typically one of the most visible effects of the disease. Scleroderma is divided into two types: limited scleroderma which only affects skin in certain areas and does not attack internal organs; diffuse scleroderma (also called systemic sclerosis) involves the skin as well as tissues beneath the skin and blood vessels and major organs (Scleroderma Foundation, 2012). Maureen had a severe case of diffuse scleroderma. While there is much variability from patient to patient, people with diffuse scleroderma are often tired, lose appetite and weight and have swelling and pain in the joints. Skin becomes very tight, shiny, and itchy. The damage from this disease typically occurs over three to five years and then the scleroderma often enters a stable/remission stage and the tightening might even reverse. For those with diffuse scleroderma resulting in major organ damage, the struggle is to make it to that stable stage before the disease kills them (Scleroderma Foundation, 2012).

Scleroderma is difficult to diagnose, as it’s symptoms initially overlap with many other autoimmune diseases like rheumatoid arthritis and lupus. Early symptoms usually manifest in three common complaints: puffy hands, Reynaud’s phenomenon (poor circulation in the hands), or joint pain/arthritis. Diagnosing scleroderma is difficult and misdiagnoses are common. Misdiagnosis is a dangerous problem, as proper, rapid diagnosis and treatment is extremely
important for a patient’s long-term outlook. There are an estimated 300,000 people in the U.S. with scleroderma and about a third of those have the diffuse form. It is about four times more common in women than men, and the usual age of onset is between twenty-five and fifty-five, although there are obviously outliers (Scleroderma Foundation, 2012). Maureen was forty-one when her symptoms started. One of the scariest things about scleroderma is that there is no cure and doctors just have to use trial-and-error to figure out what works best to manage the symptoms. Additionally, it is unsettling that the cause of the disease is unknown. My aunt lived an extremely healthy, energetic lifestyle but this could not prevent her from getting the disease. Researchers do not believe scleroderma is genetic, although a susceptibility gene has been identified which can increase one’s likelihood of getting the disease (Scleroderma Foundation, 2012).

The issue of the unknown cause of scleroderma is troubling to those diagnosed with it. In South Boston, where there are an unusually high number of scleroderma cases, women with the disease are not convinced that environmental pollution is not a trigger. After an 11-year investigation by the Massachusetts Department of Public Health, answers were slim. The study “determined that genetics, not the environment, played a significant role…that people with a family history of specific autoimmune rheumatic diseases, such as rheumatoid arthritis, Raynaud’s disease, lupus, and thyroid disease, were more likely to develop scleroderma” (Irons, 2010). However, a sample of only 41 people with scleroderma and 219 control subjects meant they could not say for certain that the environment was not a factor. Those with the disease expressed disappointment and the belief that “if we had an answer then we could fix it” (Irons, 2010). For one woman with scleroderma, she maintains the belief that “there is something in the environment that is causing this…I do think there is a genetic component, but when we are
exposed to it, it triggers the disease” (Irons, 2010). The mysterious nature of scleroderma is a theme I would like to explore in my study. I am interested in hearing participants describe how their symptoms developed and progressed. When they were ultimately diagnosed with “scleroderma,” what emotions arose? I would also like to hear of any personal theories or beliefs about the cause of scleroderma.

B. Loss

As I solidified my research topic and the sociological importance, I started searching for journal articles related to health and illness. In “The Perspective of Patients on Their Experience of Powerlessness,” a study of patients with chronic conditions, Belgian researchers conducted 40 interviews to better understand the importance of patient empowerment and the way powerlessness threatens their identities. Aujoulat, Luminet, & Deccache (2007) describe patient participation in health care decisions as a way of empowering them. Because scleroderma is not widely known and most who are diagnosed probably never heard of it, I wondered if scleroderma patients would initially feel apprehension about negotiating decisions with doctors. However, I assumed that this might change as their general knowledge of the disease increased as well as their personal knowledge of the way their bodies are affected.

In this study, the findings included shared experiences of loss of control over one’s body, loss of control over one’s emotions, and loss of control of time. These losses contributed to a general sense of insecurity. Additionally, participants felt a loss of their social and personal identities. This loss “appeared in our study to be the most distressing situation of powerlessness” (Aujoulat, Luminet, & Deccache, 2007, p. 779). Participants reported loss of identity as a result of the inability to work, the inability to participate in activities, a sense of stigmatization,
dependence on others, and conflicting self-images (Aujoulat, Luminet, & Deccache, 2007).

Based on this study, I expected much of my data to relate to the theme of loss and the different areas of life that have been negatively impacted by scleroderma. In each of my three data sources I found support for these ideas.

In “The Body, Identity, and Self: Adapting to Impairment,” Kathy Charmaz (1995) focused on chronic illness and how the ill deal with it through adaptation. I adopted her definition of adaptation and looked for signs of my participants adapting. “Adapting means altering life and self to accommodate to bodily losses and limits and resolving the lost unity between body and self. It means struggling with rather than against the illness” (Charmaz, 1995, p. 657). Adaptation is not the only way to live with illness, but adapting to the illness corresponds well with identity transformation because it involves negotiating the intersection of body, identity, and self.

Charmaz’s study was a great example for me as it used interview data from people with chronic illnesses and uses grounded theory analysis. Charmaz explained, “Some chronically ill adults hold fast to regaining their unimpaired selves. Others pursue contradictory identities. For example, a stroke patient may simultaneously want to be the passive patient today and the fully recovered worker tomorrow without realizing that the latter requires concerted effort right now” (Charmaz, 1995, p. 658). That description is a great example of a paradox within one’s identity. Especially for the portion of my research consisting of interviews, I paid particular attention to patterns and paradoxes in the narratives.

Charmaz’s findings included narratives regarding experiencing an altered body that is “alien” or “foreign territory”. “Experiencing this bodily alienation leads people to rethinking explicitly their previously held notions of body and self” (Charmaz, 1995, p. 662). She also
discussed the difficulties experienced by those who are youthful and beautiful. For my aunt, this was a struggle in the early stages of the disease when it was largely invisible and her great looks were not compromised at all. Despite looking totally healthy, she was feeling weak, fatigued, stiff, and knew something was not right. Like one of Charmaz’s participants with arthritis, “She could not enforce her identity claims as ill as long as she appeared healthy, pretty, and able” (Charmaz, 1995, p. 666).

Charmaz went on to discuss identity trade offs, which is a theme I looked for as well. “As people shift their identity goals laterally or downward, they may relinquish what others view as the more socially valued identity. They feel their losses. They think about their lives. They assess the costs and benefits of relinquishing activities and responsibilities and, therefore, identities” (Charmaz, 1995, p. 671). Despite all that they have lost, those that begin to adapt to their new lives with the disease can regain a sense of wholeness (Charmaz, 1995, p. 658). In my analysis of my Aunt’s case, interviews with other scleroderma sufferers, and monitoring of online support forums, I remained observant of evidence of adaptation in the narratives.

In a study out of a Swedish hospital’s department of rheumatology, scleroderma (also referred to as systemic sclerosis) was specifically studied. Sandqvist, Scheja, & Hesselstrand (2010) did a quantitative study measuring the work ability of fifty-seven patients. Work ability was primarily hindered by pain, fatigue, and impaired hand function (Sandqvist et al., 2010, p. 1744). “Adult life is markedly influenced by employment. Work creates routines for individuals and family, and influences the balance of daily activities. Long periods of absence from work due to unemployment are often accompanied by loss of social status and life roles,” Sandqvist et al. (2010, p. 1739) explained. Losing the ability to work is a major problem for those with scleroderma and inevitably creates an identity crisis and emotional distress. In this study, one of
the independent variables was disease duration (Sandqvist et al., 2010, p. 1740). I considered this objective variable in my study and attempted to find out whether the amount of time a participant has had the disease impacts their struggle with identity. I anticipated that it was somewhat of a bell curve – in the beginning, when the disease had not progressed very far, there might be only a few, easy identity trade-offs; as the condition worsened, they reach the height of identity crisis; and after living with the disease for a substantial amount of time, they come to accept it.

C. Health within illness

Despite living with a chronic condition, many people (my aunt included) somehow maintain a sense of health in the midst of illness. After all, they are, for a substantial amount of time, living with a disease rather than dying from it. In her study from the Journal of Advanced Nursing entitled “Health Within Illness: Experiences of Chronically Ill/Disabled People (1996),” Elizabeth Lindsey collected data from tape-recorded, transcribed conversations between researcher and participant. The researcher found that “the phenomenon of feeling healthy while living with a chronic condition emerged through the explication of six themes. These themes were: (a) honouring the self; (b) seeking and connecting with others; (c) creating opportunities; (d) celebrating life; (e) transcending the self; and (f) acquiring a state of grace” (Lindsey, 1996, p. 468).

As an example of honoring the self, one respondent explained, “‘Health is about being in control of myself, and making my own decisions. That is the most important thing. I am feeling empowered to make choices, to speak out and let my thoughts and feelings be known to others’” (Lindsey, 1996, p. 468). The empowerment described in this study complicated the assertion of
powerlessness described by Aujoulat et al. (2010). In my data analysis, I paid attention to the circumstances under which people feel more empowered rather than powerless, and vice versa.

Participants in Lindsey’s study talked about the importance of relationships, and particularly ones in which they could help the other person. Participants found that some previous relationships faded away because they were rather shallow and lacked deeper connections. Rewarding relationships came with “a balance of giving and receiving,” often difficult when a disease creates such a dependency on others. However, when participants figured out ways to do nice things for friends, they experienced great joy. Additionally, “all of the participants talked of a commitment to helping others with chronic conditions…A respondent with multiple sclerosis talked of wanting to share her knowledge with others” (Lindsey, 1996, p. 468). My Aunt’s own narrative is evidence of this desire. I looked for evidence of a continuation of this commitment in the scleroderma narratives.

To feel healthy, it was important that participants thought of their illness/disability as a “challenge, an opportunity to make changes in their lives, to learn, and to grow” (Lindsey, 1996, p. 469). They went on adventures and took risks. Celebrating life was another way of increasing energy and feeling alive. “One person explained, ‘it is living life to the fullest, feeling alive, really alive’” (Lindsey, 1996, p. 469). An important aspect of feeling alive was maintaining a strong sense of humor. Using imagination and fantasy were ways for people to transcend the self and increase experiences of feeling healthy.

The last, and to me most interesting, theme is that of acquiring a state of grace. I approached my study wondering how religion and God might show up in the interviews. I assumed that some participants would describe an intense anger at or disbelief in God, while others would delve deeper into their religion and use it as a source of strength. My Aunt fell into
the latter category, and although I do not think of her as particularly religious, she was comforted by the fact that her Irish-Catholic mother sprinkled holy water on her bed each night. This article described how “the people in the study attributed their experience of feeling healthy to an awareness of their spirituality, with a sense of connectedness, wholeness, harmony, and peacefulness…the participants talked of an attachment with God, or the Creator, and an expanded consciousness” (Lindsey, 1996, p. 469). I was interested in asking questions about the role of religion and spirituality and the way scleroderma had positively or negatively impacted an understanding of God or something higher than us.

In “Chronic Illness Self-Management: Taking Action to Create Order,” researchers asked individuals diagnosed with arthritis to write autobiographies of their lives since the disease and then conducted follow-up semi-structured interviews. Kralik, Koch, Price, & Howard (2004) gathered an understanding of how those with a chronic illness conceptualize self-management. In the research article, they included the questions they asked and I adapted these questions for my scleroderma interview guide. The questions were:

- what were your experiences of seeking medical help?; what was it like when you received a diagnosis?; what implications did you think this illness would have for your life?; how did you perceive the people around you coped or reacted to your diagnosis?; how do you live with arthritis?; what are the sorts of things that help you to live with arthritis?; could you share an experience that you will never forget because it best describes what it means to live with arthritis?; what was important to you before arthritis and what is important to you now?; how has life changed for you?; and what advice would you give to a friend who has just been diagnosed with arthritis? (Kralik, Koch, Price, & Howard, 2004, p. 261).
The findings described self-management as a construct “where the purpose was to create order from the disorder imposed by illness” (Kralik et al., 2004, p. 262). Participants were primarily motivated to manage pain and the loss of movement and strength. One person explained, “‘The hardest thing I have to cope with, apart from the pain is the restriction on my activities and the fatigue’” (Kralik et al., 2004, p. 262). Those with arthritis were also able to manage the illness by mobilizing their resources (psychological, physical, material) in order to create the best possible quality of life. As a result, they were able to maintain a certain amount of independence (Kralik et al., 2004, p. 262). By prioritizing and making lifestyle changes, those with the chronic illness were able to incorporate it into their lives.

D. Methodological Ideas

In “The Perspective of Patients on Their Experience of Powerlessness,” (2007) the researchers used qualitative methods of in-depth interviewing in this exploratory and descriptive study. Their participants had various chronic conditions, including some with autoimmune diseases, namely lupus erythematosus, multiple sclerosis, and scleroderma. They used a convenience sample and participants volunteered to be interviewed after their physician approached them with a letter from the researcher explaining the study. The average interview was 1 hour and 45 minutes long and tape recorded with consent. The location of the interviews varied according to participant preference (Aujoulat, Luminet, & Deccache, 2007). I used this model for my interviews, as some patients might prefer to be interviewed in a hospital, in their doctors’ offices, or at their homes, for example.

The interview guide utilized open-ended questions and “most participants started the interview with a spontaneous and detailed account of the history of their illness” (Aujoulat et al.,
2007, p. 774). I liked this technique for starting the conversation and started my interviews similarly by asking the participant how she started experiencing symptoms or what her life was like before the scleroderma intruded. This question lent itself well to gathering information about their normal lives pre-scleroderma and the noticeable indications that something was wrong.

In a study entitled “‘I am not the kind of woman who complains of everything’: Illness stories on self and shame in women with chronic pain,” Werner, Isaksen, & Malterud (2004) used in-depth interviews to explore “issues of self and shame” and the way they are shaped by “cultural discourses of gender and disease” (Werner, Isaksen, & Malterud, 2004, p. 1035). These researchers used purposeful sampling for a sample of 10 women. In the data analysis, they used coding and categorizing and Giorgi’s method of phenomenological analysis. The findings consisted of patterns of stories the women told. For example, they made it a point to emphasize their strength in spite of their physical disabilities (Werner, Isaksen, & Malterud, 2004). This article was most significant for its methodological information. I really liked the description of the four stages of Giorgi’s phenomenological analysis, which the researchers used. It consisted of: “(a) reading all the material to obtain an overall impression, and bracketing previous preconceptions; (b) identifying units of meaning representing different aspects of the women’s experiences, and coding these; (c) condensing and abstracting the meaning within each of the coded groups; and (d) summarizing the contents of each group to generalize descriptions and concepts reflecting the most important experiences from the voice of women” (Werner, Isaksen, & Malterud, 2004, p. 1038). I used a similar process for analysis. Additionally, I was encouraged by the fact that these researchers were able to see evidence of concepts using a very small sample of only 10 participants.
Methodology

In determining research methods, it is important that the chosen methods fit the research problem. In this case, I think the methods that fit my problem are qualitative ones because quantitative survey data would only scratch the surface of the issues and limit the personal, sensitive human aspects of living with scleroderma. My research study focused on how scleroderma affects a woman’s identity and the ways in which she deals with this identity transformation in social interactions. I had some preconceived hunches but no firm hypothesis. Thus, my study was inductive and the most important themes emerged as I gathered data and literature.

Originally, I thought in-depth interviewing would be the most effective method. One of the strengths of qualitative interviews is “exploring the stories and perspectives of informants” (Arksey and Knight, 1999, p. 34). I envisioned my data coming primarily from in-person interviews with scleroderma patients. Doing interviews allowed for the most full understanding of the experiences of a few women with the disease. Because interviews are so time consuming and we had a limited amount of time to complete our thesis projects, I chose depth over breadth by doing long interviews with a small group of people. “Random sampling strategies are not always feasible. Many populations are rare, small, or hard to find…You must seek them out through one of the targeted, or purposive, sampling strategies” (Lune et al., 2010, p. 82). Time and money constraints make a random sample impossible, but I used purposive/convenience sampling to reach female scleroderma sufferers in the area. My participants came from one rheumatologist’s office in Rhode Island. The small sample size could be seen as a weakness, but I was not looking to make sweeping generalizations. Rather, I was more interested in adding to the literature on the disease and increasing awareness. A sample of any size would do this, and,
in fact, the in-depth interviews allowed for more comprehensive knowledge to be generated because there was an opportunity for clarification and follow-up questions.

The prospective interview participants were approached by their rheumatologist and told a bit about my study. He gave them my contact information for them to contact me if they were interested in meeting and talking to me about their experiences with scleroderma. When a participant called me, we then set up a time to meet in person for about an hour and a half. I drove to wherever was most convenient and comfortable for the participant. I met one woman in her home and the other two at restaurants. I was disappointed that I was only able to secure three interviews. There were a few meetings that fell through or the person changed her mind about participating. This challenge is one that comes with interviewing, and unfortunately the rarity of the group I was studying made it hard to easily round up replacement participants. Nevertheless, using mixed methods resulted in a comprehensive finished project.

I did semi-structured interviews, rather than completely structured or completely open. I “have selected beforehand the relevant topic areas and themes to pursue” (Arksey and Knight, 1999, p. 7). The semi-structured interviews centered on themes generated from my literature review but I did not restrict the conversation to only those themes. I pinpointed some “key questions” but tailored follow-up questions to each particular interview (Arksey and Knight, 1999, p. 7). The semi-structured nature allowed for the conversation to flow well because I could turn to the interview guide as much or as little as necessary. With open-ended questions, “informants can answer the questions in terms of what they see as important” (Arksey and Knight, 1999, p. 7). In this way, I asked about certain themes but allowed the participants to steer the conversations towards what applied most to her situation and was most troubling to her.
I tape recorded all of the interviews and then did the transcription from the recording. One disadvantage of using an interview method is that it is a time-consuming process. Each interview lasted over an hour, and the subsequent transcription of the interviews took several times longer. The analysis was also tedious and not something that could be rushed through. While distributing a survey would have been much faster, surveys would have been ineffective in answering my research question because I wanted to hear the detailed narratives and stories of the patient’s experiences with the disease.

There are some validity/reliability issues associated with interviewing. However, there were steps I took to help increase the reliability and validity. First of all, doing a thorough literature review definitely added validity. The literature helped me focus on the most appropriate themes, concepts, and variables. I also increased the validity of the findings from my interview data by using a careful interview technique. This means I was careful to conduct the interviews without any leading questions, biases or judgments, or too much information about my aunt’s experiences that the participants might be inclined to conform with. However, when it was necessary for me to reveal personal facts or experiences, I answered all questions the participants posed to me completely honestly, so as to build trust and rapport (Arksey and Knight, 1999, p. 52).

In research studies, it is often beneficial to use mixed-methods. Especially for my research problem involving a rare disease, there are a couple additional forms of data collection that were necessary. By incorporating additional methods, I was triangulating the data. “The basic idea of triangulation is that data are obtained from a wide range of different and multiple sources, using a variety of methods, investigators, or theories” (Arksey and Knight, 1999, p. 21). The triangulation of methods allows for more complete data and data confirmation, thus
increasing validity. “Between-method triangulation is where two or more distinct methods (say, semi-structured interviews, observation, and diary accounts) are employed to measure the same phenomenon, but from different angles” (Arksey and Knight, 1999, p. 23). I originally intended to make interviewing my primary method, but because of difficulty getting participants and the fact that their narratives were less explicitly sociological than my aunt’s, I shifted my focus to her story. The interview data and a form of content analysis complemented a case study of my aunt’s story.

My advisor and I had a lengthy discussion about the role my Aunt’s narrative could or should play in my final paper. Because of its importance in my formulation of the research study, we agreed that it should be highlighted. The best way to incorporate the document she wrote was by doing a case study. “When they are used with other research methods, documents can be invaluable sources of background knowledge and for cross-checking the data” (Arksey and Knight, 1999, p. 17). Aside from my own time spent with my Aunt in the past several years, her writing served as my initial background knowledge into the affects of scleroderma on identity and relationships. This case study drew my attention to concepts and themes and furthered my discoveries from the literature review.

To complete the case study, I started by reading Maureen’s writing several times through and jotting down thoughts and questions. I decided the only way people would be able to adequately understand the sociological implications of her disease would be if they heard first-hand the development and progression of her scleroderma. I wanted to present a chronology of her story in a condensed form but using many of her own quotes and minimal interjections of my own until I finished presenting her story. My next step was reading through her narrative a few more times and pulling out certain quotes. I had to decide what was the most important because
I could not insert the entire 100-page document. In the case study that follows, the italicized words are those taken directly from Maureen’s writing.

I was limited in the sense that I could not extract answers to follow-up questions from this document, but my personal knowledge of Maureen’s experiences coupled with the detailed accounts she gave should provide for a rather thorough understanding. Additionally, I mitigated this limitation by interviewing my grandmother (Maureen’s primary caretaker) to clarify points in the narrative. “The case-study approach works best when it is employed to analyze cases that are deviant or defined by situational knowledge…cases that are not entirely unique, but that are highly dependent on the circumstances of their environments” (Lune et al., 2010, p. 375). I think my aunt’s piece fits these criteria, as she most likely shared common experiences with other scleroderma sufferers but yet had a unique environment of a severe, rapidly progressing case of the disease and a unique team of doctors and family members. Although her document explains just one distinct case, “the general is always present in the particular” (Arksey and Knight, 1999, p. 58). In this sense, any small, specific study can have greater implications. Her case study became the focus of my analysis because it gave me the most information to work with, both in sheer quantity and sociological significance.

Lastly, I incorporated data from a discussion board as it related to my research question. I did a form of content analysis, which is “the process of coding text, images, or other material to reveal the patterns through which key concepts appear, or to discern and identify the significant themes of the content” (Lune et al., 2010, p. 426). The content came from online discussions through the Scleroderma Foundation’s website and its Scleroderma Foundation Support Community. It is a place for those with scleroderma and family members and friends to write about particular issues or successes related to the disease and pose questions to those in similar
positions. I created an account on this site sporadically monitored the boards and read relevant posts. I sifted through them to pull out those that are particularly relevant to the idea of identity transformation and interpersonal relationships. I coded this text in the same way as the interview data and included relevant quotes in my analysis. The inclusion of this method further bolstered my case study and interview data.

While I worried a little about any ethical problems associated with using quotes from the discussion board without notifying the person that wrote it, the nature of the site seemed to allow for it. People on the forum are simply identified by an account name rather than their real names. When creating the account, they are advised not to expose any identifying information that they do not wish to be made public. The privacy policy explains, “This Site may make available chat rooms, blogs, and message boards. Please remember that any personal or other information that you disclose in these areas becomes public information and you should exercise caution when deciding to disclose your personal information.” Because it is clear that any information becomes public, I could use this data without any ethical conflict.

The most tedious data to deal with were the interviews. I transcribed the interviews and coded them to pull out points of comparison. Coding refers to “the process whereby data are recorded in some standardized form, usually conforming to a numerical format, for comparison and analysis. Coding assigns responses, observations, interactions, or other information to categories that are relevant to the research question” (Lune et al., 2010, p. 426). To code, I found key words/phrases that related to the themes that emerged from the literature review and case study. I looked for similarities across participants’ interviews and points of departure from their narratives.
I hoped to find some common feelings and experiences among Scleroderma sufferers. I expected that the disease forced them to alter certain aspects of their identities and a reevaluation of important values. I anticipated dealing with the illness would become the “career” of many sufferers, as disease-related obligations take up the majority of their time. As I mentioned, the small sample of interview participants was a limitation, but the other data sources increased validity. My analysis was also complicated by the fact that each person’s scleroderma presented very differently. In this way, it was almost as if each person had a different disease. I decided to make the focus of my study Maureen’s scleroderma. I felt the most comfortable working with her case because I saw it first-hand over a period of several years. Under the conditions of this study, there was no way I could replicate that experience with the interview participants, although with more time and a closer relationship with these other scleroderma sufferers I might have felt more comfortable analyzing their narratives.

In conducting the interviews, I wanted the participants to see our roles equally. Although I was the researcher, I wanted to make it clear that their knowledge was just as important or even more important than mine. The formation of the interview data was collaborative. I was interested in talking to women who have been diagnosed with scleroderma. While I am not an insider in this population, I considered myself a knowledgeable, empathetic outsider because of my aunt’s experience with diffuse scleroderma. My study was inductive and I collected and analyzed data simultaneously. I used the experiences of one participant to shape further questions for other participants. Additionally, I continued reading literature as I was in the data collection process. While I went into the data collection stage with a few vague hypotheses or hunches, I was not be testing a firm theory. I liked the inductive process of collecting and
analyzing data simultaneously and tweaking the research questions as data came in, thus ensuring that the study was as informative and valid as possible.

I anticipated finding that the unique, rare nature of this disease and the way it is difficult to diagnose and treat contribute greatly to the participants’ experiences. In addition, I had a hunch that body stigma, whether they use the word stigma or not, would show up a lot in the interviews and play a big part in social interactions. I paid close attention to the way the disease played a part in very close relationships as compared to more fleeting situations with strangers or acquaintances.

In my analysis of interview data, I paid attention to non-verbal cues and indicators beyond simply the words people said. For example, silences, voice inflection, and visible emotion. These cues can be very telling when it comes to topics that are difficult to speak about or have not been explored much.
Data and Analysis

A. Case Study – Maureen Brannigan

Maureen’s struggle with scleroderma lends itself well to a sociological case study. Her body’s manifestation of scleroderma was extremely aggressive and progressed rapidly. The signs and impacts of the disease became visible very quickly, and the disease forced Maureen to make certain lifestyle changes almost immediately. Her case serves as a clear example of the way a person navigates a changing identity and social roles in the midst of a poorly understood, rare disease.

One of the most important things to understand about Maureen is the way she lived her life before the scleroderma entered it. She had a busy, stressful but exciting, job with IBM and also made time to run every morning and maintain strong relationships with friends and family. There was also always time for shopping at her favorite stores, where her friendly disposition made her a favorite with the employees. In Maureen’s writing about her experience with scleroderma, she makes several mentions of the fact that she was a person who barely takes an aspirin before the onslaught of scleroderma. I used to brag about what a good immune system I had...I was never a person who thought or worried about getting sick. As I mentioned before, I knew I had a strong immune system, led a pretty healthy lifestyle. Let’s put it this way, I ran about 5 miles 5-6 mornings a week, ate pretty healthy food – I say that because I was always a chocolate fanatic, needing to go to the vending machine mostly for m&m’s most afternoons at work. I always was blessed with a pretty fast metabolism – I weighed approximately 110 pounds at 5’4” and really didn’t have to worry about what I ate – although I didn’t abuse it. I never was big on fast food, or greasy food. As of 2002, not only did Maureen have a great job, an apartment overlooking the Hudson River and downtown Manhattan, and great health, but she
was also absolutely gorgeous. With blonde hair, blue eyes, and a great smile, she definitely turned heads.

Maureen’s luck turned on Friday, December 13th, 2002 when she was hit by a car during her usual morning run. It was a hit-and-run, and the driver ran over one of Maureen’s feet, leaving her with several broken bones and unable to walk on her own. With the help of other morning joggers, an ambulance was called and Maureen was taken to the hospital. She was admitted to the hospital for several days, as the doctor needed to wait for the swelling to go down before he could operate. Maureen reflects, *Getting hit by the car was shocking and I just felt like I was so lucky because it could have been so much worse. I never felt anger toward the people who hit me, and by the way, they were never found. The hardest part was being laid up for a few months and not being able to maintain my energetic lifestyle.* You will see just the start of her resourcefulness, determination, and zest for life in the way she navigated her responsibilities after the accident. IBM allowed her to work from home, as she was largely on conference calls and online. She had a desk in her living room, and *I figured out how to get around during the day by putting things in my knapsack (lunch, coffee thermos, etc.) and carrying it on my back to my desk.* She did not let the injury significantly slow her down, although she very well could have taken the opportunity to lounge around and shirk her work obligations.

Maureen, and the rest of our family, expected the foot injury to be a minor blip in her otherwise fabulous life. She knew the recovery was something she would have to work for, but she spent time in physical therapy and was committed to running again. *My goal was to run by June – I even started making my computer passwords things like run6jun.* However, the foot injury was not the end, but just the beginning. Unusual things started happening with Maureen’s body. *One thing that does come to mind, though, is I was sitting next to me niece Amanda at the*
dinner table and she exclaims, “Hey, Aunt Maureen, your nails are blue – do you have on blue nail polish??” I looked down at my nails and they were indeed blue – not from the nail polish though. I would never wear blue nail polish – at least a few years ago – now the very dark blue is the “in” thing. Anyway – I didn’t know what that was about but it made a lot of sense later. This change was the first symptom of scleroderma, and it appeared just a couple weeks after the hit-and-run. Because of this timeframe, and Maureen’s fabulous health prior to the accident, she (and others in her close circle) always believed the accident played a part in the onset of the scleroderma. Despite her doctors’ denial of a connection, it seemed too coincidental to Maureen.

The odd symptoms continued to pile on in the early months of 2003. You see, the swelling in my fingers never went down. I felt like my hands looked like sausages. What started to concern me was that the tips of most of my fingers started turning a bluish/purple color. I knew something wasn’t right, but again, didn’t think much of it…. my hands were so swollen and I could barely open my apartment door. I also started to have joint stiffness and pain. Walking down steps was difficult for me and a simple task like opening a water bottle became difficult. …I was losing muscle strength. I was getting a little concerned about the swelling and purplish color of my fingertips. As the symptoms progressed, Maureen knew something was not right.

Following an appointment with her primary care physician, Maureen began seeing a rheumatologist, who she refers to as Dr. Smith (not his real name). Dr. Smith was a friend of a friend’s husband, and unfortunately he became Maureen’s least favorite doctor. Dr. Smith ordered blood work and Maureen awaited the results. It was mid-May 2003 and she was in Las Vegas with her mother. Maureen treated her mother, Bridget, to the trip to thank her for helping out after the foot injury. I called Dr. Smith from Vegas to get my test results. He got on the phone and said everything was fine, I had a negative ANA (anti-nuclear antibodies, which when
positive usually signals an autoimmune concern) and there was basically nothing to worry about. He said the purple color in the fingers was Raynaud’s Syndrome, which was poor blood circulation to the fingertips, therefore, when they felt cold they would turn blue. He said it was nothing to worry about, as many women experience this problem. I believe he put me on Norvac to help with the circulation. Well, I was pleased with the call – I knew nothing could be really wrong. - I was so healthy. Luckily, Maureen stayed tuned in to the signs her body was giving her. Despite this doctor telling her she had nothing to worry about, she continued to argue otherwise. Another month went by and the symptoms continued to worsen. Maureen’s mobility decreased as joint pain, stiffness, and swelling took over. She explained the situation to Dr. Smith. I am not the type of person to complain and can endure pain but this was really affecting my quality of life.... At this point it was early July and I knew something was not right. I still did not think it was serious but knew I shouldn’t be in such discomfort.... Dr. Smith said it looked like I was showing symptoms of scleroderma, rheumatoid arthritis, and lupus, but I was testing negative in my blood work.

As is common with scleroderma sufferers, it can be a long, frustrating process to reach a firm diagnosis. With symptoms that overlap with several other autoimmune diseases, misdiagnoses are common as well. Maureen sought a second opinion from a well-known rheumatologist in New York. He examined me and said it looked like I had something called Connective Tissue Disorder, which was a good name for “I’m really not sure what is wrong with you.”.... I finally got out of the parking garage and was on the West Side Highway on my way home and I actually broke down crying. It was the first time I let this get to me but I couldn’t figure out what this disease was or how sick I really was. Following this appointment, Maureen received the news of a scleroderma diagnosis. Dr. Kline said that the biopsy confirmed that I
have scleroderma and that he had never seen it progress so quickly. He said it was way above his head and Dr. Smith’s but that it was serious and I needed to see a specialist right away. Dr. Kline’s advice and recommendation varied greatly from that of Dr. Smith’s. Maureen was lucky enough to get an appointment with a specialist, Dr. Spira. Her distrust of Dr. Smith led her to seek the help she desperately needed. [Dr. Smith] said not to worry because it’s not life threatening or anything. Now I know that was the farthest from the truth.

One of the most unsettling facts about a scleroderma diagnosis may be the fact that it is generally unknown. A diagnosis of a more well-known disease, even if equally dangerous, might be easier to cope with because the diagnosed may be familiar with survivors of the disease. More research of various treatment plans and more experienced doctors might increase one’s confidence in the medical professionals. I, as well as many other people, never heard of it. I was told it was in the autoimmune family and very rare. Kathy [co-worker] called me back and said her doctor said scleroderma is a very serious disease and I need to attend to it right away. Ok, I am a bit scared now. Maureen did much of her own research on scleroderma. However, the tricky thing about the disease is its lack of uniformity. Every person with scleroderma is affected by it differently. It could be purely external and not go further than hard, tight skin and Raynaud’s syndrome. For others, the disease could be all internal and invisible from the outside. Diffuse or systemic scleroderma is the type of the disease that affects the skin, tissue, blood vessels, and internal organs. Diffuse scleroderma, in an aggressive form, plagued Maureen.

At this point in the progression of the disease, Maureen was still trying to stay involved with her job. It is also very important to understand the type of support system she had. Her mother, Bridget, widowed in January 2002, was very concerned about the changes in Maureen’s health. Additionally, Maureen’s longtime best friend who became the love of her life, named
Bob, understood something serious was going on with Maureen’s health and it was oftentimes a point of discussion when they talked on the phone each night. This team of three (Bridget, Bob, and Maureen herself) all advocated for her.

At an appointment with Dr. Spira around the end of August 2003, the doctor was unsettled by Maureen’s sky high blood pressure and the way the scleroderma was starting to affect her lungs. Fluid in the lungs had been misdiagnosed as pneumonia in a recent emergency room visit, but the scleroderma specialist identified the problem correctly. *The decision became do I get Cytoxan (a light dosage of chemo) in order to help stop the scleroderma lung progression....One of the negatives he told me about Cytoxan was that I might never be able to have children. I really never had this burning desire to have children but when you’re told you might not be able to you start to give it a lot of thought. I was 41 at this point and the window was closing in on having kids and I had no near term plans to get married. It’s not that you have to be married to have children, but for me it was. I didn’t want children bad enough to be a single parent – actually, being married and having a loving relationship was much more desired. Therefore, the chemo was more important right now.* After consulting several doctors she trusted, and talking it over with family, Maureen decided she would get the chemo drug. She needed the go-ahead from the intolerable Dr. Smith, but he was not answering any of the voicemails she left on his cell phone. Finally, through the connection of her friend, Maureen got a call back from Dr. Smith and he said he set her up for Cytoxan the next morning but he would be too busy to make it for the admission.

After a restless night, she arrived early in the morning for her first round of the drug. It took over two hours, and Bob laid with her the whole time. *It felt so strange to be having this drug enter my body – I was the type of person who barely took an aspirin.* In the subsequent
months and years, the scleroderma got worse before it would get better. Maureen’s aversion to medications, ambulances, and hospitals faded away as she encountered all of them regularly. Right around the time when she started the chemo drug, she also began working with a physical therapist that was more experienced in scleroderma rather than specialized in sports injuries. The therapist’s name was Rich. *He really cared and was just as dedicated to getting me better.*

*The entire group at Orthopedic Care was wonderful. Everyone was nice and helpful and I can’t tell you how much that means when you are not well.* In addition to her ardent praise for the wonderful staff at the PT office, Maureen deserves her own fair share of praise. *I remember going to PT and hand therapy with a small bucket for a long time because I would get sick at any time and did frequently. I would not let this stop me though. I was determined to get better and would not let this disease stop me from trying.... The office staff in my hand therapy told me I was the sickest patient they ever had and couldn’t believe I kept showing up.* Maureen’s steadfastness and mental strength carried her to the physical therapy appointments each time.

At this point, Maureen’s physical therapy schedule was as follows: *My therapy consisted of 1 hour of hand therapy followed by 1.5 hours of physical therapy. I didn’t care as long as I was doing all I could to get better.* *If you are diagnosed with scleroderma, the first thing I would tell you is to get a good physical therapist and be devoted to the therapy.* In her own words, and as I witnessed, the physical therapy helped Maureen tremendously. Although the scleroderma was still progressing, the PT work was able to slow down the damage and maintain as much mobility as it possibly could.

The diffuse scleroderma was attacking Maureen externally and internally. On the outside, her skin was tight, shiny, and itchy. She was losing body hair and her hands were almost stuck in one claw-like position. The disease made it difficult to walk and even to open
her mouth wide enough to take a bite of a sandwich. Additionally, she was losing muscle strength and more and more weight off of her tiny frame. Internally, the situation was just as bad. After trouble with her lungs, other organs were on watch. The external effects even made it hard to treat the internal ones. *They wanted to run a test and were trying to get an intravenous needle into my arm. I don’t recall the number of nurses that were sent in to try to get a needle to access a vein. It couldn’t be done; my veins were way too hard. This, as I found out shortly, was another symptom of scleroderma. I don’t think they ever got access that evening but I sure did feel like a pincushion.* The function of her kidneys became the primary concern, as a blood test showed a very low creatin level. Maureen was admitted to the hospital and put in the Intensive Care Unit, where she experienced dialysis for the first time. *Dialysis takes a while (about four hours) but it is not painful. Basically what they are doing is removing the fluids from your body along with any toxins and cleaning out your blood and putting it back in. You get very cold during dialysis because when the blood goes back into your body it is cold. It does drain you and you feel pretty weak afterwards. The weird part is that this big machine comes in and takes over the job of your kidneys.* After receiving dialysis a couple times during this hospital stay, the doctors felt that the kidney function would not pick back up and Maureen needed to continue with a regular dialysis schedule.

By now, dealing with all of the complications of her disease was practically a fulltime job. In a modified version of Karp’s “career metaphor,” Maureen’s disease can be thought of as her new career. Just as there is an adjustment period with any new job, Maureen experienced a confused, anxiety-filled time as she became acquainted with the intricacies of the disease. Then, after a while, she would feel like she had a handle on the situation. However, the scleroderma would change so much that Maureen had to go through many cycles of orienting to the “jobs” of
new symptoms. The most relatable way the scleroderma took on the role of a job or career is the way in which it dominated Maureen’s time. The intensity of the time commitment elevated with the introduction of dialysis on top of hours of physical therapy and various doctor appointments and tests and procedures. *My mom took me to my first outpatient dialysis appointment. It was located in Fairlawn, NJ and I was told that my schedule needed to be 3 days a week and it would take about 4 hours in total being there.... The doctors decided to make my schedule Tuesday, Thursday and Saturday starting at 10:00am. They purposely picked that time because there was a woman around my age, Mary P, who also had been fighting the battle of scleroderma for over four years now and had significantly improved. They thought she could be a positive influence on me and they chose to sit my dialysis chair next to hers. Mary took on the role of a scleroderma career mentor for Maureen. Mary’s disease was a few steps ahead of Maureen’s, so Mary was able to pass on warnings and advice to Maureen. Probably due in part to her friendship with Mary, Maureen cultivated a strong desire to pay it forward and pass her knowledge on to others struggling with the disease.*

Maureen writes about that first appointment at a dialysis center in her own words: *I was brought onto the dialysis floor and the first thing I noticed was how old and sick everyone was. “Oh my God, what am I doing here?” I was brought over to my chair by the dialysis nurse and introduced to Mary who was sitting in the chair next to me getting her dialysis administered. I said hello but not much more. I was afraid to talk to her and know how bad this could all get.... Dr. K came to me and asked how I was doing. I had tears in my eyes and was frozen. I said to him that my hair was also falling out.... After Dr. K left, Mary in the chair next to me said, “My hair started falling out too.” Mary had short hair but she told me it used to be long, thick, and curly. “OK,” I thought to myself, “please don’t tell me anything else – I don’t want to know.”*
sat paralyzed with fear, not able to do anything but stare ahead…. I whispered to my mom that I didn’t feel like I could go back in there again. I knew there was no choice if I wanted to live. When you are at this point and so overwhelmed with fear, not living seems might seem like an easier option though. As with any new experience, particularly involving one’s health, it was scary. Maureen tried to take it one day at a time and inch closer to a remission stage. When a doctor told her it would be multiple years before she would reach that point, it was harder to cope. One year was a time frame that she could wrap her head around and persevere through, but she did not think she could handle any longer. However, in matters of survival we can surprise ourselves, and Maureen spent four years on dialysis and physical therapy while waiting for the scleroderma’s wrath to subside.

In the meantime, Maureen and her siblings began testing to determine who would be a match as a kidney donor. The surgery itself was a long way away; they did not want to go through it all just to have the scleroderma destroy the new kidney. However, Maureen maintained her optimism that the scleroderma would settle down eventually and a transplant would be possible. As Maureen hoped and prayed for the scleroderma to subside, she continued to navigate her “career” as a scleroderma patient with kidney failure and several other complications. She describes her schedule, beginning with the trip to the dialysis center. It took approximately 35 minutes to get there (without traffic). The last three years I have spent most of my life there. I went to PT three times a week for a couple of hours (11:00-1:00) and then I would go straight to dialysis, which I was able to get on the same day as PT (Monday, Wednesday, Friday). I usually arrived at dialysis around 1:30 and left about 4:30. That was really my whole day three times a week. After dialysis I was usually tired and drained and almost always had a severe headache. I was left with no choice most times but to come home
and lay down. Tuesdays and Thursdays usually consisted of several doctor appointments, blood
tests, other tests or same day hospital procedures. Despite this intense readjustment of her
lifestyle, Maureen put in the effort to hold on to certain aspects of her identity and what made her
her before the scleroderma took over.

For Maureen, holding on to her identity meant salvaging as much as she could of her
previous physical appearance and her favorite pastime of shopping for clothing. As difficult as it
was, I always got up every morning, showered and dressed, did my hair, and even wore makeup.
I never wanted to give in to this sickness or look sick, and as much of an effort it was to get
myself together I was determined to do so…. In between doctor appointments on the days I didn’t
have dialysis or PT, my mom and I tried to fit in a little shopping. Although these values might
seem trivial or unimportant when dealing with a life-threatening disease, I truly believe these
actions helped keep Maureen’s spirits up and kept her from falling into a depression. If I didn’t
do these things I think I would have slipped into a depression and that was the last thing I
needed right then. It was a good sign that I still had an active interest in my appearance because
if I didn’t, it would have been a sign that I gave up and didn’t care – and I did care, so much. I
had way too much to live for and so many cherished people in my life to not disappoint.
She still recognized the good things in her life and did what she could to maximize her
happiness. Her positive attitude was truly impressive and admirable.

Maureen began to realize how important her optimism was when it was contrasted with
that of other patients. She was shaken when two people she knew with scleroderma passed away
in close succession. The first was a woman from the same physical therapy office. I was
stunned and shocked – I felt like she was on the same path as me. Since being diagnosed, I knew
that if I could live through this disease that I would be okay someday, but the toughest part was
living through it. Knowing this was one thing, but actually knowing people who didn’t make it was another. Soon after, a man with Maureen’s same “dream team” of doctors passed. This terrified Maureen. However, one of her favorite doctors explained to her that Jordon was the opposite of her in a critical aspect. Jordon was an athlete before and into mountain climbing and lifting weights. It’s such a cruel disease to take everything you once had away from you…He and I had the same team of doctors so I couldn’t believe that he died…he had all the same symptoms and had the same team of doctors but he was opposite of me in his attitude and the lack of support he had… I was really blessed and if I didn’t fight this disease for me I was at least going to do this for them [family and friends]. I was going through the absolute worst time in my life and never felt luckier at the same time.

Despite a positive outlook and a great support network, Maureen still experienced her fair share of bad luck as she pushed forward towards a kidney transplant. 2004 was a very difficult year. I began having blood transfusions on almost a weekly basis due to the bleeding of my stomach lining. I was also getting my stomach scoped and cauterized almost monthly. The bleeding stomach (called “watermelon stomach”) and subsequent lack of blood left Maureen very fatigued and weak. She was very unsteady on her feet even when not extremely tired, so now she was even more vulnerable to falls and fainting. On the way to dialysis one day, Maureen lost her balance, could not brace her fall, and hit her head on pavement. There was blood everywhere, and off Maureen and her mother went in an ambulance. At the hospital, they waited for a plastic surgeon because the gash was right in the middle of Maureen’s forehead. In a scene that perfectly exemplifies the relationship between Maureen and her mother, Bridget, Bridget senses a way to make Maureen a bit more relaxed. As we are waiting [my mother] knows I am worried about the new light pink jacket I had on that was now covered in blood.
Instinctively she starts washing it out in the sink in the emergency room – she was great with knowing what was bothering me – even in the time of tragedy my clothes were important. Obviously, although she loved her clothes, her health was most important in this situation. As they were on the way into the dialysis center when Maureen fell, she had not made it her appointment and still needed to get the dialysis done. You see, there is no option – you just can’t cancel this. After her four hours of dialysis, Maureen was finally able to go home from the hospital with a thoroughly bandaged forehead.

Maureen’s mobility and independence were very minimal at this point. Nevertheless, she pushed herself to do as much as she could and agreed to join the family for our annual trip to Long Beach Island. The constraints of dialysis made this difficult, but arrangements were made and Maureen’s family stepped up because it was so important to us to have her along and spend time with her. I had to contact a dialysis center in south Jersey and get set up for dialysis three times that week. I was able to get the Atlantic City center, which was about an hour from where we were staying. This needing to be done makes a change to everyone’s vacation though because I needed a ride there and a ride home, which means the person has to hang around for about four hours. Lucky for me, I didn’t even have to ask anyone – each of my brothers worked it out so that one of them would take me each time. They never seemed annoyed or put out – as a matter of fact they were happy that they were able to do this. Each one wanted his turn. How lucky does a girl get! From this excerpt, you can see what Maureen’s mindset was like. Instead of moping because she would have to take several long trips to dialysis during the week’s vacation, her perspective of the situation was focused on an appreciation for the help provided to her and she truly felt like she was the luckiest girl alive.
Towards the end of the summer, Maureen’s body threw her another curveball. *I also encountered another issue, which would come and go throughout the next couple of years. It is called C-Dif, which is a stool infection and not uncommon amongst dialysis patients. The effect of this infection is that you have constant bowel movements, which are very soft and come without warning – you have absolutely no control over when and where you are going to have a bowel movement. Sometimes it would happen and I didn’t even know it. I remember one time my mom and I were out and it happened. I had to sit in the bathroom stall as my mom had to run over to a store and buy me another pair of underwear. I learned my lesson – I carried a backup pair from then on. Most people would have confined themselves to their houses, but C-Dif takes a while to go away and I wouldn’t allow myself to stay home and get depressed. This stool infection was something I never knew about at the time. Maureen did a great job of hiding the more embarrassing implications of her disease. Her mother and her boyfriend Bob were really the only two privy to every detail of Maureen’s health.*

After seeing how the dialysis schedule worked smoothly when Maureen spent a week in Long Beach Island, Bob was pushing for her to go with him and his family to Ocean Beach in August. Maureen initially said she would go, but after Bob’s young adult daughter, Jenny, seemed anxious leading up to the vacation, it came out that she was stressed about all the complications that would be added by Maureen going with them. *She finally told Bob that she was stressed about me coming to the shore because it was their vacation and she didn’t want to have to be doing things for me. ...She is a wonderful girl and we have a good relationship. As a matter of fact, I was her confirmation sponsor several years prior. ...But being so sick is difficult on everyone. ...I felt so bad that I was affecting her life like this. Maureen was more concerned about how her illness was affecting her loved ones than feeling sorry for herself. She decided to*
forego the beach vacation with Bob, and came to see Jenny’s apprehension as a blessing in
disguise. The C-Dif was flaring up and Maureen would have been confined to the bathroom if
she had made the trip. She was very modest and would not have wanted Bob’s entire extended
family to be aware of her stool infection.

Eventually, Maureen’s scleroderma did start to calm down and approach the sought after
remission stage. During the fall of 2004, I am finally able to get my own pants on now, which is
so liberating for me. ...I have Band-Aids all over my fingers, which I have to change throughout
the day just to keep them somewhat protected. It takes about a half hour in the morning and
evening just to do this. Little by little, parts of her body were improving. Each task Maureen
regained the independence to complete was a big victory for her and increased her resolve to get
a kidney transplant and beat this terrible disease. Through an extensive physical and
psychological evaluation, Maureen’s youngest brother, Kevin, had been cleared to be her kidney
donor. The kidney transplant was initially scheduled for August 8, 2005. The stomach bleeding
was still an issue, and something that needed to go away before she could have surgery. Because
of a change with the transplant surgeon’s schedule, Maureen’s date was pushed back to August
29, which happened to be her birthday. She was not sure whether a birthday surgery was a good
or bad sign, but she was definitely disappointed about the additional dialysis. The transplant
coordinator was very cavalier about it, which was upsetting to me. This meant, in my mind,
three additional weeks of dialysis, which would be about 40 more hours of dialysis. If you have
ever done dialysis, you would understand why I was so upset.

They were able to get the stomach bleeding under control, which was supposed to be the
final obstacle. However, an infected ulcer on one of Maureen’s fingers needed to be taken care
of as well. She met with a wound specialist several times a week to work on the wound, and it
improved enough for Maureen to go ahead with the surgery. In her typical fashion, Maureen was much more concerned about her brother Kevin and the rest of his family than herself. She wrote Kevin a long letter thanking him for this amazing gift. *My worry was for my brother – I would pray to please let this be as painless as possible for him and that he would be okay and shortly be able to resume a normal life… I decided I wanted to give him something that would always remind him of his enormous gift to me. I heard that Tiffany’s had sterling silver key chains shaped like a kidney bean. I purchased this in a men’s keychain and had it engraved with “the gift of life” on it. This way, every time he took out his keys it would remind him of his amazing gift and how grateful I was. I joked and said that at least he would still be leaving the hospital with two kidneys.* Maureen was also aware of and sensitive to just how scary it all was for Kevin’s wife (also named Maureen) and wrote her a separate letter thanking her for being supportive and letting him go through with the kidney donation. The morning of August 29th, Kevin went in for surgery first. After what seemed like an excruciatingly long wait, the doctors came out and informed the family that it was successful. They then took Maureen in to the operating room and anesthetized her.

When she first woke up in the recovery room, she was very dazed. There were many visitors with gifts and cards but she slept for much of that day. Doctors and nurses came in and out to check on things. The next morning Maureen was more aware of her surroundings. A catheter had been inserted so the doctors could monitor the urine output. Maureen cannot believe it is actually working. To her disappointment, however, it is not working nearly as well as the doctors hoped. The kidney function is off to a slow start, something referred to as a “sleeping kidney.” With the kidney not working sufficiently, Maureen’s lungs filled with fluid
and there was all of a sudden a lot of commotion in her room. The doctor asked everyone to leave the room.

When Maureen woke up, the doctor was telling her how sorry he was. When they were working on draining the fluid from her lungs, they punctured a lung. She now had tubes down her throat and in her left side to help her breath. *Because of the tubes down my throat, I couldn’t talk.* Bob gave me a piece of paper to write on. My first thing I wrote was, “Am I going to die?”. Bob clearly said “no” and tried to explain what had happened. Dr. Shakabai said that I was going to have to do about 4 hours of dialysis to pick up the slack for the slow start of the kidney. I wrote on the paper, “three hours.” He looked at Bob and said, “She is always looking for us to compromise.” Although, I don’t think I won this one…. I am wheeled into the dialysis center each time and all I could think was, “I thought I would never have to do this again,” and I was secretly frightened that maybe the kidney would not start to function correctly and this would be my life again. All of her hopes hung on the success of the kidney transplant, and the fact that it might not work was never something she seriously expected or considered.

Over a weeklong stay in the hospital, Maureen received dialysis; then, the kidney function improved, the punctured lung improved, and the staff was preparing her to head home. The doctors and nurses go on and on about the importance of the anti-rejection pills and making them an engrained part of one’s routine. *As much as you want to get home there is apprehension with, “What if the kidney stops working? What if I do something wrong with the [anti-rejection] pills?”*. Nevertheless, Maureen is discharged from the hospital and happy to be home.

She feels weak and nauseous most of the time, and cannot help but feel disappointed and confused. She expected to feel much better than this post-transplant. Maureen even remembered thinking: *it’s hell after the operation – I have never felt worse. I had told my transplant*
coordinator how badly I was feeling but for some reason it seemed like she thought I was just overreacting. I would get off of the phone and say to my mom, “She just doesn’t believe me.” I hadn’t had a lot of dealing with her or the surgeon for them to know that I don’t complain unless something is really wrong. I tried to tell her this, but again, she wasn’t very forthcoming with what to do. In late September, the morning of an appointment with Dr. Shakabai, Maureen was too weak to even shower, was throwing up blood, and knew that she was still very sick. Upon seeing and talking with her, the doctor agreed and admitted Maureen to the hospital once again. The cycle of ups and downs, medical victories and setbacks, seemed to be never-ending. This time, Maureen was in the hospital for over a month. She was bleeding internally and her renal function was deteriorating. She began receiving a frozen plasma replacement therapy, which she described as torture. *It lasted a few hours each time and I would always feel like my head felt like an engine of a car, and then I would get very dizzy and throw up each time.* It was necessary for Maureen to go back on dialysis, something she thought was behind her, and the surgeon had to reinsert the tubes in her neck, an absolutely excruciating, torturous procedure completed without any pain killers.

It really seemed as if Maureen could not catch a break. One thing after another would send her back in the hospital. They started her on a steroid to help with the kidney rejection, but it made the scleroderma itself worse. It kept her ulcers from healing and tightened her skin. *I honestly didn’t know which was worse, the kidney not functioning or the scleroderma flaring up.* However, things eventually improved. *Through the power of God, the brilliance of my doctors and my strong belief in miracles, the kidney function finally started to improve and I was released from the hospital on October 25th.* How lucky am I? – I was saved again. I couldn’t wait to get home to my own bed and not be woken up several times through the night. Maureen
went home and resumed physical therapy, happy to be able to gain muscle strength back and experiencing a new sense of freedom without dialysis on her schedule three days a week.

Maureen spent some time writing about Thanksgiving Weekend 2005. Thanksgiving is always held at my house in Rhode Island and Maureen was finally able to make it that year because she did not have to do dialysis. My dad (her brother Matt) surprised her by flying in their cousins from England, Simon and Mary, and arranging for those three to stay at a spa in Newport for the rest of the weekend after Thanksgiving. In addition to an emotional Thanksgiving, the entire family went out for dinner in Newport one night to celebrate the fact that Maureen’s health was improving. Maureen says: *I mention this weekend because I felt like I was living for the first time in several years. It went as fast as good times usually do but it will be engraved in my mind forever.*

Following this relaxing weekend, there was another huge scare before Maureen entered five years of a great quality of life and absence of any substantial hospital stays. But first, Maureen had chills and almost felt like she was drunk following a blood transfusion the week after Thanksgiving. Bob took Maureen to the emergency room, and her mother arrived shortly after. However, there was a bus accident that night and chaos quickly ensued. Bob and Bridget were asked to leave the ER. No one could figure out what was going on with Maureen and the staff forgot about her for several hours as those with injuries from the bus accident were attended to. As I either never heard this story or do not have any recollection of it, I will let Maureen’s words speak for themselves:

*I realize I have to go to the bathroom very badly but I can’t move and it seems like everyone is too busy to know I was even in there. My vocal cords are even being affected and I could barely speak above a whisper. I was so frightened –What was happening to my body? –*
Why couldn’t I move? – Was I paralyzed now? – No one knows I am in here – I have to go to the bathroom – I think I am going to die. Finally, I was able to get the attention of a relative of one of the bus accident victims and asked him to get me a nurse. It took a while, but a man came in, who wasn’t a nurse but was probably an assistant of some sort and practically had to carry me to the bathroom. He was holding me up and my feet were literally dragging on the floor. I never felt this way before and knew something was very wrong. I would say for the most part I am a pretty modest person, but when you are in dire times like this, modesty goes out the window. He told me to press the bell when I was done. I couldn’t press it quick enough – sitting on the toilet I couldn’t even hold my head up as I lost any muscle strength in my neck and it was appearing throughout my body. I couldn’t lift myself from the toilet and he had to come in and pull up my underwear. I really didn’t care – I thought I was going to die at this point. The one thing I begged him for was a phone because something is very wrong with me and everyone in here is too busy to notice. I needed to contact my family. He did bring me a phone and I got Bob on his cell phone. I whispered in the phone frantically, “Please come help me, something is so wrong and I can’t get anyone’s attention.” Bob was on his way back to the hospital and called hospital security to come in and check on me until he got there. He and my mom got back to the hospital and were in my room in no time. This is when I finally got attention and admitted into the hospital – but the experience left me scared to death.

They never did figure out what went wrong. There must have been something wrong with the blood they gave Maureen in the transfusion. Maureen remarked that: Out of everything I’d been through I think I was the most scared then. Just to give you a window into how complicated her condition was, she shares information from the records of this admittance. Her primary diagnosis was Neutropenia (nerves not sending messages to muscles) and C-Diff Colitis
(the stool infection). In addition, My underlying diagnoses included scleroderma, scleroderma renal crisis, scleroderma lung disease, pulmonary hypertension, end-stage renal disease, status post living related renal transplant, history of graft function, congestive heart failure, pneumothorax post central line insertion, underlying gastric antral vascular ectasia with recurrent gastrointestinal bleed, underlying thrombosis microangioplasty post kidney transplant requiring plasmapheresis, intravenous immunoglobulin and Intensive Care Unit monitoring, underlying hypothyroidism. Now doesn’t that sound like a mouth full!

The neuropathy began to improve and Maureen slowly regained muscle strength, although she had to spend some time in a rehab facility to work on it. She faced a few other struggles shortly after (the necessary amputation of the tip of one finger and another scare related to the kidney function) but she really did enjoy her life to the fullest from 2006 until she passed in July of 2010. She spent her time doing things she loved with people she loved, and never missed an opportunity to tell a friend or family member how much they meant to her. She was one of the first people I called whenever something tough was going on in my life and I needed to put things into perspective. When I struggled with the decision to end a long-term relationship, Aunt Maureen was the one I spent hours on the phone with. Similarly, she allowed me to talk through my decision to transfer schools after freshman year. She was incredibly easy to talk to, and her unbelievable experiences convinced anyone that there is some sort of good in all situations. Although my problems were rather minor compared to what she had been through, she never minimized or discounted my emotions. She was a spectacular person and serves as inspiration for many of the good things I do.

* * *
Now that I have laid out the chronology of Maureen’s illness, I would like to delve deeper into a discussion of several sociological themes as they relate to her experiences. These themes are: visibility and stigmatization; identity trade-offs; factors for success; and faith or spirituality. In the pages that follow, I will turn to these themes and more explicitly connect elements of Maureen’s story to matters I discussed in the literature review.

I. Visibility and Stigma

One of the most interesting themes I recognized in my research was that of degree of visibility of the illness and the way that visibility impacts stigmatization. Maureen’s case is a great example of this stigma continuum because she was the epitome of health and beauty pre-Scleroderma and the disease presented significant external indicators as it progressed.

The fact that Maureen was so healthy before the scleroderma is beneficial for this observation because we can distinctly monitor her changes. For some others with scleroderma, their lives might have been plagued by illness since childhood and the scleroderma would therefore be less of an obvious addition. That Maureen’s looks constituted another distinctive part of her identity made the visible changes of her illness more foreign. Kathy Charmaz discussed this phenomenon in her article “The Body, Identity, and Self: Adapting to Impairment.” She explained, “Looking healthy can undermine a person’s credibility with health practitioners” (Charmaz, 1995, p.665). Charmaz noted that it is even more of a problem for women rather than men. I can clearly see evidence of this experience in Maureen’s interactions with Dr. Smith, the rheumatologist who kept telling her she was healthy and had nothing to worry about.
When Maureen’s symptoms were just starting to present, they seemed rather benign and almost comical to many people. Strangers felt comfortable commenting on her visible abnormalities. I surmise that people did not find it inappropriate because they simply could never fathom that the changes were symptoms of such a serious illness. Two instances in particular come to mind. During the first July after Maureen’s foot injury the previous December, she experienced very swollen feet and hands. She was down on the Jersey Shore with Bob when some strangers took notice. I was also dealing with the swollen feet and Bob was trying to tell me they didn’t look that bad. That came back to bite him when I was packing my car and a couple of people walked by to go to the beach and came over to me and asked me if those swollen ankles/feet were from horse flies biting them on the beach. I had to laugh later thinking “Oh no they’re not that noticeable...just people walking down the street could see them from the road.” Another incident occurred in relation to the same symptom. In the beginning of September, Maureen went to the emergency room because of the swelling. As we were waiting in the emergency room (which was for a while because it was very crowded that evening), several people were asking if I was there because of an allergic reaction to something (based on the swelling in my hands and feet). Again, I had to laugh to Bob saying “Oh no, it’s not that noticeable!” The signs of the disease were definitely visible at this point, but nothing that seemed too severe. She had not yet been diagnosed with scleroderma but was realizing that something serious was wrong.

These comments made by strangers were obviously not meant to be hurtful or demeaning. The fact that the people felt comfortable enough to voice the comments shows us that they viewed the symptoms more curiously and nonchalantly, almost as if they were something to make small talk about. In both instances, Maureen was able to laugh it off, but the
fact that there was clearly something visibly wrong with her and she had no idea what it was must have been very unsettling.

As Maureen’s disease progressed, the visibility increased. One of the indicators of Maureen’s illness was the port in her neck for dialysis. These tubes were inserted when it became apparent that Maureen would need dialysis regularly for a substantial amount of time. She expected two small tubes, barely visible. After the painful insertion in which she was totally conscious and needed to be held down because it was so painful, the site was bandaged up for a little while. *After the bandages were removed there were two 3-4 inch tubes protruding from my neck – one red and one blue.* “Yikes”, I thought, “this has to be a mistake – he forgot to cut the tube or something.” Little did I know, I would be walking around with these tubes for almost three years. Maureen was very self-conscious about these tubes, as they were impossible to cover up. This stigma symbol clearly communicated some sort of health problem. Because of it’s location on her body, in her neck rather than a more discrete spot, anyone who had a conversation with her in person and looked her in the eye would notice the tubes not far below her face. Maureen’s body stigma reached the point where her healthy identity became totally discredited, not just sometimes discreditable.

At this point, the scleroderma visibly altered Maureen’s facial looks as well. Admirably, Maureen did not let these changes keep her confined to her house and she continued to do what she enjoyed, as much as she was able to. With shopping at the top of the list, she spent time in public at upscale malls and boutiques. An encounter with a sales person at a makeup counter of a department store stuck in Maureen’s mind. *She looked at my eyebrows and said, “What happened to your eyebrows? They look terrible and you are missing patches of hair.”* I had lost all the hair on my body (except my head, where the hair had gotten thinner) but I forgot about
my eyebrows. I had lost hair there too and felt so self-conscious when this woman said that because the look on her face was horrified. I knew it didn’t look that bad and was taken aback by her insensitivity and the look of horror on her face. I am just mentioning this because on the whole people I encountered through out this were wonderful. But I did run into my share of people who said the most insensitive things. Maureen would try not to dwell on these things, and luckily had people in her life that always continued to tell her she was beautiful. Nevertheless, strangers’ comments exemplify the stigma associated with a non-elderly person living with a serious illness. On another occasion: One of the women, upon seeing me, said, “I give you credit for having the nerve to come out looking like that.” There are many comments made by people that I know that they don’t intend to be malicious, but hearing the comment does still make you feel a little bad. ...I always hated to see the look of pity on their faces. A Kathy Charmaz quote applies well to these experiences. “Because she had accepted her disability, and moreover, believed herself to be acceptable to others, this encounter was particularly troubling to her” (Charmaz, 1983, p. 181). Although Charmaz was not talking about Maureen, the feelings are common enough for the ill or disabled that she might as well have been referencing Maureen.

I would like to argue that a person’s sensitivity of her body stigma follows a bell curve model. Maureen’s experiences present a great example. When she first started getting sick and her symptoms were visible but seemed rather minor, she could easily brush off comments and laugh about them with Bob. Then, little by little, the symptoms got worse and Maureen’s sensitivity increased as her body was becoming more and more foreign to her. During this period, she would have been her most self-conscious and at the height of the bell curve. Later on, after living with the disease for years, Maureen became less concerned with the superficial
and more attuned to health victories rather than issues of appearance. She was used to her new body and more comfortable with the way it looked.

In Goffman’s work on stigmas, he spent some time discussing stigma management and the continuum of intimacy in the social network of the stigmatized person. In less intimate relationships and public settings, stigma management is more common. With a few people, no stigma management is necessary or perhaps not even possible. This group of people is referred to as “the wise.” For Maureen, her mother moved in with her to take care of her and became wise to the fullest extent. *There was nothing private in my life anymore.* *She listened to every phone message I got asking, “Who was that and/or what did they want?” I couldn’t have a phone conversation without it being a three-way.* *She would interrupt and add her opinion as she listened to every call. I didn’t have the mobility to move into another room or, believe me, I would have.* *She was involved with every piece of mail that came in....She is a friendly person who talks to everyone but doesn’t really get “patient confidentiality.”* ... *My mom met everyone and talked about my illness to everyone. I used to joke that I should have her sign the confidentiality form that I needed to sign each time I went to a doctor or for a test anywhere.* The fact that Maureen’s mother was supremely wise to every detail of her disease and other facets of her life oscillated from extremely comforting to a bit stressful and annoying.

II. Identity Transformation

When someone gets a chronic illness, she inevitably must reevaluate her identity. Maureen struggled letting go of her identity as a healthy, self-sufficient, independent woman. She needed to decide when to really play the “sick role” and when she wanted to avoid the association. At several points in Maureen’s story, she described an aversion to the sick role and
an effort to do things for herself. *For a good year at least, getting dressed by myself was almost impossible. It took me forever because I did not have the range of motion to lift my arms up, my elbows were so ulcerated that the slightest touch to them brought on tremendous pain and my balance was not there at all. I also had such bad, ulcerated fingers that it was too painful to button or snap anything. I felt like a child all over again, helpless; although I did everything I could to try to maintain some independence.* Loss of independence came up time and time again.

The loss of independence was probably so difficult because she had so much independence prior to the onset of the scleroderma. Maureen lived alone, made her own money, and was the one that other friends went to for help. She had worked so hard to establish herself as a successful adult that feeling like a helpless child was probably the worst thing. *I needed help with simple things (like pulling my pants up) and it’s hard to explain how extremely frustrating and humiliating that was.*

The identity trade-offs were difficult for Maureen. If she wanted to be able to do certain things, she needed to ask for or accept help. *At this point, my disease was getting worse and I was way too weak to walk more than a few steps. It was very hard for me to sit in a wheel chair. I was a fighter and I did not like to give in, but I knew if I wanted to make it to Dr. Shapiro’s office that day, I would have to succumb.* She used the word “succumb” again when discussing her lack of independence. It invokes the notion of losing or failing. *I was devastated to need to be taken care of like this. I was always an independent person who did things for myself and took pleasure in helping others. It was so hard to succumb to letting people take care of me.*

Maureen’s denial of her new position in society transformed to something more like acceptance and adaptation when there was no way to deny it and it was so much a part of her. Entering the outpatient dialysis center for the first time, Maureen had a realization. *I looked*
around and most of the patients were elderly in there. Again, the thought came to mind, “What am I doing here? This just can’t be happening to me.” But, there I was, being hooked up to machines like all of these other people. I was one of them. When she gained the ability to accept herself as someone with a chronic, life-threatening illness, she was able to stop dwelling on it and make adjustments to bridge that gap between how she felt on the inside and how she felt on the outside. As I said earlier, I wanted to try to maintain as much of my normal life as I possibly could. Even though I had two tubes hanging from my neck, bent knees, elbows, and fingers, and was now around 88 pounds, I did whatever I could to try to look good/normal. By opening her eyes to exactly what her limitations were, she could see how much she could still do.

III. Health Within Illness

The factors that cause certain people to fall apart physically, emotionally, and mentally (and others not to) are important to discuss. From Maureen’s narrative, we can clearly see that she was one of the people that somehow did not crumble because of the scleroderma, although her disease was one of the most severe doctors have seen. In Maureen’s opinion, much of her strength came from her strong support network of family and friends. I can’t begin to tell you how much support from family and friends can be your guided anchors through some very rough times. I considered myself so lucky to have this. First off, the support I got from my mom, Bob, and my siblings was so incredible. They let me know at all times that they were there and with me every step of the way. I ended up in the emergency room so many times and they all always rushed to be by my side. There was so much love and concern that I felt like the luckiest person alive. I also received overwhelming support from friends and acquaintances that have now
become friends. Without mitigating the power of these people, I would like to argue that Maureen herself was partially responsible for the reactions of these people.

With all that said, and so much more to tell you about the people in my life and who came into my life all I can say is I felt like the luckiest girl alive. I had to live through this – there were so many people pushing for me. I owed it to myself and them to fight this disease with everything I had and this is what I set out to do. I have to say, you never know how you are going to react to a situation until you are in it. If you were to tell me that all of this was going to happen to me I would have said I would never get through it, but I did and each day was a struggle – a struggle for my life. But I never gave up and I never felt sorry for myself. I am serious when I tell you that I felt lucky – I was so loved and the people I encountered through out this were so wonderful that it brought a smile to my face each day. Her personality was naturally likable and she was the epitome of a friend/sister/daughter/aunt that would do anything for the people she loved. Because of her love and positivity, her network was more apt to fight for her. If Maureen was a jerk or very unpleasant, she might not have had the support she did. Additionally, her optimism and will to fight the disease seemed to fuel the same emotions in her friends and family. It almost seemed like a cycle: with more support Maureen became more positive and determined; as she became more positive and determined, the support grew more fervent. Although it almost seems like a “chicken-or-the-egg” phenomenon, I believe Maureen was the start of the cycle because of the way she treated those around her before she could even fathom she might develop a life-threatening disease.

The story of Maureen’s unbelievable success fighting scleroderma for seven years would not be complete without mentioning one more time the role of her mother, Bridget. As I am sure she would have done for any of her children that seriously needed her, Bridget dropped
everything else and Maureen became her focus. She never complained or resented Maureen for it, and although they would bicker and get on each other’s nerves after a while, they were such a strong duo during those years and it was a mother-daughter relationship that many were envious of. About her mom, Maureen said: *There was nothing she couldn’t do. She would get me up my stairs every night, locking me arm in arm, pulling me up each step. She would kiss me goodnight, tell me she loved me and that I would get through this, and she would then throw holy water on me. It became our ritual…. Her love and commitment to me were infallible.* The relationship between Maureen and Bridget was one where they would build each other up and keep the other’s spirits high at difficult times.

To fully understand just how miraculous Maureen’s mindset was, note the way she talked about perspective and positivity. *It’s funny – prior to all of this I always had my nails done once a week – I hated the look of unkempt nails. You really put things in perspective when hit with so much tragedy. My hands are very unattractive now – jeeze, now I will never be a hand model!* But my thought it, I am lucky if this is all I am left with after all I’ve been through. *It really changes your perspective on the nonsense we can worry about. I would think back to losing sleep over a bad hair cut and think how silly and insignificant that was. You see, I am already learning so many great life lessons. I have to say, I wouldn’t have chosen this route to learn all of these things but at least I can gather some positives from all of this.* As I hope I have highlighted, Maureen’s story is one of loss and pain, but if you read her piece from start to finish you would find many more positive words than negative. Be it more genetics or her environment (or an even-split between the two), Maureen’s own mindset was perhaps the most important factor in sustaining her life with scleroderma for so long.
IV. Faith and Spirituality

The discussion of Maureen’s support system and attitude transitions easily into an understanding of the role of faith and religion. I was never a negative person and by nature friendly and happy – smiling a lot. My illness did not change this – I did keep smiling and it wasn’t forced, I truly felt blessed to have the most incredible family and friends but also I was fortunate enough now to be meeting a whole new set of incredible people coming into my life. As sick as I was I really felt grateful. You would think I would feel sorry for myself during this time, but I really didn’t – I just felt so lucky to have and encounter so many wonderful people. My faith and love for God grew even stronger. I don’t know how to really explain this but I always felt God and many angels were always with me and helping me get through this. Elizabeth Lindsey’s journal article on health within illness stressed the connection between feeling healthy and feeling connected to a higher being. Maureen’s experiences support Lindsey’s argument.

A spiritual connection was particularly important for someone with scleroderma rather than a more scientifically understood disease. People oftentimes look to God for comfort when things are happening that do not make sense or are out of their control. The development of scleroderma for Maureen was all of the above. Through this whole time, I never felt “why did this happen to me?” nor did I ever get angry with God for this either. Actually, I felt closer to God and knew deep down in my heart that this was happening for a reason – I just couldn’t fathom the reason. She did not understand why she developed scleroderma but she did not dwell on this mystery. Instead, she trusted that it was part of a higher plan. I really felt deep down inside that God had given me so much to deal with and it wasn’t going to be for nothing. I knew he was with me and in the end he had a plan. It’s at times like this that you either lose some of your faith or continue to draw from it and strengthen it. Believe me, I was getting a little angry
at him and wondering what the sense was of all of this but ultimately I believed in him and trusted his plan.
Data and Analysis

B. In-Person Interviews and Online Discussion Posts

The following data and analysis come from three in-person interviews combined with online posts from http://www.inspire.com/groups/scleroderma-foundation/, the Scleroderma Foundation’s online support community.

I. Visibility and Stigma

Meeting with other scleroderma suffers opened my eyes to the severity of Maureen’s case. At a quick glance, none of the interview participants had a very obvious body stigma. As I explained, scleroderma can manifest itself very differently from person to person. Meeting other scleroderma sufferers in person really sparked my interest in the implications of varying degrees of visibility.

For “R”, a 52-year-old woman in the field of higher education and guidance counseling, the disease presented few external manifestations. “Right now it’s pretty much all internal and then just Raynaud’s,” R explained. For “B”, a 70-year-old former executive secretary, the biggest external problem was Raynaud’s and uncomfortable cuts on her fingers. She was diagnosed with scleroderma about twenty years ago, and the symptoms were confined to her hands for about ten years. After she retired ten years ago, she started developing internal problems attributed to the scleroderma and lost approximately forty pounds. “Externally I don’t look that bad,” she explained, “Usually the reaction I get when I tell people I have scleroderma is they say ‘well you look great!’” (In-person interview; B, 1/28/13). Looking “good” or “normal” makes it much harder for these people to be taken seriously. Another woman with scleroderma echoed the frustration: “As for myself, I have no skin hardening, and everyone tells me I look
great, BUT” (Online post; Swampy1000, 8/2/12) a list of over twenty different scleroderma-related health problems followed. Literature by Kathy Charmaz explained, “Having a visibly altered body provides the experiencing person, as well as family and friends, with immediate images of change…But not all people with serious chronic illnesses have visible symptoms and disabilities” (Charmaz, 1995, p. 665). Some might wish for a less visible form of scleroderma, but that brings its own difficulties. Nevertheless, the challenges of visibility seem more distressing to some participants. “I think I’d rather have it my way. There’s less explaining to do to people, versus when you’re crippled like some other people” (In-person interview; B, 1/28/13).

As I highlighted in the case study, the degree of visibility of the disease can vary greatly and dictate stigma and social interactions. For B and J, who was 71-years-old when she was diagnosed in 2006, the effects of the disease are less shocking or deviant because of their ages. From a study highlighting the disruption caused by rheumatoid arthritis, Michael Bury discussed age. Similarities between arthritis and scleroderma make Bury’s analysis quite relevant. “The significance of age requires underlining. The images of arthritis as a disease of the elderly is common…[For younger people] it marked a biological shift from a perceived normal trajectory through relatively predictable chronological steps, to one fundamentally abnormal” (Bury, 1982, p. 171). When a woman is in her seventies, it is rather accepted, and even expected, that health issues will start to accumulate and mobility might decrease.

When I asked B about any experiences with stigma or insensitive comments from strangers, she said she really did not feel any stigma. However, she engaged in some visibility management to lessen the stigma symbols. She explained:
For years and years I never wore makeup. I’ve only really been wearing makeup for the past five years, because of these little red dots on my face and neck. I’m very self-conscious about it. So I wear makeup only to cover it, but I never used to. My husband would say ‘gee what’s wrong with your face?’ So I said the hell with it, I’m just going to put makeup on. And some days it’s worse than others. It’s weird though (In-person interview; B, 1/28/13).

The fact that she mentioned the comment made by her husband and being very aware of the broken capillaries on her face indicates that she might feel some sort of stigmatization if she did not cover up with makeup.

R’s scleroderma is particularly interesting because she is younger and plagued by the scleroderma almost solely internally. Her symptoms started with fatigue, Raynaud’s, stiffness and joint aching. It affected her lungs, making her very short of breath. She told me it was something noticeable to students that came to her guidance office. “I’m leaning against a wall, I’m like, you know, sucking wind, and they’re kind of looking at me like ‘what’s wrong with her?’” (In-person interview; R, 1/11/13). R is a very intelligent woman, a special lecturer at a private college as well as a teacher of American Sign Language and a guidance counselor. An interesting theme that emerged from my conversation with her was the way a physical disability might be ignorantly perceived as a diminished mental capacity. Regarding a particularly frustrating appointment with a cardiac surgeon, she said, “I might have a physical disability but I can do math pretty well…I said, this guy is an MD and he can’t even frickin count?” (In-person interview; R, 1/11/13). This theme continued to come up, probably because being a highly educated person is such an integral part of R’s identity.
II. Identity Transformation

It is beneficial to understand more about what these women’s lives were like before the scleroderma. R presents an interesting case. “I have immune issues because of the Hodgkin’s disease. And in fact when I had it in the seventies they took out your spleen so my immune system was extremely compromised because of that” (In-person interview; R, 1/11/13). She has external fibrosis because of the radiation therapy, and her doctors constantly struggle with the question of whether a symptom is because of the radiation or the scleroderma. Despite the Hodgkin’s lymphoma as a teenager, R considered herself healthy and active for the majority of her adult life. After the scleroderma damaged her lungs:

I gave my bike away to my neighbor’s daughter, I threw my tennis racket away…. I love biking, tennis. I love sailing, hiking, just getting outside. And with the Raynaud’s, being outside I had to cut back a little bit. But I had a yellow lab before, I have a black lab now and he’s 2 years old and I feel so bad that I can’t even take him for a walk. I have my neighbor’s kids take him for a walk (In-person interview; R, 1/11/13).

R has continued to be able to live alone, but the scleroderma forced her to step back from the hobbies she enjoyed and go on leave from her jobs. Although her health issues have not changed her personality or values, the physical limitations did cause problems with a romantic relationship. “I was going out with someone but once all of this got more intense, you know, he was very outdoorsy, loved to do stuff outdoors. So he totally went south after that. And since then I haven’t really had anyone. So I’m hoping to get back to life as normal” (In-person interview; R, 1/11/13). I can understand how difficult this would be, as R wants nothing more than to be able to do those activities. The identity transformation was mostly external, as in her
heart she still cares about the same things and finds intellectual fulfillment in the same ways she used to.

R expressed frustration with the way her disease replaced her career when her health demands increased. When asked about her typical week, R told me it was “physical therapy, physical therapy, doctors’ appointments. I try to get out, you know, my daily field trip is like going to Stop and Shop or something” (In-person interview; R, 1/11/13). She has a great, dry sense of humor, and although she could laugh about her new schedule, it was clear in our interview that she truly missed spending her time working with her brain rather than working on physical therapy. She told me, “I just need to get out, get my brain working. I feel like I can’t even speak in grammatically correct sentences. It’s like, wow, did I go to college?” (In-person interview; R, 1/11/13). Being only fifty-two and still in the prime of working years, this readjustment was difficult. At the time of our interview in January, R’s health was on the upswing and she was looking forward to getting back to work in March.

For B, the increased severity of the scleroderma almost coincided with her retirement. This major life change made it harder to analyze the effects of the scleroderma in isolation. As B discussed, some of her identity transformation might just be an effect of aging. She reflected, “You know, you get older and maybe your social life isn’t supposed to be what it used to” (In-person interview; B, 1/28/13). She has lived with the disease since her early fifties and is now seventy, so those were years filled with change. Her three children became adults themselves and started families of their own and B’s retirement certainly changed her environment for social interaction.

During the difficult year of 2012, however, it became clear that the disease was limiting her. “I like to play golf, but I was barely able to go last year. I can’t type. You can’t imagine
how much you need this finger to type. And I was, not bragging, but an excellent typist. So that has been a huge deterrent for me” (In-person interview; B, 1/28/13). She is also starting to have more stiffness in her legs and trouble walking. B goes to physical therapy two times per week in order to work on the legs.

The internal effects of the scleroderma impact her daily life in another way that would not be automatically obvious. “It’s restricted my swallowing. It’s also affected my stomach end even my colon now. I have a lot of colonoscopies and the muscles in my digestive system are not working properly. I’m a slave to the toilet” (In-person interview; B, 1/28/13). These digestive problems most definitely affect B’s social life and what she is able to do if the digestive system is giving her trouble.

III. Health Within Illness

The concept of finding health within illness and personal victories in the face of constant difficulties is one that I took particular interest in. It was a topic that my interview participants made a point to highlight even if I did not press the idea. A strong support system and mental resolve to maintain some independence and a sense of humor are some factors that contributed to the successes of these women. Similar to Maureen’s story, R’s endurance through this disease also came from her support network and her own mindset. About those in her life, she said, “I have a ton of friends, and throughout this whole thing all of my friends, at the college and at the high school, have been beyond supportive. They came over and cooked for me, cleaned my house, took me shopping” (In-person interview; J, 2/20/13). The fact that these people reached out meant so much to R. Her colleagues from the middle school, on the other hand, have been relatively absent, which causes some stress even though R tries not to let it bother her.
“Sometimes I probably obsess about it too much like ‘Why don’t they call? Why don’t they email?’ because I’m thinking, how many times during the day does a person send a personal email?” (In-person interview; R, 1/11/13). Disappointment regarding one’s lack of support can be easy to fixate on. One particular online discussion participant frequently wrote about her frustration with her husband. “I just don’t know if I can stay in a relationship with someone who doesn’t want to believe how much this disease affects my life” (Online post; belindalee, 8/4/12). “Many of us don’t have the emotional support, and that is a battle we must fight every day along with all the disease throws in front of us” (Online post; belindalee, 8/5/12).

When the support system is rather weak, mental and emotional fortitude truly separates people. Even in explaining her disappointment with the middle school colleagues, R cracks some jokes and keeps the mood light. She told me, “I have a good wit and sense of humor and that’s what has carried me through this,” although those qualities were evident even without her explicitly telling me (In-person interview; R, 1/11/13). The importance of maintaining a sense of humor and optimism is explained in the literature review as a way to feel alive and healthy. Based on my data, I would agree that this power should not be overlooked or underrated.

J explained, “I think I just act like I’m normal. I’m too stubborn to give in because once you give in it’s all over. I’m not going to stay home and brood. Whatever is going to happen is going to happen…I still wash my floors. I clean my bathroom. I can still do it. I might be out of breath, huffing and puffing, but I’d rather do it myself” (In-person interview; J, 2/20/13). This mental strength might be fueled by the knowledge that she is needed. She has an older sister in a nursing home that she visits almost every day. Although J is unmarried and lives alone, her support system is made up of mutually dependent relationships – she supports her sister and, in turn, her sister motivates her to continue fighting the disease. Her friends know about her
scleroderma, and they keep each other’s spirits up by spending time together at casinos. J told me that if she ever needs help with anything, she simply asks. This acceptance of her position allows her to adapt and do as much as possible. A nephew that lives close by helps her out a lot, and a niece drives her to her appointments in Boston every three to four months. Having a network of people to help her out is clearly beneficial; additionally, being able to assist others is an aspect of feeling healthy.

In her study, Elizabeth Lindsey found, “All of the participants talked of a commitment to helping others with chronic conditions. This help came in different forms…wanting to share her knowledge with others…initiating support groups, providing workshops, and acting as resource people for those with chronic conditions” (Lindsey, 1996, p. 468). Besides Maureen’s clear willingness to give back, my data from the online posts lent the most support for Lindsey’s finding. The overwhelming participation in the scleroderma support discussions is evidence itself. Every day, the website emails me and includes the number of new discussions and new members. On any given day, there are typically about ten to twenty new discussion topics and five to ten new members. One woman wrote, “You need to be around people who love and care about you. If you don’t feel you have anyone, go to Church. You will meet very loving and caring people. They will be there for you and help you. Plus you just met a friend who cares. ME! Please feel free to talk to me any time. I’m always here for you. I will listen to anything you want to talk about. I really do care” (Online post; Judy2412, 1/22/13). Another explained, “Giving to others, even in the smallest way, gives us perspective on how fortunate we actually are” (Online post; MrsHarris, 1/25/13). Sharing information and experiencing, and assisting those who are worse-off, is a way for people to feel better despite the disease.
IV. Faith and Spirituality

Although an entire study could be devoted to the role of faith and spirituality within an illness identity, in this work I will spend just a bit more space adding to the discussion. Interestingly, my Aunt and the three interview participants were all Catholics. This commonality is probably due to nothing more than the overwhelmingly Catholic areas in which they lived. In the online postings, one’s religion was not clear, as I could not ask the question.

Lindsey’s article considers the acquisition of a “state of grace” a manifestation of health within illness; in her study, “the participants talked of an attachment with God, or the Creator, and an expanded consciousness” (Lindsey, 1996, p. 469). Across the online discussion boards, I saw many in the scleroderma community echoing the importance and power of faith. The following post exemplifies the idea: “Having faith doesn’t mean that bad things won’t or can’t happen. Faith is our umbilical cord to God. Having faith in God and trusting his divine plan, gives us the strength to go through bad times and that strength brings us closer to God and all the things that are in him” (Online post; one_lil_red_hen, 2/20/09). Those participants who referenced a connection to God or some spirituality typically talked about their experiences with scleroderma more positively. Reflecting on my own experiences with loss and injustice, I can appreciate the peace that comes with a trust in a higher power. I cannot conceive of any reason why a strong religious faith would negatively affect an illness. Any way I look at it, spirituality increases acceptance and adaptation. However, there is no magic button a person can press to create trust in God and an acceptance of the difficult things life brings. Finding a religious/spiritual community that one identifies with might be a proactive way to find faith.

For some with scleroderma, the act of participating in religious rituals added some comfort. “I’m a pretty religious person. I go to mass every week” (In-person interview; B,
1/28/13). “I still do go to church every Sunday. I don’t blame God.” (In-person interview; J, 2/20/13). Not only did these interview participants tell me they were religious and not angry with God, but they also mentioned the fact that they participate in Catholic mass every Sunday.

While I can confidently proclaim a connection between spirituality and emotional (perhaps even physical) health, it is important to note a limitation with my data. My sample was rather small, and it may be that those who were willing to sit down for an interview or talk online are those that have already worked through the difficult emotions. Although at the time of an interview someone might harbor no ill feelings towards God, I do not necessarily know that this was the case throughout the trajectory of their scleroderma.
Conclusion

I hope this thesis shed light on the challenges of living with a rare, poorly understood disease. While scleroderma is one example, there are countless other chronic conditions that plague people and pose equally difficult problems. Awareness and open dialogue about these diseases is one way to decrease stigma and increase understanding. My thesis is one contribution to this sociological discussion of health and illness.

While I chose to focus on the themes of (1) Visibility and Stigma, (2) Identity Transformation, (3) Health Within Illness, and (4) Faith and Spirituality, my research raised other topics and issues. Entire studies could be built around one of these ideas, which include personal theories about the cause of the illness, the financial impact of the disease, and advice for those newly diagnosed.

Regarding the cause, some point to environmental factors whereas others see a strong genetic connection. In a thread about the topic, one person wrote: “Is this a air borne…is this a dairy issue….is this bad milk from those sick cows…did the cows have this in their blood….did cows with hormones the farmers accidentally shot the cow with collegan vitamins…it has to be a farming something….because the only link is….what?” (Online post; RustyHam, 12/15/10). In agreement, another said: “I have suspected the pesticides for a long time” (Online post; DaisyDo, 12/16/10). However, one of my interview participants disagreed. “I certainly think it is genetic. My sister had severe Juvenile Arthritis since she was about three years old. I definitely think this is genetic. I also have a cousin with rheumatoid arthritis, so my maternal ancestors have this problem” (In-person interview; B, 1/28/13).

Some others with scleroderma accept and concur with the popular medical opinion that the cause is unknown and rather random. “I think it’s something that was just like wrong place at
“the wrong time” (In-person interview; J, 2/20/13). “So there’s no rhyme or reason to it. I understand it’s something that just appears” (In-person interview; R, 1/11/13). Because the disease can be so debilitating, I think it is important to determine the cause and to do testing of treatment options and preventative measures. To encourage legislation to fund scleroderma research and pass the “Scleroderma Research and Awareness Act” (S.649 in the Senate; H.R. 1672 in the House of Representatives) the Scleroderma Foundation held a “Congressional Call-In Day” (Scleroderma Foundation, 2012). People were asked to call or write their congressmen on that designated day and the Foundation provided a template for supporters to use.

Living with a chronic illness poses financial difficulties as well. The type of health insurance a person does or does not have can be a source of anxiety. The financial situation of one participant put her in fairly good shape in terms of affording her care. J worked for the government as a social security claims rep. She retired in 1998 and still has Federal Blue Cross as her health insurance. “I don’t have co-pays or anything with my Federal BlueCross.” This insurance allows her to get the care she needs. She visits doctors both in Rhode Island and Boston (at least six different doctors). Having a steady foundation financially probably contributes to a sense of control and empowerment in health care choices. When patients have a reliable insurance plan and the ability to try different doctors, prescriptions and treatment plans regardless of cost, it empowers them and contributes to a feeling of health within illness.

The narratives of the other women I interviewed further the connection between financial stability and health within illness. R explained it eloquently:

“I’m fortunate that I do have good health care and I’m not limited by Medicare or Medicaid. I have an HSA of $2,000 and then anything beyond that Blue Cross will pay for. And that’s usually a good thing for Blue Cross but then for patients like me…I’m
almost like the morbidly obese person who goes to eat at a buffet. So they’re always spending money on me. Last year by the second week of February my whole HSA was already gone. If I had to pay for this anywhere out of pocket, I would be living out of my car. I can still work and have a full time income, so for people who can’t work or are older and have a limited income that must be awful (In-person interview; R, 1/11/13).

R was fortunate that her school district gave her this entire academic year off, paid for out of the sick bank. She was shocked and extremely grateful, because the sick bank has a reputation for being rather scrutinizing of the people that apply. However, they told her to take care of her health. Similarly at the college where she lectures, a friend stepped in and took over one of R’s sections to lighten her load. Although she could have until September to resume her guidance counselor position, she was doing well enough in January that she anticipated returning before the end of this academic year.

The online support groups featured several threads about money and contention about whether having a lot of money makes it easier to handle scleroderma. There were both supporters and dissenters regarding that issue. There was one woman’s response that I particularly liked. “Money can certainly be a stressor in your life and not having enough money for adequate medical care can certainly add another stressor to your life. Problems do not cause most of the stress. How you react to problems makes up most of the stress in a person’s life. Money does not buy most of the priceless things in life: friends, family, positive attitude, gratefulness, faith, ability to deal with stress, grace and peace” (Online post; MaggiMay, 1/22/13).

One of the primary goals of my aunt, and this project, was to pass on wisdom to others recently diagnosed with scleroderma. As I highlighted through Maureen’s narrative, a good
doctor can make all the difference. An interview participant agreed. “Get in with a good doctor. Don’t let it go. Seek medical advice, definitely. There are good doctors out there. So research a rheumatologist and check around. As soon as you think there is something wrong, get yourself a rheumatologist if you think you have Raynaud’s or some sort of autoimmune disease like that” (In-person interview; B, 1/28/13). Even if it takes trial and error, finding a doctor that is competent and caring is important.

The recommendation to join a support group received mixed reviews. Neither Maureen nor my three interviewees attended in-person support groups. However, one expressed the desire. “One regret is that I never joined a support group. I read about one in the paper but I never joined it. But I’m a big advocate of support groups” (In-person interview; B, 1/28/13). On the contrary, J believed going to a support group could be detrimental. “It could be depressing seeing other people with it that are worse off” (In-person interview; J, 2/20/13). It is a personal decision and certainly something that could be helpful (or hurtful). Regardless, it is important to know the option is there. Through the Scleroderma Foundation, there are local chapters and each local chapter meets for a support group about once a month.

Another suggestion involved expressing one’s emotions in a healthy way. “I found keeping a journal to be helpful!” (Online post; ncscleromom, 8/6/12). At such a confusing time, keeping a journal might reduce stress. Additionally, it could serve as a helpful record of symptoms and changes with the disease. Lastly, one participant gave this advice: “Just go along like you’re normal” (In-person interview; J, 2/20/13). While it may be difficult at time, it certainly seems like coping is easiest for those that maintain aspects of pre-scleroderma life continue to do things they enjoy (even if it is something small!).
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ADDENDUM 1 – INTERVIEW GUIDE

- **What is scleroderma**
  - When did you first notice symptoms or that something was wrong with your health?
  - What was it like trying to figure out what was wrong and getting a firm diagnosis?
  - What was it like when you received a diagnosis?
  - What implications did you think this illness would have for your life?

- **Loss**
  - Describe yourself before the scleroderma—did you have health problems?
  - Are there activities you did before the scleroderma that you no longer can?
  - Could you share an experience that you will never forget because it best describes what it means to live with scleroderma?
  - What was most important to you before scleroderma and what is most important to you now? How have your priorities shifted?
  - How has life changed for you?

- **Stigma**
  - How did you perceive the people around you coped or reacted to your diagnosis?
  - In terms of social interactions and relationships, what is most difficult about having scleroderma?
  - Who is privy to all of your struggles with the disease?
  - Do people you encounter know what scleroderma is?
- Health within illness
  o How do you think the rarity and poorly understood nature of the disease impacts your life?
  o How did you inform yourself about the disease?
  o What are your relationships with doctors like?
  o What were your experiences of seeking medical help?
  o How do you make medical decisions?
  o What are the sorts of things that help you to live with scleroderma?
  o What advice would you give to a friend who has just been diagnosed with scleroderma?

- Miscellaneous
  o Role of religion/faith
  o Financial burden – health care system