

Experience of living with systemic sclerosis - a grounded theory study**Chaudhry, S.**

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Experience of living with Systemic Sclerosis-

A Grounded Theory Study



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In partial fulfilment of the requirement for the D.C.PSYCH in Existential Psychotherapy and
Counselling Psychology

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Sidra Chaudhry

Dedication

This Professional Dissertation is dedicated to my beloved parents, especially my late father ‘Zahid Mahmood’, husband and siblings who always be there alongside with me in this journey and encouraged me to confront with this disease.

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ABSTRACT

Systemic sclerosis (scleroderma) is an autoimmune, rheumatic, and rare chronic and incurable autoimmune disease that damages healthy tissue within the skin, blood vessels, muscles, joints, connective tissues, nerves, vascular system and internal organs (Herndon, 2016). Living with systemic sclerosis is challenging as it affects every aspect of an individual's life, from family relationships to managing a job. People with scleroderma become reliant on others in order to perform everyday daily tasks such as dressing and bathing. Systemic sclerosis can cause significant changes in appearance, self-esteem and self-image that can lead to psychological setbacks (*Diseases and Conditions*, 2019).

The study aimed to explore and understand the process of participant's experience to live with Systemic Sclerosis as well as to discover their coping strategies. In order to gain this aim, grounded theory was adopted in this study. Data were gathered through face-to-face semi-structured interview with six participants who met with inclusion-exclusion criteria. Memos were also used in data collections. The result derived Model 'process of changed sense of self' in experience to live with systemic sclerosis. It means that systemic sclerosis has impacted people's daily lives and cause the existential crisis. They experience disability, social isolation, despair, death anxiety, uncertainty and lack of freedom and responsibility. As a result of these phenomena they experience changed sense of self. Alongside using their regime, they use coping strategies to deal with their disease and to manage their lives and rebuild their new sense of self.

This study could assist health-care professional (psychologist, counsellor, psychotherapist, rheumatologist, and immunologist and rheumatology nurses) to have better understanding of people' experience and psychological impact of disease and how they can cope with and learn to live with this disease and is also helpful to raise community awareness of Systemic Sclerosis and impact of disease on their daily lives.

Conditions for Resubmission

1. Explain and justify the analytic process from coding to the model beyond data.
Please see Chapter 5. Page numbers 239 to 245.
2. More reflection on literature review at two time points, Reflect on the purpose of literature review (formulation of the aims of the thesis). Justify and specify search terms, search engines, search process, and inclusion and exclusion criteria for selection of articles. Consider a comprehensive literature review on systemic sclerosis. Be more critical about the included studies.
Please see Chapter 2 Page Number 31 to 92 and Chapter 8 Page Number 340 to 346.
3. Clarify the ontological and epistemological perceptions in light of grounded theory.
Please see Chapter 3, Page Number 108 to 111.
4. Remove “phenomenological” from title
I removed it. Please check title.
5. More reflection on two types of systemic sclerosis in findings.
Please see chapter 4, Page Number 231-236.
6. Reflexivity: demonstrate more reflexivity beyond self-reflection; Deepen the reflexivity on the difference between being a researcher and being a therapist
Please see Chapter 2 Page numbers 86 to 92, Chapter 3 Page Numbers 97, 98 and Chapter 8 Page Numbers: 340-363.
7. Chapter four: be clearer about the difference in analytic process and findings.
Consider moving some materials to appendix.
I have made separate chapters for analytical process and findings (Chapter 4, Chapter 5 and Chapter 6).
8. Be more precise and correct in using existential terminologies such as “lack of meaning” and “angst”.
I have done it. Please see in Findings section.

I hereby certify that this dissertation which I submit for assessment in partial fulfilment of the requirement for award of Doctorate in Psychotherapy and Counselling Psychology is exclusively my own work and is to ensure that work is original and has not been taken from other works and to certain extent that such work has been properly cited and acknowledged within text of my work. It was ensured that study has been carried out after getting ethical approval from both New School for Psychotherapy and Counselling (NSPC) and Middlesex University on 7th of July 2015.

Signed (Candidate): _____

Middlesex Id Number: _____

Date: _____

Experience of living with Systemic Sclerosis: A Grounded Theory Study

CHAPTER 1

INTRODUCTION

1.1 Purpose of Study

The purpose of this study is to explore the experience of people living with systemic sclerosis. Systemic sclerosis (scleroderma) is an autoimmune, rheumatic, and rare chronic and incurable autoimmune disease characterized by the accumulation of excessive connective tissue within skin. The disease damages healthy tissue within the skin, blood vessels, muscles, joints, connective tissues, nerves, vascular system and internal organs (Herndon, 2016).

Systemic Sclerosis is a very uncommon disease and affects 2.5 million people worldwide, four times more common in women as compared to men. There are two types of scleroderma; one is limited scleroderma that mostly affects people's faces, hands, arms, feet and legs. People also suffer from lung and digestive problems over time. However, within this type, the disease affects people more in the skin area. In other types of 'diffuse scleroderma', the whole body is affected by disease, such as the skin, body and major organs including the heart, lungs, kidneys and stomach. The most common age to develop this disease is from 25 to 55, but now this disease is affecting children as well (Scleroderma and Raynaud's UK, 2016).

1.2 Challenges to live with Systemic Sclerosis

Living with systemic sclerosis is challenging as it affects every aspect of an individual's life, from family relationships to managing a job. People with scleroderma become reliant on others in order to perform everyday daily tasks such as dressing and bathing. Systemic sclerosis can cause significant changes in appearance, self-esteem and self-image that can lead to psychological setbacks (*Diseases and Conditions*, 2019). Prognosis varies depending

upon the complications that arise: for example, the nine-year survival rate was 38% for patients with internal organ involvement in one study, while 72% in patients without such involvement (Charles, Clements and Furst, 2006). The prognosis is poor for patients who have been diagnosed with diffuse cutaneous systemic sclerosis with associated early internal organ involvement (Medsger et al., 2003). As yet, medical treatments are limited in efficacy. Half of those affected by the illness show mild to severe depression (Thombs et al., 2008).

1.3 Phenomenology Paradigm

The phenomenological approach puts forward the fundamental question to underpin the theory and practice of counselling psychology, providing the roots for qualitative research models, as well as concerning the analysis of the central features of the counselling process and its outcome. Most of the challenges come from explicitly philosophical origins of existential-phenomenological psychology, whose centrality continues to provide the approach with its primary critiques of the natural science framework that underlies the currently dominant trends in psychological theory and research. It is within this paradigm that I have chosen to practice as a psychologist, because phenomenology challenges to perceive the human condition entirely as it manifests itself in our lived experience. Phenomenology concentrates on the question of ‘being’ itself because its focal point is concerned with the exploration of the experience of living. There are two inter-related modes of inquiry: firstly, an ontological inquiry to explore the intrinsic, universal features of existence and secondly, an ontic inquiry to examine the specific individual ways in which each of us is in the world (Cohn, 1997, cited in Van Deurzen and Adams, 2016). I chose this topic to explore the relationship between the ontic and the ontological, being most interested in exploring work as a therapist and as a researcher.

1.4. Reflexivity

My interest in this topic is arisen from my own experience of having systemic sclerosis. When collecting data, my past history made it easier for me to establish a rapport with other participants suffering from the disease. However, some of the drawbacks of having this experience included the challenge of remembering issues to discuss, remaining focused and attentive, feelings of being overly intrusive, and feelings of being overly emotional and introducing bias into the responses of participants. To ensure this is an effective research study I read journals, articles and literatures on systemic sclerosis, so that I could be fully aware of my disease. I administered interview protocols on myself as a type of pilot study; this helped me to be aware of any potential biases and did also help me to construct research questions. I found personal reflection very helpful to engage with my research topic. Holliday (2006) states that personal reflections allow for a better understanding of interview context. They also help me in finding important themes and assigning meanings to the collected data. I wish to note, however, that although my experience of having this disease may gave me some unique insights, and my experience may also lead to be less aware of aspects that did not form a significant part of my own experience of the disease. In order to reduce the effect of my bias during the interview process, I put my own feelings and emotions aside and tried to increase my levels of awareness in my own blind spots, beliefs, and assumptions about systemic sclerosis. I achieved this primarily through the use of personal therapy. Although, this was an on-going process throughout the research, my supervisor helped me ensure that my own feelings had as little an influence as possible on how I interpreted the responses of interview participants. It was good practice to have a ‘second person’ present to reflect on the interview questions (the pilot study also helped), and responses in order to examine emergent themes.

In being with the client, as an existential-phenomenological counselling psychologist, I needed to attempt to stay with the experienced truth of the client as this is related. This is so that the information and whatever implications these truths might hold may be exposed to further examination and clarification by both the researcher, (the counselling psychologist) and the client. As an existential-phenomenological counselling psychologist, within the confines of each sessional encounter, there is an attempt to 'enter' the client's experiential world with the sole intention of allowing the client a specific form of encounter with another who explores the self (Spinelli, 1994, cited in Woolfe, 2003).

Husserl (1927) proposed the transcendental phenomenology as concerning the world as it presents itself as human. The aim was to understand human experience with bracketing our pre-determined thoughts, assumptions and values about world. Phenomenology highlights the subject matter and the individual's lived experience of the world within specific contexts and at specific times, rather than in theoretical statements about the nature of the world in general. From a phenomenological standpoint, we perceive all objects and subjects together as unity of something instead of viewing them as separate from our experience of it (Husserl 1927, cited in Smith, J., 2013).

Although, transcendental phenomenology was originally a philosophical method of thinking, its methodological recommendations have proved to be of interest to researchers both in social science and, specifically, psychology. This is because phenomenology focuses on the contents of consciousness and the individual's lived experience of the world (Moustakas, cited in Sheehan, 2014). Spinelli (1989) states that phenomenological psychology explores human experiences in the meanings of diversity and variability, rather than the identification of essences in the Husserlian sense. It is also important to highlight the difference between phenomenological examinations of a phenomenon as it presents itself to the researcher and the phenomenological analysis of an account of specific experiences as presented by a

research participant. The former requires introspective attention to one's own experience, whereas the latter is an attempt to 'enter into' another's lived experience on the basis of their description of it. Therefore, in phenomenological psychological research, the research participant's account becomes the phenomenon with which the researcher engages (Spinelli, 1989; cited in Woolfe et al., 2003).

I would like to describe the relationship between the ideas of Heidegger, a key existential philosopher and Yalom, an existential psychiatrist in life-threatening illnesses. Heidegger's exploration of the meaning of being, importance of time, death and human relatedness and Yalom's writings on existential concerns, are considered relational to life-threatening illness. People living with life-threatening illnesses suddenly face the possibility of dying.

Heidegger (1962) applied the phenomenological method to understand the meaning of 'being'. In *Being and Time*, Heidegger tried to grasp death's phenomenon through understanding the 'Dasein'- what it means to be human. The phenomenology of death focuses on discovering the ways in which death grasps human understanding as an essential condition of being-in-the-world. Death is closely related to a phenomenology of life: life's being is also death. This means that all the things ultimately travel towards their end (death) when it comes into life, and death is at the same time life (ibid: 5). Being is time and time is finite, which means if our being is finite then it finishes with our death. Only then, can human beings be authentic by defying the finitude and striving to find meaning out of the fact of our death. So, it is indispensable that we incessantly project our lives onto the horizon of our death - that is called being-toward-death (Heidegger, 1962).

The threat of mortality reminds us about the existential givens that men are thrown into groundlessness, which is the concept of Martin Heidegger (1962). He stated that we are thrown into death rather than it being chosen by us. The thrownness of our existence makes us aware that we are moving towards death. Therefore, we cannot avoid ourselves facing

death in our future. Awareness and recognition of being-towards-death are something that we all must confront in order to live more authentically and live more in the moment. Heidegger (1962) talked about two basic existential modes in the world: a state of ‘forgetfulness of being’ and a state of ‘mindfulness of being’. For Heidegger, a state of forgetfulness of being denotes we are living in the world inauthentically. People are unaware, fleeing, tranquilized and they avoid making choices. Whereas, a state of mindfulness indicates that a human being lives their life in an authentic manner and becomes responsible for their choices, accepting their possibilities or limits and confronting their anxiety. Yalom (1998) reported that many dying people develop the higher awareness of the beauty of the objective world. They become aware of inner feelings and, small things that they once took for granted, now have significance in their lives. It is being in the mindfulness state that personal change in self can happen. The awareness of death motivates us to achieve something of note while we live (Yalom, 1998, cited in Berry-Smith, 2012).

Heidegger (1962) talked about the temporality in beings and time as directional and relational to having had a ‘being-ness’ and ‘being-expectant’ of a particular future (Heidegger, 1962). He perceived the ‘temporality’ as being an ecstasy, outside-of-self, of future projections (possibilities) and one’s place in history as a part of one’s generation. Possibilities are essential to our understanding of time; our projects or goals are those things that lead us to live in the world. Yalom supports the Heideggerian concept of authenticity by referring to several stories of life challenging encounters with death in his account of ‘almost-being-dead.’ He tried to use Heidegger’s description of death as a possibility of one’s own potentiality for being, non- relational, and not to be outstripped (Heidegger, 1962). The awareness of death, which we can die at any moment, reminds us that death is a boundary situation that we all share and need to transcend or overcome in some way. Death is a

condition that makes it possible for us to live life in an authentic manner (Yalom, 1998, cited in Berry-Smith, 2012).

In conclusion, life and death are inter-linked and both exist at the same time. Yalom was inspired by Martin Heidegger's concept that although the physicality of death destroys us, the idea of death saves us. Yalom (1980) tried to explain the meaning behind Heidegger's theory. It means that when people become aware and accept death, then, they start to find meaning in their lives which brings them into an authentic mode of living. In other words, being in a forgetful state, I had never thought about the concept of death before and took everything for granted. Once I became aware and accepted the inevitability of death, after my diagnosis, this compelled me to live authentically. This idea of death not only saved me but also saved my care-taker(s) through realization of the inevitability of our death and this then induced them to live their lives in an authentic manner.

1.5. Rationale of the Study

The rationale for this research is that although many researchers explore the phenomenon of having systemic sclerosis from a medical perspective, the research is going to explore the experience of living with a body that is changing as a result of a progressive, incurable disease, as well as to scrutinize the impact of a changing body on the sense of self from the existential phenomenological perspective. Most of the work discussed in the literature review has been conducted using quantitative methodology in order to explore how an individual might cope with the symptoms of having systemic sclerosis, or by measuring their quality of life with systemic sclerosis, or the appearance of self-esteem or a stressful event with systemic sclerosis. However, these studies do not explore information regarding how individuals undergo their experience of living with systemic sclerosis. However, a few researchers (as shown below) explored the living experience with systemic sclerosis using a variety of qualitative research methodologies, considering hope, despair, stigma, and

psychological problems with systemic sclerosis. I would like to explore their experience of living with systemic sclerosis by simply asking the question: ‘Tell me about your journey since being diagnosed.’

1.6. Linkage of the Study within the Field of Counselling Psychology

Systemic sclerosis is a chronic autoimmune disease illustrated by skin, joint and muscle adaptation, ending with disability and the worsening one’s quality of life. As an outcome of chronicity, people with systemic sclerosis reported greater amount of pain, fatigue and reduced physical performance (Hudson, 2009, cited in Del Rosso et al., 2013). Systemic sclerosis frequently impairs the largely observable and socially related parts of the body, such as the face and hands. These impairments may impact on social relationships, leading to functional difficulty and modifying the people’s self-image, resulting in body image disaffection that ultimately diminishes the quality of life (Keillor, 2002, cited in Del Rosso et al., 2013).

In reference to physical changes and signs, people with systemic sclerosis also describe the greater level of anxiety and depression (varying from 18% to 65%) compared to the rest of the population and other patient groups. Earlier researchers investigating the issues related with depression and anxiety, explained the various different correlations. Depressive symptoms were associated with the declination of working capabilities, social interests and the inability to take action against stressors, feelings of excessive helplessness, anguish, tiredness, lack of communal support, emotional focused coping, and the trepidation of disease collapse (Thombs et al., 2007, cited in Del Rosso et al., 2013). Roca et al (1996) stated depression was associated with those of a younger age with digital ulcers and more functional disability (Roca et al., 1996, cited in Del Rosso et al., 2013). There were also clear relationships between depression and personality traits. In very few studies, were depressive symptoms associated with the Systemic Sclerosis (SSc) severity, tiredness or other physical

symptoms (Wafki et al., 2012, cited in Del Rosso et al., 2013), although, anxiety has been substantially investigated in other chronic diseases and in rheumatoid arthritis (RA) (Vendyke, 2004, cited in Del Rosso et al., 2013). Depression and anxiety, common in patients with rheumatic diseases, are linked in Systemic Sclerosis with reduced quality of life, minimal sexual functioning and non-adherence to remedy regimes. Some studies showed that depression and anxiety levels are greater than healthy control (Haemmerlie et al., 1988, cited in Del Rosso et al., 2013). Depressive symptoms were notably associated with global disability, hand and mouth disability, weariness, and avoidance approaches in coping. Anxiety was linked with self-esteem, greater levels of apathy, social support, and with global face and hand disability. The consequential relationship between depression and the anxiety with hand disability may denote that there is an enhanced need of help in everyday life, such as with day to day tasks and working abilities; the experiencing of helplessness could increase depressive or anxiety disorders in Systemic Sclerosis patients. Depressive and anxiety symptoms link with coping avoidance strategies, as with Systemic Sclerosis patients, the adaptations are to the most noticeable and socially related body parts, such as hands and face, also creating difficulties in social relationships, resulting in avoidance conducts and social anxiety (Caldwell & Reinhart, 1988, cited in Del Rosso et al., 2013). In Systemic Sclerosis patients, self-esteem, linked to anxiety and depression, may be possibly impeded both by diminution of physical functioning, difficulties in executing daily activities and by the alteration in face and hands (Benrud-Larson et al., 2003, cited in Del Rosso et al., 2013). During my own experience of living with Systemic Sclerosis, I found that medical doctors place little emphasise on the subjective experience of patients. They only focus on the physical impact of disease. This research aims to help counsellors, psychotherapists and psychologists understand how people live with rare diseases and how they can live their life in a meaningful way.

The second reason for conducting this study is due to the fact that this disease does not come up in blood reports easily. It takes time to appear in blood reports and in some cases; it takes a very long time. Many General practitioners are unable to diagnose until after a long period of time and often misdiagnose patients as having psychological disorders. Consequently, patients become more vulnerable, disappointed, face a growing fear of rejection and disconnect with others. This research would help patients understand the psychological effects that living with this rare disease has on individuals. This paper would help them understand the existential issues that underlie how they confront rare diseases.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

There has been an insufficient amount of research into the experiences of living with systemic sclerosis to properly inform a counselling psychologist working with patients who are suffering with this disease. In this chapter I look more widely at the research literature to identify the information that could be of use for the present study and engage critically with its limitations—a lack of reliability in many studies’ sampling methods together with the narrowness in the way this complex psychological/sociological and existential phenomenon has been considered has not been approached before.

Initially, I would like to explain how and why the initial literature review was undertaken during the commencement of this study and how the literature review has been informative to this current study. There are different stages to conducting literature reviews in the grounded theory. In this study, I undertook a two-stage literature review; the initial literature review was undertaken prior to conducting the study and the other was the secondary stage, which was conducted after data collection.

Overall, the aim of the literature review chapter was to inform the reader about the basic information relating to systemic sclerosis as it could be a novel topic for the reader. This chapter tried to cover all the articles that were necessary in order to understand the phenomena and to understand the significance for investigating the study within the discipline of counselling psychology. The other aim was to identify the gap within the existing literature, why it was imperative to fill those gaps, how the pre-existing literature contributed to build the aims for this study and how the current study would contribute to pre-existing knowledge within a healthcare setting.

2.2. The Use of Literature in Grounded Theory

I commenced my literature review after my first Skype meeting with my primary supervisor. In accordance with the common principles for a literature review in constructivist grounded theory studies, the relevant literature was reviewed in two stages.

I began with an initial review to ascertain the current existing level of knowledge in this particular area and to identify a gap that might be filled by this study, as well as formulating the research questions. The grounded theory approach was used for this study. The second more comprehensive review was conducted towards the end of the data collection and analysis period in order to compare the developed theoretical categories with the existing literature. Both of these reviews are incorporated within this chapter, which is coordinated within the theoretical framework for this study (Charmaz, 2006). The initial literature review was an integral part of the research proposal and was required in order to obtain approval for the project by the Programme Approval Panel and the Board of Ethics, as a researcher is expected to justify the need for their study (Birks & Mills, 2015, cited in Connor, Carpenter and Coughlan, 2018). Priest & Roberts (2010) stated that the main purpose of the literature review was to identify a gap in the current knowledge whereas Holloway & Wheeler (2010) considered that the literature review also helped to acknowledge prior work and avoid duplicating other's work and assisted in defining the research question, thereby analysing the current study in the context of other studies (cited in Walker, 2016).

Birks & Mills (2011) perceived a limited and purposively initial review as being beneficial to the researcher in the primitive stages of their work, particularly seeing this as a useful tool for enhancing early theoretical sensitivity. In the constructivist grounded theory, the researcher is encouraged to become familiar with the literature prior to data collection. As Charmaz (2014) reported, it is impractical to expect that the researcher will commence their study with specific knowledge about the topic. She argued that restricting the extent of the literature

review would result in the researcher being uncritical in their reading and could be easily persuaded by it. Further, she claimed that the researcher's ability to build theoretical sensitivity would suggest her acquaintance with the relevant literature. She also implied that the researcher should adapt the final version of their literature review to fit their study and its findings. However, conducting the literature review before data collection was important to its epistemological framework. Therefore, the constructivist grounded theory claimed that the researcher's role could not be avoidable in the research process as the researcher could not be eliminated from data collection and analysis—both are 'created from shared experiences and relationships with respondents and other sources of data (Charmaz, 2014, p. 239). In the constructivist grounded theory, the researcher is active in the process from the selection of the topic to the study's results; as such the researcher's voice cannot be excluded. Therefore, reflexivity is important throughout when carrying out the research process. Reflexivity does not aim to remove the researcher's subjectivity from the resulting theories but rather that the data, together with the researcher's assumptions and any pre-supposed beliefs and knowledge, are included in any reviewed literature and the researcher should engage with it critically (Thornberg, 2012). Additionally, reviewing literature would assist the researcher in understanding an area which is an understudied area, highlighting the need for addressing the current study. Therefore, it is very unlikely that the researcher could conduct the study with no former reading about the topic (Charmaz, 2006). This formerly acquired information would render the source of sensitising concepts that could symbolise initial ideas as to where to engage analytically with the data and also provide a general sense of direction. However, it is significant to prioritise the data over the literature during the research process as that will uncover whether the reviewed literature is beneficial for data analysis and theory construction (Dunne, 2011). Therefore, the researcher's own life experience is imperative to address for the grounded theory study. Dressel & Langreiter (2003) stated that there are no exact

methods that could remove the researcher's subjectivity completely from the project but engaging in self-reflexivity assists in contextualising the research practice within the researcher's cultural background (cited in Ramalho et al., 2015).

Overall, reflexivity can help the researcher to recognise their position and gain a better sense of their choices and rationales in conducting the study and also to ensure groundedness. In this study, the researcher used different ranges of reflectivity strategies, such as memo writing, constant comparison methods, writing journals, personal therapy and support from the supervisors. Later in the work, the researcher compared the data, codes and categories with pre-existing literature in order to validate the results. However, the data should be given priority over the literature (Ramalho et al., 2015).

As part of my doctoral study, I started to conduct my initial literature review prior to the research project as it was my aim to enhance my understanding of the context of the area being researched and it also helped me to recognise my rationale for conducting this study, whilst limiting my influence of prior conceptualised theories (Birk & Mills, 2015). In line with the grounded theory methodology, a second literature review was carried out following completion of the data analysis in order to support my study's findings.

2.3. Study Identification and Selection

In order to research terms, I needed to develop clear inclusion criteria, which is a highly significant aspect of a review to ensure that the review questions are clearly addressed. I attempted to ensure that the criteria would not only be too narrow so as to exclude those studies that could be important to the review but also not be too broad so that it would be hard to manage. The following inclusion and exclusion criteria were constructed to facilitate the screening process.

2.3.1. Eligible Studies

I included studies within the review that were able to satisfy one or more of the following inclusive criteria:

- Studies that explored the experience of living with systemic sclerosis.
- Studies that focused on the psychological experiences of people living with systemic sclerosis.
- Studies that focused on the physical functioning (daily activities or chores) of people living with systemic sclerosis.
- Studies that addressed the impact on relationships by living with systemic sclerosis.
- Studies that focused on the existential issues by living with systemic sclerosis.
- Studies that explored the coping strategies to deal with systemic sclerosis.

2.3.2. Excluded Studies

Any study that met one or more of the following criteria would not be selected for review.

- Studies that are not published in the English language.
- Studies that focused on medical perspectives or physiological causes of systemic sclerosis.
- Studies that focused on the clinical assessment of systemic sclerosis.
- Studies that focused on the ‘comparison’ between systemic sclerosis and other diseases.
- Studies that focused on the relationship between stress and autoimmune diseases.

- Studies that had been done on any other autoimmune disease that could be secondary to systemic sclerosis.
- Studies that recruited participants under the age of 16 years.
- Studies that were conducted on the healthcare professional in relation to systemic sclerosis.
- Studies that were conducted on the carers of patients with systemic sclerosis.

Through utilising the above selection criteria, I was able to develop a list of studies that were screened against their titles and abstracts and then selected for in-depth review.

2.4. Search Terms

Different search terms were used to capture qualitative and/or quantitative data which was viewed as relevant to the focus of inquiry. I tried to use various synonyms comprising of truncations and quotations to best capture the search term.

<i>Search Terms</i>
‘Living experience’ ... ‘Experience of living’ ... ‘Daily living’ ... ‘Everyday experience’ ... ‘Daily life’ ... ‘Daily basis’
‘Coping strategies’ ... ‘Resilience’ ... ‘Dealing’ ... ‘Handling’ ... ‘Managing’ ... ‘Coping approaches’
‘Systemic Sclerosis (SSC)’ or ‘Scleroderma’ or ‘Limited systemic sclerosis (LSSC)’ or ‘Diffuse systemic sclerosis (DSCC)’

2.5. Search Strategies

Four electronic databases were used to identify studies for inclusion from 2005 to the present using the above search terms. These four electronic databases were PUBMED, the Wiley Online Library, Biomedical Central (BMC Journals) and the SAGE journals.

Each title and abstract was scrutinised with reference to the studied phenomena and then the paper was selected for review. Through this iterative process, I was able to select a total of twenty-six papers for review.

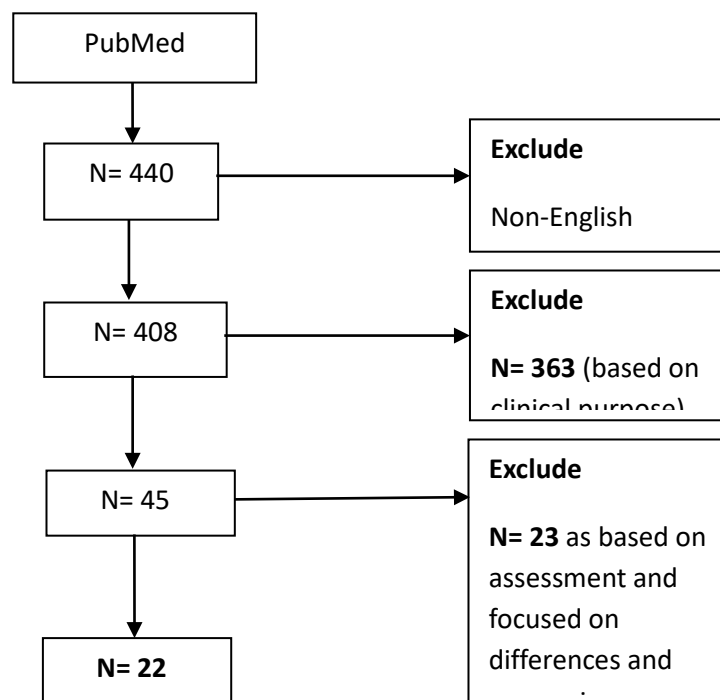
2.5.1. List of Databases

Source	Database Description
PubMed	Citations for biomedical literature from MEDLINE, life science journals and online books.
Wiley Online Library	Most authoritative collection of <i>online journals</i> , books and research resources, covering life, health and the social and physical sciences
Biomedical Central (BMC)	Portfolio of high-quality peer-reviewed journals
SAGE	The world's leading independent academic publisher with a full spectrum of the social and behavioural sciences and the humanities

2.5.1.1. PUBMED Source

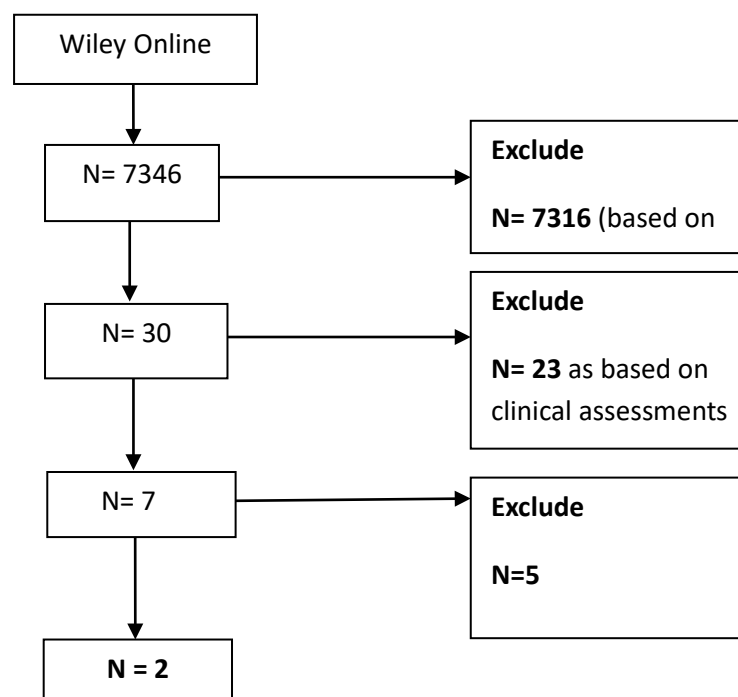
I would like to illustrate my process of selecting a paper from each electronic database. The flowchart set out below describes my process of selecting literature from PubMed. Initially I was able to identify nearly 440 articles. Out of those, thirty-two were included in other

languages and 363 articles were based on pathological causes and medical remedy. I reviewed the forty-five articles that were left in accordance with my study's aims and eligible criterion. Twenty-seven studies focused on racial differences or were more based around clinical assessments, rather than focusing on the subjective experience of living with systemic sclerosis. I excluded all of those studies that did not meet my former eligible criteria. Through this iteration process, I found twenty-two abstracts that were related to the background of my study.



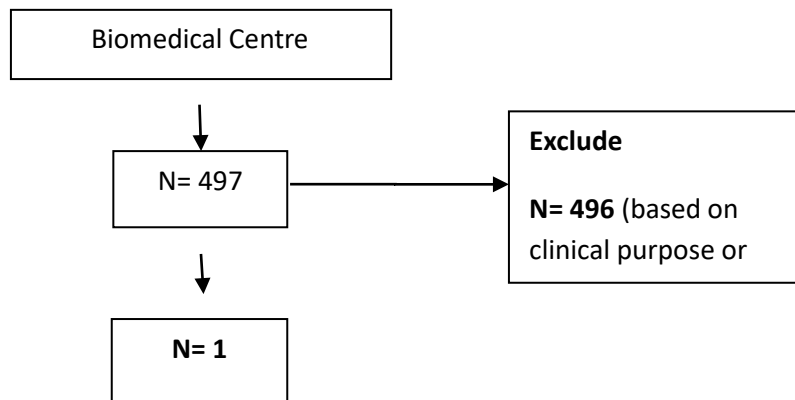
2.5.1.2. Wiley Online Library

I only found two abstracts from the Wiley online library through the iterative process. Although there was a huge amount of material, most of them were focused on physiological causes or based on antibodies that were found in systemic sclerosis, so many of them were irrelevant to systemic sclerosis. However, I found seven abstracts from the Wiley online library but five were very similar to the PubMed articles, so I ended up with only two new



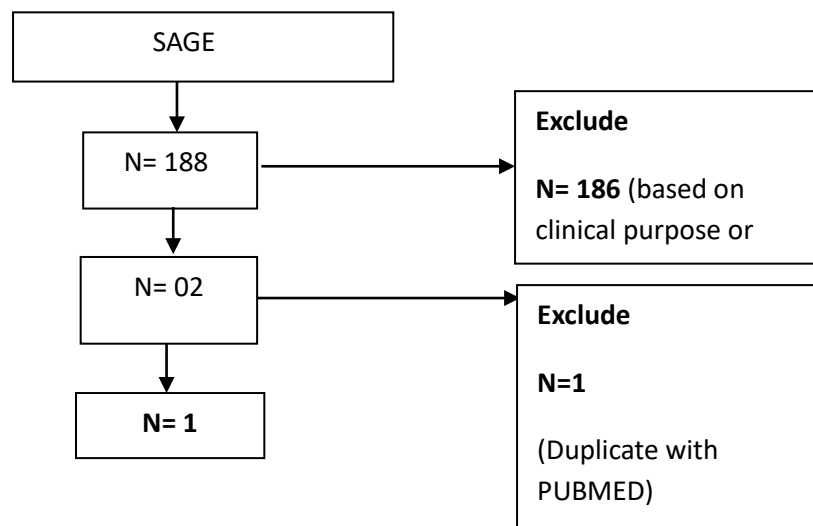
abstracts from this database source.

2.5.1.3. Biomedical Central

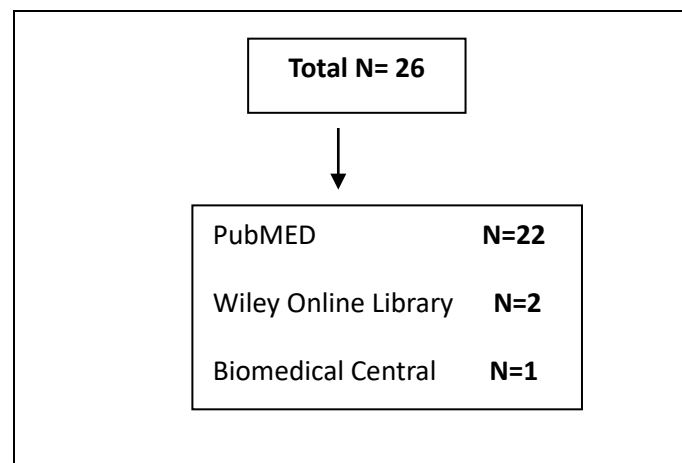


Through the above map, it can be ascertained that I only found one study from biomedical central. However, this database had a vast collection of research studies.

2.5.1.4. SAGE



I was able to identify two abstracts from the SAGE journals but found that one article was akin to PubMed. Therefore, only this one abstract was discovered from this data source. By using this approach, I was able to gather a total of twenty-six abstracts from the four different database sources. However, I had to access the Middlesex library in order to review the database sources. I reviewed all twenty-six abstracts systematically in order to fathom the backgrounds of the studies and to identify any gaps in these studies which could be filled by my study.



The literature review was conducted for two reasons. The first was to obtain approval from the Programme Approval Panel and Ethics Boards by pinpointing the issues that needed to be addressed in this current study and which covered the era of 2005 to 2015. The second reason was to review the literature from 2015 to date, after the data collection period, in order to correlate it with my studies. I integrated both literature reviews below so that the reader could easily understand the background to the study, why it was important to conduct the study and how it could contribute to pre-existing knowledge.

Below is table I which sets out the twenty-six studies, providing details of their authors, year of study, location of study and their methodologies. Most of these studies have been

conducted outside of the United Kingdom. Twelve articles out of twenty-six used the qualitative approach, three studies used mixed methodologies, six were based on quantitative methods and five abstracts had a systemic review. I reviewed each article separately and read the full text with assessing rigour as to the relevance of the study's remit. Sixteen full-text articles were accessed through the Middlesex Library, whereas the rest of the articles were retrieved through requests directly to the authors.

By re-reading the articles, I extracted themes from them in order to fully understand the previous studies that had been carried out on systemic sclerosis. I considered that these studies would be helpful to a novice reader as they would help in understanding what systemic sclerosis is and how people experience this illness. After scrutinising these studies, I discovered sixty-seven themes across twenty-six studies and refined them further, particularly identifying seven themes that people experienced by living with systemic sclerosis. In addition, these studies helped to understand the gap in the literature review that can be addressed by this current study.

Table I: Selected Literatures for current Study

	Author	Title	Country	Methods	Results	Contributions
1	Leeuwen et al. (2020)	Illness perceptions, risk perceptions and worries in patients with early systemic sclerosis	Netherlands	Focus group and Questionnaire	Three dimensions of illness perception: lack of personal control, concern (worry) about future and consequences.	This study focused on patient's daily lives.
2	Khanna et al. (2019)	Patient perception of disease burden in diffuse cutaneous systemic sclerosis	USA	Mixed Methodology	This study demonstrated that patients with diffuse cutaneous systemic sclerosis had high treatment and disease burdens such as skin changes, pain, disability and fatigue that has profoundly affected their lives and they reported no emotional support at the time of diagnosis	This study provided knowledge to the healthcare system to improve their care for patients.

	Author	Title	Country	Methods	Results	Contributions
					and afterwards.	
3	Murphy et al. (2019)	Fatigue and its association with social participation, functioning and quality of life in living with systemic sclerosis.	USA	Quantitative Method	The study revealed that fatigue is one of the main symptoms in systemic sclerosis and has played a role as a barrier to social participation and activities.	This article helped to understand the importance of management of fatigue in people who are living with systemic sclerosis though rehabilitation intervention so they could maximise their participations.
4	Milette et al. (2018)	Challenges and strategies for coping with scleroderma: implications for a scleroderma-specific self-management program.	Canada	Focused Group Thematic Analysis	Participants reported challenges in accessing information, dealing with negative emotions and accessing resource strategies for overcoming challenges were also discussed.	This study focused on patient's perspectives towards disease and coping strategies.

	Author	Title	Country	Methods	Results	Contributions
5	Milette et al. (2019)	Scleroderma patient perspectives on social support from close social relationships.	Canada	Focused Group Thematic Analysis	Participants reported that having a close relationship motivated them to learn and to get involved in enhanced support.	This article explored the patient's perspective for the social support they need and receive from close relationships to better manage their disease.
6	Basta, Afeltra and Margiotta (2018)	Fatigue in systemic sclerosis	Italy	Systemic Review	The result showed that fatigue leads to a significant impairment in quality of life, parenting, household and work ability.	This study focused on understanding the adequate management of fatigue that could lead to a marked improvement of the patient's quality of life in living with systemic sclerosis.

	Author	Title	Country	Methods	Results	Contributions
7	Gumuchian ST et al. (2017)	Understanding coping strategies among people living with scleroderma	Canada	Focused Group	This article discussed a range of coping strategies (problem-focused; emotional-focused; and meaning-focused coping) that participants used to manage systemic sclerosis.	This article helped to gain a greater understanding of the coping strategies employed by people living with scleroderma.
8	Sumpton et al. (2017)	It's Not Me, It's Not Really Me." Insights from Patients on Living with Systemic Sclerosis	Australia	Semi-Structured Interview using HyperRESEARCH software	This study identified major bodily changes and social restrictions that impacted on their social image and identity and also uncertainty for causes and prognosis.	This study contributed to understanding patients' perspectives of systemic sclerosis to inform strategies to improve their care.

	Author	Title	Country	Methods	Results	Contributions
9	Mouthon et al. (2017)	Patients' views and needs about systemic sclerosis and its management: a qualitative interview study	France	Qualitative Method Focused Group	The result showed that physical, psychological and social repercussions may lead to psychological distress and different coping strategies. They focused on more patient-physician relationships as part of their management of systemic sclerosis.	This study has contributed knowledge to the healthcare system in order to help people with systemic sclerosis.
10	Nakayama et al. (2016)	Patients' Perspectives and Experiences Living with Systemic Sclerosis: A Qualitative Study.	Australia	Systematic Review and Thematic Synthesis	This thematic synthesis reviewed that systemic sclerosis is an unpredictable illness that undermines patients' sense of certainty and controls and impairs their self-image, identity, and daily functioning.	This study helped to grasp the patients' perspectives and experiences of living with systemic sclerosis

	Author	Title	Country	Methods	Results	Contributions
11	Gumuchian et al. (2016)	Exploring Sources of Emotional Distress among People Living with Scleroderma.	Canada	Focus Group Thematic Analysis	This study revealed themes that reflected on their stressful journey of living with the disease and their emotional experience prior to receiving diagnosis and continuing throughout the participant's lives.	This article assisted to comprehend multiple sources of emotional distress due to living with systemic sclerosis and contributed knowledge into healthcare settings.
12	Cinar et al. (2013)	Coping strategies for activities of daily living in women whose hands were affected by systemic sclerosis.	Turkey	Quantitative Method	This study reported that participants had difficulties with their daily chores due to their impaired hand functions and they adapted coping strategies to manage with their hand disabilities.	This study worked as a useful resource to other people to learn some occupational skills to manage their disability.

	Author	Title	Country	Methods	Results	Contributions
13	Leon et al. (2013)	Negative effect in systemic sclerosis.	Spain	Systemic Review	This comprehensive systemic review found negative emotions in patients with systemic sclerosis. They experienced negative emotions due to their physical appearance and disease related symptoms.	This review helped to grasp the impact of the illness on a patient's emotional being.
14	Malcarne, Fox, Mills and Gholizadeh (2013)	Psychosocial aspects of systemic sclerosis.	USA	Systemic Review	This systemic reviewed found data SSc- related depression, fatigue, sleep, pain, body image distress, sexual function and breathing problem and fatigue leads to work disability and also focused on healthcare needs and psychosocial interventions.	This study focused on the impact of the disease on people's lives and to better address the psychosocial needs of a person with systemic sclerosis.

	Author	Title	Country	Methods	Results	Contributions
15	Ennis et al. (2013)	A pilot study of body image dissatisfaction and the psychological impact of systemic sclerosis-related telangiectases.	UK	Mixed Methods Questionnaire Scale and Thematic Analysis.	The study revealed that participants experience dissatisfaction with their physical appearance and especially related with Telangiectases. Using thematic analysis, four themes were found among participants such as: changes in behaviour as a result of telangiectases, self-image, and negative emotional impact of telangiectases and appreciation of life.	This researcher contributed to understanding new insights into the thoughts and feelings of patients with telangiectases and the need to address and manage related concerns.

	Author	Title	Country	Methods	Results	Contributions
16	Sandqvist, Hesselstrand, Scheja and Hakansson (2011)	Managing work life with systemic sclerosis.	Sweden	Focused Group	This article suggested that they reduced working hours, work flexibility and prioritised meaningful activities that means they used problem solving strategies and the re-designing of activities in daily life so they can balance their work life.	This study worked as a facilitator for others who could adopt these skills to manage their illness in work life.
17	Cinar et al. (2011)	Living with scleroderma: patients' perspectives, a phenomenological study.	Turkey	Qualitative Method Phenomenological Method	This study revealed four categories where the participant's life was affected such as physical manifestation as a physical impact of the disease; disappointment and fear for the future as an emotional impact of the disease; isolation as a social impact of thee disease and their behaviour.	This study contributed in grasping participant's daily life in order to understand their in-depth experience of living with systemic sclerosis.

	Author	Title	Country	Methods	Results	Contributions
18	Stamm et al. (2011)	Concepts of functioning and health important to people with systemic sclerosis: a qualitative study in four European countries.	Austria	Focused Group	This study identified a range of themes as a result of living with systemic sclerosis that included impaired hand function, household activities, paid work, drugs, climate and coldness, support from others and experiences with healthcare institutions, non-pharmacological treatment, social security and benefits.	This study developed a common understanding of bio-psycho-social perspectives in people with systemic sclerosis amongst four European countries.

	Author	Title	Country	Methods	Results	Contributions
19	Newton, Thombs and Groleau (2012)	The experience of emotional distress among women with scleroderma.	Canada	Qualitative Method Thematic Analysis	The result revealed that participants expressed distress related with scleroderma and the term depression was used who had severe experiences. In order to deal with their distress, they did not dwell on their circumstances and worked to maintain their autonomy.	This study aimed to explore their emotional distress and what they believed caused it and how they coped with it. This study would help to understand the emotional distress of people who are living with a chronic medical illness.
21	Buck, Poole and Mendelson (2010)	Factors related to self-efficacy in persons with scleroderma	Arizona	Quantitative Methods	The study concluded that participant's self-efficacy correlates with physical function and psychological variables, and could predict how patients manage their health.	This study contributed knowledge to the professional discipline that self-efficacy may increase through participation in educational programmes focusing on the self-management of these variables

	Author	Title	Country	Methods	Results	Contributions
22	Rubenzik and Derk (2009)	Unmet patient needs in systemic sclerosis.	USA	Quantitative Method Four-Point Scale	The study discovered the participant's unmet needs in psychological/ spiritual/ existential domain such as their physical difficulties to do chores, a fear of poor prognosis, feelings of depression and uncertainty about the future etc.	The study gave knowledge to the reader or clinician to better understand their functioning from a patient's perspective.
23	Thombs, Hudson, Taillefer and Baron (2008)	Prevalence and clinical correlates of symptoms of depression in patients with systemic sclerosis.	Canada	Quantitative Method	This study revealed high levels of depressive symptoms due to disease severity and its symptoms such as tender joints, gastrointestinal symptoms and breathing.	The study contributed knowledge to understanding relationships amongst disease severity and mental health problems.

	Author	Title	Country	Methods	Results	Contributions
24	Thombs, Taillefer, Hudson and Baron (2007)	Depression in patients with systemic sclerosis: A systematic review of the evidence	Canada	Systemic Review	The results showed that symptoms of depression are common amongst patients with systemic sclerosis.	This study assessed level of depression amongst patients with systemic sclerosis. It also recommended that there was a need for studies that examines depression at different time points from the diagnosis of systemic sclerosis and that investigated factors associated with high levels of depressive symptoms.
25	Suarez-Almazor, Kallen, Roundtree and	Disease and symptom burden in systemic sclerosis: a patient perspective.	USA	Qualitative Method Grounded Theory methodologies	The result concluded that participant's social lives disrupted as repercussions of systemic sclerosis and they experienced an emotional burden including depression, low self- esteem, concerns with physical	This study helped to get insight about the illness and disease burden in the lives of patients with systemic sclerosis that will be more effective overall in treatment

	Author	Title	Country	Methods	Results	Contributions
	Mayes (2007)				appearance, and uncertainty about future outcomes.	programs.
26	Sandqvist, Akesson and Eklund (2005)	Daily Occupations and Well-Being in Women with Limited Cutaneous Systemic Sclerosis	Sweden	Mixed Methods	The result revealed that people reported loss of occupations and had low satisfaction with leisure. They experienced fatigue, shortness of breath and pain that led to poorer well-being in women with scleroderma.	This study guided healthcare sectors to focus on occupational therapy intervention.

2.6. Fatigue and Systemic Sclerosis

One of the main problematical symptoms discussed in the previous literature is fatigue in systemic sclerosis and the relationship between fatigue and emotional suffering. Pre-existing literature talked about fatigue arising as a result of living with systemic sclerosis. The study by Murphy et al. (2019) identified a relationship between fatigue and physical functions, quality of life and social participation. People have a lack of social interaction and activities due to their experience of fatigue. According to this study, fatigue had an impact on a participant's life to engage with their daily tasks and activities and also hindered them in their duties and family responsibilities, thereby providing knowledge to the reader about fatigue in relation to systemic sclerosis.

Another study by Sandqvist, Akesson & Eklund (2005) supported this outcome. They were interested in exploring occupational performance, well-being (operationalised as general life satisfaction, domain-specific life satisfaction and self-rated health) and perceived symptoms in women with limited scleroderma and healthy populations. The outcome of this study supported fatigue as a prominent factor in people living with systemic sclerosis and was significantly associated with well-being. They reported that women with scleroderma felt a lower level of satisfaction with their daily chores as they experienced fatigue and could not carry out their daily occupations.

Another study by Basta, Afeltra & Margiotta (2018) integrated studies in order to understand fatigue in systemic sclerosis. The authors discovered that fatigue was prevalent in people's lives and resulted in significant impairment of their quality of life, such as parenting, household chores and workability. Not only this, fatigue was also linked with emotional suffering such as depression, pain and sleep disorders. Similar outcomes were found in the studies of Malcarne, Fox, Mills & Gholizadeh (2013); Cinar et al. (2011); Suarez-Almazor et

al. (2007); and Khanna et al. (2019). Buck, Poole & Mendelson (2010) investigated factors related to self-efficacy in people with scleroderma and found that fatigue was one of the key impacting factors. People faced difficulties in doing daily chores due to fatigue which resulted in further disability and associated lower self-efficacy, thereby causing depression or emotional suffering. However, these studies claimed that there were difficulties in both household chores and work settings due to fatigue. I found some drawbacks in these studies as they were more concentrated on fatigue rather than the impact of systemic sclerosis on their lives. I agree that fatigue is an important factor in people's lives but it acts as an intervening factor in the participants' life. These research studies were helpful in understanding that a physical experience of the illness is fatigue but it is missing how the disease has an impact on a participant's life as a whole instead of any specific factors related to the disease.

2.7. Disability and Systemic Sclerosis

There are some research studies on systemic sclerosis that reported physical limitations as a repercussion of suffering with systemic sclerosis, such as Khanna et al. (2019); Malcarne, Fox, Mills & Gholizadeh (2013) Cinar et al. (2011); Buck, Poole & Mendelson (2010); Nakayama et al. (2016); and Rubenzik & Derk (2009).

These studies reported that participants with systemic sclerosis experienced physical disabilities, such as Khanna et al. (2019) who examined patient perception towards the burden of having the disease and found that people reported a loss of independence as they had a very small social network.

Another study by Cinar et al. (2011) reported hand impairment as a part of their disability. Due to hand impairment, they have difficulty in doing their household chores, from an eating perspective and from a 'washing/clothing' perspective. Two studies correlated disability with their experienced levels of fatigue, being that of Malcarne, Fox, Mills & Gholizadeh (2013)

and Buck, Poole & Mendelson (2010). They reported that people experienced fatigue, which they found disabling, and identified significant levels of functional issues and hand disabilities in people due to systemic sclerosis. Similar reports relating to physical limitations were found in the studies of Rubenzik & Derk (2009) and Sumpton et al. (2017).

Nakayama (2016) undertook a systemic review on people's perspectives and experiences of systemic sclerosis. The author accessed the electronic sources MEDLINE, Embase, PsycINFO, and CINAHL originating from the database's inception through to 13 October 2014. He found out from these reviews that people experienced physical limitations and body restrictions due to the symptoms of their illness. They became socially limited due to their restricted movements and they had difficulty in doing their daily household chores and maintaining their jobs, which resulted in a loss of independence.

This section has helped both the reader and the researcher to understand the seriousness of systemic sclerosis and its relationship with disability. It is clear that this disease has impacted on individual muscles and joints that could lead to some level of disability. Some of the studies reported hand impairments in people whereas others connected fatigue and pain with disability. I agree that pain, fatigue and disability are inter-related with each other but I found that the emotional element in experiencing physical disability was missing from these research studies. Moreover, the research merely focused on hand impairments in terms of disability and did not explore disability on other facets of life such as cooking, washing, bathing, walking, driving, social gatherings and shopping.

2.8. Bodily Manifestations and Systemic Sclerosis

Many researchers have explored the presenting symptoms of systemic sclerosis. I believe that people may wonder what systemic sclerosis is and how people experience symptoms. Many researchers reported that people experienced pain, malaise, fatigue, body malfunction, gastro-

intestinal symptoms and sexual dysfunction. In this section, the researcher talks about symptoms which are ongoing inside of the body making them invisible symptoms to others. In bodily manifestations of illness, pain is a dominant factor that people experience by living with systemic sclerosis as reported by the study of Buck, Poole & Mendelson (2010) whereas Sumpton et al. (2017) reported pain as bodily malfunctions and Malcarne, Fox, Mills & Gholizadeh (2013) found pain and sexual dysfunction in their manifestations. Participants also reported pain and malaise that impacted on their daily activities and they experienced gastrointestinal symptoms as being a worse experience for them, perceiving their disease as a burden (Almazor, Kallen, Roundtree & Mayes, 2007).

However, I am not interested in exploring clinical symptoms but the reason to add this literature to the review was to understand the background of the disease and its invisible symptoms that may potentially impact on an individual's psychological health. Being a counsellor and psychotherapist, I felt it was imperative to add physical symptoms so that the reader could understand the nature of the illness and its impact on emotional and psychological well-being.

2.9. Physical Appearance, Social Encounters and Systemic Sclerosis

Systemic sclerosis has impacted on people's appearances such as the hardening of their skin, which is considered the first symptom of systemic sclerosis. Many people experience dry and irritable skin with the main physical appearance symptom being telangiectases, which are red spots due to the rupture of blood vessels and develops on the face and hands, with other notable symptoms being Raynaud's phenomena and hand impairments (SRUK, 2016).

I know from my counselling work with physically ill people that physical symptoms of the illness do have an impact on people's psychological well-being and it has been seen in the literature as well.

Amin et al. (2011) conducted a study on the psychological impact of facial changes in scleroderma through quantitative measures. This study suggested facial changes as the most worrying aspect of the condition. Moreover, their notable symptoms hindered them in their social encounters. Another study by Ennis et al. (2013) was carried out to determine the extent of body image dissatisfaction (BID) in patients with self-reported systemic sclerosis-related telangiectases. They used a mixed method approach to achieve their outcome. The results showed that dissatisfaction with their appearance was significantly higher in patients with telangiectases and they became self-conscious when they engaged in public places. It is evident that telangiectases impacted on the respondent's behaviour in terms of social avoidance and they used make-up to cover up their red spots. Moreover, they also expressed their lack of confidence due to telangiectases and the withdrawal that resulted.

In order to better understand the emotion experienced in systemic sclerosis, Leon et al. (2013) conducted comprehensive research in April 2013. In forty-eight studies, they found negative emotions being very high in people living with systemic sclerosis and their negative emotions were associated with their physical appearance and disease-specifying symptoms, such as swollen joints, which impacted on their relationships.

Another systemic review was undertaken by Nakayama et al. (2016). They collected twenty-six studies from electronic databases up to October 2014 in order to identify patient's perspectives and experiences of living with systemic sclerosis. One of their collaborative themes was related to the distressing transformation of their appearance—calling it disturbing facial changes. They discovered their facial changes to be the most devastating aspect of systemic sclerosis for some patients. People described themselves as unattractive or ugly which made their emotions more distressful and resulted in reduced interaction with others. Due to the impact of systemic sclerosis they were unable to do their daily tasks, could not care

for their children and could not continue their jobs. However, they accepted their new restrictions.

A recent study has been conducted by Khanna et al. (2019) to understand the impact of diffuse cutaneous systemic sclerosis symptoms and the burden of the disease from the patient's perspective. They used a mixed methods approach and conducted the study in different countries, recruiting participants with diffuse systemic sclerosis who had been diagnosed recently. Their results highlighted that participants talked about their skin changes as one of the burdens. Due to facial skin thickening, they had difficulties with eating and had oral hygiene problems. Moreover, they related their facial thickening with their identity as they were unable to recognise themselves which led them to withdraw from society and have low self-esteem and depression. Their relationships with others tended to change because of the dependency on others and having a small network which made them feel isolated.

However, other studies by Sumpton et al. (2017), Cinar et al. (2011) and Almazor, Kallen, Roundtree & Mayes (2007) discovered that respondents experienced social isolation due to their physical pain and suffering rather than just their physical appearance. Sumpton et al. (2017) carried out a study to describe patients' perspectives of systemic sclerosis to inform strategies about improving their care through using mixed methods. They revealed that the respondent experienced restricted pain and described their experience as 'wearing on the soul'. Their bodily pain, fatigue and shortness of breath were draining and caused them limited mobility. Due to physical suffering, they have the deprivation of social functions, such as loss of job or changing their careers and felt a loss of independence and self-esteem as they became dependent on others, not only physically but financially as well. They lost their social lives due to the nature of their illness. Cinar et al. (2011) also concluded that patients with systemic sclerosis had difficulty in joining social activities which eventually leads to social isolation. Almazor, Kallen, Roundtree & Mayes (2007) performed three focus groups and five

in depth interviews with individuals living with systemic sclerosis by using grounded theory methodologies. Their aim was to evaluate a patient's assessment of the disease and the burden of the symptoms in living with systemic sclerosis. The result revealed that the participants recounted their social and lifestyle disruptions as one of the worst consequences and they found their physical sufferings were the main source of their social disruptions. Another study by Murphy et al. (2019) found similar outcomes.

The above findings are informed about the impact of physical appearance on the psychological well-being of people with systemic sclerosis. However, the majority of findings were related to skin thickening or telangiectases and its impact on their social life, although one study by Khanna et al. (2019) gave insight about people's eating problems due to skin thickening.

2.10. Psychological Experience and Systemic Sclerosis

This section covers the topic of the psychological experiences of living with systemic sclerosis. I found different literature which focused on their experience of low self-esteem, body-image dissatisfaction, anxiety, depression, uncertainty and emotional distress.

According to an article by Ennis et al. (2013), individuals with systemic sclerosis reported lower satisfaction with their appearance through using a questionnaire: 'Adjusted Satisfaction with Appearance Scale (ASWAP)', whereas Sandqvist, Akesson & Eklund (2005) found dissatisfaction in their work or job. Moreover, the literature also revealed that people with systemic sclerosis experienced low self-esteem. These findings discerned lower self-esteem in relation to their skin deformities, loss of job or change in career and felt less socially functional.

People experienced low self-esteem through their perception of the burden of living with their disease. They disclosed that they were unable to be recognised by others due to tightening on

their face which then led to low self-esteem (Khanna et al., 2019). Almazor, Kallen, Roundtree & Mayes investigated a similar study in 2007 on the disease and the burden of symptoms in systemic sclerosis from the patient's perspective. They had similar outcomes relating to both physical appearance and lower self-esteem. People talked about their appearance and the impact of the disease on their teeth and consequently on their smiling and facial expressions that led to their low self-esteem. However, another study on patient's perspectives of systemic sclerosis by Sumpton et al. (2017) claimed that individual experiences lowered self-esteem in relation to their loss of work or change in career due to the nature of the illness. They became less socially functional which then resulted in a loss of independence and self-esteem.

Buck, Poole & Mendelson (2010) were interested in exploring factors related to self-efficacy in people with systemic sclerosis. However, this study also focused on the comparison between persons with limited or diffuse systemic sclerosis. Sixty-two respondents were recruited for this study and they used measuring scales related to self-efficacy and physical or psychological variables. The study found that the level of self-efficacy was significantly related with their experience of fatigue, pain, hand function, depression and their fatigability. It meant that participants who had greater pain, depression and disability had lowered self-efficacy. Their low self-efficacy led to low self-confidence and then consequently impacted on their disease management behaviour and ended with poorer health outcomes.

There is a growing body of evidence that people with medical illnesses encounter emotional suffering and depression. Similarly, many researchers have discovered that people perceive systemic sclerosis as an emotional stress and then suffer with anxiety and depression. They correlated their anxiety, depression or emotional stress with their physical suffering of systemic sclerosis and also associated it with patient-physician relationships.

In 2007, Thombs, Taillefer, Hudson & Baron conducted a comprehensive search through using the Medline, PsychINFO and CINAHL databases. The aim of this systemic review was to access the prevalence of depression amongst people with systemic sclerosis. These reviews concluded that depression was very common amongst these people. Another study in 2008 conducted by Thombs, Hudson, Taillefer & Baron was to assess the prevalence and predictors of symptoms of depression in a large sample of patients with systemic sclerosis. It was a cross-sectional study of 376 patients with systemic sclerosis recruited from the Canadian Scleroderma Research Group Registry Centre for Epidemiologic Studies Depression Scale (CES-D) along with the clinical histories that were used to access them. This study concluded that people experienced a high level of depressive symptoms due to living with systemic sclerosis and their depressive symptoms also correlated with disease severity and their manifestation symptoms. However, they also evaluated the level of depression with demographic variables and discovered that people with higher education or that were married were at a lower risk of having high levels of depressive symptoms.

In 2013, one pilot study was undertaken on body-image dissatisfaction and the psychological impact of systemic sclerosis-related telangiectases. Authors administered the Hospital Anxiety and Depression Scale (HADS) on 141 participants with systemic sclerosis. The outcome of data revealed both anxiety and depression amongst participants with systemic sclerosis regardless of their telangiectases and clinical variables (Ennis et al. 2013). Another systemic review by Leon et al. (2013) identified anxiety and depression in people with systemic sclerosis. This systemic review concluded that pain was a predominant factor that impacted on an individual's mood, not allowing them to utilise any distraction strategies so that people then suffered with depression. Other bodily symptoms such as physical appearance and sleep disturbance also facilitated the emergence of negative emotions, such as helplessness, which then ended with depression and anxiety.

People clearly experience negative emotions as a result of systemic sclerosis and feel overwhelmed when they try to deal with the disease in their everyday life, resulting in them encountering depression, anxiety, anger, frustration and fear due to the unpredictable nature of the illness. Their negative emotions were triggered more when they faced difficulties in interacting with others and were perceived to be judged by others (Milette et al., 2018). Individuals with systemic sclerosis developed fear about the progressiveness of their disease and suffered with anxiety, stress and feeling depressed together with the apprehension of physical disability (Rubenzik & Derk, 2009). Patients with systemic sclerosis reported significant symptomatic and emotional burdens which, in turn, affected their quality of life and psychological well-being, suffering with depression due to their physical pain (Almazor, Kallen, Roundtree & Mayes, 2007).

Systemic sclerosis is a chronic and rare connective tissue disease with negative physical and psychological implications. In order to gain a detailed understanding of the emotional suffering in people, a study was undertaken through the conducting of focused group discussions by twenty-two people in Canada. The results were derived through using thematic analysis. Participants experienced emotional distress as they faced a new reality and the daily struggle of living with systemic sclerosis, such as the financial burden, changing roles and social engagements. These collective themes reflected on their stressful journey of living with systemic sclerosis, which is characterised as an unpredictable and overwhelming disease which leads to emotional distress (Gumuchian et al., 2016). The study of Mouthon et al. (2017) concluded that people with systemic sclerosis experienced difficulties by living with this disease and then encountered psychological distress, each using different coping strategies. However, in their view of systemic sclerosis and its management, they emphasised their strong expectations about patient-physician relationships. They required attention and support from their physician and needed their help to accept the uncertainty of their disease.

Emotional distress has been explored amongst people living with systemic sclerosis by conducting in-depth interviews using the McGill Illness Narrative Interview with sixteen women affected by scleroderma. The analysis was derived through using thematic analysis. Participants viewed their distress as demoralisation and talked about the symptoms that caused them distress. Fatigue, pain and the threat of disfigurement were all sources of distress and caused them to be depressed (Newton, Thombs & Groleau, 2012).

Some of the literature found that worry was a psychological distress in people with systemic sclerosis. Leeuwen et al. (2020) explored illness perceptions, risk perceptions and the degree of worry in people who were recently diagnosed with systemic sclerosis. Participants diagnosed less than two years before were recruited for in-depth group discussions and a physical global assessment of disease severity was used to measure their illness severity. The results found three aspects of illness perception being personal control, concern and consequences. They concluded that people with more symptoms had less personal control which resulted in concerns for their future and they had a high score in their worry questionnaire. This study demonstrated that early stages of systemic sclerosis had a significant impact on people's lives.

Another article by Amin et al. (2011) was carried out to observe the psychological impact of scleroderma. The author revealed in this study that the most worrying aspect of their condition was their facial changes and it was very difficult for them as these changes were easily noticeable by others which resulted in self-consciousness. A similar outcome was found in the study of Almazor, Kallen, Roundtree & Mayes (2007).

A systemic review-based study discovered that body image distress in terms of their physical appearance was related to their skin and hands. They also reported problems with their sexual functions (Malcarne, Fox, Mills & Gholizadeh, 2013). Another study by Nakayama et al.

(2016) claimed that grief resulting from a loss of identity was seen amongst the respondents due to the change in their appearance. They expressed feelings of being ashamed in front of others when they did not recognise them. A similar finding was revealed by Sumpton et al. (2017) that people experienced a disintegration of identity due to their physical changes and it became noticeable when they were out, avoiding being captured in photographs with others. They expressed feelings of being ashamed due to the impact of the disease on their appearance. They described feelings of separation between their physical image and their current physical appearance. As a result, they experienced low self-image and change in their personality and perceived disassociated self-image.

People with systemic sclerosis experience uncertainty as do those with other chronic illnesses. They face uncertainty in terms of their diagnoses, treatment and the unpredictable course of their illness. They become uncertain for their future due to the nature of the illness and the effects on their overall well-being (Nakayama et al., 2016; Rubenzik & Derk, 2009; Almazor, Kallen, Roundtree & Mayes, 2007; Sumpton et al., 2017).

2.11. Coping Variables

There is evidence from the literature that people with systemic sclerosis utilise some coping strategies to deal with their daily struggles. People suffered with physical restrictions and disabilities due to their hand impairments. One study found that patients had difficulties in ‘opening glass jars’, ‘opening juice bottles’ and ‘opening bottles’ that required the movement of rotation. They tried to open it with a towel, tried to remove the edge of the palm with a knife, use the hand palm or require help from someone else such as a spouse or neighbour. Other hardships involved washing clothes or cutting out material so they used the washing machine or asked for help from tailors (Cinar et al., 2013). It was also seen in the literature that patients with supportive families were seen to be more optimistic about their disease.

People were more able to cope with the disease if they had social support and had better expectations from the physical-patient relationship in managing their disease respectively (Cinar et al., 2011; Mouthon et al., 2017).

One study explored the coping strategies utilised in work settings. In order to adjust their work situations, participants reduced their working hours to correspond with their energy levels and chose to work flexibly by changing their timing schedules and also avoiding any tasks that requested dexterity or to work in a cold environment. They also adapted their own resources such as prioritising tasks and activities according to their energy levels and received assistance for their household chores and childcare. Overall, they used problem-solving techniques and re-designed activities in their daily life (Sandqvist, Hesselstrand, Scheja & Hakansson, 2011).

Other reviews claimed that some patients started to gradually accept their condition and discovered their own strategies to somehow manage their limitations. This would include some people trying to obtain hope from their religious beliefs (Nakayama et al., 2016), being positive for their treatment by medical staff and their regular health monitoring (Sumpton et al., 2017), accessing useful resources related to systemic sclerosis such as self-help books or watching television programs (Milette et al., 2018), and obtaining support from others in terms of non-pharmacological treatments and financial coping with social security and benefits (Stamm et al., 2011).

Gumuchian et al. (2017) undertook a focused study to understand the coping strategies used by people living with systemic sclerosis. Authors analysed coping strategies through Lazarus and Folkman's theoretical model of coping, including problem-focused, emotional focused and meaning focused coping. Participants talked about seeking help from professionals or getting information about their symptoms under problem-focused coping together with emotional support from their family members and practiced some relaxation techniques and

exercises to manage their emotions. They described their coping strategies as a way of accepting the disease and adopting new attitudes towards the disease, such as taking it ‘one day at a time’ as a meaning based coping approach. In another study, the participants tried to avoid certain things or keep themselves busy so that they did not have to think about their disease and also attempted to find new ways to stay autonomous (Newton, Thombs & Groleau, 2012).

2.12. Critical Perspectives on Prior Studies

The above research studies informed the reader about the impact of living with systemic sclerosis, providing knowledge about bodily symptoms and the manifestation of the disease, their fatigue and disabilities and consequently the impact on their mental health and well-being. Being a novice researcher, I know my limitations about making any comments on other studies but I will try to highlight any gaps that may be more significant to cover during my current study. I will reflect on these gaps in both a professional and personal way.

However, these research studies have made a great contribution to the realm of systemic sclerosis research but there is still more to work on with this disease due to its incurable nature. Most of the research was based on the physiological mechanism or the relationship of antibodies and symptomology as science has been trying to ascertain the cause of the illness and its treatment over many decades, as such the cause and management of systemic sclerosis is still uncertain.

Firstly, I would like to focus on the research identified in the period from 2005 to 2015 for my initial review as that would give me the solid basis to carry out this study. As stated previously, the initial review included fifteen studies out of twenty-six articles. Out of those fifteen studies, five used quantitative methodologies, three used systemic reviews, two utilised the mixed method approach and five were based on qualitative approaches.

The quantitative studies belong to Cinar et al. (2013), Amin et al. (2011), Buck, Poole & Mendelson (2010), Rubenzik & Derk (2009), and Thombs, Hudson, Taillefer & Baron (2008) and emphasised the psychological effects and factors that are related to systemic sclerosis. These studies informed the readers that this disease had impacted on people's hand functions and then, ultimately, they experienced difficulty with their household chores, suffered with anxiety, stress, fear and worry due to the nature of their illness which affected their self-efficacy and encountered depression due to the physical pain and suffering. These studies have limitations as they are based on a quantitative response so participants are very limited in expressing themselves and they struggle to describe themselves more deeply. Moreover, these studies were more interested in finding out the factors related to systemic sclerosis, such as self-efficacy or depression, and the association to explore one of the symptoms of systemic sclerosis, such as facial changes or hand impairment, rather than their whole experience of living with systemic sclerosis. These studies were more inclined to investigate the clinical symptoms and used clinical based assessments such as the Depression Inventory, the Hospitals and Anxiety Scales or the Derriford Appearance Scale short-form. Another limitation could be the phenomenological understanding of the questions in the scale as these questions are very closed ones and with rigid responses there could be a lack of understanding the elements by the respondents or a difficulty in comprehending the terms used in the questionnaire. Additionally, it could be probable that depression amongst people with systemic sclerosis could have been inflated due to the bias related to the overlapping symptoms of systemic sclerosis and the somatic symptoms of depression. Moreover, these studies also emphasised more on statistical measures rather than their subjective experience with systemic sclerosis.

This section now analyses the three systemic reviews by Leon et al. (2013), Malcarne, Fox, Mills & Gholizadeh (2013) and Thombs, Taillefer, Hudson & Baron (2007). These systemic studies set out that people experienced negative effects as a result of suffering with systemic

sclerosis, such as anxiety and depression, and they encountered fatigue due to the impact of their disease. These studies reviewed different databases in order to draw conclusions about systemic sclerosis but they only added basic knowledge about the effects of systemic sclerosis. Other drawbacks included the review studies being based on clinical symptoms or using different questionnaires or scales to measure the psychological effects of the illness so that the results could not be generalised, for example a very limited number of studies in the review included non-homogeneous samples and there was the use of different measurements and cut-offs in the different studies. Moreover, whilst these reviews reported depression symptoms, people had depression at different times and the issue was not addressed properly.

The two studies that were based on the mixed methodology approach were carried out by Ennis et al. (2013) and Sandqvist, Akesson & Eklund (2005). This pre-existing knowledge informed readers about body image dissatisfaction being one of the symptoms of systemic sclerosis and their occupational performances by living with systemic sclerosis. It helped to know and understand through self-administered questionnaires of their concepts about how they perceived their body and how they measured their life satisfaction levels. However, it was limited to one aspect of people's lives which was in relation to their physical appearance or their life satisfaction rather than exploring them as a whole. However, I found a lack of clarity in their samples in relation to their age and the severity of the illness and types of disease. Indeed, one study used postal surveys so selection bias was inherent within the study design, as well as not selecting participants equally, whereas the other study entirely ignored participants with the diffused type of systemic sclerosis. Therefore, the results could not be generalised into other populations.

The rest of the articles were based on the qualitative approach (Sandqvist, Hesselstrand, Scheja & Hakansson, 2011; Cinar et al., 2011; Stamm et al., 2011; Newton, Thombs & Groleau, 2012; Suarez-Almazor, Kallen, Roundtree & Mayes, 2007). These studies were

carried out to gain an understanding of their work life, physical symptoms and functions amongst people with systemic sclerosis. However, although these studies helped others to understand the experiences of people physically due to the illness, how their functions have been affected or how it has impacted on their work life, there were still missing psychological, social and existential elements in these research studies. The study that focused on working life had limitations on their recruiting sample as they only included those patients who had a mild disease and were able to work for longer rather than other populations who had severe types of illness and disability, with their age being between 38 and 62 years and ignoring participants under the age of 38 years. Additionally, this study did not mention which type of systemic sclerosis the people they recruited were suffering with and there was a lack of clarity about their methodology. Another limitation of this study was the focus on their work life rather than other aspects of their life. The study by Suarez-Almazor, Kallen, Roundtree & Mayes (2007) focused on the disease and the burden of symptoms amongst people with systemic sclerosis but again they were recruited primarily with diffuse systemic sclerosis and very few with limited systemic sclerosis. However, they did not make any differentiation between the experience of burdens amongst the diffused and limited type of systemic sclerosis. Overall, this study discussed the symptoms of the disease, how people perceived these symptoms and how it had impacted on their quality of life but did not focus on the type of disease, age or severity of their illness. However, it seemed that physical symptoms of the illness had an impact on their social lives and psychological well-being, such as disruption, or depression or low self-esteem but ignored the impact of the illness as a whole on the individual or how the process of this impacted on them. Additionally, some of the respondents were interviewed in their own language, such as Spanish, so there could be language errors during the transcribing and interpretation of the results. Similar drawbacks were found by other studies related to disease duration and severity and did not emphasise as a whole the experience of living with systemic sclerosis. They scrutinised only one facet of living with the

disease and ignored other sides of it. Moreover, there was a lack of clarity in their methodology and they used less interpretation that was not based on philosophical assumptions. Due to the vagueness in their methodological approach, they did not allow for in-depth descriptions from participants which may limit the richness of the data.

Overall, these studies allowed the reader to understand the background of the illness but I have highlighted some issues related to the studies and, therefore, these studies could not be generalised so the research for this area is still undermined.

2.13. Second Review from the Period of 2016 to 2020

The second review of literature was conducted after data collection and analysis. I was able to identify eleven research studies that focused on living with systemic sclerosis which covered the period from 2016 to 2020.

The findings of these studies have contributed knowledge to understanding about living with systemic sclerosis and validated the theoretical categories from my study. However, there are still issues in these studies which undermine the subject, such as the study by Leeuwen et al. (2020) that focused on illness perception and risk perception amongst systemic sclerosis sufferers. This study informed the reader that people suffer with worry due to the nature of this illness, but the authors only recruited a sample of participants who had been diagnosed less than two years before, ignoring other participants who had been diagnosed for longer and would be more interested in exploring the relationship between illness perceptions and risk perceptions in early systemic sclerosis.

A study by Khanna et al. (2019) investigated the phenomena of disease burden in diffuse cutaneous systemic sclerosis and who had been diagnosed for more than six months. They rejected participants with other types of illness and, therefore, the result could not be generalised to the rest of the population. Moreover, this study recruited participants from six

different countries such as France, Italy, Spain, Germany, the United Kingdom and the United States so there could be a bias in the responses to living with systemic sclerosis due to the cultural and ethnical variations amongst the participants. Different researchers conducted interviews in different countries so the interpretation could be affected due to their backgrounds. Fatigue was seen as a significant factor in people living with systemic sclerosis and the study by Murphy et al. (2019) concluded that there was a relationship between fatigue and social participation in people with systemic sclerosis. However, this study only focused on fatigue in relation to social connections and ignored other factors that could be contributed to withdrawing from society. Additionally, authors used quantitative instruments to measure the phenomena so they were limited in fully expressing themselves.

Another study on fatigue was carried out by Basta, Afeltra & Margiotta in 2018. This study asserted that fatigue in systemic sclerosis was prevalent with debilitating symptoms experienced by patients. This review emphasised on the causality between fatigue and physiological factors rather than the subjective experience. Moreover, it ignored other contributing factors of systemic sclerosis that impacted on their lives. It still undermined the causes of fatigue either directly as a result of having systemic sclerosis or the side effects of the medications that are used to manage their disease. These studies also did not focus on the relationship of disease severity and fatigue.

A systemic review by Nakayama et al. (2016) focused on patient's perspectives and experiences of living with systemic sclerosis. Although it was a very informative review for the understanding of participant's living with this illness it had some downsides, such as the difference in methodologies, sample size, population characteristics, the qualitative approaches and the researcher's own background together with the fact that these systemic review studies did not clarify the findings between the diffused and limited type of systemic sclerosis. Moreover, these research studies have been conducted in different countries so it is

likely that there will be interpretation errors due to the variation amongst the population's cultural and ethnical backgrounds or their belief systems.

Furthermore, two studies by Milette et al. (2018) and Milette et al. (2019) were carried out to scrutinise the coping strategies used by people living with systemic sclerosis. These research studies give great contribution to the knowledge of the coping strategies used by people with systemic sclerosis and are helpful for medical professionals. Besides the sample size and semi-structured interviews, there were other issues in their recruitment criteria as people who were aged above 35 were ignored and they did not focus on the severity of the illness, the type of disease or the coping strategies used for managing, such as household chores.

Another two studies were conducted by Gumuchian et al. (2017) and Gumuchian et al. (2016) to identify the coping strategies and experiences of living with systemic sclerosis, focusing only on the emotional distress caused by systemic sclerosis and using the Lazarus and Folkman Model in order to understand their coping strategies. I found issues with their sampling as it varied in language with some of the participants being English and others being French so it was likely to be bias in the interpretation of the findings. Moreover, they did not focus on the severity of their disease and their coping strategies. Due to the language barrier, they used a professional transcriber so the results could be biased or altered and could have practice effects as well.

In 2017, I discovered two studies by Sumpton et al. (2017) and Mouthon et al. (2017) which explored the participant's perceptions of systemic sclerosis. However, Sumpton et al. (2017) recruited more participants with the limited type of disease than the other type and focused on their perception of illness, but it was not an in-depth investigation to understand their processes of living with systemic sclerosis. Due to the disproportionate amount of sampling, the results could not be generalised to other populations, whereas a study by Mouthon et al.

(2017) did not mention any type of systemic sclerosis and explored the patient's view in respect of their disease's origin, mechanism and evolution and was more focused on their vital body organs than their subjective feelings of living with systemic sclerosis over a period of time.

2.14. Identifying Gaps within Pre-Existing Literature

Initial reviews from the years 2005–2015 guided me to understand what pre-existing studies have been researched in the area of systemic sclerosis and I noticed that a huge amount of work had been done on systemic sclerosis in order to understand the relationship between systemic sclerosis and the physiological causes. I can understand that these studies had been conducted to rule out any potential treatments identified over the decades as it is still an incurable disease but unfortunately science has been unable, as yet, to find a successful treatment due to its complex nature. However, I was able to find fifteen articles that focused on psychological experiences and systemic sclerosis. These articles helped me to understand what studies have been conducted and what needs to be addressed in more depth. I ascertained that the majority of the existing studies were focused on fatigue, depression, anxiety, worry, symptom burden, self-efficacy, self-esteem and changes in appearance.

As a part of the methodology approach and sampling process, I identified that these studies explored largely the causality and relationship between systemic sclerosis and psychological factors, such as depression, anxiety, body image dissatisfaction and self-esteem, whilst other studies focused on the prevalence and symptoms of the disease. These studies were limited to exploring the subjective experience of living with systemic sclerosis on an everyday basis and I did not find any study which focused on living experiences and coping strategies simultaneously. However, a separate research study has been carried out surrounding coping strategies used by people with systemic sclerosis, but again its conduct was limited, such as

hand functioning related to eating and washing. Other areas such as washing, bathing, cleaning, dressing or undressing, driving, travelling, gardening, shopping, life goals and engaging with others, the self and the world were ignored in the prior research studies. Moreover, these studies explored only one facet of life such as physical symptoms or fatigue and did not focus on other aspects such as relationships with the self, others and the world.

I acknowledge that these studies have contributed to the research field and the healthcare setting but these contributions are not enough as this disease affects every part of the body and I found no single study that focused on the ‘process’ or ‘changes’ as a result of living with systemic sclerosis. These changes could be simply understood if the researcher took account of the participant’s past and then focused on the present. I noticed the gap that no study had explored the existential paradigm and other issues such as death, isolation or existential crisis. I found only one article by Sumpton et al. (2017) that talked about identity issues due to systemic sclerosis under a sub-category, but it was not deeply explored. These existing studies have helped to understand the parameters of the psychological experience but did not explore the process of living with systemic sclerosis due to the progressive nature of the illness and I found these research studies were more based on ‘labelling’ them as depression or anxiety or low self-esteem rather than understanding their psychological suffering on a daily basis as an impact of the illness upon them.

2.14.1. Literature Gaps Informed by my Academic Studies and Practice

Systemic sclerosis is an incurable long-term disease and is complex in nature to understand. Bury (1982) illustrated a long-term condition as a ‘biological disruption.’ He explained that rheumatoid diseases led a person to rethink the way they used to live. This systemic sclerosis disease is a life-altering situation that not only affects the individual with the illness but also impacts on other relationships. A person’s entire life is affected from future goals to day-to-

day living. In his paper on the ‘Chronic Illness as Biographical Disruption’, he highlighted the way in which life-threatening illnesses disrupt an individual’s social and cultural experiences by threatening their identity. Bury (1982) claimed that chronic illness affected an individual’s biography in three ways (cited in Pranka, 2018):

1. Their perceptions of life change;
2. Relationships between the ill person and their social network changes;
3. Resources: time, energy, finances and friends—these must be mobilised.

Another sociologist used the term ‘critical situation’ by Giddens (1979) and the ‘loss of self’ by Charmaz (1983), meaning the disruption of social nature. The biographical disruption is a process that focuses on significant changes in the course of an individual’s life and is seen as a ‘turning point’ where a person’s identity is changed or makes them an entirely different person as a result of the illness (cited in Pranka, 2018).

I felt that there was a gap in the theoretical model in that there was a lack of focus on the individual process as a whole, bringing up their past and relating it with their present identity to fully grasp their experience of being a sufferer and their resilience with this illness and its consequences by using strategies. I found that no study had focused on their old life when they were healthy or their process of changing by living with systemic sclerosis and the impact of the disease on their daily life, such as household chores, relationships with others, their careers, their subjective feelings, their sense of meaning and other elements that were taken for granted before, and the coping strategies in every aspect of life. My above attention is also related to the tenet of the constructivist grounded theory as Charmaz (2006) claimed that we construct our grounded theories through our past and present involvement and our interactions with people, perspectives and research practices, providing an interpretive picture of a participant’s world as their meaning and expressions are constructions of reality.

Additionally, my interest was to explore individual's experiences of living with systemic sclerosis as a whole and to discover their processes on everyday life which has been informed by my academic studies and existential training. According to the existential philosophy, we live in time and, by living, we recollect ourselves from the past and are present to ourselves now in order to project ourselves anew into the future.

Below I would like to describe how my research interest was informed by my academic studies and professional trainings.

2.14.1.1. Existential Philosophy

The existential approach has its originality in the ancient practice of applied philosophy. The existential counselling and psychotherapy process focuses on assisting people who are coming to terms with life in its complexity. Most of the dilemmas that human beings struggle with are the natural consequences of the challenges and limitations of human conditions. The aim of the existential counselling and psychotherapy is not to cure people's illnesses but rather to help them in coming to terms with the contradictions, dilemmas and paradoxes of their everyday existence. The first principle of existential psychotherapy was formulated by Karl Jaspers, Ludwig Binswanger and Medrad Boss, known as 'Daseinanalysis' or 'existential analysis.' Authors such as Paul Tillich (1952) and Rollo May (1969) analysed the approach in the United States whilst in Europe it was further developed by Victor Frankl's Logotherapy (1946, 1964), with the work of R. D Laing (1960) being stimulated in the UK (cited in Feltham and Horton, 2006).

The existential approach is focused on people's unique experiences from their own perspective and also examined their meaning of being. It is the dynamic approach that asks basic questions about human beings such as their ultimate concerns including awareness, freedom and the threat of meaninglessness and helps to accept challenges as part of their human conditions.

I would like to share in the next section some of the existential philosophers that informed my interest for this study and which is also helpful for professionals in understanding the care of people with rare incurable illnesses.

2.14.1.1. Van Deurzen's Four Worlds

I would now like to discuss Van Deurzen's (2009) existential model of the 'four worlds' in relation to my research topic— 'Experiences of Living with Systemic Sclerosis'. According to the existential philosophy, we are living in four existential worlds which are the physical world (Umwelt), the social world (Mitwelt), the personal/psychological world (Eigenwelt), and the spiritual world (Uberwelt). However, although these worlds are interlocked with each other, I would like to discuss them separately with the intention of understanding the paradoxes within each world. The aim of the existential approach is to explore the personal understanding of human existence that would be unique to them. This means that the existential-phenomenological approach invites all of the other cultural variations, as well as parameters of human existence, in order to make sense of their unique experiences within a particular context. Therefore, the existential approach does not believe in any personality theory or by labelling people, but instead attempts to clarify their worldview, values and beliefs, and their attitudes towards people and the world (Van Deurzen & Adams, 2011).

Existential therapists often consider the four dimensions of existence (Binswanger, 1963; Yalom, 1980, cited in Van Deurzen, 2009) which is shown in Figure I – The Four World Dimension below:

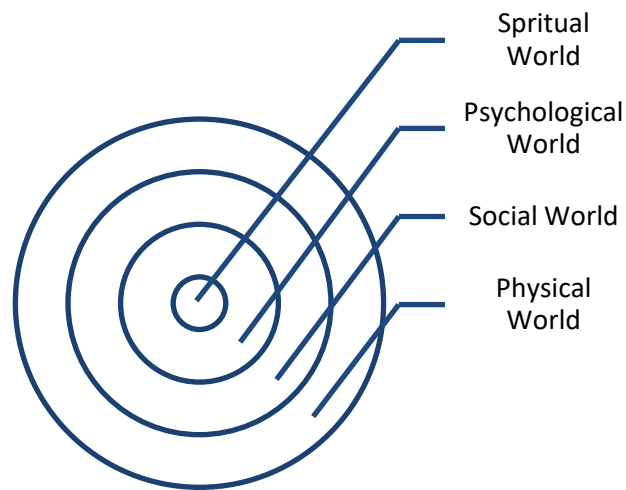


Figure 1 – The Four World Dimension

2.14.1.1.1. The Physical Dimension (Umwelt)

In this physical dimensional world, people relate themselves to the environment and the natural world in which they live. In this dimension, people are concerned with their survival and they experience paradoxes between life and death, health and illness, independence versus dependence and so on, as our body is the centre point to interact with the world and respond to the external stimuli (Van Deurzen, 2009). For people living with an incurable disease, this dimension is quite prominent in their lives as they experience conflict between life and death, health versus illness, and their body's response towards food, climate, the environment and 'things'. I have described in detail in Chapters 4 and Chapter 6 how systemic sclerosis has impacted on the participants' physical world and also how their body has changed as a repercussion of the illness over a period of time.

2.14.1.1.2. The Social Dimension (Mitwelt)

In this social dimensional world, people interact with the worlds of other people where they live and have social concerns about their acceptance by others, experiencing paradoxes between acceptance versus rejection, love versus hate, and security versus insecurity (Van

Deurzen, 2009). In this dimension, people interact with others either through cooperation or control. In this study, people interact with others through regulating their emotions; for example, if they experience rejection by another, as a consequence they feel isolated from society and shrink into their own social world. I have described in Chapters 4 and 5 how their social relationships have changed as a result of systemic sclerosis.

2.14.1.1.3. The Personal Dimension (Eigenwelt)

In this personal map of the world, people connect with their self and they have personal concerns about their identity, experiencing paradoxes between their strength versus weakness, selfhood versus me, freedom versus control and self-worth versus worthlessness and self-esteem. In this dimension, the self is the centre point to interact with their internal world and creates their sense of self through deep reflection (Van Deurzen, 2009). In this study, participants reported low self-esteem due to the changes in them from being an independent person to a disabled person, leading them to feel shame during their interactions with the world. I have described in Chapters 4 and 5 how systemic sclerosis has impacted on the participants' personal worlds.

The existential approach focuses on 'change' which is a part of human conditions. Change takes place constantly and human beings have to make an effort to stabilise their situation with these changes. They found it a challenge so they tried to avoid these changes. People habitually fear the inevitable process of transformation that everything in this world is subject to.

Existential psychotherapy is helpful for people who face 'changes' in self as a repercussion of systemic sclerosis. This approach enables clients to become more open to their own experience in all its paradoxical reality and assists them in understanding their anxiety and to become more self-reflective. The existential approach assists them in being aware of their

strengths and abilities as well as acceptance of their illness and their rapid transformations as part of their human condition. It encourages them to explore new paths and to change their attitude towards the illness and self and find new ways to improve their wellbeing (Feltham and Horton, 2006).

2.14.1.1.4. The Spiritual Dimension (Uberwelt)

In this dimension people have concerns about what their life is all about. They experience conflicts in their values, beliefs, meanings, purposes and intuitions. In my own learning, people came across this dimension when they were struggling with crisis and then reflected on their life meanings and purposes, building their worldview and their own value system (Van Deurzen, 2009). In this study, people talked about how they could start to find their life purpose and meanings after struggling with their illness. I have described in Chapters 4 and 5 how systemic sclerosis has impacted on the participants' worlds. The above Existential Model by Emmy Van Deurzen worked as a platform to explore the process of living with systemic sclerosis in each dimension and their strategies.

2.14.2. Death, Anxiety and Meaning in Existential Philosophy

I found that no studies explored issues around death, freedom, isolation and meaningless due to living with systemic sclerosis. I was interested to explore these existential concerns due to my engagement with existential philosophy. Yalom's (1980) existential approach to psychotherapy is essentially supportive and collaborative of other dynamic modalities and explains that existential psychotherapy is a stance, a call to therapists of all modalities to understand and develop an awareness of the importance of the givens of existence upon the human struggle to deal with existential anxieties and conflicts, an overlay upon other approaches. Yalom is acknowledged and respected globally for his contributions to contemporary psychotherapy, both for his theoretical understanding and his stance for

practice, which posits that a genuine, transparent, human connection in the therapeutic encounter is one that provides the most beneficial environment for emotional healing. Yalom (1980) explains existential psychotherapy as a dynamic therapeutic approach that focuses on concerns rooted in existence and asserts that holding an awareness of these issues can profoundly influence the nature of the therapist-client relationship (Yalom, 1998, 2002, cited in Berry-Smith, 2012).

In my personal experience of living with systemic sclerosis, I do relate my reactions towards the illness within Yalom's framework and the threat of mortality in the four ultimate concerns, such as death, freedom, existential isolation and meaninglessness, as described by Yalom (1980). Other existential philosophers such as Victor Frankl focused on the locus of human problems as a lack of meaning in their lives, especially in suffering and death (Yalom, 1980).

Frankl said that meaning can be found through suffering and highlighted in his work that man needs to confront the facts about failure—that he is suffering and he will die. As such, his main philosophical idea is that a meaning creates being and through his experiences of death and suffering it showed the importance of the meaning of life. However, suffering is a part of the human condition and we have to deal with this tragedy of human existence through finding the meaning of life (Yalom, 1980).

Logotherapy claims that man's foremost concern is not to seek pleasure or to avoid pain but to search for meanings in life. Man can be satisfied with his suffering if he can find meaning in the suffering. In Logotherapy, 'Logos' is a Greek word that is translated into 'meaning' and is rooted within three philosophical concepts: freedom of will; will to meaning; and meaning in life. In freedom of will, Frankl (1967) argued that humans are not just absolute products of environmental or biological conditions, but they also have the freedom to decide to shape their own life within the limits of the possibilities available to them in their state of illness. The

second philosophical concept, ‘will to meaning’, claims that we are not only free but also have the freedom to attain our goals and purposes through understanding ourselves and confronting our issues as well as our limitations in order to pursue our meaningful goals. The last philosophical concept is ‘meaning in life’, which holds the idea that meaning is an objective reality and we attempt to encourage people to reveal the best possibilities in both themselves and the world through grasping the meaning of every situation (cited in Van Deurzen, 2009).

Frankl (1967) mentioned three ways to find meaning in life (Frankl, 1967, cited in Van Deurzen, 2009):

1. By creating work;
2. By experiencing something fully or loving somebody; and
3. By adopting a positive attitude towards inescapable suffering.

Frankl (1967) believed that suffering is a part of life and that man’s ultimate freedom is his ability to choose how to respond to any set of given circumstances, even the most painful ones (Frankl, 1967, cited in Van Deurzen, 2009; Vos, 2018).

2.14.3. Other Existential Philosophers

Other philosophers such as Kierkegaard (1813-1855) are considered as a father of existential philosophy. His work was based on personal choices and commitment as a single individual. He suggested that, being a person, we are responsible for assigning meaning to our life and to live our lives authentically. In his personal account, he talked about the meaninglessness of his existence that was filled with anxiety and despair and a sense of hopelessness and depression. Basically, he defined anxiety or anguish in the sense of dread at the nothingness of human existence. The meaninglessness of his existence filled him with anxiety and deep despair and a sense of hopelessness and deep depression at the very nothingness of human existence. Kierkegaard (1844/1980) claimed that this fear is never objective, rather it is subjective

anxiety that everything in this world, including myself, will in the end, sooner or later, collapse into nothingness. In this way, he described ‘nothingness’ in the form of death that will take everything away which is uncertain and leads to experiences of anxiety (Cooper, 2003).

According to both my professional and personal understanding, people with incurable illnesses experience death as a threat that must be taken on alone and they experience a new and distressing sense of aloneness due to living with an unknown progressive illness such as systemic sclerosis, experiencing despair and anxiety. Due to the uncertain nature of the illness, they become meaningless and subsequently embrace the nothingness of their existence and experience anxiety or dread.

Rollo May (1950) talked about anxiety as an underlying cause of crisis, such as living with an incurable illness, and he stated that the world we reside in is an age of anxiety. According to him ‘anxiety is apprehension cued off by a threat to some value which the individual holds essential to his existence as a personality’ (May, 1950, p. 191, cited in Van Deurzen 2009). In this study, this threat may be either physical, as in living with an incurable illness, psychological by facing death, uncertainty or experiencing an identity crisis, or a threat that may be encountered in other aspects of their life, such as a loss of career, a change in relationship or a loss of freedom or alternative role.

Being an existential student, I identified the existential gap in the pre-existing literature in order to understand the process of living with systemic sclerosis. I also found a literature gap in relation to the self by living with systemic sclerosis as, in my understanding, self is an ongoing and life-long project that we encounter in our interaction with others and the world in general, and is rooted in the genuine human experience of living with systemic sclerosis with the need to confront truths about one’s self, others and the world.

In existential philosophy, the self is perceived as both a subjective and external reality rooted in existence, such as the existential self would be integrated as 'self-as-doer' and 'self-as-object' to construct one's self. It does mean that one has to find a purpose or goal for themselves (Johnson, 1967). Sartre (1943/1958) stated, 'existence precedes essence' which means that firstly we are born into this world with nothing then we choose for ourselves what we want to be for ourselves. Our personality or self is not something which is already innate. Instead, we first come into existence with no purpose and then we are solely responsible for finding our purpose and to take responsibility for our choices and actions.

Existentially, we perceive the self as a dynamic process of creation over time in the dimension of bodily experiences, their relationship with others, the self, the world and their life meanings and we are continuously modifying ourselves as we are constantly changing as a part of human conditions. In this study, participants experienced change as a part of their illness such as a healthy person to sickness or independence to dependence. Due to constant changes in the participants' lives due to their illnesses, it could be possible that they ponder about their identity or loss/change their life purpose and meaning that is a fundamental element of sense of self.

Being an existential counsellor, I have been working with many clients who suffer from an incurable illness or disability. By working with these clients, I have obtained knowledge about their existential sufferings and the impact on their identity. Existential suffering is also correlated with a number of clinical issues such as anxiety, depression and a reduced quality of life. It is seemed in my clinical work that loss of identity was a common part of existential suffering and encompassed physical, psychological, social and spiritual sufferings. On the basis of my existential background I was keen to investigate any changed sense of self in the participant's lives as a result of systemic sclerosis. It would also help to fulfil the gaps within

the realm of literature relating to systemic sclerosis which also helped me to build aims for this study.

2.14.4. Other Gaps within Pre-Existing Literature

Furthermore, I did not find any study that focused on systemic sclerosis in the light of Counselling Psychology and Psychotherapy as previous studies had been done in the disciplines of Rheumatology, Psychiatry, the School of Nursing, Clinical Psychology, Health Research, Plastic and Reconstruction Surgery, the Scleroderma research group and Clinical Neuroscience. Another gap that I identified in the literature was that the criteria to recruit participants was not clarified, such as duration of their diagnosis, a part of two studies by Leeuwen et al. (2020) where they recruited participants who had only been diagnosed less than two years before, whereas Khanna et al. (2019) recruited those who were suffering for more than six months. I decided to choose a flexible approach and opened the criteria to any participants who had been diagnosed with any duration which could have been less than one month to many years. I decided that this flexible approach would help me to find participants and also gave me more of a chance to obtain rich data for my study. Moreover, this open criterion would also provide an opportunity to represent the rest of the population.

2.15. Reflections

Under this heading, I would like to reflect on my learning in both personal and professional learning. However, the detailed reflection on my research process is set out in a later chapter.

I would like to explain my process for carrying out the literature review. In my first research seminar, I was able to select my research topic on ‘Experiences of living with Systemic Sclerosis’. It was a very personal topic for me as, at that time, I had been living with this disease for four years. I presented my topic to the research panel ‘what is systemic sclerosis and why I wanted to carry out this study.’

On that day, I recognised that this disease was not only rare but also had a name unknown to others. In order for others to become familiar with this disease, it was imperative to add some general material about what systemic sclerosis is and how it impacts on people's lives so that the reader can understand the impact of living with systemic sclerosis and the importance of conducting this doctorate study within this area.

After reading these articles, I found that systemic sclerosis was a really understudied area and I could not find a single study that had been conducted in the discipline of counselling psychology. I felt ignored or rejected personally and found myself really engaged with systemic sclerosis, feeling that this was something I now belonged to—that it was my identity now and I found that this illness was a substitute of me.

However, I was constantly reflecting on my personal experience of living with systemic sclerosis and continued to write a diary on my feelings, thoughts, emotions and identity at each stage of the research process, especially when I was writing my literature review because the process of finding literature acted as a threat to my existential self; getting to know about the worst case scenario of the illness was not an easy process for me. However, a part of writing my personal diary was to obtain help from my research supervisor, clinical supervisor and personal therapy so I could address my personal issues with myself and within this research work. After becoming personal with this topic, I become passionate in conducting a study on systemic sclerosis and to build a model so people could understand what its process is.

Through my academic studies, I found that there were models for other physical illnesses such as cancer which helped other professionals to understand the process of going through life with cancer. Due to these studies, not only by medical professionals but also mental health professionals, the seriousness of mental health issues in cancer patients and their process of

living with cancer have been understood. The NHS has Macmillan's services within their hospital settings so medical professional can support sufferers with cancer. This support is not available for people who are living with systemic sclerosis due to a lack of knowledge and awareness in our society. I realised that it was very important to address existential issues in people who are living with an incurable illness.

This research used the constructivist grounded theory approach by Charmaz (2006). At the outset of this study, an initial literature review was conducted prior to the research project in order to sketch the general path of enquiry without restricting journeys into original theoretical grounds. Initial engagement with the review enabled an understanding of existing knowledge and also assisted me to recognise the knowledge gap in this study and to formulate the aims of the study. My topic for this study is the experience of living with systemic sclerosis. However, it is very abstract and in order to review the existing literature, I explored my research question that is set out under my research topic.

Initially, I needed to explore my research topic to further gauge where I could get a sense of my aims for this study. In order to do so, I explored the definition of 'experience of living.' According to the Oxford dictionary, living experience is personal knowledge about the world that is achieved through direct and first-hand involvement in everyday life. It was clear to me that I was interested in participant's everyday experience of living with systemic sclerosis which included their physical activities, such as household chores, their social activities and their psychological well-being. Being an existential therapist, I was also interested to explore their existential parameters.

The aim was to address the following broad question in the existing literature:

- How do people experience their lives with systemic sclerosis?

The above definition of ‘everyday personal experience’ involved their daily engagement with their self, people and the world. That meant I was not only interested in exploring their experience of living with systemic sclerosis but wanted to discover the dynamic process of living with systemic sclerosis and to manage with the disease, such as actions and strategies to deal with their experience of living with systemic sclerosis that accorded with the grounded theory principle. Therefore, I developed further sub-research questions for review in the existing literature.

Being a counsellor, I have had been working with many clients who suffer from an incurable illness or disability or any other illness. By working with these clients, I obtained knowledge about their existential suffering and the impact on their identity. I also found that the literature had a gap in relation to psychological/existential suffering and incurable illnesses that really needed to be addressed in the research fields. Moreover, if these gaps in the literature were covered then not only professionals but also other people and caregivers would be able to better understand people living with a rare incurable illness and patients with incurable illness can receive better support from their society, community and healthcare settings.

2.16. Concluded as Aims for this Study

Although this literature is helpful for the novel reader to understand systemic sclerosis many other aspects are undermined, such as the dynamic process of these changes and the existential experience of these changes and coping strategies. These studies talked about their change of facial appearance but the existential element in relation to self and identity was missing from these research studies. Being an existential counsellor, I feel it is a very important element to address or explore in this research so that people can understand their new self and explore potential adaptations or perspectives in relation to the self by living with systemic sclerosis.

Through constantly engaging with the research process and literature reviews, I was able to build the research aims for my study:

- To understand their experience of living with systemic sclerosis.
- To explore their existential issues after living with systemic sclerosis.
- To discover how the disease has impacted on different dimensions of their lives.
- To discover how do they cope/deal with this disease.

CHAPTER 3

METHODOLOGY

3.1 Rationale for this Chapter

After reviewing the literature chapter, I started to prepare this chapter, relating to the Methodology, in order to focus on how this study would be conducted and what methods would be used to collect the data to achieve the study aims. In this chapter, I followed certain standards and rules known as paradigms, which help me to choose the methodological approach for the study. The primary debate will describe the ontological and epistemological positions that best shape this study. Following a discussion about the research paradigms, the intention of this chapter is to delineate the research paradigm, including the rationale for using a qualitative approach and the methodology for this study. I would also discuss philosophical assumptions in relation to the research question, and the methodology and methods by which the data was analysed.

3.2 Philosophical Assumptions

In order to embark on qualitative research, a researcher must use a set of specific assumptions. There are different types of philosophical assumptions that must be held which can be categorised as ontology, epistemology, axiology or rhetoric. These are explained below. Grounded theory is a qualitative approach based on the ontological relativist and epistemological subjectivity. The goal of grounded theory is to discover an emerging theory which suitably explains a process, and can be understood by those engaged in the process. Grounded theory has the goal of discovering a theory that explains a basic social process (Creswell, 2007). Charmaz (2006) presented grounded theory from a constructionist paradigm.

3.2.1 Ontology

An ontological assumption is about the essence of reality and its characteristics. The researcher embraces the idea of diverse realism. Denzin and Lincoln (2005) claimed that

“Ontology raises basic questions about the nature of reality and the nature of human beings (Denzin and Lincoln, 2005, p.183, cited in Levers, 2013).” Relativist ontology is the idea that reality is a predetermined subjective experience and nothing exists beyond our thoughts and emotions (Denzin and Lincoln, 2005, p.183, cited in Levers, 2013). This means that reality is a human experience and human experience is reality. It is beyond two people experiencing an outer world in a different way; rather their worlds are different (Stajduhar, Balneaves, & Thorne, 2001, p.2, cited in Levers, 2013).

The aim of relativist ontology is to comprehend the subjective experience of reality and several truths. Both researchers and the subjects of research hold different perspectives on reality. When examining people, qualitative researchers study different interpretations of the world in order to understand social phenomena. The qualitative researcher using phenomenology (an approach that concentrates on the study of consciousness and the object of direct experience) reports how people experience the same phenomena either differently or similarly (Moustakas, 1994, cited in Creswell, 2007). Charmaz’s constructivist grounded theory takes on the relativism of multiple social realities, which means that it does not focus on a core category, but rather it allows researchers to embrace multiple truths and give weight to them according to the perspectives of the participants (Charmaz, 2006).

3.2.2. Epistemology

Epistemology refers to the study of knowledge itself in order to understand and explain ‘how I know and what I know’ (Crotty, 1998, p.3, cited in Levers, 2013). Epistemological study explores the relationship between knower and the knowledge, and attempts to explain how knowledge is acquired (Denzin & Lincoln, 2005, p.183, cited in Levers, 2013). There are two main types of epistemology which are referred to as objectivism and subjectivism. Crotty (1998) defined objectivism as the belief that an object holds truth and meaning within itself independent of human subjectivity (cited in Levers, 2013). It stands that knowledge is generally applicable and does not consider who is studying the object. It was intended to

explore natural, universal facts (Nicholls, 2009, cited in Levers, 2013). On the other hand, subjectivism is a process where knowledge is perceived through the lenses of gender, social class, and language etc (Denzin & Lincoln, 2005, p.21, cited in Levers, 2013). Subjectivism does not refute the existence of an external reality, but does claim that knowledge is value laden. Subjectivism is more about individual reflection and interpretation. According to grounded theory, meaning is constructed through interactions between different realities of the world. These interactions allow a researcher to understand the different interpretations made by individuals (Charmaz, 2006). Charmaz (1995b) used grounded theory to extract multiple meanings and she stated that researchers have to transcend the research material in order to seek meanings in the data, and looking for and inquiring implicit meanings about implicit beliefs, values and philosophies. Moreover, interactions between the inquirer and participants lead to generating the data and meanings that researchers arch (cited in Charmaz 2006).

3.2.3 Epistemological and Ontological Perspective in Relation to this Study

In this study, I was interested to explore the question ‘how do people live with systemic sclerosis?’. This study was influenced by constructivism epistemology using a qualitative framework. Crotty (2003) sees constructivism as the epistemology placed in the middle position between the two extremes: objectivism and subjectivism. Constructivism has a relativist ontological position, which assumes subjective realities exist, and reality is a predetermined subjective experience. This was in keeping with the research question which aimed to study the participant’s subjective experience of living with systemic sclerosis. Relativist ontology focuses on multiple realities about the phenomena and takes these different realities to understand the social phenomena. This tenet of relativist ontology relates with grounded theory where it embraces with multiple social realities to collect the participant voices in order to understand their social process (Willig 2013).

In this current research, a relativist position was also taken in relation to the data collected; the analysis was underpinned by both a relativist and realist position. This current study was

interested to understand how people make sense of their world (relativist) (Willig 2001; Merriam 2009, cited in Willig 2013) as well as producing an accurate representation of the participants' construction of meanings (Willig 2012, cited in Willig 2013). However, this led to some conflict with the philosophy underpinning a relativist ontological position in relation to data analysis. From a relativist position, analysis is the reflection of a researcher's interpretation of the data, as a relativist position does not claim to produce an accurate and truthful representation of the participant's subjective world (Willig, 2012, cited in Willig, 2013). Therefore, the researcher's interpretations could influence the analysis. As such, I tried to limit my bias through my reflexivity work, personal therapy, supervision and journal writings.

3.3 Reflexivity

3.3.1 Epistemological Reflexivity

As mentioned above, reflexivity is important for any research and I need to consider the role of my assumptions that could be seen as being informed by my professional and academic background and personal experience. I am a novice in conducting qualitative research and, therefore, choosing grounded theory facilitated personal development for me through learning and understanding a new methodological approach.

In terms of my epistemological perspective, it was argued that there was an interaction between the participant and myself during face-to-face interviews. It was acknowledged that I was not neutral and already held beliefs and assumptions about living with systemic sclerosis due to my own personal experience of living with this disease. I approached my participants through accepting this reality, but also kept in mind that participants may have had different experiences, and attempted to remain non-judgemental during the interview process through adopting a phenomenological attitude and asked interview questions neutrally. Research supervision and my own personal therapy were utilised to deal with my own potential biases and assumptions. In terms of a relativist position, it is possible that different interpretations of

the participant's accounts were made and their responses explored in order to check their meanings of particular words and also to avoid any misinterpretation. These methods make part of theory-testing part of grounded theory (Willig, 2013).

In order to guard against my own assumptions, I kept writing personal journals and discussed my research analysis in my research modules with my tutor and colleagues and also with the research supervisors. I also presented my research project and analysis to others professionals during my clinical placements and engaged with peer supervision. This engagement helped me to reflect on my data interpretation and analyses and also assisted me to obtain research analyses without bias.

Epistemological reflexivity also concerns the development of the research questions. While the research question should be focused, it should be open-ended to allow theory to develop (McCann and Clark 2003, cited in Willig, 2013). In the current research, grounded theory was particularly significant in the shaping of the research question.

3.3.2 Personal Reflexivity

Being a researcher in this study, it was acknowledged that my own assumptions, interests, beliefs and experiences had the potential to affect the research process. In terms of personal reflection, I have been living with a diffused type of systemic sclerosis for the last six years and this has made me curious to explore other people's experiences of living with this disease. In my prior research experience, I had conducted quantitative research on medical and mental health issues such as diabetes, cancer, anxiety, depression and conversion disorder. In the past, my interest in conducting quantitative research on medical health issues was due to my own medical background which is pre-medical studies in Biology and my mother is a medical doctor. However, after suffering with this incurable illness, my interest in quantitative research areas shifted to qualitative methods. I found many quantitative research studies on systemic sclerosis but found very limited qualitative studies focusing on understanding process of living with experience with systemic sclerosis. Being a sufferer of this disease, I

acknowledged that there should be more research that could help to understand the subjective experience of living with an incurable disease as a whole, rather than focusing on the percentage or statistical results. So, I decided to undertake this current research, which has also showed to have a significant influence on my epistemological standpoint.

In relation to the interview process, I was aware of the importance of my reactions, so I developed empathic rapport with my participants through a warm welcome, being grateful to them for being a part of this research, introducing myself, inviting them to introduce themselves and informing them about the research project. I gave them space so they could take time to feel comfortable and respond to the interview questions and maintained eye contact during the interview conversations, attempting to remain neutral as much as possible. Mathieson (1999) attempted to address this by focusing on a ‘narrator-listener’ role rather than ‘interviewer-participant’ role in order to increase rapport with participants. In order to further increase this rapport, I tried to adopt informal styles when greeting the participants so as to reduce any barriers, as well as emphasising that they are experts in their experience and my role was to listen to what they had to share.

In conclusion, personal reflexivity focuses on how the research may have impacted me both personally and professionally (Willig, 2001, cited in Willig, 2013). I continually guarded myself through personal therapy, research supervision, peer supervision and writing personal journals.

3.4 Research Paradigm

Taylor and Roberts (2007) define a ‘paradigm’ as a broad standpoint on something (cited in Michel, 2008). On the other hand, Weaver and Olson (2006) state that paradigms are patterns of beliefs and systems that regulate inquiry within a discipline by providing lenses, frames and processes through which analysis is achieved (Weaver and Olson, 2006, p.460, cited in Michel, 2008). Hence, I discussed the paradigm chosen for this study before explaining the methodology that was used.

Weaver and Olson (2006) state that the paradigms generally exploited in fostering research are positivist, post-positivist, interpretive, and critical social theory (cited in Michel, 2008). According to Weaver and Olson, positivist paradigms are used mostly for quantitative methodologies since the philosophical assumptions used are logical positivisms based on the rules of logic, measurement, truth, principles and prediction (Halcomb & Andrew, 2005; Cole, 2006; Weaver and Olson, 2006, cited in Michel, 2008). The positivist philosopher claims that there is only one objective reality. That means valid research is revealed merely by a degree of proof that can be consistent to the phenomena that research outcomes stand for (Hope & Waterman, 2003, cited in Michel, 2008). The post-positivist paradigm takes a scientific approach by examining the relationships between phenomena and stresses the importance of empirical data for our understanding of these relationships.

The qualitative methodology shares its philosophical underpinning with the interpretive paradigm which holds the belief that there are many truths and several realities (Weaver & Olson, 2006, cited in Michel, 2008). Moreover, the interpretive paradigm is part of a group of methodological approaches that offer an opportunity for research participants to express themselves (Cole, 2006; Weaver and Olson, 2006, cited in Michel, 2008). The ideology of constructivist grounded theory is another member of this group of theories which emphasises the importance of giving a voice to participants. Additionally, Cole asserts that qualitative researchers are more interested in unearthing information on how people experience and think in certain situations, instead of making judgements about whether those beliefs and feelings are valid (Cole, 2006, cited in Michel, 2008). The theory of social constructivism (often combined with interpretivism) can be used as part of qualitative research. Social constructivists embrace assumptions that people attempt to understand the world where they live and work. Individuals construct subjective meanings of their experiences—meaning directed towards specific objects or things. These meanings are experienced and multiple, directing the research to search for the complexity of views instead of narrowing meanings

into a small subset of ideas. The objective of this research is to understand the research participants' experience of living with systemic sclerosis. Through the use of open-ended questions, people are given the opportunity to direct the discussion of their interpretation more easily. These subjective meanings are negotiated socially and historically. They are not merely imparted on people in isolation but are created through interaction with others (hence social constructivism) as well as the prevailing historical and cultural norms. Similarly, constructivist researchers seek to explain the interaction process that occurs between individuals. They emphasise the particular contexts in which people live and work in order to understand the historical and cultural settings of the participants. Researchers suggest that their own backgrounds outline their interpretation and they place themselves in the study to recognise how their interpretation emerges from their persona, cultural, and historical experiences. The aim of a researcher is to make sense of how others interpret the world (Creswell, 2007).

3.5 Qualitative Approaches

The qualitative approach was chosen to conduct this study. It is imperative to recognise that qualitative research has been considered as a fragment of psychology since the beginning. Wundt and Dilthey (1833/1911), who are considered to have founded the field of psychology, claimed that a true 'human science' could be found merely on the analysis and interpretation of meaning and experimental-approach work with limited topics such as perception, neuropsychology and memory (Rennie, 1994, cited in Woolfe, et al., 2003). The work of nineteenth century philosophers such as Husserl and Brentano led to the emergence of phenomenological psychology (Valle & Halling, 1989, cited in Woolfe, et al., 2003). Danziger (1998) helped develop qualitative research methods. Qualitative researchers such as Heppner et al (1992), McLeod (1994) and Watkins and Schneider (1991) have influenced the discipline of counselling psychology (cited in Woolfe, et al., 2003).

Bergin and Garfield (1994) predicted a future development within psychotherapy research, which was 'the endorsement of narrative, descriptive, and qualitative approaches' within the

field. They stated that this 'is a momentous change in attitude that is probably to become more patent in the conduct and reporting of inquiries' (Bergin and Garfield 1994:38, cited in Woolfe, et al., 2003). Other published texts by Frommer and Rennie (2000) & McLeod (2001) also reflected on the impact of qualitative methods in counselling psychology and psychotherapy (cited in Woolfe, 2003).

Qualitative research is the analysis of stories, including narratives of people's experiences about certain phenomena in a way which gives insight into real world phenomena. It can be said that a qualitative approach is more about the focus on language as opposed to mathematical methods. Good qualitative research requires that the researcher takes into account all the descriptive accounts of the phenomena under investigation. Theoretical insights can then be gained from this data (Creswell, 2007).

There are different approaches that can be employed to interpret the qualitative research data. The main disciplines of qualitative approaches are phenomenology, grounded theory, narratology, and discourse analysis.

In qualitative study, researchers go to and fro between the data gathering and analysis in a cyclical process. It was felt that grounded theory was a methodology best suited for this study due to numerous reasons. Grounded theory methods helped me to get started, remain involved, and finish the project. During the research process, grounded theory methods encouraged me to look on data in fresh ways and explore ideas and concepts about the data through early analytical writing. Through using the grounded theory methods, I could direct, manage, and reorganise the data collection and, furthermore, construct an original analysis of the data. Grounded theory methods comprise of systematic, flexible guidelines for gathering and analysing qualitative data to build theories 'grounded' in the data themselves. The guidelines suggest a set of general principles and heuristic devices as opposed to formulaic rules to construct theory. Grounded theory helps to assemble data and to build a theoretical category from the beginning of the data. I endeavoured to learn what occurs in the research settings and

what research participant's lives are like. I intended to study how research participants explain their statements and actions, and ask what analytical sense I can make of them (Charmaz, 2006).

Being a researcher, I focused on what was happening in the study settings and interview statements so that I could learn about my research participant's lives. I concentrated on what I could hear, see, and sense during the interviews. I started with information and created the data through my observations, interactions and the materials that I gathered about the research topic.

3.6 The Rationale for Choosing Grounded Theory

The decision to choose a qualitative research method was linked to the nature of the research question and the aims and objectives of the current research. This study focuses on 'dynamic change or processes' as a consequence of living with systemic sclerosis. I was interested to develop theory in order to understand the dynamic changes of their experience of living with systemic sclerosis.

I was more interested to explore the 'process' and 'change' as result of living with systemic sclerosis, in the same way grounded theory relates with 'process' and 'change'. This is what made me choose grounded theory as it correlated with the study's aims and objectives, such as individual experience changes in physical, social and psychological dimensions or perceiving different selves after suffering with this disease.

Most grounded theories are considered to be important theories because they explore problems in certain substantive areas, such as studying how people reconstruct their identities after having a life-threatening illness. The rationale behind grounded theory can extend into considerable areas and into the realm of formal theory which means generating abstract concepts and defining relationships between them in order to comprehend problems in multiple substantive areas (Kearney, 1998, cited in Charmaz 2006). Each exploration within each new and important area can help researchers improve formal theory. Grounded theory

works as a method thereby enabling us to learn about the world we are examining and represents a process for building theories in order to comprehend them. We are a part of the world we study and the data we collect. We generate our grounded theories by using our past and present experiences and by engaging with others and their individual perspectives and research practices. Grounded theories work as constructions of reality based on research participants' meanings and experiential views. Using grounded theory means that the researcher can stop and record new data and information as it comes to them. Sometimes, we embrace new ideas late in the research process and this may, in turn, entice the researcher back to the field in order to discover an even deeper perspective. In this way, grounded theory methods represent a special skill that the researcher can use in his research (Charmaz, 2006).

I believed that if I chose the quantitative approach or other qualitative approach, then it might not have been possible to look at these dynamic changes affected by living with systemic sclerosis. Grounded theory also gave a flexible procedure where I used to go to and from the field due to its iterative process of data collection and analysis in order to develop theory. Moreover, grounded theory is well-suited with a range of epistemological perspectives and similarly, can be used flexibly to suit the research as well as the research's epistemological beliefs (Chamberlain, 1999, cited in Willig, 2013).

3.6.1 Three Epistemological Questions

In order to understand ontological and epistemological roots in this methodology, I sought out answers for three epistemological questions in order to select grounded theory for this study, mentioned in Carla Willig's book '*Introducing Qualitative Research in Psychology (2013)*'.

3.6.1.1 What Kind of Knowledge Does Grounded Theory Aim to Produce?

Grounded theory was designed to identify and explicate basic social processes. Their procedural step to gathering data and analysis leads to building concepts and categories emerging from the data. The intention of grounded theory is to discover theories that are already 'grounded' in the data. I wanted to generate theory to understand how this disease has

changed a person's life in each dimension of the world and to understand the process of these changes impacted by the disease rather than just exploring their experience of living with the disease. As Glaser (1999: 840) puts it, '[G]rounded theory *is what is*, not what should, could or ought to be' (original emphasis) (Willig, 2013). In this way, grounded theory has a realist orientation and its aim is to produce the knowledge of action and processes that reside in the data and then emerge from the data with help from the researcher. It means that potential knowledge is 'out there' and the researcher has captured it through analysing and reanalysing the data. Through categorisation and theorising of the data, readers are able to understand these processes made by the researcher. In this way, grounded theory takes a positivist approach to produce knowledge (Willig, 2013).

3.6.1.2 What Kinds of Assumptions Does Grounded Theory Make About the World?

This question relates to ontology assumptions as it is concerned with the nature of the world and asks 'what is there to know?' Grounded researchers are interested in the ways people negotiate and manage their social situations, and how their actions contribute to the revealing of their social processes. Grounded theory believes that social events and processes have an objective reality in the sense that they occur regardless of the researcher and that they can be scrutinised and documented by the researcher. This proposes realist ontology. However, grounded theory also thinks that social realities are negotiated by human beings and that participant's interpretations of events shape their outcomes. In this way, grounded theory gives a symbolic interactionism perspective; this means that 'the world' that is studied by research is the outcome of human participation and negotiation in their changing world (Willig, 2013).

Researchers using symbolic interactionism assume that people construct selves, society and reality through interactions and believe that language and symbols play a crucial role in making and sharing meanings and actions. It identifies that we act in response to how we perceive our situations (Charmaz, 2014). Although it is not a compulsory part of constructivist grounded theory processes, it is considered as a major theoretical perspective associated with

grounded theory to develop the theory. Where people are known to share their world and their understandings are shaped by the same beliefs, values and attitudes, they learn how people behave according to how they interpret the world around them. People interact with the world and adapt situational behaviours to shape meaning and society. This is what grounded theory focuses on; ‘process’ and ‘change’ as a result of a disease on their physical, social and psychological dimensions and their resilience to live with this disease by asking research questions, such as ‘how do people live with systemic sclerosis?’ or ‘what is the impact of the disease on their physical health, social relationships and within their self?’ and ‘how do they experience existential crisis if they encounter it and how do they deal with their illness?’. On the whole, I wanted to understand the impact of disease on a participant’s world, their way of dealing with it and then the consequences, in order to create a theory that would be helpful for mental health professionals in understanding their client’s dynamic process in living with systemic sclerosis on a daily basis.

3.6.1.3 How Does Grounded Theory Conceptualise the Role of the Researcher in the Research Process?

In grounded theory, being a researcher, I am very active in the process of scrutinising what is happening in the field and taking field notes during and after interviews in order to better grasp what is going on in the participant’s lives and rely on ‘rich’ data to develop theories for the phenomena. In the social constructionist version of grounded theory, I am more than a witness as I construct a particular understanding of the phenomenon under inspection. From a social constructionist standpoint, grounded theory is itself a social construction of reality, rather than capturing social reality. Constructivist grounded theory acknowledges the researcher’s contribution to the data (Willig, 2013).

Grounded theory’s theoretical and epistemological bases place it to examine a broad range of open-ended research questions (such as in this study, I was interested to explore ‘how do people live with systemic sclerosis?’) that focus on processes, patterns and meanings within

that context that entails crucial inspection of subjectivity of experience and similarly guides me to initiate inquiries from their research participant's view. Grounded theory can be employed where existing research is under-defined, such as there being limited research in the area of systemic sclerosis that focuses on the existential crisis and to explore coping strategies using a qualitative approach.

Moreover, grounded theory is not only focused on an individual's interpretation of their experience but has a broader remit. The goal of grounded theory is largely to develop an inductively driven theory of examining basic social or psychological processes (Glaser & Strauss, 1967) in which I focus on the process of living with systemic sclerosis in physical dimensions such as daily life activities, the social dimension of relationships, psychological dimensions such as uncertainties or anxiousness and these dynamic experiences which are as a result of living with systemic sclerosis. I was interested to scrutinise these impacts of the disease on participant's lives.

The rationale to explore 'dynamic changes or processes as a result of systemic sclerosis' is linked to my own personal experience of living with the disease. My personal experience defined my research project and my existential understanding of my own experience has led me to think about other experiences from an existential position too. However, I kept in mind that it would not be necessary for the participant to experience the same as me but my own experience of living with systemic sclerosis gave me a passion to conduct this study and gave me the confidence to examine this process or change in their lives after living with systemic sclerosis.

I wrote the following statement of my own attitude with regard to the study that defined my process or dynamic change as a result of systemic sclerosis:

In order to pursue a professional doctorate in existential psychotherapy and counselling psychology at the NSPC, I am undertaking training in the existential approach. Being an existential trainee as well as sufferer, I perceive this disease as an existential crisis. I believe

that this disease has had an impact on the whole of my life and I would like to use the word 'transition' here (for my identity) since I am in the transition from an independent life to a dependant life. I confronted the fact that this disease not only affects people's physical worlds, but also their social, personal and spiritual world. In terms of living with this disease, I can see how it has affected many facets of my being-in-the-world. It is a supreme challenge to accept this disease as it affects my choices and my freedom, and has taken away all those things I was used to doing. It made me a totally different person, not only in terms of my appearance, but also in my thoughts, my choices, my values, and my beliefs. A curious thing about this process and about how other people with systemic sclerosis live with this disease, and how they feel and cope with it, has prompted the current development of my research project.

The grounded theory explains a basic process in this context and pursues researching it as phenomena of interest. This focus on social processes allows grounded theory to scrutinise how social structures, situations and relationships affect patterns of behaviour, interactions and interpretations. In terms of researcher reflexivity, the self-reflection of therapist, counsellor and psychotherapist also perceive grounded theory methods as a suitable approach for psychotherapy research.

3.7.Ontological and Epistemological perceptions in light of grounded theory

In this section, I wanted to present the philosophical underpinning of this study. My ontological standpoint of 'how I view reality' is explained together with a clarification of my views relating to my knowledge about the social world, which is my epistemology. Building on this philosophical framework, I chose the constructivist grounded theory by Charmaz (2006).

3.7.1. Ontological Position in relation to grounded theory

Ontology defines how the nature of 'being' is understood. For this study, the constructivist grounded theory (Charmaz, 2006) was used on the basis of philosophical assumptions and

study aims. My research question is ‘how do people live with systemic sclerosis, what their experience is of their illness and how do they cope with it?’ This research question exhibits the processes in the participant’s life that is related to the tenet of grounded theory. Grounded theory is a systematic, inductive, iterative and interactive approach to collecting data and analysing it so that a theory can be generated. The inductive nature of grounded theory correlated well with my ontological and epistemological stance as it helped to discover the participants’ experiences of living with systemic sclerosis.

This study holds ‘relativist perspectives of ontology’ as it is based on the reality of people who are living with systemic sclerosis. Their experience of living with their disease is to ‘exist’ in the world. Grounded theory focuses on the ‘process’ and ‘dynamics’ of phenomena where participants are engaged. I was interested in their unique experiences of living with systemic sclerosis and how they have dealt with it which took the form of ‘realism’, as reality is a predetermined subjective experience, and to be defined as ‘reality’ depends on their perspectives. In order to analyse realism, I consider that there is no absolute truth and believe that different people can have similar or different views with regard to living with systemic sclerosis. This tenet of relativist ontology relates with grounded theory where it embraces with multiple social realities to collect the participant’s voices in order to understand their social process. In my ontological viewpoint, people construct their meaning within the social world, which correlates with the constructivist grounded theory notion that research activity is concerned with making meaning.

Ontologically, I took the interpretivist-constructivist attitude that human beings are not subject to universal laws, rather they construct meaning within their social setting. Human beings are unique individuals so they have unique perspectives and assign their meaning-making to their situations. In this way, it allows people to hold different viewpoints on phenomena, for example my experience of living with systemic sclerosis will be different from my research participants. However, understandings could be equally valid and also influenced by their

social factors. These different interpretations of the same phenomena are considered as true representations because, within this ontological position, context is important and the subjective experience such as thoughts and feelings are within the realm of scientific enquiry (Brustard, 2008, cited in Walker, S. 2016). I situated myself as a social scientist who claims that understanding human experiences from the context of their life-world is as significant as focusing on explanations, predictions and control (Holloway & Wheeler, 2010).

3.7.2. Epistemological Position in relation to grounded theory

In relation to my ontological belief that people construct meaning within their social setting, this also influenced my view of what kind of knowledge should be sought to better understand my research topic (David & Sutton, 2004); hence, my ontological view shaped my epistemology. I am interested in obtaining information about how they interpret their lives so that I can learn something of the truth of their lives.

In this study, epistemology takes the stance of constructionism as it focuses on the ways in which people make sense of their world and claims that meaning is constructed through the human interaction with each other and their world. In this study, I focused on the construction of reality, explaining the ‘processes of interactions amongst participants’. By adopting this approach, I found that my constructionist understanding of this study was in accordance with Charmaz’s (2006) constructivist version of grounded theory, as she claimed that theory is constructed by the researcher’s interaction with the participants, their perspectives and the research practice. My epistemological position to understand how participants interpreted their lives also fitted well with Charmaz’s (2006) standpoint in that any theoretical rendering offers an interpretive picture of the world which is being studied rather than an exact picture of it (Charmaz, 2006).

Under the previous section of epistemology, I described the ‘role of the researcher’ in a qualitative study and also epistemological reflexivity. In terms of my epistemological position, as a researcher, a trainee counselling psychologist and as someone living with the same

condition, I am interested in what goes on in the participant's world and their personal meaning by living with systemic sclerosis. In this sense, I am a constructivist and situated myself as a social constructionist in that I accept that realities and meanings are co-constructed in the social world and, being a trainee counselling psychologist, my attention is in the relational and social that is focused on subjectivity, inter-subjectivity and on the importance of social context. As an epistemological position of constructivism is the claim that people construct reality by assigning meaning to the world around them.

In this study, I am interested in the participants' experiences of living with systemic sclerosis, exploring their 'world' which creates dynamic perspectives with the belief that it is constantly changing or evolving in reality. My aims are correlated with the dynamic properties of grounded theory, which are processes and actions. In order to implement the constructivist grounded theory method, it is significant to highlight the epistemological position of the researcher. Charmaz (2006) also emphasised the role of the researcher in the eventual theory and their relationship with the participants. It also acknowledges my role as co-constructor in this study and, by using the flexible grounded theory approach by Charmaz (2006), it also provided a platform where the researcher could concentrate on their own analysis and interpret an original theory that reflected their specific data (Charmaz, 2006).

This study is based on constructivist epistemology and ontology in relation to the grounded theory, which is consistent with the constructivist grounded theory research design by Charmaz (2006), by 'placing priority on the phenomenon of study and seeing both data and analysis as created from shared experiences and relationship with participants and other sources (Charmaz, 2006: 330)'.

3.8. The Phenomenological Method

Under this section, I would like to explain about other types of phenomenological methods and how grounded theory is the most suitable for my study and not the other approaches. The philosopher Edmund Husserl (1859-1938) founded the phenomenological research method,

which was later criticised and developed, most notably, by figures synonymous with the philosophical movement, such as Martin Heidegger, Jean Paul Sartre and Maurice Merleau-Ponty (Woolfe, 2003). Deemed both a philosophy and a method, broadly speaking, Husserl's phenomenology can be described as "the unprejudiced, descriptive study of whatever appears to consciousness, precisely in the manner in which it so appears" (Moran, 2002, p.1, cited in McNamara, 2005). Thus, exercising phenomenology requires a "bracketing of presuppositions and commitment to description. The purpose of phenomenological methods is to accomplish a realistic and inclusive description of the way in which a phenomenon is experienced by an individual or group of people (McNamara, 2005). The job of the researcher is to engross him or herself to such an extent that the essence of what is being studied becomes clear through the bracketing off of her prior assumptions. Below are other types of qualitative approaches and the reason to choose grounded theory.

3.8.1 Interpretative Phenomenological Analysis (IPA)

Jonathan A. Smith developed the relatively recent qualitative method IPA in 2009. He drew IPA from Husserlian phenomenology to scrutinise experience in its own terms through using Epoche. IPA focuses on the research participant's world and then it explores the researcher's own postulation through the interpretative process (Smith & Osborn, 2008, cited in Smith, et al., 2013). Therefore, IPA is linked with hermeneutics and is not just related to phenomenology. In IPA the researcher takes the insider view and explores how participants make sense of their experience of their own social and personal world. IPA is the underpinning of symbolic interactionism that places an emphasis on deriving meanings within their own personal and social world (Smith & Osborn, 2008, cited in Smith, et al., 2013).

IPA considers individuals as experts concerning their own experiences and as people who can present researchers with a comprehension of their own beliefs, opinions, and commitments through giving their own accounts in their own detailed formulation as far as is possible (Reid, Flowers & Larkin, 2005, cited in Smith, et al., 2013). IPA is a phenomenological method used

to explore an individual's experience of living through events and is derived from philosophical assumptions about social constructions which mean that people understand their own experience through their perception. In terms of double hermeneutic, the researcher is not only being a human making sense of his own world but he is also approaching the participant's world that they have described. The way of getting the participant's experience is partial and complex, so IPA draws attention to the value of the researcher's role in influencing the process (Smith & Osborn, 2008, cited in Smith, et al., 2013).

3.8.1.1. IPA and Grounded Theory

Grounded theory is often perceived as a substitute method for research when considering IPA for a research study. Grounded theory was originally developed by Glaser and Strauss in 1967. They offer a logical, systematic, and sequential guide to qualitative researchers. This was operated through using co-axial coding and a distinctly structured method for theory development.

Researchers using grounded theory predominately start by creating a theoretical-level description of a certain phenomenon in terms of 'dynamic change and process' as a result of systemic sclerosis on individual lives that would help to generate theory and help other professionals to understand their experiences after suffering with this disease. It often takes large sampling, particularly in juxtaposition to IPA. Constructivist grounded theory shows the greater flexibility of process, and a lucid epistemological position (Creswell, 2007).

Certainly, there is a substantial overlap between IPA and grounded theory. They both offer an inductive attitude to inquiry. IPA largely offers deeper investigations of lived experiences of a small sample of participants focusing on convergence and divergence between participants, whereas a grounded theory study of a similar topic works much more on a conceptual explanatory level based on a large sample. In this study, I was more interested in exploring the participant's actions and what participants do during their crisis, focusing more on a deep explanatory level of analysis which better suits grounded theory than IPA (Creswell, 2007).

3.8.2. Narrative Analysis

In phenomenology and grounded theory analysis, participants' accounts tend to become converted into more common themes or categories. It could be possible to diminish the search for the actual meaning of underlying stories. Narrative analysis comes in many forms and works on different analytical processes. Narrative research emphasises stories informed by individuals. Pinnegar and Daynes (2006) reported that narratives can be both a method of study and a phenomenon of study. As a method, it makes a start with experiences as articulated in actual and informed accounts by individuals. Narrative inquiry focuses on the studying of one or more individuals, assembling information through gathering their stories, reporting individual experiences, historical ordering (or using life span stages), and the meaning of experiences behind the stories (cited in Creswell, 2007).

There are different types of narrative analysis but what the different approaches of narrative analysis share is in the subtlety and complexity in which the individual creates meaning, and also in the impact of context on different stories informed by individuals. One type of narrative analysis is biographical study where research focuses on the experience of a person's entire life in chronological order (Creswell, 2007).

This method focuses on an individual's experience and in the telling of stories that have happened in their life. It is more about gathering the history of an individual's life and it is about personal reflection of events in a certain context. This study was not concerned with people's events and in building them up into a story using a plot line, especially in terms of their chronological connectedness. Instead the study was focused on discovering the participant's experience of living with systemic sclerosis and how they cope with that experience, feelings or phenomena, rather than in the settings themselves. Therefore, it was felt that narrative analysis was not appropriate to consider for my study.

3.9. Constructivist Grounded Theory

The constructivist grounded theory by Charmaz (2006) was used for this study in order to discover the process of people living with systemic sclerosis. Grounded theory has aimed to develop a theory, a theoretical investigative schema of a process (action or interaction) and ‘grounded’ in the data. Participants in the study would all have experienced the process and dynamic changes as a result of systemic sclerosis, and the development of a theory might help explain, practice or provide guidance for further research.

Grounded theory as a qualitative approach was firstly developed by Glaser and Strauss (1967) investigating the social processes of death and dying in the hospital in the United States in the mid 1960s. In their book, ‘The Discovery of Grounded Theory (Glaser & Strauss, 1967), they expounded a rigorous set of inductively driven research strategies designed to process, systematically, from a set of specific observations to a general conclusion in order to explain and understand people’s views, actions and life experiences within the specific context in which they were living. The grounded theory method uses a series of explicit strategies for data collection and analysis and intends to produce an inductively driven theory of social or psychological processes grounded in the data from which it was derived (cited in Charmaz, 2006).

The grounded theory approach was adopted for this research for many reasons. One of the main reasons was in order to explore ‘how people live with systemic sclerosis: how does it affect their lives and how do they cope with it?’ I was interested in discovering a theory which was derived from the participant’s interview data. Grounded theory focuses on examining processes, conducting a study of action and making abstract interpretations based on the understanding of data. Grounded theory was selected due to its inherent flexible guidelines as it helped me to go back and forth between the data and the field in order to generate theory, and because it is composed of as a set of principles and practices. Furthermore, grounded

theory methods complement other qualitative approaches rather than opposing them (Charmaz, 2006).

Researchers can employ grounded theory strategies with a variety of data collection methods. Charmaz exploited these methods merely as a tool as opposed to a set of rules to apply. Grounded theory methods provide guidelines for using the data to discover how people make sense of their experiences and act upon it. Through grounded theory, researchers are able to gather rich data that presents a solid resource for making significant analysis. This detailed analysis helped to understand the participants' feelings, thoughts, views, actions and moreover the context and structure of their lives (Geertz, 1973, cited in Charmaz 2006). This rich information also helps the researcher to construct grounded theories through various kinds of data, for example field notes, interviews and information contained in reports and records.

For this study, the constructivist grounded theory was chosen because it puts its emphasis on the phenomena of study and perceives both data and analysis as constructed from shared experiences and relationships with participants and other sources of data (Charmaz, 2006). The aim of the study was to understand how participants experience change in their daily lives as a result of systemic sclerosis. A constructivist theory focuses on how people look at their situation. It not only postulates the interpretative work that research participants carry out, but it also allows the emerging theory to become an interpretation (Bryant, 2002, cited in Charmaz, 2006). The theory relies on the researcher's perspective; it has no basis other than that. The constructivist approach enables the grounded theorist to learn how, when, and to what extent, the studied experience is actually rooted in more extensive and frequently, less obvious positions, situations, and relationships (Charmaz, 2006).

Through using the constructivist grounded theory, researchers can bring a more reflective attitude to the research process and consider how their theories are developed, including reflecting on (prior place) where both researcher and research participants expound meaning and actions. Charmaz (2000) assumes that both data and analyses are based on social

constructions which reflect thoughts, views, actions and processes. Researchers can be aware of their own assumptions and suppositions and can find out how to deal with these. Researchers can bring inappropriate preconceived ideas into their work when they are unaware of their initial assumptions. Consequently, constructivism stimulates the researcher's own reflection into their own interpretations as well as those of their research participants. The reason for choosing grounded theory is that it presents qualitative inquirers and explicit, practicable stages to follow when dealing with qualitative data. Nonetheless, few researchers have claimed that the procedure of grounded theory analysis is an art that depends solely on intuition and creativity and considers that it should be understood through a practical apprenticeship rather than learned by following what is in a book (Stern, 1994, cited in Charmaz, 2006).

The essential idea of constructivist grounded theory is to give a voice to participants and encourage researchers to gather a range of different voices, observations, and participant beliefs (Charmaz, 2006).

There are different general steps to the analysis mentioned in Creswell's (2007) *Handbook of Qualitative Research*, and I followed these steps in order to generate a theory (Creswell, 2007):

- Stage 1: Interview was conducted. It would help to generate the model through collecting all information.
- Stage 2: There are stages involved in the data. I grouped the information concerning the phenomena under study by fragmenting the data; this is called "open coding". I then identified further subcategories within each group and looked for information that would demonstrate extremes on a continuum of the property or subcategory.
- Stage 3: At this stage, I collected information using a coding paradigm or logic paradigm called 'axial coding' where I had identified a central phenomenon,

discovered causal conditions (i.e. classifications of conditions that impact on the phenomenon), resilience (i.e. the actions that come from a central phenomenon), categorised the context and intervening conditions (i.e. narrow and broad conditions that impact on the approach), and defined outcomes for this phenomena.

- Stage 4: I then proceeded to write a ‘story line’ that connected the categories: this is called ‘selective coding.’
- Stages 5: Lastly, I established and visually illustrated a conditional matrix that made clear the historical, social and economic situations impacting on the central phenomenon. However, this was an elective stage in which I thought about the model from the narrowest to the broadest prospective.

3.10. Ethics

In order to conduct the study, I needed to obtain ethical approval from different awarding bodies such as the Scleroderma Society, the New School for Psychotherapy and Counselling and Middlesex University. I contacted the Scleroderma Society to recruit and interview participants within their building. I gained a consent letter from the Scleroderma Society in order to recruit and interview my participant (see Appendix A-Consent Letter from Scleroderma Society). Beyond obtaining the consent letter from the Scleroderma Society, and the awarding bodies for the ‘DCPsych Counselling Psychology and Psychotherapy’ programme, ethical clearance to proceed was also sought and obtained from the New School of Psychotherapy and Counselling (NSPC) and Middlesex University (see Appendix B for copies of NSPC and Middlesex University’s letters of ethical approval).

As a counselling psychologist in training, and registered member of the BPS, I also paid due attention to the ethical guidelines for minimum standards of ethical approval as laid out by the BPS (BPS, 2004). Upon successful completion of the DCPsych in Counselling Psychology and Psychotherapy programme, I will apply to become a chartered member of the BPS, which

will in turn enable me to apply for registration with the Health Professions Council (HPC). As such, it was appropriate that I also considered the HPC's guidance on conduct and ethics for students (HPC, 2009) when conducting this piece of research.

The participants' consent concerning their involvement in this research was, of course, an ethical necessity. In line with current guidelines from all three governing bodies, the participants were each sent an information sheet as well as a consent form in advance of their participation (see Appendix C Information Sheet and Appendix D Consent form). The information sheet acknowledged: the purpose of the study, the possibility that extracts from the interviews could potentially be used in published works, the disadvantages and risks concerning participation, my obligation to report any identified professional misconduct and the participant's right to withdraw from the research.

Another important ethical consideration emphasised by the NSPC, Middlesex University and BPS awarding bodies, there was the possibility that participants in this study might become upset or distressed if they evoked any uncomfortable memories during the discussion concerning their experience of living with systemic sclerosis. There were also predictions that certain kinds of depression, distress and anger may occur, as there is the risk of these conditions developing and causing more problems in the future. These predictions are based on other researches. If the participant experienced difficult emotions after the interview, they were able to contact the Scleroderma helpline or if they had any further questions about this study, they would be able to contact the New School for Psychotherapy and Counselling (NSPC), (details on the Information Sheet.) Furthermore, prior to their involvement, all participants were informed about how they could contact me within a reasonable period if, following participation, they experienced stress, harm, or had any related concerns (see Appendix E - Debriefing).

During the process of setting up the interview, it was critical to discuss the purpose of the research, how the information gathered in the interview would be used, the method of

interview recording, how the interview data would be protected, plans for protecting confidentiality, and how and when recordings would be destroyed. There is research evidence that systemic sclerosis is a highly distressing disease and half of the patients reported depression (Thombs et al., 2008). I was aware of how to deal with potential concerns (for example participants may mention having suicidal thoughts). In order to reduce the risk to the participants, I checked with them about any mental health issues prior to selection for this study. If it was the case that any of the participants had any past history of suicide or was considered a suicidal risk then they would not be recruited for this study. However, I did not find any participants with any potential suicidal risks.

To help offset the risk of participants becoming upset or distressed, all participants selected for interview were offered to engage in therapy if they felt upset or distressed after the interview. They were directed to Scleroderma Support line and other therapy services such as the Samaritans which provide a 24-hour telephone emotional support service as is appropriate to those who are house-bound (due to the nature of systemic sclerosis). They were also directed to face-to-face therapy services (i.e. Phoenix Aid Centre and Befriending Networks) if they were experiencing loneliness and social isolation. They were also asked to contact the New School for Psychotherapy and Counselling (NSPC) if they had any concerns about the interview or this research, (details were also provided on the Information sheet). Furthermore, I contacted the participants two weeks' after to check whether they'd had any concerns or problems following the debriefing.

In line with the provisions of the Data Protection Act 1998, it was also ensured that participants received a high standard of personal information security/confidentiality. The interview was digitally recorded and then immediately encrypted and kept in a secure place. After transcribing the interview, information was temporarily stored on a passport-protected computer. The information was then subsequently removed. All the information that the participant provided was identified only by a project code and stored on an encrypted USB

stick and on a password-protected computer. All transcripts were rendered anonymous and any identifiable information was omitted at the time of write-up.

Returning to the discussion regarding the HPC stipulation, those students operate within the limits of their own competencies; it is worth noting how these guidelines encouraged me to conduct semi-structured interviews prior to meeting any of the participants in this study. As a qualified existential psychotherapist, I was used to conducting one-to-one therapy sessions with clients, but not semi-structured interviews. It was therefore important that I hone in on my interviewing techniques to avoid the possibility of turning the research interview into a therapy session (McLeod, 2014, cited in Georgiadou, 2016). That said, it was no doubt the case that psychotherapy training played a role in helping the participants to feel comfortable enough to open up during the interview process.

3.11. Interview Design

After the recruitment process, I started working towards the interview design as the interview is a crucial step in any research process, not only for data collection but it also presents a paramount point where data is constructed between interviewer and the interviewee.

In qualitative research, the interview is a vital technique to gather data from the research participants. This quality of the data collected in the interview depends on both interview design and on the skill of the interviewer. In respect of the interviewer's skill, I am a clinical psychologist and a trainee counselling psychologist and I have had experience of conducting clinical interviews and counselling sessions with other clients. It is often assumed that if someone is clinically trained, they are considered as sufficiently trained to conduct research interviews. I have explained my research skills and counselling skills in a previous section under 'Reflexivity' where I explained how I used my counselling skills as a researcher.

In terms of the interview design, I chose semi-structured interviews with open-ended questions in order to explore people's experiences of living with systemic sclerosis through audio-recordings of the interviews after taking their consent and delivering all ethical

considerations. I had a list of interview questions prepared in advance as one of the ways to control interview conversations. I was familiar with the downside of open-ended questions as it is hard to get uniformity across respondents; therefore I attempted to remain neutral in their response and bracketed off any assumptions. On the other hand, open-ended questions provide a platform to both the researcher and participants for further exploration if something is unclear during the interview.

In this study, I chose the individual face-to-face interview approach as the interview method to obtain detailed information about their experiences of living with systemic sclerosis. Through individual face-to-face interviews, I was able to establish a rapport with the participants more easily and could also observe their non-verbal responses. Individual face-to-face interviews are most suitable when the subject matter is very sensitive. This study topic is very sensitive and personal for both me and the participants, so individual face-to-face interviews gave personal space to both me and them to explore themselves fully in a comfortable environment. This also provided flexibility for both me and the interviewee to explain the purpose and rationale of the study and clarify their questions by using probing questions to follow up on new ideas in a way that is not possible with other methods.

3.11.1. Interview Schedule

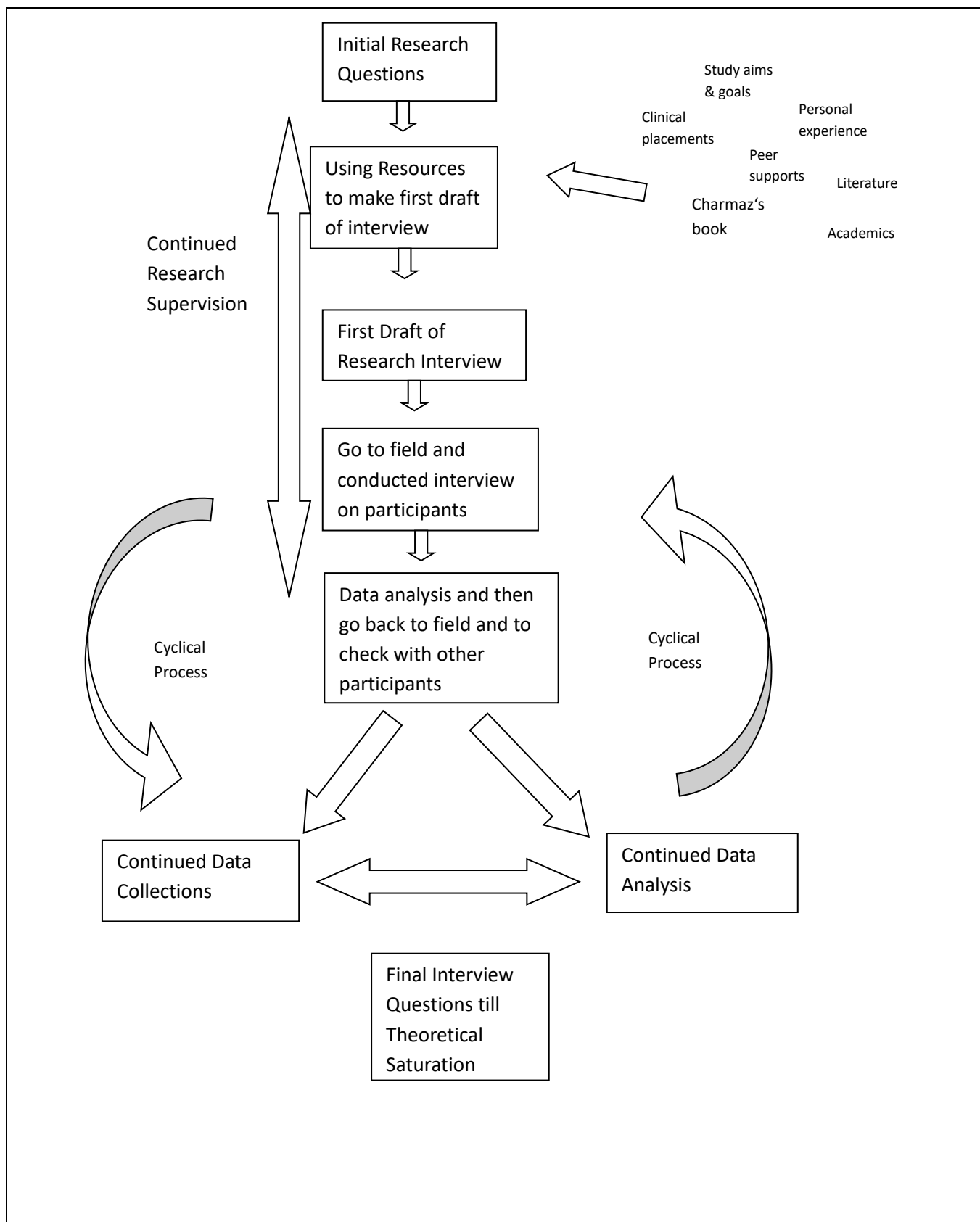
The repetitive versions of the interview schedule (see Appendix F & G) contain brief introductions of the context of the study with thirteen to fourteen open-ended questions, followed by further probe questions, in order to understand the participant's experience of living with systemic sclerosis, with a debriefing at the end of the interview.

I started the interview with broad questions so that participants could familiarise themselves with the research topic. However, I kept in mind about the research aims and the purpose of what I was looking for in this study. I chose the 'leap ahead approach' by asking broad question then allowing participants to choose their path to describe their experience of living with systemic sclerosis and also with the intention to build more rapport with the participants.

I was quite aware about time-limited interviews to achieve the study aims. Therefore, I gradually explored specific questions to obtain more focused responses relating to the purpose of the study.

It was not straightforward to develop a series of interview questions for this study. In order to construct the research questions, I firstly focused on my research question and my interests to explore in this study which was linked to the study goals and my intuitions from my own experiences of living with this disease. I developed an initial interview schedule through focusing on study goals, personal experiences, working with clients living with physical illnesses, sharing experiences with other people living with systemic sclerosis during my hospital appointments and obtained some guidance from Charmaz's book; I wanted to explore their process of living with systemic sclerosis and Charmaz has good examples of interview questions for grounded theory study. Being an existential trainee, I also added questions in relation to Emmy's ideas of a 'four-world dimension'. The rationale of using Emmy's four-world dimension is to focus on their 'lived experience' which consists of four worlds: physical, social, psychological and spiritual. In my personal and professional experience, Emmy's four worlds explain 'living experience' in a broader sense, such as not only focusing on their experience, but also reflecting on the emotions, paradoxes and resiliencies in each world. I feel that Emmy's four worlds emphasise more on being 'in process' or 'dynamic change in each world' which is relevant to grounded theory, such as the impact of the physical world on the social, psychological or spiritual world that is made up of 'My world' or 'SELF'. This process of intersecting four worlds is reflecting 'process or dynamic change' in individuals which is also parallel to grounded theory. Initial interview schedules were elaborated in some detail in proportion to the epistemological position of this study and to discuss the initial draft of the interview questions.

Below is Figure II to show the process of interview schedule and data collection:



However, due to the flexibility of the interview design, the interview questions depended upon conversations between me and the participant. After the first interview, I was able to understand the participant's experience in her views and added new questions to the interview list which I obtained from the first interview and then went back to the field to recheck this with other participants. In this way, I revised interview schedules after interpreting and analysing earlier interviews so I could develop an explanatory theory by narrowing down the questions in order to obtain accurate data. Through this iterative process, I incorporated interview questions through reflecting on study goals, existential frameworks, interviews, personal experiences, literature reviews and through discussions with supervisors and colleagues.

3.12. Sampling and Recruitment

When the study gained ethical approval, the task of recruiting six to eight research participants was able to begin. The selection criteria for participants were limited to women who had been diagnosed with systemic sclerosis by professionally qualified medical doctors.

The reason to choose only women was due to the rarity of this disease. According to one report by Scleroderma news in 2017, the occurrence rate of scleroderma in men compared to women was estimated at about one man per every three or four women. As it is a very rare disease, it was very difficult to find participants who were suffering from it. Therefore, I only chose women to increase the chances of securing participants as men with this rare disease could be very hard to find. Initially, recruitment took place at the Scleroderma Society. I published an article on the study in the Scleroderma Society magazine which was distributed to members of the Scleroderma Society diagnosed with systemic sclerosis across the UK. I posted a request for individuals willing to participate in a phenomenological study focusing on exploring the experience of women, aged between 30 and 65, and living with systemic sclerosis. Scleroderma age onset is between 30 and 55. The rationale to choose participants aged above 30 is to control my bias as I was diagnosed with this disease at the age of 22 and

conducted this study under age of 30. This helped me to separate my experience of living with systemic sclerosis from my participants and to control my bias, assumptions and thoughts in relation to my experience with this disease. The rationale to limit the upper age to 65 was the likelihood of securing more participants with this disease. I noticed during my hospital appointments and the contact with my disease fellows that there are age variations in this disease. In order to increase my chances of recruiting participants, I set the age criteria for the study between 30 and 65. Instead of setting broader criteria, I did not get the required number of responses and so I later posted advertisements on several internet scleroderma forums (such as www.healthunlocked.com and www.inspire.com). I chose to limit my research to six participants as “the goal of qualitative research is to produce intensive, authentic descriptive accounts of experiences and action, and if too many informants are recruited, it will prove impossible to do justice to their contributions in the research report” (Mcleod 2001, p30).

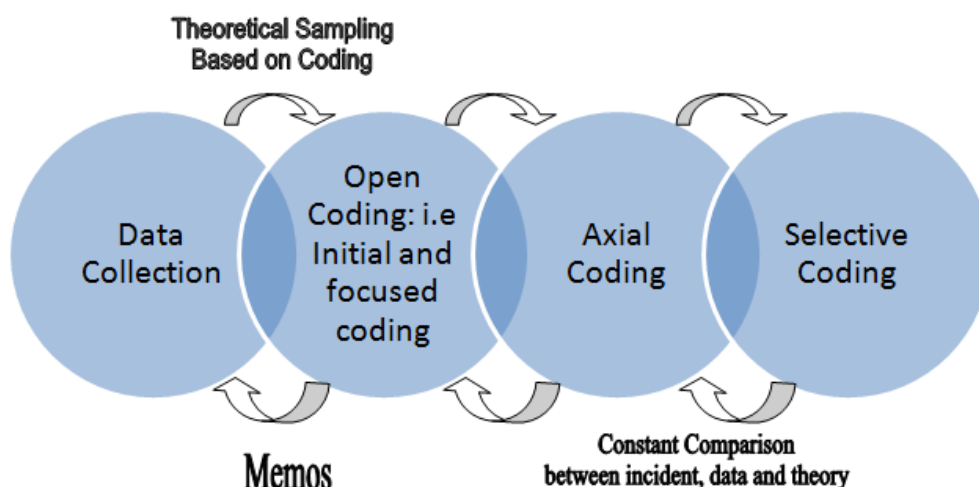
All volunteering participants for the study were provided with an outline of the purpose of the research as well as information about myself and, for each participant, a risk assessment was completed. They were assured of confidentiality and were informed of their rights to withdraw from the study. I conducted pilot interviews which helped me to develop and refine the interview agenda. The individual interviews each took place face-to-face and were approximately 60-90 minutes in length. Thereafter, all the interviews were recorded and transcribed, according to Charmaz’s grounded theory.

The recruitment process was guided by the principle of maximum variation/heterogeneous purposive sampling as I set some criteria, such as only women being selected or that the participants were in a relationship and had also been officially diagnosed by their professionals. However, I did not set any criteria for the length of the initial onset of the disease, duration of diagnosis, duration of treatment or types of systemic sclerosis for recruitment purposes due to the rare nature of the illness. As explained, I chose only female participants for this study because it helped to increase the probability to recruit a sample as

this disease is four times more common in women than men. Therefore, I chose variations in demographic variables such as age variation, length of initial onset of disease, duration of treatment and types of systemic sclerosis, so I could gain rich information from participants and could gain greater insights into the phenomena by looking at it from all angles which helped me to identify common themes that were evident across the sample. Sampling was aimed towards an explanatory theory construction rather than for population representativeness as grounded theory looks for saturation where research can describe theory. I decided to focus on one gender due to the rarity of disease. The women who participated in the study would be aged 30-65, diagnosed with systemic sclerosis, and in relationships. The demographic for this study was chosen to control my biases for this study as I am also suffering from this disease. Initially, I selected sampling criteria (much like a heterogeneous purposive sampling) prior to conducting any research based on the research topic and questions. I found a small number of people to interview based on the pre-set of criteria. After conducting initial interviews in a grounded theory study, I analysed this data. Based on the outcome from these initial interviews, I used theoretical sampling to choose new participants, modify interview questions and to add new data, as data collection progresses in order to generate theory. Through initial interviews, I analysed the interview data and scrutinised what data was needed to be obtained next and where it could be found in order to develop my research theory. This theoretical sampling was continued through moving back and forth between sampling, data collection and analysis, until I found data saturation to generate a theory.

Figure III Data Collection and Data Analysis

(As per Charmaz, 2014)



3.13. The Sample

In this section, I explain the demographic profile of the research participants. Six female participants were recruited for this study. Participants ranged in age from their forties to their mid-sixties. Four out of six left their jobs due to the disease, whereas the other two were working part-time at home, but were planning to end their jobs soon. Pseudonyms were allocated to each of the participants. Their short profiles are listed below:

Heaven is a forty-six-year-old lady. She has been married for eighteen years and has retired from being a technical assistant due to her disease. She has been suffering from the disease for the last ten years but she was officially diagnosed as having limited systemic sclerosis three years ago. She has been receiving treatment for the last fourteen months and considers herself, on a scale of 0-10 for the severity of the disease, to be 8 out of 10 (see Appendix F- Demographic sheet).

Tina is a fifty-eight-year-old lady. She has been in a relationship for the last ten years and worked as a freelancer at home. She has been suffering from the disease for the last six years but she was officially diagnosed as having diffuse systemic sclerosis five years ago. She has

been receiving treatment for the last five years and considers herself, on a scale of 0-10, to be 5 out of 10, moderate for the intensity of the disease (see Appendix F-Demographic sheet).

Juhi is a forty-nine-year-old lady. She has been married for the last nineteen years and worked part-time in her own farmhouse. She has been suffering from the disease for the last thirty years but she was officially diagnosed as having limited systemic sclerosis one year ago. She has been receiving treatment for the last nine months and considers herself, on a scale of 0-10, to be 7 out of 10 for the severity of the disease (see Appendix F-Demographic sheet).

Caroline is sixty-three-year-old lady. She has been married for the last thirty-one years and lost her job due to her disease. She has been suffering for the last ten years but she was officially diagnosed as having diffuse systemic sclerosis nine years ago. She has been receiving treatment for nine years and considers herself, on a scale of 0-10, to be 7 out of 10 for the severity of the disease (see Appendix F-Demographic sheet).

Lucy is a fifty-nine-year-old lady. She has been married for the last forty years and lost her job due to the disease. She has been suffering from the disease for the last eleven years but she was officially diagnosed as having diffuse systemic sclerosis six years ago. She has been receiving treatment for five years and considers herself, on a scale of 0-10, to be 9 out of 10 for the severity of the disease (see Appendix F-Demographic sheet).

Tania is a fifty-four-year-old lady. She has been married for the last ten years and was on sick leave. She has been suffering from the disease for the last two years but she was officially diagnosed as having limited systemic sclerosis three months ago. She has been receiving treatment for the last three months and considers herself, on a scale of 0-10, to be 10 out of 10 for the severity of the disease (see Appendix F-Demographic sheet).

Table II: Demographic Information						
Name	Heaven	Tina	Juhi	Caroline	Lucy	Tania
Age	46	58	49	63	59	54
Sex	F	F	F	F	F	F
Marital Status	Married for 18 years	Relationship for 10 years	Married for 19 years	Married for 30 years	Married for 40 years	Married for 10 years
Occupation	Retired as technical assistant	Used to as self-employ at home	Used to work in her own farm part time	Unemployed	Unemployed	On sick leave, plans to leave job
Year of onset of disease	10 years ago	6 years ago	30 years ago	10 years ago	11 years ago	2 years ago
Number of years since diagnosis	3 years	6 years	1 year	9 year	6 years	3 months
Type of Systemic Sclerosis	Limited Systemic Sclerosis	Diffuse Systemic Sclerosis	Limited Systemic Sclerosis	Diffuse Systemic Sclerosis	Diffuse Systemic Sclerosis	Limited Systemic Sclerosis
Duration of treatment under consultant	Last 14 months	Last 5 years	Last 9 months	Last 9 years	Last 5 years	Last 3 months
Severity of disease	8/10	5/10	7/10	7/10	9/10	10/10

3.14. Procedure

A scleroderma charity was contacted with a view to explaining the basis of this research so that participants could volunteer for the study. After gaining consent from the Scleroderma Society and ethical approval from DCPSYCH awarding bodies (NSPC and Middlesex University), six participants were recruited from the Scleroderma Society. They were then informed about the procedure of data collection in the study. An email was sent informing them of the level of commitment involved, her right to withdraw at any time, the method by which she would be interviewed and also issues concerning confidentiality and anonymity. When the participant had been fully informed and agreed to participate in the research, a consent form was given to her to sign. An appointment was arranged by e-mail (or other agreed method). The selected participant was involved in face-to-face interviews. The process included a 60-90 minute audio-recorded semi-structured interview (see Appendix G-Interview Questions) followed by a non-taped debriefing session which provided an opportunity for each participant to be able to express her emotions and ask questions about the interview. To help offset the risk of participants becoming distressed or upset, each participant selected for interview was provided with the Scleroderma support line number.

3.15. Data Collection

The fundamental aim of the qualitative research interview here was to elucidate the variability and individual experience of living with systemic sclerosis. The most widely recognised interview classification in phenomenological research is the semi-structured interview (Willig, 2013). I chose the semi-structured interview for this research because it allowed me some control over the course of the conversation; focus could be maintained on the relevant issues while allowing flexibility in the light of the content and processes that arise in dialogue with the interviewees.

The interview was a directed conversation (Lofland and Lofland, 1984, 1995); the interview allowing an in-depth exploration of the particular experience of living with systemic sclerosis,

and thus, was a useful way for interpretive inquiry (cited in Charmaz 2006). The in-depth nature of an interview encourages each participant to interpret their own experience. I sought to comprehend the topic and each research participant had relevant experience to shed light on it (Seidman, 1997, cited in Charmaz, 2006). Being a researcher, I asked the participant to explain and reflect on her experience in terms of what happens in everyday life.

For this grounded theory study, I asked open-ended questions and focused on interview questions in order to gain detailed information about the topic. Intensive qualitative interviewing fits grounded theory methods particularly well. Both grounded theory methods and intensive interviewing are open-ended but also directed, shaped yet emergent, and paced yet opened. Grounded theory methods involve the researcher organising data collection and analysis, and in turn, these methods provide researchers with more control over their data (Charmaz, 2006).

Grounded theory methods rely on a similar type of flexibility as in-depth interviewing. My aim was to understand what was happening right from the beginning of the research and try to follow predetermined ideas about what was happening in the field. Additionally, I sought other ideas through examining the data and then going back to the field and gathering focused data in order to answer analytical inquiries and to fill conceptual gaps. Similarly, the combination of flexibility and control intrinsic to in-depth interviewing methods fitted the grounded theory strategies in terms of improving the logical perspective of the analysis.

I chose questions with caution and used them to encourage the participant's reflections in order to explore, rather than interrogate (Charmaz, 2006). These questions are based on symbolic interactionism which focuses on exploring the participant's views, events, and actions. During the interview process, I also took on board certain things such as the participant's comfort level, their sitting position, the availability of water, tissues, and coffee, looking to their needs rather than just focusing on acquiring juicy data. Secondly, I paid attention as to when to probe and when not to and, in the meantime, tried to experience things

from the perspective of the participant's views and beliefs and ended the interview questions on a positive note by bringing the rhythm and pace of the interview back to a normal conversation level before ending the interview.

The interview was tape-recorded but I still took notes concerning key points during the interview, in order to stay on track and remember what I needed to ask next. Being a sufferer myself, I realised my own pre-conceived ideas and feelings concerning this disease and it was challenging for me during the interview to find a balance between exploring questions and forcing responses. Being an existential trainee, I focused on my participant's material and entered into my participant's world and adopted the phenomenological attitude during the interview. I suppressed my own thoughts and feelings during the interview, remained active during the interview and was alert to interesting leads (Gorden, 1987, cited in Charmaz 2006). I shaped interview questions in order to obtain richer material and, at the same time, suppressed my own preconceived ideas. During the interview, I allowed the participant to reflect on phenomena by giving prompts such as 'Tell me more?', 'How?', 'What?', and 'Why?' types of questions in order to obtain richer data. I realised that grounded theory methods worked well when you engage with the data collection as well as the data analysis. I attempted to understand the participant's meaning, intentions, and actions in order to produce the analysis using grounded theory methods and used this descriptive information to develop the theoretical statements.

During the transcribing of the interviews, I recognised how the participant's words were impacting on me. In order to deal with these issues, I wrote down in my journals and notes about my own experiences and then discussed this with my research supervisors. I also explored my experiences in my personal therapy which helped me to understand my own world and keep it separate from my participant's world. I was able to understand what the participant was sharing with me. I also realised that I was too preoccupied with what my next

question would be and as a result I was speaking loudly in order to achieve better voice quality.

3.16. Rigour

Rigour means to correctly use the appropriate research method and it is a vital aspect of the quality of research processes and outcomes (Ezzy, D., 2002, cited in Korstjens and Moser, 2017). Strauss and Corbin (1990) emphasised on enhancing rigour in grounded theory researches. In this study, rigour was found through assessing the credibility, transferability, dependability, and confirmability, as illustrated by Lincoln and Guba (1985).

Credibility means that the study should be a precise account of the participant's original data (Lincoln & Guba, 1985, cited in Korstjens and Moser, 2017). In this research, credibility was achieved through conducting interviews, analysing that data and writing research segments synchronously. In this way, the research continually reassessed the data to elucidate and validate categories.

Lincoln and Guba's (1985) study mentioned a second tenet of trustworthiness in a qualitative study which is transferability, meaning the results can be transferred to other settings and contexts (cited in Korstjens and Moser, 2017). To enable this transferability, I provided the descriptive data, so the reader could understand the phenomena being studied. This description intended to permit any future researcher to fathom what context could be relevant to their study. This study has the capacity of transferability in that the results can be transferred to other studies in other areas; for example, this study is based on people's experiences of living with one of the autoimmune diseases, systemic sclerosis, but the results also illustrated people's experiences with other autoimmune diseases, incurable diseases and life-threatening illnesses. This study model also increased the possibility that other researchers could review the suitability of transferring the study outcome to other settings.

Dependability focuses on the importance of a researcher recognising the varying context within which the study takes place (cited in Korstjens and Moser, 2017). This study intended

to scrutinise not only the varying context of the world in which the study occurred, but also the changes that happened during the period of study. Through the use of audiotapes, transcribed verbatim, I attained dependability and also re-evaluated the data as to its accuracy. The above three processes were utilised to establish confirmability by reviewing all analyses and procedures and verifying documentation during the research. After conducting a pilot study, I presented my analysis at placement settings and shared the experience in research groups, receiving feedback from the supervisor relating to the validity of the themes to their transcript. I continued in the process of checking and re-checking the data to ensure the correct path was taken during the course of the research. Confirmability was achieved through the confirmation of concepts with other participants through constant comparative processes.

It was appropriate to use the Glaserian criteria to assess the quality of the study and ensure it suited the elements of relevance, fit, workability and modifiability (Glaser, 1978, cited in Holton, 2008). Relevance refers to the applicability of generated theory to a particular field by recognising the main concern and covert behaviour used by people to sort out this problem (Glaser 1998, cited in Holton, 2008). Through this, professionals are able to understand the people's problems and re-examine their needs to use the service. The core category, with its sub-categories and core processes, were discussed with the supervisors and it linked with the literature reviews which confirmed that the framework was relevant across the disciplines, such as rheumatology, gastrointestinal, dermatology, oncology, neuropathy, heart and lungs, podiatric, vascular and other faculties, such as pain management, chronic illness and chronic fatigue.

'Fit' means how sufficiently the categories articulated the patterns in the data. These concepts and categories were derived directly from the research data instead of opting for it from literature reviews (cited in Holton, 2008). These categories were persistently compared and adjusted again and again until the emergent framework described all the discrepancies in the study and a theoretical saturation was reached.

Workability refers to the ability of theory that is not only described as the main problem with its resolving strategies in the studied phenomena, but also to interpret and predict what is going on in the data and what may happen now and in the future (cited in Holton, 2008). The current theory is to offer the understanding of the predicting attitudes about a person's experience of their illness.

Modifiability refers to reducing the need for testing and verifying because it can never be entirely right or wrong (cited in Holton, 2008). This current theory could be further customised by obtaining new data from more interviews, and exploring other issues, such as how the weather impacts on their experiences. This category could then be further integrated into the existing framework.

CHAPTER 4

FINDINGS

Data analysis is a process of dynamic dialogues between the researcher, interview, memo and other manuscripts such as observation and the reflective account (Creswell, 2007). It is an evolving process that takes place simultaneously with stages of data collection. Being a researcher, I focused on engendering the in-depth data to elucidate patterns, categories, properties and dimensions of studied phenomena (Strauss & Corbin, 1998, cited in Creswell, 2007). Grounded theories helped me to organise the data in a clear and concise fashion.

4.1. The Collected Data

The collected data highlighted two key subjects that were addressed in the research questions; the first addressed participants' experiences and the second explored their coping strategies. In two areas, data was also engendered on the impact on participants' lives, daily activities and existential crisis. To build new categories, I reassessed the recorded written transcripts again and again. I used some participant's narratives and text as an illustration in terms of representing meaning. I attempted to engage with data as much as possible in order to grasp the categorisation and used constant compared methods to make connections between researcher and research data.

4.2. Coding and Categorisation

The methodology utilised for data analysis was Constructivist grounded theory by Charmaz. I received supervision from an experienced researcher in Constructivist grounded theory and other qualitative research approaches. A verbatim record of interviews was required by constructivist grounded theory. Transcription therefore was the first step of my analysis. This process itself was a form of interpretative activity (Smith, Flowers and Larkin, 2013), as although it records every word spoken, it was reliant on my concepts of social interaction and non-verbal communication within the interview.

After the transcription of the first interview, analysis involved a close reading of the text two or three times. After reading it two or three times, I started the process of defining what that data are about, otherwise known as coding. Coding refers to naming segments of data with a label that simultaneously categorizes, summarizes and accounts for each piece of data. I tried to make interpretative rendering that begins with coding and illustrates the life being studied. Grounded theory coding acts as the backbone to our analysis, then these theoretical integrations gather these bones into a working skeleton and form the analytic shapes and build the analysis. Coding helps us to understand action and processes in the study and makes the crucial link between data and constructs an emergent theory to explain this data. Coding helps us to understand what is happening in the data and begin to grapple with what it means (Charmaz, 2006). Grounded theory coding consists of at least two main phases: the initial phase involves naming each word, line, or segment of data and the second phase is focused: a selective phase that uses the most significant or frequent initial codes to sort, synthesize, integrate and organize large quantities of data (Charmaz, 2006).

I am describing coding process to data analysis below:

4.3. Initial Coding

Strauss and Corbin stated initial coding as ‘breaking data into small parts and depicting concepts to stand for blocks of raw data. At the same time, one is meeting the criteria for concepts regarding their properties and dimensions,’ (Corbin and Strauss, 2006, p.195, cited in Creswell, 2007). Through this way, initial coding permits for an opening of the text by separating data into smaller components which are examined in detail and compared to discover similarities and differences.

In the initial coding, I remained open to exploring both the data and the theoretical categories. This initial coding helped later to define core conceptual categories. Through comparing data with data, I learnt what research participants viewed as problematic and began to treat it analytically. I attempted to observe actions in each part of data rather than applying any pre-

conception categories to the data. Initial codes are provisional, comparative, and are grounded in the data. They are provisional because I aimed to remain open to other analytical possibilities and constructed codes according to the data.

There are different types of initial coding such as word by word coding; line by line coding; and incidents to incidents coding (Charmaz, 2006).

4.3.1. Line by Line Coding

In the current study, line by line coding was commenced instantly after completion of transcribing the first interview. The whole interview text was read in order to grasp an overview about the participant's statements (Strauss & Corbin, 2008, cited in Charmaz 2006). The transcripts were initially coded manually and then, these codes were transferred to a computer file using Microsoft Word 2007. Manual coding was helpful to explore microanalysis and facilitated me to explore the data deeply and helped to assign codes to relevant lines at the same time. Line by line coding permitted me to make comparisons of new data with what was already coded (Glaser, 1978, cited in Charmaz 2006). The text was then separated into smaller components which showed themes, actions and interactions that were significant in coping to live with Systemic Sclerosis. These concepts were examined for similar themes and then bracketed together with these themes and allocated a high order label that led to category development (Strauss & Corbin, 1998 cited in Creswell 2007).

I chose line by line coding for my research analysis and labelled each line of my written data (Glaser, 1967, cited in Charmaz 2006). I considered line by line coding as an arbitrary exercise as not every line includes a complete sentence and not every sentence may appear to be important. I found line by line coding to be a useful tool for dealing with rich data. Line by line coding helped me to remain open to the data and to make differences in meaning, expressions and sounds. During the coding to the data process, I scrutinized data in order to grasp what participant had say and had struggled with. This helped me to find implicit

concerns as well as explicit statements and also guided her focus in later interviews with the next participants.

In order to do line by line coding, I initially broke down the data into its component parts and then defined actions and discovered tacit assumptions. To assess those assumptions, I went back to the field and verified with other participants. Coding helped me to develop theoretical categories. In addition, the constant comparative method was employed to develop and refine theoretically relevant categories in order to grasp abstract data into patterns or concepts through diverse groups and sub-groups. Constant comparison was practiced at several stages of data analysis, including the stage of coding and categorising. Moreover, I did constant comparison among meaning units and discovered remarkable similarities and differences among sections of text. This helped me to recognise the initial concepts to build a theory.

The early result of the initial coding was 102 initial concepts for participants' experiences and 38 initial concepts for participants' coping strategies (see Table VII). The previous concepts were continually compared to recognise similarities and differences, and to discover and create new categories. They were then organized on a separate piece of paper, and bracketed into one table to discern the emerging sub-categories (Glaser & Strauss, 1967, cited in Creswell 2007).

Table III INITIAL CODING: Line by Line Coding

Excerpt 1 *H.H, 46 year Old, Limited Systemic Sclerosis*

Deep muscles	It affects me in many ways. I've had quite deep
Pain in legs and arms, severe joints pains	muscle pain in my legs and arms; have severe joint
Pains in all body	pains in my fingers, wrists elbows shoulders and
Fatigue	neck, chronic fatigue which is slightly better since
Problem with swallowing, acid reflux	I've been on medication, problems with
Problems with cognitive process	swallowing, acid reflux. I have problems with
Small diffuse white matter	cognitive processing I've had a brain scan that
Psychometric Testing	shows small diffuse white matter so I've had
Hard to thought process	psychometric testing for that and although they've
Understand by doctors	said that it is mild and not associated to another
Difficult to remember or follow	disease, they understand that the impact is hard on
Struggle to have conversation	me to sort of process the way I used to thought
Difficulty to understand	processing if I was to read some instructions I find
Earlier losses	it difficult to follow or remember. I struggle to
	have a conversation with more than one person. I
	just can't keep up and I can't absorb things so I
	used to be able to do that one of the things I was
	good at was attention to detail. I used to work for
	the Fire Service answering emergency telephone
	calls and you had to be able to have a high degree
	of accuracy, react very quickly, be able to think
	very quickly so to lose that is really hard.

Some of the theoretical categories were found in my initial codes. Research participants' actions and statements reflected their world and sparked off new ideas to pursue. This line-by-line coding demonstrated that their disease has impacted on their way of being, not only physically but also psychologically. It also reflects their identity transition from an old person to a new person. They had been going through different treatment measures in order to deal with their problems (action) and they got support from medical professionals (social coping). Through initial coding, I kept separate data from categories and focused on processes and this helped me to understand and to explore further. Through this process, I was constantly refining my data and directed further inquiries early on in the data collection. During the initial coding in grounded theory, I also used 'constant comparative methods' to make analytic distinctions at each level of the analytic work. I compared data with data to find similarities and differences. Firstly, I juxtaposed interview statements and incidents within the same interview, and then I did compare the same thing in different interviews when I was conducting interviews with other participants. During the initial coding, I focused on research data through the participant's eyes rather than basing it on my assumptions. Through initial coding, I fulfilled two criteria which are required to accomplish a grounded theory analysis. These two criteria are fit and relevance. In term of Fit, I found my study fit the empirical world when I constructed codes and developed them into categories that crystallize participant's experience and in term of Relevance, I presented an analytical framework that explained what is happening and builds a relationship between the implicit processes and structures visible (Charmaz, 2006). By examining the data, I was able to make fundamental processes explicit, and made hidden assumptions clear, and gave participants new insights.

In the first stages of analysis, coding is mostly descriptive and these labels are affixed to discrete illustrations of phenomena. As coding move forwards, I was able to recognise high-level categories that analytically incorporate low-level categories into meaningful units. After

developing 102 initial concepts and 38 coping strategy concepts, I allocated them into incidents, events, and actions within the data that were perceived as indicators of studied phenomena. These concepts were gathered for the same themes and grouped together to allocate the high order label in order to initiate category development (Strauss & Corbin, 1998, Creswell 2007). The total initial codes were 140. Out of 140 initials codes, 102 initial codes were based on experiences of living with Systemic Sclerosis and 38 codes were based on coping strategies. I made 23 high order categories of 102 initial concepts and 5 high-order categories of 38 coping strategies concepts. Below, I would like to describe these 23 high-order categories for experiences of living with Systemic Sclerosis and 5 high-order categories for coping strategies (see Table VII for 140 Initial codes). See Table IV below:

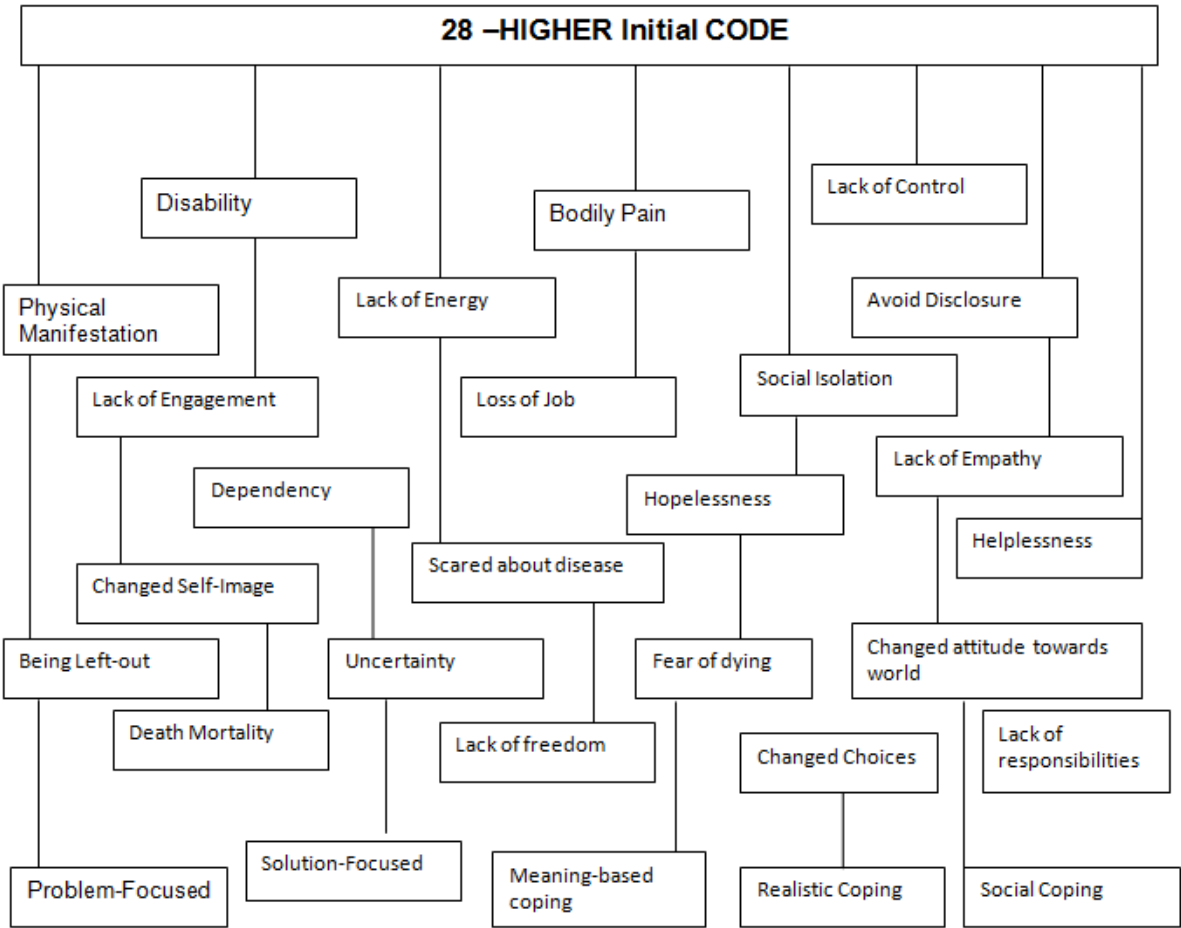


Table IV: 28 Higher Initial Code

Below are 23 high order categories of 102 initial codes (see Table VIII Initial Higher Codes):

4.3.1.1 Disability

Participants with systemic sclerosis talked about their experiences in terms of difficulties with doing household work such as changing bed sheets, cleaning and scrubbing floor, cooking, scrub floor, cooking, dusting, washing up, difficulties to lift mattress, bottles and heavy things, difficulties to cut vegetables due to lack of hand grip, difficulties to use washing powder due to skin problem, difficulties to grip things, chop, carve, touch things out of fridge, frozen thing; restricted moments such as difficulties to bent down such as tie shoes lace, unable to do gardening, difficulties to get in and out of bed, difficulties to open jars, tin opener, open bottle caps, screw things, difficulties to do shopping such as unable to holding bags in hand, difficulties to drive due to eye dryness, unable to hold weight due to lack of hand grip; difficulties to dress up such as changing clothes, bra, socks, to do button and zip in and out, difficulties to wear electric gloves due to its weight, difficulties to wear jewellery, difficulties to make hair, difficulty to take on and off socks, difficulties to take shower, hard to use keyboards due to ulcers, difficulties to go outside due to Raynaud's and ulcers, deformities of fingers, unable to arm up and to do walk, troubling to get in and out of bath etc; cognitive problems like having brain fog, difficulty to find words, slow in thinking and movement, difficulties to concentrate and understand things, indecisive, forgetting things, functioning difficulties, not sharp cognitive abilities; and depending on others to do daily tasks. I made each code as part of higher order category known as disability.

4.3.1.2 Bodily Pain

Participants with systemic sclerosis expressed feeling dreadful fatigue, pain, body swelling and stiffness; a painful body such as aching muscles and joints, headaches, body ulcers, scars, neck pain, abdominal pains, feeling cold and breathlessness; painful to do any tasks; tense on

body and painful for undergoing investigation. I allocated each code into higher order category known as bodily pain.

4.3.1.3 Physical Manifestation

Participants with systemic sclerosis who suffer from Raynaud's problem; loss of weight; insomnia; stomach problems such as burping, indigestion and refluxes; swallowing problem; abdominal distress; sore throat due to reflux; other complications of disease such as deficient nutrients as low vitamin D and anaemic, right knee injury, hypertension, getting neuropathy, cough, infection, high blood pressure, fever, Sjorgen disease, heart palpitation, thyroid, sudden flare up of disease; skin problems such as red spots, bad complexion, facing tightness, thin skin; feelings breathlessness; body stiffness and joint and muscles problems, Bodily appearance changes such as deformities of finger, mouth getting smaller, face stiffness and tightness, puffiness in hand and body, ulcers in hands and feet; skin tightening, lip worse, bruises in body, swelling joints, fatty finger and hand; toothache; headache; lack of flexibility in body. I assigned all of these codes into one high-order category called physical manifestation.

4.3.1.4 Lack of Control over Body

Participants with systemic sclerosis expressed lack of control over body such as cognitive problems like having brain fog, difficulty to find words, slow in thinking and movement, difficulty to concentrate and understand things, indecisive, forgetting things, not sharp cognitive abilities; side effects of medication problem; lack of sexual desire; getting worse disease with time; lack of control over disease such as loss of under arm hair, thin hair, difficulty to weight loss, breathing issues, living with pain; sleep problem due to disease. All of these initial codes converted into one high order category known as lack of control over body.

4.3.1.5 Lack of Energy

Participants with systemic sclerosis expressed lack of energy such not have enough power to go outside; to do anything; force to do certain things due to pain; breathlessness issues during any things; tiredness during household work; when go outside; playing with grand children; to have sexual relationship. I gathered all of these lower order categories into high one known as lack of energy.

4.3.1.6 Job Loss

Participants who are living with systemic sclerosis that have lost their job due to difficulties with work and suffering symptoms such as ulcers and body pain; struggling to continue work or taking extra time to complete work due to pain, getting worse if continue with work; avoiding disclosure about disease at job; took off from work due to health getting worse and loss of jobs. I gathered all these initial codes into higher-level categories known as job loss.

4.3.1.7 Lack of Engagement with Family

Participants living with systemic sclerosis have suffered lack of engagement with family due to a lack of understanding by others including husbands, boyfriends, family, friends etc; lack of contact with family members including parents, children, siblings and others; lack of support by others including family; lack of sexual desire due to disease. All of these lower-level categories were accumulated in to higher one called as lack of engagement with family.

4.3.1.8 Avoid Disclosure

Participants with systemic sclerosis feared disclosure of their illness and tried to avoid disclosure including fear of disclosure about illness in social gatherings such as alert to sit at job, disclosure about illness in winter if they take off gloves, avoiding meeting with others, avoiding use of a stick in public places, fear of being noticed by others such as using sticks or

scooters and their sitting positions, difficulties to go in social places. I gathered all these lower-level categories into higher-level category known as avoid disclosure.

4.3.1.9 Social Isolation

Participants with systemic sclerosis experience social isolation including lack of social relationship with others including friends and colleagues, withdrawal from relationship; lack of social contacts (social withdrawal) from social activities such as outing, go outside and gym and dancing club, hosting parties, avoiding to go outside and meeting with friend and others; difficulties to go in social places due nature of disease such as restricted movement; fear of social stigma to get government support; trying to ignore others to avoid feeling of embarrassment; unable to do shopping due to restricted movements; embarrassing to eat food in restaurant due to swallowing issues; lack of engagement with others including doctors; avoiding to interact with people due to changed in appearance and disease manifestations, fear of judging by others due to restricted movements or using aids to walk; staying at home to avoid disclosure about their disease to others. All these lower-level categories turned into higher-level category known as social isolation.

4.3.1.10 Lack of Empathy by Others

Participants with systemic sclerosis experience lack of empathy by others such as lack of empathy by others including friends, parents, colleagues and others, lack of response by friends, doctors and others; feelings of rejection by others such as nasty attitude of others, doctors, judging by others; lack of empathy by friends and other people; lack of understanding by husband, family, siblings and work colleagues and lack of communication with professionals. I transferred all these initial codes into higher-level category known as lack of empathy by others.

4.3.1.11 Dependency

Participants living with systemic sclerosis are dependent on others to do daily tasks such as difficulties with shopping; dependent on husband, family and others to do daily tasks; financial issues due to loss of job; fear of burden on partner; fear of being catered by another person and being a caged animal. I assembled all these initial codes into category 'dependency.'

4.3.1.12 Hopelessness

Participants living with systemic sclerosis experience hopelessness including experiencing a lack of sense or meaning; hopelessness including not having old goals, no cure, about their future, loss of hope to live longer; sadness and no hope for the future, feelings of despair including no hope for future, sadness in not getting support by children, lack of satisfaction with life, feelings of disappointment by friends; feeling of lonely; helplessness to experience pain; No want/wish to live with disease; feeling of depressed to have disease due to restricted movements and own limitation due to disability; lack of positive attitude towards life; feelings of frighten by being vulnerable, ill and dependent; feelings of depressed due to side effects of treatments. I collected all lower-level categories into higher-level category known as hopelessness.

4.3.1.13 Helplessness

Participants living with systemic sclerosis experience helplessness due to feelings of frustration about disease; loss of independency; feelings of being annoying and dependent on others to do daily tasks, annoyed by limitations due to disease; feelings of helplessness such as pain, out of control, no better for treatment, having to use socks aids, disease out of control, weight gain, not having old goals more, lack of sleep, cognitive problem; feelings of depress due to side effects of medication; feelings of sad to know about incurable, frustration on side effect of medication, on being dependent on others; on change in appearance, on super-power

existence and due to lack of understanding by partner; feelings of helplessness to live with incurable disease; feelings of overwhelmed and stress due to lack of control over disease including fear of passing out; feelings of powerlessness such as weak, fiddly to wear jewellery; worry about financial issues; perceiving themselves as caged animal; fear of being catered by other person and fear of living with disability. I gathered all lower-order initial categories into higher one known as helplessness.

4.3.1.14 Being Scared about Disease

Participants living with systemic sclerosis felt scared about the disease including feelings of strangeness due to the disease including undergoing investigations, fear of invasive investigations, feels disgusted to have ulcers, awful about disease, upset by use of stick, red spots on forehead, feeling bad due to parent's concern, feelings of vague due to disease, scrambling words due to weakness, feelings of petrify; anxious about consequences of disease such as fear of ending up with wheel chair, fear of finger loss due to digital ulcers, fear of getting worse such as stomach problems, blood pressure, ulcers, lungs issues, concern about mental health issues due to disease, nightmares to loss tooth; fear of living with disability; feelings of being overwhelmed and stress; feelings of nuisance due to disease; low self-image, feelings of hypochondriac and feelings of robbed. All these lower-level categories were assembled into one higher-order categories known as being scare about disease.

4.3.1.15 Changed Self-Image

Participants living with systemic sclerosis experienced changes in self-image such as changed sense of self, feeling like a hypochondriac, feeling useless and not able to have sexual relationships, awful to depend on others, snappy person, quick-tempered, less tolerant to stand in a queue, feeling demoralized for depending on others; mood swing such as angry to stand in queue, feelings of nuisance on changed body image, self-pity and worthless life; loss of self-confidence due to cognitive issues, changed self-image and changed in self-identity; feelings

of useless due to not fulfilling responsibility as a wife and mum, changed outlook towards life and not more doing previous goals; lack of satisfaction with life and lack of sexual desire; changed in appearance such as dreadful hand and skin, perceived themselves as an ugly mouth, eye, skin, look like scruffy by wearing layers of cloth; fear of losing teeth, hate self when look in mirror, weight gain, no find self attractive more and fatty hand; changed self-image such as perceived themselves as caged animal, perceived themselves as an old woman due to use of sticks or aids, feelings of embarrassing to use sticks in public places, lack of in trust in things, feeling of robbed by disease; feeling of worry to getting old including using sticks, and socks aids and fear of getting other illness such as hypochondriacs. These entire initial lower-level categories were transformed into higher-level category known as changed self-image.

4.3.1.16 Being Left-Out

Participants experience being left out due to living with systemic sclerosis. This higher- level category 'being left out' was made up through assembling initial lower-level codes such as lack of understanding by partner and friends and doctors; depressed about having disease and its consequences, such as loss of job, loss of independency, feelings of being left out due to social isolation, staying at home, lack of empathy from others, feelings of loneliness in presence of partner support; sadness due to lack of sexual desire; loss of trust on super-power existence; feeling of loneliness such as staying at home, avoiding to share with them, scary to go social places, feelings of nuisance to go out of house, feelings of burden on others, feelings of shame to get support from govt, avoiding use stick in public place, feeling of embarrassment when people noticed red spots, using sticks, feeling of shame to eat in outside due to digestive issues; feelings of awful by asking help from others and lack of motivation to go outside.

4.3.1.17 Uncertainty

Participants living with systemic sclerosis expressed uncertainty, including worry about the outcome of the disease, a worry of getting old, fear of getting worse from disease in future; unknown anxious such as thinking about severity of the disease before dying, a shortened life, unknown about causes of disease, concern about future including outcome of disease and financial management, fear of unknown about disease and unknown about changing choices; trying to find answers to have flare up again; trying to get answer such as why not to have sexual drive, why having this disease and trying to get unknown future; unknown about causes of disease and about body change and thinking about own mortality after disease. All these lower level categories were assembled into higher one category called as uncertainty.

4.3.1.18 Fear of Dying

Participants living with systemic sclerosis experience fear of dying due to disease mortality rates. Participants reported fear of dying including nightmares, death terror nightmares, dying with pain, concern about lungs deterioration and dying earlier than expected. I collected all these codes into one category known as fear of dying.

4.3.1.19 Changed Attitude Towards World

Participants living with systemic sclerosis experience changed attitudes including changed attitudes towards the world such as finding the world horrible, finding the world as a threat, seeing the world as temporary and smaller; changed attitudes towards life such as temporary and short. I assembled all these codes into one category called as changed attitude towards world.

4.3.1.20 Embracing Death Mortality

Participants living with systemic sclerosis experience death mortality fears including confronting mortality and accepting the reality of death. I converted these codes into one category know as embrace with death reality.

4.3.1.21 Lack of Freedom

Participants living with systemic sclerosis experience lack of freedom including lack of control over the disease such as destiny, weight gain, disease symptoms; and side effects such as light-headedness; feelings of loss of control such as loss of independent, dependent on others for small things, feelings like a caged animal, feelings of trapped by disease, feelings of robbed by disease; lack of freedom such as to dress up, to choose and do what want, restricted life to do; restricted life to travel due to illness such as difficulty to do shopping, lack of freedom to go outside, unable to go out own such as visiting friends, boundaries to travel due to disease, bounded at home; loss of financial freedom such as limited money, worry about financial issues as a freelancer and financial dependent on others. All these lower-level categories turned into higher-level category known as lack of freedom.

4.3.1.22 Changed Choices

Participants living with systemic sclerosis experience changes in choices due to nature of disease. I constructed a higher-level of category 'changed choices' by assembling lower-level categories including loss of control over disease, feelings out of control and unable to approach medical doctor; changed choices such as not liked to wear layers of clothes before but they have to wear now due to disease; loss of freedom to choose and do what want; change like and dislike; changed priorities such as more focused on family and friends, used to do things a lot for future before but now living one day to next day, not more walk to dogs as they liked before and use computer now that dislike before.

4.3.1.23 Lack of Responsibility

Participants living with systemic sclerosis experience lack of responsibility due to their disability. I transformed these initial codes such as reduced responsibilities in being a mother, wife, daughter, friend and lack of ability to care for dog; dependent on others for small things and unable to take charge of anything such as financial responsibility; loss of job; feelings of

useless due to not fulfilling their responsibilities; changed role and responsibilities into one high-order category known as lack of responsibility.

I made 5 higher-order categories out of 38 initial codes of coping strategies (see Table VIII Initial Higher Codes).

4.3.2.1 Problem Focused Coping

Participants used problem-focused coping to deal with their experiences of living with systemic sclerosis. Problem-focused coping includes initial codes of other strategies such as seeking professional help, including scleroderma society help, physiotherapy and from an occupational therapist; using treatment measures such as Investigation Blood test, Illoprost treatment, x-ray and lung function test and more test to monitor organs, barium test etc to rule out problems; self-help by taking supplements such as vitamins and magnesium oil, bandage to knee erupted and self-monitoring; trying to get better with medications to treat infection, control blood pressure, pain, stomach problem, chiropractor to reduce stiffness, stomach problem; finding different ways to deal with disease such as using own strength to cope, avoiding stress, alerting during taking bath to avoid fall slip, having rest to manage tiredness, taking rest intervals during household work as to deal with pain and tiredness; getting help by pension for financial issues; thinking of Dignitas if disease get worse to avoid resuscitated etc. I added all these participants' strategies into one higher-level category known as problem-focused coding to deal with their issues.

4.3.2.2 Solution-Focused Coping

Participants with systemic sclerosis used solution-focused coping to deal with their problems and to manage daily living tasks. The solution-focused coping included other strategies such as managing emotions - sadness, annoyance, loneliness; and expressing feelings by crying, walking out, sharing feelings with husband to deal with sadness, frustration, depression and sadness, try to ignore other people attitude, read books to change mind of being ill, dependent and vulnerable, watching TV, using meditations and using mindfulness to seek hope, reduce

anxiety and feel better; finding different ways to clean home such as asking help by others, manage to clean floor by lying on it, getting thinner matters to change bed sheet, using tools to clean home such as using clothes, steamer, separate hover for each floor; using different ways to change duvet such as 'lay it flat and shove its corner'; trying to divide task to reduce pain; trying to do things one at one day; finding different ways to work in kitchen such as asked help by family, use brisky mixture in kitchen, finding other ways to cook meal, open jars, use hand mixer as tool, use big knife to grip hand, finding other ways to clean dishes, use food mixer as a tool and using dishwasher to wash dishes; different ways to do shopping such as asking help by others, using trolley for shopping, carrying shoppers in arms as managing, using backpack to hold things and bags with wider shoulder strap during shopping, hanging bags to trolley and to hold things to forearm for shopping; wearing gloves to hold trolley for shopping and to lean on trolley to feel relax; using different ways to open jars/bottle cap such as asking help by others and using rubber cap to open bottles; using different ways to screw up, using ring pull can to open and to buy little bottle to lift; using different strategies/resources to manage reflux such as half brick under head and legs, using extra pillows to control reflux, walk to control reflux, try to eat dry biscuit to control reflux, avoiding to take large meal before sleeping, change diet, drink water to swallowing food, using electric beds, changing diet plan and sitting up in bed to control refluxes and sleep in up to control refluxes to manage stomach symptoms; wearing gloves to deal with Raynaud's when outside home, wearing warm clothes, moving to warm places; using silver and electric socks, thick woollen socks, sheep skin sleepers, using ski gloves and using heating pads for foot and hand when go outside; using heater to avoid cold at home, finding different ways to manage pain such as pain killer, taking medications, get relax by taking hot bath, get help by warm shower and using hot tub to relief pain, swimming three times a week help to flexibility, joining health club, getting relax by staying at home, using memory foam to reduce muscular pain, laying on back, using soft pillows; exercising distraction strategies such as listening

music, exercise to deal with sleep problem; other ways to manage the disability such as asking help by others, took off from work to take rest, getting help from rehabilitation to splints on hands, to use bath chair, renovating home according to disability needs, finding other ways to get in and out of bath, finding twisting ways to get dress up, to use socks aids, prefer to live in Bungalow as to avoid stairs up, to use electric chair to bath, to use physical adaptations to drive car such as steering and electric brakes, to use long straps to dress up and wearing stretchy clothes and avoiding to wear clothes with zip, use stick and scooter to deal with disability, getting financially support from government; different ways to cope with visible symptoms of disease such as use cream to cover red spots, try cover red spots with makeup, dressing like scarf's that covers spot, use nail paint to look nice hand, try to cover red spots on forehead by hair. I transferred all these lower-level categories into higher-level category called 'solution-focused coping.'

4.3.2.3 Meaning-Based Coping

Participants with systemic sclerosis used meaning-based coping strategies to deal with their disease and to motivate themselves such as adopting a positive attitude towards the disease, thinking positive and view changed appearances as normal progression, using medicines to cope with side effects; feeling lucky to count blessing such as to have disease in middle age instead of suffering in young age, and getting professional help and treatment, supportive partner; not getting worse disease at the moment; not having ulcers for finger loss; to have own property and living in a nice place; getting pension for financial support; not having habit of extra-vagant; able to use adaptations to do shopping; family support; skin getting improve through medications and other blessings; seeking meaning from religion, getting source of meaning to work in charity, grand children, through their work and partner, trying to find out new goals, getting internal support from being Christian and religion values of love to friends and family; gaining satisfaction from beautiful sunrise, enjoying morning, to enjoy nature beauty such as birds, butterflies and taking care of animals; finding different ways to get

courage such as from grandfather and soldiers who were in WW1 and from other who have severe disability and constant pain whole life; getting courage to know about cure of other disease and making hope for cure, knowing own power; getting motivation by GOD to alleviate disease; self motivating through work; getting motivation from grand children, getting happiness by grand children, warm weather and sunshine and being in good company; trying to figure out about disease and its consequences through investigations and problems and putting weight due to side effect; using humour to cope with disease such as laugh etc; trying to make sense of experience such as understanding own limitations due to disease; understanding own values of life and others such as empathy for others, to learn to values for self and life, motivating others, helping other to focus on positive things, hope for future not much affected by disease, recognise important to health, understanding other with illness, learn more tolerant for other people, understand life is precious, value life more, guide other not to read on internet, help other to understand disease and encouraging other to have hope. I assembled all these lower-level categories into higher-level category 'meaning-based coping.

4.3.2.4 Social Coping

Participants with systemic sclerosis used social coping to deal with their disease. Social coping included strategies such as being supported by others to hold and lift things such as shopping, and getting support by scleroderma helpline, siblings, friends including making new friends, family, children and partners to do household tasks such as prepare meals, taking bath, dress up, get in and out of bed, lifting object, open jar, clean up home, to shopping, getting out of bath, dressing up such as tie button, buckles, socks, wear jewellery, to stairs up, sharing feelings etc, motivated by a partner; relaxing by going to the cinema; going to warm places for holidays; tried to ignore other people comments; using humour to cope with disease in social world; All these lower-level categories gathered into one higher-level category 'social coping.'

4.3.2.5 Realistic Approach

Participants with systemic sclerosis used realistic coping strategies to live with their disease such as acceptance disease; getting more information about disease through accessing internet, leaflet, reading forums to discuss sharing pain; worries about outcome of disease after listening other's pain in forums; using scleroderma helpline to get support etc; accepting death mortality; confronting with awareness own limitations due to illness; trying to make sense of the disease; trying to be realistic and accept the loss of sexual desire and other impacts resulting from the disease. All these initial codes were put together into one category known as realistic approach.

4.4 In Vivo Codes

Grounded theorists mostly refer to codes with participant's special terms as in vivo codes. Their specialized words give a useful analytic point of departure (Charmaz, 2006). These in vivo codes enabled me to keep the participant's interpretation of their views and actions within the coding itself. I made in-vivo coding to data using two types of in-vivo codes and flagged general terms as in-vivo codes which are used by participants but have significant meanings and also flagged up the innovative words that captured significant meanings and experience. In this study, Participants used 83 in-vivo codes (see Table IX). 18 out of 83 codes are innovative codes that contain specific meanings and experiences for the participants (see Table X). In vivo codes are when the important words or group of words (usually verbatim quotes from participants) are themselves used as labels, whilst categories are groups of related codes. Categories are referred to as "theoretically saturated" when new data analysis returns codes that only fit existing categories, and these categories are sufficiently described in respect of their properties and dimensions (Charmaz, 2006).

I would like to describe the innovative codes that were used by research participants during interviews that held specific meanings and experiences for them: Here are the innovative codes that are used by first Participant:

4.4.1 Grieve

First participant used the term ‘grieve.’ In general, we understand its meaning as a greater sadness to loss of someone else. But participant consider ‘grieve’ as referring to the life she currently has, she has lost her previous life that she used to be spent and experienced a lot of sadness and depending on others for daily tasks and the consequent loss of her job because of the disease and disease has changed her sense of self.

Below are verbatim quotes from the first participant transcript that showed the in-vivo codes:

“I understand its part of the process I think, like grieving isn't it, it's sort of grieving for, for the life, the person you've, you feel like you've lost, but then it, it, I know I have to go through that process but I don't want to be in that process too long, I want to move on to acceptance.”

4.4.2 Self-compassion

Participant used the word ‘self-compassion’ which meant getting internal support through feeling self-compassion: a lot of people struggle and tell themselves that it is not their fault if they have illnesses and to understand that it is not something that they have brought on themselves. It gave me more of an idea of choice and emphasised that they did not chose to have this kind of disease.

Below are verbatim quote from first participant transcript:

“What I'm learning to do is, is feel self-compassion, which is something that I think probably a lot of people struggle with so, I think by stripping it back and doing, and feeling self-compassion you can then look at sort of I think.”

4.4.3 Rewarding

Participant used the words ‘rewarding life’ which to her means having rewarding relationships in terms of friends who are no longer in left her life and have been really supportive to her. Her goals are to find some work that is rewarding-to help others and just to try and live as rewarding a life as possible. She wants something that gives her identity and perceives herself as a worthy person and achieves positive things for her life.

Below are verbatim quote from first participant transcript:

*“My goals are to find some work that is rewarding,
to help others and to just to try and live as rewarding
a life as I can and then I don't really have all the goals
we had before.”*

4.4.4 Boom and Bust

Participant used words ‘boom and bust’ that means many health conditions oscillate their symptoms, in one time it is in control and another time it is out of control. It’s like participants experience the sudden flare up of the condition. One day participant can be very active and do tasks and feel less pain in the body but other days the body rejects even simple tasks. It is a cycle of crash and a need to take rest for recovery. This process not only impacts on physical ability but also impacts on emotional wellbeing and moods swing from pleasure to disappointment and to her this means working on her beliefs and thought processes and to trying to cope with changes but she didn’t find it necessary to always be positive due to the psychological aspect of the disease and to give herself time to sort of rebuild and again go to slow down and push herself.

Below are verbatim quote from first participant transcript:

*“To give myself physically the time to sort of rebuild...to
really slow down because I always used to push myself so
I was just doing the boom and bust.”*

4.4.5 Devastated

Participant used the word ‘Devastated’ which means ‘destroying’ or an extremely painful experience. Participant used this word to express her feelings when she first time came to know about her disease and found herself baffling at that moment and not able to understand what it actually was. Participant expressed her shock to hear about her diagnosis and scared to know about her future. It was the participant’s way to express her pain and how this disease may destroy her.

Below are verbatim quotes from first participant transcript:

“I was devastated really erm confused didn't understand what it meant erm I read the literature I was given rather than going onto the internet and looking for the worst case scenarios it's very difficult to not think the worst so yeah it was it was scary.”

Here are innovative codes that are used by second Participant:

4.4.6 Battle

Participant used term ‘battle’ to express her experience of living with systemic sclerosis. To battle means to gain control of something, an encountering between two things. In terms of participant’s experience of living with systemic sclerosis, participant used this word ‘battle’ to express her struggle to deal with symptoms and new symptoms. It is like on-going process as participant tried to manage disease symptoms but with addition of flares ups of disease, she found this more stressful to cope with.

Below are verbatim quote from second participant transcript:

“New things happen like now I'm starting to get peripheral neuropathy and more things start to happen like twitching muscles, tingling in my hand and my feet and it's, it's just more things crop up so they send you back to that really scary place again so you have to battle with that I had quite a while about three years.”

Here are innovative codes that are used by third Participant:

4.4.7 Fear of choking

Participant used words ‘fear of choking.’ Generally, fear of choking is related to anxiety and panic symptoms but in this case, participant has fear of choking due to the disease’s impact of gastrointestinal symptoms. It gives the sense of the participant’s fear of dying as well as consequences if she has bad reflux in her stomach that lead to a fear of choking, the participant talked about the loss of a friend due to choking issues. She tried to manage this with medication but is still anxious about even worse consequences from the disease in the future.

Below are verbatim quote from third participant transcript:

“It’s a fear of choking I suppose one of the other things that I haven’t discussed is erm we have very specific needs you and I, we have very specific needs and as long as those needs are understood our lives can be more manageable so water with drinking exactly not lying down flat one of the things that scares me.”

4.4.8 Out of Control

Participant used word ‘out of control’, meaning not able to manage more and unable to recognise her limitations due to bad reflux. Participant has massive fear of choking due to reflux, this is what she terms as out of control and accepts her limitations as being a human, but she feels frightened that being out of control makes her weak.

Below are verbatim quote from third participant transcript:

“If I have a bad episode of reflux because you’re just so out of control, fear, yeah this panic, lack of control, where you know if you’ve got, constantly got fluid coming up and you just can’t stop it”

Here are innovative codes that are used by fourth Participant:

4.4.9 Nuisance

Participant used this term ‘nuisance’ to describe her feelings of annoyance and irritation in having this illness and how this disease has changed her sense of self and compelled her to do those things that she disliked before and restricted her to stay at home.

Below are verbatim quote from fourth participant transcript:

“It’s changing a lot it’s a nuisance because to get out the house I’m just so slow and slow in thinking, you’re constantly fiddling it is a nuisance, It’s a nuisance to wear layer of clothes and nuisance to change body image etc.”

4.4.10 Fear of Being Catered by Other Person

Participant used this term ‘fear of being catered for by another person’ to describe her feelings of living with this disease. She accepted her death reality but does not want to live the rest of life depending on others for small things. She talked about her concern of being catered for by

another person as she used to work as a carer for others. But this disease swapped her role from being carer to being cared for only by her partner and no other carer services.

Below are verbatim quote from fourth participant transcript:

*“Well you're going to die anyway, there's nothing you,
you have the fear of being catered by other person I wouldn't
like to be cared for because that, that's basically because I've been
a carer and had to care for people.”*

Here are innovative codes that are used by fifth Participant:

4.4.11 Feeling of Robbed

Participant used this term ‘feeling of being robbed’ which means stealing something by forcing or without will. In terms of participant, she felt that this disease had taken everything away from her and robbed her of life without knowledge or permission. She felt the disease was robbing all of her life, wishes, desires and dignity, leaving her feeling only helpless and trapped, unable to escape from this unwanted experience and just left with feelings of resentment. She felt that someone entered her life without her permission and took everything away from her and left her alone.

Below are verbatim quote from fifth participant transcript:

*“I feel like I've been robbed I've worked all my life...now
you can see how it affects me! I feel robbed I never thought
I was gonna do this! I haven't got because you were robbed
of it I'm going to die sooner than I would have done and that
makes me robbed.”*

4.4.12 Hypochondriac

Participant used this term ‘hypochondriac’ to describe her physical symptoms due to the disease. This disease is not limited to one part of the body, it is a systemic disease, so involves all parts of the body and people with this disease have unexplained symptoms. She feels these unexplained symptoms indicate she may be a hypochondriac, which psychological symptoms are resulting from anxiety where people complain about physical symptoms due to no reason.

She feels a lack of understanding in her symptoms by other people and a fear of being judged and rejected by other people and perceived as self-obsessed.

Below are verbatim quote from fifth participant transcript:

*“Stiff joints, painful hands, painful feet, erm, tightness of skin,
depression 'cos not knowing, erm, reflux, being sick,
it's trying to remember them all isn't it! [laughs] sound
like a hypochondriac!”*

4.4.13 Caged Animal

Participant used term ‘caged animal’ to describe her feelings of living with systemic sclerosis. Her words being like a ‘caged animal’ gave sense of a place where she does not want to be. It’s like loss of freedom, feeling trapped and nowhere to escape. She feels helpless and bounded by her disease. This is what she could not control and having limitations to fly from this position. Her comments showed her helplessness over the disease, how her disease has snatched things from her, including her independent life. She depends on others to do daily tasks and has to wait for someone else if she wants to pursue something. It’s like she needs others in order to fulfil her wishes and sometimes, not being able to express what she wants at that particular time. Being like a ‘caged animal’ shows that she is restricted to live her life.

Below are verbatim quote from fifth participant transcript:

*“I feel like a caged animal, I feel trapped,
really angry on depending on others.”*

4.4.14 Live Each Day as It Comes

Participant used these words ‘live each day’, meaning dealing with things as they come rather than making plans for the future. Participant made plans to focus on the present and to live fully, instead of delaying plans for the future. Participant used this approach to deal with the disease on daily basis. It means dealing with illness by taking it one day at a time, not creating future plans but doing ordinary pursuits as the future is uncertain. For most people, living one day at a time tacitly acknowledges their fragility.

Below are verbatim quote from fifth participant's transcript:

*"I have to live each day as it comes 'cos I don't know
what tomorrow's gonna be like live each day as it comes,
'cos every day's different isn't it, every day you never know
how you're going to feel, when I'm feeling good and the
sun's shining, I want out, I want to go out."*

4.4.15 Vulnerability

Participant used the word 'vulnerable' to express her experience of living with systemic sclerosis. Being vulnerable means to be physically and emotionally wounded. She feels weak due to the physical impact of the disease and causes her frustration due to being dependent on others for little tasks and due to lack of empathy from others. She has vulnerability due to the disease.

Below are verbatim quote from fifth participant's transcript:

*"Being vulnerable, being ill, being dependent
take away courage and frightened me."*

4.4.16 Knock-On Effect

Participant used the term 'knock-on effect' to express how one symptom of a disease is related to other symptoms. Participant living with systemic sclerosis experiences physical symptoms such as pain and fatigue, which then trigger the psychological symptoms such as frustration, depression etc.

Below are verbatim quote from fifth participant's transcript:

*Pain erm, not being able to do things, frustration
[sighs] depression, see they all have a,
a knock-on effect don't they?*

Here are innovative codes that are used by sixth Participant:

4.4.17 Demoralized

Participant used the word ‘demoralized’ to express her feelings of living with systemic sclerosis. Being demoralized means to be upset due to the destruction of being able to function normally as she was used to. Participant feels that it is an incurable disease and it is scary to live in this way for rest of her life. To live with this disease made them anxious and uncertain for future.

“I do find it a bit demoralizing when I got to spend every day like you know, with it hurting like this, is that what it's like for the rest of my life now.”

4.4.18 Taken for Granted

Participants used this phrase ‘taken for granted.’ Participants expressed their lesson that they learned from this experience. They realized how they used to underestimate their life values and did not use their life as they’d wished to use it. Through getting this illness, they are able to understand their life values and start to live for now, instead of delaying their life goals for tomorrow. Having taken life for granted, participants felt guilty about not having to think about having disease in their life. But since suffering the disease, they have started to value and enjoy their life and value things that were taken for granted before.

Verbatim quotes from first, fifth and sixth Participant’s transcript:

“Not to take life for granted but I wish I'd known that before and made the most of things and done, lived for now I think (Participant 1)”

“I took my life as granted you never think it's gonna happen to you do you? I had to- never heard of scleroderma – before I think we're all guilty of thinking it always happens to someone else, it never happens to you (Participant 5).”

“I started to value the things in terms of, before I, taking the things for granted but after this disease I started to enjoy my life (Participant 6).”

In vivo codes reflect assumptions and actions. Exploring these codes allowed me to understanding what was happening and what it meant. These codes anchor the analysis in the research participant's world and made the relationship between my interpretation of the participant's meaning and their actions and their overstatements and actions. In order to see everything in-vivo codes, please refer to Table IX and X -In vivo codes.

4.5. Focused Coding

Focused coding is the second paramount step in coding. These codes are more selective, conceptual, and directed compared to above line by line coding (Glaser, 1967, cited in Charmaz 2006). After developing line-by-line coding for co-researchers, I started focused coding which was not less of a challenge for me. I started synthesizing the larger amount of data which meant I transferred the frequent earlier codes to large amounts of data. I intended to refine those codes through focused coding. Through focused coding, I decided which initial codes were imperative to keep and to make most analytic sense for categorising data. I found focused coding to be a non-linear process and discovered that some statements were explicit whereas they had been implicit in previous events. Through active involvement in research, I made new threads for analysis. I tried to keep codes active and closed to the data. Through focused coding, I moved across interviews when I conducted interviews with other participants and made comparisons between participant's experiences, actions and interpretations.

Table V. FOCUSED CODING

Excerpt 1 *H.H, 46 year Old, Limited Systemic Sclerosis*

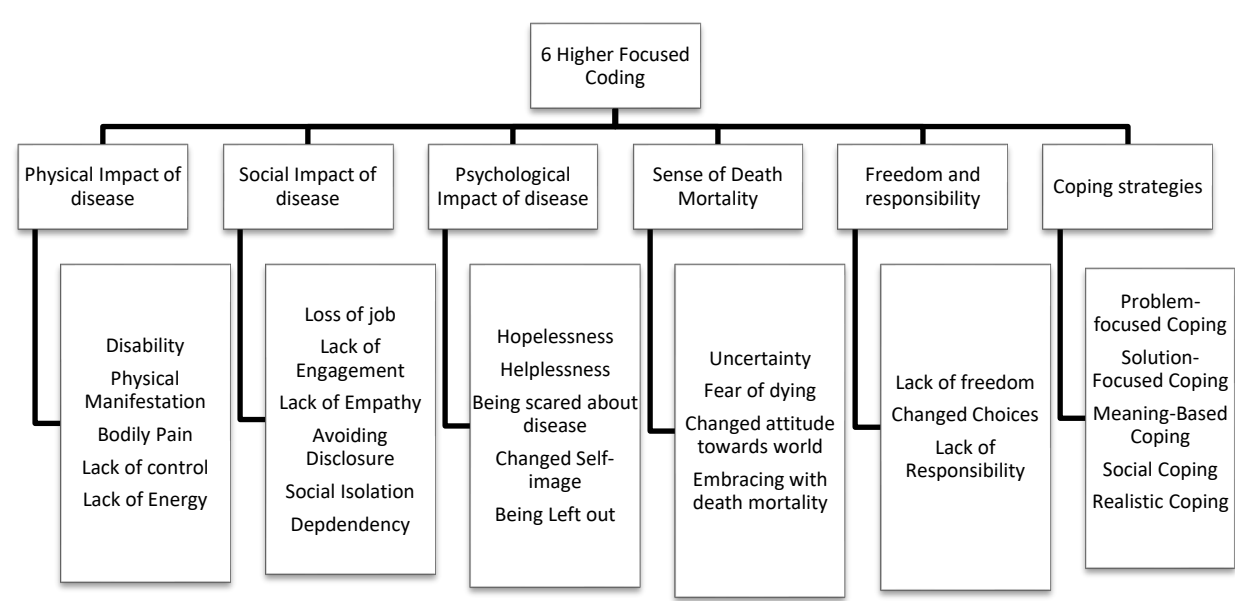
Physical Impact of disease

It affects me in many ways. I've had quite deep muscle pain in my legs and arms; have severe joint pains in my fingers, wrists elbows shoulders and neck, chronic fatigue which is slightly better since I've been on medication, problems with swallowing, acid reflux.

Psychological Impact of disease

I have problems with cognitive processing I've had a brain scan that shows small diffuse white matter so I've had psychometric testing for that and although they've said that it is mild and not associated to another disease, they understand that the impact is hard on me to sort of process the way I used to thought processing if I was to read some instructions I find it difficult to follow or remember. I struggle to have a conversation with more than one person. I just can't keep up and I can't absorb things so I used to be able to do that one of the things I was good at was attention to detail. I used to work for the Fire Service answering emergency telephone calls and you had to be able to have a high degree of accuracy, react very quickly, be able to think very quickly so to lose that is really hard.

Consequently, I was able to make 6 focused coping categories (including 5 focused coding for their dynamic experience of living and 1 for strategies) out of the above 28 categories (included 23 categories of initial coding for living experiences with systemic sclerosis and 5 for initial coding of strategies used to deal with systemic sclerosis). See Table VI for six higher Focused codes.



These six focused coding are physical impact of disease, social impact of disease, psychological impact of disease, sense of death mortality, freedom and responsibility, and coping strategies (see Table XI, XII and XIII for more details):

4.5.1. Physical Impact of Disease

I made the ‘physical impact of disease’ as a focused group to capture, synthesise, and understand the sub-categories of disability, bodily pain, physical manifestations, lack of control over disease, and lack of energy. Participants told me how their disease had affected them physically (physical pain in muscles, joints, stomach, cognitive problems and changed physical appearance (see Table XI, XII and XIII for more details). Participants were asked to

describe their disease and they talked about their symptoms in detail including their path to diagnosis.

Participant 2 talked about her journey to diagnose:

“I was diagnosed in 2011. I was first of all sent to a neurologist because I was getting strange, because they noticed I was getting puffy arms and hands, and my very hard fingers, um neurologist had no idea just, referred me to er, dermatologist who said I know what it is, and then sent me to a rheumatologist and properly diagnosed probably in 2011. (2nd Participant).”

Participants 3 and 4 talked about her initial onset symptoms:

“Looking back my, I've had Reynaud's Syndrome since my mid-teens, nearly always just my hands rather than my feet or any other extremities and I have always had what I consider a very thick skin I do get very deep chaps, deep splits in the, in the skin. (Participant 3).”

“I went down to the doctor and said I'm getting stiff and quite strange, I started to get really ill, fever, erm basically I was, I was starting to do too much I was trying to work fever, all the joints swelled up (Participant 4).”

Participants experience not only physical symptoms at an early stage but also experience the emotional suffering after diagnosis. After hearing the news that they suffer from an incurable disease, participants experience different emotions such as being scared, frustrated, demoralized and feelings of devastation.

Participant 5 expressed her feelings after diagnosis:

“It scares me thought I was gonna die when you read my GP printed a lot off computer about scleroderma and told me to go home and read it and I went home (Participant 5).”

Participant 6 expressed her feelings after diagnosis:

“It was, worrying erm, I was obviously aware that the disease is different for everybody so erm, you know my [coughs] my grandmother lived to be 101; I might live to be 101 but I might live to be 51 (Participant 6).”

This physical impact of disease has five sub-categories that they experience to live with systemic sclerosis:

4.5.1.1 Disability

Participants experience disability after suffering with this disease. They feel that this disease has taken away their independence from them. For the interview question ‘how has the disease impacted on their day to day lives?’ They talked about their restricted movements, difficulty to do household activities, difficulty to do daily tasks due to their physical symptoms of disease and that they depend on others to do many daily duties for them. Due to their hand deformities, joint and muscles pain, they are unable to cook meals, wash clothes, clean the home, change their clothes, get in and out of the bath and even open the jars and bottles. This disease has restricted them in living life the way they did before.

Participant 4 talked about how disease has changed things in her life. She perceived herself slow and slow in thinking and she is not like she used to be. She takes ages to get out of bed and she needs help of her partner to get in and out of bath due to restricted movements. Participant 3 perceived herself quiet limiting due to her ulcers, joints problem and Raynaud’s. She was unable to cut vegetables, cooking, washing, and cleaning due to disease impact on her body. Participant 3 talked about her disability:

“My outlook has changed which I say probably having a lower life expectancy with disability I know that a lot of my life I will feel pain now, that I will be restricted in, in a lot of or some of what I want to do.”

Participant 5 talked about her disability:

“[laughs] loads, I can't do buttons up, I can't walk my dogs, I can't go out for a walk, I couldn't feel my fingers and toes you know, erm, there's lots of things I can't do, my husband has to help me prepare meals, bathe, out of bed.”

4.5.1.2 Bodily Pain

Participants experience bodily pain such as dreadful fatigue, body swelling and stiffness, a painful body such as muscles, joints, neck pain and headaches, ulcers and scars; and they experience pain when doing many tasks. Participants also shared their experience of how their bodily pain is affecting their whole life and affecting their emotions.

Participant 2 responded about pain to the question about impact of disease on daily lives. She got depressed when having pain and the uncertainty of having to live with pain forever. And she had a fear of dying in a painful way.

“At the moment I do, I went through quite a bad phase last year when I did feel very depressed and felt that my, where am I gonna go from here. I guess worry about the pain and whether I can deal with it, whether I'm gonna have it forever, and that's when I start to think is it worth it. So yes I have felt like that (Participant 2)”.

She reported about a fear of dying in a painful way and talked about how pain is interfering with her engagement in social life. She avoids interacting with people when having pain.

“I'm not hugely frightened of dying; I think I'm more, I'd rather die than experience severe pain. More pain is very common (Participant 2)”.

Participant 5 talked about her painful body and expressed how her painful body is impacting on her emotional levels and causing her more frustration with things and making her less tolerant. Below is excerpt taking from Participant 5 showing her impact of pain on her emotions and behaviour.

“I'm less tolerant. I'll give you an example, we can go food shopping and I don't want to be in that queue any more, I push my trolley away and walk out 'cos I can't stand there, I start getting pain and then I get angry.”

She feels relaxed when her pain goes away:

“Yeah it's a relief as soon as I sit in the car the pain goes 'cos I'm sitting down and it's like, ahh, (Participant 5).”

Participant 6 talked about her pain and how she is struggling to live with pain and how pain is stopping her engaging in people's daily lives. She is finding medication does not help to relieve the pain. It seems she perceives her pain as out of control and feels the pain is taking away everything from her life; she could live with tiredness, but not with pain. She experiences depression due to pain.

Participant 6 talked about her experience with pain:

“I could sit around all day and say "I can't do that, I can't do that" so I do try and make myself do some things But it is painful.”

4.5.1.2.1 Good days vs. Bad days

Using constant comparison methods, Participants 5 and 6 talked about how the intensity of the pain makes their day good or bad. Participants defined their good days when they have no pain, or not as much as they have in other days, and not feeling tired or ill when they get up in morning, even it does not mean they are free from pain.

On good days, they want to go out and be able to walk and enjoy fresh air and feel less immobile and become more relaxed by getting in the sunshine. Good days with less pain make their life worthy, joyous and happy. Participants defined bad days as having worse pain, being unable to travel outside and felt more tired. They have to drag themselves out of bed and be forced to do anything, it's an effort to eat and they feel helpless over their disease progression. They feel angry, down, depressed and sad due to lack of control over disease and feel like life is ruined by the disease and pain. During bad days, they become snappier with others, disliking themselves and feeling worthless.

Participant 5 defined good day as:

“Good days, I'll say to my husband I feel good today, I'll come with you to walk the dogs I like being out, I like walking and fresh air.”

Participant 5 defined her bad day as:

“I have days where I don't want to get up in the morning I have days when I want to shout at my husband but it's not his fault it's, it's me, I do take it out on him sometimes I am aware that but it's not about him, it's about yourself, it's my frustration about how I'm feeling and it just comes to a point where I explode.”

Participant 6 expressed good day as:

“I am the worse it hurts so if I'm not quite as tired. I'd still got this dreadful pain in my arm that feels as, pulsates it feels as if someone's stabbing me then pulling the knife out then pulling the knife then stabbing me and then pulling it, it feels like that all the time.”

Participant 6 expressed bad day as:

“Bad days are when you have to drag yourself out of bed and sort of, force yourself to do anything even like, sometimes I just feel like I can't be bothered even to eat anything because It's just like too much effort.”

4.5.1.3 Physical Manifestation

Participants reported physical manifestations such as Raynaud's problem, lungs problem, Insomnia, weight loss, stomach problem as burping and indigestion food, refluxes, swallowing problem, abdominal distress, digestion issues with juice and red wine, a sore throat due to reflux, low vitamin D and anaemic, a right knee injury, hypertension, neuropathy, coughs, infections, high blood pressure, fevers, Sjogren's disease, heart palpitations, thyroid issues, skin problems such as red spots, bad complexion, face and skin tightening, thin skin, breathlessness problems, body stiffness, joint and muscles problems, deformities of fingers, mouth small and stiffness, puffing hands and body, toothache, headaches, lack of flexibility, ulcers, bruises on body, joints, swollen fingers, fatty fingers and hands. Due to physical manifestations of disease, participants experience emotional responses such as shame,

sadness, annoyance etc. Due to this physical manifestation of disease, participants avoid engaging with social activities.

Participant 2 talked about their physical manifestations:

“I have lot of fit do like the pain and a lot of the yeah the joints are sort of swollen and things makes me feel more, self-conscious and even down to things like eating I've noticed that a lot of foods I can't, I realise they're sort of making me feel more ill than you know, bloating and things like (Participant 2).”

Participant 3 talked about her physical manifestation of disease:

“I did lose some weight I have put weight back on again but I definitely lost weight but I think it looks as though I'd lost more because my erm, face had tightened upper, I get the telangiectasia it doesn't affect my fingers yet but I do get very puffy fingers (Participant 3).”

Participant 4 reported her physical manifestation of disease:

“The mouth is different, the eyes are funny erm there's, the skin on my face reacts sometimes if I flare up.”

Participant 6 talked about her physical manifestation as visible signs:

“The visible signs are like the red spots, they look really obvious but other people say they don't show that much but I can see them, and my fingers are really swollen and every time I look at them I just think oh my fingers are so fat” and my feet..People don't see my feet but my feet swell up.”

4.5.1.4 Lack of Control over Body

Participants talked about lack of control over body such as cognitive problems like having brain fog, difficulty to find words, slow in thinking and movement, difficulty to concentrate and understand things, indecisiveness, forgetting things, functioning problems, reduced cognitive abilities, side effects of medication problems, lack of sexual desire, loss of under arm hair, thin hair, difficulties losing weight, breathing issues, sleep disturbances, and an emotional helplessness over the lack of control over the disease and its deterioration.

Participant 1 talked about her experience of cognitive problems due to disease:

“I have problems with cognitive processing I've had a brain scan that shows small diffuse white matter they understand that the impact is hard on me to sort of process the way I used to thought processing if I was to read some instructions I find it difficult to follow or remember.”

Participant 2 talked about her sexual problems due to disease:

“Obviously there's a problem in that we used to do so much activities and now I've, it's less, sex is much more formulaic because I'm not very agile it's not as exciting as it used to be because I can't really do lots of things because I'm a lot tired.”

Participant 3 talked about her medication's side effects:

“The Lozatom Potassium I started on the lowest dose and I did have a couple of light-headed episodes soon, I did have a few light-headed moments and that's when I was taking it in the morning so we swapped so I took it at night.”

Participant 4 talked about her getting worse of disease with time:

“It was quite mild at that time apart from the Reynaud's and the reflux, started methotrexate and that took a year really to get back walking, to doing a little bit of housework, and then well it had gone from being nothing, so it, it's, gets worse every year now and got Sjogren's.”

4.5.1.5. Lack of Energy

Participants experience lack of energy due to physical manifestations of disease. Participants reported lack of energy in terms of not having enough power to go outside or be physically active, certain things causing pain, breathlessness issues, tiredness during household work, tiredness when going outside, playing with grandchildren and lack of energy to have a sexual relationship.

Participant 1 talked about her experience of being exhausted:

“Some days I can get up I can have a shower and then have to get straight back into bed because I feel so nauseous, exhausted, in pain erm, I struggle all the time with using my hands, just from the pain.”

Participant 2 talked about her tiredness due to disease:

“Little things like making the bed I find hard and in other ways I suppose it has in that I'm a lot tired, I don't go out as much as I used to. I don't feel sometimes I'll last the distance, I think that I'm gonna get tired.”

Participant 4 talked about her lack of energy:

“I could walk as far as the gate but I could hardly walk at all, I didn't have the energy to walk. Basically you're useless in that department well because there's no feeling in there because it's been took away from you're tired.”

Participant 6 talked about tiredness:

“I think that's because I've gone through the menopause, I just don't really feel like it, that sort of thing, I don't know If it, I don't think it has really, no except that I'm tired I suppose, in terms of tired-so from that point of view.”

4.5.2. Social Impact of Disease

This focused group ‘social impact of disease’ was selected to combine the sub-categories of job loss, lack of engagement with family, avoiding disclosure, social isolation, lack of empathy from others, and dependency (see Table XI, XII and XIII for more details). Participants shared how their social lives have been affected due to the physical impact of the disease. Participants were asked to describe their social relationships impacted by the disease.

Participants talked about their social relationships:

“It has because I feel like I have to explain it so that people know why I can't do x or why I can't do and some people are either willing to go along with that or find it too difficult or whatever and those are the people that sort of drift away really so it does (Participant 1).”

“We don't have much of a social life so it's not, it's not something I've come across, so (Participant 2).”

“Probably, 'cos I don't, I don't really want to go out and things any more, it's just easier to stay at home (Participant 6).”

This social impact of disease has six sub-categories that they experienced in living with systemic sclerosis:

4.5.2.1. Loss of Job

In this study, participants told about their loss of work due to the physical impacts of the disease and their disability. Participants struggled with their physical symptoms such as swelling joints, muscles, skin problems, restricted movements, cognitive issues, breathlessness problems etc. This manifestation of symptoms stopped them being active at work and restricted them in continuing their job. Participants reported difficulty to work due to disease symptoms such as ulcers, body pain, taking extra time to complete work and symptoms worsening by continuing work. They were slow in work and wanted to hide the disease from other colleagues at work. Initially, they took time off from their jobs but consequently, they lost their jobs as they were unable to cope with their problems.

Participant 2 talked about her struggling during job:

“Painkillers didn't get rid of it, so that was stressing me out a lot because this was actual, quite debilitating at times, you know I had to do a job and you know, you'd sit there and you've got this screaming headache.”

Participant 4 shared her experience of struggling during job:

“No because they'd notice silly things I hadn't noticed before, you tend to flick from one thing to the other, just it, and then shortly they'd noticed and I'd decide, I'm not working with them anymore.”

Participant 5 talked about her job experience:

“I felt they thought, I was being fake, I felt alienated, I don't think they believed what I was telling them. I left the job.”

4.5.2.2 Lack of Engagement with Family

Participants told about their lack of engagement with family due to the impact of the disease and their disability. Participants reported that their family was shocked after hearing about their disease but had lack of understanding from others including husband, boyfriend, family

and friends about their disease and how this would affect them. They had lack of contact with family including parents, children and siblings, with some avoiding sharing their feelings with them and found lack of support by others. Participants reported that they had lack of sexual desire which also impacted on their relationships with partners and the partner's lack of understanding about the impact of the disease on sexual activities.

Participant 3 shared her experience when disclosing information to partner:

"He's very much "oh well I'm sure things won't be too bad" and so he's, I suspect he is actually covering up, a little bit of fear within him that either he is gonna lose me early or that he will have a very disabled partner to look after, but he never shows that, he's not that sort of man who would actually talk about that."

Participant 4 told about hiding disease from her mother:

"No because I still look the same. I've never ever told my mother. I've never ever told my mother but she's 88 years old, no I've told her, she wouldn't understand what is the disease or what is ...? well my family respond like it goes in one ear and out the other they don't understand it."

Participant 5 told about her family response:

"Shock when I told them, I don't think they quite understand how bad it is from day to day, they don't quite understand that today I can be happy and jolly, and tomorrow I'm snappy and angry, they don't understand that side but I try not to show it."

Participant 6 shared her experience when informed to her family:

"He didn't really say much, they don't really say much do they, and he's quite a quiet person anyway I know He's quite worried about what will happen if I can't work, sort of thing."

4.5.2.3. Avoid Disclosure

Participants have physical manifestation of the disease and they use some adaptations in order to walk and cover themselves with layers of clothes to hide their Raynaud's traits. Participants attempted to hide their disease from others, reporting their fear of disclosure about the illness whilst in social gatherings such as alert to sit at job; disclosure about illness in winters if take

off gloves, using sticks in public places, and their restricted movements and disability. They perceived fear of judging by others and try to avoid talking about sexual problem and to avoid talking about disease with others and attempted to hide their disease from family, friends and work colleagues. Therefore, they avoided to interact with others in order to hide their disease.

Participant 3 shared her fear of disclosure about illness:

“Most noticeable symptom in the winter is my Reynaud's, you take your gloves off and phew, you're white there and you're purple there, and, and occasionally I might see somebody you know at the doctor's surgery somebody looking at my fingers.”

Participant 5 shared her experience to use stick in public places:

“People notice when I use stick in social life that bothers me and perceived me as old lady, I have had a mobility scooter I didn't use it, I'd rather not go out than use, bath lift no-one sees it so I can cope with that although I don't like it, I have to use stick And I can cope with it but if other people saw it...I try and shut it off, I try not to look at people to see if they're looking at me.”

Participant 6 shared her experience to disclose the disease's visible signs:

“Well I just, there's really, there's nothing you can do is there, I suppose I could try covering them with make-up but then it could rub off on your clothes so like I won't wear my hair up like that because I have some red spots up on my forehead so I always make sure my hair covers them.”

4.5.2.4. Social Isolation

Due to the physical impact of the disease and lack of understanding from others, they feel social isolation. Participants reported lack of social relationships with others including friends and colleagues, a withdrawal from relationships, lack of social contacts (social withdrawal), avoiding social activities such as outings, going outside, attending the gym and dancing clubs, no more hosting of parties, no going out with friends, avoid meeting with others; difficulty to go certain places due to disease symptoms; not having a social life due to restricted movement; social stigma to get government support; ignoring others to avoid feelings of embarrassment, unable to do shopping; embarrassed to eat food in restaurants. They

experienced lack of engagement with others including doctors and avoiding interaction with people due to changes in appearance and disease symptoms and fear of people noticing the disease because of walking, red spots, sticks etc. consequently, they started to disengage with others and isolate themselves from society.

Participant 1 expressed her feeling of isolation:

“This disease has affected my social activities and social relationships. It makes me feel lonely because at the end of the day it's you that's left with it to deal with, and I think it feels quite isolating really.”

Participant 2 shared her experience about impact of disease on social life:

“Sometimes but I avoid things I think I just go I'm not going to do it. Whereas I used to think oh I might be missing out, I should. Now, I go if I don't feel like it I'm not going to. When I am in pain I'll avoid social things.”

Participant 4 talked about her social isolation in this way:

“Sometimes I avoid going out. I think, I can't be because some of my friends. I think it's really cold and I go white and I've got the windows open and I can't go there or if I go there.”

Participant 5 reported about her alienation:

“I felt they thought, I was being fake, I felt alienated, I don't think they believed what I was telling them no 'cos I don't go out very often [laughs].”

Participant 6 expressed her social isolation in this way:

“Probably, 'cos I don't really want to go out and things any more, it's just easier to stay at home. I don't really like to go out on my own but I don't feel confident.”

4.5.2.5. Lack of Empathy by Others

Participants experience lack of empathy from others including friends, parents, colleague and other and they do not get respond by friends, doctors and other. Participants reported feeling of rejection by others such as nasty attitude of others, doctors and judging by others. Their

husband, family, siblings, family has lack of understanding about their disease and have lack of communications with their professionals.

Participant 1 talked about lack of understanding by family and work colleagues:

“Rest of my family they sort of don't understand, because I don't look as there's anything wrong really you know, work colleagues, that was really difficult because I didn't work in a very supportive environment, it's so difficult to understand.”

Participant 3 shared about lack of communications by doctors:

“My doctor and my rheumatologist haven't actually explained very much about the disease that, they are aware of the fact that I use the internet.”

Participant 5 shared lack of understanding by others:

“cos it means, see I don't like talking about it a lot because they don't understand, I don't want them to think that I'm making it sound worse than it actually is, I think they do have lack of understanding, same as my husband, I don't think he quite grasps it, he's read some, erm, but they have no lived experience.”

Participant 6 talked about her experience of lack of empathy from friends and work colleagues:

“Maybe they're not very good friends [laughs]. This disease has impacted on my work, relationship with my work colleagues. Well one of them, she used to text me and things all the time and since I've been off work she hasn't texted me.”

4.5.2.6. Dependency

In this study, participants talked about how they are dependent on others for doing daily living tasks from wearing jewellery to cooking. They talked about their difficulty to do shopping and to do daily tasks. To do these daily tasks, they ask for help from their husband, family, and others. They also depend on others financially due to loss of work and they feel a burden on partner.

Participant 2 expressed how she is depending on other for doing daily chores:

“I rely more on other people, you know the fact that I could just do my shopping at –things like changing the bed, even that just seems daft I –I need my boyfriend to put - tuck the sheets in 'cos I cannot lift the mattress.”

Participant 3 shared her fear of burden on partner:

“He will have a very disabled partner to look after erm, it's more likely my husband will have to care for me than at the moment, than I would have to care for him, in, in terms of you know, physical dependency.”

Participant 5 expressed her feelings in regards of dependency and also reported her dependency in terms of her personal care:

“Well I've got no freedom 'cos I have to depend on other people. Being vulnerable, being ill, being dependent take my courage away. I can't shower 'cos I had a really bad fall in the shower, took the skin off my nose, and it scared me, he has to help me in and then I call him and he helps me get out.”

Participant 5 talked about her financially dependent on Govt support as she is unable to work:

“Well, no 'cos we, we're both on benefits and I, something I've never done before and I don't like it, there's a stigma attached to it isn't there?”

Participant 6 talked about her dependency on partner and daughter to change clothes and jewellery:

“I just struggle like zips and things I get my husband always does zips up for me or my daughter does depending but I try to buy things that are stretchy or that don't have zips and, I try to make sure I buy things that are easier to put on. I never change jewellery, I can't undo it my husband does.”

4.5.3. Psychological Impact of Disease

I made the ‘psychological impact of disease’ as a focused group to capture, synthesise, and understand the sub-categories of hopelessness, helplessness, being scared about the disease, changed self-image and being left out were gathered and put into one focused group called psychological impact of disease (see Table XI, XII and XIII for more details). In this study, I

asked participants ‘How has the disease changed the way you think or feel about yourself?’ in order to explore their emotional responses due to living with this disease. Due to physical impact of disease, participants experience different range of emotions.

4.5.3.1. Hopelessness

Participants feel hopeless due to suffering from an incurable disease. Participants experience hopelessness in different contexts and expressing their emotions. When I explored the contents of emotions, I found the feelings of hopelessness as themes due to living with an incurable disease. Participants reported lack of sense of meaning as disease is not curable, then what it is meaning to live, and they left their old goals as and loss of hope to live longer. Some of participants reported sadness as they do not have any hope for their future. They talked about their feelings of despair as they have no hope for the future and sadness in not getting support by their children and have lack of satisfaction with life. With regard to their old values they cannot adhere with them now and feel disappointed by the attitudes of their friends. Participants feel hopeless as initially they tried to cope with their job and be optimistic to possible cures with their treatments. But with the time, they embraced it with reality and lost their jobs. Due to lack of social support and loss of work, they feel loneliness and do not wish to live longer with this disease. Participants reported hopelessness because of their restricted movements and their limitations due to disability. Due to loss of their independency, they have a lack of positive attitude towards life and are frightened by being vulnerable, ill and dependent on others. Therefore, they lost their wish to live longer.

Participant 2 talked about lack of hope to cure with disease:

“No I don't - I think because it's so many aspects of it that's why they treat each individual thing and it's still all experimentation Certain parts might be cured But certainly not I can't imagine the whole thing unless they find some I certainly don't think so at the moment.”

Participant 3 talked about her worry about no living longer:

“Worrying, I was obviously aware that the disease is different for everybody so erm, you know my [coughs]

*my grandmother lived to be 101; I might live to be 101
but I might live to be 51."*

Participant 6 talked about lack of hope to cure and lack of satisfaction with life:

*"I don't think there's any hope of it being cured, I do not
satisfy with my life because I don't feel like I ever do anything
meaningful, one day is the same as the next day you know and
they all run into one as not really doing much."*

4.5.3.2. Helplessness

Participants experience helplessness due to physical impact of disease and that they cannot live their lives as they were used to. Participants reported feelings of frustration due to lack of independency and annoyance due to being dependent on others for doing daily chores from wearing jewellery to taking baths. The disease has limited their moments, they have to ask for help from others, even for little things and found themselves helpless due to lack of control over pain, not benefiting from treatments, lack of control on disease progression, loss of old goals and lack of control over cognitive problems. They get treatment to manage their symptoms, but due to the side effects of medications, they become helpless as they cannot control the disease or the side effects of medications. Participants felt lack of understanding by others and perceived lack of social support as helplessness.

Participant 2 expressed her feelings of frustration:

*"With myself really I mean it is the disease that's doing it but
I suppose I feel frustrated about myself really, I kind of take it
out on myself, which is daft really but yeah."*

Participant 3 expressed her feelings of frustration due to pain:

*"Obviously there's actual pain, and it's very severe pain
at times, frustration, because it does stop me from doing
some things, or it adds extra time to my work."*

Participant 4 expressed her feelings of annoying when talking about illness that represent feeling of helplessness:

*"I don't, I come out with silly things, I, come on let's
about something else, I don't want to talk about illnesses.
It gets on your nerves. you avoid them."*

4.5.3.3. Being Scared About Disease

Participants reported being scared when they came to know about disease first time and become frightened due to having incurable disease. Participants reported their feelings of worry, being scared, anxious, annoyed and petrified when they came to know about the disease and are anxious about consequences of disease such as ending up with wheel chair, fear of loss finger due to ulcers, fear of getting worse; Concern about stomach problem, blood pressure, ulcers, lungs, concern about mental health due to disease traumatic to read on internet, fear of living with disability and other complications.

Participant 2 talked about her fear when came to know about her illness:

“Well when I was first diagnosed I was very frightened, very frightened, and I got very upset, thinking of all the possibilities of where we were going.”

Participant 3 talked about feeling of worry about other complications

“My blood pressure has just started to rise so I've had to up my er medication so in fact that is, it's worrying obviously because that might be a sign of, of hypertension caused by the scleroderma.”

Participant 5 talked about feelings of scare and petrify when she came to know:

“It scared me I thought I was gonna die when, you read my GP printed a lot off of the computer about scleroderma and told me to go home and read it and I went home and read it and I cried, I was probably like you, petrified.”

Participant 6 talked about her fear of consequences living with disease:

“I knew a lot about that you're likely to end up in a wheelchair with that so I didn't really know anything about it either, he did give me a booklet..”

4.5.3.4 Changed Self-Image

Participants talked about their changed self-image due to physical impact of the disease. In terms of their changed appearance, they feel their hand and skin look dreadful and ugly, their mouth, eyes and skin, look poor, they feel scruffy by wearing layers of cloth, they reported hate towards self when looking in mirror and experience weight gain and find themselves no

longer attractive due to fatty hands and found change in their identity such as looking like an old woman by using a stick and being disabled and dependent on others.

Participant 5 reported perceiving herself as a snappy person and quick-tempered and less tolerant to stand in a queue. Participants reported that due to changes in their appearance, they felt loss of confidence and started to see their life as worthless as they were unable to achieve their old goals and feeling useless as they are not fulfilling their responsibilities of being a wife and mum and consequently they experience lack of satisfaction with life. Participants express different ranges of feelings due to changed self-image such as feeling like a hypochondriac, feelings of uselessness not to have a sexual relationship, awful on depending on others, feelings of demoralization for depending on others, mood swings, angry to stand in a queue, feelings of nuisance on changed body image, feeling like a caged animal, feeling of being robbed by disease, changed self-identity, fear of getting other illness, feelings of embarrassment in having to use sticks and looking like old woman.

Participant 3 talked about her fear of consequences due to disease:

“My facial tightening if that gets a lot worse, the calcinosis and the digital ulcers, it's mainly frustration and annoyance obviously I'd worry a little bit about my ulcers because I know that if they get very bad then it could lead to gangrene or amputation.”

Participant 5 talked about her self-image:

“Well sometimes I hate myself I look in the mirror, I don't like what I see, sometimes I hate myself.”

Participant 6 talked about her self-image

“I don't think that I look nice in anything I wear or anything, I've put on weight. I don't like my body.”

4.5.3.5. Being Left out

In this study, participants talked about being left out due to physical and social impacts of the disease. Participants reported that they felt a lack of understanding by partners, friends, and doctors and felt depressed due to having the disease and its consequences such as loss of job

and loss of independency. Due to lack of empathy from others, participants avoid going outside and preferred to stay at home. They avoid sharing their problems with others. Due to depending on others, participants experience feelings of being scared, a nuisance, and feelings of burden, shame, embarrassment and loneliness. Participant 6 reported about her feelings of being left out from her super believers as she was a religious person. After not getting support from her believers, she has lost trust on every religion. To avoid these feelings, they preferred to stay at home.

Participant 3 talked about her feeling of embarrassment whilst outside:

“If I'm eating something I have to have water because the food will get stuck, and occasionally I might regurgitate food because it hasn't gone down, and that is one of my most concerning things because obviously socially that can be quite embarrassing.”

Participant 5 expressed in this way:

“I don't see them as often as I used to-I wanna be left alone, I feel lonely sometimes, I know he's supportive and he loves me, I don't doubt that, I just feel, yeah, lonely.”

Participant 6 talked about her feelings of being left out:

“I'm not at work I don't really see most of them well most of them, like with through work and things and they just don't, I think they just don't contact me now.”

4.5.4. Sense of Death Mortality

I made the ‘sense of death mortality’ as a focused group to capture, synthesise, and understand the sub-categories of uncertainty, fear of dying, changed attitudes towards world and embracing death reality which were gathered and put into one focused group called sense of death mortality (see Table XI, XII and XIII for more details). In this study, I asked participants ‘How has the disease affected your sense of mortality?’

4.5.4.1. Uncertainty

Participants expressed their feelings of uncertainty when they were talking about their illness. They reported about their worry about outcome of disease, their concerns about getting old

and getting worse of disease in future, and ended with shortened life. They expressed their anxious to find answer of their disease's flare up and causes of their disease, even they know it is unknown cause still. They manifest their unknown anxious about future and their future financial issues how they will survive as they have lost their jobs as well due to disease impact of their lives. During this unknown anxious, they also embrace with their own mortality after having disease. Their uncertainty comes with their feelings of being scared, worried, angry and frustrated.

Participant 3 shared her fear about future due to having disease:

"We have very specific needs and as long as those needs are understood our lives can be more manageable so water with drinking exactly not lying down flat one of the things that scares me as I get older. I suspect I will more in the future, if I get more severe symptoms, complications."

Participant 5 reported about her uncertainty about disease:

"Frustrating because you don't know what's gonna happen next, you don't know how bad you're gonna get, erm frustrating because you don't know scary because you don't know how you're gonna get."

Participants 6 shared her feelings of unknown due to disease:

"Anger really I'm just quite angry as to why did it affect me because no-one can give you any answers as to why, and what can be done about it and that seems to be, no answer to that really so it's kind of more like really angry, why hasn't anyone."

4.5.4.2. Fear of Dying

In this study, participants expressed their fear of dying after suffering with an incurable disease. Participants reported their fear of dying in different ways such as nightmares, death terror, dying with pain, concerned about lung deterioration, dying earlier as unexpected.

Participant 1 shared her fear of dying in this way:

"I do have a massive fear of dying now. I never used to, I have nightmares I think it's actually more around the suffering beforehand and, and what it would be like, and I've never ever thought of that before."

Participant 2 talked about her fear of dying:

“I think my biggest fear was when I was diagnosed with the lung and then I thought oh I've only got ten years at most sort of thing.”

Participant 5 shared her nightmares and fear of dying with pain:

“I can tell you, I'm falling and I can't stop myself falling. I have fear of dying with pain because if I'm in pain and I'm dying.”

4.5.4.3. Changed Attitude towards World

In this research, participants reported their change attitude towards world. They expressed their attitude in various ways such as find world as a horrible, finding world as threat, see world smaller and life and world as temporary and they perceived life as short.

Participant 3 shared her thoughts about perspectives:

“Does it make any sense to say the world seems a bit smaller in that I don't feel I will have the freedom to do exactly what I want, erm there will be restrictions even if the disease gets no worse for me.”

Participant 5 talked about her perceptions about world and life:

“I perceived life and world is temporary. I feel I have taken my life as granted after disease. Now I become more sensitive more other illness.”

Participant 6 shared her perception about world:

“World, I don't really think of it as being particularly bad or particularly good, it's just where we live. I embraced with reality about life and world as temporary. It's not a permanent thing.”

4.5.4.4. Embrace with Death Mortality

Participants talked about their fear of dying and also talked about their death mortality.

Participants confront with their death mortality and accept death reality. They found it as out

of control and recognized their limitations being a human and accept it will embrace not only them, but every human being.

Participant 3 talked about her embracing death mortality:

“cos we're all gonna die sometime, but it's the foreshortening and not doing everything you wanted to do in life that, I say the irony is that once you're dead you're dead and you can't look back and regret that [laughs] it's a strange thing.”

Participant 4 talked about embracing with death reality:

“But just know that life is short, if we want to do something, it has to be done now, not next year, it has to be done now because each year I'm a little bit worse.”

Participant 6 talked about her experience:

“After this disease you have any sense of death awareness, we're all gonna die sometime and when we're dead we're dead and what's the point in worrying about it, so but after the disease. Do you have any thoughts about it, or maybe I will live five years.”

4.5.5. Freedom and Responsibility

I made the ‘sense of freedom and responsibility’ as a focused group to capture, synthesise, and understand the sub-categories of lack of freedom, changed choices and lack of responsibility which were gathered and put into one focused group called sense of freedom and responsibility (see Table XI, XII and XIII for more details). In this study, I asked participants ‘How has the disease affected your sense of freedom and responsibility? This focused group ‘freedom and responsibility’ was made up to gather same themes of lack of freedom, changed choices and lack of responsibility.

4.5.5.1. Lack of Freedom

Participants reported their lack of freedom due to physical impact of disease. Participants reported that they have lack of control over disease in terms of destiny, weight gain, disease symptoms; light-headedness as side effects etc. they have lost their independency and dependent on others for wee things and feel less free for travel due to their restricted life such as difficulty to shopping, not going outside, unable to go outside on their own. They have

boundaries to travel freely and bounded at home. They perceive lack of freedom to choose dress and to opt what they want and have restricted life to do daily chores. They reported that they depend on other due to limited money and loss of job. Participants, who reported lack of freedom, also feel about themselves as angry, frustration, caged animal, trapped by disease, and feeling of robbed by disease.

Participant 2 shared her feelings of restricted life as lack of freedom:

“I feel more restricted about what I can do, I wouldn't, when I was younger I used to quite happily go off on my own and Experience things; now I don't- I'd feel I'd need somebody with me. So yeah so it has restricted me.”

Participant 3 talked about her lack of travel freedom:

“Might be in travelling, in, in just day to day things like living and as you say getting dressed and undressed things like that, I feel less free in that respect.”

Participant 5 talked about her loss of freedom:

“Well I've got no freedom 'cos I have to Depend on other people.”

4.5.5.2. Changed Choices

Participants reported that they have changed their choices and life priorities according to their disease and managing to live with their disease. They reported they did not like to wear layers of clothes, but now they have changed their habits and wear layers of clothes due to the nature of the disease and changed their likes and dislikes and their priorities as participants focus more on their family and friends and want to spend time with them as before they are used to do things a lot and those are important. Instead of going outside, they prefer to use a computer to make contact with the outside world due to the nature of the disease and their restricted movements.

Participant 3 shared how disease has changed her choices:

“I suppose changed priorities a little bit in terms of this say focus on friends and family and making the most of the good things and the sort of attitude of ohlife's too short to get stressed

*about minor things but little things that don't really matter in life
I tend to think, just let them get on with it [laughs]”*

Participant 5 talked about her changed priorities

*“We had a life, because we did things, those were important,
well now they're not because we can't so my priority is just
living one day to the next, taking each day as it comes,
looking after each other.”*

Participant 6 talked about her changed priorities:

*“I mean I like walking in the woods with the dog and things
and I can't do that anymore and you know things I don't like,
doing things on the computer, which I can do, obviously, but
I have to do more of that.”*

4.5.5.3. Lack of Responsibility

Participants reported lack of responsibility after suffering from this disease. They have lost their independency and are dependent on others for daily chores. Therefore, they are unable to fulfil their responsibility in being a wife, mother, daughter and caretaker etc. It is hard for them to take charge of anything including financial responsibilities. They perceive themselves as useless due to not fulfilling responsibilities. It was found that their roles and responsibilities have been changed with other family members.

Participant 3 talked about her lack of responsibility:

*“I probably feel slightly less free in that I'm already a bit more
dependent on others so things like opening the jars, there are some
things I can't do easily now and I know that's likely to become
a lot worse so it's like.”*

Participant 4 talked about her lack of responsible being a wife:

*"I can't really be responsible - well it's alright being responsible
for a dog but not, I can't be responsible now yeah it's affected
being a wife.”*

Participant 5 talked about her lack of responsibility:

*“Because I used to wait on him hand and foot, Now
it's changed, it's, he's looking after me.”*

4.5.6. Coping Strategies

This focused group ‘coping strategies’ were selected to synthesise the sub-categories of problem-focused coping; solution-focused coping; meaning-based coping; social coping and realistic approach (see Table XI, XII, XIII and XVII for more details).

4.5.6.1 Problem-Focused Coping

Participant 1 reported how she used problem-focused coping to deal with her illness such as taking her medications to feel slightly better:

“I’ve had quite deep muscle pain in my legs and arms; have severe joint pains in my fingers, wrists elbows shoulders and neck, chronic fatigue which is slightly better since I’ve been on medication, problems with swallowing, acid reflux.”

Participant 2 used problem-focused strategies through seeking professional help and treatment measures such as investigations to find out the problem:

“I was first of all sent to a neurologist because of getting puffy arms, hands, and fingers. Neurologist had referred me to dermatologist then it was just a whirlwind of tests, loads of tests and then I finally got diagnosed with the diffuse.”

Participant 3 mentioned her problem-focused strategies through seeking professional help and getting treatment for her disease’s symptoms and monitoring her health through regular blood tests:

“I’ve always had dreadful hands, ulcers they come and go, I do have Illoprost treatment at the start of the winter, I saw my rheumatologist last week and my blood pressure has just started to rise so I’ve had to up my medication. I had an echocardiogram and pulmonary function tests to monitor.”

4.5.6.2. Solution Focused Coping

Participant 4 reported her solution focused strategies such as using alternative methods and tools to do daily household chores including cooking, cleaning, washing, opening bottles and jars, showering and dressing as an attempt to regain some control on her independence.

“I want to mix anything this arm will hurt, and there's no strength in it. I buy a hand mixer. I can't use a tin opener, just use the ring pulls and use a little things not the heavy things. I get the steamer out just give it a very good clean and then, you can, you can manage it with a cloth.”

Participant 5 talked about her solution to cope with Raynaud's and reflux:

“I wear as much clothing as possible on my feet and on my hands but when you're at home there's not a lot you can do I have a pair of camping slippers, they're made from down, and they're quite warm but I still wear two pair of socks indoors, silver socks and thick woollen socks but I still wear a pair of sheepskin slippers as well.”

“I have been known to sit up in bed prop myself up with pillows we have a spare room so when I'm bad I go in the spare room and I sit in the corner and prop myself up, and go to sleep like that.”

Participant 6 talked about her managing with presenting symptoms and dealing with household chores:

“Well there's nothing you can do is there, I could try covering them with make-up to hide red spots but then it could rub off on your clothes. I wear things that are higher round my neck, or a scarf. I've got a dishwasher [laughs] so, I don't have a problem with that.”

“I just struggle, I can't zips and things I get husband always does zips up for me or daughter does depending but I try to buy things that are stretchy or that don't have zips and, you know I try to make sure I buy things that are easier to put on.”

4.5.6.3. Meaning-Based Coping

Participant 1 reported about her internal supports as a meaning-based coping:

“I really feel quite strongly about wanting to help other people, not necessarily with scleroderma, but that's where I was saying about the empathy and the compassion and understanding the difficulties that people face, in life, and

some way of dealing, something like that.”

Participant 2 talked about her blessing and perceiving herself as lucky and reported gaining satisfaction through her work and gets courage by helping others as meaning-based coping:

“I enjoy my work very much so that satisfies me greatly because I'm freelance and I'm constantly having to find new work so that's always a slight worry but I do, that really satisfies me, my work.”

“I think you can just by being supportive; I think it's good to talk about it main thing, people that, whether they have this disease or any other disease, it's important to try and get them to be positive, 'cos it's must better to be positive, than negative.”

Participant 3 used meaning-based coping strategies to deal with her illness. She counted her blessings as a way to think positively and she sought meaning based coping from her religion.

“Faith, as I said I'm a Christian, the love of friends and family it is this sort of tolerance of, other people's disabilities, lack of, slowness. I wasn't an impatient person before but I'm much more understanding of that in other people now.”

4.5.6.4. Social Coping

Participant 4 talked about dealing with social life and getting support from others in order to rebuild her social life.

“It makes you closer really close he's very caring, he's very caring. I'm quite content with my husband. A lot of my friends have still got children, young ones, I'll go and let the dog out.”

“Well I'm sort of retired, spare time I go swimming but that's a health club type of swim, everything's nice and warm and meet with others.”

Participant 5 reported her social coping as getting support by her partner and friends:

“He does most of that as well. We go together for shopping, he does holding bags, I don't think I could live without help.”

“My friend, she always asks me about it but I just deal with it, she's a very sympathetic, kind, warm person.”

Participant 6 reported about her coping in social life and sometimes used humour.

"I laugh about the Reynaud's 'cos it's my, everyone always says to me "oh you've got your white hands again" I'm not bothered by the Reynaud's. I am bothered in fact that it hurts."

4.5.6.5. Realistic

Participants used realistic coping by accepting their disease and their limitations in being a human and they tried to get more information about the disease and embraced their death reality and recognised their limitations due to living with systemic sclerosis and accepted the consequences of the disease on them.

Participant 1 recognised her limitations due to the disease and accepted it:

"I feel frustrated at myself that I'm not able to do things that I'm a bit useless but then I counter that with the fact that it's not my fault and that I'm not choosing to be like that. I've just got to live for now and deal with it. I think you've got to be realistic rather than."

Participant 2 shared her experience to focus on the present and accepted her disease:

"Well I just accept and, I have to try and keep that away and just deal with the now-to be present- not to be jumping on the exactly there's no point in doing that."

Participant 3 talked about her learning to live with the disease and accepted her limitations:

"I've just sort of learnt to live with disease. I'm actually scared of dying 'cos we're all gonna die sometime I have to accept that my life very likely will become a lot more limited but yes it will be more limited but doing as much as I can and as I say remaining positive."

Participant 4 talked about her limitations to control the disease and accepted her death mortality:

"Well you're going to die anyway, there's nothing you, you are what you are, you can't change it. You have to accept it because you can't do that and go back to how you were before and back."

Participant 5 accepted her disease and its limitations on her:

“Over time you learn a bit to accept, you become more accepting of your condition we do it together, I can't chop I can't carve, I can't touch things out of the fridge etc. I'll try it, and I shouldn't.”

Participant 6 talked about accepting limitations and death mortality;

“I can't go to work, I can't do anything after that, it's just you have to plan to only do sort of one thing on a day, and then come that day you might actually feel "no I can't do it anymore" so I've just always thought well we're all gonna die sometime and when we're dead we're dead and what's the point in worrying about it, I've always thought that we're here for a certain amount of time and then die.”

Grounded theory is a comparative approach where I juxtaposes data with other data, with other categories and compares categories in order to make more refined data (Charmaz, 2006). Therefore, I started to analyse data early and attempted to build groups. Through implementing comparative analyses, I was able to recognise the group of common themes through personal insight. The amalgamation of developing themes manifested various connections that transpired as a visual mode (Creswell, 1998, cited in Charmaz 2006). Through this process, I was able to identify six major categories. However, I started to write down memos during this process.

4.6. Memo-Writings

Memo-writing is the central step between data collection and writing a draft of papers. While writing memos, I reflected on data and analyzed ideas about codes from different angles (Glazer, 1967, cited in Charmaz 2006). Memo-writing comprises a pivotal approach in grounded theory because it leads to scrutinizing data and codes early on in the research process. Writing memos helped me to be active in the research process and enhance the abstract ideas for this study. Through memo writing, I was able to persistently make comparisons and connections between data, between data and codes, between the codes of

data and other codes, between codes and category, and between category and concept and articulated ideas about these comparisons (Charmaz, 2006). Through actively engaging with materials, I was able to develop ideas, and to refine this data-gathering. I made analytical notes to clarify categories.

Memos prompted me to transform my ideas into narrative form. Writing memos helped me to elaborate processes, assumptions, and actions within codes or categories and encouraged me to separate emergent categories and split them into their sub-categories and memos guided me to figure out which codes could be used as analytical categories (Charmaz, 2006). In order to write memos, I brought raw data and preserved collecting evidence for analytical concepts from the start. I used participant's verbatim material to ground abstract analysis and made it the basis for making claims about it. During this process, I remained aware of my emotions, ideas, biases, and reactions to reflect on the ways that these would shape analysis. Below are memos that demonstrate the relationship between illness, codes and categories.

4.6.1. Memo 1: How does the impact of the disease on appearance lead to avoiding disclosure?

Through above participants' data, it seems to me that participants with systemic sclerosis suffer from physical consequences of the disease. This disease impacts on physical appearance giving face puffiness; black circles under the eyes and making blood vessels appear in the face. The participants believed that people noticed them and consequently disliked their appearance and this led to them to have low self image and to become more self-conscious about their image. In order to deal with their feelings and thoughts, they covered their face in public places which leads to the concept of 'Avoiding Disclosure' (see Figure IV)

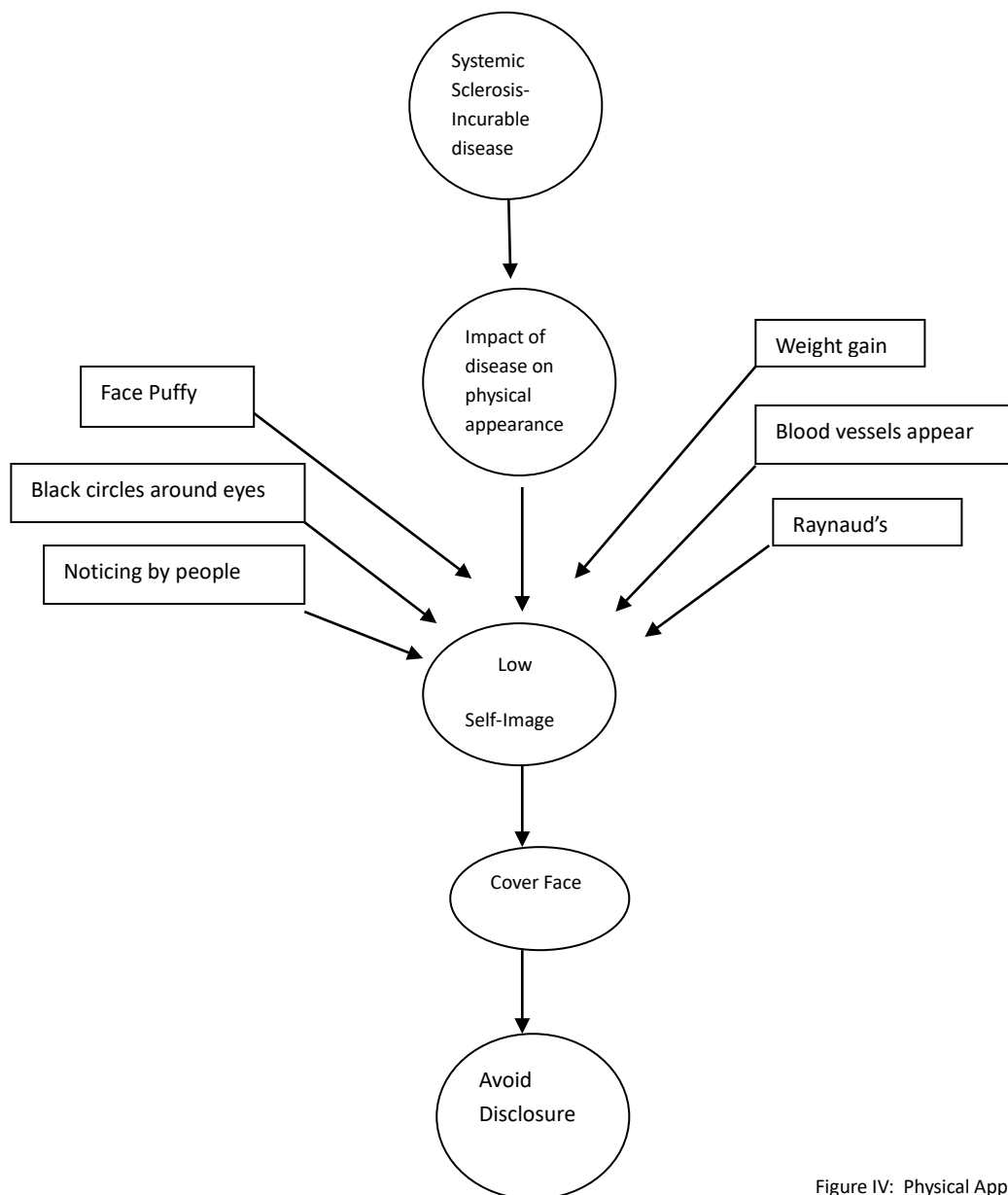


Figure IV: Physical Appearance and Avoid disclosure

4.6.2. Memo 2: How does the impact of disease lead to social isolation?

Through above participant's data, it seems to me that participants with systemic sclerosis suffer from other physical consequences. This disease also impacts on a person's cognitive function with problems such as concentration problems, thought processing problems, struggling to conversations, inability to absorb things, inability to understand things, inability to bear noisy environments. Their cognitive problems due to illness have impacted on other parts of life such as making them lose their job which required a high degree of accuracy and reach quickly, loss of skills like cooking skills and driving skills that required them to be attentive. They have difficulty speaking with a lot of people and they tried to pretend to themselves that they are fine but they are in fact unable to do so and felt the lack of empathy from others. They reduced their contact with people in order to hide their problems from others and ultimately this led to social isolation (see Figure V).

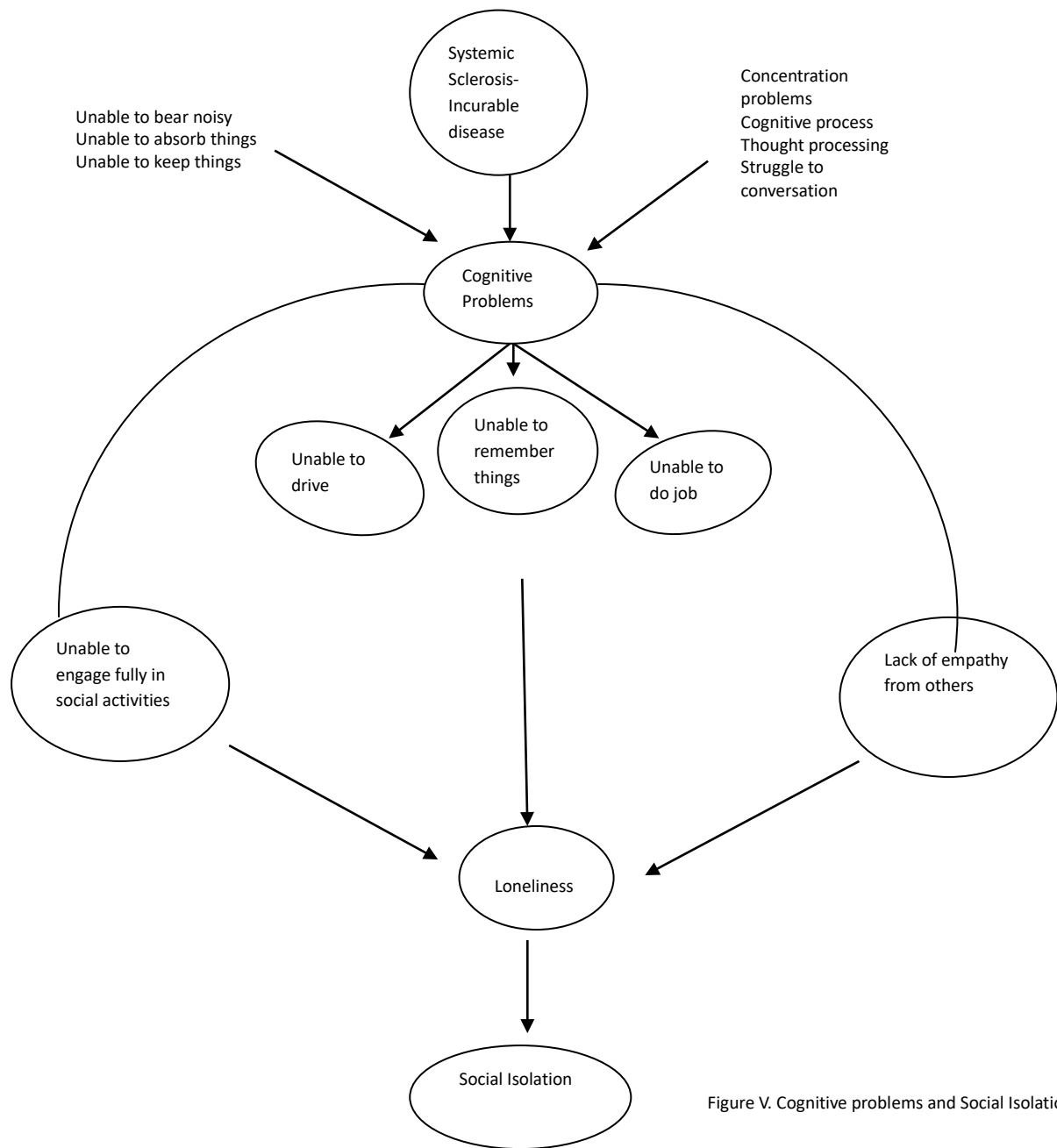


Figure V. Cognitive problems and Social Isolation

4.6.3. Memo 3: How incurable disease has impacted on searching for new Identity?

Through above participant's data, it seems to me that participants with systemic sclerosis suffer from other physical consequences. This disease impacts on their physical pain giving deep muscle pain in their legs and arms, hands, blood vessels, with severe joint pains in their fingers, wrists elbows, shoulders and neck, and chronic fatigue, problems with swallowing, acid reflux and bloating. This physical pain has dramatically impacted on their daily activities like cleaning, washing, cooking, and dressing, shopping, and led to a lack of social activity. They are no longer able to work and are dependent on their partner each day. Being a disabled person has triggered a lot of emotions in them such as annoyance, frustration, and feelings of worthlessness. Due to their disability, they have lost their some aspects of their previous life and this has resulted in a changed sense of self. They experienced a grieving process regarding the loss itself and they felt helpless about having this kind of disease that made them lose aspects of their identity and they adopted some kind of behaviour such as crying, annoying and snappy with husband order to deal with their emotions. But with time, they realized that it is not their choice to choose disease for themselves, and they started to accept it and search for new aspects of their sense of self by doing some worthwhile work (see Figure VI).

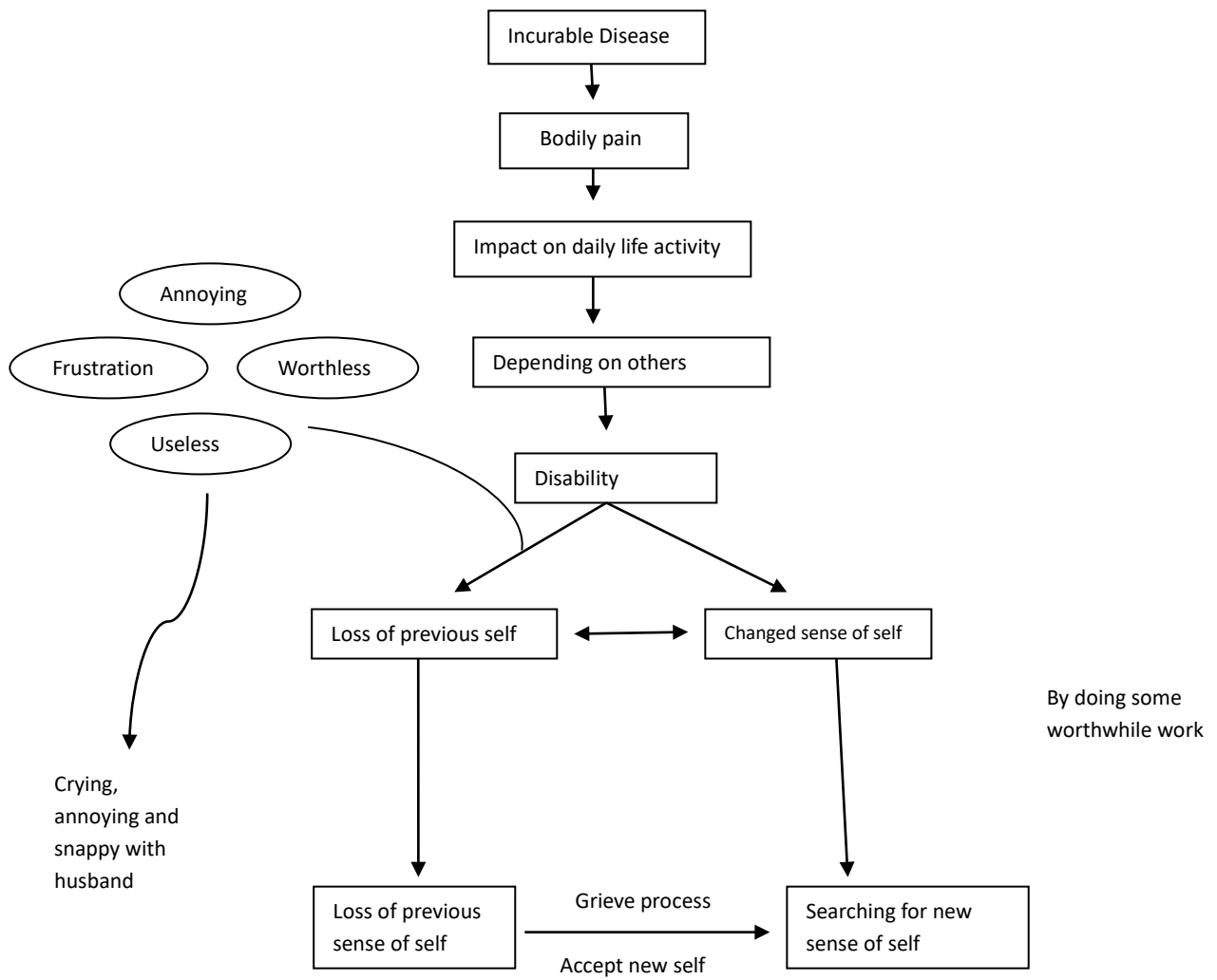


Figure VI: Incurable illness and Searching for Identity

4.6.4. Memo 4: How incurable disease impacts on existential crisis?

Through above participant's data, it seems to me that participants with systemic sclerosis suffer from physical consequences. This incurable disease has made individuals disabled to the extent that it changes the participant's sense of self. This changed sense of self raises questions around existence itself, life goals and values. After losing some aspects of their previous identity, participants confront their existential crisis and search for new meanings, goals and values for self and rebuild the self again (see Figure VII).

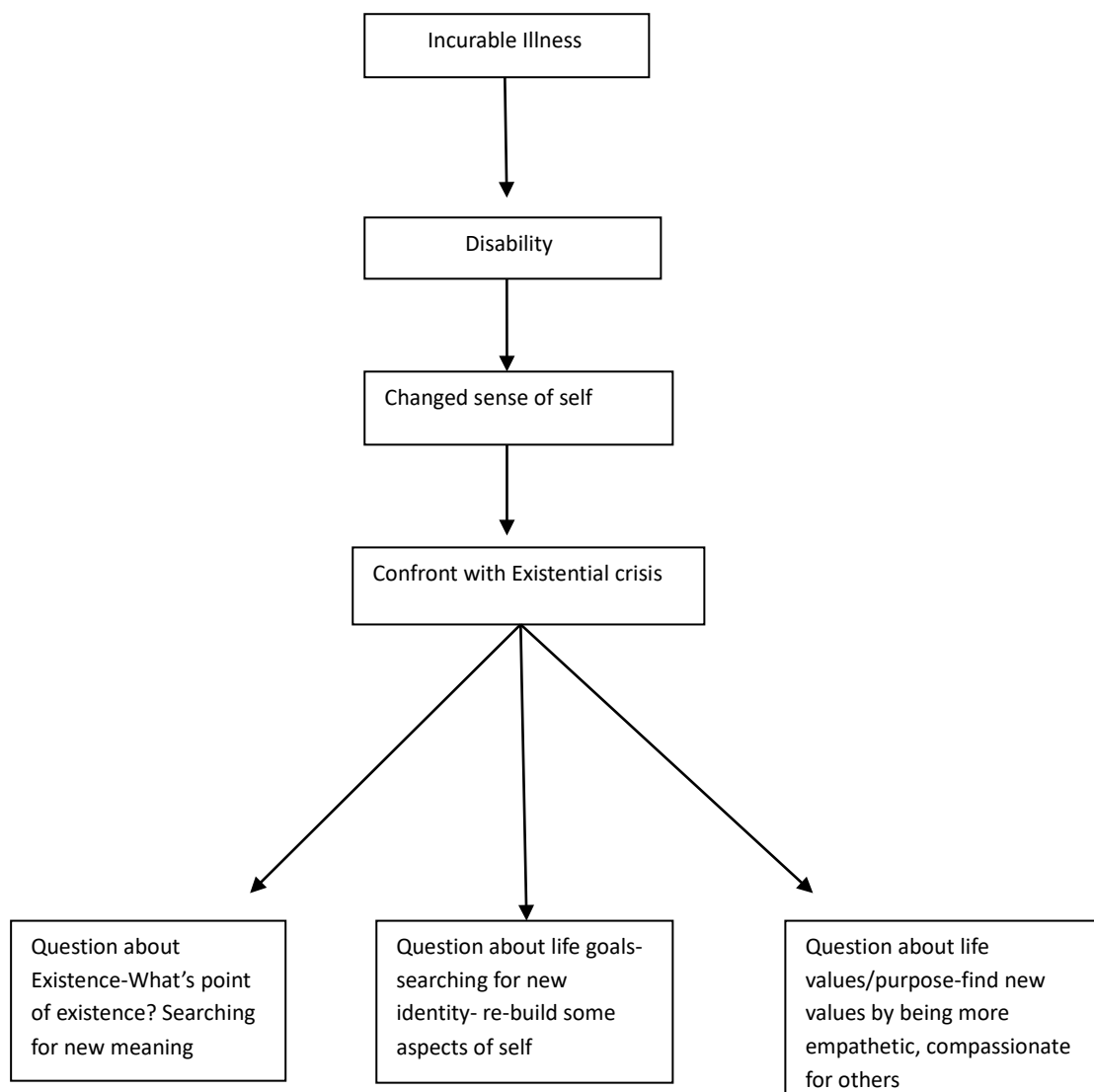


Figure VII: Incurable disease and Existential Crisis

4.6.5. Memo 5: how participants experience their illness in physical, social and psychological world and how these worlds are interconnecting to each other?

Through above participant's data, it seems to me that participants living systemic sclerosis experience disability due to physical impact of disease such as bodily pain, muscles stiffness, joints pain and swelling, restricted movements and restricted life to do daily chores. Due to disease impact on their physical world, they bound themselves at home and withdraw themselves from social world due to their experience of job loss, lack of contact with other, avoid disclosure, dependent on others, and lack of empathy from others, feeling of rejections by other and fear of burden on others. Due to their isolating from society, they experience despair due to their feelings of sadness, hopelessness, annoying, depression, worry, helplessness, lack sense of meaning, and scare about outcome of disease (see Figure VIII).

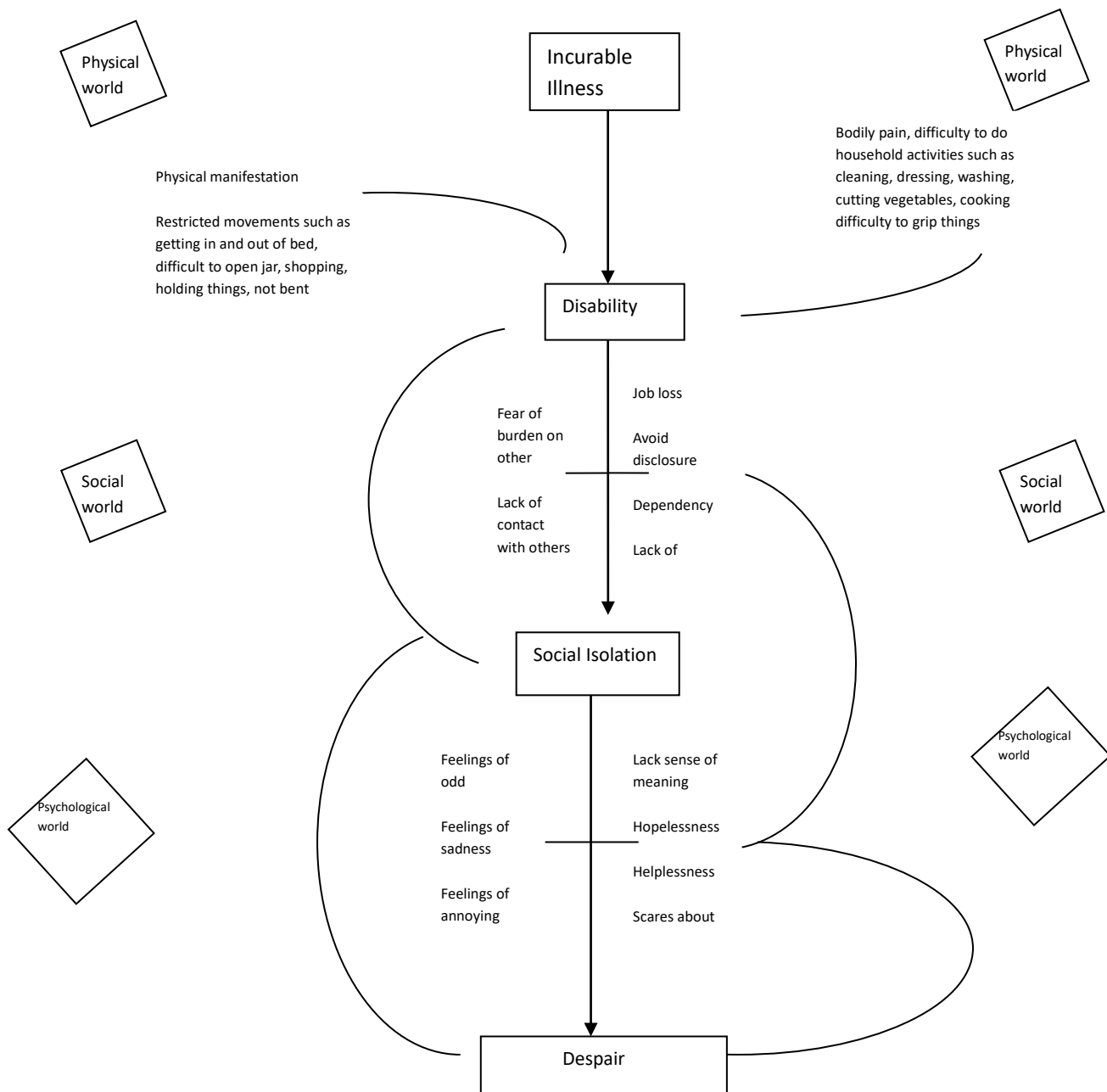
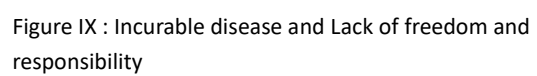


Figure VIII: Incurable illness and worldview

4.6.6. Memo 6: how incurable chronic illness lead to lack of freedom and responsibility?

Through above participant's data, it seems to me that participants with incurable illness experience their impact of physical, social, psychological world and confronted with their existential crisis and wonder about what is point to live if we die and their meaning of life. In confronting with their existential crisis, they experience death anxiety and having lack sense of meaning and lack of freedom and responsibility (see Figure IX).



4.6.7. Memo 7: How incurable illness leads to awareness of death mortality?

Participants with incurable disease experience disability due to physical impact of disease and suffering from other complications of disease, it impacts on their prognosis. Due to awareness of their death mortality, they experience fear of dying, nightmares, worry about outcome of disease, dying with pain and loss hope to live longer. But using meaning-based coping and realistic approach, they accept their limitations being a human and changed their attitude towards life and accept their death mortality (see Figure X).

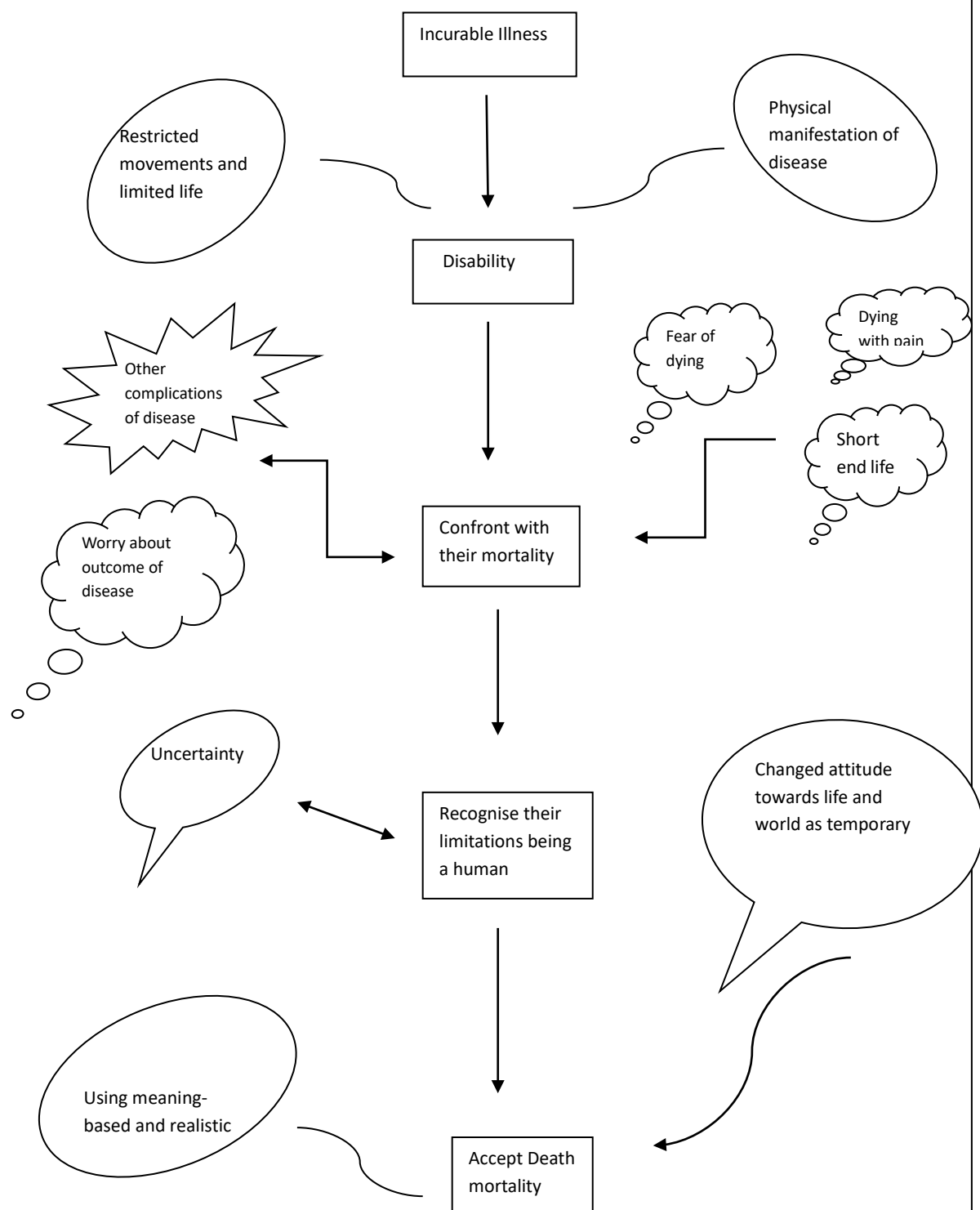


Figure X: Incurable disease and Death Mortality

4.6.8. Memo 8: how incurable illness impacted on participant's self-image and their way to cope.

Through above participant's data, it seems to me that participants with incurable disease reported their physical manifestation of disease that affected on their mobility and end them with limited life. Due to their restricted self, they experience intense emotional such as embarrassing, shame, demoralizing, nuisance, feeling of robbed by disease, feel like a caged animal, sadness, frustration and helplessness. Then they perceived themselves as a worthless person and dependent person on others and as an old woman who use stick or scooter and having restricted movements and have low self-image. Using solution-focused coping and realistic coping such as using cream and make up to cover their physical manifestation of disease and accept their disease as out of their control and recognise their limitations, they accept themselves with their disease and start to ignore other's comments (see Figure XI).

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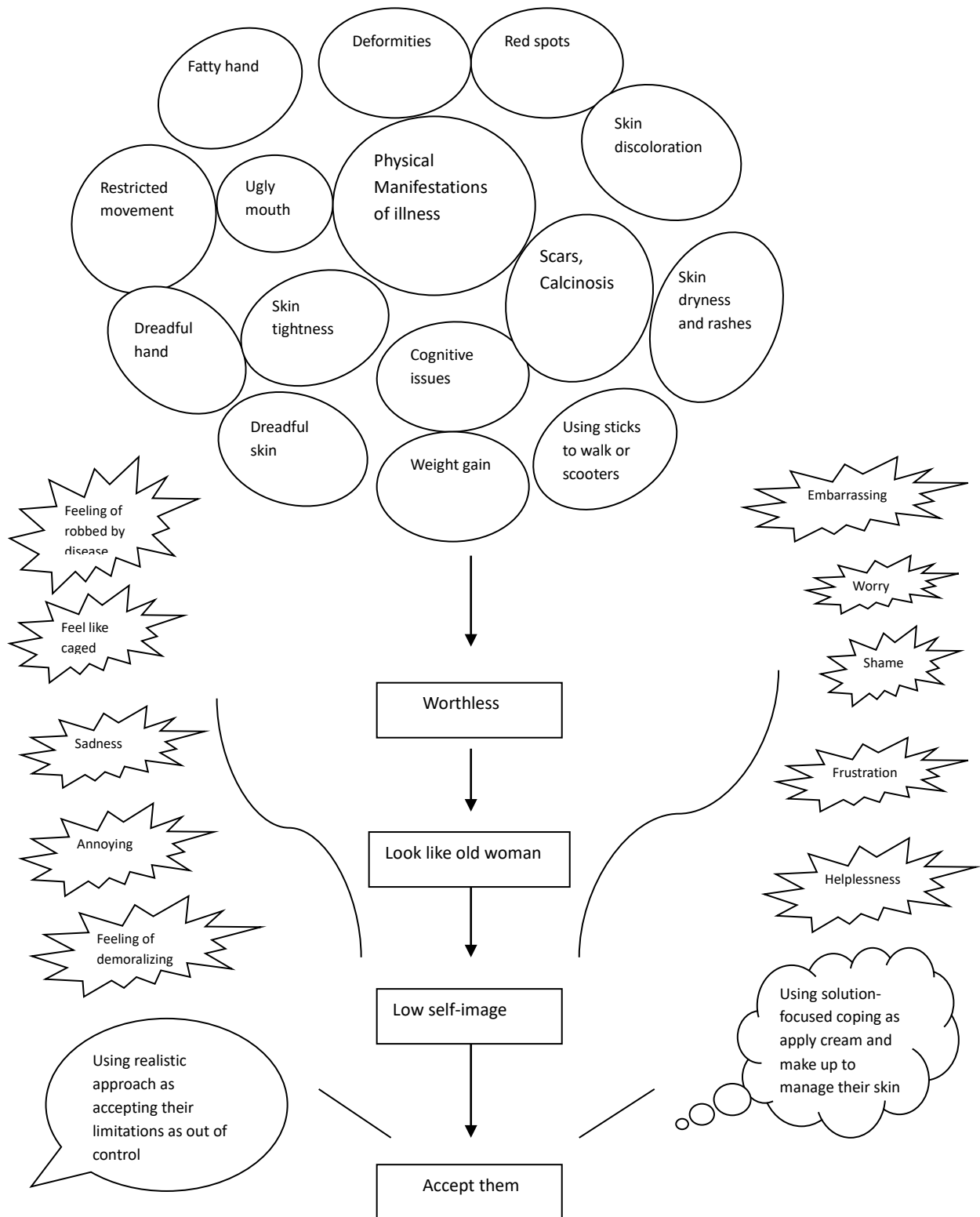


Figure XI: Incurable disease and self-image and coping styles

4.7 Axial Coding

Axial coding is third step of coding presented by Strauss and Corbin (1990). This coding is linked up to categories and subcategories. Axial coding identifies the characteristics and dimensions of a category (cited in Creswell, 2007).

Strauss (1987) perceived axial coding as developing a dense quality of relationships about the axis of a category. Therefore, axial coding follows the development of a major category, while it may be in an initial phase of development. The purpose of axial coding is to classify, integrate and organize large amounts of data and recollect them in new ways after open coding (Creswell, 1998, cited in Charmaz 2006).

Initial coding breaks data into separate codes. Axial coding is a stage where all the fracturing data comes back together again in a logical and consistent whole. Axial coding responds to questions such as ‘when, where, why, who, how, and with what consequences.’ With these questions, a researcher can explain the studied phenomena fully; however Corbin and Strauss stated that linking connections between categories takes place on a conceptual rather than descriptive level. The aim of axial coding is transferring data into concepts which makes a connection of categories with sub-categories and explores how they are related. Clarke perceived the axial coding as elaborating the category to develop theory and use diagramming to amalgamate pertinent categories (Charmaz, 2006).

An integrative diagram intends to associate categories with categories to shape a substantive theory of action. Strauss and Corbin use a set of scientific terms to make connections among categories during axial coding. To do this, they assembled participant’s accounts into components of a systematizing method to answer their questions.

This systematic method included, described in *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis* (Charmaz, 2006):

- 1) Conditions: it means the situations that shape the structure of studied phenomena;
- 2) Actions/Interactions, participant's strategies that they use in response to their issues, events and incidents;
- 3) Consequences; it means the outcome of actions that arise after using strategies. Strauss and Corbin apply conditions to answers to the 'why, where, how come, and when' questions. Actions/interactions respond to whom and how questions. Consequences reply questions of 'what happens' by using these actions/interactions.

In this study, I started axial coding when specific categories emerged from the analysis of the six research interviews, which allowed the development of the following categories and the relationships about the axis of a category.

This axial coding is based on all participants' interviews. The grounded theory model for living with systemic sclerosis is developed using the Charmaz's constructivist grounded theory from six participants interviews, displayed in Figure IX.

4.7.1. Causal Conditions of Phenomena Related to Living with Systemic Sclerosis

Causal conditions mean categories of conditions that influence on lives of people with systemic sclerosis. In this research study, there are two kind of causal conditions that derived from data that led to phenomenological experiences related to living with systemic sclerosis. These causal conditions explicate (a) Impact of the disease on daily life and (b) Existential crisis (see Table XIV).

4.7.1.1. Impact of the Disease on Daily Life

The 'impact of the disease on daily life' category was formed as one of the causal conditions that affected the people who live with this disease. The disease has impacted on the sufferers' daily lives in ways that I have divided into three major categories concerning the physical

world, the social world, and the psychological world of the participants. These three categories have different subcategories and are interlocked to each others (See Table XIV).

Participants reported physical symptoms such as Raynaud's, body swelling, stiffness, a painful body, restricted movements, body deformities, stomach problems, breathlessness and cognitive problems (see Table XI, XII, and XIII for more details). Due to the physical impact of the disease, participants reported their job loss and becoming dependent on others to do daily tasks including washing, cleaning, dressing, cooking, shopping, and also financially. These physical consequences of disease impacted on their independence and they lost their job. Due to their restricted movements and nature of their disease, they started to withdraw from social relationships and perceived lack of empathy from others. Although their family supported them during this crisis they still reported lack of understanding by family and others as they were unable to experience their positions. Participants reported their fear of disclosure about illness in a social world as some participants used sticks to walk and mobility scooters, Raynaud's manifestations if outside, and other manifestations of illness. They do not want to disclose their illness to others, and therefore they avoid going outside, they could not host more parties at their place as they are dependent on their family and have feeling of burdens on others. They avoided going outside with their friends and family due to the physical impact of the disease such as stomach problems. They become dependent on others to do shopping as it is difficult to use a trolley and hold shopping bags due to the physical restrictions. They feel ashamed and embarrassed due to depending on others and disclosure of the illness if go outside, so they decide to isolate themselves and try to live indoors.

Due to physical and social impact of disease, they experience different ranges of emotions such as frustration, embarrassment, nuisance, annoyance, sadness, being scared, crying, etc. Because of the physical and social impact of the disease, they feel helplessness (such as the disease is out of control, loss of control over bodily changes and being dependent on others for little things), hopelessness (such as not living longer, despair, no hope for cure, depressed to

have disease, lack of satisfaction with life, disappointment by friends), scared about having the disease and anxious about the consequence of the disease and reported changed self-image including dreadful hands and skin, ugly mouth, hating self, not more attractive, looking like an old woman and feeling left out by others. Participants reported they have lost most aspects of their lives. In my view, these three worlds are interwoven and impact on daily life.

4.7.1.2 Existential Crisis

The second causal condition consisted of an existential crisis they experienced due to living with incurable systemic sclerosis and struggling with questions such as what's the point in living? These thoughts raised existential questions around their life purpose and goals; questions concerning their being and uncertainty. This existential crisis was divided into two categories: (a) Sense of Mortality (b) Freedom and Responsibility (See Table XIV).

In first sub-category of existential crisis, participants reported their concern about mortality and talked about their worry about the outcome of the disease, fear about dying with a shortened life. They found it difficult to understand the disease, worried about what was not known and anxious about the disease's progression. Participants reported fear of dying, nightmares, fear of dying with pain but they accepted it as their own limitations in being human. After being confronted with an incurable disease and their sense of mortality, they have changed their attitudes towards them self and the world and perceived life as shorter, horrible and temporary. They have confronted their sense of mortality and accepted their death reality as inescapable.

In the second category of existential crisis, participants reported their lack of freedom and responsibility due to the nature of their disease. They reported lack of control over disease and their destiny to having this disease, disease manifestations and side effects of medications that they use to manage their symptoms. They feel helpless as they are bound to take these tablets that they do not want to take and loss of their independency. They feel less free for travel and dependent on others if they want to go somewhere and lack of freedom to choose to go

anywhere because they have to see other availabilities. They are unable to go outside on their own due to their disease and have bounded themselves indoors. They expressed feelings of being trapped by the disease and feeling robbed by the disease as they have lack of freedom on their lives and this disease has changed their choices as they need to do what is better for health rather than what they want to do. Due to the nature of the disease, they have changed their priorities, before they liked to go outside and focus on them but now they have to think about others and preferred to stay at home. Before they preferred to go outdoors but now they focus more on online chats as they stay at home. They have to wear layers of clothes to protect themselves from Raynaud's attack, this is why they never like to wear layer of clothes as they perceive themselves as not attractive due to layers of clothes. Due to the nature of their disease, they lack of responsibility as a mother, wife, daughter and friend. They depend on other for small things such as lack of responsibility for their own tasks and not take charge of anything. Due to the lack of freedom and responsibility, they perceive themselves as useless. After confrontation with their existential crisis, they experience lack of meaning in their lives. However, they start to search for meaning over period of time.

4.7.2 Phenomena Resulting from the Impact of the Disease on Daily Life and Existential Crisis

Causal conditions – the impact of the disease on daily life and existential crisis in which the participants experienced subjective central phenomena in six core categories as reported by the participants: (a) Disability (b) Social Isolation (c) Despair (d) Death Anxiety (e) Uncertainty (f) Lack of freedom and responsibility (see Table XV).

The first core category 'Disability' has different sub-categories, reported by the participants such as bodily symptoms and pain, restricted movement, loss of previous activity, restricted household activities and a dependency on others to do daily tasks. I found these sub-categories to be related to each other and shared a concept, I therefore developed a single core-category of 'Disability' which means that participants experience difficulty in doing daily tasks such as

dressings, cooking, cleaning, shopping, travelling, washing and depending on others to accomplish these tasks. They have restricted movement due to muscles and joints affected by systemic sclerosis. They depend on others to go outside as well as their manifestations of disease limiting them to engage with social activities. Due to the physical impact of the disease, they experience lack of energy and not enough power to do daily tasks and felt tiredness whilst doing household work. This relates to disability being defined as ‘a physical or mental condition that limits a person’s movement, actions, and senses (Equality Act, 2010).’

The second core category ‘Social Isolation’ has sub-categories of rejection by others, lack of empathy from others, lack of understanding by others, lack of contact with family including parents, children, siblings and others, loss of job, loss of old relationships, withdrawal from social activities, fear of disclosure about illness, fear of social stigma, lack of support from family, disengagement with others etc. I put these sub-categories into one single core-category ‘social isolation’ due to the inter-relating relationship of these sub-categories. It makes sense that participants living with systemic sclerosis experience impacts on their social life as seen in the way they avoid contact with people and found a lack of support from others because others could not understand their condition and disease which left marks on their face like red spots, Raynaud’s etc. They tended to cover up their face or looked down to the floor in order to avoid any interaction with others which showed their fear of disclosure that they were ill. They lost their job due to being unable to cope in their work environment as people displayed a lack of empathy and they did not get any support from their family and was rejected by others. Some participants used sticks and scooters to walk outside but they experienced shame and embarrassment to use outside. Therefore, they avoid using these mobility adaptations. Due to their disability, and other symptoms of the disease, they were reluctant to join social activities leading to a lack of social contact with old friends and a loss of friendship and a loss

of previous plans. I found these sub-categories related to social isolation meaning near or complete lack of contact between the individual and society.

In the third core-category 'Despair,' there are other sub-categories of helplessness, powerlessness, hopelessness, sadness, negative attitudes towards self, scared about disease, feelings of worthlessness and loneliness. In my view, 'Despair' refers to sadness with no hope of a cure and being unable to handle life's experiences impacting on their social relationships as well as on their self-image. Due to their disability, participants experience sadness and depression in having the disease and recognising their own limitations due to the disease. They reported lack of positive attitude towards life and experienced loneliness and hopelessness due to loss of previous goals and no cure for the disease. Participants experience helplessness due to being out of control over pain and dependent on others for little tasks. They reported being scared about the disease and its consequences such as ending up in a wheelchair and fear of losing fingers and their fear of getting worse from the disease. Due to the physical and social impacts of the disease, they experience a changed sense of self such as changes in appearance, feelings of hypochondria, dreadful hands and skin, perceive themselves as ugly and scruffy due to wearing layers of clothes and they experience low self-esteem when with other people. They withdrew from relationships with others and stay in their homes and feel loneliness. They found their changed self-image and changed identity in terms of loss of independence, loss of job, loss of relationship, loss of previous household activity, and loss of some previous goals and purpose of life, and loss of previous plans. They reported lack of satisfaction with their lives as they have lost old meanings and goals for their lives. The participants suffered from an incurable disease and they have no hope of a cure. Living with an incurable disease, they feel helpless, powerless to continue living in the way they were used to and they have changed appearances due to the physical impact of the disease. In this way, they experience despair as a single core-category due to their inter-connecting relationships.

In the fourth core category 'Death Anxiety,' there are other sub-categories such as a fear of dying, nightmares, the distress of dying, never thinking about death before illness, the changed view about the world and other people, seeing the world as temporary, the fear of isolation, the loss of physical existence. I found all these sub-categories to be inter-connecting and developed a single core-category of death anxiety. Participants reported that when they first came to know about their incurable disease, they started to think about their mortality as it is an incurable progressive disease. Participants reported their fear of dying, nightmares, dying with pain and consequences about disease and embraced their death reality. Participants reported as having taken their life for granted and not thought about their death. After diagnosis with this disease, they embrace with their death awareness and they have now confronted their sense of their own mortality and have intense fears about dying and have had nightmares since that day when they encountered the fact of their own mortality.

The fifth core-category 'Uncertainty' has sub-categories of fear of the unknown concerning the illness outcome, fear of the unknown, anxiety about the future, thinking about getting worst, managing the illness in the future. Participants reported their worry about getting old with the severity of the disease and anxious about having flared ups again. They are worried about future financial management and unknown bodily changes. They try to find answers about the cause of the disease and thinking about mortality after the disease. Due to the inter-connection of each sub-category, I tagged it as 'Uncertainty' which showed the participant's anxiety about the future as well as fear about the outcome of their illness.

The last core-category 'Lack of freedom and responsibility' grouped the difficulties concerning making choices, feelings of being controlled by others, loss of freedom, the inability to make choices freely, the lack of decision making power for the family, household planning etc, the inability to travel freely, the inability to take responsibility, the lack of faith in her own ability to make choices, loss of control over bodily changes due to disease, loss of responsibility in being a mother, wife and daughter as well as the loss of previous meanings in

life. Due to physical and social impacts of the disease, participants experience lack of freedom in their lives such as avoiding going outside and lack of control over the disease and side effects of medications. They keep themselves at home and avoid visiting their friends and experience difficulties doing shopping on their own; they have to await other's availability if they want to go shopping. Participants reported this disease has changed their priorities as they do things that they didn't like before such as they need to wear layers of clothes to protect themselves from Raynaud's whereas they did not like to wear layers of clothes before. Due to loss of previous freedom and responsibility, they perceive themselves as useless and worthless and unable to take charge of their life.

In this group, I found all these to be related to loss of freedom and responsibility that means they dread and display anxiety about making choices for their life and assigning a meaning for their life. As a result of lack of freedom and a loss of their old identity, they experience lack of meanings, however, they are struggling to find meaning and relate to what their freedom allows them to do and to make new choices in accordance with their limitations.

4.7.3. The Context in which Strategies Developed to Adapt to Living with Systemic Sclerosis

Strategies for coping with systemic sclerosis were constructed in response to their disability, social isolation, despair, death anxiety, uncertainty, and lack of freedom and responsibility. These strategies were affected by specific contextual factors related to both causal conditions that are the impact of their disease on daily lives and their existential crisis. These contextual factors are composed of (a) sensations (b) duration of onset symptoms (c) duration of diagnosis (d) duration of treatment (e) length of relationship (see Table XVI and Figure XI). Sensations experienced by the participants ranged from mild to severe intensity in bodily pain, joints and muscle stiffness, swollen, tense body and dreadful fatigue. The duration of their disease varied from 1 year to 9 years, although they reported their onset symptoms from two years upwards but it took time to diagnose them due to the tricky nature of the disease.

Participants reported their treatment timeline varying from three months to five years. Participants reported their stable long-term relationships from ten years to forty years (see Table XVI and Figure XI).

4.7.4. Intervening Conditions Influence Strategies to Help Cope with Systemic Sclerosis

There are also intervening conditions that influence the participant's choices about adapting to cope with systemic sclerosis. Intervening conditions included (a) type of disease (b) other health problems (c) side effects of medications (d) pain phobia (e) lack of facilities (f) lack of awareness about counselling process (see Figure IX). Three out of six participants were suffering with a diffused type of systemic sclerosis whereas the other three participants were suffering a limited type of systemic sclerosis. These types of systemic sclerosis impacted on choosing the coping strategies to live with systemic sclerosis. Other health problems are causing more complications to their health and worsening their disease. These others problems affected their choice to cope with their disease. Participants reported that their other health problems related to their disease are varied such as osteoarthritis, arthritis, low vitamin D, anaemia, hyper-tension, Sjogren syndrome, psoriasis, under active thyroid and chronic knee problems. Participants experienced side effects of their medications such as nausea, insomnia, headaches and allergies but they were unable to stop these medications and unable to control their side effects and experienced frustration and annoyance. These side effects of medications have influenced their choice to opt for their coping strategies. In this study, participants reported their lack of knowledge and awareness about the counselling process. I feel it is another intervening factors that has impacted on their capacity to choose coping skills; they did not find help for their emotional experience and have limited knowledge about how counselling can help people who are suffering with an incurable disease, as one participant reported, *"I suppose it might do, I don't know, I've never really thought much about counselling, I've always thought it was a bit odd!"* and another participant said, *"how is*

talking to someone else gonna make it any better, you know they're, they're just gonna have their ideas.” Another said, “our illness is, is all complex, I don't know how a counsellor would understand it.”

Only one participant used the counselling service to cope with her illness. She reported, *“I've just finished the CBT because I wasn't coping emotionally with the disease and what it had taken away from my life, the way it's changed my life. I have self-referred again and I'm actually waiting to, to see a clinical psychologist equipping myself the best way I can to deal with this.”*

The three participants reported on their pain phobia, including their fear of invasive treatment and investigations. These phobias were contributing more on their emotional experience of the disease and making them more anxious about the disease and its treatment procedure, it influenced their way to cope as one of the participants used sedation for her gastrointestinal investigations and another used a CBT approach to deal with her needle phobia, as people with this disease have to check their blood test on a regular basis but it is very hard to get the veins due to disease's impact on their skin, vessels and veins. She said *“I undertook cognitive behavioural therapy to get over the needle phobia, to be able to have a blood test, to diagnose the disease and now I have monthly blood tests and IV, yeah that side of it scares me a lot because of the phobias.”*

Participants talked about their lack of facilities, such as not getting appointments in short time and lack of understanding about their emotional experience by consultants. They have no treatment facilities or specialist services near to their homes. They have to travel in remote areas to access their medical appointments and their facilities. Due to the nature of their disease and its impact on their physical self, they become more tired and exhausted whilst travelling to attend their appointments.

One participant reported their lack of facilities in terms of having of no proper heating at her home. She said, *“The other thing is our house is a big old farmhouse and it's not very well*

heated. We have a kitchen with a nice warm Aga cooker in which keeps the room next to it, where we, we eat and we watch television warm but the rest of the house isn't very well heated.”

4.7.5. Strategies/Actions Taken to Cope with Systemic Sclerosis

In the above context and the intervening conditions, six phenomena (disability, social isolation, despair, death anxiety, uncertainty and lack of freedom and responsibility) led to the development of five core strategies to assist in living with systemic sclerosis: (a) problem-focused coping (b) solution-focused coping (c) meaning-based coping (d) social coping (e) realistic coping (see Table XVII). The strategies within each core category are described in Figure XI.

Participants who experience disability phenomena used problem-focused strategies in order to manage their symptoms such as taking their medications to feel better and to control other flare ups of the disease as well as to manage their days, treatment measures such as blood tests and lung function tests and other investigations to monitor health, self-help such as taking supplements and avoiding stress and seeking professional help. Participants used solution-focused strategies to find different ways to deal with their disability such as cleaning the house by asking help from others, using tools to clean the home, dividing tasks to minimize pain, trying to do things once a day, using kitchen tools such as food mixers, dishwasher, big knives to grip, using trolleys for shopping, asking others for help with shopping, carrying shopping bags with different parts of the body, using bags with wide straps to get grip, using rubber caps to open bottles or use ring pulls to open bottles, using gloves as heating to avoid Raynaud's attack, wearing warm clothes and layers of clothes to avoid cold, using hot water bottles and sheep skin woollens and heating pads to protect themselves from attack, using extra pillows under the head and legs to avoid reflux, changing diet plans, using bath chairs to take a shower, using stick aids and scooters to walk, using physical adaptations to drive cars such as steering and electric brakes, buying stretchy clothes, using face cream to cover red

spots and applying makeup and nail paints to perceive themselves better and manage their pain by taking painkillers, taking hot baths and warm showers, swimming to get a little flexibility in their body, using memory foam to manage their pain and listening to music and doing exercise to deal with their sleep problems. These strategies were employed by the participant in order to try to be independent.

Relating phenomena of social isolation, participants used solution-focused strategies and social copings they manage their emotions such as sadness, annoyance, and loneliness by expressing and sharing this with their partner. They watch television to distract themselves from their feelings and do meditations and use mindfulness techniques to seek hope and feel better and reduce their anxiety. They walk outside and try to ignore other attitudes. They read books to change their mind and distract themselves from being overwhelmed by the disease. Participants used the social coping skills by getting support from their family, siblings and friends and they help them to manage their daily lives such as dressing, cooking, shopping, travelling and cleaning etc. They get support from the Scleroderma Society helpline and use Scleroderma Society forums and make new friends and use humour to cope with their feelings about disease. They get relaxed by sharing their feelings with other members in the forum and with their new friends and joined health clubs as well to make new social lives and get relaxed by going to the cinema and going to warm places for holidays with their partners. These strategies were used by the participants in order to try and engage with the outside world.

In relation to their phenomena of despair and lack of freedom and responsibility, they used their solution-focused coping strategies to manage their emotions and seeking hope through mindfulness and meditations. They used social coping to interact with other people in order to rebuild their new social relationship and shared their feelings with other people at the Scleroderma Society forum and joined different health clubs and internet forums to interact with others. These participants used meaning-based coping to deal with their feelings of despair. They adopt positive attitudes towards disease and counted their blessing such as

monitoring their disease improvements and getting financial support from the government, and having supportive partners. They are seeking their meanings such as in their religion, in their work at charities or from their grandchildren, trying to find their goals and create new values such as being loving to friends and family, trying to get satisfaction from a beautiful sunrise, natural beauty such as birds, butterflies, animals and finding different ways to build courage by observing other people who are more disabled than them, trusting in their religion, self-motivated through work, through going to warm places, and building courage by learning of cures for other diseases, creating hope for a cure. Participants were receiving internal support from their religion and religion values and trying to figure out about their disease and its consequences, making sense of their disease and understanding their limitations due to the disease. Through meaning-making strategies, participants become more compassionate and empathetic as to find new purposes in life and making new values for self and others such as motivating others to focus on positive things and become more understandable for others, living with an illness and guiding others, helping others to understand their life and disease and encourage others to have hope for a cure, in order to manage their emotions and new purpose in their life. Through using this meaning-making strategy, participants attempt to seek new meanings and new values for their life and new purpose for their life in order to re-build their sense of self. The participants used these strategies to make sense of their own experience, and in order to seek a new meaning in their life.

In relations to their phenomena of death anxiety, uncertainty, despair and lack of freedom and responsibility, participants used realistic coping to deal with their disease and to manage their emotional experience. Participants accepted their disease and its consequences and they tried to get more information about the disease through reading articles, reading online forums and website and talking with other people to get more information about the disease. Participants embraced their death awareness after getting this illness and with time, they accepted their death mortality and recognised their limitations due to illness and trying to make sense of the

disease through being realistic as it is an incurable disease. The participants accepted their disease in order to live more authentically.

4.7.6. The Consequences of Strategies to Cope with Systemic Sclerosis

The strategies used by participants have consequences. These consequences are (a) empowerment (b) being-in-the-world (c) searching for new meaning (d) being-in-time (e) changed sense of self ((f) live authentically (g) hopeful (h) wish to live.

Through using these strategies, the participants are able to feel empowerment which means using different ways to manage their pain and disability through medications and adopting different strategies and tools to regain some independency in their lives. Through using solution-focused coping and social coping, they are able to make new relationships with others, make new friends, go outside, join health clubs and go on holidays with partners and using humour to engage with world. Due to the nature of her illness, they isolated themselves from society and did not take part in any social activity. Through realistic, social and meaning-based coping, they are now able to experience being-in-the-world and relating to others, and focusing on their relationship with the outside world.

Through using meaning-based coping, participants are able to search for new meaning through helping others to seek satisfaction, trying to get meanings to life through reflection, enjoying natural beauty, seeking meaning through religions and doing work for society welfare and trying to get meaning through religion, welfare work, food bank and guiding others and getting sources of meaning from grandchildren and through nature's beauty such as sunrise, sunset and gardening etc.

Through using realistic coping, they are able to focus on being-in-time which means they live in present moments and thinks about now, instead of planning for the future. Participants recognise their limitations being a human and being a sufferer and they accept their death mortality and plan to focus on present moments instead of jumping for the future and they

start to live one day at a time and take each day as it comes rather than planning for their future and they enjoy their present moments.

Through using meaning-based coping and realistic approaches, participants accepted their changed sense of self, focusing on present moments and enjoying the quiet and getting satisfaction through helping others and, warm weather, sunshine. They have changed their previous self-concept and their life goals and accept their new sense of self. With this changed sense of self, they start to value life more in that they used to take life for granted before and understand the importance of life and have more tolerance for other people, value self and their friends, interact with family and appreciate what they have, giving more value to simple things and trying to be happy more with simple things and understand life values and be more empathetic for others. Through using the meaning-based coping, they found a new purpose in their life, and changed the meaning of their life as well. Before, they did not feel sufficient empathy for others who have the disease but after their own personal experience, they are able to become compassionate for others, with a new purpose to their life and they learn to live in a more meaningful way.

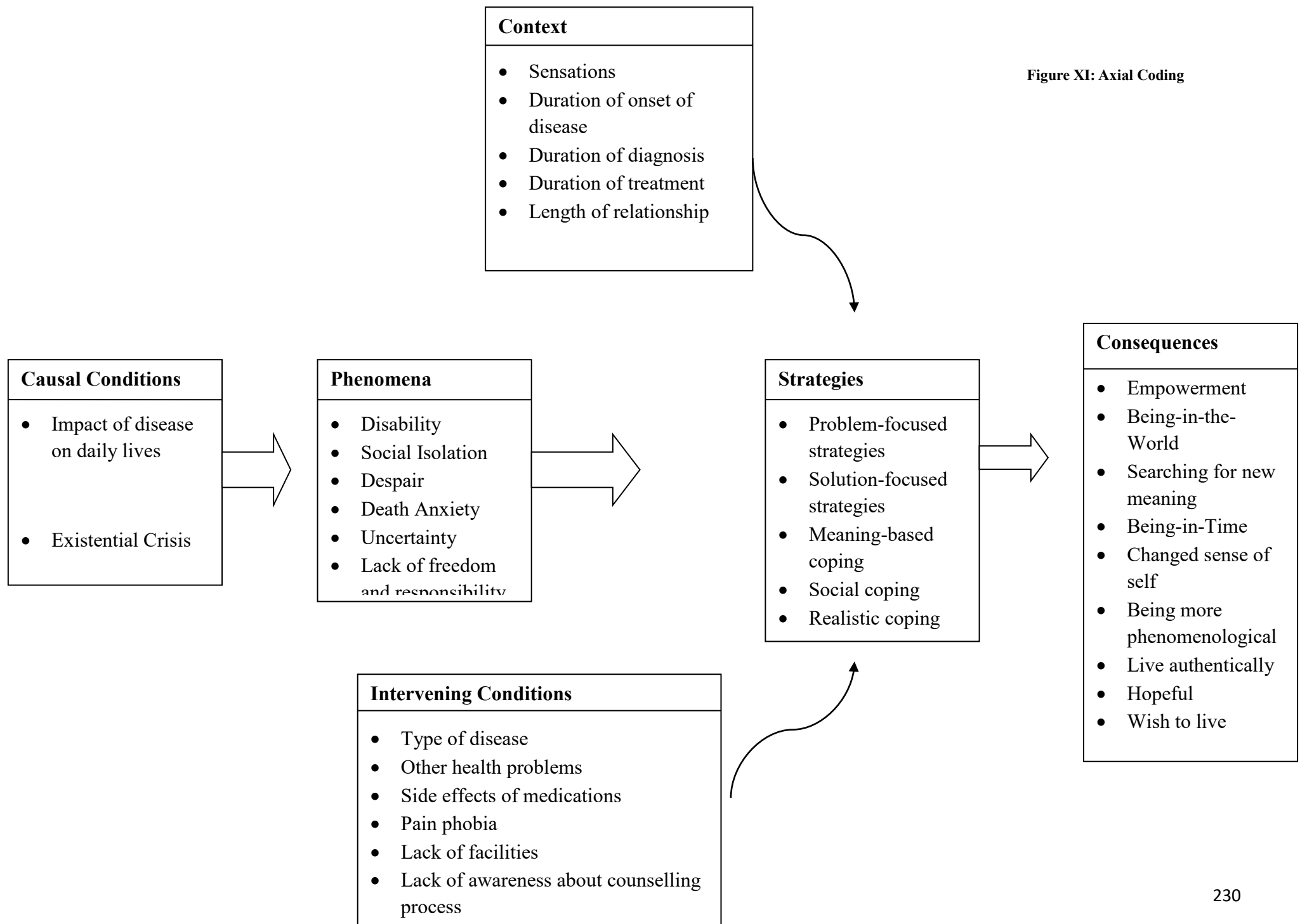
Through using meaning-based coping and realistic coping, participants have started to think phenomenologically, which means they have started to give value to little things that they took for granted before. They understand the values of life and make more sense of their experience by being more reflective and ready to explore their experience being a sufferer and focus on them self and try to be present in moments and making meaning for their experience.

Through experiencing the idea of their own mortality and their disability and using the meaning-based coping and realistic coping, they manage themselves through accepting their own limitations and possibilities as a human being as well as being a sufferer and understand what their disease allows them to do and not to do and they try to live authentically, living their life fully and focusing on what they feel and want in their life.

Through all of these strategies, participants feel hopeful to get better with medications and they have hope to be cured in the future and hope to find more ways to live with this disease and more able to do their physical tasks and expect to gain their independency back to some extent and they get courage through knowing cures for other diseases and hope for a cure themselves.

Through using all these strategies, participants wish to live in a meaningful way such that they want to explore the world, have a good night's sleep, have intimate feelings again, wish to live longer, wish to do all the old things such as study and work etc, a wish to fulfil their own wishes and make new friends, being positive in life, treasuring good things, to write their own epitaph and wish to cure disease, wish to be young again and regain their independence, wish to do certain things and go to warm places and to be rid of disease and explore other ways to fulfil wishes. Through using all these strategies, they are now able to rebuild themselves in terms of making new relationships, new choices and a new plan for them.

Figure XI: Axial Coding



4.8. Reflection on Two Types of Systemic Sclerosis in the Findings

There are two types of systemic sclerosis (scleroderma); one is limited scleroderma which mostly affects people's faces, hands, arms, feet and legs and where patients can also suffer from lung and digestive problems over time. However, within this type, the disease predominantly affects people's skin. In other types of 'diffuse scleroderma', the whole body is affected by the disease, such as the skin, body and major organs, including the heart, lungs, kidneys and stomach (Scleroderma and Raynaud's UK, 2016).

Six participants were recruited for this study. Out of the six participants, three had the diffused type of systemic sclerosis and the others had scleroderma, the limited type of systemic sclerosis.

4.8.1. Intensity of Pain

In order to see the difference in the participants' experiences of living with systemic sclerosis, their data was segregated into the two types of systemic sclerosis. I scrutinised the participant's data carefully and discovered 'Intensity of Pain' as a factor that somehow made their experience of living with systemic sclerosis more distinct amongst these two types of illness. Participants with the limited type perceived their level of illness more severe as compared to participants with the diffuse type of disease.

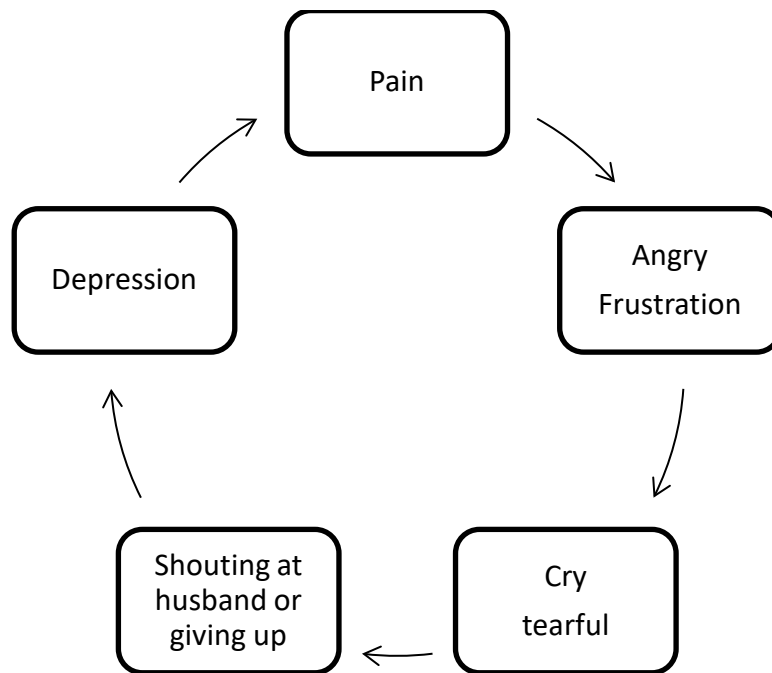
In this study, I found that participants with the diffuse type of systemic sclerosis were more sensitive to experiencing pain than other groups of illnesses. A part of the psychological and subjective experience of pain is also related to the mechanism and pathological role of systemic sclerosis as the diffused type of scleroderma has a greater effect on joints, muscles, ligaments and tendons and is related with musculoskeletal pain. In my findings, I found that participants with the diffused type presented their bodily pain more in muscles, neck and joints which led to restricted movements of the body than the other group. It does not mean

that participants with the limited type of disease did not have joint or muscle pain as they agreed that whilst they also experienced pain in their body it was to a lesser extent.

In order to understand their relationship with pain, two participants evaluated their intensity of pain as good days and bad days, as pain is a subjective experience. I found that the fifth participant, who had the diffused type of systemic sclerosis, and the sixth participant, who suffered with the limited type of systemic sclerosis, talked about how the intensity of their pain resulted in a good or bad day. Through inspecting the data repeatedly, I identified that a participant with the diffused type gave more detail on the intensity of their pain which made their days as good or bad. They reported that they were able to walk when they had less pain and expressed their relationship of pain with their emotions in that less pain made her happy. It was clear to me that pain also impacted on their relationship with the world.

On a bad day, she would become more frustrated, depressed and angry due to the severe pain in her body. She also expressed that the pain led to unhealthy behaviour, such as shouting at her husband whilst she knew that it was not his fault. It seemed to me that pain not only impacted on their mood but also resulted in maladaptive behaviour. She reported that pain also affected her self-image as, when she was in more pain, she hated herself and perceived her life as worthless due to being unable to do anything for herself. She articulated her feelings as a 'knock on effect' meaning pain led to anger and maladaptive behaviour and ended with depression. However, she reported that she does cry and is tearful in dealing with her emotions and just tries to accept her condition. The model set out below illustrates that pain plays a role on feelings, mood and behaviour synchronously.

Figure XII: Pain Model



On the other hand, the participant with the limited type of disease expressed the role of pain in her daily life by describing her days in a more categorical way, such as reporting that a good day was when she had less pain. She disclosed her bad days being when she has to drag herself out of bed and make the effort to eat or do anything. She feels self-pity and experiences helplessness, reporting that she copes with her bad days by getting support from her husband.

It seemed to me that participants have better control over their mind, body, actions and themselves generally when experiencing less pain. However, their illness remains in the background of their lives. They expand their spatial and temporal horizons, reporting: “on my good days, I walk so far with the dog and like being out”. On good days, they experience their sense of being and find more opportunities to be the selves they wish to be. They forget self-doubt, questions about self and their fears during good days. Davis (1963) and Wiener (1975) stated that ill people may “normalise” their pain and fatigue, worrying that it pervades even their good days (cited in Charmaz, 1997). Further, they reported their bad days as

having less control over mind, body and actions, with limited choices about activities. In addition, they experience uncontrollable feelings such as shame, sadness and frustration towards themselves. Their spatial awareness and horizons become smaller during bad days and they sink into feelings of alienation.

Moreover, whilst I found that participants generally developed a fear of dying due to the progressive nature of the illness, I found that participants with the diffused type of systemic sclerosis associated their fear of dying with pain but participants with the limited type experienced a fear of dying not related to their pain. It was clear to me that pain is a dominant factor in the participants' lives that have the diffused type. In my findings, the second and fifth participants expressed their fear of dying with pain with one of the participants considering the choice of 'Dignitas' in their later stages instead of suffering with pain. However, I did find this 'fear of dying with pain' amongst participants who had the limited type of illness, in spite of having pain.

Pain is a common experience associated with scleroderma and is a predictor of the level of physical functioning (Benrud-Larson et al., 2002), disability (Miller, Rehberger, Gunther & Schmitt, 2012) and psychological factors such as depression (Benrud-Larson et al., 2002; Miller et al., 2012). However, it is a subjective experience and varies amongst individuals. In this study, I found the relationship between pain, disability and depression to be a cycle across all the participants' data but with a greater presence in the participants with the diffuse type of disease (cited in Kearney, 2015).

4.8.2. Coping Variables

In terms of coping strategies, I did not find any significant differences amongst the coping strategies depending upon the type of systemic sclerosis being suffered. The participants virtually all used the same level of coping strategies to deal with their disability, social

isolation, despair, death anxiety, uncertainty and existential angst, whilst their pillars of support and the intensity of the disease varied amongst them.

The findings highlighted a difference in religious coping styles amongst two participants. The fourth participant, living with the diffuse type, reported that she became more religious in order to alleviate her symptoms. On the other hand, the sixth participant living with the limited type of disease lost faith in religion; she was catholic before and she believed that if there was a higher being then she would not be suffering like this. In terms of the severity of the disease, she rated herself as being at the severe level of the disease and the duration of her treatment was only at three months when the interview was conducted. It could be possible that her loss of trust could be related to her recent diagnoses and treatment.

4.8.3. Fatigue

I found fatigue to be a distinct category amongst all the participants, irrelevant as to the type of disease they were suffering with. After reading the research data many times, I discerned that participants with the limited type of disease encountered 'fatigue' more than pain when asked about their experience of living with systemic sclerosis on a day to day basis, whereas participants with the diffused type put more emphasis on pain and tiredness than fatigue. In my own understanding, fatigue has some correlation with the sensation of pain and the severity of the disease. Participants with the limited type of systemic sclerosis experienced both fatigue and pain which impacted on their perceived level of illness. It might be suggested that participants with the limited type could be perceived to class their disease as worse than the other group due to experiencing both fatigue and pain. However, the other group with the diffused type expressed their feelings of tiredness.

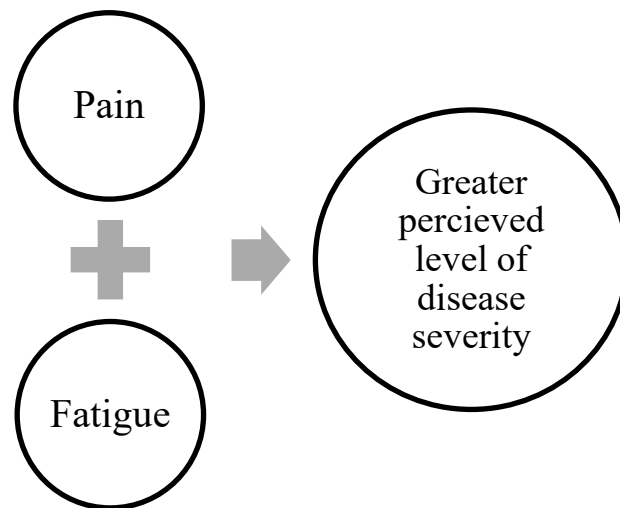


Figure: XIII

I also endeavoured to ascertain the relationship between experiencing fatigue and the duration of treatment. I was able to discern that participants with the limited type of systemic sclerosis who were having or had received treatment varied from a period of three to fourteen months, whereas the other group's duration varied from five to nine years. Participants with the diffuse type of systemic sclerosis also assumed that fatigue and the duration of treatment interplays with each other. Participants who are receiving treatment for a few months are more prone to experience fatigue than those who are receiving treatments for years. In respect of their coping style to both pain and fatigue, they used similar levels of coping strategies, such as resting or managing their tasks differently.

In addition, whether suffering from limited or diffuse systemic sclerosis, the time elapsed for all participants between the first symptoms and diagnosis varied widely depending on their medical journey. I did not find any difference in participants with regard to their diagnosis journey.

4.9. Theoretical Saturation

Theoretical saturation means a situation where a researcher is not getting more new information in relation to particular categories and all concepts and categories are well developed. This idea of saturation was first denoted in grounded theory. Qualitative study

used saturation mostly to define the data satisfaction. Theoretical saturation is a point in grounded study where researchers are not getting any new information from further data (Charmaz, 2007). Thomson (2011) articulated that there is no fixed sample size to determine the reaching of theoretical saturations.

The categories are saturated when gathering new data no longer achieves new theoretical data and not disclosing new properties of core theoretical categories. Glaser (2001) talked about saturation as not getting the same themes repeatedly and abstract concepts that yield various properties of the pattern until no new data appears (cited in Charmaz 2007).

In this study, I made categories theoretical and converted them to an abstract and general level along while protecting their relationships to the data from which I established these categories. I interviewed six participants and found saturated data after interviewing the third participant. At the sixth participant's interview, I stopped to recruit more participants for this study as I found my data was 'saturated'. The rational of grounded theory evokes saturation as the standard to apply to your categories. Glaser and Stern (2001) focus on continuing sampling until all categories are saturated and this logic surpasses sample size that may be very small (cited in Charmaz 2007).

Dey (1999) disputes the idea of saturation on two points: the meaning of saturation and its outcome. He was criticised to use the word 'saturation' because he sees the categories suggested by information. Therefore, he preferred the term 'theoretical sufficiency' which means data is sufficient to make theoretical categories and he perceived the words 'theoretical sufficiency' better to conduct grounded theory research. Being a researcher using grounded theory, I was open to observe what's happening in the field and grappled with it (Charmaz, 2007). I stopped recruiting more participants when new information was no longer appearing about studied phenomena. It gave evidence of fully saturated data to me. According to Charmaz, sample size for meaningful studies relies on the research question at hand

(Charmaz 2014). This study research question was to explore ‘how people experience living with systemic sclerosis and how they do cope with this disease.’ I found the data saturated after interviewing three participants but I carried on conducting interviews until the sixth participant’s interview. During conducting interviews, I did constant comparisons throughout all the analysis and made clear all relationships among categories. Then, I ceased conducting more interviews when I had theoretical saturation, then I started to write up all of my analysis.

4.10. Selective Coding

The final step of the coding process is selective coding. In this process, I integrate and refine all categories and recognise the ‘central category’ that related to all other categories by which theory is developed (Strauss & Corbin, 1998, cited in Creswell 2007). To do selective coding, integration is an important part in bringing data together analytically to form a theory. There are several techniques to integrate the work introduced by Strauss and Corbin (1998). There are four ways to recognise the central category such as writing stories, memos, using diagrams and conceptualization. For this study, writing a storyline and diagram was used to identify the central category. The first step to integrate the data is to develop the central category that is main concept within study (Strauss & Corbin, 1998, cited in Creswell, 2007). In this study, the central category for my study was set out as ‘a process of changed sense of self in experiences of living with systemic sclerosis,’ this central category being linked to all other categories and sub-categories in order to make an explanatory story. The central category must be conceptual so other research can be undertaken using the theory in other areas. This analysis process and integration with other categories are important to develop the theory. Whilst struggling to discover the central category, I wrote a storyline delineating their feelings about what is happening in a participant’s life. Writing about participants’ lives helped me to integrate these thoughts and the data. The writing of the storyline helped to

understand the participant's experience of living with systemic sclerosis and also helped to discover their resilience to live with this disease.

In order to develop a storyline, I focused on axial coding to organise the components into conceptual parts of context, conditions, process or consequences and described the process through actions and interactions in response to their conditions and then linked with consequences as outcomes of these actions. This process helped to make sense of what was going on within the data and this context, condition, process and consequence provided the research as a framework to build the story.

Using a story line, a theoretical model was developed through integration of categories and sub-categories in axial and focused coding. The next chapter explained analytical point from coding to generate model and its process to develop theory for this study.

CHAPTER 5

ANALYTICAL PROCESS FROM CODING TO MODEL

In order to better understand the analytical process from coding to model, I gathered all the codes and subcategories and developed relationships amongst the categories so that a model of the ‘process of changed sense of self’ could be created.

‘I’m a different person; I don’t know what my identity is anymore?’ The beginning of my analytic story towards building the model of the ‘process of changed sense of self’ was when I found that participants perceived themselves differently. In analysing their different self, the participants talked about their loss of sense of self in terms of their appearance, their independency, their relationship to their world and their previous goals. I identified some central categories in the ‘process of changed sense of self’ that were most significant in this study and which also entailed other codes to be put together to form a coherent analysis.

I found that the participants experienced the ‘process of changed sense of self’ from two analytical perspectives:

1. Loss of Old Self

2. Disrupted Self or Biographical Disruptions

5.1. Loss of Old Self

In order to grasp how they now see their life in the world, it was imperative to learn about their past life— ‘who were they before?’ During this analytical process, I attempted to focus on their relationship with temporality in terms of how they defined themselves at different stages of their life, including their past, their present and their projections for the future with acceptance of their condition by way of developing coping strategies. I noticed from the

participants' data that they described their experience of living with systemic sclerosis by comparing their present self with their past life, which supported my analytical process.

The following is an extract from the first participant in order to understand the analytical process:

'It's very difficult and I've put on a lot of weight because of not being able to be as active (Appearance) and I was a very sort of physically active person before, so my body has changed significantly and I can't cut vegetables up because I can't put pressure on anything; I can't lift pans. I used to do a lot of ... I used to go to the gym a lot. I used to do a lot of walking, cycling ... erm gardening and that was the biggest enjoyment I had in life really and so a lot of that .. that's gone (Earlier Losses). I feel frustrated at myself that I'm not able to do things, erm, that I'm a bit useless (Emotional Process), I've just got to live for now and deal with it. I think you've got to be realistic rather than worry' (Resilience). The goals in my life were to progress, career-wise, but also the big thing was the travelling and learning about other areas of the ... of the world. My goals are to find some work that is rewarding, erm, to help others (Future).'

In relation to the above quote and analysis points, it seemed to me that the participants talked about their changes in appearance and their difficulties in carrying out their daily tasks and then compared themselves with their past, to how they were before. This participant has been living with this disease for the last three years and talked about her past self as though it had happened yesterday, an analytical process of a changed sense of self, meaning time permeates in the participants' stories. They looked back at the past through the prism of the present and their stories told us about the meanings of moments, with these telling moments marking and symbolising turbulent changes. The

participants recounted both how they were before having this illness and how they are now.

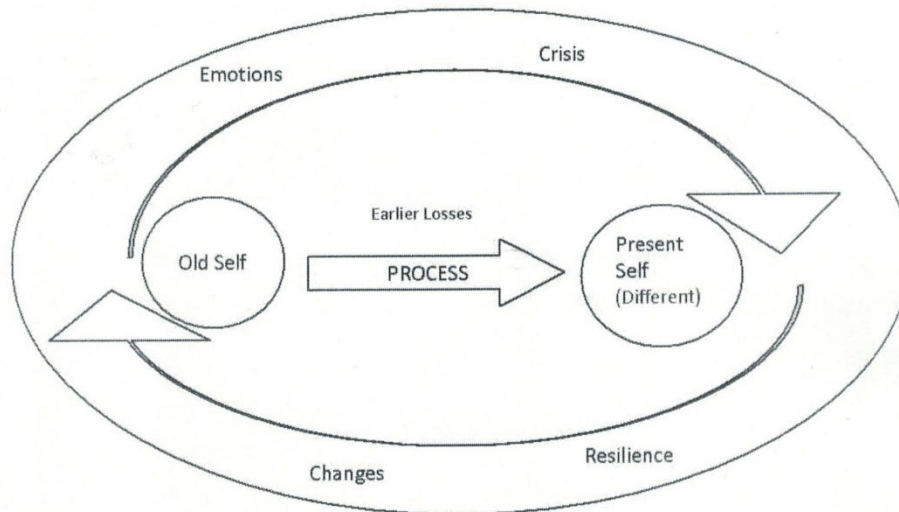


Figure XIV: Process of Earlier losses

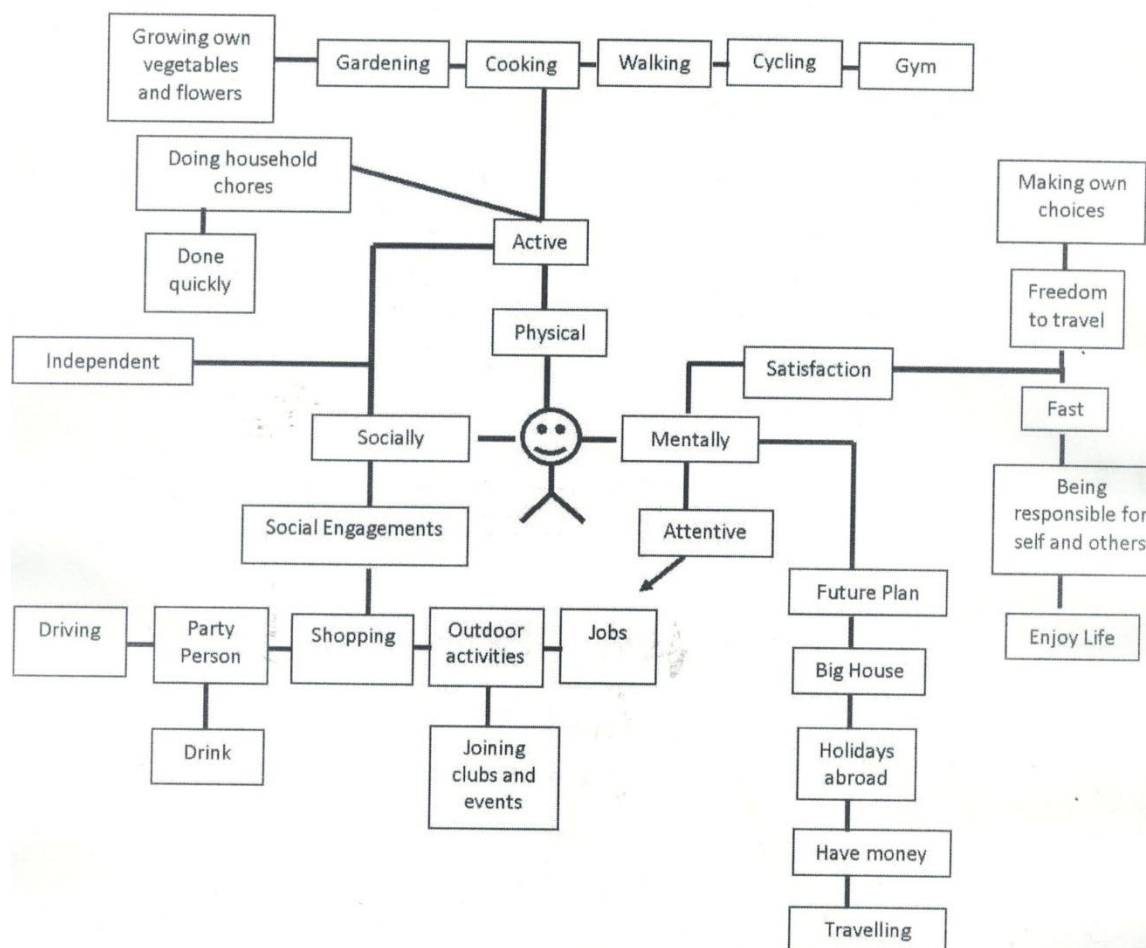
In this study, the participants talked about their loss of self in terms of their appearance, their independency, their relationship to their world and their previous life meanings. I found a central category of the ‘process of changed sense of self’ most significant in this study, which also entailed others codes together in a coherent analysis. In order to comprehend ‘what had happened to them after suffering with this illness’ and to build a theoretical model for this study, I needed to know about the participant’s past life and who they were before. This analytical process is related to the principles of grounded theory, a theory that was generated by using our past and present experiences and by engaging with others and their individual perspectives and research practices (Charmaz, 2006).

In order to grasp their process of the ‘loss of their old self,’ I started to discuss with them questions such as:

1. Who were they before suffering with this illness?
2. How they defined themselves before having systemic sclerosis?

I analysed the participants' data, codes, categories and concepts that were developed through the process of the initial, focused and axial coding during the iterative process. Through the process of memos and using constant comparative methods, I engaged with the research process and also developed analytical concepts in order to build the theoretical model for this study.

Figure XV below is a flowchart which illustrates 'how the participants defined themselves before having this illness'.



In the above Figure XV flowchart, it appeared to me that they defined themselves by way of their attributes such as working women, being active, their physical appearance, and their engagement with daily chores, being active in the social world and feeling free and responsible to plan for the future.

A loss of self symbolises more than just the physical losses. It means the loss of their way of life; the way people know, define and feel about themselves. Their identifying attributes have disappeared. The foundations of their lives have weakened or crumbled. Loss of self alters how people compare themselves with others and how they locate themselves in their world. It means losing the way they know of how to be in the world and, moreover, in its most intense form, is to lose their personal and collective worlds (Ciambrone, 2007; Charmaz, 1983, 1997; Mathieson & Stam, 1995, cited in Charmaz, 2011)). These resulted in chaos erupting with communities disappearing and lives being irrevocably changes. Loss of self resides at the far end of a continuum of the reconstruction of the self, regaining a valued self at the other end. Both are played out in a situation that ranges between certainty and uncertainty.

In this study, the participants compared their present selves with their past selves synchronously, which contributed to developing the model of the changed sense of self by living with systemic sclerosis. Participants talked about their old self as being an independent person as they used to work and were able to do their chores on their own. They referred to themselves as being party animals which gave me the sense that they were socially engaged people. They used to feel confident when they interacted with others and they set their future goals because they were healthier at that point.

'I used to walk very fast, now I can't, what with the muscle stiffness and the neck and the breathing ... erm ... yeah so, I used to do things very quickly. I used to be quite a party person, used to drink quite a lot and go out.' (Participant 2)

'I wanted to travel the world. I was, before we moved to Cumbria, before I was diagnosed, I was in a very good job earning lots of money but never having the time to spend it, so when we moved to Cumbria the plan was to do up our cottage and travel, well 'cos we've both been ill we can't travel anymore.' (Participant 5)

In the above extract, the participant related her present self with her past, where she referred to herself being quick in the past and very active, and then she mentioned her present and the loss of her abilities to do those things again as a consequence of this disease. The participants shared her former goals in what they had made for themselves and that they were unable to accomplish their goals now. The participants related themselves with their past which gave an indication of the 'different person' they were in the present. Through an iterative cycle of their past and present self, I was able to understand the process of the changed sense of self due to living with systemic sclerosis. Through this process, the participants experienced feelings of crisis, change and adapted resilience. By drawing the flowchart, I was able to learn about their old sense of self that existed before living with systemic sclerosis and also helped begin my analytical process to build the theoretical model for this study.

5.2. Disrupted Self or Biographical Disruption

'You were robbed of it weren't you, it was taken away from you'. The second analytical point I found in this study was the 'disrupted self'. In this regard, participants lost their old self and found themselves in a more vulnerable state. I found that there was a relationship between their perceived self and the biographical disruption over a period of time as they described their sense of self (the past, the present and a projection of their future).

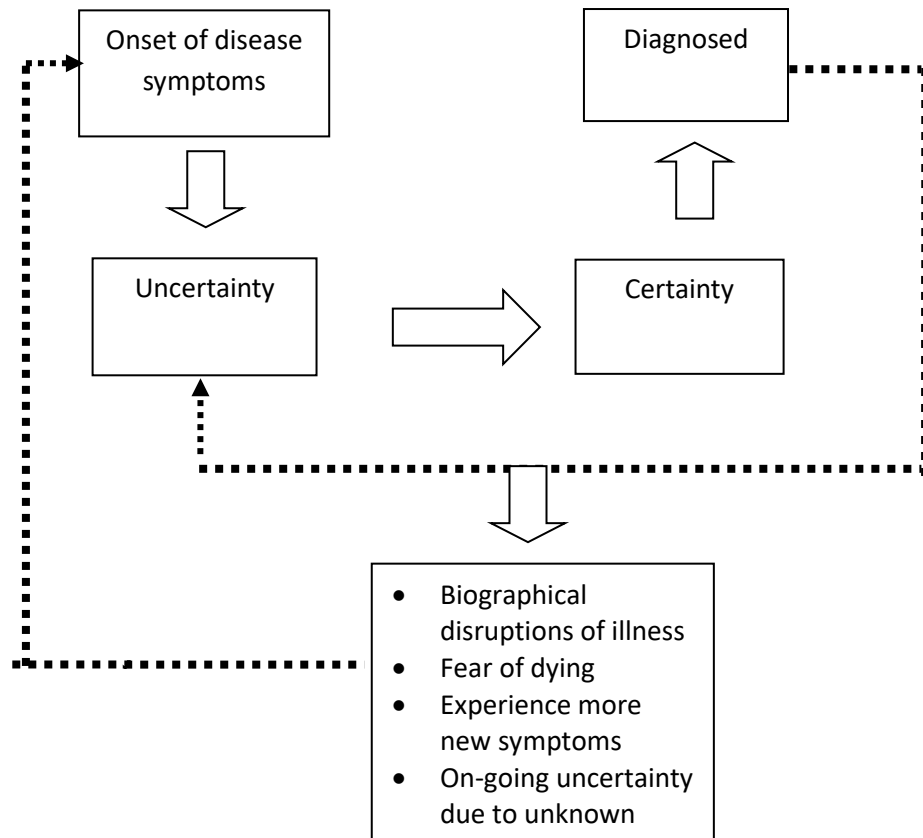
In order to understand their process of 'disrupted self' or their 'biographical disruptions,' I started to investigate with questions of their 'process of a changed sense of self' as a result of living with systemic sclerosis:

1. What happened when they were diagnosed (Remote Past)?
2. In what ways has the disease changed them (Past)?
3. How do they see themselves now or who are they now (Present)?
4. How do they think about their future or how are they planning for the future (Future)?

It is my understanding that the participants' biographical disruptions began when they experienced the initial symptoms of the illness and were uncertain about this disease. The initial onset of the symptoms amongst individuals varied from two years to thirty years. During this period, they were unaware about their illness but, at the same time, they were suffering with different presentations of symptoms. Overall, it took quite some time to diagnosis them and they found this journey very stressful and upsetting. They experienced a lack of understanding from others or felt judged by others as they did not perceive them as being ill, indeed two participants felt they were being treated as hypochondriacs. From the participants' data, it seemed that they had struggled to learn about their health problems and it was not a straight forward diagnostic process. All participants were diagnosed through different routes of referral and, eventually, they were diagnosed with systemic sclerosis. Participants reported their feelings of being scared and about the uncertainty due to the incurable nature of their disease. This was the point when they first felt shock, anxiety, frightened and upset. They suffered from a fear of dying and experienced uncertainty as a biographical disruption of the illness.

On the one hand, they became certain about their suffering and their illness but then their certainty altered into uncertainty again due to the unknown cause, nature and progression of the illness (see Figure XVI).

Figure XVI: Repetitive Cycle of Uncertainty to Certainty



In order to understand their biographical disruption, I endeavoured to look at the data to learn about their dynamic changes over a period of time. I found a 'fluctuation' in their experiences due to the unpredictable nature of the illness. Participants experienced being scared, a fear of dying and an uncertainty as a result of an incurable illness. Participants reported 'changes in their appearance' and physical pain, disability, restrictions on their self, a dependency on others for daily chores and a restricted social life over the course of time. They perceived themselves as being older than their actual age. This disease also impacted on their sexual relationships with their partners. They reported that they did not feel excited nor very agile in this respect as a result of the disease. Participants reported that they could not take charge of their responsibilities as they used to do before. They found that their roles had been changed and others had to take care of them, not only in respect of day to day chores but also for their personal tasks. Participants reported depression on different points after diagnosis.

One participant expressed that her depression was not only due to the disease but was related to her inability to 'be responsible for her cows due to fatigue'.

'I was quite depressed at the time and I think I was ... that it wasn't only because of the scleroderma, it was because of what was happening with the cows and this fatigue.' (Participant 3)

Whereas, another participant described their depression as a non-linear process of systemic sclerosis due to the uncertain nature of the illness during a bad phase last year.

'I went through quite a bad phase last year when I did feel very depressed and felt that ... where am I gonna go from here.' (Participant 2)

The fifth participant revealed her depression at a time when she was on chemotherapy for eighteen months and it did not help her at all; she described it as:

'Pain, erm, not being able to do things, frustration, [sighs] depression, see they all have a ... a knock-on effect.' (Participant 5)

It suggested to me that her pain was causing depression and then it caused more suffering and ended with frustration. One participant also reported depression when she did not find help through medication. Moreover, participants also experienced a loss of the goals they had set in their lives, goals for the future. They were unable to follow them due to the uncertain and progressive nature of their illness. For the moment they were not setting any goals and felt there was no meaning in life. It seemed to me that they were in the process of accepting their illness.

In this disrupted self, they described their feelings as being demoralised, devastated, frustrated and sad due to the uncontrollable and uncertain nature of their disease. In order to understand their disrupted self, I gathered focused codes and sub-categories and linked them with each other, putting them into major categories as to who shared their characteristics and properties with each other. Please see the Figure XVII below.

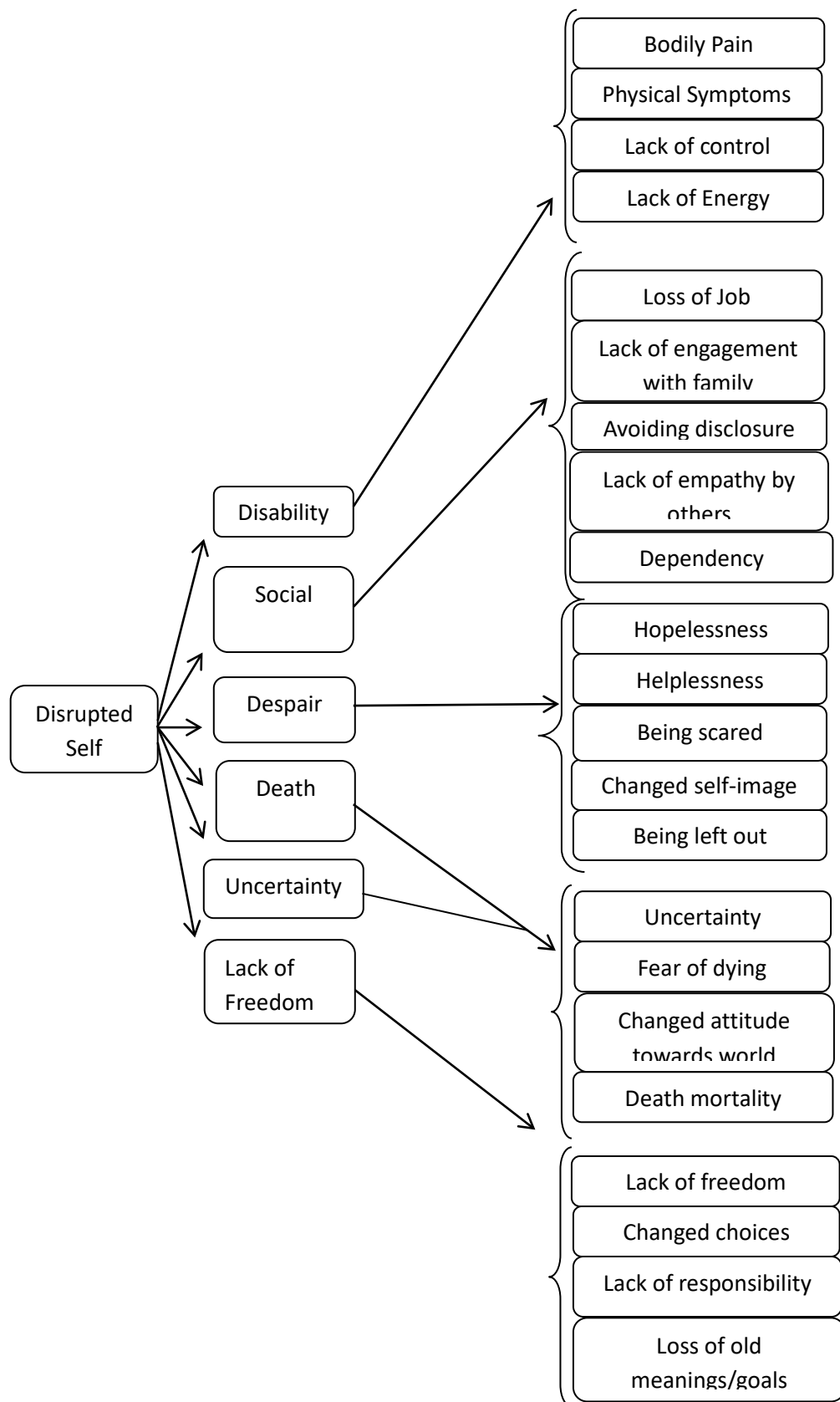


Figure XVII: Disrupted Self

The above diagram illustrated their ‘earlier losses and experiences’ as result of the disrupted self. The participants’ old sense of self altered into a disrupted self, due to the impact of the disease on their daily lives, leaving them to experience an existential crisis. Participants reported that the disease had taken away everything from them, as far as what they were used to.

I created the flow chart (Figure XVIII) below so that it could describe the whole analytical process in order to build the core-categories of the ‘process of a changed sense of self’ by living with systemic sclerosis. During this disrupted self, they experienced disability, social isolation, despair, death anxiety, uncertainty and lack of freedom. I was able to develop these categories through focused and axial coding (Please see chapter 4 and Tables and Figure for detail under Appendices sections). All these categories have sub-categories of the shared characteristics and properties within each category and I have also related them to other categories which led to the development of the core-category of the ‘process of a changed sense of self’.

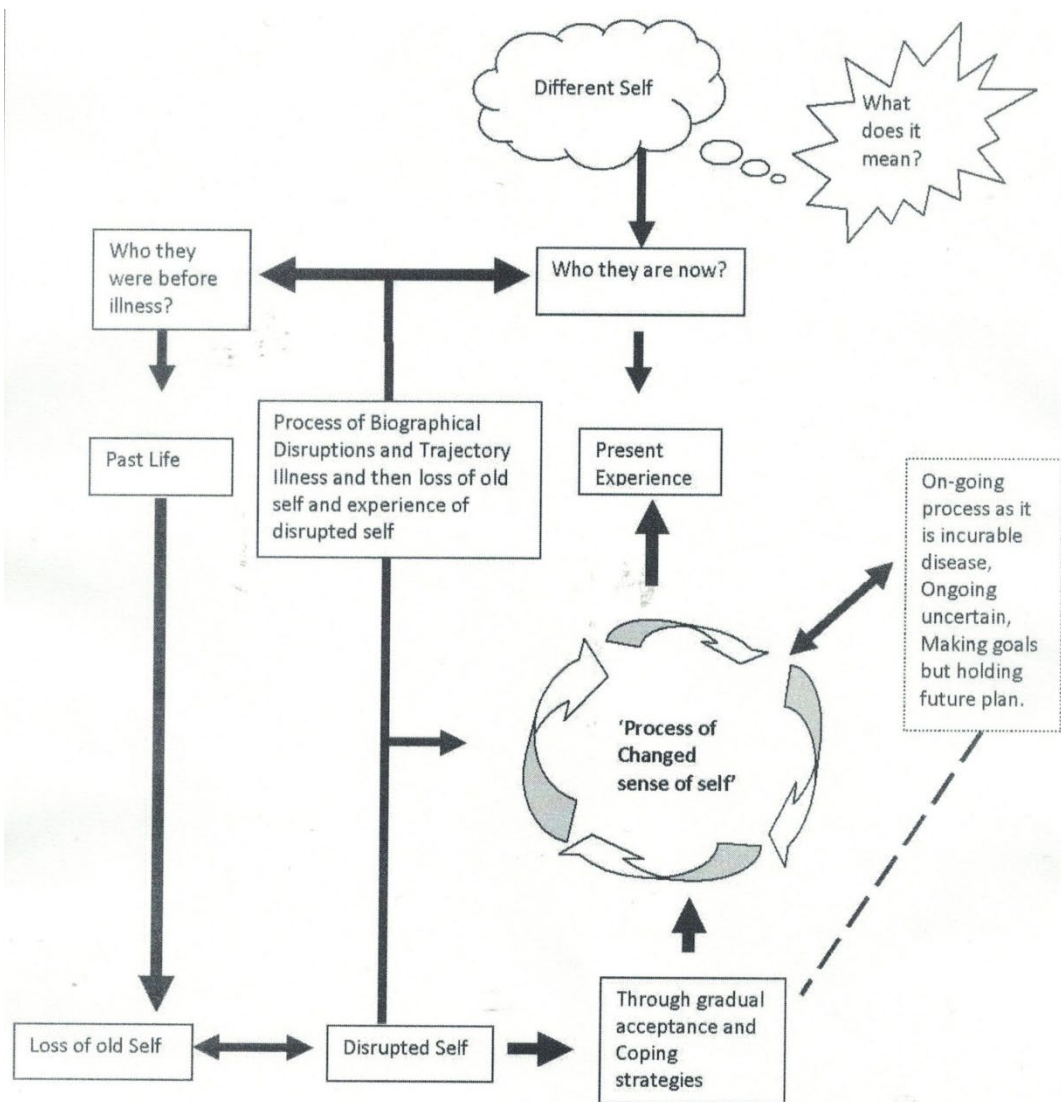


Figure XVIII: Analytical process for creating Model

In this disrupted self, participants suffered from physical disabilities in being able to carry out their daily tasks such as dressing, cooking, cleaning, shopping, travelling and washing and were dependant on others to accomplish these tasks. They experienced physical pain and had restricted movements due to the underlying nature of the disease and had a lack of energy. Therefore, they had to ask others to help them in order to complete their daily tasks. Due to their disability, they have restrictions on going outside on their own and they rely on others to travel. They also avoid contact with other people due to the manifestation of the disease and felt a stigma and a lack of understanding by others. Some of the participants reported that if they tended to go outside, they had to use sticks and scooters which embarrassed them and so compelled them to stay at home. Due to the nature of the disease and the disability, they felt reluctant to go outside and preferred to stay at home, thereby resulting in social isolation. As a result of this social isolation, they started to feel despair, helplessness, hopelessness, negative attitudes towards the self and loneliness, which again raised questions about self and identity. They found that their changed self-image and identity came in terms of loss of independence, the loss of work, loss of relationships, loss of previous household activities and a loss of some previous goals, a loss of purpose in life and a loss of previous plans. They reported a lack of satisfaction with their lives and a lack of meaning as they had lost the old meanings and goals for their lives.

The participants suffer from an incurable disease and they have no hope of a cure. By experiencing loneliness and uncertainty due to the nature of the illness, they suffer with death anxiety and nightmares surrounding a fear of dying as they cannot control their disease and do not have a cure. They experienced uncertainty in relation to the disease, they do not know how they contracted it and they suffer with unknown anxiety due to the progressive nature of the illness. Due to their disability and social isolation, they experience a lack of freedom in their lives such as travelling, shopping, working and socialising. They feel like ‘caged

animals’, as the fifth participant reported. They felt trapped and robbed by an illness, they do not feel freedom.

However, over a period of time, the participants developed their coping strategies and they accepted their illness as incurable, as well as accepting they have to live with the uncertain nature of the illness. They utilised different strategies in order to manage their daily chores and interact with others together with the support of their partner. They try to manage their life ‘one day at a time’, which does not necessarily mean that they are not thinking about their future but rather it means they are making plans for their future and time will tell. They have accepted the limitations imposed on them by their illness and recognised the way they can adapt and what they can do within their limitations.

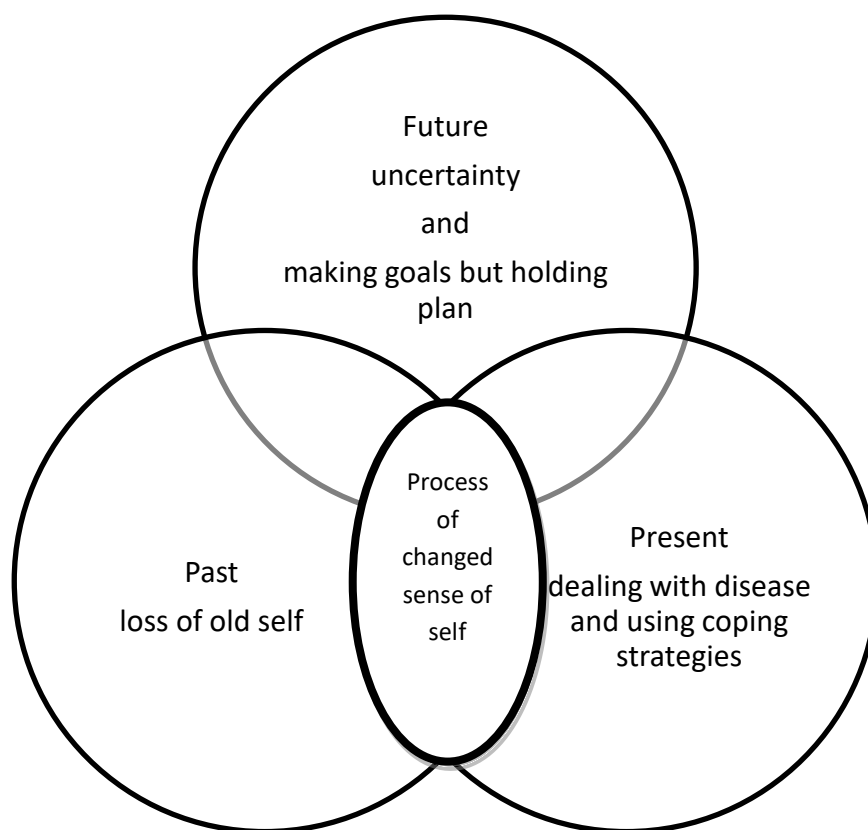


Figure XIX: Self in Past, Present and Future

It suggests to me that they have developed their relationship with their illness and accepted that they have to live with a certain level of uncertainty. By creating a relationship with their illness and dealing with their biographical disruptions, they have made new goals and set new values for their life, such as altruistic behaviour, charitability, helping others, enjoying the beauty of nature and spending time with families and animals. They see themselves as having a stronger future and express feelings of hope for a cure for this illness.

The above two analytical points helped me to develop a core-category 'process of a changed sense of self'. I choose the 'process of a changed sense of self' as I feel it is an iterative process which never ends or completes. It is an ongoing process due to the incurable nature of the illness. In the next chapter 6, I described systematic stages of theoretical Model 'process of changed sense of self' in response of living with systemic sclerosis.

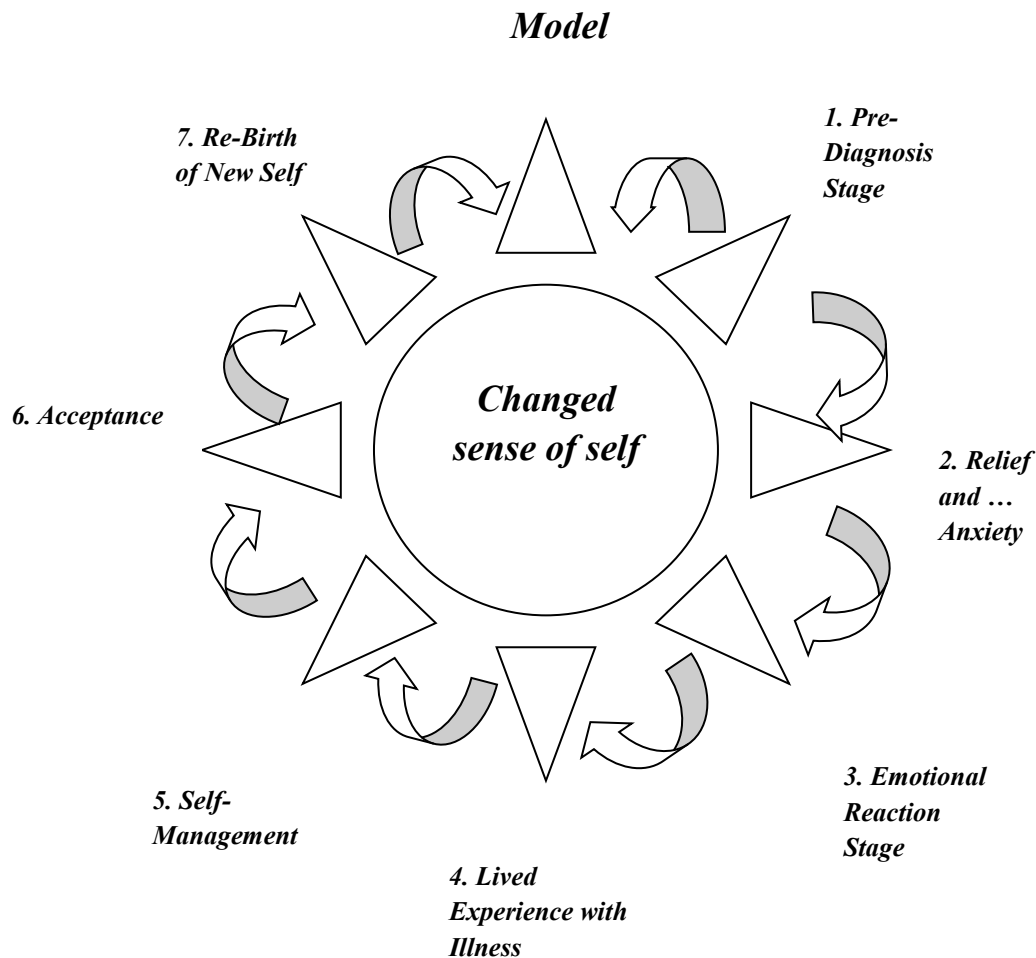
CHAPTER 6

THERORETICAL MODEL

6.1. Constructivist Grounded Theory as a ‘Process of Changed Sense of Self’

My findings and analytical process enabled me to develop the following model of a ‘process of a changed sense of self’ as a result of the experience of living with systemic sclerosis. After the analytical process, I was able to develop the systemic stages to understand the ‘process of a changed sense of self’ by living with systemic sclerosis.

This model displays that people’s experiences of living with systemic sclerosis were contextualised in the ‘impact of the disease on their daily lives’ and an ‘existential crises due to their struggle with the physical, social and psychological impacts of the disease’ and ‘confronting their death mortality and lack of freedom and responsibility’ (see Figure IX and Figure XXXII). Their experience of living with systemic sclerosis has seven stages to the cycle. This seven-stage cycle explains the model of the participants’ process of a ‘changed sense of self’ in living with systemic sclerosis by way of the participants’ data. See below Figure XXX for Model.



6.1.1. Seven Stages of Cycle in ‘Dynamic Process of Changed sense of Self’

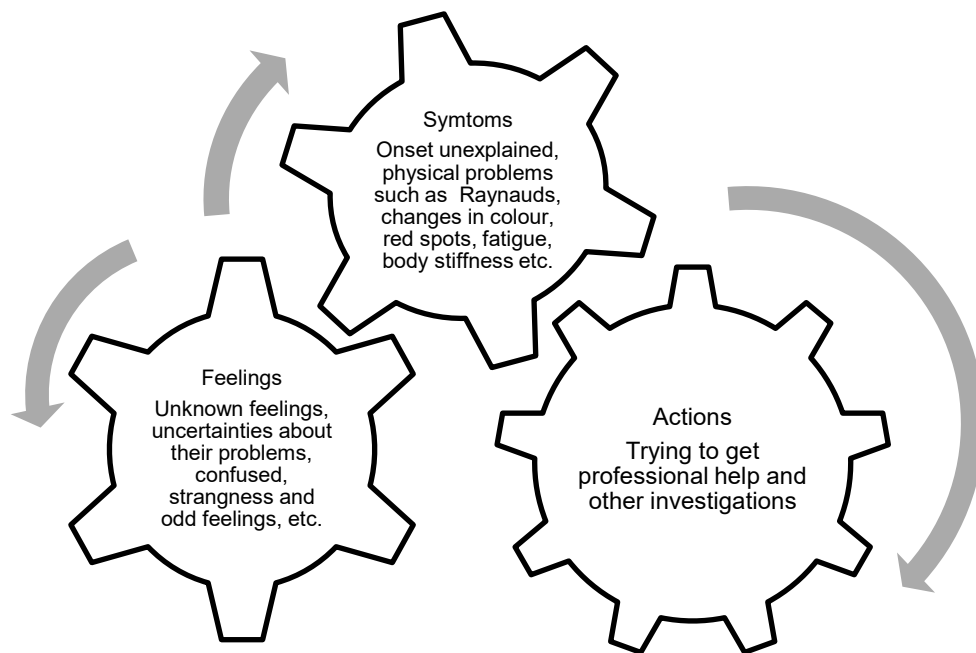
Stage 1: Pre-Diagnosis

At this stage, prior to diagnosis, a participant’s experience is one of anxiety about the cause of their symptoms and they do not understand what is going wrong with their body. As quoted from the second participant: *‘I was getting strange, because they noticed I was getting puffy arms and hands, and my very hard fingers ... neurologist had no idea just referred me to a dermatologist’*. They expressed their feelings of being unknown, or unheard of and strange, thought of as being a hypochondriac. The fourth participant expressed their feeling of being

strange: *'I went down to the doctor and said ... erm ... I'm getting stiff, and I'm getting quite strange'*. Some of the participants felt changes in their body, such as joint pains, red spots, swelling, and fatigue and skin issues, as initial manifestations of the disease. For example, the sixth participant reported: *'well I first noticed the little red spots but I thought that they weren't anything, but the main thing I noticed was like the dreadful fatigue, really tired all the time and aching, sort of, in my joints'*, and one participant exhibited initial problems with their breathing (for more detail, please refer to the Initial Coding, Focused Coding and Axial Coding). The participants reported their feelings of being a hypochondriac, such as the quote from the fifth participant who said: *'Stiff joints, painful hands, painful feet ... erm ... tightness of skin, depression 'cos not knowing ... erm ... reflux, being sick, it's trying to remember them all isn't it! [laughs] sound like a hypochondriac!'*

Participants started to receive consultations from doctors and underwent investigations so they could find out about their physical problems, as explained by the second participant: *'the neurologist had no idea, just referred me to a dermatologist who said I know what it is, and then sent me to a rheumatologist, so that took quite a few months to go through the system. So, I was properly diagnosed probably in summer of 2011'*.

In reviewing my findings, it appears to me that the participants experienced unknown and strange symptoms, feeling like a hypochondriac, despite the painful changes in their body as a result of systemic sclerosis. The findings for this theme demonstrate a process which I have depicted in a diagrammatical way below Figure XXI Pre-diagnose:



Stage 2: Relief and Anxiety

The participants felt some relief in finding out what they were suffering with but, on the other hand, they also experienced feelings of fear and being scared, such as in the quote from the first participant: *'Relieved there was a diagnosis then really scared, yeah, because I, on top of the disease itself, I have ... I had a phobia of anything like needles, going into hospitals, any sort of physical invasive treatment'*. After diagnosis, whilst a participant felt relief in knowing they were not a hypochondriac, as quoted by the third participant: *'I ... hopefully they are aware of the fact that I'm not a hypochondriac'*. The participant tried to read leaflets and read internet forums to obtain more information about their illness: *'My doctor and my rheumatologist haven't actually explained very much about the disease but they are aware of the fact that I use the internet'*.

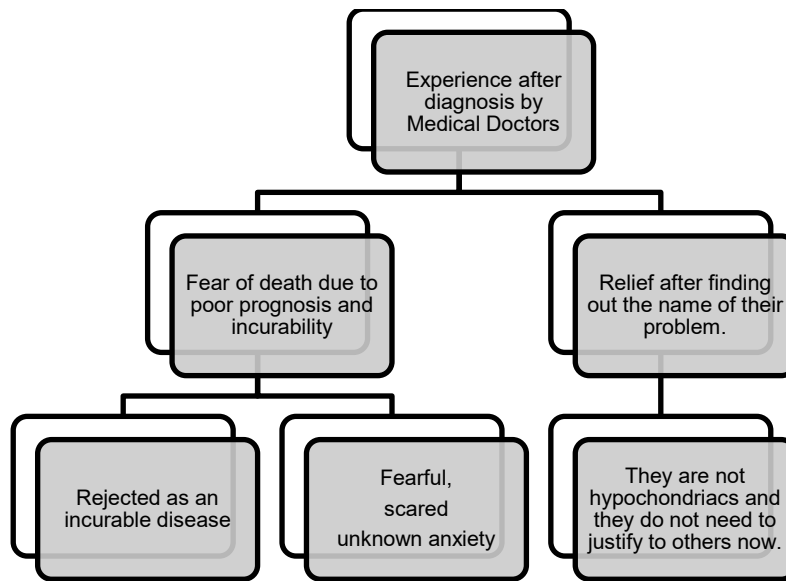
The participants experienced uncertainty and were scared about dying from this illness, such as quoted by the second participant: *'The not knowing, the uncertainty ... erm ... I suppose my biggest fear is dying of my lungs because I've lost fifty ... almost fifty percent*

capacity of my lungs now and in the past year I've lost another ... I've lost seven percent in the last year, so it's scary'.

Another quote from the fifth participant: *'It scares me, thought I was gonna die when you read what my GP printed, a lot off the computer about scleroderma and told me to go home and read it and I went home'*, and from the sixth participant's quote: *'It was, worrying, I was obviously aware that the disease is different for everybody, you know my [coughs] ... my grandmother lived to be 101; I might live to be 101 but I might live to be 51'*. There is also the shared experience of having an incurable illness, such as: *'I think it's more depressing that the ... erm ... there's no relief from the symptoms, and the fibromyalgia which is what he ... he said the aches and things were seems worse than...'*

However, it was very hard for them to accept their illness as an incurable illness. In the first instance they rejected it as an incurable disease, but, with time, they accepted their illness as incurable, as quoted by the second participant: *'Well I just accept and, you know, just accept that's the way it is'*; the fifth participant quoted: *'I was depressed and angry, more than I am now because over time you learn a bit to accept, you become more accepting of your condition'*. The third participant talked about their future as being limited: *'You know, I have to accept that my life pr ... very likely will become a lot more limited'*.

It appears to me from my findings that the participants experience relief on one side, but on the other side they experience feelings of being scared, a fear of dying, and nightmares due to the incurable nature of their illness. The findings for this theme demonstrate a process which I have depicted in a diagrammatical way below Figure XXII:



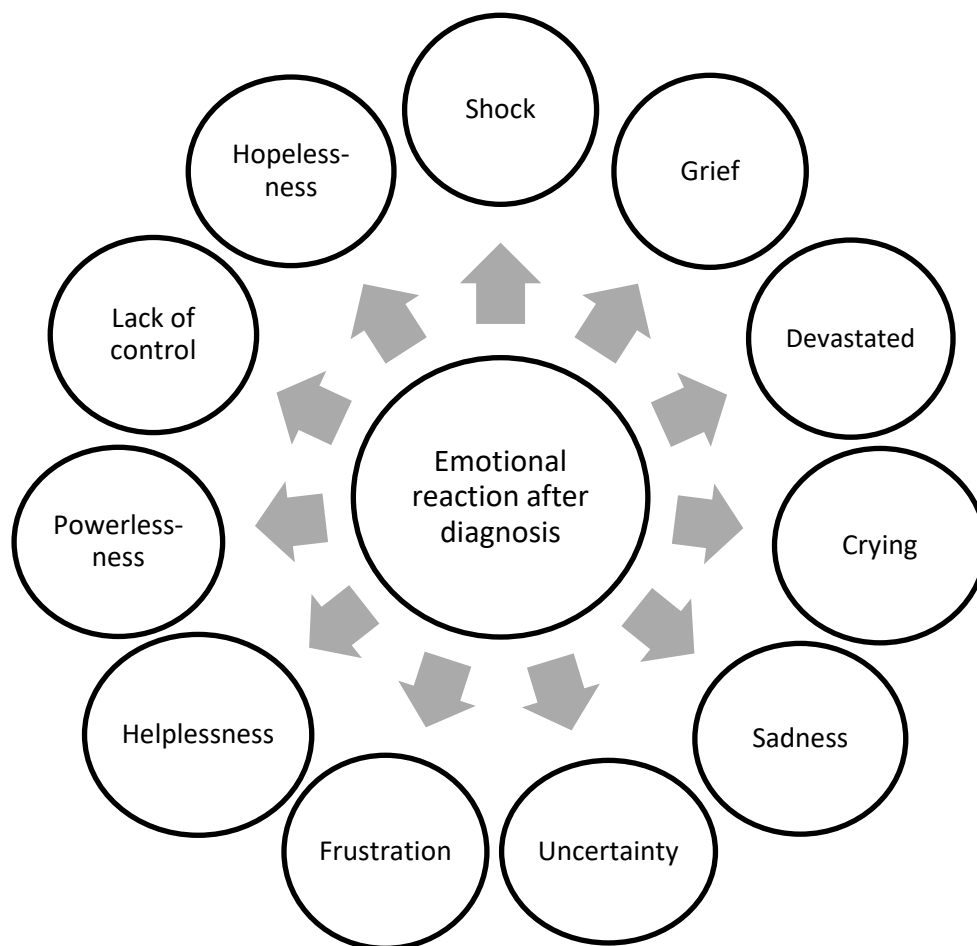
(Figure XXII- Relief and Anxiety)

Stage 3: Emotional Reaction after Diagnosis

In this third stage, the participants reported their initial feelings of grief, shock, devastation, frustration, and demoralization, such as that quoted by the first participant: *'I was devastated, really confused, didn't understand what it meant'*, and also reported feelings of sadness and grief, such as: *'sadness ... I find that really difficult and it's something that ... it's not something I wouldn't say I've got to anybody. I could talk to someone about it actually in my personal life, but I understand it's part of the process I think, like grieving isn't it, it's sort of grieving for ... for the life, the person you feel like you've lost'*. The second participant said: *'With myself really, I mean it is the disease that's doing it but I suppose I feel frustrated about myself really, I kind of take it out on myself, which is daft really'*. The third participant reported shock: *'shocked as if I hadn't been aware of the disease. I didn't know much about it; I'd just read a little bit on the internet'*. Whereas the sixth participant expressed their feeling of being demoralized, stating: *'I don't know, when I do find it a bit demoralizing, I think ... when I think ... have I got to spend every day like this gets you down a bit, you feel a bit "oh no, am I gonna have to live like this"'*.

These above findings seemed to suggest me that due to their experiences of this illness, which has made them feel scared, uncertain and helpless due to the lack of control in their bodily pain and feelings of powerlessness that their sense of being has been taken from them. Some of the participants believed that their illness would be temporary and it would be cured with treatment, but, over time, they realized that it would be permanent and incurable for the rest of their life and they have learnt to accept they have to live with this disease. (For more detail, please refer to the Initial Coding, Focused Coding and Axial Coding).

Below are Figure XXIII that shows participant's different emotional reactions after diagnose.



(Figure XXIII- Emotional Reactions after diagnose)

When sharing this news with their family, the participants reported a lack of understanding from family members. One of the participants reported that her husband understood her after a while, but her family could not understand her illness as she quoted: *'It took quite a long time for my husband to ... well probably both of us to understand what was going on. One of the things my husband thought was how I was starting to get lazy. Since I've been diagnosed, he's been a lot more understanding and he's a lot more physically supportive but the rest of my family, they sort of don't understand, they sort of ... they try to understand but they can't because I don't look as though there's anything wrong'*. Another participant reported a lack of understanding by their partner as she did not like him to pity her, such as: *'I don't think he understands because I look normal and because I try to do things that I normally would do; he knows I can't walk as far as I used to be able to and things, but because I try I think he thinks that it's not as bad as it is 'cos I don't think ... I try not ... I'm the sort of person that ... I don't like pity'*. The third participant reported the response of their partner in this way: *'He's very much "oh well I'm sure things won't be too bad" ... erm and ... and err ... so he's ... I suspect he is actually covering up a little bit of fear within him ... erm that ... that either he is gonna lose me early or that he will have a very disabled partner to look after...'*

By analysing this data, it seems to me that when sharing the news of their diagnosis with their families, participants reported a reaction of shock, but subsequently still experienced a limited acknowledgement of their illness and also a lack of understanding by family members, including husbands, parents, siblings and friends. Although they reported that they did share the news with their partners first, it was very difficult for them to understand their illness and they reacted shockingly, but with time they came to understand the problems and limitations imposed by their illness; not only did they accept the illness, they also supported them in their daily life tasks.

Stage 4: Lived Experiences with this Illness

After accepting their illness, they talked about their lived experience with systemic sclerosis. According to this study, systemic sclerosis has impacted participants' daily lives, such as in their physical, social and psychological worlds, and they experience an existential crisis in terms of their lack of freedom and responsibility, death anxiety and a lack of meaning in their lives, as derived from the participant's data.

Due to the disease's impact on their physical, social, and psychological worlds, and confronting their existential crisis, the participants experienced the phenomena of disability, social isolation, despair, death anxiety, uncertainty and lack of freedom and responsibility in response to the loss of their old sense of self. In sub-categories, participants experienced helplessness, sadness, annoyance, frustration, hopelessness, lack of satisfaction with their life, loss of old life goals, a loss of meaning and old values, and a low self-image in response to the loss of some aspects of their past self. (For more details, please refer to the Initial Coding, Focused Coding and Axial Coding).

In the diagram set out below (Figure XXIV), I have attempted to explain the six subjective phenomenon's that were experienced during the process of deriving the changed sense of self.

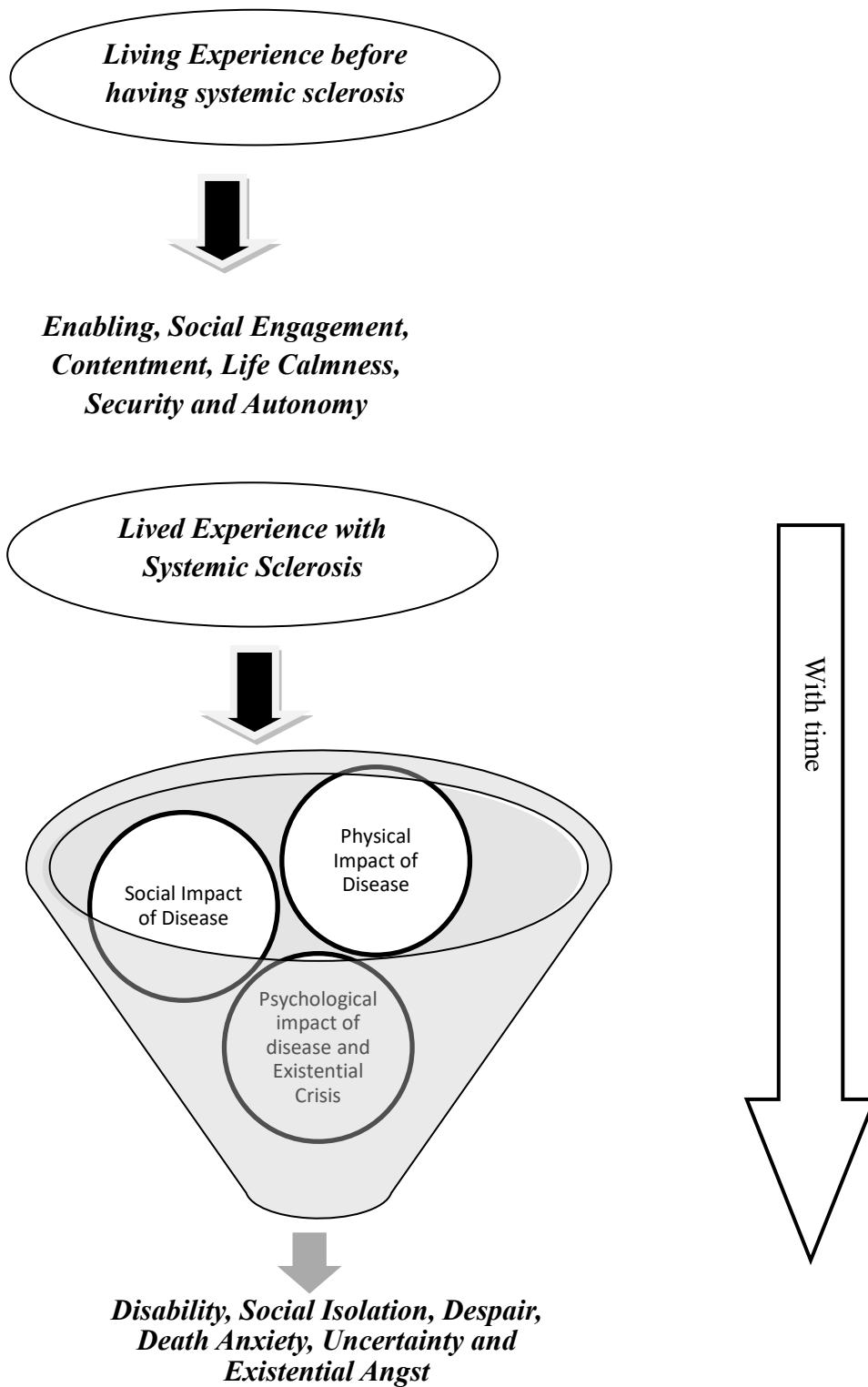


Figure XXIV: Lived Experience with systemic sclerosis

(a) Enabling to Disability

I use the word ‘enabling’ here because the participants used to do their daily chores on their own before having this illness. After contracting this illness, they became dependant on others to accomplish their daily tasks. The participants experience ‘disability’ as a central category that is affected mostly in their physical world. In their physical world, participants reported bodily symptoms and pain that restricted their movements to walk and travel, to go shopping for their personal possessions and to do household chores such as cleaning, washing clothes, ironing, cooking and washing dishes; their restricted movements also impeded their ability to dress and change their clothes, as quoted by the second participant: *‘I find housework very difficult to do, things like washing up are a bit of a problem’*. They became dependant on others to do the simple tasks they were no longer able to do, such as hold a knife for cutting vegetables or holding other objects due to the restricted hand and body muscle movements, as quoted by the first participant: *‘yeah, I can’t manage with the cooking from the point of view of, I can’t cut vegetables up because I can’t put pressure on anything; I can’t lift pans’*.

They are unable to walk and travel on their own due to their body joints and muscles that are affected by the disease, as quoted by the second participant: *‘I find it quite difficult, I can’t walk for a long time uphill, my stamina is a lot less than it was. When I used to go on holiday, I’d walk all day; I can’t do that now’*. They have to rely on others if they want to go outside which leads to fewer engagements with other people, as quoted by the first participant: *‘I don’t know how to word it really I ... I feel ... I do feel sort of quite disengaged so and ... and because I’ve had to give up work’*. Not only do they struggle with physical disability, they also experience cognitive limitations as they believe that their cognitive processes are not as fast as it was before, as quoted by the first participant: *‘I have problems with cognitive processing, they understand that the impact*

is hard on me to sort of process the way I used to thought process ... if I was to read some instructions I find it difficult to follow or remember'. Participants reported a lack of energy and fatigue if they attempted to do their daily tasks and then did not find enough energy to complete their daily chores, as quoted by the second participant: *'I'm very tired most of the time because at the moment I'm suffering from insomnia*'. Participants also became dependant in respect of their personal hygiene activities, such as bathing and showering, and needing help to change clothes, as quoted by the third participant: *'Well I'm not very often wearing clothes that need a collar button, jewellery is difficult because of the ... you know ... necklaces are difficult and bracelets*'. They need to ask their partner's help for bathing and showering, or they use some disability adaptations to enable them to try on their own, as quoted by the fifth participant: *'I can't shower 'cos I had a really bad fall in the shower, took the skin off my nose, and it ... it scared me*'.

As a result of struggling with their disease, it seems to me that they've lost their previous sense of self as they were used to doing their household chores, working their jobs and travelling on their own; they used to be very active to carry out any type of work, used to making meals on their own, and to look after others, such as by cooking, cleaning and caring for others. The participants lost the skills they used to carry out their daily chores, such as cooking, dressing, bathing and showering, washing, cleaning and travelling. The participants lost their 'enabling skills' and see themselves as disabled. (For more details, please refer to the Initial Coding, Focused Coding and Axial Coding).

Below is Figure XXV to show how enabling is reducing and their disability is increasing:

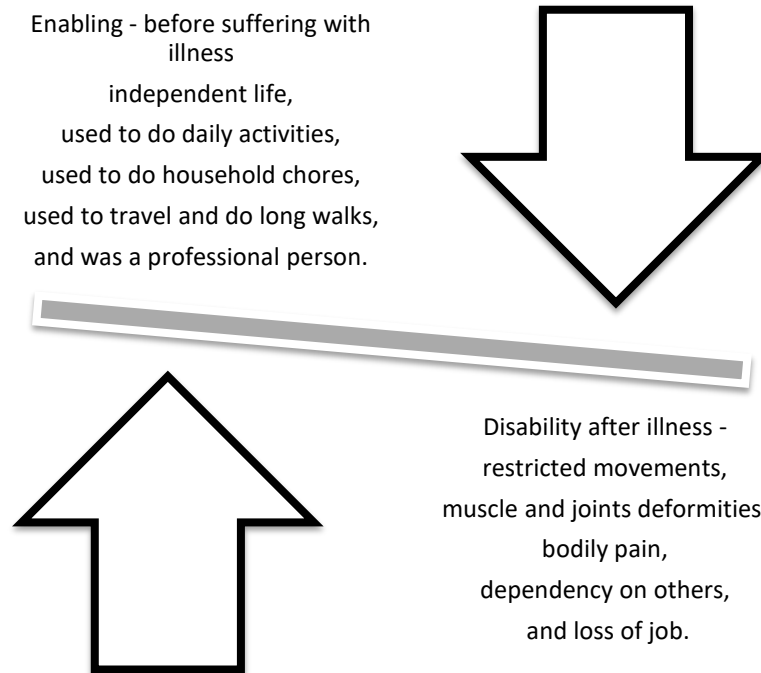


Figure XXV- Enabling to Disabling

(b) Social Engagement to Social Isolation

I use the word ‘social engagement’ here because the participants used to engage with other people before contracting this illness, such as at work, going outside, attending and hosting parties, travelling and shopping, as quoted by the second participant: *‘so I used to do things very quickly. Before I was ill, I was out a lot, I had ... I was a bit of a party animal so I used to go out a lot and party’*. Due to the physical impact of the disease, they experienced ‘social isolation’ as a central category that significantly affected their social world. In their social world, participants experienced a lack of understanding by others including friends, family and partners, and a lack of empathy from others who could not comprehend their problems, as quoted by the first participant: *‘a lot of people can’t understand that and it makes me quite ... erm ... I get quite agitated’*.

Due to restricted movements, they have reduced contact with their families, friends, and relatives as they are dependent on others to travel, as quoted by third participant: *'I'm not able to socialise as much as I ... as I could before ... erm ... so I'm not that active really and I look for other things I can do'*. The restricted movements and physical manifestation of their illness results in them isolate themselves at home. The fourth participant reported feeling awful due to the physical manifestation of the illness: *'It's difficult when you go out, it's alright if I'm on my own, 'cos I can do what I want but if I'm with anybody, because you're constantly running to the toilet, if I was ... erm ... dependent on others I'd find it awful'*.

They've avoided disclosing their illness to others due to the fear of social stigma and a withdrawal in themselves from social relationships. Some have lost their jobs due to their physical limitations, and others are struggling to still do their job, as they find that the bodily pain impedes them in doing their work and giving it their full attention, as quoted by the second participant: *'you know I had to do a job and you know, you'd sit there and you've got this screaming headache...'* They reported a lack of understanding from others, such as quoted by the first participant: *'the rest of my family they sort of don't understand ... erm ... they sort of ... they try to understand but they can't because I don't look as though there's anything wrong really ... you know work colleagues, that was really difficult because I didn't work in a very supportive environment'*. Some of them have made new friends, whereas participants who used to work, reported that their old friends did not contact them after their illness was diagnosed, as quoted by the fourth participant: *'I was on top of it really and when I was at work and people were saying things ... erm ... because they weren't really friends with me'*.

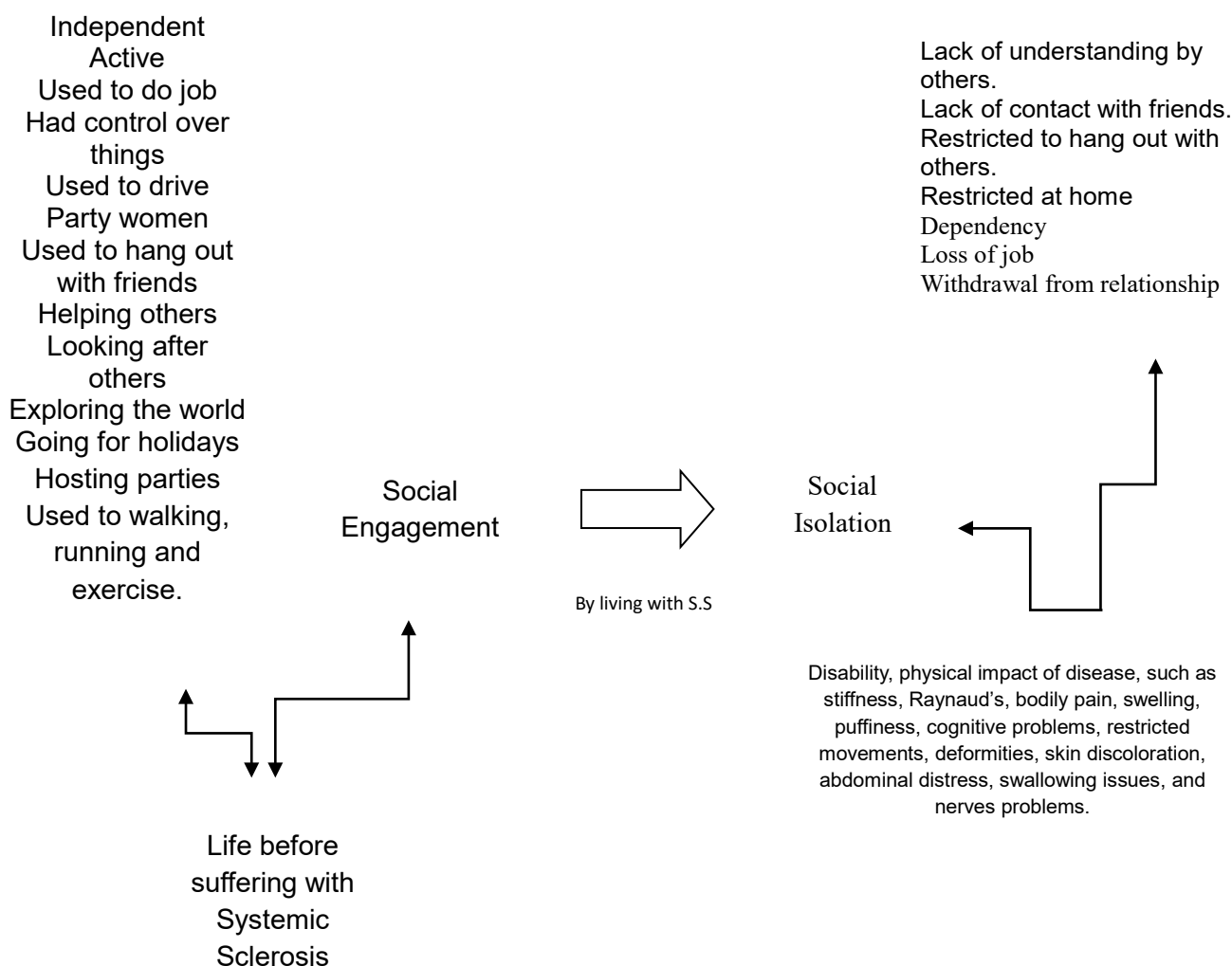
Due to the physical manifestation of their disease, they cover their body with make-up, as quoted by the second participant: *'oh cream, yes to cover the red spots, yeah I've got rosacea but my rosacea's actually really good at the moment...'*; cover themselves with extra layers of clothing, as quoted by the fourth participant: *'I'm now wearing lots of clothes and sometimes it makes you look really scruffy'*; or they look down to the floor in order to avoid any interaction with others, as quoted by the fifth participant: *'I try and shut it off, I try not to look at people to see if they're looking at me'*. Some participants use sticks or other disability adaptations to walk about outside, but they experience shame and embarrassment and so they avoid going outside, as quoted by the fifth participant: *'old people, old people, old lady yeah, I have had a mobility scooter ... I didn't use it, I'd rather not go out than use that'*, and as quoted by the third participant: *'the food will get stuck, and occasionally I might regurgitate food because it hasn't gone down, and that is one of my most concerning things because obviously socially that can be quite embarrassing'*.

From the participants' data, it appears to me that due to their disability and the physical manifestations of the disease, there is a lack of contact between the individual and society, just as some of the participants considered themselves a party person, but now they avoid attending any parties or joining any clubs and have lost the ability to what they did before. Whereas participants reported that they were working people before, and were used to participating in social activities, such as going abroad for holidays, attending parties, inviting people to their home, enjoying shopping and interacting with the world of other people, now they have bound themselves to their home, watching television and being dependent on others to go outside.

Due to struggling with their disease, they appear to have lost their previous sense of self, as they were used to going on holiday, having broad social activities, used to attending parties, used to doing their jobs and being an independent person, used to travelling on their own, used to riding bicycles, used to being very active, used to taking long walks, used to being a gymnast, and used to looking after others including their partner, friends, siblings and children. They do not like to get support from the government and used to be a part of many health clubs, as quoted by the third participant: *'I would then go for a walk, or yeah ... and sometimes we are, as in my example, I was very used to do things in a very quick way'*, and quoted by the fourth participant: *'I used to work as a carer'*. The second participant stated: *'When I used to go on holiday, I'd walk all day'*; the sixth participant quoted: *'I used to go to like the WI which is like a little ... a club, women's club ... erm'*; the first participant stated: *'I used to take on ... I was probably the one that took on most of the responsibility and decision making ... erm ... planning finances, all of that ... erm ... because that's what I was ... I was good at it, better at it than him I suppose'*; and as quoted by the fifth participant: *'we were used to doing the things quick ... quickly, oh yes see when ... when I did a lot of walking my husband used to say to me, slow down, slow down it's not a race'*.

Due to the impact of systemic sclerosis on the participants, this illness altered their sense of being in relation to the social world, moving from social engagement to social isolation. (For more details, please refer to the Initial Coding, Focused Coding and Axial Coding). The findings for this theme (Figure XXVI) demonstrate a process which I have depicted in a diagrammatical way below.

Figure XXVI- Social engagement to Social Isolation



(c) Contentment to Despair:

I use the word ‘contentment’ here because the participants talked about their independent life, and the goals and aims they had for their future. They used to do work and do their daily tasks on their own, such as cooking, driving, travelling, shopping, going out and attending work. Due to the physical and social impact of the disease, they feel helplessness, as quoted by the sixth participant: *‘a bit useless really and I don’t like the feeling of helplessness, but I cannot do things’*; the second participant stated: *‘I feel frustrated about myself really ...’*; the first participant reported: *‘I do feel that frustration, I used to be able to do this and I cannot do this, why is it taking me so much longer ...’*;

and as quoted by the fifth participant: *'Really angry, I feel like a caged animal, I feel trapped'*. They experience powerlessness due to the impact of the disease, as quoted by the second participant: *'again it's frustrating and upsetting ... erm ... but I can't do anything and the problem with that is going to get worse so I won't be able to eat lots of food ...'*; the first participant stated: *'the fatigue and feeling like everything drains out of you and if you're not somewhere that's frightening'*; with the fifth participant stating: *'I have ... yeah because you were robbed of it weren't you, taken away from you, I do, it, it dropped me, I couldn't do anything'*; and by the fourth participant: *'if I can't get a top off you can actually trap it into a door'*. Six participants quoted: *'... making me feel even worse, so, yeah it does, it has, since I've realised, it's not curable'*.

They reported hopelessness, as quoted by second participant: *'Yeah, I was a bit hopeless'*; the third participant stated: *'I don't think realistically, no hope for my life but might be for future generations'*; the fifth participant stated: *'I'd like to get rid of scleroderma, I'd like there to be a cure but then I'd like there to be a cure for everything and that's never gonna happen is it'*; the fourth participant: *'no hope because it's autoimmune ... erm ... there's no cure'*; and the sixth participant stated: *'I don't think there's any hope of it being cured'*. They have experienced sadness, as quoted by third participant: *'it is something that has made us both very sad, yeah okay that's all I need and as we are short of time ...'*; with the fourth participant stating: *'well you ... you're not going to change, so again the sadness'*; and the fifth participant stated: *'sad sometimes, sometimes I don't think about it, but when I do think about it, it makes me sad'*.

Participants expressed negative attitudes towards their self, as quoted by the first participant: *'I feel frustrated at myself that I'm not able to do things, that I'm a bit*

useless'; they are scared about the disease, as quoted by the second participant: *'I'm a bit scared that it's gone so I kind of tend to push it away rather than face it'*; they have feelings of worthlessness, as quoted by the first participant: *'I have had a big problem with what ... what my worth is'*; the second participant stating: *'I went through quite a bad phase last year when I did feel very depressed'*; the fourth participant quoted: *'you're useless in that department, well, because there's no feeling in there, because it's been took away from you, you're tired'*; and as quoted by the sixth participant: *'I do find it a bit demoralising I think the rest of my life now ... not worth living'*. Participants reported loneliness, as quoted by the second participant: *'when I am in pain, I'll avoid social things, I get upset and depressed about it'*, and the fifth participant: *'I feel lonely sometimes, I know he's supportive and he loves me, I don't doubt that, I just feel, yeah, lonely'*.

In relation to the above themes that have arisen from the participants' data, it seems to me that they experience 'despair' as a central category in their psychological world. In this world, the participants have experienced helplessness and powerlessness due to their disability and lack of control of the disease. They feel very sad as they've lost their functional skills and have reduced responsibilities, as quoted by the first participant: *'It's sad because I liked having the responsibility and I liked to be able to do that and the freedom to make my own decisions and, yeah so I ... I do find it hard'*. As they believe that there is no hope of finding a cure for their illness, they are also concerned about the progression of their illness over time. They experience negative attitudes towards their self, feelings of worthlessness due to being dependent on others, and they experience loneliness as they are restricted in their ability to interact with other people, particularly when they were used to social interaction, as quoted by the second participant: *'I used to*

go out a lot and party ... erm ... have fun really', and by the fourth participant: *'I can't ride a bike any more ... whatever I did, I used to be always out on a bicycle'*.

The participants report that their disease has not only impacted on their physical and social world, but also affected their social image due to their limitations, as quoted by the first participant: *'I hate the way I look ... erm ... more conscious of how I look in my face'*, and as quoted by the sixth participant: *'I think I look old, like I'm about 80 when I use my stick'*. They do not have any hope that they can return to living their life as they were used to before. Participants reported nightmares after being diagnosed with their illness as they were fearful about their future, about living with this illness and the risk of maybe ending up in a wheelchair, as quoted by the sixth participant: *'I knew a lot about that and knew that you're likely to end up in a wheelchair'*, and the fear of dying, such as quoted by the first participant: *'I do have a massive fear of dying now. I never used to, I have nightmares'*. There is a worry of being hospitalised and living with horrific pain, as quoted by the second participant: *'I'm scared of living with pain forever and I have a fear of dying in a painful way'*, or having their fingers or toes amputated due to the Raynaud's phenomena of the disease, as reported by the third participant: *'... because I know that if they get very bad then it could lead to gangrene or amputation'*. One of the participants reported that she has planned for Dignitas (a swiss organisation supporting assisted suicide) as she could not bear the bodily pain as her disease progresses in the future.

In their psychological world, the above themes arising from the participants' data appears to suggest that the participants reported very low levels of self-image due to the impact of the disease changing their appearance, particularly their face, hands and skin, as quoted by the second participant: *'they noticed I was getting puffy arms and hands, and*

my very hard fingers'; with the third participant reporting: *I've always had dreadful hands*'. They feel ugly and scruffy due to wearing layers of clothes, as quoted by the fourth participant: *I'm now wearing lots of clothes and sometimes it makes you look really scruffy*', which forces them to avoid interacting with other people, leading to a lack of confidence about themselves and feeling isolated at home. Their illness has changed their identity as they are not who they were before, as quoted by the first participant: *I don't know what my identity is any more*', and the fifth participant stated: *'cos I ... I, yeah it has, 'cos I'm not who I was*'.

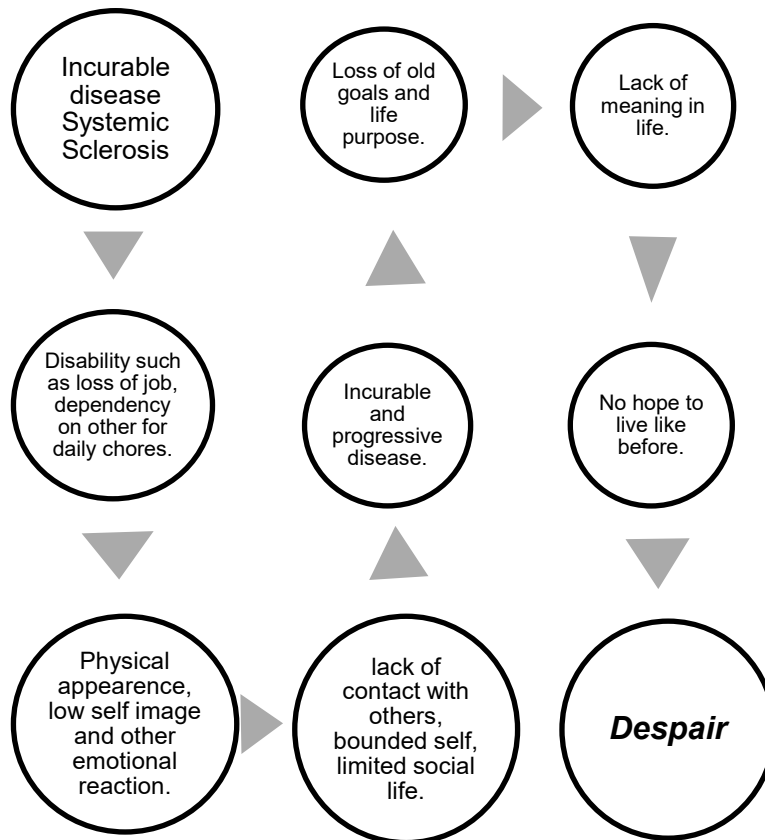
Due to the consequences of their disease on their physical, social and psychological wellbeing, they have become dissatisfied with their lives and grieve for the loss of their previous future goals that they had made for their future.

As a repercussion of illness, they were unable to do their accomplished goals and life purpose and resulted in lack of meaning as they have no hope for a cure to be able to live their life again as before and they feel helplessness to continue living in this way. However, before suffering with this illness they were satisfied with their life, as they were able to do their own household chores and were free to do anything and travel on their own, to have future plans, such as going on a world tour, carrying on work until they receive their pensions, planning to go abroad on holiday, achieving promotions in their job, wanting to enjoy life and take adventures around the world.

It suggests to me that during this dynamic process of living with systemic sclerosis, the participants most significant experience was their loss of an independent life, including their work, dependence on others, restricted movements and reduced life goals. Through living in this way, they've changed their sense of being from 'contentment' into 'despair'. In this way, participants experienced a loss of their old sense of self due to

living with systemic sclerosis. (For more details, please refer to the Initial Coding, Focused Coding and Axial Coding).

The findings for this theme demonstrate a process which I have depicted in a diagrammatical way below.



(Figure XXVII- Contentment to Despair)

(c) Life Calmness to Death Anxiety

I use the word ‘life calmness’ as the participants describe the fact that they never used to think about death and the realities of life before contracting this illness, and as such were not suffering with death anxiety. Due to the impact of the disease in their daily lives and also understanding the prognosis of their illness, the participants experienced death anxiety as part of their existential crisis.

Participants reported that they never thought about their death before. They used to believe that they would live longer, as quoted by the second participant: *'I used to think I'd ... I'd live to be really old, now I don't. I don't expect to live longer'*. Some of the participants referred to the fact that their parents and grandparents had lived to more than 100 years of age so they believed they would be the same, as quoted by the fourth participant: *'when ... my life is shortened, I'll never be around, I'm not going to be around probably, I'm never going to live as old as my mother'*.

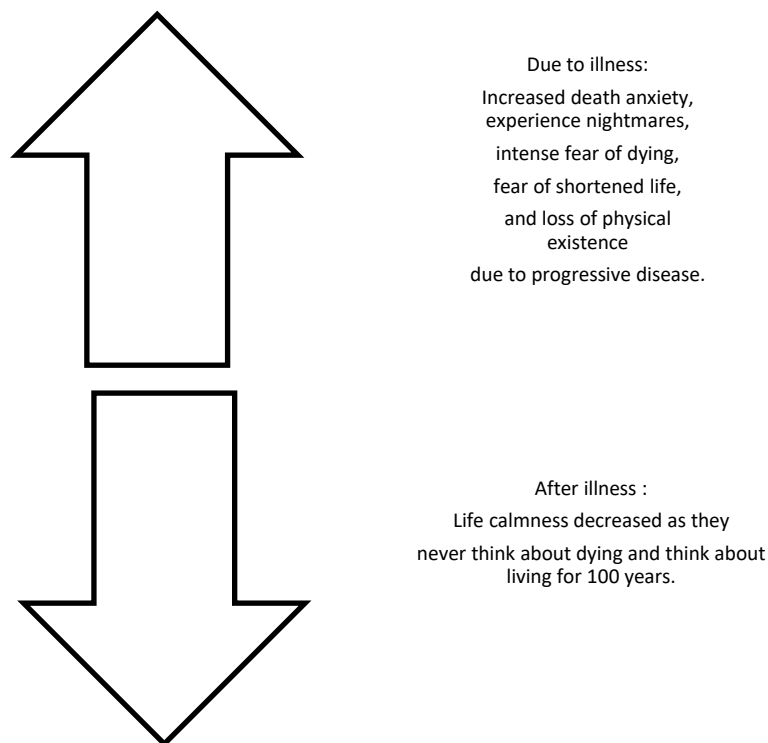
Their illness awoke their sense of mortality and caused severe intense fears about dying and experiencing nightmares, as quoted by the first participant: *'I do have a massive fear of dying now. I never used to, I have nightmares ... I don't think there's any sort of major depth to them other than, if I can remember them rightly I think it's just a dream that I am ... I'm gonna die, and that I'm alone'*, and as quoted by fifth participant: *'I try not to think about it too much ... sometimes I think I've got a fear of dying, sometimes I think it's part of life. It ... we've all got to die sometime'*.

It seems to me that they forgot about death and took their life for granted, living with a sense of calmness without thinking about their mortality, as the third participant reported: *'I did tell my brothers and my husband and some close friends, ah, but I am very much in terms of ... you know I might live to be 101 with no bad problems, I might drop down dead in three years' time'*. They also have a fear of dying and experiencing pain, as quoted by the second participant: *'... of living with pain forever and I have a fear of dying in a painful way'*.

The fifth and sixth participants just accepted death, rather than thinking about it more, and took it as being a universal truth, such as quoted by the fifth participant: *'I try not to think about it too much, sometimes I think I've got a fear of dying, sometimes I think it's*

part of life. It ... we've all got to die sometime', and the sixth participant reported: *'we die when we die, I could get run over by a bus tomorrow you know, what's the point in worrying about it?'* According to the participants, their perspective towards life and the world has been drastically changed after contracting this illness as they see the world now as temporary, as quoted by the second participant: *'it's a big world and a lot of horrible things happen in it'*, the fifth participant stated: *'the world is temporary and life is temporary'*, and the first participant saw *'the world as harsh and [that] life is very superficial'*.

The above themes seem to suggest that the participants experience the dread of isolation and a loss of their physical existence. In this way, their life calmness has turned into death anxiety. (For more details, please refer to the Initial Coding, Focused Coding and Axial Coding). The findings for this theme demonstrate a process which I have depicted in a diagrammatical way below:



(Figure XXVIII- Life Calmness to Death Anxiety)

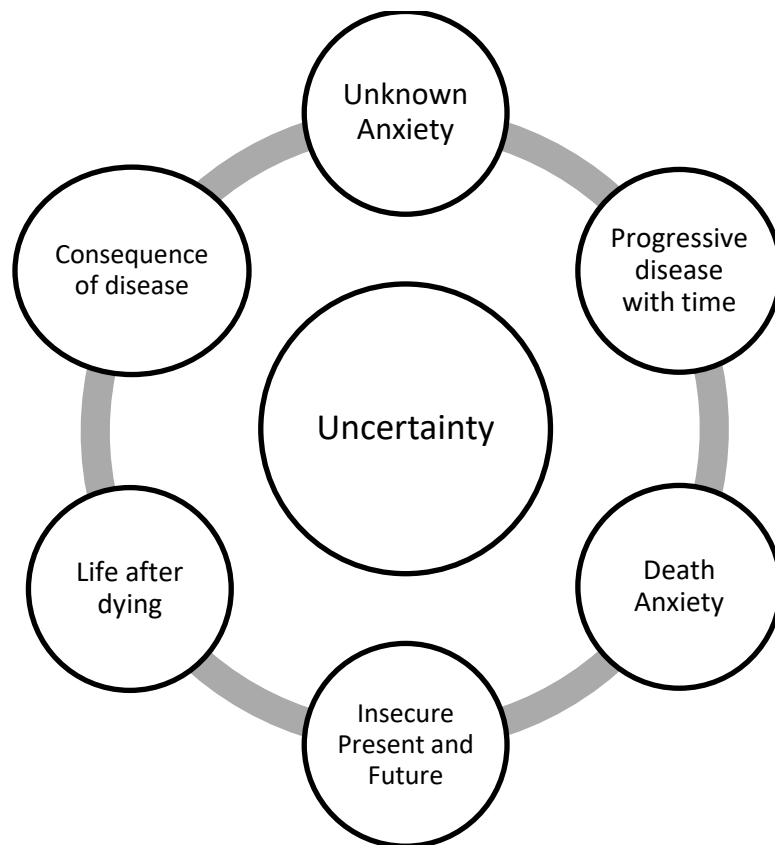
(d) Security to Uncertainty

Due to the impact of the disease in their daily lives and confronting their death anxiety, participants experience uncertainty as part of their existential crisis. Participants reported that they never thought before that they will become ill or they could die due to consequences of their illness. As the first participant stated: *'I think it's actually more around the suffering beforehand and what it ... what it would be like, and I've never ever thought of that before. I don't know whether I thought I was super-human and was never gonna get ill, but I haven't really, I've never had anything before that made me think that I wasn't gonna live to a very old age before I got ill'*. Participants experiences were very scary due to the unknown nature of their illness, such as quoted by the second participant: *'When new things happen, like now, I'm starting to get peripheral neuropathy and I'm being investigated for that at the moment and more things start to happen like twitching muscles and I've got tingling in my hand and my feet and it's ... it's just more things crop up so they send you back to that really scary place again'*.

The participants also expressed their fear of the uncertainty, such as quoted by the second participant: *'The not knowing, the uncertainty ... erm ... I suppose my biggest fear is dying of my lungs because I've lost fifty ... almost fifty percent capacity of my lungs now and in the past year I've lost another ... I've lost seven percent in the last year, so it's scary'*, and the third participant described the unknown nature of their illness in that: *'It's the fear of it, it's not exactly the unknown because you ... you know as you read, you know what could happen but it's ... it's this not knowing definitely'*. The fourth participant talked about death and the progressive nature of their disease: *'I don't think I'd like to be 75 with this disease due to the progressiveness of the disease'*. The first participant reported their dreams and nightmares about the fear of dying, such as: *'I can*

remember them rightly, I think it's just a dream that I am ... I'm gonna die, and that I'm alone'.

In the above themes arising from the participants' data it seems to suggest that the participants reported that they have unknown anxieties due to the nature of their illness. On the one hand it is incurable, so they do not have any hope of recovering from this illness but rather they have a fear of the progressiveness of the disease leading them to experience death anxiety; whereas on the other hand, they are experiencing unknown anxieties towards their future as a consequence of their illness and what would happen after dying. The participants reported that they never imagined that they would suffer such an incurable illness and that the future life goals they had made would not be achievable as their lives would be drastically changed due to suffering with systemic sclerosis. Due to this disease, the participants' security for their present and future moments altered into uncertain anxiety. (For more details, please refer to the Initial Coding, Focused Coding and Axial Coding).



(Figure XXIX- Security to Uncertainty)

(e) *Autonomy to Lack of freedom and responsibility*

I use the word ‘autonomy’ here because the participants talked about being independent and feeling free in the way that they dressed, travelled cooked, hosted parties, earn money, took charge of their responsibilities, and went on holidays. The participants reported that they had a lack of freedom to travel and experienced anxiety in having to be dependent on others, such as quoted by the first participant: *‘I don’t feel that I’m free to just do whatever I want anymore because there’s so much thought that has to go into I ... erm ... into, to doing things so I suppose an example would be this trip to London ... erm ... there had to be so much planning gone into it and then what if I’m not well or what if this happens and that causes a lot of anxiety so that’s ... that freedom has gone’*. The second participant expressed their experience in this way: *‘... freedom slightly because I*

feel more restricted about what I can do, I wouldn't when I was younger, I used to quite happily go off on my own and experience things; now I don't ... I'd feel I'd need somebody with me ... erm ... so yeah so it has restricted me', and the fourth participant quoted: *'If you're going on holiday anywhere you've got to make sure that like ... like it's warm, you've got to make sure it's warm, you've got to make sure you've got bedding, it's like ... erm ... we're going on holiday in July and we've got to take a sleeping bag with us I think because I will be cold'.* The fifth participant expressed: *'My freedom has gone, I feel really angry ... I feel like a caged animal, I feel trapped'.*

The participants reported that they were dependent on others for little things, such as opening jars and having to cook a meal, and the fifth participant expressed her difficulty in this way: *'but my husband has to help me to cook food, he is not very good at cooking otherwise he would do it, so we do it together. I can't chop, I can't carve, I can't touch things out of the fridge, I mean my fingers go bright red now, it's 'cos they're getting warm ... erm ... I can't take a joint of meat out the oven 'cos it ... my hands can't grip it ... roast potatoes'.* The third participant articulated: *'I probably feel slightly less free in that I'm ... I know I'm already a bit more dependent on others so things like opening the jars ... there are some things I can't do easily now and I know that's likely to become a lot worse ...'* The sixth participant expressed that her husband had to help her to cook meals as she gets pain in her hands if she tries to do too much: *'I don't know ... make a cup of coffee or cut up food or like ... even cooking and that, which I used to like doing a lot of, making cakes and things, it ... it's that sort of thing ... it really hurts your hands'.*

The participants reported their difficulties with shopping, such as quoted by the third participant: *'sometimes obviously if you're carrying bags it's restricting the flow in your fingers'.* The sixth participant expressed her difficulty in doing shopping in this way: *'If*

it's cold, in the fridges, when ... just touching the trolley makes my hands go ... but I do find gloves are really bad as well. I lean on the trolley, so I've got something to lean on when I walk round. I always go with my ... my father 'cos he can't drive anymore and he always puts it into the car for me'. The second participant stated their difficulty for shopping as: 'I can't buy much as I could not hold bags due to the disease, I've got a little backpack which I use as a bag so I always have it on me so I find it easier to carry stuff on my back but not too much ... so I can do that and I could do two smaller bags if ... if it's not really heavy, so I can do that'. The first participant reported she could not do any shopping: 'shopping ... my husband carries everything he does the majority of the shopping ... erm ... I don't like going anywhere near the freezer section or the chiller section, even in the summer ...'

The participants also reported their difficulties in cleaning their home, such as quoted by the second participant with regard to changing bed sheets: *'things like changing the bed, even that just seems daft I ... I need my boyfriend to put ... tuck the sheets in 'cos I cannot lift the mattress'*; the first participant expressed her difficulty to cleaning in this way: *'the cleaning I can maybe do one room on a good day, if I try and do more than that then ... well it sets me back several days'*; and the third participant quoted: *'cleaning ... because of my ulcers I'm always ... one of the worst things is ... is just banging things, you're banging your fingers against things'*.

The participants reported that their cognitive processing had changed, as quoted by the second participant: *'I am not as quick as I used to be'*, and the first participant expressed her difficulty in cognitive processing in this way: *'I have problems with cognitive processing, they understand that the impact is hard on me to sort of process the way I used to ... thought processing ... if I was to read some instructions I find it difficult to*

follow or remember. I struggle to have a conversation with more than one person. I just can't keep up and I can't absorb things as I used to'; the fourth participant described their difficulty in cognitive processing as: 'I am forgetting things and having difficulty to understand things, I'm like having brain fog, it's when you're fuzzy-headed and I never used to be like this'.

The fifth participant shared her problems with concentration as: *'I have problems with concentration but it's not all the time, I read a lot, because I don't do a lot and sometimes I can't ... I just can't sit and read a book because I can read the same paragraph over and over again and it doesn't seem to go in, so I get onto the next paragraph and think, hang on a minute, I've missed a bit but I haven't, I've read it 3 or 4 times'.* Participants reported that they had restricted their travel habits due to their illness as they had to circumspect for their health, as quoted by the fourth participant: *'There's some places you can't go with this but not all like ... I would love to go to Kenya but there's no way, there's no way I can go to Kenya because the Yellow Fever and raw sewage, you have to keep away, but there's other places I can go to'.* The sixth participant expressed her loss of confidence to go out on her own, such as: *'I don't really like to go out on my own 'cos I think what happens if something happens and I ... you know ... so I, don't like to go out on my own, so from that point of view, I mean I could go out on my own but I don't feel confident to'.*

The participants shared that they had less responsibility due to their illness, as quoted by the fourth participant: *'... erm I can't really be responsible ... well it's alright being responsible for a dog but not ... not erm ... I can't be responsible now',* and the third participant quoted: *'it's more likely my husband will have to care for me more than at the moment, than I would have to care for him, in, in terms of ... you know ... physical*

dependency'. The fifth participant reported her loss of responsibility in this way: *'because I used to wait on him hand and foot, now it's changed, it's ... he's looking after me'*. The sixth participant reported her loss of responsibility and expressed her wish to do things for him: *'... to a certain extent because I can't maybe do, you know ... Richard always gets up and makes me a cup of tea and things you know, so just those little things you know, that maybe I might have made him a cup of tea when he came home from work and that sort of thing'*.

The participants reported that their choices had been changed due to the impact of the illness, such as the fourth participant who quoted: *'I'm ... before having this disease I was very erm ... I don't like to wear sweaters and jackets but since I have started this disease as with Reynaud's, now I have to wear the layers of clothes which has changed, it has changed my nature'*. The fifth participant reported their changed choices after contracting the illness in this way: *'my husband's been out in the car and I turn the radio off when I get in, I like quiet, I don't like lots of noise so it ... maybe scleroderma has affected me in that way, I don't know, but I don't like a lot of noise and when my grandchildren are gone, my husband says "oh put the telly on", but I say no ... no let's just enjoy this quiet'*. The sixth participant described their changed choices such as: *'I mean I like ... erm ... like walking in the woods with the dog and things and I can't do that anymore and erm ... you know things I don't like, like doing things on the computer, you know which I can do, erm ... obviously, but I have to do more of that'*, and the first participant quoted her difficulty in choosing food and eating: *'I've noticed that a lot of foods I can't eat, I realise they're sort of making me feel more ill than ... you know, bloating and things like that so ... and all the healthy things that they tell me ... what they tell us that we should be eating, they say to me don't eat brown bread, wholemeal things like that, so it's very difficult'*. The participants reported that they have a lack of

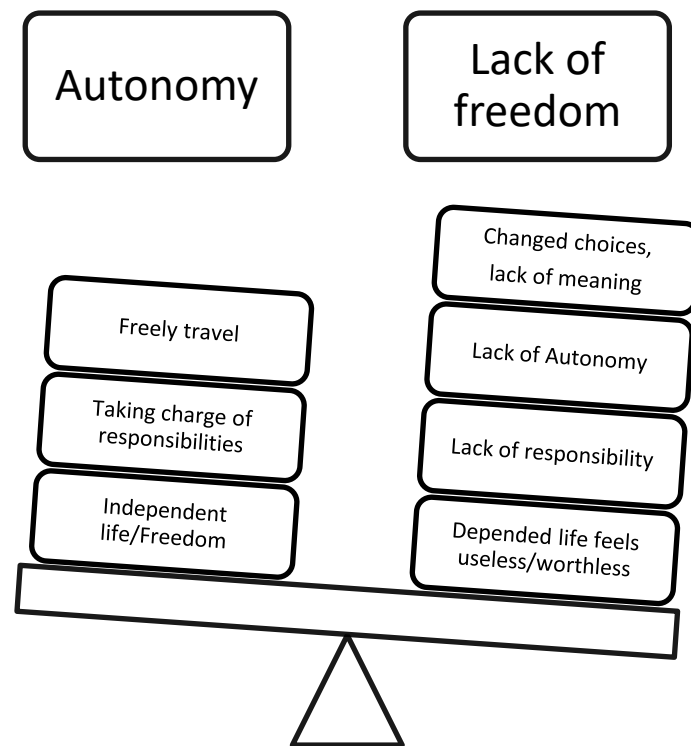
meaning in their lives after this illness as their old goals for life has changed because they cannot achieve those goals due to their illness, such as quoted by the fifth participant: *'I haven't got any goals now. I had goals before, such as I wanted to travel the world. I was, before we moved to Cumbria, before I was diagnosed, I was in a very good job earning lots of money but never having the time to spend it, so when we moved to Cumbria the plan was to do up our cottage and travel, well 'cos we've both been ill we can't travel any more. It would not be achievable now'.*

The sixth participant reported a loss of meaning as: *'I don't really feel like I have much meaning. I feel meaningless [coughs] well like my normal life has ended and now I don't feel like there's any ... any point really, there's no meaning, there's ... there's nothing to look forward to. My old goal was to teach A-level but I am unable to do it now',* and the first participant mentioned: *'I'm with my husband so, it's our life together, erm ... change our ... our goals, and ... and I don't know where that's gonna go yet, because I want to work again at some point but I don't know whether I'm going to be able to, what I can cope with. And I don't feel that unless I can work that I'm gonna, necessarily find my identity again if that makes sense'.* The second participant expressed their life values before having the disease as: *'before I was ill, I was out a lot, I had ... I was a bit of a party animal so I used to go out a lot and party ... erm ... have fun really and I think since being ill that has, it's ... it's just changed all that ... erm ... because my values have changed, and also I can't ... it doesn't mean the same and I can't do as much, so in that respect I have ... it has changed me',* and the fourth participant expressed: *'I can no longer do a day's work'.*

This all suggests to me that due to the impact of the disease in their daily lives and confronting their existential crisis, participants experience lack of freedom and

responsibility and unable to do things that they were used to and then resulted in loss of the old meaning of their life. Participants reported that due to living with a disability and being dependant on others, they have lost some aspect of their freedom and the ability to make choices freely, being dependent on others for tasks such as cooking a meal, cleaning, travelling outside, and having to wear layers of clothes to protect themselves from Raynaud's phenomena, even though they do not like to wear layers of clothes. Their cognitive processing was also affected as part of their disease as they have difficulty in concentrating on things. They report that they are unable to make financial decisions as they had to resign from their jobs and be financially dependent on their families or rely on government benefits. Due to suffering with this illness, not only have they lost their freedom, they have also lost their ability to take responsibility for their self and others. Before having this illness, the participants were free to move around and go anywhere, doing what they wanted to do and prioritising their tasks, but after contracting their illness they became dependent on others, having to check the availability of others in order to go outside or if they wanted something to eat. The participants reported that they have lost their life goals and their future has a lack of meaning compared to before. Having lost their autonomy as a result of this disease and becoming dependent on others has made them feel awful. Participants experience a lack of meaning in their life due to a lack of autonomy and responsibility towards their self and others, having to change their choices to accommodate their symptoms which is annoying and frustrating, leaving them feeling helplessness and despair due to this incurable disease.

During this dynamic process of managing the impact of their disease, their autonomy, lack of choices, responsibility, anxiety and a lack of meaning has taken the form of lack of freedom and responsibility. (For more details, please refer to the Initial Coding, Focused Coding and Axial Coding).



(Figure XXX- Autonomy to Lack of freedom and responsibility)

Stage 5: Self-Management

In order to deal with these phenomena, participants used action strategies, such as problem-focused coping, solution-focused coping, meaning-based coping, social coping and realistic coping.

Participants utilising problem-focused coping includes seeking professional help, using treatment measures, taking medications, and self-help—by taking supplements such as vitamins and magnesium oil. One example of problem-focused coping was given by the first participant who reported how she used this to manage her illness, such as taking her medications to feel slightly better: *'I've had quite deep muscle pain in my legs and arms; have severe joint pains in my fingers, wrists, elbows, shoulders and neck, and chronic fatigue, which is slightly better since I've been on medication, problems with swallowing, acid reflux ...'* The second participant used problem-focused strategies of self-help: *'I self-medicate*

because I know it's not things that you can ... it is dangerous, so I bought magnesium oil to rub on my skin, I'm taking ... the other thing I asked for was to have a test of all the B supplements'. The third participant mentioned her problem-focused strategies through obtaining treatment and undergoing investigations: 'I've always had dreadful hands ... ulcers ... they come and go, I do have Illoprost treatment at the start of the winter. I saw my rheumatologist last week and my blood pressure had just started to rise so I've had to up my medication. I had an echocardiogram and pulmonary function tests to monitor me'. The fourth participant went for a splint, as she quoted: 'I could hardly walk actually, erm ... and then I had the rehabilitation from the next week ... splints on hands'. The fifth participant reported how she manages her symptoms: 'Medication, I still get it sometimes, erm ... yeah, you just take your medication to cope'.

Participants with systemic sclerosis used solution-focused coping to help deal with their problems and allow them to try to manage daily living tasks. The solution-focused coping included other strategies, such as managing emotions by sharing them with a husband or wife, reading books, watching television, practicing meditations and mindfulness, finding different ways to undertake household chores, and changing their diet plan; all types of different strategies to try and manage the disease and its manifestations. The first participant shared her solution-coping skill as: *'sort of mentally with the ... I think they call it mindfulness and so I'm doing that and, looking at different ways I can adapt, for instance I like gardening so ... but I've sort of ... making adaptations so that I'm gonna be able to do bits of that'*. The second participant reported her solution-coping skills as: *'well I just do normal things you know, watch programmes or, you know ... or ... but I'm lucky in that I have a boyfriend. I think if I was single now with the disease, I would find it harder ... because I have this very supportive boyfriend, I find it a lot easier to cope'*. The third participant talked about her solution-coping skills to manage her symptoms as: *'I do tend to have my gloves*

with me a lot more now, I do tend to often have bags ... erm ... even, something with a shoulder strap'.

The fourth participant described their solution-coping skills in this way: *'If you want to mix anything you know ... you know very well this ... this arm will hurt, and there's no strength in it so you ... obviously I buy a hand mixer. You buy things with two handles rather than with one handle'.* She went on to describe the other ways that she deals with her disability: *'I can't use a tin opener, that's about the only thing I can't do in the kitchen is use a tin opener. Just use the ring pulls and use little things not the heavy things. I'll get the steamer out and just give it a very good clean and then, you can manage it with a cloth'.* The fifth participant talked about her solution to cope with Raynaud's and reflux as quoted: *'I wear as much clothing as possible on my feet and on my hands but when you're at home there's not a lot you can do ... I have a pair of camping slippers, they're made from down, and they're quite warm but I still wear two pairs of socks indoors, silver socks and thick woollen socks but I still wear a pair of sheepskin slippers as well'.* Her approach to manage her stomach reflux states: *'I have been known to sit up in bed prop myself up with pillows ... we have a spare room so when I'm bad I go in the spare room and I sit in the corner and prop myself up, and go to sleep like that'.* The sixth participant reported how she manages her disease manifestations in public places as: *'Well there's nothing you can do is there. I could try covering them with make-up to hide red spots but then it could rub off on your clothes. I wear things that are higher round my neck, or a scarf. I've got a dishwasher [laughs] so, I don't have a problem with that'.*

The participants reported their support from their family as: *'I just struggle, I can't use zips and things ... I get ... my husband always does zips up for me or my daughter does,*

depending, but I try to buy things that are stretchy or that don't have zips and, you know I try to make sure I buy things that are easier to put on'.

Participants with systemic sclerosis used meaning-based coping strategies to deal with their disease and to motivate themselves, such as adopting a positive attitude towards the disease, improving their skin condition by using medications and other remedies, seeking meaning from religion, looking for ways to work in charities, grandchildren, through their work and partner, trying to find new goals, obtaining internal support from being Christian and turning to their religious values, appreciating the love of friends and family, gaining satisfaction from a beautiful sunrise, enjoying the morning, enjoying nature's beauty such as the birds and butterflies, taking care of animals, finding different ways to build courage, such as through history, and their grandfathers and soldiers in WWI, understanding their own value of life and having empathy for others—an altruistic behaviour.

Participants reported about their meaning-based coping strategies in helping others, as quoted by the first participant: *'I really feel quite strongly about wanting to help other people, not necessarily with scleroderma, but that's where I was saying about the empathy and the compassion and understanding the difficulties that people face, in life, and some way of dealing with something like that'.* The second participant got satisfaction and courage from her work, as quoted: *'I enjoy my work very much so that satisfies me greatly, because I'm freelance, I'm constantly having to find new work so that's always a slight worry but I do ... that really satisfies me ... my work'.* The third participant counted her blessings by practicing her religion as a meaning based-coping strategy, as quoted: *'Faith ... as I said I'm a Christian, the love of friends and family ... it is this sort of tolerance of other people's disabilities, a lack of slowness. I wasn't an impatient person before but I'm much more understanding of that in other people now'.* The fourth participant reported her coping

strategy of helping others, as quoted: *'I work for the food bank, there's lots of things I can do for the food bank, yeah, and then I do another one. Yeah, I get a lot of satisfaction because I think it's ... yeah ... I'm not doing all the heavy work but I can still get a lot of satisfaction'*.

The fifth participant reported her meaning-based coping strategy stemming from her grandchildren: *'the reason I get up in the morning is for my grandchildren, they're the ones that keep me going, and helping other people to do this study so they can get help from the study, to do charity, my grandchildren ... erm ... warm weather, the sunshine [laughs] ... erm ... being in good company'*. The sixth participant expressed her meaning-based coping strategy as: *'basically for the children and my grandchildren and also my daughter's pregnant'*.

Participants with systemic sclerosis also used social coping strategies to deal with their disease. Social coping included strategies such as being supported by others to hold and lift things, like shopping, getting support from the scleroderma helpline, their partner, siblings and new friends in how to deal with the illness, and relaxing by going to the cinema, to warm places for holidays, and using humour to cope with the disease in their social world. The first participant shared her social coping skill for shopping as: *'holding bags and things, I find that really painful, it digs in because I've got sort of ... erm ... it's like the swelling and things, but I tend to try ... if I am carrying things, I carry them on my forearms and so yeah that's really difficult just ... but even picking bigger things up because I can't grip because of the pain, I'm sort of using different parts of my body'*. The second participant quoted her social coping as being with her boyfriend and being engaged with the scleroderma society: *'My boyfriend helped me and really motivated me and the Scleroderma Society actually existed, you know I should look into things like that more, and there are things where I can help other people'*. The third participant reported that she went to the cinema or engaged in other activities within the social world, as quoted: *'I'm very interested in wildlife ... erm ... I do some*

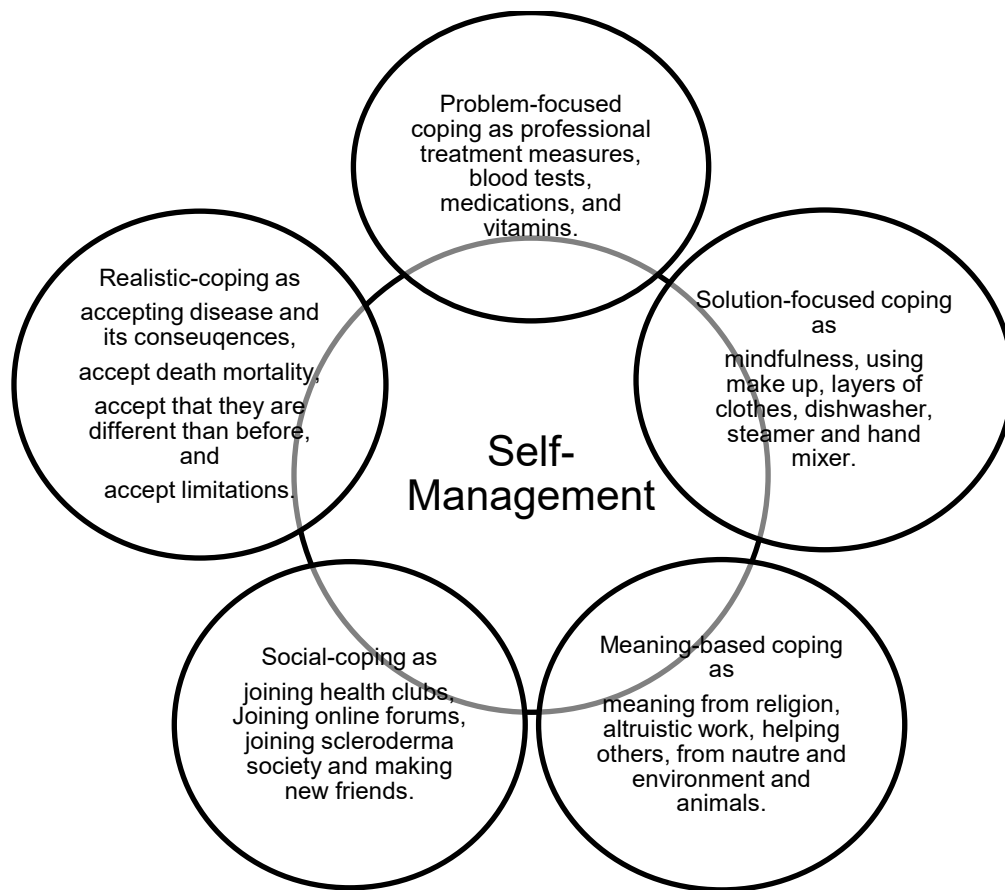
wildlife photography so I ... I will go for a walk round ... erm ... and you know, watch some birds or some butterflies and ... ah nice! [laughs] or occasionally just go to the cinema with some ... with some friends and watch a good film'.

The fourth participant talked about managing their social life and getting support from others in order to rebuild that part of her life, such as: *'It makes you closer, really close, he's very caring, he's very caring. I'm quite content with my husband. A lot of my friends have still got children, young ones ... I'll go and let the dog out'*. She joined a health club: *'Well I'm sort of retired, in my spare time I go swimming but that's a health club type of swim, everything's nice and warm and I meet with others'*. The fifth participant described their social coping in this way as: *'He does most of that as well. We go together for shopping, he does holding the bags, I don't think I could live without help'*, and also said: *'my friend, she always asks me about it but I just deal with it, she's a very sympathetic, kind, warm person'*. The sixth participant reported that she used humour to cope, as she quoted: *'I think 'cos I've got quite a good sense of humour I try, I try not to let things erm ... you know ... stress me too much'*.

Participants with systemic sclerosis used realistic coping strategies to live with their disease, such as accepting the disease, obtaining more information about the disease, accepting the death mortality, confronting their own limitations due to the illness, trying to make sense of the disease, and trying to be realistic and accept the consequences that come hand in hand with this disease. The first participant recognised her limitations as she stated: *'I feel frustrated at myself that I'm not able to do things, that I'm a bit useless, but then I counter that with the fact that it's not my fault and that I'm not choosing to be like that. I've just got to live for now and deal with it. I think you've got to be realistic rather than worry'*. The second participant expressed their acceptance and of coping in this way: *'Well I just accept it and I have to try and keep that way and just deal with the now ... to be present ... not to be jumping*

on the future... there's no point in doing that'. Participant three talked about accepting her illness as she quoted: 'I've just sort of learnt to live with disease. I'm actually scared of dying 'cos we're all gonna die sometime ... I have to accept that my life very likely will become a lot more limited but ... yes it will be more limited, but doing as much as I can and as I say remaining positive'. The fourth participant quoted: 'Well you're going to die anyway, there's nothing ... you are what you are ... you can't change it. You have to accept it because you can't do that and go back to how you were before and back'. The fifth participant accepted her disease as she quoted: 'Over time you learn a bit to accept ... you become more accepting of your condition ... we do it together. I can't chop, I can't carve, I can't touch things out of the fridge etc. I'll try it, and I shouldn't', and the sixth participant reported: 'I can't go to work, I can't do anything after that, it's just you have to plan to only do, sort of, one thing on a day, and then come that day you might actually feel "no I can't do it anymore" so I've just always thought well we're all gonna die sometime and when we're dead, we're dead and what's the point in worrying about it. I've always thought that we're here for a certain amount of time and then die'.

Through using these strategies, the participants were able to construct their new sense of self through empowerment, being-in-the-world, searching for new meanings, being-in-time, and hopeful with a wish to live. (For more details, please refer to the Initial Coding, Focused Coding and Axial Coding). The findings for this theme demonstrate a process which I have depicted in a diagrammatical way below:



(Figure XXXI- Self-Management)

Stage 6: Acceptance

Through using the above strategies, participants were able to manage their illness and learn to accept and live with their illness. The first participant reported her acceptance in this way: *'I've just got to live for now and deal with it. I think you've got to be realistic rather than worry'*. The second participant focused on the present and accepted her disease as she quoted: *'Well I just accept it and I have to try and keep that away and just deal with the now ... to be present and 'as you just start ... you just accept it after a while and you just go, just get on with it, and so yeah, so I've had quite a sort of positive attitude towards it'*. The third participant shared her way of learning to live with the disease and accepted her limitations as: *'I've just sort of learnt to live with the disease. I'm actually scared of dying 'cos we're all gonna die sometime, I have to accept that my life very likely will become a lot more limited, but yes it will be more limited but doing as much as I can and as I say remaining positive'*.

The fourth participant reported that she had accepted her mortality in this way: *'Well you're going to die anyway, there's nothing you ... you are what you are, you can't change it. You have to accept it because you can't do that and go back to how you were before and back'*.

The fifth participant accepted her disease and the resulting limitations in this way: *'Over time you learn a bit to accept, you become more accepting of your condition, we do it together'*.

The sixth participant expressed her way of managing to live with systemic sclerosis and her way of accepting death mortality as: *'It's just ... you have to plan to only do sort of one thing on a day, and so I've just always thought well we're all gonna die sometime and when we're dead, we're dead and what's the point in worrying about it. I've always thought that we're here for a certain amount of time and then die'*.

It appears from the above that the participants have started to accept their illness and that this will impact the rest of their life. Before, they believed that their disease would be cured and that they would not need to live with this disease forever. However, it suggests to me that after living with this disease for a long time, they've started to accept that they are suffering with an incurable disease and also accept the impact of disease (For more details, please refer to the Initial Coding, Focused Coding and Axial Coding).

Stage 7: Changed Sense of Self to Rebirth of New Self

After using coping strategies and accepting their disease, the participants experience a changed sense of self, as they have lost some aspect of their old self and, through managing their disease; they are able to build their new sense of self. Participants experienced their dynamic process of changed sense of self in three phases: (a) the pre-illness phase; (b) the changed sense of self phase due to the impact of the illness; and (c) the rebirth of the new self phase.

a) Pre-Illness Phase

In this phase, participants reported on their life as it was before having the illness in that they did not depend on others, were used to going to work and earning a living, and undertaking their household chores such as cooking, cleaning, travelling and shopping. I have set out some quotations below to describe their lives before contracting the disease.

The first participant reported about her working life and that she used to do physical exercise: *'I used to be able to do that ... one of the things I was good at was attention to detail. I used to work for the Fire Service answering emergency telephone calls. My body has changed significantly so I used to do a lot of ... I used to go to the gym a lot, I used to do a lot of walking, cycling ... erm ... gardening and that was ... that was the biggest enjoyment I had in life really and so a lot of that's ... that's gone'*. The second participant reported that she used to be involved in different activities and would be fast at carrying them out: *'I used to walk very fast, now I can't, what with the muscle stiffness and the neck and the breathing ... erm ... yeah so, I used to do things very quickly. I used to be quite a party person, used to drink quite a lot and go out'*. The third participant reported that she was used to doing gardening and was very active as she stated: *'I used to really enjoy gardening ... erm ... we have a big garden. I used to grow a lot of my own vegetables, as well as the flowers, and go for a walk. I was very used to doing things in a very quick way'*. The fourth participant shared her life before suffering with the disease as: *'well I'm used to it because I used to work with special needs. I've worked in the care sector. I used to work ... well I worked at all sorts of care but I used to change dozens of duvets. I used to have this beautiful, thick hair, it was really dark'*. The fifth participant reported that she was very active and used to take care of two dogs, was used to doing things very quickly and used to doing her own chores, as she said: *'I was very active, I used to go fell walking,*

I had two dogs and would walk them and I used to be a gymnast and used to finish my meals long before my husband. I used to do all sorts of things with my hair'. The sixth participant shared her pre-illness life in this way as she quoted: 'I used to do a lot of gardening. I used to go to like the WI which is like a little ... a club, women's club ... erm ... it's only once a month, so I used to like doing a lot of making cakes and things'.

b) Changed Sense of Self Phase Due to Impact of Illness

In this phase, participants reported that after contracting the disease, they experienced their changed sense of self by way of their appearance, their difficulties in doing things on their own that they used to do before, the dependency on others, and changed life goals.

i. Changed Sense of Self in Appearance

Participants experienced a changed sense of self in their appearance and were not able to do things that they used to do, which made them frustrated and annoyed. The participants experienced feelings in themselves of being different in appearance, such as that quoted by the first participant: *'I hate the way I look, more conscious of how I look in my face because the blood vessels, even though I haven't got much, my face can be puffy ... erm ... black circles under my eyes and I'm sure I notice it a lot more than other people do so in that respect'*. The second participant stated: *'I've aged a lot, looks-wise, through the stress of the disease; also I'm not very agile. So, it sort of ... you know ... it's not as exciting as it used to be'*. The third participant shared her changed appearance in this way: *'yeah my neck is thinner ... erm ... I did lose some weight, I have put weight back on again but I definitely lost weight but I think it looks as though I'd lost more because my face had tightened. I don't get the telangiectasia as yet but I do get very puffy fingers. I've always had dreadful hands as far back as I can remember, the ulcers ...'*

The fourth participant perceived herself as ugly due to the impact of the disease on her face and stated: *'well, I think I'm ugly sometimes because I used to have this beautiful, thick hair, it was really dark, now look at it, it's all gone thin'*. The fifth participant expressed her appearance since suffering with the illness as she said: *'I want to change how I look and don't want to go out because I look in the mirror and I don't like what I see. I have a weight issue at the moment, I can't lose any weight, I've put on some weight and I can't get rid of it and I've not been eating'*. The sixth participant shared the impact the disease has had on her appearance: *'I don't think that I look nice in anything I wear or anything ... well I know I've put on weight and I think my hands are really fat. I don't like my body and I won't wear my hair up like that because I have some red spots up on my forehead so I always make sure my hair covers them. I don't like to use sticks in social places'*.

(ii) Changed Sense of Self in 'not able to do household chores and less socially engaged'

The participants experienced a 'changed sense of self' as they have had difficulties in undertaking household chores and becoming less engaged due to the impact of the disease on them. The first participant quoted her disengagement with others and left her job: *'... so my body has changed significantly, so I used to do a lot of ... I used to go to the gym a lot, I used to do a lot of walking, cycling, gardening and that was the biggest enjoyment I had in life really and so a lot of that's ... that's gone'*. The second participant quoted: *'I used to be quite a party person, drink quite a lot and go out'*, and continued: *'when I am in pain, I'll avoid social things and cleaning is hard - I find I can't Hoover'*. The third participant reported her difficulty in doing daily household chores and gardening as she quoted: *'It's getting harder to ... my ... my grip is not as strong, I've even got one of those rubber cap things you can put over ...'*

erm ... yeah I am ... I'm definitely more clumsy and less dextrous with my fingers and my husband often has to open bottles', and 'I didn't have as much time as I wanted but I used to enjoy my gardening; obviously, because of the reflux, now I do hardly any gardening at all and that quite upsets me'.

The fourth participant reported her difficulty in opening bottles, riding bicycles and being less socialised due to the impact of the disease: *'well I can't ride a bike any more ... what I did ... I used to be always out on a bicycle. I can't ride my bike anymore and I don't like being with people, sometimes, in fact if ... in fact if they're good friends, yes, they're okay because they know what I'm like, and they ... they will tolerate me, but I walk so slow now and I can't use a tin opener, that's about the only thing I can't do in the kitchen is use a tin opener'*. The fifth participant expressed her difficulty in cooking as she quoted: *'we do it together, I can't chop, I can't carve ... erm ... I can't touch things out of the fridge, I mean my fingers go bright red now. I can't take a joint of meat out the oven 'cos it, my hands can't grip it ... roast potatoes'*. The sixth participant reported that she used to go to women's clubs and make cakes, but now she has difficulties due to her hand pain, as she quoted: *'I used to go to like the WI women's club ... erm ... it's only once a month, but I don't do that anymore either because I just can't go out in the evenings, so I used to like doing a lot of making cakes and things, ... it ... it's that sort of thing, it really hurts your hands'*.

Due to a dependency on others, the participants feel they are a burden on others and experience low mood, annoyance, and frustration at this, as quoted by the first participant: *'I just tend to be very, very quiet, I've cried yeah'*; the second participant stated: *'I just get frustrated by it and so I get, I suppose a bit moody about it'*; and the third participant expressed: *'I get annoyed with it sometimes'*. The fourth participant expressed her feelings of annoyance and sadness as: *'Sadness, annoyance ... erm*

fear, not of actual mortality but as a potential for severe disability'. The fifth participant expressed frustration in depending on others stating: *'Frustrated due to burden on others. I give you an example, we can go food shopping and I'm in a queue, suddenly I don't want to be in that queue any more, I push my trolley away and walk out 'cos I can't stand there, I ... see I can't stand for long so...'* The sixth participant expressed: *'it's annoying because if you want something and there's no-one there...'*

(iii) Changed Sense of Self as Unable to Accomplish Old Goals, Purpose and Meaning

The participants experienced a 'changed sense of self' as they became dependent on others to carry out daily tasks. Due to their disability and the impact of the disease on them, they could not accomplish their old goals and purposes which led to lack of meaning in their lives. Below I am providing some quotations from participants to support these findings, such as first participant who quoted: *'I don't know what my identity is any more, yeah ... erm ... we sort of knew where we were going with our life and what we wanted to do and that has all changed ... erm ... and so that's something and, we need to ... as I say change our ... our goals, and ... and I don't know where that's gonna go ... identity again, if that makes sense'*. The second participant quoted herself as being restricted and her experience of the illness as: *'I feel more restricted about what I can do, I went through quite a bad phase last year when I did feel very depressed and felt that where am I gonna go from here. I guess worries about the pain and whether I can deal with it, whether I'm gonna have it forever, and that's when I start to think is it worth it?'*

The third and fourth participants reported old goals as being their jobs, as quoted by the third participant: *'My goal was to do my job'*, and quoted by the fourth participant as: *'I can no longer do a day's work'*. The fifth participant has questioned her life purpose as: *'I've thought of that ... what is the point yeah, well, why was I put on this earth in the first place, I've not achieved much, I've had a good life but I've not achieved much and another old goal was, before I had scleroderma, yeah, we was going to buy a holiday home abroad'*. The sixth participant expressed being unable to accomplish her goals in this way as she quoted: *'It's really frustrating like ... well because I can't do what I used to be able to do, I just think then what the point in me is really? Well like my normal life has ended and now I don't feel like there's any ... any point really, there's no meaning, there's ... there's nothing to look forward to. I always feel ... I wanted to teach A-level but I could not now...'*

c) Re-birth of New Self

Over time, participants were able to accept their illness and learn to live with it. They used different coping strategies in order to regain some independence and to overcome their limitations, (please see above quotations under the heading of Acceptance and Coping Strategies), and they started to build new relationships, such as by joining a health club and online forums. Through using coping strategies, it seems that the participants have experienced a re-birth of their new self by making new life goals and creating a new purpose for themselves. I use the word 're-birth of new self' as the participants perceived themselves 'differently', as quoted by first participant: *'Yeah I'm a different person ... erm ... I just think I'm more aware, I'm more compassionate, I'm more empathic ... erm ... I'm a lot calmer than I used to be. I suppose I'm a lot more aware of the here and now rather than rushing through life just working and doing things, so yeah, I think my mind has broadened'*.

The second participant perceived herself as a loud party animal: *'I was out a lot, I had ... I was a bit of a party animal so I used to go out a lot and party ... erm ... have fun really and I think since being ill, it's just changed all that because my values have changed ... it has changed me, yeah'*. The third and fourth participants reported themselves differently in terms of their appearances, such as quoted by the third participant: *'Disease has changed the way I look, that I've got dreadful skin, a thin neck and lost most of my weight and my friends notice this change'*, and the fourth participant stated: *'I'm different now, yeah a lot different, especially in my appearance, well you have to ignore it but I don't like being with people sometimes, the mouth is different, the eyes are funny etc'*. The fifth participant expressed herself differently by stating that she felt 'robbed' as quoted: *'I was very active and I used to be a gymnast. I feel like I've been robbed. I used to finish my meals long before my husband. I don't want to go out because I look in the mirror and I don't like what I see, I have a weight issue at the moment, I've not been eating and I feel like I've been robbed ... a lot of that's been taken away from me by scleroderma because you were robbed of it'*. The sixth participant reported differently in terms of their appearance and social affects, quoting: *'I don't like my body but it's changed and in my eyes I'm younger than someone who would use a stick. I think I look old like I am about 80. Well I've always been the sort of person that just goes out when they feel like it and goes to visit friends and things and I ... yeah I feel like I can't do that now and I don't really want to go out and things any more, it's just easier to stay at home'*.

Through accepting their illness and using coping strategies, participants reported that they had developed new life goals and found a new purpose, re-valuating themselves according to the limitations of their disease, as the first participant reported: *'I want to do something worthwhile so I suppose in one way it's a positive because although I've worked in public service all my career I want to do something more to help other people, and I think that*

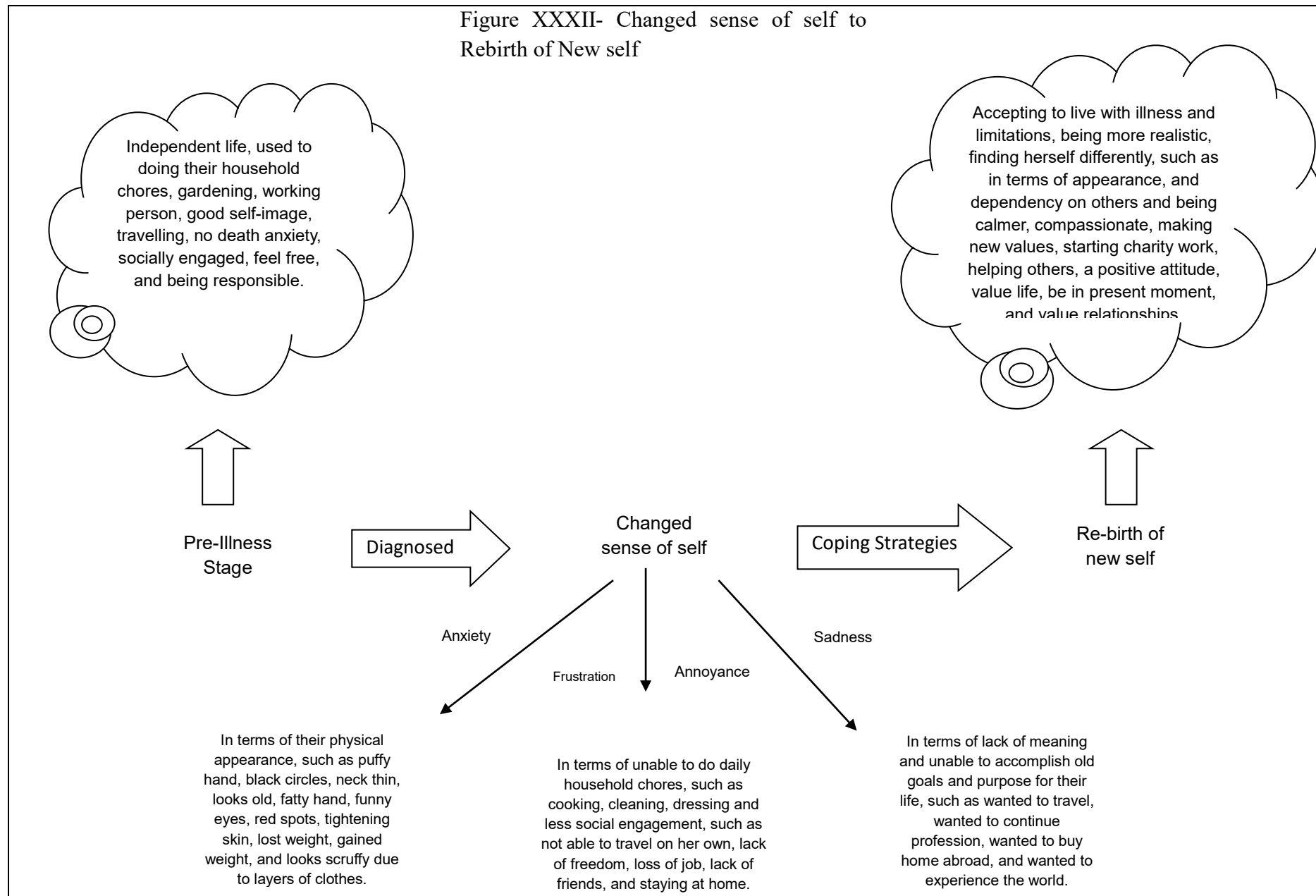
will give me more of a sense of my goals are to find ... find some work that is rewarding, to help others and to just to try and live as rewarding a life as I can. Before I was having to build up enough savings, move to another part of the country and have a bigger life and a bigger house ... sorry ... things like that, and we were gonna do a lot of foreign travel so those goals have changed. I think they have to be sort of realistic'. The second participant expressed their new life goals and purpose as valuing her relationship and wanted to be happy, as she quoted: *'yes ... change my goals and purpose of life, my goals ... I would say, I value what I have much more, you know I value, well certainly particularly the value of my boyfriend, I value ... you know ... the things that I might not do in another year, to be happy ... erm ... to, I mean not just for me, that sounds quite selfish, to kind of enjoy it as much as you can, use it as much as you can, you know, experience places as much as I can'.* The third participant expressed her life goals as a healthy and active one, wanting to be positive and to live her life fully, as she quoted: *'I'd like to stay as healthy and active for as long as I can. I am quite positive and hopefully I will remain positive – it's just more about living life to the full, not wasting life and to help make society happy. It's almost treasuring the good things in life more, more valuing the good things in life more. I want to be happy and I want the people I love to be happy and ... and yeah I want to be loved and to keep loving'.* The fourth participant reported that her values have changed since living with this illness as before she wanted to travel but now she wants to help others, as she quoted: *'I've changed my values as I wanted travel before but now I work for the food bank, there's lots of things I can do for the food bank ... yeah and then I do another one. I get a lot of satisfaction, because I think it's ... yeah, I'm not doing all the heavy work but I can still get a lot of satisfaction ... it gets me quite excited, you know, helping others'.*

The fifth participant expressed her meaning for her future life as to do charity work, understanding their life value now as she quoted: *'my new goal is charity, helping others*

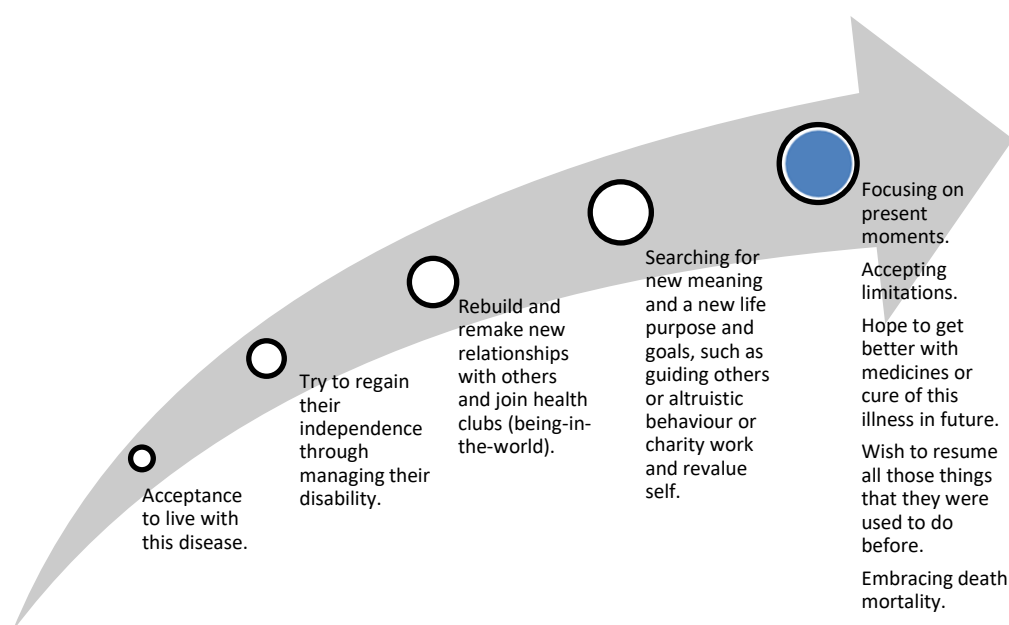
... getting married fulfils a lot of things in my life so ... and life is precious. I value life more right now'. The sixth participant reported that she is more spiritual and a religious person and she has started to value things and helping others as her life goal, whereas before she focused on herself and her enjoyment, she quoted: 'In terms of values change, I have become more spiritual, and a more religious person. I have become more about helping other people after this disease; before having the disease I am more focused on self, enjoyment, blah blah ... now I am taking the thing seriously. I started to value the things in terms of ... before I take the things for granted'.

The above findings suggest to me a theoretical model for this study as a process of changed sense of self into the rebirth of a new sense of self. The findings for this theme demonstrate a process which I have depicted in a diagrammatical way below:

Figure XXXII- Changed sense of self to
Rebirth of New self



From the above findings, which have arisen out of the participants' data, it appears to me that the participants have developed their new sense of self through accepting their disease and its consequences on their appearance, as well as the imposed restrictions on their life, such as difficulties in undertaking household chores and restricted travel. Through using coping strategies, they are able to manage their disability and also create new goals and look for new meanings in their life. They have started to find a new value for themselves (as quoted above) such as appreciating what they have, valuing their friendships, valuing their life more and changing their view towards life; they start to feel happy about simple things which they used to take for granted before. They start to create their new life goals, such as enjoying places which allows for their limitations, managing their disease, interacting with family, helping others and enjoying present moments.



Through using coping strategies, they have developed a new sense of self in terms of accepting their limitations, finding and building new relationships, and searching for new meanings by looking for a new purpose and creating new goals for themselves.

Through using the above strategies, they start to create their new meaning for life, such as helping others by working in charities, benefitting from a source of meaning through their grandchildren, achieving satisfaction from their religious beliefs and steering away from their old meanings. They have had to start wearing layers of clothes which they felt made them appear scruffy and not look nice, the way they did before, but they know they have to wear these layers to protect themselves from a Raynaud's attack, contributing to the change in their sense of self (as quoted above). They have changed their identity—maybe they were perceived as a party person and used to drink and have fun, but now they have accepted their limitations, including their slowness in thinking and being slow to accomplish their work or pace in an activity. By using these strategies, they try to separate themselves from the disease by not defining themselves by their disease but accepting their death mortality, perceiving life as it is, seeing the world as temporary and changing their life values with more focus on the self, recognising the importance of their health, rebuilding their relationships with others and looking for new meanings.

In this new sense of self, participants have tried to get better with medication and still have a hope of finding a cure in the future. They have the courage to find other better ways of living with this disease and also report their wish to live longer, including a desire to resume all those things that they were used to doing and wishing to live with less pain, go to warm places and explore the world with a wish to regain their full independent life again.

6.1.2. Summary of Constructive Grounded Theory for my Study

My constructive grounded theory is that systemic sclerosis has impacted people's daily lives and lead to an existential crisis. They experience disability, social isolation, despair, death anxiety, uncertainty and lack of freedom and responsibility. As a result of these phenomena they experience a 'process of changed sense of self'. Alongside using their regime, they use coping strategies to deal with their disease, manage their lives and rebuild their new sense of self.

CHAPTER 7

DISCUSSION

The present study was conducted to investigate how people live with systemic sclerosis, and how they cope with this disease using the grounded theory approach. The findings of the study were based on interviews conducted with six female participants. Using the grounded theory approach, I was able to understand what impact the disease has upon the participants' daily lives, how they experience such impact and how they cope with their disease. I was also able to propose a theory of 'Process of changed sense of self in experiencing life with systemic sclerosis.'

7.1. Summary of Findings

In this study, I examined the intersection between living with chronic illness and constructing a self. In this way, participants shift between being immersed in it and keeping it contained. They struggle to maintain control over their self-image and over their lives. Each participant's struggle is grounded in their particular experience of managing their daily lives, engaging with their illness and making sense of their experience. Meanings attached to their illness self swung and altered as their disease progressed.

Due to their illness, they experience emotions such as pain, frustration, helplessness, sadness and social alienation as supported by Malcarne (2013) and Nguyen & Thanh (2009). However, as participants deal with their illness, it suggests to me that they experience loss, crisis, disruption as supported by studies of Özkan, Teskereci & Kulakaç (2013); Sandgqvist, et al., (2005) and Suarez-Almazor et al., (2007). Through using various strategies, they begin to reconstruct their new selves, as supported by studies of Gumuchian (2018); Mouthon et al., (2017); Cinar et al., (2014) and Sandgqvist et al., (2004) etc. To find out how illness affects them, I looked at their everyday life such as home, work, and social life, and how illness impacts upon them and their social context. I found out that people experience their changed

sense of self by confronting the experience of their disease and, through using coping strategies, was able to re-build their new sense of self.

7.2. Discussion of findings

I would like to discuss in detail how people live with this disease and experience their changed sense of self and, through using coping strategies, they reconstruct their new sense of self.

7.2.1. Process of Changed Sense of Self Supported by Literatures

Prior to diagnosis, participants felt feelings of 'strangeness' due to suffering with unexplained symptoms and were likely to perceive themselves as hypochondriac and psychologically affected, as supported by these findings from studies of Mouthon et al., (2017) and Malcarne, V., et al., (2013) and Newton, E., et al., (2012) etc.

Once diagnosed, participants felt relief at finding their condition had a name. Receiving the diagnosis had the effect of validating their problem medically which also resolved and identified these problems. They accepted their diagnosis and ended the search for justifications and explanations to others, as supported by studies of Nakayama, A., et al., (2016); Mouthon, et al.,(2017)., Cinar, F., (2013) and Stamm, T., (2011).

However, participants reported their initial response to their diagnosis as shock, devastation, fright, frustration and uncertainty, due to unknown causes as confirmed by studies of Leeuwen (2020); Gumuchian, et al., (2017) and Suarez-Almazor et al., (2007). Some participants perceived their illness as temporary and had hoped to recover with treatment, but with time, they came to accept it as a permanent and incurable disease as evidenced by studies of Mouthon et al., (2017) and Gumuchian, et al., (2016).

When sharing news of diagnosis to their families, participants reported a reaction of shock, but subsequently still experienced limited acknowledgement of their illness and also a lack of understanding by family members, though they still felt comforted by their respective

partners as supported by studies of Sumpton, et al., (2017); Nakayama, et al., (2016) and Amin K., et al., (2011).

In this study, as participants pushed themselves into their physical selves, they reported depletion of energy levels as a result, and, experiencing disability, they made restrictions upon their life, finding their ability to concentrate adversely affected, which impacted upon their sleep. Living with incurable illness is challenging for participants, not only physically, but also in conquering the stigmatizing judgements, invasive questions, and feeling of worthlessness. The disease has impacted upon their feelings, their actions, and the meaning they give their life. This experience of living with illness is also supported by studies of Buck, U., Poole, J. and Mendelson, C., (2010); Leeuwen, N., et al., B (2020)., Suarez-Almazor et al., (2007) and Newton, E., et al., (2012). Living with this disease also results in ongoing problems and unforeseen difficulties. People with chronic illness find themselves experiencing isolation from others. They experience a contrast between their present selves and the self as lived prior to diagnosis. This calls into question their sense of self and, in addition, challenges taken-for-granted notions about their individual aptitude. However, most people attempted to keep their illness at one side of their lives and keep their self-concept to the other (Conard, 1987, cited in Charmaz, 1997).

Experiencing their disability and limited levels of activity, and due to the loss of some aspects of their past selves, participants experience discord between themselves and their world. Through this, they experience crises more keenly, which changes their present experience and negatively impacts on them due to anxiety regarding the future. Experiencing this crisis kept them alert about what is happening to them. Flaherty (1987) said people with chronic illness experience their present subjectively and this awareness pulls people out of the past and compels them into their present reality (cited in Charmaz, 1997). Participants experience this crisis as not only deleterious to health, but also as sabotage to their loss of self and way of

life. This loss also brought substantial changes in their relationships. Upon realizing that their illness is permanent, participants view their illness as intrusive. It affects their daily lives of activities and creates a perceived threat of control over self and situations, and results in uncertainty. They suffer from the subjective phenomena of disability, social isolation, despair, death anxiety and lack of freedom and responsibility. These phenomena are supported by studies of Suarez-Almazor et al., (2007) and Rubenzik et al (2008).

Charmaz (1983) reported that threat of loss of control leads to the threat of the loss of self. People need to deal with their illness in order to establish more control over their lives (cited in Charmaz, 1997). After gaining awareness of their illness, participants started to use treatment measures in order to control their symptoms and attempt to ensure prevention of flare-ups. With time, participants attempted to accept their disease and its consequences over their lives including their now-established disabilities. They acknowledge their illness and attempt to manage their pain, fatigue, swelling, limitations and lethargy through using regimes, as supported by studies of Cinar et al., (2013); Nakayama et al., (2016) and Newton et al., (2012). Corbin and Strauss (1984) reported people chose to live with disease and admit the presence of their illness, by attempting to try to adjust to it. By accepting their disease, they also admit the limitations and boundaries imposed by the illness, and manage illness within their set limitations (cited in Charmaz, 1997). Charmaz (1987) reported that acceptance shapes both future and present, and accepting the identities and other beliefs to be “appropriate” for them discloses ill people’s views of self and their implicit theories of identity. Their level of acceptance reflects the degree of assault upon the self that they can endure. Moreover, it reflects their constraints of defining the self and of being recognised by others (cited in Charmaz, 1997).

As Schneider and Conard (1983) reported, loss of control leads to embarrassment, and additional stigma produced by illness (cited in Charmaz, 1997). Participants depend on others

for the completion of daily chores, including dressing, cleaning, washing, and supporting financial well-being, depending on their levels of social and economic support. This dependency also impacts on their self-concepts and their meanings as verified by studies of Nakayama et al., (2016); Suarez-Almazor (2007) and Sandgvist, et al., (2005). Initially, participants struggled, remaining in work and being independent for as long as possible, but ultimately had to leave their jobs. To some extent, they protected themselves financially, by choosing early retirement, and in having their own homes and properties. Participants also found their relationships changed due to the impact of their illness. They reported that their partner and their siblings shared in their household work. Their illness takes away their spontaneity from shared sexual experience, and creates reluctance to engage in the activity due to impaired libido. They perceive themselves as fragile and clumsy in the way that they engage. Their relationships with friends and family become sporadic due to their lack of energy and inability to provide companionship and because of their limited levels of activity. Participants also kept their illness hidden due to their fear of loss, rejection by others and stigma as confirmed by the research of Sumpton et al (2017); Sandgvist, et al., (2005) and Suarez-Almazor et al., (2007).

Therefore, they tried to contain themselves at home, and if they went outside they used solution-focused strategies such as using cream, gloves, scarf, and trying to manage without aids to mobility such as walking sticks in order to hide their disease from others; which is also supported by studies of Cinar et al (2014); Sumpton, et al., (2017) and Gumuchian et al (2017).

Due to impact of their illness on their physical and social world, they experience despair and question self-concepts which subsequently immerse them deeper into their illness. The disease has re-formed their self-concepts as well as their bodies and lives. Participants experience the susceptibility of their bodies and this result in their changed physical, social,

and economic dependencies. Participants living with disease shrink their social world and they pull themselves into their inner world and push away from the external world. They restrict their boundaries, restructuring their priorities and also struggle with the constraints of illness and their disability.

Participants continually compared their past with their present immobility and dependency. Participants go back to their past memories when they involve themselves in the world, post-diagnosis. They perceive their future as a threat of danger and death as supported by studies of Suarez-Almazor et al., (2007); and Nakayama et al., (2016).

When participants face their limited world, they then become aware of the loss of self. Participants' physical conditions placed impositions upon their limited social life and therefore they experienced a limited sense of self. As long as these boundaries of the self remain limited, the more rhythmic life becomes. Participants lose their ways of shaping and giving meanings to their days due to their illness. Being immersed in illness, people isolated themselves from the outer world and they lose their common interests, shared with friends and family as established in earlier life. They avoided meeting people and preferred to stay in their homes. Due to their social isolation, they experience feelings of loneliness, sadness, frustration, helplessness, and hopelessness. Participants felt robbed by disease and began to perceive themselves rather like a caged animal as supported by studies of Suarez-Almazor et al., (2007); Rubenzik et al (2009); and Amin et al., (2011). As Lopata (1969) articulated, social isolation transforms directly into emotional isolation and loneliness (cited in Charmaz, 1997). Participants also experience shame and embarrassment due to their 'burdening' on others and which in turn reflects their fear of illness and death. Participants avoided disclosure about their illness. They talked about their illness with relatively few people such as those at work, family etc. They perceived a lack of understanding from others and feared judgment of their illness by others. They found themselves ignored, rejected, and stigmatized

which impacted upon their sense of self. Participants experienced some degree of loss in terms of friendship, work, and family life. Therefore, people chose to avoid disclosure about their illness to avoid stigma and to avoid their feelings of embarrassment in an attempt to maintain their relationships. Participants with disability could not choose to hide their illness and disclosed it to the public if they, for example, walked slowly and used sticks and/or a scooter in public places. Then, however, they felt a lack of control over themselves and experienced frustration and helplessness. According to Ponse (1976), in losing acceptance and autonomy, ill people experience instant interactional risk such as being rejected and stigmatized for disclosure of illness and being unable to manage other's response and losing control over their own emotions (cited in Charmaz, 1997). In this way, when participants start to lose their autonomy due to their condition, they then risk loss to their self-esteem, so they avoid disclosing illness. They try to present a public face based upon their pre-diagnosis identity, but could not maintain this on returning home. Living with incurable illness takes place within social and personal context. Strategies to deal with their illness change with the progression of the disease. Participants firstly refused to acknowledge their illness but with the time they accepted their illness as part of their lives. People learn to live with illness when they adopt strategies to get through the day and modify them as their conditions progress (Jobling, 1977, cited in Charmaz, 1997). To overcome their social isolation, they try to engage themselves through using different strategies such as watching television, listening to music and reading books. With time, they started to make new relationships with others as confirmed by the studies of Nakayama et al., (2016); Milette, K.,(2019).

Due to their crisis, they turned themselves inward and lost hope; eventually, this turning inward strengthened them as they moved closer to awareness of their death. Their experience of illness caused them to question and embrace their identity, and also prompted their social isolation as supported by studies of Milette, K., (2019) and Stamm et al., (2011). They

embraced with their identity, comparing their past selves with their present appearance. They became overwhelmed by these identity questions and found themselves a different person from their past selves. Participants became dependent on others for their daily tasks which also spurred their identity questions. They lost their previous positive identification of the past due to their illness; as one participant said "this disease has taken everything away from me."

Although they are trying to rebuild their sense of self again, and are attempting to assert control over it, the present self is still inconsistent with their past one. These inconsistencies between the present and past identities lead them to raise questions of identity. Through their questioning about identity, they achieved a deeper sense of resolution and sense of being; they used solution-focused strategies and meaning-based strategies to make sense of their being and they rejected their old self-image that they used to accept. With this illness, they are more able to explore their true sense of being and understand the importance of self.

Due to struggling with disease and in their daily lives, they confronted their existential issues about self-worth, meaning of life, living at all and its limitations. To embrace their limitations and restricted life, they experienced a different range of emotions such as hopelessness, meaninglessness, frustration, anger, resulting in despair, as supported by other studies such as Sumpton et al., (2017) and Suarez-Almazor (2007).

With meaning-based coping, they attempt to take control over their lives through organizing aspects of daily life. They persistently define themselves before and after the illness. Participants seek help to do daily tasks through getting support from husbands, and children. Participants try to do daily chores on their but own, but some tasks cannot be executed due to their disability and they transfer the burden to their partner and their children. They teach their partners and children how to do the washing, cleaning, dressing and cooking. After living with this illness and recognising their loss of some aspects of self, they initiate and

create their life for themselves. They describe themselves as a totally different person from their past self.

Participants deal with their illness through different ways; for example, they might hold their shopping bags in their arms as they have difficulty in gripping things in their hands.

Some of the participants re-developed their organizational skills. One woman started to work at her home as a freelancer as she was unable to manage her job in her office due to coldness and physical limitations as supported by Sandqvist (2005). Therefore, she started her business at home so she could take rest periods. By learning skills to manage themselves, participants drew on their hopes and expectations of self.

Although participants experience less anxiety and pain by staying at home, they confront their existential questions such as who am I, or what is the point to live? In the home, participants reported that they made adaptations according to the needs of the illness, but still they became more limited as they cannot make any amendments to parks, roads, buildings, or public spaces. Therefore, participants avoided going outside and kept distance from their family, friends and colleagues, resulting in lost contact with friends and finding no energy to make new friendships. Participants depended on others for their daily tasks. In order to gain a sense of control, they attempted to do them independently but involving support from others. In this way they tried to feel less of a burden on others. Most of the participants moved to countryside areas and far from city life, as they felt tense in urban areas and preferred to live in countryside and green rural places in order to feel relaxed. This however, also alienated them from social life.

People experienced boredom, decreased medical coverage and lack of resources and facilities in these rural areas as confirmed by another study of Stamm et al., (2011). Participants with incurable illness were compelled to reorganize routine. They took note of particulars such as eating times and diet, whereas they had not previously been conscious of this prior to

diagnosis. They changed their schedule as the intensity of their illness changed. This scheduling assisted them to feel less uncertain as they attempted to assert control over themselves. Comaroff and Maguire (1981) said people with chronic illness construct their routine in order to protect themselves and to preserve their lives. However, they perceive their life as out of control when they engage with their work and relationships. Being isolated and immersed in routines characterised by their illness also situated them in their past due to their lack of sense of being. They rejected their present sense of being and located themselves in their past (cited in Charmaz, 1997). As Maines, Sugrue and Katovich (1983) discuss, present realities shape what people recollect. People locate themselves in the past due to their loss, unchanged time and social isolation. Participants who lost mobility and independence struggled to counter a present sense of self by letting others know about their past achievements (cited in Charmaz, 1997).

However, through sharing their past self, they brought their past into the present, and gained strength to manage their present conditions. Incurable illness also radically affected the participant's time structure as they became more focused on their present and in planning for this. Participants chose to live one day at a time; it is their way to find relief from pain and managing their feelings of uncertainty. Jaques (1982) and Mead (1932) described that ill people focus on their present and meanings of the present place time horizon and give material to images of past and future (cited in Charmaz, 1997).

Participants managed their illness through living one day at a time, meaning that they put future plans on hold in order to manage their uncertainty towards the future. This was supported by a study of Sumptom et al., (2011) and Nakayama et al., (2011). Through living one day at a time, participants focused on their illness, treatment, and regimen and tried to establish control over them. Through focusing on their present, they avoided focus on their future in terms of further disability and death. Through staying with their present, they

brought their awareness into the present and successfully rejected their projected future, managing themselves whilst facing uncertainty. Living one day at a time also helped them to lessen their anxiety about the worse consequence of disease in the future, and helped handle their fears, guilt, anger and self-pity and therefore create a sense of control over these feelings. By gaining feelings of control over the day and the sense of self, participants felt some improvements in their illness and got a sense that they were winning against illness.

Living with incurable illness triggers the awareness of mortality. Through living one day at a time, this also provides them with finding their meaning in life and to define their new values. Through managing their days, they perceive their future leaking through their present as making new goals for life, new purpose of life and new values for self; participants then permit their future to reflect upon their present in order to see hope again. Living one day at a time encouraged others to find meaning and a sense of achievement. Some participants still have hopes for complete recovery or cure in the future through trying to control illness in the present. Through this, participants with incurable illness revised plans for the future, with guidance from their past and hoping to recapture it. Charmaz (1973) mentioned that ill people create a future map and assume they will realize this in future. Through recapturing their past, they get hope to live in the same way, regaining their old sense of self and being able to interact with others as before (cited in Charmaz, 1997). Participants compared their past selves with present selves to understand their present and learn about their future. However, their desire to recapture a past self also reflects on their pain of the loss of old self. Their grief of losing the past self intensified when they confronted their limitation imposed on trying to reclaim it. Sartre (1988) supposed that it is hard to bring the real self back, compared to burying it. Participants' grief faded when their new self emerged. Lewis (1985) talked about living one day at a time, and that this can become a direction to commemorate life instead of using it as forced strategy for sustaining it (cited in Charmaz, 1997).

Participants identified their new sense of self through their grief and existential crisis. They experienced feelings of loss, shock, shame, being demoralized, embarrassment, annoyance, frustration and helplessness. These emotions shake the self and impact on the uncertainty participants experienced. Goffman (1963) suggested that ill people experience distance from past to present and shrink as past mirrors into the present. Scheler (1961) proposed that people re-experience their past emotions that imprint into their structure of self (cited in Charmaz, 1997).

Marris (1974) said ill people feel angry with their situations, but handling such situations results in positive continuity of self over time; through scrutinizing the past, they settle their problems within it. Transcendence of self refers that self is more than its body and much more than an illness. Participants accepted themselves through making and taking choices, rather than accepting their illness in terms of stigmatizing images. Both loss and transcendence appear from experience of illness and the meanings that the participants confer upon it. Loss of self derives from how participants gave meaning to their physical and mental competency. This then shades their self-definition and comes from the social meaning and spiral effects of illness, such as side effects of medication. People experience loss of self when they depend on others for little things. They struggle against their loss in order to live in the present, as they indeed had in the past, and to fulfil their responsibilities. Their self-acceptance leads to autonomy to recognise there are still choices. Loss of self reflects on their loss of autonomy and undercuts their actions, emotions and beliefs to create their self; thus, the illness spreads out through the participant's life and pervades their social world. They evaluate their boundaries and choices in order reconstruct their valued aspects of self, and are both more aware about them and more attuned to their bodies (cited in Charmaz, 1997). This is illustrated by participants who avoided going outside so they could keep their disease private, and using cream, gloves, and make-up to hide their symptoms. This is their choice to deal

with their illness and maintain control. They made sense of their feelings and their pain and became more aware of their self and their meanings and changed involvements. They reconstructed positive consequences such as empowerment, Being-in-the-World, searching for new meaning, Being-in-Time, a changed sense of self, living authentically, being hopeful and wishing to live. Cooley (1902) noticed that emotions and feelings make foundations for the self, and Hochschild (1979) talked about the 'emotional-work' to comprehend the present feelings related to the past self. Through surpassing their past selves, they try to build new lives and new social worlds for new self-images in order to remake their sense of worth. By confronting their existential crisis, they anchor to the loss of past self, from which new possibilities for the present and future emerge (cited in Charmaz, 1997). Participants attempted to construct their new sense of self through communicating with their present and experience themselves as real and authentic. Being an authentic person, they stop thinking about the past and allow themselves to focus on the present, enabling themselves to make a real self and start to live authentically through re-making new values and focusing on what they want to do and choose for themselves. Through this, they attempt to re-build their sense of self and a valued self in the present. Jones (1988) stated that evaluating these goals makes the present worth living (as cited in Charmaz, 1997). Participants with incurable illness attempt to live one day at a time and establish their goals purely for one day, but with time, they learn to make some future goals such as doing enjoyable things, living in the present, helping others, having empathy for others, being compassionate towards others and doing voluntary work etc. Participants make future plans but in their head they live in the present. Their learning to live in the present reflects a particular form of present. They attempt to take control of themselves and their lives with illness. They perceive their future as dreadful due to their progressive disease. People embrace their death mortality and their quest for immortality that gives them life meanings as these are supported by the research of Nakayama et al.,

(2016). Some participants found their meanings through their religious or spiritual beliefs. Through accepting their limitations in being human, they look at themselves as having new possibilities and accepting their death. Through doing this, they feel triumphant over illness and death and accept their new sense of self. Participants project themselves into a future along with their hopes and new goals and reconstruct their sense of self through searching for new meaning, new purpose and new life goals as supported by studies of Gumuchian, et al., (2016).

In conclusion, participants with incurable illness attempt to remake their lives through planning and organizing their tasks. They learn what it means to live with illness and disability. Depending on others to do daily little tasks such as bathing, washing, cleaning, dressing and cooking harms their image of self. However, to some extent they try to manage their daily tasks in order to re-build their sense of self and gain a sense of achievement and satisfaction. Their new sense of self helps them to preserve their physical health, their social relationships, their morale, and their autonomy.

7.3. How my findings relate to Existential Philosophy

The way a person lives in this world at any particular time of their life can be drawn on a general map of human existence (Binswanger, 1963; Yalom, 1980; Deurzen, 2010) that comprises four basic dimensions of existence. People relate to their world and environment around them and focus on their ability for health and illness as well as their relationship to their own mortality; it is related to physical dimensions (Umwelt). In this world, participants accept their limitations based on their natural boundaries such as their disease and disability, and their incurable disease meeting with their own mortality awareness. Due to death mortality, they experience vulnerability and wish to live a long life. In their state of vulnerability, they depend on others for their physical care and safety. In these dimensions, participants experience the dilemmas and tensions between life and death. They experience

the anxiety to stand in tension between the finite and infinite. Kierkegaard sees anxiety as a way of becoming more self-reflective about the process of conquering the space between nothing and eternal (cited in Deurzen, 1997).

With time, they embrace the reality of life as temporary. They embrace with their death reality and accepted their life change and loss due to disease. Participants used the problem-focused strategies and solution-focused strategies to regain some control over their lives to achieve some independence, and accept their limitations and death reality. People relate to other people and interact with social world around them. People rely on others not just for their physical needs but also their emotional survival in their social dimension (Mitwelt). Participants confront with aloneness in their dimensions. Participants talked about their difficulties to maintain their relationships due to the impact of the disease. They avoided social situations due to their disability and to keep their condition hidden. Initially they tried to maintain contact with others but they found a lack of understanding of their problems, perceiving a lack of empathy and a fear of judgement from others. They also found some relationships became distant. As a result, participants started to make less contact with others and isolated themselves at home. Due to the physical impact of disease, they avoided intimate relationships with their partners and avoided interacting with social life. Through using the solution-focused strategies and social coping, participants tried to rebuild their relationship with others and joined different social clubs and forums in order to make relationships to engage in social activities. They understand that they cannot separate themselves from others. It reminded me of the Heidegger concept of human being as Dasein (literally 'being there') in *Being and Time* (1962) or Being-in-the-world that means that a human being is basically always in a world, in context and in relation and never in isolation. Heidegger focused on our mode of Being and stressed human beings' immersion in, and openness to, the surrounding world and self as a single entity 'Dasein' instead of seeing them as two beings as object and

subject. Human beings manifest in a particular way to the world that throw light on being itself and coming to the presence (cited in Van Deurzen, 1997).

Heidegger's descriptions of Dasein brought the notion of Time that is always present for all of us. We are not in fixed self; instead, we are always becoming ourselves with time through our past and projecting it toward a future. Participants stuck with their past selves, and in the present found themselves in a different self and focused on why they are now and then projecting themselves into a future. Existentially, we are predominately directed towards future in a sense of certainty of our future death and to resolve anticipated problems. Heidegger said our past comes to us from out of our future, which causes us to scrutinize our past and bring it back to mind, to learn from and to make present, and give existential meaning to the present. Through this process, participants made them present to ourselves and this gave them existential meaning of the present. Their present transpired out of the encounter between past and future. By living in the present moment and focusing on their here and now, participants take steps to live authentically. Dasein is 'thrown' to the world pre-existing with objects, projects, relationships and a 'situatedness' that restricts our freedom and our understandings. We immerse ourselves in this world through daily activities that we engage in pre-reflectively without thinking (cited in Van Deurzen, 1997).

According to Sartre, existence precedes essence; that is, we are thrown to a world where we birth ourselves and through living in this world, we construct our essence of who we really are and make our unique place in the world. So, we exist first, and in this process, we construct ourselves. Jasper (1951) debated about limit situations as inevitable realities that human beings should be confronting. Participants living with incurable disease confront their limit situations and recognise both that which is not within grasp, and what are their own limitations. Through embracing their limit situations, they motivate themselves to start communications with the world of other people. We are thrown into an inescapable world.

The world of Dasein is a 'with world' (Mitsein or Being with) which means that human beings are always in relation to others and in relation to things, themselves, and ideas (cited in Charmaz, 1997). According to Rollo May (1969) each person in this world is at the centre of a web of relations. In this study, participants perceived themselves alone physically, and isolated from social life. Even though they said they are socially isolated, they are still in relation with others through their daily engagements with the outer world such as buying necessary things from a shop, getting their medications, or attending hospital appointments. Through sharing the world with others, we experience care or concern for the welfare of others that has attributes of Dasein, which means things matter, because Dasein is not in isolation and cannot help but be connected to (i.e. care about) its world. Heidegger (1927) places it's fallen with others (Verfallen). Being human is always being involved with others, and we care about others in spite of ourselves; we have to fit in with them and attempt to satisfy them (cited in Van Deurzen, 1997).

Participants become aware of their frailty and mortality through their incurable illness and confront their isolation and their need for others through loss of relationships. By comparing their past selves with present selves and confronting their existential anxiety, they embrace their limitations and possibilities imposed by their disease. Through being open to their existence, managing their difficulties, taking ownership of their existence, and by being present, they choose authentic living.

In the personal world, people are concerned about their issues of choice, freedom, responsibility and personal integrity and this is created by their inner thoughts that are merely of themselves. Due to the impact of disease on their physical and social selves, participants experience despair in their psychological world and confront their isolation as they experience their disease alone; others could not understand their experience and could not live a long life due to the prognosis of disease. They separate themselves from the world. They

lose hope in a cure for their disease as it is incurable, and lose hope of their health improving due to the progression of disease over time. They lose the sense of their self in most aspects of their life they were used to before, and lose some aspects of their life meanings and goals. Awareness of their own personal reflections triggers existential anxiety (angst) about their responsibility not only towards themselves but also towards others in terms of their interconnectedness. Existential approach sees the human being as an embodied consciousness that is able to reflect upon itself, always in context. People create their identity through engaging with the world that is inescapable; in this way, participants with incurable disease isolate themselves from social life and isolate themselves at home, dependant on others and experiencing physiological changes due to the physical impact of their disease. They raised questions about their identity 'who they are?' We experience and interpret the world through our body and respond to the world. Heidegger pointed to this as 'mood' in the terms that it saturates our lived world with meaning by attuning to the world. Existential therapists believe that the body is what we are rather than something we have. Nietzsche focused on listening to the body in order to become embodied. In this study, participants reported their feelings of sadness or frustration; initially they attempted to ignore this through some distracting techniques but then they became attuned with their feelings to become embodied (cited in Deurzen, 1997).

We construct self through making choices and connections to the world. Existentially, the sense of self is a dynamic centre of gravity of individual networks of physical, social, personal and spiritual worlds that we are continuously modifying. Existential approach believes in self as non-fixed. Through confronting with their existential crisis following incurable disease, participants struggle to live with their illness as they constantly compare their present with their past selves and raise questions about their identity. However, they attempt to create a new sense of self through resilience. Participants also experience the

limited choice for themselves due to their dependency on others. Due to this, they experience lesser engagement with life. It results in a lack of sense of their life purpose, goals and meaninglessness. Nietzsche (1883) said life is an endless succession of moments that can be related and relished regardless of what they are. People who are unable to comprehend this way of living find themselves stuck with their mortality and meaninglessness; they not only reject their life but also themselves. Through experiencing their existential crisis, participants experienced their lack of freedom and responsibility and are anxious about their possibility non-being (Tillich 1952). Tillich said anxiety and courage are two side of a coin as similar to life and death; they are interlinked to each other. He said when we are living, then death is waiting as an inner emptiness and it fills when we suffer any loss or threat to our existence. Through using meaning-based coping and realistic coping, participants start to make sense of things and find meanings in life - as Frankl (1967) said, meaning is the most vital element for living a worthwhile life. He said that finding a meaning is a more vast and significant task than the tasks we had to achieve before we came here: the task of suffering with courage and dignity. Through finding their new life meanings, they aim to affirm their values and accomplish to their life goals. May (1969) state that, through accepting their anxiety, the task is to centre oneself in oneself, and to search for their power to choose and assert on their values and to live by one's own convictions (cited in Charmaz, 1997).

Whilst confronting with their death mortality, participants talked about their limitations and accepted death as an inextricable part of life. However, they have questions in their mind; 'what is the point to life if we die?' They experienced sadness and isolation with their awareness of death and have fear of dying and nightmares. These sorts of questions compel them to find their life meanings and their life values. They changed their values as they became more empathetic and compassionate towards others, and sought activities that benefit others such as charity work and helping others, especially other disabled and ill people.

Participants began to choose altruistic behaviour to seek satisfaction. This resonates with Heideggerian (1962) statement that physicality of death destroys man; the idea of death saves him. In my own understanding, participants become overwhelmed by their fear of dying and this impeded upon them to engage with reality and the lack of freedom over their life and their experienced lack of freedom and responsibility. But their facing of death as reality assists them to re-examine their life and attune with their true sense of self, what they are, and what they want in their lives. Heidegger (1962) described two modes of existing in the world; that is, the state of forgetfulness of being, and the state of mindfulness of being. In the state of forgetfulness of being, participants immerse themselves in everyday life and lose themselves in their characters. In this way, people are not taking ownership for themselves and living inauthentically. While in a state of mindfulness of being, people become aware of themselves and they become embraced with their reality and their possibilities and limitations. Heidegger (1962) applied the phenomenological method to understand the meaning of being. In *Being and Time*, Heidegger tried to grasp the death's phenomenon through understanding the 'Dasein' - what it means to be. The phenomenology of death focuses on discovering the ways in which death grasps human understanding as an essential condition of being-in-the-world. Death is closely related to a 'phenomenology of life- life's being is also death.' This means that all the things ultimately travel towards their end (death) when it comes into life, and death is at the same time life (ibid: 5). Being is time and time is finite, which means if our being is finite, then it finishes with our death. Then, human beings can only be authentic by defying the finitude and striving to find meaning out of the fact of our death. So, it is indispensable that we incessantly project our lives onto the horizon of our death- that is called 'Being toward death' (Heidegger, 1962). Through embracing with their death reality, participants experience death anxiety, Jasper called it as 'fragility of being', Kierkegaard said it was a 'dread of non-being', Heidegger refers to the term of 'impossibility of further

possibility' whereas Tillich used the term 'ontological anxiety'. Through using meaning-based coping and realistic coping, participants accept their death reality and their limitations, and re-construct their new values and purpose for their lives (cited in Van Deurzen, 2009).

After confrontation with their existential crisis and using their strategies, participants strive to find meaning in their lives. Frankl said that deprivation of meaning in life leads to greater frustrations, emptiness and depression in person and experience the existential vacuum. He said that people tried to conquer their physical and psychological suffering through searching for meaning in their life. Nietzsche expressed and Frankl often cited: 'He who has a why to live can bear with almost any how' (in Frankl, 1984: 97). Sartre (1958) said that human beings are free to choose their own meanings and values in every condition, and Heidegger (1929) said that freedom is a reaction to the need of a specific situation, and to listen to the call of our conscience instead of escaping from it. Frankl articulated three categories of life meanings. In this study, participants chose the third category, attitudinal values, which means that participants stand toward suffering and changed their attitude to a situation that they cannot alter and then they discover their attitudinal meanings to life. Frankl (1998) claims that human essence has ability to transcend as well as to confront bodily experience (bodily pain) and with it psychological suffering. Through accepting their disease, participants attempt to find their meanings in their suffering instead of finding a cure for their disease (cited in Van Deurzen, 2009).

Through using various strategies (see Chapter 4); participants are able to construct their new sense of self. They reported their wish to live life in meaningful way, and began projecting their wishes towards their future in a particular way. Rollo May described the wish as imaginative, playing with the possibility of some act occurring, and he described 'wish' as a process of willing (cited in Van Deurzen, 2009). In this new sense of self, participants figure out their limitations imposed by their disease and then they choose their wish to live under

their limited boundary and re-make their values, goals and purpose life and consequently commit themselves to this course of action.

7.4. Implications

This section will highlight implications of the present search in the field of counselling psychology and psychotherapy as well as within healthcare sectors.

7.4.1. Implications for Psychotherapy Theory and Practice

The outcomes of this study aim to help professionals (counsellors, psychotherapists and psychologists) to understand people's experience to live with a rare incurable disease. In this study, it is concluded that disease has impacted on participants' daily lives, and confronted with their existential crisis and experience subjective phenomena of disability, social isolation, despair, death anxiety, uncertainty and lack of freedom and responsibility. As a result, they experience a change in their sense of self. People with rare incurable disease might find benefit in existential therapy, cognitive-behavioural therapy and other therapies in order to deal with their dilemmas.

The results of this study show the potential value of existential modality for people who are living with a rare incurable disease as this approach does not focus on labelling people; rather, it focuses entirely on their life experience and their existence in the world (Van Deurzen, 2009). It explores what it means to be alive. This approach addresses the questions that people ask themselves especially in state of existential crisis. In this study, participants raised the question around their meanings, purpose, goals; what is the point of life if we are to die etc. This approach is suitable with these questions. Existential approach is based on phenomenology in order to understand how we relate to the world, to grasp the world itself better, and comprehend the self that is created in the process of relating and making sense of experience. Existential therapy does not seek to cure the illness, but rather helps to find the way to live in order to improve others' lives and encourage people to take ownership and

responsibility of their choice. The aim of existential approach is to explore, describe and clarify participants' dilemmas and enable them to stand courageously against the tensions of life in a way that dignifies and strengthens them, whilst also considering the context of the world in which they live. Existential therapy also emphasizes the need to work on four dimensions of existence of the individual, that are the Physical world (Umwelt), Social world (Mitwelt), Psychological world (Eignwelt) and Spritiual world (Uberwelt). The intent of the existential approach addresses all of these human existences equally and explores the contradictions and paradoxes in each world in order to understand each person's existence in the world (Van Deurzen, 2009).

In this study, participants experience a changed sense of self. Existential approach focuses on the personal world of people in order to explore their relation with the self, not only their relationship with others and the work on meanings of their own reactions. Existential approach encourages the increasing of ability to see oneself at the centre of relating and not to isolate them with an estranged view of self. Existential therapists help to draw people's attention to the self as a centre and engender their abilities to make subtle adjustments to what is more helpful towards vital living. Existential philosophy does not assert our 'fixed self'. It claims we are free to becoming ourselves. Therefore, existential therapists assist people to disclose reality as sense of self and meaning in relation to the world, and make sense of it and explore their being-in-the-world (Van Deurzen, 2009). In this study, participants lost some aspect of their old life and experienced loss of meaning in their life. Frankl (1984) introduced the logotherapy to help people to find meaning in their lives. Moreover, the result of this study showed that people used meaning-based coping and realistic approaches to accept their mortality and to find meanings for their life. It is the goal of the existential approach to help the client to grasp their life meanings through acceptance of life and death, and embrace their

uncertainties, which are useful for people who are living with incurable disease and unknown consequences of their disease (cited in Van Deurzen, 2009).

Existential approach is based on philosophy where the therapist helps others to understand their lives fully, not to merely focus on brain and bodily functions. The result this study showed that people with a rare incurable disease experience their lives not only physically but also emotionally. The existential approach helps people to accept their limitations and boundaries and also focuses on their sense of being.

Cognitive behavioural approach is another form of therapy that places emphasis upon each individual's thoughts, feelings, and behaviour and teaches about coping skills to deal with their problems. In this study, participants talked about events such as how they feel in social life or how people respond towards them. CBT might be useful for those people to examine how they think about such events and how it affects on their feelings and behaviours. Participants also experience anxiety, fear of dying, panic attacks, needle phobia, and investigations phobia. In this perspective, this approach might be helpful to monitor their unhealthy thoughts and exchange them for more useful ones, as CBT approaches are more focused on creating healthy thought patterns; consequently, this leads to more healthy behaviours (Feltham, C. and Horton, I. 2006). CBT also focuses on creating skills to manage psychological problems and also on developing skills to manage individual's lives. In this study, CBT may also deliver the psycho-education to understand the psychological impact of the participant's disease and how they can experience emotionally what would affect their behaviour towards self, other and world (Feltham, C. and Horton, I. 2006)

This study is not merely to benefit people with systemic sclerosis but also for people with autoimmune disease, people with an incurable disease, and people with a life threatening disease (as systemic sclerosis has all these traits), and carers of people with systemic sclerosis. It aims to help to understand each individual's dilemmas in living with this disease,

and also explore what it can be like to cope with this disease, and to be helpful for caregivers in terms of increasing awareness about the disease and its underlying impact on affected people, so that they can better understand people with systemic sclerosis and can help carers emotionally connect with them.

This study would be helpful for psychologists, counsellors, psychotherapists, rheumatologists, immunologists and rheumatology nurses to understand the psychological impact of the disease and to recognise the patient's emotional state and how they can cope with, and learn to live with this disease. The reason behind choosing the rheumatologist, immunologist and rheumatology nurse is because in my own experience, I feel they need to know more about the psychological, emotional impact of the disease. I am also suffering from this disease, and in my experience, I found out that the rheumatologist merely focuses on the physical impact of the disease and ignores the impact of disease in a psychological and emotional dimension. I feel if they understood the patient's psychological and emotional states, and referred them to regular counselling services, then the patient's wellbeing can be improved.

7.5. Limitations of the Study

The current study is certainly not without its limitations. This study has a number of limitations; possibly the most significant being the relatively small sample size; therefore, the results could not be generalized to all the population.

7.5.1. Impact of the Variations on the Research Findings

I decided to choose participants who exhibited maximised diversity in terms of demographic variables, such as age, onset of illness, duration of illness and the treatment duration of the illness, due to the rarity of the disease. However, I have ignored variations such as types of disease, years since diagnosis and the duration of treatment whilst interpreting and discussing my research analysis; those results could be one of the limitations of this study. The reason to ignore these variations was due to the rarity of the disease. Before initiating the study, I took

on a mindset homogenous to the sample, but I faced a lot of issues in recruiting the participants, particularly because it is a very rare disease and the participants have restricted mobility, affecting their ability to travel, and so many were unwilling to attend. After discussing this with my research supervisors, I did broaden my inclusive criteria so that I could recruit participants for my study. In terms of the variations affecting my findings, there could potentially be an argument for age being an impacting factor as many perceived their restrictions in life not only related to their illness, such as the second participant, aged 58 years, who said: *'A lot of it might be to do with my age, I don't know'*. Whereas the fourth participant aged 63 years, said: *'I think a lot of it is disease, not an age factor'*.

Six female participants were recruited for this study and the participants ranged in age from their forties to mid-sixties. Four out of the six left their jobs due to the disease, whereas the other two, whilst working part-time at home, were planning to end their jobs soon.

In terms of the impact of the variations on the study's findings, the research discussed the experience of living with systemic sclerosis in terms of their demographic variation.

The first participant has a limited type of systemic sclerosis and, whilst she has been suffering from this disease for the last ten years, she has only been receiving treatment for the last fourteen months; she considers herself to have a severe level of the disease. The third participant with limited systemic sclerosis has been suffering for the last thirty years and has only been receiving treatment for the last nine months; she considers herself to be suffering with a moderate level of the disease compared to the first participant who has been ill for ten years. However, the last participant with limited systemic sclerosis has been experiencing this disease for the last two years, whilst only receiving treatment for the last three months, but she rated her disease at severe level, again compared to that of the first participant.

In respect of diffuse systemic sclerosis, the second participant who has been suffering from the disease for the last six years, and receiving treatment for the last five, perceives her

experience of living with disease at a moderate level, whereas the four participant has been suffering for ten years and has been receiving treatment since the end of her first year of diagnosis; however, she still rates her experience of the disease at a moderate to severe level. Moreover, the fifth participant, who has been suffering for the last eleven years, but only diagnosed six years ago and been receiving treatment for the last five, perceives herself to be at the worst level of the disease. Overall, through an analysis of these findings, I was able to conclude that the length and type of the disease does not have an impact on the perceived level of the disease.

In terms of variation in the onset of the disease, and the duration between diagnosis and receiving treatment, I did not find that the impact of these variations had any influence on their experiences. My findings highlighted their subjective experience of the disease regardless of any length of treatment. In my findings, it appears to me that all the participants' experiences of their disease appear to be at a severe level. They all rated themselves above 7/10 for the severity of the disease, except for one participant, who is aged 58 years—she rated herself as 'moderate', being 5/10. In addition, I found a difference in the timing of the onset of her symptoms, and the duration between diagnosis and receiving treatment, compared to the other participants as the onset of her symptoms started six years ago—she was diagnosed at the same time and then obtained treatment within one year—whereas other participants who shared this same severe level of the disease had gaps between the onset of the symptoms and obtaining a diagnosis of systemic sclerosis.

Overall, my aim was to be able to understand the participants' experiences of living with systemic sclerosis. Therefore, in my research findings, I attempted to understand their subjective experience of living with systemic sclerosis as a whole, regardless of their age, years since diagnosis, biographical trajectories, and the time between the onset of the illness and receiving treatment. However, I did not put emphasis on the impact of the characteristic

variations in my findings, which unfortunately is a drawback of this study and as a result cannot be generalised to the rest of the population.

One of the potential limitations in the study is that the researcher and each participant travelled to the Scleroderma Society office where interviews were conducted. Both researcher and participants experienced difficulty in travelling far, and research was conducted in the winter season. These could be factors affecting participants' experience to live with disease. Other limitations are participant's age, marital status and gender. Only female participants from 40 to 65 were recruited and no participants were included above and beyond this age limit. It was also limited to those who were in a stable, long-term relationship. Single, separated or divorced participants were not included. Other limitations are that the research does not consider specific types of systemic sclerosis, nor does it include any type of systemic sclerosis and not specific duration to receiving treatment. This study could not be generalized to all the population. However, the reasons to make these inclusion criteria limited in age, type of disease etc were due to its rarity. It was very hard to find participants for this study. This study was also geographically limited as only people who live in England were included. It might also be possible that people experience their illness in different ways, and use coping strategies differently based on their age, type of disease, duration of illness and relationship status. Therefore, this could then affect the overall sample size and ultimately the results.

7.6. Future Recommendations

This study found individual experiences of living with systemic sclerosis and coping strategies to manage it. For future recommendation, I would suggest conducting an experimental study to monitor the participant's changes and improvements in their experience in living with systemic sclerosis both before and after receiving short-term counselling. It would be of benefit to grasp how counselling can help them to live with the disease in better way. I would recommend that this study be extended to people who live outside England in

terms of colder areas and also to conduct study on people who are single; also, to extend the study to men as they were also excluded from this research. In addition, future study should explore different gender experiences of living with, and differences in coping skills, in terms of managing daily lives whilst living with systemic sclerosis.

7.7. Conclusion

The purpose of this study was to discuss the analysis related to pre-existing literature, and also to discuss the emerging theory of ‘changed sense of self’. The results of these findings were also utilized in relation to the existential literatures, and then described the implications of this study in the field of counselling psychology and psychotherapy and also to investigate how this study could benefit to other health sectors to promote the people’s well-being as whole.

CHAPTER 8

REFLECTION

A Reflexive Account of the Research Process

8.1. Introduction

In this section, I outline how I adopted a reflexive stance to this study. I attempt to explain my understanding and use of reflexivity within the study and also discuss my reflections throughout the research process, including choosing the topic, the literature review, and the research methods, and interview and data analysis.

8.2. Taking a Reflexive Stance

Reflexivity is considered as a valuable instrument in order to achieve a rigour of qualitative research. In qualitative studies, researchers place themselves within their research and do not see themselves as outsider agents of social situations. It is very important for researchers to be a part of their research otherwise it could lead to questions of validity being raised. This is because of the way qualitative researchers position themselves in their research, that is they do not regard themselves as objective observers of social situations (Colaizzi, 1978, cited in Walker, S. 2016) but see themselves as participants in a dynamic relationship with the research being undertaken (Ryan & Golden, 2006, cited in cited in Walker, S. 2016). If researchers do not have an objective position with respect to their research, questions regarding the validity of the research arise.

In order to identify any potential impact to the personal dynamics of the research setting, the researcher needs to widely utilise reflexivity in relation to data collection methods and analysis. In qualitative interviews, the researcher, a human being, is the data collection tool rather than an object. Being a human, we hold back our beliefs, assumptions, personal histories and values that may be seen as an influence on data gathering and could raise questions about the study's validity. According to Gabrielle, Jackson & Mannix (2008), the

researcher should discuss any personal and professional factors in the study that could affect data collection, data analysis and interpretations. Reflexivity describes the relationship between the researcher and the object of the research (Brannick & Coghlan, 2007, cited in Walker, 2016).

Therefore, taking a reflective stance is considered to be an integral part of the research process for this study. From the commencement of the study, I kept a reflective research diary so I could engage with my personal processes. Being a novice researcher, it helped me to ensure that the evolving theory demonstrated a degree of trustworthiness. On the other hand, this study was based on the constructivist grounded theory by Charmaz (2006). It was necessary to take a reflexive stance so I could inform the reader how the researcher conducted this study and how it related to the research participants and represented them in the reports. In order to gain more trustworthiness, I added extra texture to this research by illustrating a complete view of the research process. In this way, my study was able to systematically develop an insight into my work and assisted me in guiding the course of the research. I chose to keep a reflective diary throughout my research process and in this research diary, I recorded observations, thoughts, feelings and reactions that came up during this research journey.

During the data collection process, I noted down my feelings, thoughts and observations at the end of each interview with the research participants and also monitored myself during the course of that day as I was aware of my attachment with this research topic. I found that my pattern was very much related with Finlay's notion of reflexivity. During the data analysis stage, I reflected in my diary about my thoughts and emerging ideas. It seemed to me that my reflective diary had become a part of the theoretical sensitivity, as claimed by Glaser & Strauss, in that it is the researcher's personal and temperamental [abilities that are] bent and their ability to have theoretical insights into their area of research (Glaser & Strauss, 1967). It

helped me to recognise the theoretical insights into this study and also facilitated the emergence of a theory. Birks & Mills (2011) stated that theoretical sensitivity is a skill in identifying and extracting from data those concepts that are significant for the emerging theory. Charmaz included theoretical playfulness, whimsy and wonder and, in particular, the ability to remain open to theoretical possibilities, as integral parts of theoretical sensitivity (Charmaz, 2006). My research diary aided me in allowing ideas to build a theory during the process of coding and categorising the stages of analysis. Alongside the diary, transcripts and memos also facilitated as a practical technique to build abstract concepts from the groups of data. I am going to describe my reflexivity in my capacity as a researcher during the entire research process, as well as being a therapist and a sufferer of the disease.

8.3. Reflexivity during the Research Process

8.3.1. Reflection on the Journey from Choosing the Topic to the Research Methodology

The decision to conduct this study and start my journey was made when I was first diagnosed with this disease. However, I was not quite clear on exactly what I really wanted to scrutinise under the phenomena. I was just interested to listen to other's experiences of living with systemic sclerosis. I remembered that I was quite exhausted for about two years after receiving my diagnosis and would say that I felt rather 'lost' for myself. I really did wonder and question whether that was a normal response towards the diagnosis or if it was something wrong with me. However, whilst I was receiving personal therapy so that I could try and sort myself out, on the other hand, my former role as a co-researcher encouraged me to learn of others experiences of living with this disease. I was a novice qualitative researcher and was totally unaware about any IPA, grounded theory or other qualitative approaches. However, I had a good level of experience in conducting quantitative studies in the past so, in this way, I was somehow familiar with the research process.

My doctorate research journey began when I first attended a research seminar in my academy and I expressed my wish to conduct a study on the experiences of living with systemic sclerosis. I received a response from my two supervisors that they were happy to supervise me for this study. Their positive responses boosted my confidence levels and built up a level of trust in myself for me to carry out the study. In the meantime, I was enrolled for the advance research seminar where I came across a variety of qualitative research methods. In order to choose the appropriate research methodology, I focused on what I wanted to learn from conducting the study. However, it was a very hard time for me to grasp the qualitative concepts and the philosophical assumptions in relation to the qualitative approaches. It took me a while to comprehend each qualitative approach's tenets and principles. I read various text books, resources, journals and online articles and had discussions with my research supervisors and peer groups. With the passing of time, I started to feel confident in myself in relation to understanding the research methods. At the same time, I wrote down my thoughts, ideas, curiosities, wishes and passions in my diary so that I could get a sense of what I wanted to learn and understand from this study. In my reflective diary, I noticed my 'altruistic attitude' to help others by conducting this study and this attitude was also represented in my professional training in psychology counselling.

By living with this disease, I have found that many people do not know what the disease is or even how to pronounce it? I noticed this from my own personal therapy where the therapist struggled to understand its name and the nature of the disease. Within my academic setting, my colleagues and tutors were very cooperative but their facial expressions communicated odd messages to me such as 'what is it?' In this current era, the majority of people are familiar with other diseases that are incurable such as HIV, cancer, and tuberculosis, but they are less aware of the rare autoimmune diseases such as systemic sclerosis.

In my diary, I noticed that I highlighted that:

I have a wish to help people with systemic sclerosis by providing counselling to them free of charge. This is basically the reason to choose the topic for my doctorate study so I could understand how they perceive their lives and in what ways they are emotionally suffering.....?

How I am suffering.....?

I felt very embarrassed by other's reaction towards my disease. It seemed to me 'odd' when they said to me 'what ... sorry?' and I had to repeat the name. Now I would prefer to say only:

I am living with an incurable disease.....

Not only the name but people also find the symptoms as strange and they never heard of such symptoms before.

My topic was accepted by the research supervisors and I then had to choose my aims for the study and select the methodology so I could obtain answers to my research question.

Before commencing the literature review, I reflected on my passions and what I wanted to look at in this study, which was the 'participant's experience of living with systemic sclerosis.

I reflected back on what 'living' means or rather, for example, 'how do I define 'living'.

What does 'living' mean for me?

If I focused on 'living' in my personal experience then I would say that 'living' is web of physical activity, social network and mental wellbeing

What does 'experience' mean?

What does it mean to 'cope'?

However, I also read some literature before choosing my research methodology so that I could identify any conceptual gap in my pre-existing knowledge. Moreover, reading existing knowledge was also required to enable me to set out and write my research proposal and gain ethics approval from the university's board of ethics and was imperative to creating my research aims and goals. Following a review of other studies and conversations with other patients during hospital appointments, together with my own personal experience, I was able to build my research aims. I could say that I achieved my research aims based on prior studies and the personal experiences of living with systemic sclerosis.

I am a professionally trained counsellor and I know some ways in which to deal with my emotions and to accept this illness. I am privileged from my mental health studies and my psychologist role.

I really want to scrutinise:

How do people experience their illness and how do they cope? How do they perceive themselves after this disease.....?

My professional knowledge and also my personal experience with other people led me to choose the 'constructivist grounded theory' to help professionals and the public generally to understand the nature of this illness and the impact it has on people's lives, as well as create a systemic model so that readers can understand the process of living with systemic sclerosis. The reason to choose grounded theory was to produce a model for professional people so that they can fathom and understand how to live their lives with this disease and assist them in coping with their disease.

8.3.2. Reflection on Constructing the Final Version of the Interview Questions

My next step was to think about constructing the interview questions. I started to note down in my diary what questions I needed to ask in order for me to obtain the information I required to answer my research questions. It was a supreme challenge for me to form the interview questions and I used different resources to build my interview questions, such as personal experiences, study aims and goals, Charmaz's book, peer support, academic resources, clinical placements and literature reviews.

I wrote in my journal about my personal experience of living with the disease and focused on how it has affected different aspects of my life. During my work placement, I spent time with people living with this chronic illness and I had an idea of how they experience their lives and their self. In my prior clinical work, I discovered that these people have questions about their identity and felt 'loneliness' as an impact of their illness. They also experienced a threat to their mortality.

Being a novice grounded researcher, I used to read Charmaz's book and her guidelines which also gave me the knowledge and confidence to build interview questions. Through utilising various sources, I was able to build my first interview draft under the guidance of the research supervisor. I had an extensive conversation with my supervisors regarding the interview questions and they also asked me these questions to monitor my responses and ascertain the rigour of the interview questions. I used Charmaz's long list of guidelines that are set out in her book '*A constructivist grounded theory: A practical guide through qualitative analysis (2006)*' to construct the interview questions. My clinical work with the chronic illness also illustrated how people with long-lasting illnesses perceive their world and their sense of self. It gave me the idea to build some questions around their relationship with their self, others and the rest of the world. Moreover, in my academic studies, I read a lot of theoretical and

existential models that helped me to understand people's 'life-world', particularly Van Deurzen's four dimensional models and Yalom's model.

I was able to understand with Van Deurzen's model that a person's world, or life-world, is composed of four worlds. I used Van Deurzen's model to construct questions that would allow me to understand the participant's world as a whole. Yalom's model of working with cancer patients guided me through people's reactions towards their illness and their mortality which helped me to grasp their psychological reactions towards illness and their ultimate concerns. By reading pre-existing studies on systemic sclerosis, of which there was a limited amount, cancers and other autoimmune diseases, I was able to identify what other studies had learned.

Through collaborative work and all of my gained knowledge, such as academic studies, personal experience, clinical work, existing literature and peer discussion, I was able to construct my interview questions.

The interview time was limited to around sixty to ninety minutes and included only one meeting with the participant. My first draft was quite extensive and I could not accomplish it within the time-limit. I amended the interview questions and reflected on what was related to the research and what manifested my personal experience. Through surveillance, I was able to develop an interview sub-question list. However, the first interview that I carried out for my pilot study was quite elaborate and during the pilot I identified some questions that were unimportant and ascertained new information that could be significant for this current study.

In my note diary, I highlighted some reflections:

Reflection note:

First pilot got new info like phobia etc? Reflection on switching role with client as a researcher and as a psychologist. Bracket thoughts, fear of biased ... new info about cognitive things ... embraced more info and added for next participants.

Following synchronisation of the data collection and analysis, I added new information to the interview questions and omitted what seemed unimportant or duplicated and then went to the field work again to verify it with the next participant:

Reflection Note:

Second participant: Learning notes from pilot study; add more questions to verify pilot questions; Embrace more new info like impact disease on sexual relations and side effects of medication; test phobia and cognitive issues by pilot study and found it in second participant as well.

More reflection on switching role with client as a researcher and as a psychologist. Focused on skills 'bracketing thoughts', reflection on own experience, fear of bias;

Reflection on participant's old age factors and disease. More questions on forgetting things?

Returning again to the field work, I tested the new questions which had been created from the previous participants and obtained new information about their experiences as a result of living with systemic sclerosis. This new information was added to the interview sub-questions and reformulated again under research supervision and I again returned to the fieldwork to verify this information.

Reflection Notes:

Third Participant: verified former information and found in this interview that participant talked more about their difficulty to put on little things such as jewellery or personal clothes etc.....

I felt confident through the process of data collection and analysis and felt excited more than anxious for the interview and analysis.

However, these questions were also added into the interview sub-questions and a final version of the interview question list was achieved following the third interview. I did not find out anymore new information at that stage and so I continued with three more interviews but again did not obtain any new information.

On the other hand, I developed interview questions to include early in the interview about their everyday life with the intention of making them relax in the process of talking. I envisaged that these initial questions would also play a role in building trust between myself as a researcher and the participants so that they could easily reveal their stories during the interview. In order to put them at ease, I also added some initial demographic questions, not only to reduce their anxiety levels but to assist me in setting a flow for the interview. For demographic information, I asked about their name, age and marital status, the length of their relationship, their occupation and basic questions related to their illness. These questions also reminded me that the aim of the interview was to gain the participants' perspectives and their thoughts, feelings, choices and experiences surrounding their disease. I noticed that I had created an elaborate list of interview questions because I did not wish to silence the participants in any way but rather that I wished to promote and focus on what Mishler (2005) stated was the voice of their life-world, whilst further conceptualising the data (cited in Walker, S. 2016). I recognised that focusing on their life-world was paramount and that the ultimate grounded theory would be connected with the accurate rendering of the processes impinging on participant's lives.

8.3.3. Reflection on the Analytical Process

The research analysis process began after the initial interviews had been carried out with the participants and continued until a theory emerged. I started my data collection on 20th November 2015. It was a really cold day and we had booked the interview in for the

afternoon and I had to travel far away from my home. I remember being very anxious on that day as it was my first experience in conducting a qualitative interview, although I had experience of conducting clinical interviews in the past. I got a sense that my illness was also contributing to me experiencing anxiety. Being a sufferer, I am dependent on my family for my basic needs but being a researcher, I was in a position where I needed to take care of my participants' needs, which led me to feel some uncertainty. Fortunately for me, it was an advantage that the interview was conducted at the Scleroderma society's premises as I have been a member since 2012 and so their staff knew about me, the nature of the illness and its impact on people's lives. They looked after all of the necessities that were required during the interview.

I started to write down in my research diary about my concerns of being bias, not being able to control myself in the research interviews or the potential for me or the participant to become tired or not feel well. I also used to suffer a lot of uncertainties and concerns about my health and in order to deal with these issues, I started to discuss them with my research supervisor and also aired my concerns in my personal therapy. I used my therapeutic skills on myself in order to help meet my challenges of suffering, such as reminding myself that I am a human being, recognising my limitations and 'normalising' my feelings, reminding myself how I tackled these things in the past both in my placement and academic settings.

On the way to the society's premises, I was continually reflecting on my feelings and found myself feeling some discomfort. I was reflecting on my relationship with the weather as it was a really dark cold day and I was thinking of whether to conduct the interviews in the summer rather than the winter. I reached the premises twenty minutes before our interview time and I met with one of the staff members from the scleroderma society. I received a warm welcome from her and felt quite relaxed after meeting with her and having her show me the interview room, along with all of the basic necessities that are required by people who are

living with systemic sclerosis. After observing the interview set up, I was quite relaxed and felt well prepared for the interview.

I found my interview with the first participant very positive and a good rapport was easily established. I found that my participant recognised that I was also living with systemic sclerosis and we shared common ‘symptoms’ such as the room’s heating, sitting in the chair, the deformities of my hand and the restricted movements. It reminded me of the concept of ‘inter-subjectivity’ as we shared our ‘illness’ with each other. However, the first interview was a mixed combination of being both friendly challenging. During the interview, I made notes in order to allow for clarification and further exploration and, although it went very well, I was feeling very tired and felt a heaviness in my chest. I wrote in my reflective journal and used my therapeutic skills to understand what I was feeling and what was actually triggering these feelings in me. Set out below was my reflective note:

20 November 2015

Why is my chest so heavy? What is triggering me?

I am quiet for the last half an hour and making an effort to talk to my family. I do not understand why I am feeling like that. I am feeling emotionally tired right now. I am sad? Yes, but for what? I already know about my disease and I already know it is incurable then what is making me sad? Maybe I did not completely accept my disease as incurable as I am having this for a few years and my first participant is having it for many years and she did not cure? Maybe it triggered me?

Today from this interview I got insight to another’s problem due to this disease. I was concerned about a lack of cognitive process and I came across by participant it is part of my disease. Maybe it is

affected? I cannot say anything but tomorrow I am having my counselling and I will discuss it there.....

Following my first interview, I started to transcribe the content which took several hours. Within my diary I outlined an emerging sense of ideas about the analysis which started to gather during different stages of the data collection. I intuited that I was learning to use my chosen research methodology. In my experience, I did not find that the relationship between the data collection and the analysis was not an essentially linear process. I noticed in my diary that, in the initial stage of analysis, I was attempting to understand the grounded theory process of coding. Following line by line coding, I was attempting to see the process in my data, such as events, feelings, behaviour and coping in order to ensure the grounded theory method was utilised. In my diary, I also had extra notes about the new information and re-formulation of the questions. I was satisfied that I was using the inductive approach to the data collection and analysis. I also had an entry in my diary to ask questions: What is the participant telling me about her experience? What does it mean for them and for me as a researcher? These questions helped to separate my experience from theirs.

After reading the first transcript multiple times, I attempted to do the initial and focused coding, developing provisional categories and linking them with each other in order to grasp what I needed to ask next and what needed to be omitted from the interview questions. This diary also reassured me that I was being 'active' in my research process, which is a very important factor in grounded theory analysis. By following the above procedures, all research interviews were conducted in the same way and the reflective diary was continued after each interview, as well as transcription and analysis. However, I realised by reading my diary later that I was 'confident' in myself by my fourth interview and research analysis. I found that I

was quite concerned about my skills and my ability as a researcher in conducting the interview and data analysis. I expressed my anxiety at different stages of the interview process and had to review whether I was moving in the right or wrong direction with the interview and research analysis. However, I felt quite contented when I found ‘similar’ codes, categories, themes and concepts across all the participant’s data as a result of constant comparison methods.

In terms of data analysis, it was quite problematic to manage line-by-line coding due to the richness of the material. I found it quite tricky to decide which codes needed to be added or omitted. In order to understand the data for this study, I made notes in my diary in relation to my research aims. I reflected on different questions in my diary such as:

What participants said about their lives? How were they diagnosed? What are their feelings when diagnosed? How do they live their day to day life? In what dimension do they describe their lives and their coping styles. What do these codes mean and impact on readers?

How would I know if these codes need to be omitted? If omitted what would be the impact on my analysis or findings? How has the reader found it? Do either of those codes have any meaning for the data?

In my diary, I attempted to be very thought-provoking so that I could understand my data from every angle as I wanted to produce a true picture of the participants’ lives. During this process, I reminded myself that I am a student and that I know my limitations but I was being receptive so as to get help from others, such as research supervisors, colleagues and academic tutors. I saw many authorised videos online that really helped me to understand ‘how to do

line by line coding’ and I read various text books, particularly by Charmaz who aided me in doing my line by line coding.

During my last interview, I wrote down in my diary that I felt ‘sad’ as it was my last interview and I had become quite confident during the interview process. On the one hand, I had learned to sharpen my interview skills and, on the other, I had undergone real ‘obstacles’ to secure potential participants for my study. I was quite frustrated about my inclusion-exclusion criteria used to recruit participants and I sensed that this was my biggest mistake with the age and relationship criteria as I was unable to find participants. Through reflecting on my diary and personal therapy, I found myself in an impatient position and perceived myself as a student who just wanted to complete his or her tasks. I addressed my ‘impatience’ through my research supervision, my personal therapy and the writing of my personal journal, being able to ‘be with my study’ rather than ‘doing’ it. These tactics really helped me to be ‘in-touch’ with my research journey. With adopting an attitude of ‘patience’, I was continually refining codes and categories alongside reading the participants’ transcriptions, reassuring myself that all of my data followed the ‘grounded theory principles’.

Subsequently, I was able to develop theoretical categories through the repetitive process of ‘doing the methodology’. In the diary, I reflected on my growing understanding that the theory must evolve from these building blocks of data if it were to truly be a grounded theory. This had implications for the constructivist grounded theory and its philosophical support in that social reality is constructed by their experience of living with the disease. Therefore, how participants portrayed themselves in the data would be suggestive of how they constructed their social reality. If my theory were to be congruent with a constructive view, then the participant’s life-world should be a relevant part of the data to be considered in the analysis (Watson & Girad, 2004).

These reflections that I have charted above are helpful not only for the ongoing process of the research but also continuous learning for myself as a researcher.

8.4. Reflection on Being a Sufferer

Charmaz (2006) and Strauss & Corbin (1988) claimed that it was hard to separate ourselves from who we are and what we already know. These fixed ideas are intrinsically derived from our values and knowledge being affected by the wider social perspective (cited in Willig, 2013). I have been suffering with systemic sclerosis for the last four years. Hence, there is a concurrence with Charmaz's (2006) account in that the structure of grounded theory is connected to the pertinent experiences of the past, those experienced in the present and the interactions with the whole research process. In this spotlight, I reflected on my ideas and thoughts relating to my experience of living with systemic sclerosis as a resource that increased my insight into the study's inquiries and magnified the sensitivity to the data. In the meantime, to preserve an openness to the data under analysis, reflexivity on my own background assumptions and relationship with the data was imperative. Throughout this study, I have recognised and incessantly reflected on my previously gained knowledge by way of my personal therapy and research supervision. I asked my therapist to administer my interview questions on me in order to not only understand my position and explore my personal meaning in relation to this disease, focusing on my own coping strategies of how to live with it, but to focus on how my assumptions could impact on my role in this research and its process by writing my reflexive journal. I was able to separate my experience from my participants' experiences through re-practicing these interview questions and by an exploration of my unique experience of living with a disease. I constantly wrote notes in my journal about my thoughts and ideas during the research process. Even when I was not in touch with my research module, I was still 'being with this research topic' due to me living daily with the disease. I always wrote down my personal experiences during my personal

engagement with the world. During the literature review, I came across some new terms and information about this incurable illness, such as the linking of scleroderma and cancer. However, it was quite daunting for me and in order to manage my own fears, I worked through this with personal therapy, my research and clinical supervision.

By taking a constructivist attitude in grounded theories, I have acknowledged the appropriate process of interpreting the data and the fieldwork in order to retain levels of trustworthiness within the results (Holton, 2008). Reflexivity is a constant process that needs to be performed throughout qualitative research, which was vital to this study and directly related to my place within the research process.

My research question has a close link with my own personal life and it was crucial for me to look critically at my own journey and the interest I had in this study before attempting to interpret other people's experiences. Before conducting the interviews, I undertook some reflective work around my research question. The reason for doing this was to identify my own vulnerabilities concerning the experience of living with systemic sclerosis, to review my assumptions on this topic and to deal with these assumptions. In order to do this, I kept a reflexive journal to keep myself aware of my participants and also my own behaviour during the research process. In this way, I might be able to make my own views clearer concerning the experience of living with systemic sclerosis. I wrote the following statement as my own attitude with regard to the study:

I am 27-year-old single lady, diagnosed four years ago with a diffused type of systemic sclerosis. I have been receiving treatment from a consultant for the last three years and I consider myself to be 9 out of 10 on the scale of intensity for the disease.

I am sceptical of academic studies when authors perceive themselves as 'experts' on a certain topic and I have tried to avoid language that suggests objectivity which may convey an impression of authority. My role within this research is that of a co-constructor: what I

present is my own experience and is bound by the inter-subjective component of social context, which is about 'shared experiences'. I perceive living with systemic sclerosis as challenging and potentially life changing and it has an impact on every aspect of life, as can be seen in the questions I asked the participants, my allocation of themes and sub-themes to the data, and in my decisions about which extracts to integrate into my discussion.

Being a sufferer and living with this disease, I perceived myself as an insider but it was significant to recognise my position when meeting with other participants. I reflected on my different 'selves' in the research, such as being an outsider, a student, a researcher, an Asian lady, a listener and a trainee counselling psychologist. My various 'selves' within the research process had a strong relation to the participants' motivations to engage in the interview process. Due to the different selves that I presented, I cautiously portrayed different aspects of myself in the research process, while relentlessly reflecting on its effects on the process in order to achieve plentiful and unprejudiced data for this research, abiding by the ethical issues in my mind. Within each interview setting, the representation of my different selves was dynamic, acknowledging the co-construction of 'who we are' among my participations and during our interactions (Reinharz, 1997). During each interview, I recorded my notes in a research diary to reflect on my connections with the participant and the effect of my role.

8.5. Reflection as a Therapist

In this session, I would like to bring in my role of working as a therapist during this research journey. Reflexivity is a dynamic skill that we learn and use as a therapist. Being an existential trainee, I have recognised the power of reflexivity whilst working with clients, which Yalom (1980) also utilised in his work with his clients. Being an existential therapist, I acknowledge the importance of reflexivity in terms of working alliances with clients and enabling clients to become agents in their own lives. Being a researcher, I have used my own reflexivity as self-awareness to recognise their identity, bias and context, as well as to

discover how these can influence the research process and outcomes. With being an existential therapist, I have implemented my reflexivity beyond self-awareness which means that I monitor and explore therapeutic relationships to facilitate the therapeutic process and to understand a client's world. I did use my therapeutic skills during my interviews but I want to highlight firstly how my therapeutic skills became a challenge in my role as a researcher and I will then explain how my therapeutic skills helped me during my research process.

Being a therapist, whilst my role is to understand my client's world and make sense of their experience, it is my understanding that therapists do not have any 'authority' to control the direction of dialogue as it depends on each client and what they want to bring to each session. It is not uncommon that sessions can vary from topic to topic and, as a therapist, I am used to being patient with the client's material. During my research interviews, it was challenging for me to keep a balance between remaining patient and exploring the interview questions due to the limited time of the interview. I needed to remind myself that it was not a therapeutic relationship but rather a researcher-participant relationship. Working with clients and being a therapist, I do not have 'pre-set goals to achieve'; it is all based around the client's expectations for the counselling and we just work on those expectations which can be changed in later sessions. It seemed to me that the therapeutic approach was very flexible, friendly and helped to negotiate an approach to helping clients; indeed, the research approach is quite rigid to negotiate for a therapist. On the one hand, I found my therapist skills as a challenge when conducting research interviews and, on the other, the therapist traits I have facilitated me in dealing with the research challenges, such as constructing questions or monitoring participants' emotions during the interview. It was quite a personal topic for me so I used my therapeutic skills in order to deal with my challenges of suffering, such as reminding myself that I am a human being, recognising my limitations and 'normalising' my feelings and reminding myself of how I tackled these problems in the past, such as in my

placement and academic settings. Being a therapist, I was able to construct the interview questions at a general level but keeping in mind that it should not be a therapeutic question.

My clinical skills helped me to conduct research interviews in terms of building relationships, confidentiality, managing emotions and constructing questions but there are still differences between both disciplines. Being a therapist, I did not hold any prior information about the clients, who they were and what they would bring into the counselling session and my therapeutic work was merely focused on the clients coming to terms with their situation. However, research interviews are very different as the questions come from the researcher's own agenda and somehow give power to controlling the interview's direction and having some dominancy of whether to ask the next question or not. In this case, being a therapist, I found myself to be a little 'inauthentic' as I was more 'doing' rather than 'being' with the research participants and looking for answers to my study's objectives. However, I understood that it was not a therapist-client relationship but a researcher-participant relationship who met on one occasion to achieve a particular purpose.

Being a therapist helped me to learn some of the research elements but it also became a threat for me in breaching the boundary to turn a researcher-participant relationship into a therapist-client relationship. One of the challenges was to stay with the participant's stories by showing 'patience' to them. Being a therapist, it is not uncommon for a whole session to be just about one topic but in research interviews where I had a semi-structured interview, I had to go through these interview questions within a particular time-limit in order to obtain the answers. However, I learned through practicing with my research supervisor and self-help activities when to interrupt participants and to ask the next question within the time-limit.

I found my therapist role a privilege when conducting research because it helped me to comprehend the research concepts and processes, particularly with regards to reflexivity, and it also assisted in gathering rich data from participants. As I mentioned previously, I had no

prior experience in conducting qualitative studies so my experience of conducting clinical interviews and my therapeutic inquiries facilitated me in carrying out qualitative research and to construct interview questions. It is common in counselling sessions for the client to not understand the therapist's viewpoints or the questions being asked in order to deeper explore the issues so the therapist has the skills to manipulate the questions in a generic form or has the ability to form questions during the process, particularly during research interview. In the past, participants have had difficulties in understanding my questions around their sense of mortality and sense of self so my therapeutic skills assist me in reformulating the question instantly during the interview. Moreover, being a therapist, I am used to being conscious when working with clients, such as making notes about my observations and their behaviour, which was also applied whilst conducting the research interviews.

My therapeutic skills helped me to engage with the participant's material as much as I could through adopting a phenomenological attitude. I found qualitative interviews and counselling work similar in a phenomenological way as both were concerned generally with people's subjective experiences and how people understand and make sense of their experiences and their relationships, where their stories can be explored in depth. As Bondi (2013) stated, counselling practices and qualitative interviews focus both on meaning and where one person listens to the other and makes sense of the other's experience (cited in Georgiadou, 2016). Being an existential trainee, I was able to 'bracket off' my assumptions, values and beliefs in relation to my experience of living with systemic sclerosis. I stayed within my participant's world and explored their feelings and meanings and made sense of it.

Being a therapist, I am used to working with sensitive health related issues that impact on people's mental health and well-being. This research is based on sensitive health-related topics that might arouse painful memories during the research interviews and could lead them to become distressed. I utilised my therapeutic knowledge of what steps needed to be taken if

participants were at risk during an interview and how I could protect my participants from the risk of self-harm. Counselling practices have similar confidentiality rules as in research interviews. Therefore, I had already obtained consent from the participants, as I used to do with my therapeutic clients, and took down all necessary information that I might need in the case of an emergency. I have the ability to use my counselling attributes and skills with research participants during interviews and provide them with the space where they could express themselves more fully; these counselling attributes helped me to build a stronger rapport with the participants and encouraged them to share their experiences allowing me to obtain quality data for the study.

Being an existential therapist, I am used to following Heidegger's concept of 'leaping ahead', meaning to allow the client to take charge of their session and choose what they want to bring to the session whereas, in research interviews, I initially choose a mixture of 'leaping ahead' and 'leaping in' by the formulation of central questions that were neutral and would let them tell their stories freely with an 'indication' to the participants of 'what the research is about'. I viewed myself as a co-constructor of knowledge and by asking central questions, I was able to build discussions with the participants (Charmaz, 2006).

Despite these challenges, with being a trainee counselling psychologist I have developed these counselling attributes and skills within my training, such as listening attentively, intuitive inquiry, summarising, probing for deeper explorations and being empathetic. I used these skills in the research interviews to explore the participants' experiences of living with systemic sclerosis. Moreover, counsellors and psychotherapists are also perceived as being an 'expert' in reflexive practice, which is enormously beneficial in qualitative research (Etherington, 2004). In my qualitative study, I focused on reflexivity regarding their identity, their bias and context, and reflected on how these factors influence the research processes and outcomes. Being a counsellor, reflexivity goes well beyond self-awareness, whereas a

therapist focuses on therapeutic relationships to understand a client's world. I used my counselling reflexivity skills to understand my participant's world and the context in which they constructed their lives, noticing their responses during an interview setting. Finally & Evans (2009) conceptualised these practices as relational centred research which indicated to the efficacy of those values common in therapeutic practice, such as being present, experiencing an embodied intersubjectivity, interacting dialogues and co-constructing meanings (cited in Georgiadou, 2016). However, at all stages of the research process, I also allowed myself to shift position in consideration of the multiple dynamics engaged. Through a reflective process, I became aware of, and able to deal with, these different roles in the research milieu.

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APPENDICES



APPENDIX A

The Scleroderma Society

Bride House

18---20 Bride Lane

London EC4Y 8EE

Office 020 7000 1925

Helpline 0800 311 2756

info@sclerodermasociety.co.uk

www.sclerodermasociety.co.uk

President: Professor Dame Carol Black DBE, FRCP, FMedSci

Vice Presidents: Professor CP Denton PhD, FRCP Professor A Herrick FRCP, MD

Wednesday, 13 May 2015

Dear Sidra Chaudry,

Re: Experience of living with systemic sclerosis– a phenomenological enquiry

I am delighted to inform you that the Scleroderma Society is supportive of your research project. Once ethical approval has been awarded the Scleroderma Society can assist you in identifying patients with systemic sclerosis to interview as part of your data collection for your project titled: 'Experience of living with systemic sclerosis – a phenomenological enquiry'.

Upon ethical approval we advise that you contact myself, Chloe Kastoryano, to begin steps in identifying participants. The Scleroderma Society has meeting rooms that can be used for the interviews. These are based in the Scleroderma Society's office in London. These are shared meeting rooms, with three other charities in the building, and so notice of at least 2 weeks is often necessary.

I look forward to hearing more about your research in due course.

Yours sincerely

Chloe Kastoryano

Policy and research Advisor,

The Scleroderma Society

(020 7000 1925

APPENDIX B

Ethics Approval by NSPC and Middlesex University

Sidra Chaudhry
32 Mansfield Drive Hayes
Middlesex UB4 8DZ

17th July 2015

Dear Sidra

Re: Ethics Approval

We held an Ethics Board on 7th July 2015 and the following decisions were made.

Ethics Approval
Your application was approved.

Please note that it is a condition of this ethics approval that recruitment, interviewing, or other contact with research participants only takes place when you are enrolled in a research supervision module.

Yours sincerely
Prof Digby Tantam

Chair Ethics Committee NSPC

APPENDIX C



Information about a research project:
Experience of Living with Systemic Sclerosis- A
Phenomenological Enquiry
Being carried out by
Sidra Chaudhry
As a requirement for a D.C. Psych in Existential
Psychotherapy and Counselling Psychology from
NSPC and Middlesex University



NSPC Ltd
Existential Academy,
61-63 Fortune Green Road,
London
NW6 1DR

Middlesex University
The Burroughs
London NW4 4BT

1. Invitation Paragraph:

You are being invited to take part in a research study. Before you decide to participate, it is important for you to understand why the research is being done and what it will involve. Please take your time to read the following information carefully, and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take your time to decide whether or not you wish to take part.

2. What is purpose of the study?

The study is being carried out as part of my studies with NSPC Ltd and Middlesex University. The purpose of this study is to explore the experience of living with systemic sclerosis. Living with systemic sclerosis is challenging as it affects every aspect of life from family relationships to holding a job.

The participants will be eligible to participate in this study according to the following criteria based on sample demographic information:

- Only females would be included.
- All participants aged between 30 to 70 years would be included in the study.

- Professional medical doctors should have given the diagnosis.
- The target population would be either married individuals or those in a stable relationship.

You are being asked to participate because you have replied to my advertisement for people who are living with systemic sclerosis and you fulfil the criteria listed above.

3. What will happen to me if I take part

I would like to interview you for 60 minutes; it could be shorter or longer than this (up to a maximum of 90 minutes). Taking part in the research will involve you participating in a semi-structured interview, in which you will be asked to answer a number of questions. There will be no right or wrong answers to the questions, what is vital are your particular answers and thoughts. The interview will be conducted at Scleroderma Society's building. The information from the interview will be combined with information from other participants for analysis. I will use the qualitative method 'Constructive Grounded theory by Charmaz' to extract the main themes of what you and others tell me about the experience of living with systemic sclerosis.

4. What will you do with the information that I provide?

I will try to transcribe myself. If the interview will be transcribed by another person then I will inform you and will not use your full or last name in the interview and the person transcribing the interview will not know who you are. The interviews will be digitally recorded and then immediately encrypted and kept in a secure place. The supervisors may ask to see the data collected prior to anonymization. There would be no other individuals involved who could see the data until it has been anonymized. Audio files will be kept on a computer until after completion of the project. All the information that you provide me will be identified only with a project code and will be stored on the encrypted USB stick or on a password-protected computer. Once transcribed, the audiotapes or any other documents will be destroyed.

The information will be kept at least until 6 months after I complete the project and will be treated as confidential. If my research is published, I will make sure that neither your name

nor other identifying details are used. Data will be stored according to the UK Data Protection Act and the Freedom of Information Act.

5. What are possible disadvantages and risks of taking part?

Some of the questions may cause distress to you and could result in a discovery of an unknown aspect related to disease that may need to be treated. In the interview, I shall be asking you about your experience of living with systemic sclerosis. However, talking about personal experience may be distressing. If so, please let me know, and if you wish, I will stop the interview.

Whatever you tell me will be confidential. However, if you should tell me something regarding terrorism, money laundering, child abuse then I am required by law to pass this information on to a third party. In UK law, there exists a 'duty of confidentiality'. A duty of confidentiality can be established in situations where information is passed, in confidence, to the confidant (the receiver of the information). Exceptions to this duty of confidentiality occur if I am required to do so by law - where there is a legal compulsion, as a result of police investigations or court proceedings, or where there is a disclosure of the information made 'in the public interest', as defined by the courts.

In order to reduce the risk to each participant, I will assess you prior to interview. Therefore, I can avoid recruiting anyone who may be suicidal. During this initial call, if anyone presents as being suicidal then I will direct them to therapy services such as Samaritans, Society's helpline and Phoenix Aid Centre that will help them with these feelings. I will also notify GP, friends or family if given permission. If any participants mention suicidal thoughts during the interview, I will carry out a risk assessment and only in the event of there being a risk I will take further action. I will take further steps in order to assess and protect each person.

- I will stop the interview and you will not be recruited for the study again if you are at risk.
- I will gather information about your specific thoughts of suicide and assess how 'real' the threat is, whether or not you have a plan? Have you thought where you will do it?

- I will determine if you have means to carry out the plan, history of suicide attempts, family history of suicide, your mental health history, and history of use of medication, alcohol or illicit substances.
- If I evaluate you as high risk for suicide, then I will act quickly to protect you. This may mean staying with you until assistance arrives or you are transported to a hospital. For example, emergency referral to a local hospital and calling 911 for an evaluation of the situation.
- I will be available to assist in developing a plan for your safety. The plan for safety will depend on the level of risk and available resources. For example, if I decide that although you have suicidal ideation, but there is no intent or plan, nor history of suicidal attempts, but you do have bouts of depression then I may refer you for therapy such as Samaritans or Phoenix Aid Centre (see the Debriefing). This referral will help you with these feelings as will discussion with your GP or trusted family members to garner support or assistance.

6. What are the possible benefits of taking part?

Being interviewed about your experience of living with systemic sclerosis has no direct benefit, although some people may find it an opportunity to improve the understanding of living with systemic sclerosis and how they can manage this illness. Therefore participants could find this beneficial. This research can also help to increase the sense of hope, to understand the psychological consequences of this disease and participants will also demonstrate altruism by transmitting an understanding of this disease to the rest of population.

7. Consent

You will be given a copy of this information sheet for your personal records, and if you agree to take part, you will be asked to sign the attached consent form before the study begins. Your participation in this research is entirely voluntary. The completion and return of your consent form will be taken as your informed decision to participate. You will be asked questions about

your experience of living with systemic sclerosis. If you do decide to take part, you may also withdraw at any time before, during, or after the interviews without justifying your decision.

8. Who is organizing and funding your research?

The study is self-funded. However, the study is organized by Sidra Chaudhry (myself) and is under the supervision of the New School of Psychotherapy and Counselling and the Department of Psychology of Middlesex University and also Pamela James & Catriona May (supervisors).

9. Who has reviewed the study?

All proposals for research using human participants are reviewed by an Ethics Committee before they can proceed. The NSPC research ethics sub-committee have approved this study.

10. Expenses

This study is self-funded. Therefore, I will not pay travel or incidental expenses to research participants.

Thank you for reading this information sheet.

If you have any further questions, you can contact me at:

NSPC Ltd

***Existential Academy,
61-63 Fortune Green Road,
London
NW6 1DR***

admin@nspc.org.uk

If you have any concerns about the conduct of the study, you may contact my supervisor:

Supervisor: Pamela James

pamjamesr@aol.com

Or

**The Principal
NSPC Ltd *Existential Academy,*
61-63 Fortune Green Road,
London NW6 1DR
admin@nspc.org.uk
0044 (0) 20 7435 8067**



APPENDIX D

Information about a research project:

Experience of Living with Systemic Sclerosis- A Phenomenological Enquiry

Being carried out by

Sidra Chaudhry

**As a requirement for a D.C. Psych in Existential
Psychotherapy and Counselling Psychology from
NSPC and Middlesex University**



Consent Form

Title of study and academic year: Experience of Living with Systemic Sclerosis- A
Phenomenological Enquiry-April 2012-March 2016

Researcher: Sidra Chaudhry

Supervisor: Pamela James

I have understood the details of the research as explained to me by the researcher, and confirm that I have consented to act as a participant.

I have been given contact details for the researcher in the information sheet.

I understand that my participation is entirely voluntary, the data collected during the research will not be identifiable, and I have the right to withdraw from the project at any time without any obligation to explain my reasons for doing so.

I further understand that the data I provide may be used for analysis and subsequent publication, and provide my consent that this might occur.

Print name

Sign Name

Date: _____

To the participants: Data may be inspected by the Chair of the Psychology Ethics panel and the Chair of the School of Social Sciences Ethics committee of Middlesex University, if required by institutional audits about the correctness of procedures. Although this would happen in strict confidentiality, please tick here if you do not wish your data to be included in audits: _____

APPENDIX E

Information about a research project:



Experience of Living with Systemic Sclerosis- A

Phenomenological Enquiry

Being carried out by

Sidra Chaudhry

**As a requirement for a D.C. Psych in Existential
Psychotherapy and Counselling Psychology from
NSPC and Middlesex University**



Debriefing

Study Title: “Experience of living with Systemic Sclerosis- A Phenomenological Enquiry.”

I would like to say thank you for taking part in my study. Without your participation, it would not have been possible to carry out this research. Your participation will help to raise perception, understanding and awareness about the impact of Systemic Sclerosis. The goal of the research is to discern the main themes of living with Systemic Sclerosis: death anxiety, freedom & responsibility, isolation and meaninglessness. Systemic sclerosis can cause significant changes in appearance, self-esteem and self-image that can lead to psychological setbacks such as depression, anger and distress. Even though these issues could possibly arise in my study, I anticipate that I will observe other patterns due to the essence of the condition and the impact of it in every dimension of life.

If any queries or worries emerge, please feel free to call me on the number on your information sheet.

If you experience difficult emotions after the interview, you will be able to contact the Scleroderma support line or if you have any further queries regarding this research, you may contact the New School for Psychotherapy and Counselling (NSPC), details will be given on the Information Sheet. Furthermore, the researcher will contact you in two weeks time to check whether anything from the interview has caused concern or problems.

You could also contact the Samaritans. They provide 24-hour telephone emotional support, as it is suitable for people who are house bound. You can visit the Samaritans website: <http://www.samaritans.org/>. If you wish to have face-to-face therapy service, then you can contact the Phoenix Aid Centre. Please visit the website: <http://phoenixaidcentre.com/>. You can also contact the Befriending Networks if you feel loneliness and social isolation. You may visit the website: <http://www.befriending.co.uk/contactbns.php>. All the contact details for these support services are listed below.

If you want to know any further knowledge about Systemic Sclerosis or desire to know more from previous research, please go to the Systemic Sclerosis Society web page: <http://www.sclerodermasociety.co.uk/Systemicsclerosis2.php>. Moreover, if you require support in relation to your suffering or you need help, support groups can also be located through this web page. The Scleroderma society (UK) sets up meetings all through the UK over the duration of the year, comprising the annual convention where you can communicate with others about Systemic Sclerosis. Scleroderma Society is also a member of National Voices and The Arthritis and Musculoskeletal Alliance (ARMA). For further information, please go the web page: <http://www.nationalvoices.org.uk/> and <http://arma.uk.net/>. If you want to know any guidelines for all rheumatological conditions you can visit this web page: <http://www.rheumatology.org.uk/>.

Scleroderma Support line: 0800 311 2756

Phoenix Aid Centre: 0208 445 5652

Befriending Networks: 0131 261 8799

If you have any further questions, you can contact me at:

NSPC Ltd

Existential Academy,

61-63 Fortune Green Road,

London

NW6 1DR

If you have any concerns about the conduct of the study, you may contact my supervisor:

Supervisor: Pamela James

pamjamesr@aol.com

Or

The Principal

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Appendix F
Demographic Information

1. **Name (Initials):** _____
2. **Age:** _____
3. **Sex:** _____
4. **Marital Status:** _____
5. **Occupation:** _____
6. **Year of Onset of symptoms:** _____
7. **Number of years since diagnosis:** _____
8. **Type of systemic sclerosis:** _____
9. **Duration of treatment under consultant:** _____
10. **Severity of disease:** _____
11. **GP Name and Address:** _____
12. **Next to Kin in Emergency:** _____

Questions to be confirmed that participants have received their diagnosis by Professional Medical Doctor:

- Let's take you back to when you were diagnosed.
- Who diagnosed you? When and where did your diagnosis take place?

Appendix-G

Interview Schedule-List of Interview prompts and questions

Introduction

Can you tell me about something of your disease? What happened when you realised you had the disease.....and what it was like?

How did you feel about being diagnosed at that time?

- Tell me about your journey since being diagnosed.

Sub-questions would be asked in order to obtain the further information about living with systemic sclerosis within their experience of being diagnosed as having systematic sclerosis.

- Can you tell me how do you think that disease has affected to you in your day to day life?
Possible prompts: what about body? How do you respond to your body? What challenges face you? What things are difficult to do?
- Can you tell me how this disease affects on your relations with other people?
Possible prompts: Tell me more about partner, family, friends, and work colleagues? What areas of your life does it affect? How your family response toward your disease? Tell me about any person who has helped you most after diagnosis?
- How has the disease changed the way you think or feel about yourself?
Possible prompts: Do you see yourself differently now than before you were diagnosed? In what ways? What do you do in your spare time?
- How disease has affected on your sense of identity? Values change?
Possible prompts: Where do you find peace? Has this disease affected your ability to do the things that usually help you spiritually? What is goals/purpose of your life? Have these goals changed after your diagnosis? What do you want from your life? What is a source of meaning for you in life?
- How disease has affected on your sense of self?
Possible Prompts: How do you feel about yourself after being diagnosed? What thoughts and feelings are generated with the experience of living with systemic sclerosis? How do you cope with it?
- [If] How has your disease affected your sense of meaning? *Possible Prompts: Do you feel that life is worth living for you and how? How you will create a meaningful life? How do you satisfy yourself? What do to satisfy? Change goals after having illness?*

- How has your disease affected your sense of freedom and responsibility?
Possible Prompts: Tell me more about it? Being a responsibility, mother, sister, friends etc, freedom in travelling? Financial? How for you? How cope? Feelings generated? Dealing with feelings? Responsibility for children? Change Choices? likes and dislikes, priorities?
- How disease has affected on your sense of mortality?
Possible prompts: Do you think that life continues after death? Have your meaning of existence changed after diagnosis with this disease? How do you find meaning in your illness? What is there in your life that gives you internal support? How do you want to live? How see world after disease? Change meaning for life? See life as temporary? Where seek help? Feelings generated? And coping? Wishing for rest of life?
- Can you tell me about any most important lessons that you have learned through this experience?
Possible prompts: Tell me about it in detail?
- Can you tell me if there is anything that can make you feel happy/hopeful/ strong?
Possible prompts: From where do you get courage? Where do you seek consolation?
- Can you tell me about something that take your courage away from you/ that makes you frightened/weak?
Possible prompts: Tell me more about it. How deal and cope with feelings?
- Can you tell me how you would guide someone who has the same disease like you?
Possible prompts: Tell me more about it? In psychological way? Feeling? Coping? Meaning for you to guide other?
- How do you see yourself in future?
Possible prompts: How should you live your life? What? How openly? Feelings? What plan? Coping to do it?
- Did you seek counselling when you learned your diagnosis or while you are receiving treatment? Self-referred? Or by consultant/GP?
Possible Prompts: Why do you seek counselling? If not, what about the counselling process will be helpful to you? What is hindering? Feelings? how getting help and cope?

Ending the Interview

Do you have any questions for me? What was your experience of this interview?

TABLES

TABLE VII
INITIAL CODING

*Mean =Frequency

140 Initial coding represented participant's experience of living with systemic sclerosis and their coping styles.

Affecting on daily lives Difficulty to digest food (6)*	Difficulty to do household work such as bed sheets, clean floor, scrub floor, cooking hover, dusting, washing up, difficulty to lift mattress, bottles and heavy things ; Difficulty to cut vegetables due to lack of hand grip, difficulty to use washing powder due to skin problem; difficulty to grip things; chop, carve, touch things out of fridge, frozen things (44)*	Restricted household activity such as difficulty to bent down to tie shoes lace; unable to do gardening; Difficulty to get in and out of bed; Difficulty to open jars, tin opener, open bottle caps; screw things; Difficulty to do shopping such as unable to holding bags in hand; Difficulty to drive due to eye dryness, unable to hold weight, lack of flexibility, Lack of hand grip such as Restricted movements such as Difficulty to dress up such as changing clothes, bra, socks, to do button and zip in and out, Difficulty to wear gloves due to its weight, difficulty to wear jewellery; difficulty to make hair; difficulty to take on and off socks; Difficulty to take shower; Difficulty to use keyboards due to ulcers; Difficulty to go outside due to Raynaud's and ulcers; deformities of fingers, arm up, walk, difficulty to do any tasks, Slipped many times to get out of bath, difficulty to use shower and get in and out of bath etc (55)*	Cognitive problems like having brain fog, Difficulty to find words, Slow in thinking and movement, difficulty to concentrate and understand things, indecisive, Forgetting things , functioning problems , Not sharp cognitive abilities (15)*	Dependent on others to do daily tasks (8)*
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Dreadful fatigue (12)*	Living with pain (13)*	Body swollen and stiffness (8)*	Painful body such as muscle, joints, headache, body, ulcers, scars, neck, abdominal, cold, breathlessness (43)*	Painful to do any task (15)*
Tense in body when listen loud music and noisy Pain (8)*	Painful procedure of investigations (8)*	Skin problems such as red spots, bad complexion, face tightening, thin skin (42)*	Breathlessness problem (14)*	Side effects of medication problem (6)*
Sleep problem due to disease (15)*	Body stiffness Joint and muscles problems, and deformities of finger, Mouth small and stiffness, face tightness Puffing hand and body, toothache, headache, lack of flexibility, ulcers, Tightness skin, lip worse, Bruises on body, Joints Finger swollen, Fatty finger and hand (40)*	Cognitive problems like having brain fog, Difficulty to find words, Slow in thinking and movement, difficulty to concentrate and understand things, indecisive, Forgetting things, functioning problem , Not sharp cognitive abilities (15)*	Lack of sexual desire (8)*	Getting worse disease with time (8)*

Lack of energy such not have enough power to go outside; to do anything; Force to do certain things due to pain (6)*	Tiredness during household work; when go outside; playing with grand children; to have sexual relationship (16)*	Lack of control over disease such as Loss of under arm hair, Thin hair, Difficulty to weight loss, breathing issues, Living with pain (14)*	Breathlessness issues during any things (8)*	Difficulty to work due to disease symptoms such as ulcer, body pain etc (7)*
Took off from work due to disease getting worse (10)*	Loss of Job (8)*	Struggling to continue job such as took extra time to complete work at job due to pain; Getting worse to continue work; slow in work; Avoid disclosure about disease at job (10)*	Lack of understanding by other including husband, boyfriend, family, friends etc (9)*	Lack of contact with family including parents, children siblings and other (12)*
Lack of support by others including family (6)*	Lack of sexual desire due to disease (8)*	Shocked by family to hear about her illness (6)*	Try to hide her illness from others including parents, husband, siblings and other (11)*	Noticed by others about physical symptoms of disease including using of stick and scooter, sitting position (14)*

Lack of social relationship with others including friends and colleagues; Withdrawal from relationship (13)*	Fear of judging by others including hide feelings from others; Avoid to talk about sexual problem; Avoid to talk about disease with others; Avoid to share feelings (11)*	Fear of disclosure about illness in social gathering such as alert to sit at job; disclosure about illness in winters if take off gloves, avoid to meet with others, Avoid to use stick in public places, Fear of noticing by others, Difficulty to go in social places (14)*	Lack of empathy by others including friends, parents, colleague and other; Not get respond by friends, doctors and other (10)*	Feeling of rejection by others such as nasty attitude of others, doctors, judging by others (12)*
Lack of understanding by including husband, family, siblings, work colleagues, family and people (9)*	Lack of empathy by friends and other people (10)*	Lack of social contacts (Social Withdrawal) from social activities such as outing, go outside and gym and dancing club, hosting parties, no go out with friends, avoid to go outside and meet with others; Difficulty to go in social places due disease symptoms; Not having due social life due to restricted movement; Social stigma to get govt support; ignore others to avoid feeling of embarrassment, unable to do shopping; Embarrass to eat food in restaurant (32)*	Lack of communication with professionals (8)*	Difficulty to do shopping (16)*
Dependent on husband, family and others to do daily tasks (15)*	Financial issues due to loss of job (8)*	Lack of engagement with others including doctors; Avoid to interact with people; Avoid to meet with people due to changed in appearance and disease symptoms; Fear of judging by others; Lack of support by doctors; avoid to meet with mom as to avoid disclosure; Noticing by people about disease such walking etc (19)*	Fear of being catered by other person (2)*	Fear of burden on partner (20)*
Caged animal (3)*	Lack of sense of meaning (6)*	Hopelessness including not having old goals, no to cure, about future, Loss of hope to live longer (33)*	Feeling of lonely (14)*	Bad tempered to have pain (13)*

No want/wish to live with disease (4)*	Depressed to have disease, quit from job, on restricted movements and own limitation due to disability (8)*	Sadness no hope for future feelings of despair including no hope for future, sadness not getting support by children, Lack of satisfaction with life, Disappointment by friends (11)*	Lack of positive attitude towards life	Frighten by being vulnerable, ill and dependent (2)*
Depressed by medication's side effects	Feeling of frustration on disease (41)*	Feeling of helplessness such as pain out of control, no get help by treatment, to use socks aids, disease out of control, to weight gain, not having old goals more, lack of sleep, cognitive problem, Depress due to side effects of medication; Feeling of sad to know about incurable, Frustration on side effect of medication, Frustration due to lack of understanding by partner, live with incurable disease (50)*	Loss of Independency 2	Feeling of annoying on dependent on others to do daily tasks, annoy on limitations due to disease (25)*
Feeling of overwhelmed and stress due to lack of control over disease including fear of passing out (5)*	Fear of living with disability (12)*	Feeling of powerlessness such as weak, fiddly to wear jewellery Worry about financial issues (11)*	Frustration on being dependent (8)	Annoying on changed sense of self including change in appearance (2)*

Sadness (9)*	Frustration on super-power existence (4)* Loss trust on super-power	Feeling of strange due to disease including undergoing investigation; Fear of invasive about investigation; disgusting to have ulcers; Awful about disease; Upset by use of stick; Red spots on forehead; Feeling of bad due to parent's concern; feelings of sorry for self; Vague due to disease; scrambling words due to weakness; Feeling of petrify (27)*	Feelings of robbed	Depressed about to have disease and its' consequences such as loss of job, loss of independency (5)*
Lack of understanding by partner and friends and doctors (6)*	Changed self-image like Feel like caged animal; Feeling of robbed by disease; Bad feelings due to difficulty words; Changed self image; changed self-identity (6)*	Anxious about consequences of disease such as ended up with wheel chair, fear of loss finger due to ulcers, fear of getting worse; Concern about stomach problem, blood pressure, ulcers, lungs, concern about mental health due to disease traumatic to read on internet (41)*	Feeling of being left out due to social isolation and lack of empathy from others and stayed at home, still alone even having partner support; Sadness not to have sexual desire more due to disease; Loss of trust on super-power existence (13)*	Worry about outcome of disease including Feeling of worry to getting old; Fear of getting worse of disease in future; Thinking about severity of disease before dying; End with shortened life (32)*
Changed attitude towards world such as find world as a horrible; finding world as threat; See world as	Fear of dying including nightmares, death terror nightmares, dying with pain; Concern about lungs involvement; Die earlier as unexpected (19)*	Feeling of worry about incurable disease including overwhelmed and stress; Feeling of nuisance due to disease; low self-image nightmares of losing teeth; feeling of hypochondriacs (26)*	Confront with death mortality (7)*	Changed attitude towards life such as see life as temporary; Life is short (6)

temporary and
smaller (7)*

Confront with
sense of mortality
(9)*

Accept death reality (4)*

Changed sense of self including feeling of
hypochondriacs; Feeling of useless not to have sexual
relationship; Awful on depending on others; Snappy
person; Quick-tempered such less tolerant to stand in
queue, Feeling of demoralizing on depending other;
Mood swing; angry to stand in queue; Feeling of
nuisance on changed body image; Loss of confidence;
Self-pity; Worthless life; not more doing previous
goals; Feeling of useless due to not fulfilling
responsibility as a wife and mum; changed outlook
towards life; Lack of satisfaction with life (42)*

Lack of control over
disease such as
destiny; weight gain;
disease symptoms;
light-headedness as
side effects out of
control (8)*

Loss of
independency
such as Feeling of
less free;
Dependent on
others for wee
things; feel like
caged animal;
feeling of trapped
by disease; feeling
of robbed by
disease; lack of to
dress up; lack of
freedom to choose
and do what want;
restricted life to do
(13)*

Lack of travel
freedom due to
disease such as
restricted life due
to illness such as
difficulty to do
shopping-lack of

Changed in appearance such as dreadful hand and skin;
See herself as ugly mouth, eye, skin, look like scruffy
by wearing layers of cloth; Fear of losing teeth; Hate
self when look in mirror; Weight gain; No find self
attractive more; fatty hand; not look nice (22)*

Loss of financial
freedom such as
Limited money;
Worry about
financial issues as a
freelancer
dependency on for

Loss of control
over disease
including Feeling
out of control to
approach specialist
(3)*

freedom; no go
more places and
outside unable to
go out own;
unable to visit
friends now;
boundaries to
travel due to
disease; bounded
at home (39)*

finance (6)*

Changed choices
such as changed

Not liked to wear
layers of clothes;
Loss of freedom
to choose and do
what want;
change like and
dislike (8)*

Changed priorities-more
focused on family and
friends; Used to do things
alot and those are important
but now living one day to
next day; Not more walk to
dogs as she likes; use
computer that dislike before.
(6)*

Feeling of worry to getting old including using sticks,
and socks aids; Fear of getting other illness-
hypochondriacs; Use trolley during shopping as seen as
normal person Look like old woman by using stick;
Perceived self as old; Feeling embarrass to use sticks
look like old woman; Embarrass if other notice to use
stick and scooters; Lack of in trust in things; Lack of
sexual function (20)*

Lack of responsible
being a mother, a
wife, a daughter,
friend and lack of
responsible to care
for dog (14)8

Dependent on
others for wee
things such as lack
of responsibility-
no like to take in-
charge of
anything; lack of
financial
responsible; loss
of job; Feeling of
useless due to not
fulfilling
responsibility (7)*

Changed role and
responsibility
(6)*

Professional help including
scleroderma society help,
physiotherapy and
occupational therapist (14)*

Feeling of loneliness such as loneliness;
stay at home; Avoid to share with them; Scary to go
social places; Nuisance to go out of house; Feeling of
burden on others; Shame to get support from govt;
Avoid to use stick in public place; Feeling of

Treatment measure
such as Investigation
Blood test, Illoprost
treatment, x-ray and
lung function test
and more test to

Self-help by taking
supplements such
as vitamins and
magnesium oil,
bandage to knee
erupted and self-

		embarrassment when people noticed red spots; Feeling of shame when noticing by other such as eat when with others; Feeling embarrass to use sticks; Feeling awful by asking help from others; Supported by husband still feel lonely; Embarrass if other notice to use stick and scooters; Embarrass to eat food in restaurant; Lack of motivation to go outside ; Noticed by other people when used stick (30)*	monitor organs, barium test etc to rule out problems (21)*	monitoring (11)*
Try to get better with medications to treat infection, control blood pressure, pain, stomach problem, chiropractor to reduce stiffness, stomach problem (29)*	Finding different ways to deal with disease such as using own strength to cope; avoid stress; alert during taking bath to avoid fall slip; rest to manage tiredness; take rest intervals during household work as to deal with pain and tiredness (12)*	Feeling of unknown including Finding answers to have flare up again; Trying to get answer not to have sexual drive; Unknown about causes of disease; Concern about future; fear of unknown about disease; Unknown anxious; Feeling of unknown future; Unknown about changing choices; Unknown about duration satisfaction; Worry about future financial management; Try to find answer why having disease; Try to get unknown; Feeling of unknown future; Unknown about body change, Think about own mortality after disease (35)*	Getting help by pension for financial issues (4)*	No wish to live if disease get worse to avoid resuscitated (6)*
Find different ways to work in kitchen such as asked help by family; use brisky mixture in kitchen; finding other ways to	Find different ways to clean home such as asked help by others; manage to clean floor by lying on it; get thinner matters to change bed sheet; use tools to clean home such as using clothes, steamer, separate hover for	Managing emotions of sadness, annoying, loneliness by expressing feelings; crying; walk out; watch TV to cope with sadness; getting meditations; use mindfulness to seek hope and feel better and reduce anxiety; walk, share feelings with husband to deal with annoy, sadness, frustration and depression about disease; try to ignore other people attitude; read books to change mind of being ill, dependent and vulnerable; watching Tv and	Different ways to do shopping such as asked help by others; use trolley shopping; carrying shoppers in arms as managing; use backpack to hold things; use bags with	Different ways to open jars/bottle cap such as asked help by others; using rubber cap to open bottles; use different ways to use screw up;

cook meal, open jars Use hand mixer as tool; use big knife to grip hand; finding other ways to clean dishes; use food mixer as a tool; use dishwasher to wash dishes (8)*	each floor and use tools; different ways to change duvet ‘ lay it flat and shove its corner’; try to divide task to reduce pain; try to do things one at one day (15)*	avoid to think about disease (30)*	wider shoulder strap during shopping; use bags to hold things to forearm for shopping; try to divide task to reduce pain; try to do things one at one day; use gloves to hold trolley for shopping; lean on trolley to feel relax; use hand bags and hang on trolley (14)*	use ring pull can to open; use little bottle to lift (15)*
Different ways to cope with visible symptoms of disease such as use cream to cover red spots; try cover red spots with make up; dressing like scarf’s that covers spot; use nail paint to look nice hand; try to cover red spots on forehead by	Use different strategies/resources to manage reflux such as half brick under head and legs; Use extra pillows to control reflux, walk to control reflux, Eat dry biscuit to control reflux; avoid to take large meal before sleeping, change diet, drink water to swallow food, use electric beds; change diet plan and sitting up in bed to control refluxes; sleep in up to control refluxes to manage	Use gloves to keep warm and to deal with Raynaud’s when outside home, and during shopping, heating at home, wear warm clothes, move to warm places, use heater to avoid cold, Use gloves, heating pads for hand and foot and wear four layers of dressing, hot bottle; use silver and electric socks, thick woollen socks, sheep skin sleepers; use bigger shoes, camping shoe due to layers of socks; use ski gloves and heated gloves; Keep heating pads and other stuff , getting info about temperature before going holidays, sleeping bags (pro-active) to manage Raynaud’s (33)*	Different ways to manage pain such as pain killer; taking medications; get relax by taking hot bath; get help by warm shower and use hot tub to relief pain; swimming three times a week help to flexibility; Join health club; getting relax by staying at home; use different strategies to	Adopt positive attitude towards disease such as think positive and see changed appearance as normal progression; aspects of medicine as cope with side effects (9)*

hair (7)*

stomach symptoms (18)*

manage pain such as
memory foam to
reduce muscular
pain, lay on back,
use soft pillows,
distraction strategies
such as listening
music; exercise to
deal with sleep
problem (22)*

Seeking meaning
from religion;
getting source of
meaning to work
in charity; getting
source of
meaning from
grand children;
try to find out
new goals ;
getting internal
support from
being Christian
and religion
values of love to
friends and
family (9)*

Feeling lucky to count
blessing such as to have
disease in middle age, not in
young age, and having
medications, having
professional help, supportive
partner, as not getting worse
disease at the moment,
boyfriend and full mobility
in hand and not have ulcers
and to live in nice place and
to have property and getting
pension for financial
support, not having habit of
extra-vagant, use
adaptations to do shopping,
family support; skin getting
improve through
medications and other

Different ways to manage the disability such as asked
help by others; took off from work to take rest;
Rehabilitation to splints on hands; use bath chair;
renovate home according to disability needs; different
ways to get in and out of bath; different twisting ways to
get dress up; use socks aids; live in Bungalow as to
avoid stairs up; use electric chair to bath; use physical
adaptations to drive car such as steering and electric
brakes; use long straps to dress up; use socks aids; use
stick and scooter to deal with disability; use lift bath;
getting financially support from govt; try to divide task
to reduce pain; try to do things one at one day; buy
stretchy clothes to wear and avoid to use clothes with
zip; foot up to tie lace; Plan to make some raised bed to
do gardening; use trolley for shopping; hold bags in
forearm; use backbags, and asked help by others (31)*

Finding different
ways to get courage
such as from
grandfather and
soldiers who were in
WW1 and from
other who have
severe disability and
constant pain whole
life; Motivated by
GOD to alleviate
disease; Self
motivating through
work; getting
motivation from
grand children; get
happy by grand
children, warm
weather and

Gaining
satisfaction from
beautiful sunrise,
enjoying morning;
to enjoy nature
beauty such as
birds, butterflies;
take care of
animals; through
work, partner, live
in a nice place (8)*

blessings (25)*

sunshine and being
in good company,
courage to know
about cure of other
disease and making
hope for cure;
Knowing own power
(15)*

Try to figure out about disease and its consequences through investigations and problems and putting weight due to side effect (12)*	Use humour to cope with disease such as laugh etc (8)*	Understand values of life and others such as Empathy for others; Learn to values self and life; Motivating others; help other to focus on positive things; hope for future not much affected by disease; recognise important to health; understanding other with illness; Learn more tolerant for other people; understand life is precious; value life more; guide other not to read on internet; help other to understand disease; encouraging other to have hope (20)*	Try to make sense of experience such as Understand own limitations due to disease (8)*	Get supported by others including to hold and lift things ; shopping; scleroderma helpline to get support (24)*
Getting relax by going cinema; going to warm place for holidays (6)*	Try to ignore other people comments (5)*	Get supported by family including partner, and children for household tasks such as prepare meals, taking bath, dress up, get out of bed, lifting object, open jar, clean up home, to shopping, getting out of bath , dress up such as tie button, buckles, socks, wear jewellery, to stairs up, sharing feelings etc, motivating by partner (93)*	Use humour to cope with disease in social world (7)*	Get supported by siblings (7)*
Supported by friends including making new friends (8)*	Acceptance disease (28)*	Getting more info about disease including internet, leaflet; use forums to discuss, Sharing pain, worries about disease in forums; use scleroderma helpline to get support etc (22)*	Accept death mortality (8)*	Awareness own limitations due to illness (36)*

Try to make sense
of disease
including try to
be realistic and
accept of loss of
sexual desire due
to disease and
other impact of
disease (15)*

TABLE VIII
INITIAL HIGHER CODES

***Mean =Frequency**

23 out of 140 initial higher coding represented participant's experience of living with systemic sclerosis and their coping styles.

Disability	Job loss	Lack of freedom	Hopelessness
Bodily Pain	Lack of engagement with family	Changed choices	Helplessness
Physical Symptoms	Avoid disclosure	Lack of responsibility	Being care about disease
Lack of control over body	Social Isolation	Changed Self-Image	Changed attitude towards world
Lack of Energy	Lack of empathy by others	Embrace death mortality	Fear of dying
Uncertainty	Dependency	Being Left out	

TABLE IX
IN-VIVO CODES
***Mean = Frequency**

83 In-vivo coding used by research participants to live with systemic sclerosis:

Scare (22)*	Sadness (4)*	Petrify	Uncomfortable (2)*	Nuisance (5)*	Hypochondriac (9)*	Dreadful fatigue	Tired (10)*
Agitate	Anxiety (5)*	Battle (2)*	Embarrass (2)*	Excited	Lonely (2)*	Self-pity	Dependant
Weak (2)*	Self-compassionate (3)*	Terrible	Upset (9)*	Weird	Cage animal	Demoralizing	Guilty (2)*
Angry (18)*	Rewarding (3)*	Depression (15)*	Disability (5)*	Strange	Tense	Dreadful pain	Useless (4)*
Fearful	Awful (4)*	Worry (29)*	Fatigue (4)*	Fed up	Snappy (2)*	Helplessness	Devastated (8)*
Phobia	Empathy (3)*	Uncertainty	Reassure about treatment (7)*	Disgusting	Horrendous	Isolate	Boom and Bust
Lonely (2)*	Frustrate (26)*	Accept (2)*	Panic (5)*	Feeling of shame	Ashamed	Horrible	Pulling knife in and out
Annoy (10)*	Harsh	Irritate (6)*	Dreadful (4)*	Fear of being catered by other person	Quick tempered (4)*	Hate (3)*	Feeling of robbed (2)*

Stronger	Live Each Day as It Comes	Upsetting (4)*	Out of control (20)*	Ignore	Resentful (2)*	Grateful (3)*	Fear of choking (2)*
Grieving (5)*	Strange 3	Hopelessness	Distressful	Ugly	Vulnerable (10)*	Frighten (6)*	Knock-on effect
Taken for granted (3)*	Stress (5)*	Lucky (5)*					

TABLE X
INNOVATIVE CODES
***Mean = Frequency**

18 innovative codes out of 83 in-vivo codes were found in this study

Grieving (5)*	Boom and Bust	Fear of Choking (2)*	Fear of being catered by other person	Caged Animal
Self-compassionate (3)*	Devastated	Out of Control (20)*	Feeling of robbed (2)*	Live Each Day as It Comes
Rewarding (3)*	Battle (2)*	Nuisance (5)*	Hypochondriac (9)*	Vulnerability (10)*
Taken for granted (3)*	Demoralized	Knock-on-effect		

TABLE XI
FOCUSED CODING

Physical Impact of disease	Psychological impact of disease	Social Impact of disease	Sense of Mortality
Lack of Freedom and Responsibility	Coping Strategies		

TABLE XII
FOCUSED CODING WITH INITIAL HIGHER CODING

Physical Impact of Disease	Social Impact of Disease	Psychological Impact of Disease	Impact of disease on Sense of Mortality	Impact of disease on Freedom and Responsibility
Disability	Job loss	Hopelessness	Uncertainty	Lack of freedom
Bodily Pain	Lack of engagement with family	Helplessness	Fear of dying	Changed choices
Physical Symptoms	Avoid disclosure	Being care about disease	Changed attitude towards world	Lack of responsibility
Lack of control over body	Social Isolation	Changed Self-Image	Embrace death mortality	
Lack of Energy	Lack of empathy by others	Being Left out		
	Dependency			

TABLE XIII
FOCUSED CODING WITH HIGHER AND INITIAL LOWER CODING
Number = Frequency

PHYSICAL IMPACT OF DISEASE

Disability	Bodily Pain	Physical Symptoms	Lack of control over body	Lack of energy
Affecting on daily lives Difficulty to digest food 3	Dreadful fatigue 12	Raynaud's 23 Lungs affected 3	Cognitive problems like having brain fog, Difficulty to find words, Slow in thinking and movement, difficulty to concentrate and understand things, indecisive, Forgetting things , functioning problem , Not sharp cognitive abilities	Lack of energy such not have enough power to go outside; to do anything; Force to do certain things due to pain 6
Difficulty to do household work such as bed sheets, clean floor, scrub floor, cooking hover, dusting, washing up, difficulty to lift mattress, bottles and heavy things ; Difficulty to cut vegetables due to lack of hand grip, difficulty to use washing powder due to skin problem; difficulty to grip things; chop, carve, touch things out of fridge, frozen things 44	Living with pain 13 Body swollen and stiffness 8 Painful body such as muscle, joints, headache, body, ulcers, scars, neck, abdominal, cold, breathlessness 43	Insomnia 3 Lose weight 2 Stomach problem as burping and indigestion food, refluxes, swallowing problem Abdominal distress, Hard to digest juice Unable to digest red wine	15 Side effects of medication problem 6	Breathlessness issues during any things 4 Tiredness during household work; when go outside; playing with grand children; to have sexual relationship 16
Restricted household activity such as difficulty to bent down to tie shoes lace;unable to do gardening;	Painful to do any task 8 Tense in body when listen loud music and noisy Pain	Difficulty to swallow, Sore throat due to reflux 31 Other complications of disease such as deficient nutrients as Low vitamin D and anemic , right knee	Lack of sexual desire 2	

Difficulty to get in and out of bed;
 Difficulty to open jars, tin opener,
 open bottle caps; screw things;
 Difficulty to do shopping such as
 unable to holding bags in hand;
 Difficulty to drive due to eye
 dryness, unable to hold weight, lack
 of flexibility, Lack of hand grip
 such as scourer and socks aids, to
 use towels 38

Restricted movements such as
 Difficulty to dress up such as
 changing clothes, bra, socks, to do
 button and zip in and out,
 Difficulty to wear gloves due to its
 weight

difficulty to wear jewellery;
 difficulty to make hair; difficulty to
 take on and off socks;

Difficulty to take shower;
 Difficulty to use keyboards due to
 ulcers; Difficulty to go outside due
 to Raynaud's and ulcers;
 deformities of fingers, arm up,
 walk, difficulty to do any tasks,
 Slipped many times to get out of

Painful procedure of
 investigations

injury, hypertension,
 Getting neuropathy, cough,
 Infection, high blood
 pressure, Fever , Sjorgen
 disease, Heart palpitation,
 thyroid, Flare up of disease

31

Skin problems such as red
 spots, bad complexion,
 face tightening, thin
 skin,42

breathlessness problem 4

Body stiffness Joint and
 muscles problems, and
 deformities of finger,
 Mouth small and stiffness,
 face tightness Puffing
 hand and body, toothache,
 headache, lack of
 flexibility, ulcers,
 Tightness skin, lip worse,

Getting worse disease
 with time 8

Lack of control over
 disease such as Loss of
 under arm hair, Thin
 hair, Difficulty to
 weight loss, breathing
 issues , Living with
 pain 14

sleep problem due to
 disease 15

bath, difficulty to use shower and
get in and out of bath

etc 55

Cognitive problems like having
brain fog, Difficulty to find words,
Slow in thinking and movement,
difficulty to concentrate and
understand things, indecisive,
Forgetting things , functioning
problems , Not sharp cognitive
abilities

15

Dependent on others to do daily
tasks 3

Bruises on body, Joints

Finger swollen, Fatty
finger and hand 40

TABLE XIII
FOCUSED CODING WITH INITIAL HIGHER CODING
(Continue)

SOCIAL IMPACT OF DISEASE

Job loss	Lack of engagement with family	Avoid disclosure	Social Isolation	Lack of empathy by others	Dependency
Difficulty to work due to disease symptoms such as ulcer, body pain etc 7	Lack of understanding by other including husband, boyfriend, family, friends etc 9	Fear of disclosure about illness in social gathering such as alert to sit at job; disclosure about illness in winters if take off gloves, avoid to meet with others, Avoid to use stick in public places, Fear of noticing by others, Difficulty to go in social places 14	Lack of social relationship with others including friends and colleagues; Withdrawal from relationship 13	Lack of empathy by others including friends, parents, colleague and other; Not get respond by friends, doctors and other, 10	Difficulty to do shopping 3
Struggling to continue job such as took extra time to complete work at job due to pain; Getting worse to continue work; slow in work; Avoid disclosure about disease at job 10	Lack of contact with family including parents, children siblings and other 12		Lack of social contacts (Social Withdrawal) from social activities such as outing, go outside and gym and dancing club, hosting parties, no go out with friends, avoid to go outside and meet with others; Difficulty to go in social places due disease symptoms; Not having due social life due to restricted movement; Social stigma to get govt support; ignore others to avoid feeling of	Feeling of rejection by others such as nasty attitude of others, doctors, judging by others 8	Dependent on husband, family and others to do daily tasks 15
	Lack of support by others including family 4				financial issues due to loss of job 4
	Lack of sexual desire due to disease 8	Fear of judging by others including hide feelings from others; Avoid to talk about sexual problem; Avoid to talk about disease with others; Avoid to			fear of burden on partner
Took off from work due to disease				Lack of empathy by friends and other people 10	fear of being catered by other

getting worse 10	Shocked by family to hear about her illness 3	share feelings 11	embarrassment, unable to do shopping; Embarrass to eat food in restaurant 32	Lack of understanding by including husband, family, siblings, work colleagues, family and people 9	person
Loss of Job 8		Try to hide her illness from others including parents, husband, siblings and other 11	Lack of engagement with others including doctors; Avoid to interact with people; Avoid to meet with people due to changed in appearance and disease symptoms; Fear of judging by others; Lack of support by doctors; avoid to meet with mom as to avoid disclosure;	Lack of communication with professionals 3	caged animal
		Noticed by others about physical symptoms of disease including using of stick and scooter, sitting position14	Noticing by people about disease such walking etc 19		

TABLE XIII
FOCUSED CODING WITH INITIAL and HIGHER CODING
(Continue)

PSYCHOLOGICAL IMPACT OF DISEASE

Hopelessness	Helplessness	Being Scare about Disease	Changed Self-Image	Being Left-Out
Lack of sense of meaning 2	Feeling of frustration on disease 41	Feeling of strange due to disease including undergoing investigation; Fear of invasive about investigation; disgusting to have ulcers; Awful about disease; Upset by use of stick; Red spots on forehead; Feeling of bad due to parent's concern; feelings of sorry for self; Vague due to disease; scrambling words due to weakness; Feeling of petrify 27	Changed sense of self including feeling of hypochondriacs; Feeling of useless not to have sexual relationship; Awful on depending on others; Snappy person; Quick-tempered such less tolerant to stand in queue, Feeling of demoralizing on depending other; Mood swing; angry to stand in queue; Feeling of nuisance on changed body image; Loss of confidence; Self-pity; Worthless life; not more doing previous goals; Feeling of useless due to not fulfilling responsibility as a wife and mum; changed outlook towards life; Lack of satisfaction with life 42	Lack of understanding by partner and friends and doctors 5
Hopelessness including not having old goals, no to cure, about future, Loss of hope to live longer 33	Loss of independency 2			Depressed about to have disease and its' consequences such as loss of job, loss of independency, 5
Sadness no hope for future	Feeling of annoying on dependent on others to do daily tasks, annoy on limitations due to disease 25	Anxious about consequences of disease such as ended up with wheel chair, fear of loss finger due to ulcers, fear of getting worse; Concern about stomach problem, blood pressure, ulcers, lungs, concern about mental health due to disease traumatic to read on internet 41		Feeling of being left out due to social isolation and lack of empathy from others and stayed at home, still alone even having partner support; Sadness not to have sexual desire more due to disease; Loss of trust on super-power existence 13
feelings of despair including no hope for future, sadness not getting support by children, Lack of satisfaction with life, Disappointment by friends 11	Feeling of helplessness such as pain out of control, no get help by treatment, to use socks aids, disease out of control, to weight gain, not having old goals more, lack of sleep, cognitive problem, Depress due to side effects of medication; Feeling of sad to know about incurable,	Feeling of worry about incurable disease including overwhelmed	Changed in appearance such	Feeling of loneliness such as loneliness; stay at home; Avoid to share with them; Scary to go social places; Nuisance to go out of house; Feeling of burden on others; Shame to get support

Feeling of lonely 4	Frustration on side effect of medication, Frustration due to lack of understanding by partner, live with incurable disease 50	and stress; Feeling of nuisance due to disease; low self-image nightmares of losing teeth; feeling of hypochondriacs 26	as dreadful hand and skin; See herself as ugly mouth, eye, skin, look like scruffy by wearing layers of cloth; Fear of losing teeth; Hate self when look in mirror; Weight gain; No find self attractive more; Fatty hand; not look nice 22	from govt; Avoid to use stick in public place; Feeling of embarrassment when people noticed red spots; Feeling of shame when noticing by other such as eat when with others; Feeling embarrass to use sticks; Feeling awful by asking help from others; Supported by husband still feel lonely; Embarrass if other notice to use stick and scooters; Embarrass to eat food in restaurant; Lack of motivation to go outside ; Noticed by other people when used stick 30
Bad tempered to have pain 3				
No want/wish to live with disease 4		Feelings of robbed	Changed self-image like Feel like caged animal; Feeling of robbed by disease; Bad feelings due to difficulty words; Changed self image; changed self-identity 6	
Depressed to have disease, quit from job, on restricted movements and own limitation due to disability 8	Feeling of overwhelmed and stress due to lack of control over disease including Fear of passing out 5	Fear of living with disability 3	Feeling of worry to getting old including using sticks, and socks aids; Fear of getting other illness-hypochondriacs; Use trolley during shopping as seen as normal person Look like old woman by using stick; Perceived self as old; Feeling embarrass to use sticks look like old woman; Embarrass if other notice to use stick and scooters; Lack of in trust in things; Lack of sexual 20	
Lack of positive attitude towards life	Feeling of powerlessness such as weak, fiddly to wear jewellery Worry about financial issues 11			
Frighten by being vulnerable, ill and dependent	Feel like caged animal Frustration on being dependent			
Depressed by medication's side effects	Fear of being catered by other person Fear of living with disability 9 Annoying on changed sense of self including change in appearance 2 Frustration on super-power existence 4 Loss trust on super-power			

TABLE XIII
FOCUSED CODING WITH INITIAL and HIGHER CODING
(Continue)
IMPACT OF DISEASE ON SENSE OF MORTALITY

Uncertainty	Fear of dying	Changed attitude towards world	Embrace death mortality
Worry about outcome of disease including Feeling of worry to getting old; Fear of getting worse of disease in future ; Thinking about severity of disease before dying; End with shortened life ³²	Fear of dying including nightmares, death terror nightmares, dying with pain; Concern about lungs involvement; Die earlier as unexpected 19	Changed attitude towards world such as find world as a horrible; finding world as threat; See world as temporary and smaller 7	Confront with sense of mortality 9
Feeling of unknown including Finding answers to have flare up again; Trying to get answer not to have sexual drive; Unknown about causes of disease; Concern about future; fear of unknown about disease; Unknown anxious; Feeling of unknown future; Unknown about changing choices; Unknown about duration satisfaction; Worry about future financial management; Try to find answer why having disease; Try to get unknown; Feeling of unknown future; Unknown about body change, Think about own mortality after disease 35	Confront with death mortality 7	Changed attitude towards life such as see life as temporary; Life is short 6	Accept death reality 4

TABLE XIII
FOCUSED CODING WITH INITIAL and HIGHER CODING
(Continue)

IMPACT OF DISEASE ON FREEDOM AND RESPONSIBILITY

Lack of freedom	Changed choices	Lack of responsibility
Lack of control over disease such as destiny; weight gain; disease symptoms; light-headedness as side effects out of control 8	Loss of control over disease including Feeling out of control to approach specialist 3	Lack of responsible being a mother, a wife, a daughter, friend and lack of responsible to care for dog 14
loss of independency such as Feeling of less free; Dependent on others for wee things; feel like caged animal; feeling of trapped by disease; feeling of robbed by disease; lack of freedom to dress up; lack of freedom to choose and do what want; restricted life to do 13	Changed choices such as changed Not liked to wear layers of clothes; Loss of freedom to choose and do what want; change like and dislike 8	Dependent on others for wee things such as lack of responsibility-no like to take in-charge of anything; lack of financial responsible; loss of job; Feeling of useless due to not fulfilling responsibility 7
Lack of travel freedom due to disease such as restricted life due to illness such as difficulty to do shopping-lack of freedom; no go more places and outside unable to go out own; unable to visit friends now; boundaries to travel due to disease; Bounded at home 39	Changed priorities-more focused on family and friends; Used to do things alot and those are important but now living one day to next day; Not more walk to dogs as she likes; use computer that dislike before 6	Changed role and responsibility 6
Loss of financial freedom such as Limited money; Worry about financial issues as a freelancer; dependency on for finance 6		

TABLE XIV

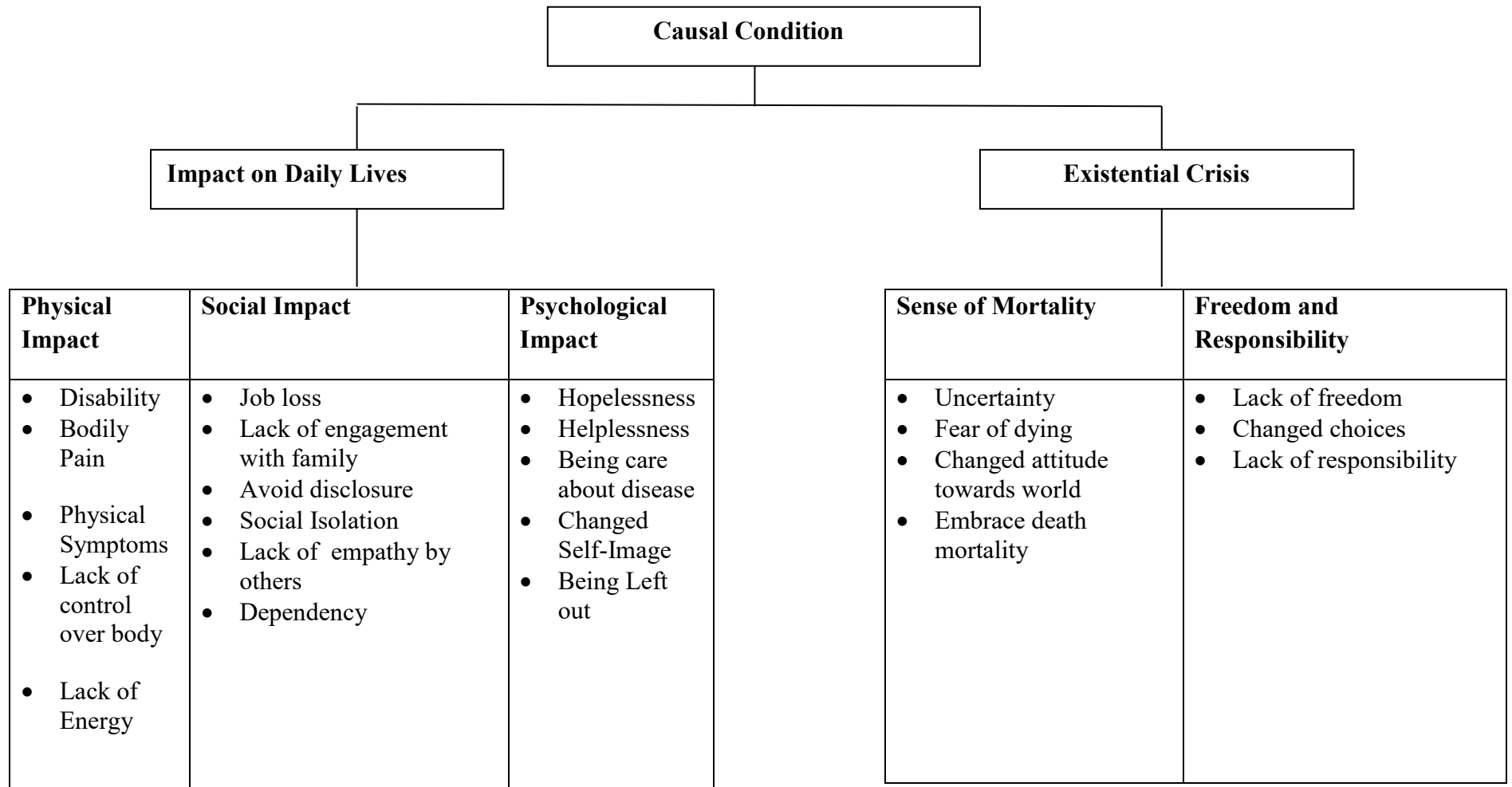


TABLE XV

Central Phenomena



Disability	Social Isolation	Despair	Death Anxiety	Uncertainty	Lack of freedom and responsibility
• Bodily symptoms • Shifting symptoms • Physical sensation due to disease • Unsettling • Body pain, • Restricted movements • Loss of previous activity • Difficulty to dress up • Restrictive household activities • Dependent on others to do daily task • Affecting on cognitive ability • Feeling of weak • Loss of control on executive skills like unable to drive • Difficult to take care of personal hygiene	• Feeling of rejection by others • Lack of empathy by others • Lack of understanding by others • Loss of job • Loss of old relationship • Withdrawal from social activities • Fear of disclosure about illness • Fear of social stigma • Lack of support by family, disengage with others • Difficult to accommodate in social environment • Feeling of being left-out • Unhelping Job environment • Feeling of detached from others	• Feeling of helplessness • Feeling of powerlessness • Hopelessness • Feeling of sadness • Negative attitude towards self • Feelings of worthless • Loneliness • Feeling of block • Feeling of distress • Feeling of frustration • Change body appearance • Feeling of awful • Interpretation image of self	• Fear of dying, • Nightmares • Distress of being dying • Never think about death before illness • Changed view about world and people • See world as temporary • Fear of isolation • Loss of physical existence • Feeling of losing control self • Find world as hard	• fear of unknown about outcome of illness • Fear of unknown, anxious about future • Thinking of getting worst about illness in future • Unknown anxiety • Predicting unknown	• Difficulty to make choice • feelings of control by others • Loss of freedom, unable to make choice freely • Lack of decision making power for family, household, planning etc, • Unable to travel freely • Unable to take responsibility • Lack of trust on self-ability to make choice • Loss of control over bodily changes due to disease • Loss of responsibility as a wife • Loss of all previous meanings for life

TABLE XVI

Context	Participant 1 46 Limited Systemic Sclerosis	Participant 2 58 Diffuse Systemic Sclerosis	Participant 3 49 Limited Systemic Sclerosis	Participant 4 63 Diffuse Systemic Sclerosis	Participant 5 59 Diffuse Systemic Sclerosis	Participant 6 52 Limited Systemic Sclerosis
(a) intensity of disease	8 out of 10	5 out of 10	7 out of 10	7 out of 10	10 out of 10	10 out of 10
(b) duration of disease	3 years	6 years	1 years	9 years	6 years	2 years
(c) duration of treatment	14 month	5 years	9 month	9 years	5 years	3 month
(d) length of relationship	18 years	10 years	19 years	31 years	40 years	10 years

TABLE XVII

STRATEGIES

Problem-focused coping	Solution-focused coping	Meaning based coping	Social coping	Realistic Approach
Seeking for professional help including scleroderma society help, physiotherapy and occupational therapist 14	Managing emotions of sadness, annoying, loneliness by expressing feelings; crying; walk out; watch TV to cope with sadness; getting meditations; use mindfulness to seek hope and feel better and reduce anxiety; walk, share feelings with husband to deal with annoy, sadness, frustration and depression about disease; try to ignore other people attitude; read books to change mind of being ill, dependent and vulnerable; watching TV and avoid to think about disease 30	Adopt positive attitude towards disease such as think positive and see changed appearance as normal progression; aspects of medicine as cope with side effects 9	Get supported by others including to hold and lift things ; shopping; scleroderma helpline to get support 24	Acceptance disease 28
Treatment measure such as Investigation Blood test, Illoprost treatment, x-ray and lung function test and more test to monitor organs, barium test etc to rule out problems 21	Find different ways to clean home such as asked help by others; manage to clean floor by lying on it; get thinner matters to change bed sheet; use tools to clean home such as using clothes, steamer, separate hover for each floor and use tools; different ways to change duvet ‘ lay it flat and shove its corner’; try to divide task to reduce pain; try to do things one at one day 15	Feeling lucky to count blessing such as to have disease in middle age, not in young age, and having medications, having professional help, supportive partner, as not getting worse disease at the moment, boyfriend and full mobility in hand and not have ulcers and to live in nice place and to have property and getting pension for financial support, not having habit of extra-	Get supported by siblings 2 Supported by friends including making new friends 8 Try to ignore other people comments 5	Getting more info about disease including internet, leaflet; use forums to discuss Sharing pain, worries about disease in forums; use scleroderma helpline to get support etc 22
Self-help by taking supplements such as vitamins and magnesium oil, bandage to knee erupted and	Find different ways to work in kitchen such as		Use humour to cope with disease in social	Accept death mortality 4

self-monitoring 11	asked help by family; use brisky mixture in kitchen; finding other ways to cook meal, open jars	vagant, use adaptations to do shopping, family support; skin getting improve through medications and other blessings 25	world 4	Awareness own limitations due to illness 36
Try to get better with medications to treat infection, control blood pressure, pain, stomach problem, chiropractor to reduce stiffness, stomach problem 29	Use hand mixer as tool; use big knife to grip hand; finding other ways to clean dishes; use food mixer as a tool; use dishwasher to wash dishes 8		Get supported by family including partner, and children for household tasks such as prepare meals, taking bated, dress up, get out of bed, lifting object, open jar, clean up home, to shopping, getting out of bath , dress up such as tie button, buckles, socks, wear jewellery, to stairs up, sharing feelings etc, motivating by partner 93	Try to make sense of disease including try to be realistic and accept of loss of sexual desire due to disease and other impact of disease 15
Finding different ways to deal with disease such as using own strength to cope; avoid stress; alert during taking bath to avoid fall slip; rest to manage tiredness; take rest intervals during household work as to deal with pain and tiredness 12	Different ways to do shopping such as asked help by others; use trolley shopping; carrying shoppers in arms as managing; use backpack to hold things; use bags with wider shoulder strap during shopping; use bags to hold things to forearm for shopping; try to divide task to reduce pain; try to do things one at one day; use gloves to hold trolley for shopping; lean on trolley to feel relax; use hand bags and hang on trolley 14	Seeking meaning from religion; getting source of meaning to work in charity; getting source of meaning from grand children; try to find out new goals ; getting internal support from being Christian and religion values of love to friends and family 9		
Getting help by pension for financial issues 4	Different ways to open jars/bottle cap such as asked help by others; using rubber cap to open bottles;	Gaining satisfaction from beautiful sunrise, enjoying morning; to enjoy nature beauty such as birds, butterflies; take care of animals; through work, partner, live in a nice place 8		
Thinking of Dignitas if	use different ways to use screw up; use ring pull can to open; use little bottle to lift 5		Getting relax by going cinema; going to warm place for holidays 3	
	Use different strategies/resources to manage reflux such as half brick under head and legs; Use extra pillows to control reflux, walk to control reflux, Eat dry biscuit to control reflux; avoid to take large meal before sleeping, change diet, drink water to swallow food, use electric beds; change diet plan	Finding different ways to get		

disease get worse to avoid resuscitated 6 (Participant 5)

and sitting up in bed to control refluxes; sleep in up to control refluxes to manage stomach symptoms 18

Use gloves to keep warm and to deal with Raynaud's when outside home, and during shopping, heating at home, wear warm clothes, move to warm places, use heater to avoid cold, Use gloves, heating pads for hand and foot and wear four layers of dressing, hot bottle; use silver and electric socks, thick woollen socks, sheep skin sleepers; use bigger shoes, camping shoe due to layers of socks; use ski gloves and heated gloves; Keep heating pads and other stuff, getting info about temperature before going holidays, sleeping bags (pro-active) to manage Raynaud's 33

Different ways to manage pain such as pain killer; taking medications; get relax by taking hot bath; get help by warm shower and use hot tub to relief pain; swimming three times a week help to flexibility; Join health club; getting relax by staying at home; use different strategies to manage pain such as memory foam to reduce muscular pain, lay on back, use soft pillows, distraction strategies such as listening music; exercise to deal with sleep problem 22

Different ways to manage the disability such as

courage such as from grandfather and soldiers who were in WW1 and from other who have severe disability and constant pain whole life; Motivated by GOD to alleviate disease; Self motivating through work; getting motivation from grand children; get happy by grand children, warm weather and sunshine and being in good company, courage to know about cure of other disease and making hope for cure; Knowing own power 15

Try to figure out about disease and its consequences through investigations and problems and putting weight due to side effect 12

Use humour to cope with disease such as laugh etc 8

Try to make sense of experience such as

asked help by others; took off from work to take rest; Rehabilitation to splints on hands; use bath chair; renovate home according to disability needs; different ways to get in and out of bath; different twisting ways to get dress up; use socks aids; live in Bungalow as to avoid stairs up; use electric chair to bath; use physical adaptations to drive car such as steering and electric brakes; use long straps to dress up; use socks aids; use stick and scooter to deal with disability; use lift bath; getting financially support from govt; try to divide task to reduce pain; try to do things one at one day; buy stretchy clothes to wear and avoid to use clothes with zip; foot up to tie lace;

Plan to make some raised bed to do gardening; use trolley for shopping; hold bags in forearm; use backbags, and asked help by others 31

Different ways to cope with visible symptoms of disease such as use cream to cover red spots; try cover red spots with make up; dressing like scarf's that covers spot; use nail paint to look nice hand; try to cover red spots on forehead by hair 7

Understand own limitations due to disease 8

Understand values of life and others such as Empathy for others; Learn to values self and life;

Motivating others; help other to focus on positive things; hope for future not much affected by disease; recognise important to health; understanding other with illness; Learn more tolerant for other people; understand life is precious; value life more; guide other not to read on internet; help other to understand disease; encouraging other to have hope20