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'A Nothing Disease?'

An Interpretive Phenomenological exploration of the lived experience of Systemic Lupus Erythematosus (SLE)

by

Frances Lloyd

This thesis is submitted in partial fulfilment of the requirements of the award of Doctor of Philosophy at Oxford Brookes University

Submitted for an examination in December 2014

Abstract

The purpose of this research study has been to gain a deeper understanding of the lived experience of systemic lupus erythematosus from the perspective of the person who has the condition. A qualitative interpretive phenomenological approach was adopted influenced by Heidegger (1962) with emphasis on existential and interpretive dimensions over time. This comprehensive study involved a varied and diverse sample of thirty-two participants to allow differing experiences and multiple voices to be heard.

The main data collection method was multiple, unstructured interviews. The participants also used a variety of other methods of their own choice including journals, art, music and photography to express 'what lupus means to you?' An integrated approach was used combining both the media of the participant's choice, with an in-depth unstructured interview discussing their media. These varied data collection methods allowed valuable insights into the participant's everyday world. The study used Wertz's (1983) method of analysis.

Three main findings were identified including, self-doubt and doubt, entrapment and coping and regaining resilience. Self-doubt and doubt explores the participant's ongoing uncertainty about their symptoms, embodiment and condition and the continual doubts which they experience from others regarding the reality of their illness experience.

Entrapment explores the many constraints and barriers that the participants experience in everyday life including the disease itself which enforces loss of control, continual change and disruption, challenges to self identity and integrity, relationships with others and themselves in terms of existential possibilities and goals. There were

also a multitude of constraints and barriers imposed on the participants from health services and organisations. All these experiences engender the feeling of a 'nothing disease', a feeling of losing themselves.

Coping and regaining resilience explored the wealth of coping strategies used within the participant's everyday life and the ways they had been able to overcome adversity and find ways of moving forward regaining resilience.

The study has identified multiple things which negatively impact upon those living with lupus, as well as positively impacts on a person's ability to live and cope in everyday life. This opens up possible ways for reducing these constraints and that would have a positive impact on the person living with SLE.

These constraints indicate some of the priorities health services and organisations should be focusing on to assist those with lupus to regain a more homelike being-in-the-world. The findings have real implications for the development of health care delivery which is person centred, designed around real needs and enables an improved quality of life. This study has been a further important step towards gaining an in-depth understanding of the everyday being-in-the-world of SLE.

Contents

Figures

Acknowledgements

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1.0 Chapter 1 - Introduction

Prologue: -

'*One time he said you never know a man*
until you stand in his shoes and walk
around in them'

(Lee 1960: 308)

This study is orientated towards the understanding and interpretation of the human experience of day to day living with systemic lupus erythematosus (SLE) and will follow a qualitative research design. An interpretive phenomenological approach was employed.

Lupus is little known and is often physically invisible. It has a complex origin which is difficult for patients and families to understand and its existence is often doubted, and neglected by care agencies, benefit and social services.

Amy a participant in this study expressed, "It is a nothing complaint".

"The thing with lupus, it's a nothing complaint......nobody's heard of it, nobody understands it and nobody's interested and people think I'm just making a fuss over nothing ... because they think it's a few aches and pains, but, it's so much more than that, lupus has affected my whole body... and my whole life. So on top of everything else, lupus has given me a disease which nobody recognises, it is a nothing disease, and I can't even get the help I need" (Pg 12, 235-241 T3).

This study aims to give patients a louder voice by attempting to reveal a glimpse of the lived experience of lupus. This knowledge should

add to the overall understanding of this disease by health care clinicians and possibly lead to service changes.

This chapter will give a general introduction into SLE, to allow insight into the aetiology, concepts and history of the disease. Then, the process of forming the research questions is described, followed by initial literature; methodology and current NHS care policy review.

1.1 Aetiology

Lupus is a challenging, complex disease affecting many individuals and their families. Yet, the chances are that if the proverbial man on the Clapham Omnibus heard the word lupus for the first time, his reaction would be "what?" If enlightened further, bafflement would ensue.

The incidence of lupus (SLE) within the United Kingdom (1994) was 7.89 per 100,000 for females, and 1.53 per 100,000 for males. The overall female to male ratio was 5.2:1 (Somers et al 2007). Lupus UK (2009) reported that it is believed that 50,000 people suffer with SLE in the UK, with ninety per cent being female. Worldwide, it would appear to be more common than leukaemia, multiple sclerosis and muscular dystrophy (Hughes 2000). In Europe and America, it is more common in women whose origin is Afro-Caribbean, Chinese and Asian (Arthritis Research Council 2004). Lupus predominantly affects young women during their childbearing years (McElhone et al 2010) affecting multiple facets of a patient's health, leading to a poor quality of life (Jolly et al 2010).

Technically, lupus in known as systemic lupus erythematosus (SLE) where systemic refers to, tissues anywhere in the body being potentially affected. If only the skin is implicated, the condition is

known as discoid lupus. When internal organs are involved, it is known as SLE.

The condition is complex and problematic involving many medical disciplines. It is chronic, there being no known cure and alleviation involves the use of potent drugs with possible problematic side effects. The cause may be a combination of factors such as heredity predisposition, environment, viral infection and hormones (Hughes 1994). It is an autoimmune disease where the immune system is abnormally stimulated and fails to distinguish adequately between self and other. Hughes (2000) discussed that those with SLE have a death rate three times that of the general population, while Jacobsen et al (1999) reported a 4.6-fold higher mortality rate compared to the general population. However, active research on SLE over the last decade has contributed to an improved prognosis and higher survival rates with more patients living into old age. Concurrently increased SLE patient survival rates have resulted in increases in the incidence of SLE related disabilities and quality of life issues (Hochberg and Sutton 1988).

The more common symptoms are fatigue, pain, arthritis, cardiovascular disease, nephritis, weight loss, hair loss, rashes, fever, and blood clotting difficulties, psychosis, sun sensitivity and pulmonary involvement. Lupus plays the cruel trick on those with it, often looking fit and well, while feeling very ill. This escalates further the lack of recognition of their condition and their feelings of isolation. Lupus may also make childbearing impossible or difficult. Lupus follows a fluctuating course being unpredictable, remitting and relapsing.

To live with lupus means interpreting on an almost daily basis an array of symptoms, and having to live with an unreliable body. It provides

3

many severe challenges to those diagnosed with it and also to health professionals. For the lupus criteria please refer to Appendix.1

Lupus is an autoimmune disease. A disease can be defined as an illness with a prolonged duration, which hardly ever resolves spontaneously and is rarely cured completely. It is complex and varied in terms of its nature, how it is caused and the extent to which it impacts on the community (Australian Institute of Health and Welfare 2012). Due to its nature lupus is a chronic condition with 'health problems that require ongoing management over a period of years or decades' (World Health Organisation 2002:11) and is a long term condition, 'that cannot, at present, be cured, but can be controlled by medication and other therapies' (DH 2008:10). Corbin and Strauss (1991) described chronic illness as long term and being a combination of having to control symptoms; live with a disability and adapt to psychological and social changes. The illness will be progressive and take varying courses, having daily effects on individuals and families. In addition, one or more of the following are present at diagnosis or during the trajectory 1) limitation of function 2) disfigurement 3) dependency on medication 4) medical care above normal need for ongoing health (Coffey 2006).

1.1.2 Diagnostic Difficulties

Isenberg (2010:8) a rheumatologist involved with the diagnosis of lupus wrote this caveat for his fellow practitioners:

'Assume nothing and anticipate anything'

The inconsistency and many manifestations of lupus make it a very difficult disease to diagnose. Although every case of lupus is different, there is one common link, the immune system. SLE develops when

the body becomes allergic to itself. The immune system overacts and too many antibodies are produced, which are directed against the body tissues. Any part of the body can be affected.

In approaching diagnosis, the individual must firstly show clinical evidence of a multisystem disease. The second diagnostic tool is to investigate the functioning of the cells of the immune system. The American College of Rheumatology (ACR) have reached a consensus of criteria for defining SLE. This list was last revised in 1997. It consists of those symptoms which are statistically important and so many other features within the patient pool are rejected.

ACR (1997) Criteria for the Classification of Systemic Lupus Erythematosus (Hochberg 1997)

A person is said to have SLE if four of the eleven criteria are present at any time.

1.1.3 Skin Criteria:
1. Butterfly rash (lupus rash over the cheeks and nose)
2. Discoid rash (a thick, disc-like rash that scars, usually on sun exposed areas)
3. Sun sensitivity (rash after being exposed to ultraviolet A and B light)
4. Oral ulcerations (recurrent sores in the mouth or nose)

1.1.4 Systemic Criteria
5. Arthritis (inflammation of two peripheral joints with tenderness, swelling or fluid)
6. Serositis (inflammation of the lining of the lung or the heart)
7. Kidney disorder (protein in urine sample or abnormal sediment in urine seen under the microscope)

8. Neurological disorder (seizures or psychosis with no other explanation)

1.1.5 Laboratory Criteria

9. Blood abnormalities (haemolytic anaemia, low white blood cell count, low platelet count)
10. Immunologic disorder (blood testing to determine specific antibodies , lupus; anti-DNA, antiphospholipid)
11. Positive antinuclear antibody (ANA) blood test

It must be emphasised that these are the criteria for systemic lupus erythematosus, which is at the centre of this study. There are other less severe forms of lupus, which will not come within the remit of this investigation. To complete diagnosis, the symptoms recede and recur. Often sufferers look well and lupus can mimic other diseases such as multiple sclerosis and rheumatoid arthritis (Hughes 2000).

In the early stage, laboratory tests may be inaccurate not confirming other diagnostic features. Because of these false-negative tests, diagnosis is never made on the laboratory tests alone. Currently, the ACR Criteria are the best accepted guidelines for diagnosis, but they do not go unchallenged. Some rheumatologists feel that they are insufficiently comprehensive; others question the inclusion of some criteria (Philips 2001). Revisions of the list are certain in the future.

A diagnosis should be made after detailed consideration of personal medical history, family medical history, physical examinations and laboratory test results. It is no wonder that diagnosis is often very difficult and lengthy. With an astute rheumatologist, it may be fairly quick, but there have been cases where diagnosis has taken ten years or longer. Some patients are never diagnosed (Lahita and Phillips 1998). Sufferers can find themselves in a diagnostic limbo.

Their bodies are obviously ill but they are unable to discover the cause. Even though lupus patients can have different signs and symptoms and nothing is common but the diagnosis, the majority share incredible exhaustion (Lahita 2004).

Lupus is primarily a women's disease. Often women are loathed to present their symptoms, which may sound neurotic. Also, there is a general lack of awareness of the disease, as it does not capture media attention. On diagnosis, the first reaction may be shock and disbelief as many patients are ignorant of the disease. Even today, patients read or hear that lupus is invariably a fatal disease and become acutely anxious. Once diagnosed lupus is a companion for life and a hard journey is ahead. Many demands will be made on the patient and their family. There may be adverse reactions from society. The sufferer must endure close medical scrutiny and acquire knowledge of the disease, the medical treatment, the therapy and most importantly themselves.

There is a concept held that SLE is more than one illness (Hughes 2000, Isenberg 2010). This is based on the waxing and waning of the disease, the elusive trigger which starts the disease and the differential selection of organs. It may be a series of illnesses, all with the basis of an autoimmune response.

To increase their confusion and feelings of otherness, these newly diagnosed patients have to contend with entrenched concepts which somehow involved autoimmunity, butterflies and wolves. It is not uncommon for those diagnosed with a disease to refer to for example their 'heart trouble' or their 'ear trouble'. When informed that their complaint originates in their immune system, the situation is not so definitive. People may or may not be able to give proper names to the numerous components of the immune system. Commonly, ideas will

have been gleaned from media or perhaps school lessons. Research carried out by Martin (1994) concluded that media coverage of the immune system does not encompass successfully the actual body process. The dominant media message would seem to be one of warfare which is unhelpful to patients.

1.2 History of Immunity

The metaphors used are to fight, battle, beat, enemy and conflicts. There effect is to create perturbing perceptions, with inferences of blame on the patient. Often the picture conveyed shows a defended state (the body) with a well-defined boundary between the body and the outside world. Therefore, the crux of the immune system must be its ability to distinguish 'self' from non-self'. With this idea, those patients diagnosed with an autoimmunity disease face a depressingly negative impression. Often, they interpret autoimmunity as the distinction between 'self' and 'nonself', no longer functioning. Their image extends to 'mutiny, self destruction and civil war' (Root-Bernstein 1993:87) which engenders feelings of self blame.

1.3 Confusing Entrenched Concepts

Napier (2003: 82) classified lupus as a 'socially meaningless disorder', meaning that patients are unable to use familiar cultural models of disease to give meaning to their illness which would enable them to make some sense of lupus. Napier (2003: 87) extends his concept to state, that this lack of social meaning leads to 'genuine existential doubt about the meaning of self'.

Yet, those newly diagnosed cannot fail to notice the multiple references in clinic posters, literature and web pages, to butterflies and the more sinister wolves. Their confusion is reinforced by having

8

a disease named after the Latin for wolf and with one atypically associated with animal symbols.   These symbols have historical origins which seem to persist. Facial lesions were supposed to resemble the bite of a wolf or the shape of a butterfly. Alternative meanings are now being projected; the butterfly a symbol of hope and the wolf a challenge to overcome this disease.   But, the older entrenched concepts linger and serve to increase the confusion and loneliness of patients.

1.4 History of lupus

No two people with lupus present the same variation of symptoms and during their lives, manifestations will change day by day and year by year. With a disease of such protean nature, it is not surprising that the identification of SLE has spanned centuries.

As well as everything the patient suffers, there is the added indignity of having a disease called lupus. This is the Latin name for wolf. Hippocrates may have been the first physician to describe the rash, which makes such a distinctive pattern over the nose and cheeks (Lahita 1987). It is a mystery why this name is used. Various suggestions have been given; the face appears to have been attacked by a wolf, and sometimes serious rashes destroy facial tissue which appears to be like an attack by a wolf (Lockshin 1991).   In the thirteenth century, Rogenius describes facial lesions, which he named 'lupus', using the then, medieval Latin word for ulcerated (Smith and Cyr 1988).

In 1828, a French doctor Pierre Casenave published the teachings of his tutor Laurent-Theodore Brett, who first applied the name lupus erythematosus.   This contained the Ancient Greek word for red, and literally means red rash (Wallace 2000).

Observations move from descriptions of external symptoms to widespread systemic signs. Maritz Kaposi of Vienna University, published articles in 1873, describing more severe symptoms associated with the rash (Lahita 1987). In 1895, William Osler (Chief of Medicine at John Hopkins Hospital) realised that individuals with lupus erythematosus had a disease involving the central nervous system, musculoskeletal, pulmonary and cardiac systems. He defined the condition chronic, with a relapse-remit pattern, and coined the term systemic (Lahita 1987).

For many years, the medical community were baffled by this unpredictable and atypical disease. Were all these different symptoms caused by a common factor? Other identifiable diseases had clear-cut symptoms and were infections. The concept of autoimmunity was difficult to envisage and hampered by medical disbelief. It was thought impossible. In the 1900's, Paul Ehrlich doubted that the immune system would permit 'anti-self' action. His view was so strongly held that early signs of autoimmunity diseases were largely ignored (Talbott 2002). During the 1920's and the 1930's, details were discovered of how lupus affected kidney, heart and lungs through the stalwart work accomplished by a dedicated number of pathologists.

Not until 1941, did Dr Paul Klemperer (Mount Sinai Hospital New York) propose on the basis of numerous post-mortem studies that lupus was a collagen disease. This term remained in use for fifty years (Lahita 1987). It is now known that this name could be misleading, but, at the time, it was a step forward in the evolution of the classification of lupus as an autoimmune disorder based on antibodies.

In 1945, Cambridge scientist Robin Coombs developed reliable techniques to detect antibodies to red blood cells. These

autoantibodies gained recognition (Lockshin 1991). From then on, rapid advances were made. Malcolm Hargraves (at the Mayo Clinic) observed atypical while blood cells, first in bone marrow, and then in the blood of lupus sufferers. Here was a more accurate test for diagnosis. These cells became known as L.E. cells (Lupus erythematosus). They represented a systemic inflammation.

A colleague Dr Philip Hench demonstrated in 1949, that a newly discovered hormone, cortisone, could bring about dramatic improvements in SLE patients (Isenberg and Morrow 1995). Otherwise, only aspirin and skin salves had been available until in 1890, Thomas Payne of St Thomas Hospital recognises for the first time that anti-malarial drugs could moderate the pain and fatigue of lupus.

In the 1950's and 1960's other tests for autoantibodies were being developed, the major one being an antibody specifically working against the body's D.N.A (deoxyribonucleic acid). This anti-nuclear antibody (ANA) leads to accurate detection of lupus.

Pregnancy for lupus sufferers had been risky, because of the development of artery and vein thrombosis, strokes and miscarriages, and in 1983 Dr Hughes of St Thomas Hospital identified an antiphospholipid antibody responsible for these complications. Treatment was devised to counteract this antibody.

Research into autoimmune diseases is by its nature highly complex. The number of studies on this disease is large and concentrates on four main areas; the dysfunction of the immune system; the complex genetics involved, the study of hormonal influences and environmental factors.

1.5 Personal experience and the forming of the research questions

The forming of the research question and aims is 'to discover a passionate concern that calls out to the researcher' (Moustakas 1990: 27).   Yet, in the formulation of these questions, it is important to understand the context in which they were conceptualised; the motivations that lie behind them and the beliefs around the questions being asked.   As van Manen (1990:1) relates 'the questions themselves and the way one understands the questions are the important starting points, not the method as such'. The following discussion will explore my interest within this area, motivations, conceptualisation of the study and how the aims came to fruition.

My innate curiosity was aroused in 2002 when I was introduced into an unfamiliar world on being diagnosed with SLE.   My life changed completely and I was now viewed as a patient and had become reliant on others. My familiar world was foreign. It was one of medical treatments, pain and the dawning realisation that part of who I was, had now vanished. Through the numerous long visits and stays in a London hospital, there was ample time to listen, talk, interact, question and observe others with this lived experience.   Although I inhabited this unfamiliar terrain, my curiosity was aroused by these absorbing, intimate and private stories where the often repeated maxim was 'nobody understands'.   Feeling free to talk within the confines of the clinic, their words flowed freely. Then, their hidden life worlds began to be revealed. Each opened up their own realities; how they felt, thought and perceived lupus. This strange bewildering, multidimensional lived experience affected every part of their existence, yet it was buried, unknown save to them. It was an experience that seemed misconstrued with little understanding.

After years of experience as an occupational therapist, it was second nature for me to bring to bear my holistic training into my thoughts and observations. It was difficult to reconcile the discrepancy between the medical treatments available at the clinic, important as this was, with these day to day life worlds. Each of us was waiting for a review of our medication which might control some symptoms. This was the entirety of treatment for most. Many questions sprang to mind; how aware were the clinicians of the 'other worlds' in which these patients existed? And should not these lived experiences be a major contribution to a more 'joined-up' interdisciplinary disease decision management?

The impetus for this research study stems from these encounters and my own experience of living with SLE. This immersion and study conception was not a spontaneous process, but a slow porous uptake, allowing time to dwell, reflect and contemplate. My recollections of those times revolve around the intense descriptions and stories; my felt sense of the other; observations and a deep interest to discover and understand more. In an endeavour to understand further, I undertook a preliminary literature search.

1.6 Initial Preliminary literature search

At the onset of this study a preliminary search on current qualitative literature in lupus was undertaken to ascertain justification for the research. At some stage within any research study there is a need to review the evidence and carry out a full literature search. Whether this proceeds or follows the data collection and preliminary analysis depends upon the methodology being used. Interpretive phenomenology advocates a full literature search is not undertaken until all data has been collected and data analysis has finished, maintaining that it is not advisable for the researcher to have ideas

shaped too much by others in advance (Schwandt 1997, van Manen 1990).

A very basic literature search was employed to establish whether any similar research had already been undertaken to justify the need for the current research and to identify gaps in the evidence, and how the topic has already been framed. Using the keywords lupus/SLE, phenomenology and lived experience and the databases CINAHL, Medline, PsycINFO, and dissertation abstract, six research studies were identified. Two research studies could not be obtained and, therefore, four of the research studies will be discussed following the outline of CASP (Critical Appraisal Skills Programme).

The first two studies were carried out by the same research team from the Rheumatology Department at Dudley, University of Birmingham, Lupus UK, and the University of Auckland New Zealand. The first study was entitled 'Concealing the evidence' (Hale et al 2006), the importance of appearance concerns for patients with systemic lupus erythematosus. The goal of the study was to explore the psychosocial concerns caused by changed physical appearance, with the stated importance in the developing understanding of SLE essential to providing patient-centred, healthcare services. Semi-structured interviews were carried out with 10 females aged between 26-68 years, who had been diagnosed with SLE from one to twelve years.

Data was analysed using Interpretative Phenomenological Analysis (IPA), and the study briefly explains IPA. This approach seeks to describe and provide understanding of people's experience of a phenomenon by studying in-depth a small number from a relatively homogeneous group (that is women with SLE in this study). Interpretative phenomenological analysis (IPA) is a qualitative methodology with considerable potential for research in therapy

related settings. In this study, IPA was used to obtain individual in-depth accounts of patient's experiences and understanding, which are interpreted in light of existing literature within the field. The study does not describe if alternative methodologies were considered, although IPA is appropriate for the goal of this study.

Recruitment of participants is explored with a detailed explanation of the selection. Ten female participants diagnosed with SLE were randomly selected (five each) from two clinics. All the participants chosen to be in the study were provided with information sheets. Semi-structured Interviews were conducted, using a guide by one researcher and lasted between one and two hours. This was justified as stating that this was in line with the IPA methodology. Interviews were audio-recorded, and field notes taken. Data saturation was discussed as not being a prominent feature of IPA and reflexivity was not discussed. Ethical issues were mentioned in relation to obtaining approval.

Analysis is discussed in some detail. Date was analysed using an idiographic approach primarily by the first author. Analysis was discussed among the authors who corroborated the thematic descriptive and interpretative elements of the analysis. After analysis, participants confirmed the thematic interpretations. Although the method is not explained in depth, there are examples of the data to support the findings, but not how these were selected. The researcher's role is not explored which would have been interesting as the researcher specialised in Rheumatology.

Analysis revealed three themes concerning appearance issues. The participants described public self-consciousness after the onset of SLE; cosmetics and clothing were used skilfully to appear 'normal' and to hide the 'self' and assert control but could increase feelings of

difference and isolation; and self-imposed isolation was also described and may relate to depression.

The understanding of family, friends, colleagues and healthcare providers was important. The findings are explicit, with a lengthy discussion, relating back to the goal of the study, current literature and future thoughts for health care teams. The awareness of the psychosocial concerns of SLE patients with life-changing skin disease may enable multidisciplinary healthcare teams to offer a more sensitive practical service. The physical and emotional needs of SLE patients need to be ascertained and appropriate educational and psychological services are required. The research is valuable as it highlights the limited medical care available; the importance of education regarding SLE and the necessity to learn to self-manage the condition. Caution is mentioned regarding the transferring of results to other populations with SLE particularly cultures and geographical areas. The study also discusses future research, with larger studies to allow theory generation.

The second study by Hale et al (2006) is entitled 'Joining the dots' for patients with systemic lupus erythematosus: personal perspectives of health care from a qualitative study. This study discusses the patient education and healthcare interactions that were forthcoming from a previous study (Hale et al 2006). The aim of the study was the examination of the perceptions of patients with SLE regarding their healthcare provision in the UK. The study was important as healthcare teams need to be aware of the continuing biopsychosocial impact of SLE to improve communication and minimise SLE patient's isolation. Whether at the time of the first study the aim of this second study was explored with participants was not discussed. Again IPA (Interpretative phenomenological analysis) was used and there was no discussion as to the justification of using this method. In both

studies the same participants and methods of recruitment were employed.

The results included four recurring themes; diagnostic difficulties; nobody can understand; are they really listening; and joining the dots. These themes were related to the literature. Some very specific findings were discovered with reference to local healthcare facilities including; interdisciplinary teams should be formed, and all services need to have open communication from primary up to tertiary care. This study does provide a valuable first step towards understanding health interaction issues and concurs with other research.

The third study to be discussed is by Jones (2003) entitled 'depression and anxiety in patients with systemic lupus erythematosus'. This MSc study from the University of Alaska Anchorage aimed to develop an understanding of the experience of depression and anxiety in SLE patients. The researcher discussed the importance of the study and how this increased understanding may contribute to more effective assessment and intervention for SLE patients and as a consequence, lead to a better quality of life.

A qualitative methodology was chosen as the researcher was attempting to gain knowledge and understanding from the perspective of the patient. The study reported that it was using a phenomenological interpretative Heideggerian design to explore the lived experience of depression and anxiety in patients with SLE. A short account of the history of phenomenology from Husserl to van Manen was given, but the researcher did not discuss the reasoning behind why the research methodology by van Manen (1990) was chosen.

Participants were volunteers from the lupus foundation of Alaska and had all experienced depression and anxiety since diagnosis of SLE. Eight women were selected between the ages of 45-68 years and they were all taking anti-depressant medication.

Data was collected by an interview with each participant, lasting one hour to one and a half hours, and the participant decided on the setting for the interview. Interviews were audio-taped and transcribed, and each participant could review their transcript. An interview guide was used to ensure that the same area of inquiry was covered in each interview, but this was open-ended to allow flexibility. No modifications or saturation point were mentioned.

The researcher was a nurse and expressed maintaining awareness of personal bias and preconceptions, but reflexivity was not discussed. The only account of the researcher's response to the events during the study was their exposure to compassion fatigue as a result of the emotional experience of interviewing and the interview material. The researcher did not critically examine their role and bias.

Ethical issues had been taken into consideration and approval had been obtained from the University of Alaska and Alaska lupus foundation. Each participant was given information, and informed of the strict confidentiality. The study did not discuss the special ethical issues involved relating to mental health research.

Data analysis was in two phases; firstly demographic information was tabulated, and secondly the use of a hermeneutic phenomenological approach. There was an in-depth description of thematic analysis with themes clearly derived from sufficient data.   Seven themes were found; it's a black, depressing disease; it just felt like my life was over; I should be able to do that; I never really had problems with anxiety,

until I got sick; I don't do things that I want to do; I feel like they are getting short changed, and what was going to happen to me.

Findings clearly emerged and are discussed with reference to the research question. The researcher gave no explanation of how data was selected from the original sample and no contradictory data was taken into account. Credibility was discussed, and reference was made to an audit trail, (although this was not shown) communication with the thesis committee, and participant validation.

Seven recommendations were made for future research on depression and anxiety in patients with SLE. These include social support in managing anxiety and depression in SLE; coping and adaptation skills; assessing the grieving process and studies involving culturally diverse individuals. Also, the study makes recommendations in nursing practice and support for patients and families.

This study does supply some interesting findings and insights into the patient's experience of SLE. The researcher does state which school of thought they are following, namely van Manen's (1990) hermeneutic phenomenological method but does not supply any detail regarding the philosophy, background or method.

The fourth study, Rennegarbe (2002) explores the lived experience of rural women with systemic lupus erythematosus. This PhD thesis is from Southern Illinois University. The purpose for this study is stated clearly as an exploratory study to describe lived experiences of rural women with SLE. The goal was to gain a greater understanding of methods used by this population and explain and define rural women's chronic disease response. Two research questions guided the study namely; what are the underlying themes that account for the lived experiences and the socio-demographics characteristics of the

participants. The purpose of the study was to provide information for health care providers in assisting those with SLE in controlling their disease.

A qualitative methodology was used and was described as an exploratory qualitative approach. The researcher relates that a combination of a phenomenological and life history approach was used; however, there was no discussion of the research design, philosophies or type of qualitative methodology. The selection of participants is described in detail, both for the pilot and primary study. Twenty participants were selected via the researcher, other health professionals, and some of the participants using a snowball sampling approach. The criteria for selection were females who had SLE, residence in rural areas and had phone contact. Initial contact was made by phone when study objectives were described. This was followed by written information. A detailed socio-demographic analysis of the population was given. As females in rural areas were being studied, it was justified to use the telephone to interview and collect data.

Semi-structured questionnaires were used with some open-ended questions. A literature review and pilot study with eight participants was used, to modify the questionnaire. The pilot study results were also included in the final data analysis. The participants had one interview on the phone which lasted between 30-45 minutes, and this was audio-taped. The researcher transcribed the tapes. The researcher reports that data saturation occurred after 17 individual interviews, but does not discuss this any further. The researcher does describe and declare personal involvement, being a rural woman with SLE and a registered nurse. The researcher reported keeping a reflective journal, but again this was only briefly mentioned. She did describe a little about her life with SLE. The study did not discuss

potential bias or influence throughout the study. The research questionnaire was adapted after the pilot study, and a discussion with supervisors, which resulted in changes to the order of questions and some wording.

Details and ethical issues were clearly explained to the participants, and an ethics committee did not seem applicable. There was no follow-up of the effects of the study on the participants. There is an in-depth description of the analysis using thematic coding, with sufficient data. The phenomenological analysis was confusing as the researcher appeared to be focusing on unearthing the plot, and patterns of experience. Based on the review of the literature and pilot study, seven domains were used to examine lived experience of the research participants. A total of 21 themes were identified for the seven domains, which were supported by quotes. These included; the concept of lupus, such as physical and psychosocial, response to diagnosis, such as moments of uncertainty, frustration followed by relief, and moments of fear; perceptions of cause, such as hereditary, hormonal; triggers of lupus, such as clinical and modifiable factors; control of lupus, such as physical, psychosocial challenges; life adjustments and learning to manage; support, such as who is supportive, what is considered support, support groups, and computers. Contradictory data was not mentioned, nor criticism or discussion of the researchers role and bias.

There is an adequate discussion of the findings. The researcher does discuss triangulation, credibility, peer examination, dependability and transferability, but does not say how precisely they carried this out or achieved this. The researcher does discuss the contribution that this study can make to existing knowledge, such as the importance for health educators to have a general understanding of a chronic disease such as lupus; the psychosocial issues of isolation particularly

on rural women with the condition and the need for more information. A number of recommendations are made regarding future research; these include a follow up from this study; the need for more in-depth research on SLE; support systems and the internet as a source of information and support.

This study is interesting as it does discuss real issues and insights into patients with SLE in rural areas in America. It reports to be phenomenological, yet only mentions phenomenology in passing and does not say anything about it or show any evidence of this in the methodology.

The studies by Rennegarbe (2002) and Jones's (2003) could come under the heading of 'new' phenomenology, described by Crotty (1996) as a hybrid phenomenology which is embraced by nurses particularly in North America. Crotty (1996) has argued that new phenomenology is descriptive, subjective and lacks critique as the emphasis is focused on experience and not the original intentions of phenomenology which seeks the essence of the phenomenon. New phenomenology focuses on experiences described by people who have lived them. The questions do not seek the pre-reflective experience but include thoughts and interpretations of the experience. If the researcher wants a subjective understanding of the experience from the participant, new phenomenology is appropriate. Much of the nursing research based on new phenomenology has a concern to understand the human condition rather than the phenomena as such and this in itself can increase the knowledge base of health professions.

1.7 The Aim for this study

The main aim for the study is to explore the question 'what is it like to live with SLE?'

The specific objectives are:

(1) To provide an understanding of the lived experience of SLE from the perspective of the person who has the condition

(2) To describe the everyday life world of SLE, employing the phenomenological existential of spatiality (lived space), corporeality (lived body), temporality (lived time) and relationality (lived human relation).

(3) To employ reflexivity throughout the research study to allow for a rigorously grounded theory of the lived experience of SLE

(4) To discover findings from this study which may assist in making evidence-based recommendations to improve services and change health care delivery

1.7.1 Selection of Methodology

The research paradigm chosen for this study is a qualitative, phenomenological design. Denzin and Lincoln (2000) discuss how a research paradigm is a set of beliefs that guide the action.   A number of authors have tried to capture the essence of qualitative research. One meaning apposite to this study is given by Bryman (1998) who describes it as a naturalistic, interpretive approach concerned with understanding the meanings which people attach to phenomena. Qualitative research is valuable in exploring views and concerns, beliefs and attitudes (Miller 2004). It allows the researcher to understand the perspectives of the patients themselves, rather than from an outsider's perspective (Chan and Spencer 2004b). Cresswell (1998) describes qualitative research as the formation of a holistic,

complex picture in words to understand a social or human problem. Applicable characteristics of qualitative research are; exploratory and descriptive focuses; collection of data in natural settings; emerging design; human as the instrument and immediate and on-going analysis. Qualitative research is dependent on using the most appropriate approach.

The most salient question in deciding which is the preferred qualitative approach to be chosen is, does this study want to discover the shared lived experience of one quality or phenomenon in others? An affirmative points the direction towards phenomenology.

Interest in qualitative research has grown as researchers have sought to capture individual experience. As far back as 1975, Strauss and Glaser (1975) used grounded theory methodology to revolutionise research into chronic illness. Emphasis was placed on social and psychological aspects in contrast to the predominance of empirical and analytic research (Lubkin 1999). There is large body of research into chronic disease which tends to fall into two categories. There are those studies which are specific to one disease and there are those which investigate a particular aspect across a number of chronic conditions.

Personal narrative phenomenology has been employed to study the lived experiences of spouses of chronically ill (Eriksson and Svedlund 2006); lived experience of dialysis-dependency (Martin-McDonald 2003); and the 'lived-experience' from women with systemic lupus erythematosus (de Barros et al 2012). Lived experiences have been gathered using Heideggerian hermeneutics, chronic pain and fibromyalgia (Ranhein and Haland 2006), waiting for a liver transplant (Brown et al 2006), experiences of close relatives of chronically ill (Ohman and Soderberg 2004). With regard to the plethora of

research, Finlay (1999) warns that the complexity of ideas embedded within phenomenology is challenging and can lead to confusions in its application.

1.7.2 Proposals from the National Health System regarding long term conditions

Over past years, the ethos of government publications has been to create a patient-led NHS (DH 1997, 1998a, 1998b, 1999). The New NHS: Modern, Dependable (DH 1997: 8.5v) stated that this could be brought about 'through measuring the way in which patients and carers view the quality of treatment and care that they receive'. This wealth of lay knowledge was central to NHS strategy (DH 2004). However, there are limitations in obtaining the opinions of patients (McIver 1993) and limited evidence that patients' impact on improving care (Guaspari 1998).

After reports of people with long-term conditions being dissatisfied with NHS services (DH 2003) the Expert Patients Programme (EPP) was launched (DH 2004, 2005). Delivered by trainers and volunteers, the idea is that patients are given the skills and knowledge to manage their own condition. However, the Healthcare Commission (DH 2004) results indicated that those with chronic conditions actually wanted more input into understanding of their day-to-day lives.

During the last decade, evidence-based practice has become a major concern for health care policy makers. To achieve this is a complex undertaking which involves appraising different sources of evidence, collating this evidence into clinical guidance and then evaluating the change (Muir Gray 1997, 2004). Sackett et al (1996: 72) emphasised the ever changing nature of evidence-based medicine, defining the concept as, 'the conscientious, explicit and judicious use of current

best evidence in making decisions about the care of individual patients'. Liaschenko and Fisher (1999) list three different types of knowledge that make up evidence-based medicine, one being person knowledge. This is an understanding of what living with a particular condition or disease is like. The NHS Modernization Agency (Wilcock et al 2003) is adopting the world of the patient methodology to help include qualitative evidence about the world from the patient's point of view. This may form a base for person-centred practice.

To stay true to the concept of the patient-centred approach, understanding the persons lived experience and everyday world is important. Understanding this can assist in devising interventions based on knowledge that would impact on the everyday world of the patient and achieve an improved quality of life. Programmes can then be tailored around real needs rather than assumed needs which others feel would benefit the patient. Health professionals need to give space to the voice of the everyday life world (Barry et al 2001).

Galvin and Todres (2013), Todres and Holloway (2006) and Todres et al (2007, 2009) present a proposal of a model which could be a foundation for a more humanising, holistic practice. It integrates with existing patient-centred approaches, which may be in danger of succumbing to consumerism. It can provide a deeper philosophical path.

1.8 Anticipated Outcome from the research study

To obtain a glimpse of the participants lived everyday being-in-the-world of SLE and to gain further understanding of their physical, psychological and social needs and difficulties. To gain knowledge of the persons repertoire of coping strategies and to identify shortfalls within supporting services to enhance quality of life.

1.9 The structure of this thesis

Chapter two, the literature review, explores the literature specific to the lived experience of adults with systemic lupus erythematosus. The chapter will discuss the selection criteria, search strategy and the critical appraisal. This chapter will also develop a synthesis of themes explored within the literature to assist in gaining a broader understanding of the literature, but also the experience of those living with SLE.

Chapter three the philosophical perspectives explores my pathway of reasoning to ascertain the most suitable phenomenological approach for this study. The phenomenological paradigm is explored and I discuss my justification for using interpretive phenomenology influenced by Heidegger's (1962) philosophical inquiry 'Being and Time'. The chapter also explores my personal philosophy, experience and reflexivity.

Chapter four the methodology, explores and discusses the methods employed within the research study including recruitment of participants, the sample size, the various data collection methods, the integrated approach combining both a media of the participant's choice with an in-depth interview and the ethical dimensions.

Chapter five the analysis discusses my rationale for the choice of analysis. Wertz's (1983) method of analysis including the preparatory phase, psychological analysis of the individual and the psychological analysis of the general are explored in depth. Two sample analyses are presented to allow the reader an opportunity to follow the procedures and judge the soundness of the conclusion. Criteria for evaluation and reflexivity are also discussed.

Chapter six introduces the findings and discussion chapters six, seven and eight and discusses generally the three themes that emerged, namely, self-doubt and doubt, entrapment and coping and regaining resilience. Chapter six then continues and discusses self-doubt and doubt in depth exploring the participant's ongoing uncertainty about their symptoms, embodiment and illness, pre-diagnosis and diagnosis experiences and the continual doubts they experienced from others regarding the reality of their illness experience, engendered by the perception of lupus being physically, socially, culturally and medically invisible.

Chapter seven, findings and discussion chapter discusses the second theme, entrapment and explores the multiple constraints and barriers the participants experience in everyday life including the disease itself which enforces loss of control, continual change and disruption, challenges to self identity and integrity, relationships with others and themselves in terms of existential possibilities and goals. There were also a multitude of constraints and barriers imposed on the participants from health services, organisations and society's misunderstandings about the condition.

Chapter eight, findings and discussion discusses the third theme, coping and regaining resilience and explores the wealth of coping strategies used within the participant's everyday life and the ways they had been able to overcome adversity and find ways of moving forward regaining resilience. They had sought information and learnt as much as they could and acknowledged their body, listened to its signs and reactions and altering their everyday life accordingly. They established a new and worthwhile relationship with their body and had become experts in their embodied knowledge and understanding.

Chapter nine, a summary of the findings and discussion chapters, discuss some aspects in the findings and discussion chapters and the lupus literature. The chapter will also discuss the strengths and limitations of the study and the disengagement process.

Chapter ten, conclusion, will synthesize the empirical findings to answer the study's research question and will also discuss recommendations and the initial dissemination thoughts and plan.

2.0 Chapter 2 - Literature review

2.1 Introduction:

The main focus of this chapter is to explore the literature specific to the lived experience of adults with systemic lupus erythematosus. The chapter will discuss the selection criteria, search strategy and the critical appraisal. A full overview of each study identified including the focus, research design, sample, method and analysis is presented in Appendix 2 (characteristics of the included studies). This chapter will also develop a synthesis of themes explored within the literature to assist in gaining a broader understanding of the literature, but also the experience of those living with SLE.

Interpretive phenomenology advocates a full literature search is not undertaken until all the data has been collected and data analysis has been finished (Schwandt 1997, Heidegger 1962, van Manen 1990). This is to maintain an open attitude and not be predisposed to interpret certain things about the phenomenon based on other's conclusions. This concept is discussed further within chapter three, the phenomenological paradigm. On completion of the analysis, an extensive and comprehensive literature search was undertaken.

The chapter begins by discussing the selection criteria, search strategy and the assessment of eligibility of studies.

2.1.1 Selection criteria

Inclusion criteria: Studies that explore the lived experience of adults (aged 18 years and over) with SLE. The review primarily focused upon qualitative studies as these can provide a range and depth of understandings about the experiences, perspectives and beliefs of

SLE from the insider's perspective. Mixed method and quantitative studies were included if there was an emphasis on exploring the experience and perspective of adults living with SLE. For example, surveys exploring the insider perspective of interactions with health professionals. All studies were in English, titles and abstracts were examined and if they met the inclusion criteria, primary papers of potently relevant studies were sought and reviewed. The literature review was carried out over a twelve month period.

Exclusion criteria: Studies were rejected if they had a major focus on quantitative methods and did not focus on exploring the experience and perspective of adults living with SLE, or were non-primary research articles (commentaries, reviews, conference abstracts) or were summary reports that did not contain sufficient information to be assessed. Studies were also excluded if the study focused on specific medical aspects of SLE, rather than explore the experience of people diagnosed with SLE. Non English articles were excluded due to lack of resources for translation.

2.1.2 Search strategy

The search strategy was in two parts. The first part of the search for this review employed MEDLINE (1946 to November 2012), Embase (1980 to November 2012), PsycINFO (1946 to November 2012), CINAHL (1982 to November 2012), AMED (1985 to November 2012), BNI (1992 to November 2012), HMIC (1979 to November 2012), and Health Business Elite (1940 to November 2012).

The search strategy terms included, adult, systemic lupus erythematosus/ lupus, research, qualitative, quantitative, mixed methods, phenomenological studies, existential studies, patient, perspective, experience, lived experience, life-world, quality of life,

adaption, psychological, social support, anxiety/depression, emotions, self-esteem, life style, social aspects, family, employment, roles, social adjustment, invisible conditions, fatigue, pain, symptoms, unpredictability, interviews, focus groups and open-ended.

This stage of the search yielded 2561 citations. The search results included: MEDLINE: 837 citations, Embase: 1561 citations, PsycINFO: 69 citations, CINAHL: 72 citations, AMED: 13 citations, BNI: 6 citations, HMIC: 2 citations, and Health Business Elite: 1 citation.

Of these 865 were duplicate articles and 1623 failed to meet the inclusion criteria at title or abstract for reasons including medical aspects related to SLE/ non patient experience/ protocols and clinical guidelines and non-SLE related studies.

The first part of the search strategy yielded 73 potential titles/abstracts. Research articles were sought with the assistance of a local NHS library; 3 articles could not be obtained and were excluded. On further evaluation of the full article, 31 studies were rejected as they failed to meet the inclusion criteria.

Step two of the search strategy aimed to ascertain whether any additional valuable studies had been missed. To achieve this the following sites were employed, the Cochrane Library, Dissertation abstracts, Web of knowledge, Web of Science, Sage publications, Ovid SP, Kings Fund, DH-Data, BMJ, ProQuest and Google-scholar (from 1940 to 2012). The same search strategy was used as in part one.

Even though I had searched the databases which should replace the need to use Google, as a final check to ascertain if I had missed any

obscure or difficult to find research exploring the experience and perspective of adults living with SLE, I searched Google. I used the term lupus/ systemic lupus erythematosus and the lived experience of adults with SLE and experience of adults living with SLE. The web sites of lupus organisations in the UK and abroad such as Lupus America, Canada, organisations and universities involved with SLE, as well as the grey literature including books and articles were also searched.

Step two search yielded a total of 17793 titles/abstracts. The search results included the Cochrane Library: 0 citations, Dissertation abstracts: 12 citations, Web of knowledge: 965 citations, Web of Science: 713 citations, Sage publications: 48 citations, Ovid SP: 31 citations, Kings Fund: 0 citations, DH-Data: 0 citations, BMJ: 4 citations, ProQuest: 47 citations, Google-scholar: (from 1940 to 2012). The Google search yielded 9751 citations and the lupus organisations and grey literature identified a further 9 titles/ abstracts.

Of these 4744 were duplicate articles and 12982 failed to meet the inclusion criteria at title or abstract for reasons including, quantitative methods focusing on medical aspects related to SLE/ non patient experience/ not-SLE related, not-English.

The second part of the search strategy yielded 67 titles/abstracts. From these, 6 articles/thesis could not be obtained and were excluded and a further 58 studies were rejected on full examination of the article as they failed to meet the inclusion criteria.

The reference lists of articles obtained were scrutinized. This yielded a further potential 6 citations, of which 1 article could not be obtained and 4 failed to meet the inclusion criteria. From the two searches a total of 43 studies were identified as meeting the inclusion criteria.

2.1.3. Assessment of eligibility of studies

Assessment of the eligibility of studies throughout this process was difficult and very time consuming. Inclusion and exclusion criteria were refined and clarified throughout this process. It was difficult to classify some research as either qualitative or quantitative because they contained different aspects of both, therefore the inclusion criteria focused on whether the study explored the experience and perspective of adults living with SLE. It was important to keep focused on the inclusion and exclusion criteria.

A full overview of each study identified including the focus, research design, sample, method and analysis is presented in Appendix 2 Characteristics of the included studies.

The next areas the chapter will discuss include the critical appraisal, the development and synthesis of themes explored within the literature and the general impressions regarding the search.

2.2 Critical appraisal and the development of themes.

Appraisal was performed on the included qualitative studies using some of the main elements of the Critical Appraisal Skills Programme (CASP) quality assessment tool for qualitative studies (CASP 2006) and Ryan et al (2007) helped informed the evaluation. The CASP addresses certain criteria such as, is the study context clearly described? Is there evidence of researcher reflexivity? Is the sampling method clearly described and appropriate for the research question? Is the method of data collection clearly described and appropriate to the research question? Is the method of analysis clearly described and appropriate to the research question? Are the claims made

supported by sufficient evidence? That is, did the data provide sufficient depth, detail and richness?

I included all studies that met the inclusion criteria regardless of the study quality (Glenton et al 2013). I used the Critical Appraisal Skills Programme (CASP 2006) to help identify weakness in the study methodologies and this helped to interpret and assess the findings.

Coughlan et al (2007) and Long et al (2002) helped inform the evaluation tool for the identified quantitative research studies. These studies were survey and questionnaire oriented, but had insider perspectives and experiences.

I used the quality assessment when judging the relative contribution of each study to the development of relationships and the identification of key findings and emerging themes across the studies. This was not easy, it was complicated by the various reporting styles and was difficult to identify key themes especially if studies had only described and summarised what the person had said. I tried to synthesise these themes and categories into a framework.

2.2.1. The development of a synthesis of themes explored within the literature.

Five main themes were identified from the literature. I have signposted these to make it easier for the reader. These include:

2.3 Pre-diagnosis and diagnosis experiences

2.4 The experience of interactions with health professionals and medication.

2.5 The experience of the impact of lupus on the person's quality of life. This includes the subthemes, the experience of pain, fatigue, visual changes, psychological and perceived needs.

2.6 The experience of illness representations and beliefs of SLE and the experience of mental representations of lupus and self/ personhood.

2.8 The lived experience of lupus. This includes the subtheme coping and positive consequences of living with lupus.

The funnel approach has assisted me to present the themes under these broad heading (Hofstee 2006). I have tried to put the themes in an order, which helps guide the reader towards the studies closer to this research study. The order may also assist the reader to understand the experience and the literature.

2.2.2 General impressions regarding the search

The majority of studies during the search strategy had a major focus on quantitative methods focusing on specific aspects. Considering the complexity of SLE, it is not surprising that the centre of attention for the research literature is medically orientated involving a variety of specialities. For example: genetics (Piotrowski et al 2012), chemistry (Robak and Robak 2012), epidemiologic and molecular biology (Lee et al 2012), allergy (Kunyakham et al 2012), immunology (Zandman-Goddard et al 2012), gastroenterology, heart and lung, circulation and neuropsychology (Shucard et al 2011), haematologists, nephrologists, transplantation and inflammation (Liu and Zhou 2012), movement, rehabilitation and bone (Costallat et al 2012), neurology, arthritis and rheumatology (Vinet et al 2012, Greco et al 2012, Wolfe and Rasker 2006, Wolfe et al 2009), musculoskeletal, pain (Katsiari et al 2011, Abu-Shakra et al 1999), fatigue (Jump et al 2005, McKinley et al 1995), dermatology and nutrition.

During the search, care had to be taken with the term 'phenomenological studies', as this also identified biological

structures, such as articles on brain scans. The term phenomenology in science can be applied to a body of knowledge relating to empirical observations (Thewlis 1973). The term lupus also identified numerous studies on wolves.

An important aspect of carrying out research is to obtain reliable primary sources which cover the phenomenon under investigation. However, some qualitative studies appear to be elusive to access. An example of this is an American dissertation "The World of the Lupus Patient" (Fernandez 1992). This PhD Thesis was in the library archives at the Centre for Applied Phenomenological Research at The University of Tennessee. The e-mail address for contact with the author was unresponsive. Although attempts were made to gain access to the study through John C Hodges Library Tennessee, sometimes only a personal visit to a university may be necessary, which was not possible.

Sources create their individual criteria for the selection of material to be published and this can include some bias against qualitative research. Paterson et al (2001) give the example of MEDLINE failing for ten years to publish papers from the journal 'Qualitative Health Research'. It is hoped that a representative collection of research, accomplished in the specific field of this research investigation, has been sourced. However, it must be acknowledged that this review is not exhaustive.

The chapter now moves on to explore and discuss the themes within the literature.

2.3. Pre-diagnosis and diagnosis experiences

2.3.1 Pre-diagnosis experiences

So what do we know from the literature about the pre-diagnosis experiences of people who suffer from lupus? Mendelson (2009), Stockl (2007), Hatfield-Timajchy (2007) and Waldron and Brown (2007) have discussed these experiences.

Corbin and Strauss (1985) and Nettleton (2006) referring to chronic illnesses as a whole, discussed how patients can be left for years in a diagnostic limbo. Mendelson (2009:390) called this period before receiving a diagnosis 'the luminal state'.

Mendelson (2009) from a feminist perspective used ethnography, and a narrative approach to explore the gendered nature of diagnosis for females with lupus, using van Gennep's (1960) rite of passage as a conceptual framework. Twenty-three participants were recruited from online lupus listservs and bulletin boards. Participants were requested to provide a narrative in writing of their experiences with lupus. Participants also completed questionnaires and this data was merged with the narrative to create an integrated case study for each participant.

The findings identified limited support, gender bias and stereotypical attitudes towards females by health professionals. Doctors appear to prioritize conditions with a known biological basis and they dismissed symptoms as an overreaction to minor health issues. This resulted in negative perceptions of health professionals.

Rich data can be provided by narrative approaches, but the participants must possess literacy skills, if meaningful descriptions are to be written. Presumably, the sample selection processes identified

such participants, along with the other criteria. Such a sample of unrepresentative participants would give doubt to the validity for making generalisations. The questionnaires used parallel to the stories would provide a foundation giving credence to the stories. The returned stories ranged from 387 to 6,018 words and covered the lifetime of the participants. As such errors can arise with memory and inaccuracies when self-reporting.

Stockl (2007) gave additional explanations for the diagnostic delay. This study used ethnographic observations in combination with grounded theory methods to explore the difficulties of diagnosing SLE from a medical viewpoint and describing the impact this has on patient's lives. Thirty participants participated in one semi-structured interview at a hospital or at home. The author also participated in lupus self-help group meetings and debates on the internet with SLE mailing lists.

The findings found the difficulties encountered when diagnosing a syndrome such as SLE, which has the trait of elusiveness. There is an overabundance of symptoms which do not match diagnostic criteria. An ambiguous diagnosis can lead to existential uncertainty in patients, and this can affect the doctor-patient relationship. The study identified the importance of health professionals learning from the patient and using this experiential knowledge in clinical practice.

The aim of Hatfield-Timajchy (2007) study was to describe the impact of diagnosis delay, treatment options and support group participation. This anthropological cross-sectional study used quantitative and qualitative methods with forty-two participants from Atlanta, Georgia who was in pre-or-post diagnosis. Two participants drawn from the overall sample became case studies. The quantitative element was a structured questionnaire and psychosocial measures. The qualitative

part of the study involved an open-ended interview and observations at support group meetings. The two case studies were interviewed multiple times over six months to one year.

This study identified a number of findings related to diagnostic delays including, the physician's disregard of subjective experience and the participants were subjected to psychosomatic diagnosis before reaching confirmation of lupus, which resulted in a loss of trust in doctors.

The sample included a diverse range of participants with variations in severity of lupus, symptoms and needs. They were required to complete a questionnaire and it would seem that the purpose sampling selected literate participants. The researcher took part in a series of group meetings over a lengthy time span (2000-2004) which allowed data to be collected longitudinally and this provided a rich source of information, with generalisations possible for the particular geographical area. The two case studies provided an in-depth investigation. Throughout the thesis the researcher reflected on their interactions with participants and the development of strong friendships over time. A similar study with male participants would be of great value but a challenge knowing the discrepancy between male and female incidence of SLE.

Waldron and Brown (2007) a qualitative study with 10 participants using one face to face interview and content analysis explored the effects of the long delay in diagnosis on patients.

The study found that those with less severe symptoms experienced prolonged delays. As a consequence of diagnostic delay patients could be extremely unwell by the time of diagnosis, because their condition had deteriorated due to ongoing mismanagement. Patients

had endured many unsatisfactory consultations, treatments and procedures. The study recommended that patients without a diagnosis need to be managed during this time. The relatively low number of participants, with each participant having only one interview makes generalisations difficult.

Similar themes have been acknowledged in the lupus literature by, Waldron et al (2012), Hale et al (2006), de Barros et al (2012), Mattsson et al (2012), Whitehead and Williams (2001), Mendelson (2006), Stamm et al (2007), Goodman (2005), Porter (2000) and Sansom (2010).

2.3.2 Diagnosis experiences

The experience of diagnosis for people with lupus has been explored by Waldron et al (2011), and Waldron et al (2012).

Waldron et al (2011) explored the patients' perspective of receiving a diagnosis of SLE, so as to identify the information needs of those newly diagnosed. The study used grounded theory and the forty-three participants participated in one focus group session. Clinicians assessed disease severity and completed a disease activity index. Transcripts were analysed by thematic inductive analysis.

The findings included two main themes, 'impact of early information', identified how information was scant, difficult to absorb and this left the participants feeling afraid and confused. 'Information received versus information sought', identified that few participants had received clear information and this meant they had to find it elsewhere which could result in distress.

The study identified that at diagnosis information was inadequate and patients wanted detail information. The study did not report any details of their comprehensive literature review for the development of the semi-structured interview schedule.

Waldron et al (2012) used grounded theory with 43 participants and focus groups and thematic inductive analysis. This study explored the patients' perspective of receiving a diagnosis of SLE. The finding identified 'consequences of receiving a diagnosis', which highlights the feelings of relief at finally having a diagnosis. However the manner in which this was delivered was often inappropriate which affected how patients adjusted to future management of their condition.

'Impact on individual lives' explores the feeling of empowerment when symptoms were finally recognised, but the diagnosis of a relatively unknown condition impacted on the support they received from those around them. The study identified that this time is important to how a diagnosis and the response to management is accepted.

Similar themes have been acknowledged in other lupus studies by, Hatfield-Timajchy (2007), Stockl (2007), Waldron and Brown (2007), Mendelson (2006), (2009), Baker and Wiginton (1997), Whitehead and Williams (2001), Jones (2003) and Hale et al (2006).

2.4 The experience of interactions with health professionals and medication

2.4.1 The experience of interactions with health professionals

The experience of health interactions in people living with SLE has been explored by Hale et al (2006), Whitehead and Williams (2001), and Sansom (2010).

Hale et al (2006) used phenomenology with 10 participants, semi-structured interviews and interpretive phenomenological analysis. The study explored patients' perceptions of their health care provision. The findings identified that GP's and health care providers not specialising in lupus had poor knowledge of SLE. Concerns about the level of understanding contributed to the participants feelings of isolation. Communication was a major issue within health care interactions. Participants wanted more information and points of contact. So many different disciplines were involved that the participants were confused as to whom to approach. They wanted integrated healthcare; 'the dots joined up'.

The sample, in this study, was purposefully geographically isolated and small, because the aim was to explore in detail the experiences of participants within a specific area. The findings cannot be generalised across other regions or health care systems. The focus was on females with SLE but the issues may also concern males with SLE and there could be specific differences. A detailed account of interpretive phenomenology analysis was given.

The aim of Whitehead and Williams' (2001) study was to find out if participants with lupus are active partners in the medical management of their disease. This qualitative and quantitative study had 45 participants and used questionnaires.

The findings indicate that few of the participants with lupus are active partners in the medical management of their disease. Indeed most appear to be relatively powerless in relation to the medical profession. All the participants felt it was important they were listened to; yet only (40%) reported that this happened. They wanted to 'be heard', taken seriously and to be involved in decisions, yet, (57.8%) had not been offered any services to help with living with lupus. Doctors could

appear rude, dismissive, patronising and (36.4%) felt interpersonal skills of doctor's was their worst experience. A study comparing male participants' experiences would be interesting, as well as the views from GP's and the medical profession.

Sansom (2010) used a discourse analytic approach to attempt to give voice for a more accountable and responsive lupus management in medicine. The author, who has been diagnosed with lupus, took a critically engaged stance rather than assuming a neutral role. Two positions were adopted, that as 'patient' and as 'participant observer'. Fifteen participants were recruited, and two of these were involved in a pilot study to fine tune the 'research task'. All communications were conducted by post or internet. The participants were asked to write their 'lupus story', either freestyle or following a structured outline, which requested experiences of doctor relationships and management.

The author contributed her story and there were thirteen e-mailed and two hand written stories. The findings indicated significant patient concerns regarding doctor/ patient relationships and a loss of self-empowerment. Participants felt knowledgeable doctors were needed and there was a lack of joined up care. The research concluded that more accountable and responsive lupus management was a priority.

The author adopted a critically engaged stance admitting to a belief of chronic deprivation in lupus management. This could have had a strong influence on the narratives of the participants.

Similar themes have been acknowledged in other lupus studies, Hatfield-Timajchy (2007), Mattsson et al (2012), Porter (2000), Archenholtz et al (1999), Schattner et al (2010), Danoff-Burg and Freidberg (2009), Mendelson (2006), and Baker and Wiginton (1997).

2.4.2 Medication experiences

Medication experiences in people living with SLE have been explored by Chamber et al (2009) and Kumar et al (2011).

Chamber et al (2009) a qualitative study with 31 participants using questionnaires, face to face interview and framework analysis explored the reasons why patients with SLE did or did not take their medication, as prescribed. A purposive sample thirty three participants was selected and each participant was interviewed once.

The findings identified four themes to explain why the participants took their medicines; fear of their condition deteriorating; the belief that there was no alternative treatment; moral obligation; lack of understanding of SLE which discourages regime change. For those who do not take their prescribed drugs; belief that long-term medications are unnecessary; fear of adverse effects, and difficulties in obtaining the medication. Participants reported poor interaction with clinicians, and a lack of information. They expressed a desire to have gainful discussions with their doctors, to obtain a clear rationale for their drug prescriptions.

The research suggested that the patient-clinician communication was vital, in improving drug adherence. Robust methods were used throughout the study. The purpose sampling was of sufficient size to represent a wide range of the characteristics under investigation. The self-reporting of drug adherence may not reflect reality, because of patient's unwillingness to give accurate replies and difficulty in memorising complex drug regimes.

Kumar et al (2011) used qualitative methodology to explore the health beliefs of Asian patients, and the factors that influenced their beliefs

about medicines. Thirty-two participants with SLE or Rheumatoid Arthritis from a UK Hospital, took part in focus groups either in English or Punjabi /or Urdu.

The findings identified that beliefs about the causes of disease and the influence of religious beliefs had an impact on the way patients viewed medicines for SLE and RA. These beliefs appear to impact on the way in which patients participate in managing their disease and adopt behaviours that promote self management. One of the factors which affected the patients' view of the necessity for particular medicines was the difficulties in communication with health professionals. The study did not discuss or give any examples of questions that were asked within the focus groups.

Similar themes have been acknowledged in other lupus studies, Hatfield-Timajchy (2007), Beckerman (2011), Porter (2000), Hale (2006), Mattje and Turato (2006), Mattsson et al (2012), de Barros et al (2012), McElhone et al (2010), Stamm et al (2007), Goodman et al (2005), Auerbach and Beckerman (2011), Danoff-Burg and Freidberg (2009) and Whitehead and Williams (2001).

2.5 The experience of the impact of lupus on the person's quality of life

The experience of the impact of lupus on the person's quality of life includes the subthemes, the experience of pain, fatigue, visual changes, psychological and perceived needs.

2.5.1 The impact of lupus on the person's quality of life

The impact of lupus on the person's quality of life has been explored by McElhone et al (2010), Archenholtz et al (1999), Jolly (2005),

Robinson et al (2010), Pettersson et al (2012), and Stamm et al (2007).

McElhone et al (2010) aimed to identify the impact of living with SLE including 'its treatment and the patient's perceived well-being in physical, mental and social domains of life' (McElhone et al 2010: 1641, Yazdany and Yelin 2010, Ferrans 2005). The studies purpose was to provide data for the development of a SLE disease-specific health related quality of life (HRQOL) questionnaire. Formerly, the generic Medical Outcome Survey (SF36) had been used, but this lacked important SLE domains. The study used an interpretive phenomenological approach with a sample of thirty participants using semi-structured interviews. Each participant was interviewed once for approximately 60-90 minutes at home or at the hospital. A variety of questions were used, to explore prognosis, effects of treatment and aspects of participants' lives that were difficult or enjoyable.

Eleven themes emerged including: prognosis and course of disease, body image, effects of treatment, emotional difficulties, inability to plan, unpredictability, fatigue, pain, career prospects, pregnancy issues, loss of income, memory / concentration loss, and reliance on others to assist with everyday tasks. Most participants reported the negative impact of SLE on their lives, such as loss of independence and not being able to perform their roles. Some participants found positive aspects to having SLE.

The findings of this study identified themes which SLE patients felt important, and these can inform clinicians. Unfortunately, this study did not involve any male participants in the sample. Some of the findings will extend to them but they may have specific concerns regarding masculinity. For such a study, where the data collected is to be used for further important work, the purposive selection of

participants should cover a wide range of criteria. This was so in this study except that the geographical area was restricted. The validity of this study was demonstrated by triangulation with both qualitative and quantitative data from other SLE populations. An example of coding and one exemplar from each of the themes was presented to support trustworthiness.

The aim of Archenholtz et al's (1999) study was to determine what aspects of life Swedish patients with SLE and RA found to be, most important to their quality of life, most dissatisfied with and whether they perceived a change in the quality of life in the last year. This qualitative study had a sample size of fifty SLE participants and fifty Rheumatoid Arthritis participants, who were interviewed by telephone.

Both groups reported similar themes. The overall findings suggested that SLE had a greater impact on the participants, especially regarding lack of control over their body, and lack of understanding of the disease by others. The participants felt they had inadequate reserves of energy, no freedom from pain and limited independence. They wanted more up to date information and strategies that increase their sense of control. The study did not discuss the telephone interview in any depth or whether there was any issues using this method.

Jolly (2005) attempted to raise awareness of the quality of life of patients with SLE compared with other common chronic illnesses. The author stressed that the study, at most could only be of value as a suggesting hypothesis. The sample consisted of ninety participants from a rheumatology clinic.

The lupus database at the University of Chicago contains the self-administered Medical Outcomes Study Short Form-36 (SF-36) which

is applicable to measure HRQOL across chronic disease and has developed to cover SLE patients (Jolly and Utset 2003, Thumboo et al 1999, Strand et al 1999). The responses from questionnaires were analysed longitudinally over time. Scores for the reference chronic diseases, hypertension, cognitive heart failure and diabetes were taken from surveys of the general USA population. The comparison groups were not matches or controlled for many variables.

The HRQOL of those with SLE appeared to be significantly worse when compared with other chronic diseases, and affects all measurements; physical functioning; physical role; emotional role; mental health; vitality; pain; general health and social functioning at an earlier age. The deterioration of quality of life over years was profound (Fortin et al 1998). The general health of SLE patients was significantly lower than all comparative groups.

The study design did not permit definitive conclusions, as the groups were not matched or controlled for many variables. The choice of comparison chronic diseases did not include other autoimmune diseases, which would be of interest and possibly would have made a more trenchant comparison.

The objective of Robinson et al (2010) study was to determine the key SLE health issues from the patients' perspectives. The study used a phenomenological; mixed-method approach involving thirty-three participants. The study included (1) literature review of SLE HRQOL issues, (2) qualitative and quantitative research on HRQOL issues among SLE patients using focus groups and the questionnaire designed from (1) and face-to-face interviews.

To design the questionnaire for part (2) of the study, a worldwide literature review of SLE HRQOL issues was carried out. The top five

health issues identified in the literature were: fatigue, (N=8); depression (N=7); pain (N=4); helplessness (N=4) and inability to cope with the disease (N=4). Other HRQOL issues included: impaired work (N=3); and anxiety or distress (N=3). A questionnaire was developed and included six domains to inquire about health issues: symptoms, physical functioning, social functioning, cognitive functioning, emotional health and aspirations. The questionnaire was composed of YES/NO answers with an importance scale which ranged from 0 (not at all important) to 5 (extremely important).

To capture the patients' perception of disease impact a sample of 23 participants participated in two focus groups with the questionnaire being administered at the end. Following analysis, five frequent symptoms emerged: pain (83%); fatigue (61%); skin manifestations (43%) and poor emotional health (30%). Leading areas for functional impairment consisted of work (57%) and domestic and parenting roles being compromised (25%).

The last step in the study involved face-to-face interviews with 10 participants. These explored: 1) health issues identified by the focus groups and 2) additional health issues that may exist. Participants reported a decline in activities of daily living over time. Lack of energy, tiredness and fatigue were linked to the effect they had on roles and tasks. This was especially in relation to family, social life and work related issues. With a decline in their physical and psychological health and the unpredictability caused by SLE; they experienced a down-ward spiral.

The validity of Robinson et al's (2010) findings could be affected by the limited geographical area of the sample, as participants were recruited from a single rheumatology practice. However, due to the sample of participants involved, all having mild to moderate SLE,

perhaps a more realistic 'real-world' assessment of SLE health issues could have been provided, rather than purely focusing on the severely ill population. There could be limitations with the questionnaire namely, the degree of validity of using such a scale and the introduction of suggestiveness within the questions.

Pettersson et al (2012) carried out an extensive cross-sectional study to explore the most distressing symptoms of SLE and determine how these related to health-related quality of life. They employed a large sample of three hundred and twenty-four participants who gave written responses to two opening questions: 'what SLE-related symptoms have you experienced as most difficult'? And 'what symptoms do you presently perceive as most difficult'? Participants also completed a number of self-assessment measures answering each item based on their feelings during the past week.

A mixed method approach was used for data analysis. Each participant's response was categorised. Within each category, participants reporting a specific symptom were compared with non-reporters and analysed for demographics, disease duration and the results from the questionnaires.

The results identified twenty-three symptom categories, with the most frequent being fatigue (51%); pain (50%). Only participants reporting fatigue scored lower on both physical and mental aspects of HRQol. The study emphasised the need for further support and interventions to help reduce the symptoms of pain and fatigue, as this could improve the quality of life in patients with SLE.

The results of this study are based on data from only one cohort, which makes generalizations difficult. The study used open questions, which could detect important areas to the individual that would be

missed with closed questions. However the results are dependent upon how the participants interpreted the questions based on their knowledge, and perceptions of their illness-related distress. Future research could involve following symptoms over time to detect symptom change and distress.

Stamm et al (2007) aimed to explore the array of concepts important to SLE patients and to compare these with present instruments assessing disease activity, damage and health status. Twenty-one participants participated in one focus group, concerning problems around daily functioning. Five open ended questions were formulated around functioning in daily life based on the International Classification of Functioning, Disability and Health (ICF) model. The study compared the concepts from the five focus groups with those concepts covered by other SLE Activity Scores and health surveys.

The findings identified a high number of concepts belonging to the physical domain, which suggests these were particularly important to the participants. Participants talked about body image, appearance and self confidence which are not covered by any of the instruments. In the focus groups it was noted that each environmental factor could have positive and negative consequences for example, medication can control the disease, but it has side effects, and family members support and care, but can also be over protective. The study concluded that environmental factors are not covered by any of the standard instruments used in SLE clinical trial and an appropriate instrument should be developed.

The study's rationale for using focus groups was that, group members and the moderator could generate more in-depth and diverse information than other methods such as surveys or individual interviews. However focus groups can have disadvantages, as some

participants may be reluctant to share personal or sensitive information in a group session, or some members may dominate the session. Many participants who had agreed to participate did not attend. The study did not report whether they attended another focus group or were included in the total sample number. The study did carry out one focus group on a rheumatology ward and invited inpatients to attend. However, new concepts developed were minimal. Other than this one focus group the study did not attempt to include acutely ill patients with SLE.

2.5.2 The experience of pain

The experience of pain in people living with lupus has been explored by Hatfield-Timajchy (2007), Mattsson et al (2012), and Pettersson et al (2010).

Hatfield-Timajchy's (2007) anthropological cross-sectional study had a sample of 42 participants and used open ended interview, observations and a questionnaire. This study explored the meaning of pain for SLE patients through narratives and the McGill Pain Questionnaire (MPQ) (Melzack 1975). The McGill Pain Questionnaire (MPQ) indexes current pain descriptions, using a 78 adjective list which is grouped into four categories; sensory, affective, evaluative and miscellaneous qualities of pain. Once adjectives are selected which reflect current types of pain, each adjective is linked to the location on a human figure which corresponds to the participants current pain experience. The participants drew on a picture of a human body, their current pain including its position and intensity.

The current level of pain experienced by the forty-two participants was described as discomforting; mild or distressing and horrible levels of pain. Mild or discomforting pain was experienced by (60%) ranging from 3-41 locations on their body. Distressing levels of pain on a

regular basis was experienced by (63%) of the participants; with (27%) of these experiencing distressing levels of pain constantly; and (57%) of the participants experienced constant pain. Pain was described as 'exhausting' and 'tiresome'. Participants also tried to explain that they experienced pain 'everywhere'. The study is of particular interest as the pictures convey clearly the visual representations of pain affecting every part of the body and the overwhelming levels of pain experienced.

Mattsson et al (2012) conducted a qualitative study with 19 participants using focus groups, and identified that pain in SLE could fluctuate quickly both in intensity and location and was difficult to understand. It affected everyday life and the ability to perform activities. While, Pettersson et al (2010) conducted a qualitative study with 33 participants using focus groups and questionnaires and found that the perceived pain of patients is associated with a deepened perception of fatigue.

Similar themes have been acknowledged in other lupus studies, Robinson et al (2010), Archenholtz et al (1999), McElhone et al (2010), Baker and Wiginton (1997), Danoff-Burg and Freidberg (2009), Jones (2003), and Porter (2000).

2.5.3 The experience of fatigue

The experience of fatigue in people living with lupus has been explored by Bray (1998) and Pettersson et al (2010).

Bray (1998) aimed to determine the relationship between fatigue, perceived quality of life, depression and disease activity in people with SLE. A conceptual framework inspired by McKinley et al (1995) 'model of fatigue', was used with twenty-five participants with SLE.

The aspects of fatigue investigated included 1) physical fatigue, 2) cognitive fatigue, 3) emotional fatigue, 4) fatigue uncertainty, and 5) general fatigue.   Interviews, questionnaires and assessment scales were either completed at the participant's home or the lupus association. Overall fatigue was calculated by combining all the assessment scores.

The study reported how the sensation of bodily tiredness manifested itself as trembling, and the desire to rest or sleep. Some of the participants felt that fatigue did not cause any cognitive issues; others disagreed.   Fatigue uncertainty was expressed as participants not knowing when their fatigue would occur, or how long it will last. Participants described their experience of fatigue as fighting an invisible and unknown entity. Participants who reported greater fatigue also reported more irritability and depressive symptoms. Fatigue may contribute to loss of valued activities and this could lead to an increased potential for depression (Katz and Yelins 1995). Similar findings have been found in research related to fatigue in other conditions (Tack 1990b, Robinson and Posner 1992). The study highlights the importance of health professionals supporting those with SLE to develop ways of coping with fatigue.

Participants who did not attend support groups may have been under represented. Many participants struggled with the questionnaires and the researcher assisted, however the responses and calculations may not be accurate. Longitudinal studies may provide further insight into the fatigue experience and adaption over time.

Pettersson et al's (2010) qualitative study with 33 participants using focus groups, questionnaires and content analysis, explored the complex meaning of SLE-related fatigue.   Four themes were identified: 'nature of fatigue', 'aspects of fatigue', 'striving towards

power', and 'control and factors influencing the perception of fatigue'. The themes identified that fatigue was constantly present. The body felt heavy with movement difficult, and there was a foggy-headedness. The fatigue was unpredictable leading to feelings of anger, sorrow and powerlessness. The participants described how they strove to gain control and to balance fatigue with daily life. Pain, family, healthcare and society were factors that strongly influenced fatigue. SLE-fatigue would seem to be an overwhelming phenomenon; always unpredictable and controlling most of their life.

The sampling was highly selective, in that, all participants had a high level of fatigue. However this would be necessary for a pioneering study of such an elusive subject as the fatigue experience in SLE. The strength of qualitative research lies in obtaining rich data. It would seem that the choice of discussion focus-groups was successful. The participants interacted promoting the surfacing of hidden aspects. This study makes a major contribution to the exploration of the complexity of the meaning of SLE-fatigue, emphasising its core significance.

Similar themes have been acknowledged in other lupus studies, Mendelson (2006), Archenholtz et al (1999), Jones (2003), Beckerman (2011), Robinson et al (2010), Pettersson et al (2012), McElhone et al (2010), Mattsson et al (2012) and Shortall et al (1995).

2.5.4 The experiences of visual changes

The experience of visual changes, appearance and body image in people living with SLE has been explored by Seawell and Danoff-Burg (2005) and Hale et al (2006).

Seawell and Danoff-Burg (2005) using questionnaires investigated the relationships among sexual dissatisfaction, body image and physical

and psychological functioning in fifty-four participants with SLE and a demographically similar comparison sample of twenty-nine healthy participants.

The findings identified that the negative impact of SLE on body image and sexual dissatisfaction is greatest when levels of fatigue and depressive symptoms are high. The results imply that more active disease states are related to poorer psychosocial outcomes.

The sample was all female and did not appear to have severe levels of SLE. Participants were asked to invite a healthy friend to participate and this may not be representative of the general population because participants are likely to befriend persons who are demographically similar to themselves. The study does not comment on any issues regarding the questions or scales used and whether the participants had completed all areas.

Hale et al (2006) 'concealing the evidence' 'sought to understand the psychosocial concerns of SLE patients with changing appearance concerns. This study used phenomenology with ten participants having one semi-structured interview. Interpretive phenomenological analysis revealed, three themes, 'concealing the evidence'; 'social and physical isolation' and 'a double edged sword'. At the start of each interview, one important finding emerged, namely an over-riding sense of public self-consciousness.

All the participants remembered vividly the first time that they became aware that their appearance was arousing public interest. At that point, they felt that their 'self' was an object of social attention. When they were well they had merged into the crowd and their self was 'hidden'. The participant's reaction was to attempt to conceal their body by changing their style of clothes and application of cosmetics.

Sometimes, these were unsuccessful, merely accentuating the defects.

All participants expressed the anxiety that builds up in them, because of their self-consciousness. They retreated from an unsympathetic world, which could include family and friends. Avoiding social interaction and becoming isolated in their homes, increased feelings of difference and this could relate to depression. The study's findings should encourage clinicians to provide a sensitive approach and practical help.

This study is an opening to the field of appearance concerns which would seem to be of greater importance to SLE-patients than had formerly been realised. However, the geographical selection area was localised, the sample was not diverse and all participants were females. Research with male participants is needed, to explore their experiences of public self-consciousness, as they cannot, so easily, resort to body concealment techniques. The study described in depth the sample, methods and interpretive phenomenological analysis.

Similar themes have been acknowledged in other lupus studies, Druley et al (1997), Mattsson et al (2012), Porter (2000), McElhone et al (2010), Auerbach and Beckerman (2011), Robinson et al (2010), Stamm et al (2007), Shortall et al (1995), Danoff-Burg and Freidberg (2009), Mattje and Turato (2006) and de Barros et al (2012).

2.5.5 Psychological experiences

Psychological experiences in people living with SLE have been explored by Beckerman (2011), Jones (2003), Shortall et al (1995), Schattner et al (2010), Druley et al (1997) and Karasz and Ouellette (1995).

The purpose of Beckerman's (2011) qualitative study with 32 participants using focus groups was the identification and clarification of the unique psychosocial challenges for those living with SLE. In each focus group participants were asked to respond to a series of general open ended questions.

Thematic analysis identified the themes: a) 'depressed that I'm not who I used to be', reported feelings in relation to body image, reduced physically function and self-concept;   b) 'anxiety about the uncertainty of the illness' and c) 'coping with the physical and emotional fatigue', reported the feeling of being unable to cope emotionally, financially and physically. The findings indicated a high vulnerability for self-reported feelings of depression. Participants also identified what had been the most helpful in coping with lupus. This included, information and education about lupus, emotional support from significant others and internal strengths such as religion.

The researcher reported the focus groups allow shared experiences, but they may also inhibit some participants from being open. The participants were all receiving ongoing support from a social worker and may not be representative of all patients living with SLE.

Jones (2003) aimed to develop a better understanding of the experience of depression and anxiety in SLE patients. This phenomenological interpretive study had a sample size of eight participants. Each participant had one interview which lasted approximately one to one and half hours.

A number of themes were identified: 1) 'it's a black, depressing disease', reports how SLE-depression was something that never entirely went away and required management on a daily basis; 2) 'my life was over'; discusses how death was a prominent theme; 3) 'I

should be able to do that'; reports reduced physical, cognitive and functional abilities; and how participants could not carry out previous roles which leads to depression 4) 'I never really had problems with anxiety' reports how several participants experienced anxiety; 5) 'I feel they are getting short changed', discusses the impact on relationships with others, and 6) 'what was going to happen to me' reported how the participants feared the uncertainty of the future.

The study identified that patients need help to learn how to cope with lupus. The study recruited participants who were on anti-depressant medication and had the experience of depression and anxiety. This may not give a clear picture of the effects of SLE on psychological well being in other participants with SLE. A longitudinal study may show how perceptions can change over time and whether depression and anxiety remains.

Shortall et al's (1995) cross sectional study with 80 participants using questionnaires and assessments examined the relative contribution of factors associated with anxious and depressed mood, and clinical anxiety and depression in SLE. The study found that (78%) of participants identified depression as a problem. Anxiety emerged as an important concern, levels of anxious mood was higher than depression. This suggests a wide range of psychological and social factors contribute to anxiety in SLE.

The study concluded that SLE disease activity is not related to depression alone but is associated with other factors, such as restricted lifestyles, physical disability, a perceived decline in cognitive abilities and appearance issues leading to social isolation. The study highlights the importance of the meaning and perceived consequences of the illness for the person.

The study used questionnaires and assessments, which have the intrinsic difficulty of the interpretation of the questions. These methods can lack depth and ideally would be supplemented by other methods such as interviews or focus groups.

Auerbach and Beckerman's (2011) cross sectional study with 378 participants used questionnaires and found similar findings to Shortall et al (1995). Auerbach and Beckerman's (2011) study aimed to identify and clarify the unique psychosocial challenges for those living with lupus and develop a model to determine how different factors influence SLE patient's psychosocial needs.

The study found illness had intruded upon every aspect of the participant's life. Illness intrusiveness is a concept reflecting the subjective illness experience which encompasses illness and treatment-induced disruptions to the person's daily life, valued activities and interests (Devins et al 1984). The highest general causes of depressive and anxious feelings were changes in appearance and limitations in physical abilities due to SLE. The more chronic the symptoms, the more likely it was that feelings of depression would ensue. The study identified the importance of enhancing the person's sense of control through providing information.

Schattner et al (2010) investigated the role of illness intrusiveness on the depression experienced by those with SLE in an attempt to differentiate between illness-related and personality-related aspects. This longitudinal study had a sample of thirty participants and used questionnaires. The findings showed that the depression is preceded by changes in illness intrusiveness and symptom concealment. The impact of SLE on lived experience, rather than the illness per se, can carry a depressogenic effect.

The study presents yet another window into the complex depression inter-relationships. A longer study time and inclusion of a more diverse sample of participants would more adequately represent the variability of the 'disease'. As with all studies using self-reporting and analogue scales, findings will be very subjective. These instruments may not represent nuances of experience. However these were administered within the participant's home, which allowed the researcher, to assist and clarify aspects.

Druley et al (1997) had 74 participants and used questionnaires. They examined emotional and physical intimacy in coping with lupus. The study found that patients with SLE face the continuous dilemma of how much do they share with significant others. They may be able to share frustrations at not being able to do things, where they will not share concerns regarding the future course of their disease (Burke et al 1976). The study identified that the participants tended to conceal symptoms/ concerns from partners and this tendency is related to negative effects in relation to coping with psychosocial issues (Gottlieb and Wagner 1991).

Being able to share concerns with others, and having good interpersonal relationships can be a major contributor to coping with SLE. Intimacy has been shown as influential in buffering stress (Prager 1995). Concealment denies the person the opportunity to make sense of their experience through its retelling, and contributes to a sense of isolation which increases vulnerability to depression and enhances distress for SLE patients as well as their partners (Coyne and Smith 1991).

Participants in the study were recruited from one lupus group and did not have a confirmed diagnosis of lupus. A further limitation may be that information was from one person and not the partner.

Karasz and Ouellette (1995) had a sample of 64 participants and used assessments, structured interview, and questionnaire. The study examined the relationship between disease severity, social role strain and psychological well being. The study hypothesised that disease severity would affect well-being by producing role strain, which leads in turn to depression, isolation, and other signs of psychological distress.

The findings identified that severity of illness affects psychological well being; disease activity was significantly related to role strain; and role strain mediated the relationship between disease severity and well being. The causal relationship between role strain, role function and psychological outcomes was reciprocal, and can be viewed as a 'vicious circle' (Wachtel 1987: 45). When illness does not affect role strain, it has little effect on psychological well being. Social role performance mediates between disease and distress and therefore supporting SLE patient's roles and performance, would aid the reduction in psychological distress.

Participants in the study were recruited from one hospital. The study did not discuss the structured interview in any depth, or the specific questions used. However, in using three different methods to collect data the information gained may be richer.

Similar themes of depression, emotional distress and anxiety have been acknowledged in other lupus studies, Danoff-Burg and Freidberg (2009), Mendelson (2006), Wittmann et al (2009), Schattner et al (2008), de Barros et al (2012), Hale et al (2006), Wiginton (1999), Moses et al (2008), Rennegarbe (2002), Seawell and Danoff-Burg (2005), Robinson et al (2010), Mattsson et al (2012), Porter (2000), Bray (1998), McElhone et al (2010), Da Costa et al (1999), Devins et

al (2000), Guzman and Nicassio (2003) and Lindmer and Lederman (2009).

2.5.6 The experience of perceived needs

The experience of perceived needs in people living with SLE has been explored by Moses et al (2005) and Danoff-Burg and Friedberg (2009).

The purpose of Moses et al's (2005) study was to ascertain the extent and variability of unmet care needs over time of people living with SLE. Three hundred and eighty-six participants completed the surveys. The finding identified that that (94%) of participants had one or more unmet needs. The unmet needs of SLE patients were in fact higher than those reported in cancer and rheumatoid arthritis (Siegel et al 1991, Jacobi et al 2004). The most prevalent unmet needs related to physical symptoms, such as fatigue and pain. The study also found that that five of the highest levels of unmet needs were in the psychological domain. For example (72%) of participants reported the need for help related to (a) coping with fears related to a disease flare (b) frustration with not being able to do what they used to do; (c) anxiety and stress and (d) feeling down. Depression and anxiety were higher in this population than studies in arthritis and cancer (Foot and Sanson-Fisher 1995, Rainbird 1999). The results suggest a persistence of high levels of unmet need.

The survey results serve to underlie the chronic nature of SLE and the need for health and other care services to meet the comprehensive care needs of SLE patients. All the participants were drawn from a convenience sample (lupus association), and this may reflect a bias in terms of associated member characteristics which makes generalisations difficult. The study was limited to a 6-month period

and this may mean an insufficient time to reflect change in disease activity. The study used yes or no answers and a 5-pont scale which may not indicate the participant's experiences.

The purpose of Danoff-Burg and Friedberg's (2009) study was to assess unmet needs of patients with SLE. The study also sought to determine whether findings similar to those in Australia (Moses et al 2005, 2008) would be found with a sample of participants, with SLE, in the United States. This study had a sample of 112 participants who completed a survey.

The findings concluded that all participants perceived at least 1 unmet need. The greatest unmet needs (98.2%) were related to physical difficulties, such as, help with tiredness, pain and activities of daily living. The vast majority (91.1%) reported psychological or existential needs such as coping with the fear of SLE, and help to overcome stress and anxiety. The findings ran parallel to those of the Australian research (Moses et al 2005, 2008) and in general reflect the high prevalence of perceived unmet needs of those with SLE.

The study recommends that patients should be referred to professionals with expertise in patient and psychological intervention. The authors analysed the possible reasons for the relatively small uptake (11%) in their extensive recruitment (sent to 980 addresses). Possible reasons included illness or people did not want to be reminded of lupus. Future research could focus on how unmet needs develop and change over time, as well as the age of participants as this was indicative of higher levels of unmet needs related to physical symptoms, activities of daily living and psychological functioning.

Similar themes have been acknowledged in other lupus studies, Hale et al (2006), Seawell and Danoff-Burg (2005), Bauman et al (1989), Keller (1999), Philip et al (2009) and Trench et al (2000).

2.6 The experience of illness representations and beliefs of SLE and the experiences of mental representations of lupus and self/ personhood

2.6.1 Experiences of illness representations and beliefs of SLE

The experiences of illness representations and beliefs in people living with SLE have been explored by Wiginton (1999), Baker and Wiginton (1997), Goodman et al (2005) and Taieb et al (2010).

Wiginton (1999) carried out a qualitative study using a cognitive mapping strategy to ascertain patients own perceptions of living with lupus. A modified version of the Self-Q technique (Barr and Merchant 1992) was used to construct the cognitive maps. The sample had twenty participants; ten had been diagnosed for at least five years and were designated as an 'expert' group. The remaining ten had been diagnosed for two or less years and were the 'novice' group. The researcher interviewed each participant, asking the question: "When you think of lupus, which words come to mind? They are instructed to brainstorm, writing down words or phrases that came to mind. Each concept was written on a card, large cards for major concepts, and smaller cards for components of major concepts.

Once completed, each participant attempted to place the cards into a pattern, below a master card entitled "Living with lupus". Then they connected the concepts with lines giving the relationship directions. In this manner, each participant constructed a cognitive map. Each was very complex and quite unique. Maps could be reconstructed until

the participant was satisfied. Lastly, the components of each map were taped into position. Each map was analysed to obtain qualitative data. The total number of concepts identified was 355, with unduplicated concepts totalled 192.

There were no significant differences between the 'expert' and 'novice' groups. The number of concepts revealed and the complexity of the linkage showed a dramatic picture of how potentially lupus can affect all areas of life with no two lupus patients presenting the same picture. Fourteen of the participants thought they were not experiencing a flare, while six considered themselves to be in a flare. Those not in the flare reported significantly more self-management than those considered to be in a flare. This may indicate that the impact of a flare outweighs attempts at self-management.

The concept, pain, was identified by (55%) of participants. But to clarify this, at the time of the interview, this does not mean that (45%) were feeling no pain, rather that pain did not present itself as important. In addition to pain, uncertainty, unpredictability, misunderstanding by others, fear, lack of support, dependence and depression were primary concepts.

This study was a step towards providing a basis for improvements in cognitive-mapping technique, and for research with larger sample sizes, including males. With lupus so inconsistent in nature, treatment regimes must be individualised. Cognitive mapping could be a first step in treatment techniques. The author raises the difficulty of separating the patients existing illness beliefs and entrenched through experiences from childhood from those that their diagnosis would suggest. The mapping system can provide additional concepts that may not be identified by participants through interviews only or a questionnaire.

Baker and Wiginton (1997) with a sample of thirty-eight participants used structured interviews with open-ended questions to explore participant's perceptions of causes, mechanisms and consequences of lupus. The interview was followed by a written questionnaire.

The findings found that the participants' illness representations often conflicted with medical information and recommendations. The participants expressed confusion about the following aspects of SLE: 1) use of terms such as chronic, rather than episodic; 2) the difference between disease causes and flare triggers, and 3) differentiating between symptoms of lupus and side effects of medication. The study recommended that emphasis should be given to the identification and explanation of triggers known to increase the severity of SLE rather than focus on specific causes.

Protection against interview bias included, strict adherence to the interview protocol, and coding of interview transcripts by trained research staff.

Goodman et al (2005) used phenomenology with 36 participants, and semi-structured interview and interpretive phenomenological analysis. The study aimed to obtain data about the lived experience of SLE and provide preliminary insights into the ways in which initial illness representations are generated and whether any changes in those representations are evident over time. The interview questions covered 5 areas of the illness representations stage of the self-regulatory model (Scharloo and Kaptein 1997).

The findings identified that participants used a variety of names to identity the illness representations. Some were neutral, calling it lupus, while others referred to it as; 'being loopy' or a bit of a 'nuisance'. The majority of participants reported huge physical, social, and

psychological consequences of SLE. Changes in participants illness representations appear to have occurred over time, but these changes depend upon numerous factors such as increased personal experience, social support, perception of environmental demands and the severity of the illness.

This study conducted only one interview with each participant and this allowed a larger sample size. Participants were able to provide think descriptions about what having SLE meant to them. Longitudinal studies would be more likely to elicit the patterns of changes.

Taieb et al (2010) had a sample of 33 participants and used semi-structured interview and interpretive phenomenology analysis. The study explored the beliefs about the causes of SLE. The explanatory model framework developed by Kleinman (1980) helped in the construction of the semi-structured interview schedule.

The findings found that nineteen participants reported autoimmunity as the main cause. To most their own antibodies destroying their lives was a difficult concept to understand. Some understood it as a disease they had created themselves. Their body possessed a 'death wish' and was carrying out self-suicide. Other causes reported were that SLE was an infection and contagious. Two thirds cited genes and heredity, with stress, emotions, personalities, worries and family events as triggers. Some believed strongly in transmission over generations, linked to the thought of it being a latent disease waiting to attack. Others believed it was a test from God or punishment for past behaviour, or other religious or magical beliefs. These findings are fairly similar to those of Schatter et al (2008) except that single causes were not cited but rather rambling complexes of many.

There was a marked discrepancy between the narratives of the participants and professional explanations. To treat SLE patients, it is important to consider their belief explanations as an extra element in the construction of treatment plans.

The authors discussed the limitations of their research, namely the size of the sample and its cross-sectional structure. They had aimed for in-depth analysis which was a lengthy process and did not seek data saturation. The results showed extracts of verbatim accounts. Longitudinal studies were recommended.

Similar themes have been acknowledged in other lupus studies, Schattner et al (2008) and de Barros et al (2012).

2.6.2 Experiences of the mental representations of lupus and self/ personhood

The experiences of the mental representation lupus and self/ personhood in people living with SLE have been explored Wittmann et al (2009), Schattner et al (2008) and Nowicka-Sauer (2007).

Wittmann et al (2009) had a sample of 12 participants, and used semi-structured interview, multiple assessments and content analysis. This study aimed to improve understanding of the relationships between suffering, coping resources and personal development in SLE. The study tested whether the aetiology of suffering might be explained by Cassells (1982) model, which attempted to describe the phenomenological distinction between pain and suffering.

One of the assessments used was the PRISM (Pictorial Representation of Illness and Self Measure) a visual instrument to assess and quantify suffering caused by illness (Buchi et al 2002,

1998). Participants were shown a white A4 metal board, which has a fixed yellow disk at the bottom right hand corner. Each participant was asked to image that the board represented their life as it currently was, and the disk represented the participants 'self'. Subjects were handed a red disc and asked to image that it was their illness. They were then asked to put the disc on the board where they thought it was in their life at this time. The distance between the two discs represents illness and self and is inversely related to the burden of illness. PRISM can be used with multiple discs which represent individually important dimensions of a person's life, such as relationships, range of activities, and roles. These discs show the relationship between the illness and other aspects of the person's life.

Analysis revealed four themes; changes due to the illness; causes of suffering; quality of suffering; and coping with suffering. Suffering was considered to be a psychological aspect or perception of the physical illness. Participants reported that having symptoms after a time of being symptom free caused suffering. Certain factors, such as, illness duration, degree of pain and the threat to life mediated the relationship between illness and suffering. Somatic suffering was closely associated with pain, and this stopped the achievement of important personal goals and caused psychic suffering. Psychic suffering reduced life to a minimum and was described as having no energy, faith or hope. Participants reacted to suffering by withdrawing, and activating coping strategies, such as distraction techniques.

The findings were consistent with the concept of suffering as a psychological process triggered and sustained by an appraised threat to the person 'self'. The results indicated that recognising personal growth in response to the illness-experience may reduce suffering.

The combination of qualitative and quantitative methods aided triangulation. The study did not apply a purposive sampling strategy and this may have risked the exclusion of particular forms of suffering associated with either very severe or milder forms of SLE. The sample consisted of female participants and therefore the results may not apply to males, as suffering and personal growth may be different between genders.

In an effort to understand the 'lived experience of SLE', Schattner et al (2008) attempted to gain an insight into the mental representation participants may have of their SLE. This phenomenological study examined the place that SLE occupied in the inner lives of fifteen participants using open ended face to face interviews and thematic analysis. Two main salient themes emerged; 1) personification, the illness is experienced as a persecutor, the self as its victim, and 2) protagonization, illness is an adversity, a trial to be overcome, and the self is the hero facing it.

In constructing a meaningful narrative, participants had regarded the illness as an entity unto itself, a mental representation, or an object. Their body had betrayed them and they could find no causes for their illness. To these participants, the illness had assumed the role of a principal character and various traits were attributed to the mental representation of SLE. The illness could be linked to that of an evil, brooding presence rather than to 'self'. The wish to be rid of lupus could be interpreted as the wish to destroy the object which is necessary for survival and preservation of self. Other themes included overcoming their adversary, with self being the heroine fighting for survival, and emotional concerns, such as loss, and dependency. Each participant showed means of coping and adaptation which were tuned to their individual lived experience.

One point of contention within the study is the choice of female participants because of their 'vulnerability to psychopathology and mood disorders' (Schattner et al 2008:467) with no proof for this statement.

A victim's role has also been reported by Mattje and Turato (2006) a qualitative study involving five participants' using semi-structured interviews. In this study lupus symbolized an insidious way of destroying personal integrity and was viewed as an evil enemy with many faces from which there are no known defences.

Nowicka-Sauer (2007) examined lupus patients' perspectives through disease drawings. A sample of thirty-eight participants was asked to draw their disease. Every participant had the same colours to choose, and there was no time limit. The analysis occurred through the participants talking about their pictures with the psychologists. The pictures uncovered many dimensions of living with the disease. Lupus was conveyed as 'having many faces', 'a monster' and the drawings conveyed the variety of symptoms, the expansiveness and aggressiveness of the disease, and fear of the future. The study showed how, every participant had their own illness perception and can 'experience' their own illness in their own unique way. This study provides glimpses into the SLE experience that cannot always be gained from interview or traditional tests alone.

Similar themes have been acknowledged in other lupus studies, Mattje and Turato (2006), de Barros et al (2012) and Taieb et al (2010).

2.7 Recapitulation of the synthesis of themes explored within the literature.

So far, four main areas have been discussed:

2.3 Pre-diagnosis and diagnosis experiences; 2.4 The experience of interactions with health professionals and medication. 2.5 The experience of the impact of lupus on the person's quality of life. This area includes the subthemes, the experience of pain, fatigue, visual changes, psychological and perceived needs. 2.6 The experience of illness representations and beliefs of SLE and the experience of mental representations of lupus and self/ personhood.

The final theme within the literature to be explored is the lived experience of lupus which includes the subtheme coping and positive consequences of living with SLE.

2.8 The lived experience of lupus

The lived experience of SLE has been explored by Mattsson et al (2012), Mendelson (2006), Mattje and Turato (2006), de Barros et al (2012), Rennegarbe (2002) and Porter (2000).

Mattsson et al's (2012) a qualitative study with 19 participants using focus groups and content analysis aimed to describe how patients, with established SLE, experienced their illness in everyday life including both negative and positive aspects. Each participant attended one focus group and the interview guide was developed from the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation 2001). It covered the influence of the illness on the participants' bodies, their ability to be active and participate in everyday life and the characteristics of the person which facilitated or hindered everyday life. A general question started the

discussions. "How has your experience of the disease SLE influenced you?" (Mattsson et al 2012: 3).

Two themes emerged; 'multifaceted uncertainty' contained the categories 'an unreliable body', 'obtrusive pain and incomprehensible fatigue'; 'mood changes' and, 'reliance on medication and health care'. 'Focus on health and opportunities' included: 'learning process implying personal strength', 'limitations and possibilities in activities and work', 'a challenge to explain and receive support' and 'living an ordinary life incorporating meaningful occupations'.

The findings were complex and were expected to be mainly negative. Surprisingly, the findings showed that those with established SLE, although experiencing multifaceted uncertainty, also showed personal growth. Healthcare professionals from different disciplines participated in the focus group discussions to stimulate data production, but these may have influenced the findings in limiting the areas covered to caring or medical aspects. Group interviews could be inhibiting to some participants while others could dominant the direction of debate. All the participants' had their lupus well controlled; the findings may have been different if they had been in an acute stage of SLE or cognitive impairment. The study explained the methods and procedures in detail.

Mendelson (2006) explored the daily experiences of participants living and managing lupus. This ethnographic study, informed by a feminist perspective had a sample of 30 participants and used in-depth interviews, questionnaires, and narratives via e-mail. The findings suggested that living with lupus involves a medically and socially complex life. There were overlapping themes of uncertainty, a sense of shifting identity and managing a financial burden. The pattern of unpredictable periods made planning difficult and the participants

shifting sense of identity was the result of needing to modify roles due to uncertainty, and symptoms which interfered with daily life. The participants found it difficult to learn to live with the limitations placed on them by SLE.

The study provides dimensions, and voices the impact lupus can have on daily activities. These findings provide a foundation for further study. With the interviewing the author attempted an in-depth study with a small sample size. There was importance placed on obtaining a diverse sample of participates. But this work is confined by the strong feminist perspective. It would be difficult to make generalisation to the male perspective of the lived experience of lupus.

Mattje and Turato's (2006) qualitative study with 5 participants used a semi-structured interview and content analysis to explore life experiences with SLE. The study aimed to identify and interpret the meanings of becoming ill and adaptation mechanisms in lupus. After categorising the interviews, the discussion employed psychodynamic theories.

The findings identified that participants used up continuous mental energy trying to control the disease and keep it in remission. Participants could oscillate between affliction and carelessness (not taking medication, thinking they are well, not following advice and then becoming ill and seeking medical advice). Participants viewed themselves as 'different', and without defences against a powerful enemy. The only thing they could do was to retreat from life, which caused depression. The study does not explore in any depth the sample, interview or analysis procedure.

To explore the 'lived experience' de Barros et al (2012) investigated how SLE has affected the lives of patients. The study had a sample of

12 participants and used a semi-structured interview and phenomenological existential analysis. Participants were asked: 'How is it for you to have lupus?'

The findings identified; SLE was a difficult condition to deal with; the participants' lives have changed especially around body image as the result of treatment. SLE could cause anxiety, fear because of its unpredictable course and is perceived as a danger. SLE had invaded their world and interrupted the continuity of life and this was a source of suffering. Restrictions reinforce dependency and participants felt dominated by the health professionals.

The structure of the lived experience of lupus showed rejections, uncertainties, frustrations, submission and dissatisfaction. The study did not discuss the sample of participants chosen or elaborate on the interview or analysis process.

Rennegarbe's (2002) qualitative study had a sample of 20 participants and used a telephone interview. The study aimed to describe the lived experiences of rural participants with SLE to gain an understanding of the methods used for coping. Questions for the interview were identified from the literature. The findings identified that living with lupus resulted in physical challenges, psychological challenges, disease management and life adjustments. The most important support was that of being understood.

The study recommended that health providers need to have more understanding and support patients in how to manage and control their lupus. Interviewing by phone was a necessity due to the geographical distances and the researcher having lupus. However, this method can have disadvantages in establishing a rapport with the participant.

Porter (2000) used grounded theory with 12 participants and in-depth interviews. The study investigated the effects of lupus on the daily experiences of participants during its most active stages to determine how debilitating and disabling was this condition. The participants participated in two in-depth, open ended interviews focusing on, the affect on physical activities; employment and how carers assist/ or do not assist in controlling the daily symptoms.

The findings identified that many of the participants' experienced physical changes, and problems of cognitive loss; including, problem solving and the retrieval of words all of which were frightening. This can lead to a disruption in roles and quality of life. A flare up of lupus can mean being unwell and bed-ridden for days or even weeks at a time. Being ill with lupus means being more reliant on others for support and this can result in relationships and roles becoming disrupted. Many learnt how to adjust their tasks.

The researcher had lupus and this was reflected upon in the thesis. He collected all the date and this may have influenced the direction and focus of the interview. The researcher was male and some of the information requested during the interview may have inhibited some of the female participant's.

2.8.1 The experience of coping and positive consequences of living with SLE

The experience of coping and positive consequences of living with SLE has been explored Mattsson et al (2012), Baker and Wiginton (1997) and Wittmann et al (2009).

Mattsson et al's (2012) qualitative study with 19 participants using focus groups and content analysis, reported that participants learnt

about the disease and how to manage life with illness. Positive assets were having the will to struggle on.   While, Baker and Wiginton's (1997) qualitative study with 38 participants using a structured interview and questionnaire found that the majority of participants carried out self management techniques to control their lupus.

Wittmann et al's (2009) qualitative and quantitative study, with a sample of 12 participants, using semi-structured interview and multiple assessments and content analysis, discussed how personal growth was demonstrated, with priorities being developed and emotions and personal insight increasing in strength.

Similar themes have been acknowledged in other lupus studies, Pettersson et al (2010), Schattner et al (2008),   McElhone et al (2010), Mattje and Turato (2006), de Barros et al (2012), Karasz and Ouellette (1995), Porter (2000), Chambers et al (2009), Hale et al (2006), Jones (2003), Rennegarbe (2002), Hatfield-Timajchy (2007), Archenholtz et al (1999), Mendelson (2006), Beckerman (2011), Sansom (2010), Goodman et al (2005), Seawell and Danoff-Burg (2005), Auerbach and Beckerman (2011), Bauernfeind et al (2009) and Whitehead and Williams (2001).

2.9 Summary

SLE, with its unpredictable symptomology, breaks through the boundaries of numerous medical disciplines. It is an illness with linkage to immunology, pharmacology, neurology, genetics, endocrinology and many other specialisms'. Quantitative research past and on-going abounds as scientific explanations remain the principal focus. This research has provided a foundation and stimulus for qualitative studies, which seem to have gained momentum over the years.

This chapter has explored the literature on the experience of adults living with SLE. The forty-three studies identified consisted, in the main of individual studies showing a wide diversity in methodological frameworks, sample size, methods and analysis.

Within the various methodological frameworks stated, there were examples of phenomenological approaches (Robinson et al 2010, Goodman et al 2005); grounded theory (Porter 2000, Waldron et al 2012); ethnographic (Mendelson 2006); cross-sectional (Danoff-Burg and Freidberg 2009); longitudinal (Moses et al 2008) and mixed methods (Pettersson et al 2012).

Depending upon the methodological approach and the emphasis of the study, sample sizes varied. Moses et al (2008) for example, had a sample of 386 participants and used surveys. One of the strengths of this method is that considerable amounts of data can be obtained from large numbers of participants. Mattje and Turato (2006) on the other hand, had a sample of 5 participants and used semi-structured interview and content analysis. Face to face interviews can provide rich in-depth data, but the sample size needs to be manageable because a large amount of data can be produced.

Within the individual studies, there were variations in age range, severity of illness, mobility, literacy, gender, and disease duration. Schattner et al's (2008) phenomenological study with 15 participants using face to face interview and thematic analysis for example had a sample of first and second generation immigrants and so in many ways were disadvantaged because of their minority.

Twenty-four studies had a sample of all female participants (Hale et al 2006, Hatfield-Timajchy 2007), while nineteen studies included both genders (Bray 1998, Chambers et al 2009). Considering the ratio of

lupus in females and male is 9:1 (Lupus UK 2009) there is a likelihood of a higher response from females than from males. Pettersson et al (2010) for example, acknowledged the low response from male participants and therefore limited the sample to females.

The studies displayed a wide diversity in date collection methods. Interview techniques: one-time telephone interview (Archenholtz et al 1999); one face-to-face, semi-structured interview (Hale et al 2006); structured interview (Baker and Wiginton 1997) and multiple interviews over 6 months to a year (Hatfield-Timajchy 2007). There were considerable variations in the length of the interview. Stockl (2007) for example lasted 30 minutes to 2 hours, while de Barros et al (2012) reported 11-30 minutes, which appears a very short time to explore the 'lived experience of SLE'.

Other studies carried out one focus group (Beckerman 2011), or one- or two focus groups (Robinson et al 2010). Mendelson (2009) collected patient narratives via email, while Nowicka-Sauer (2007) used drawings.

Some studies discussed field notes (Goodman et al 2005, McElhone et al 2010), and presented a range and depth of insight into the participants perspectives through think descriptions (Hatfield-Timajchy 2007, Nowicka-Sauer 2007, McElhone et al 2010).

The studies show an array of individual research topics, the impact of diagnostic delays (Hatfield-Timajchy 2007); appearance concerns (Hale et al 2006); health care provision (Hale et al 2006); medication adherence (Chambers et al 2009). A considerable amount of research has been carried out on quality of life (Archenholtz et al 1999, Robinson et al 2010) and the focus on development of other (HRQOL) questionnaires (McElhone et al 2010, Stamm et al 2007).

With this proliferation of single qualitative studies, comparative analysis and interpretation present difficulties. From this vast array of literature, certain themes were revealed; an unsettlement of identity (diagnostic delays, uncertain prognosis, feelings of guilt, fear, becoming a burden, hopelessness); life changes due to fatigue, pain, flares; isolation due to social indifference, and the struggle to maintain physical and psychological stability.

Some studies have demonstrated how HRQOL of those with SLE appeared to be significantly worse when compared with other chronic diseases (Jolly 2005), with a deterioration of quality of life and a persistence of high levels of unmet need over time being profound (Moses et al 2005, Danoff-Burg and Friedberg 2009). Studies have also demonstrated that pain and fatigue are prominent and pervasive features of everyday life (Pettersson et al 2012, Robinson et al 2010).

Although male participants have been included in a number of studies (Goodman et al 2005, Beckerman 2011) their voice still appears to be almost unheard within the research. To obtain sufficient male participants would require extending the geographical areas. With a disease demonstrating such a gamut of expressions over time, more longitudinal studies would make an interesting and valuable contribution to the literature, as would more diverse methods such as drawings and photographs.

Each study has its merits and can be meaningful, and offer aspects into the lived experience of SLE. But is an all-encompassing representation possible? Paterson et al (2001:4) refers to individual studies 'as the pieces of a jigsaw puzzle' with researchers lacking a glimpse of the complete picture of the phenomenon under investigation.

In this study, I have provided a comprehensive in depth insight into the lived experience of SLE. The approaches I have used have enabled the participants to describe their experiences in more detail than has been previously captured before.

Thirty two participants (4 male and 28 females) were involved. All had varying age ranges from 23 to 83, and had been diagnosed with SLE from 18 months to 54 years. Interviews were face-to-face, in-depth, unstructured, multiple and had no time limit. The conversation began by the researcher asking an initial question, opening up the experience to be explored. The interviews had no specific schedule; it was entirely up to each individual to express their lived experience in the way they wanted to, giving them control of their interview. The participants' chose where to have their interviews; the majority was within their home.

Participants voluntarily provided pictures, photographs, journals and music to facilitate the communication and expression of those experiences, which at times can be difficult to communicate solely through the spoken word. An integrated approach combining the participant's media with an in-depth unstructured interview was used and this helped capture the richness of experiences.

These methods have provided an additional insight into the person's everyday being-in-the-world. From such a wealth of information, a wider portrayal has emerged; one that had remained hidden between the jigsaw pieces.

3.0 Chapter 3 - Philosophical Perspectives

3.1 The phenomenological paradigm

This chapter traces my pathway of reasoning through a forest of philosophical stances and explains my decision making process in choosing the approach which was employed in the study. The phenomenological paradigm 'worldview' will be explored, which includes the ontology and epistemology leading to a methodology compatible with the study's aims and ontological beliefs of the researcher (Guba and Lincoln 1994:105). The study explored the insiders' perspective of the lived experience of SLE. Through an in-depth understanding of their life-world, evidence-based recommendations will be advanced for the development of health care delivery. Reflexivity is employed throughout to allow for a rigorously grounded theory of the lived experience of SLE.

There were numerous considerations which had to be reflected upon when choosing the methodology and methods for the study. Firstly, the ontology, which is the nature of reality, was crucial to understanding the overall perspective from which the study was designed and carried out. Secondly, the ontology and epistemology were closely intertwined. Understanding these concepts and their interconnection helped guide the decision making process. This is important because distinct philosophical influences are embedded in the perspectives that are brought to the process of gathering, interpreting and understanding the data. Throughout this decision making process was the need to maintain a methodological coherence, and an open and transparent communication to the reader (Hertz 1997).

Lastly I as the researcher needed to consider how my position, presence and perspective could be examined and how I would employ reflexivity throughout the study (Finlay 2002b, Dobson 2002, Ballinger 2006). In particular, as I have the insider experience, living with SLE, I had to consider how reflexivity could be employed to allow explicit questioning of my involvement. Alvesson and Skoldberg (2000:vii) suggest this means 'interpreting one's interpretations, looking at one's own perspectives and turning a self-critical eye onto one's authority as interpreter and author'.

3.2 Ontology

Ontology concerns the form and nature of reality and the nature of our being. Reality could be viewed as something 'out there' to be apprehended. The assumption is that the world is structured by law-like generalities that can be identified, predicted, manipulated or controlled to yield universal statements of scientific theory (Denzin and Lincoln 2000, Munhall 1989). However these quantitative reductionist conceptions of causality cannot grant the primacy of human purpose and agency (Rychlak 1969) and can lead to loss of meaning and the omission of context (Habermas 1971). In human communication, there is no one-to-one correspondence between a given message and its meaning. There are multiple interrelated different realities (Keen 2003).

To somehow get to this network of meanings and lay them bare is the goal of phenomenology (Wertz 1999). Phenomenology re-asserts the primacy of the individual and their experience (Giorgi 1983). Lived experience presents to the individual the many truths and realities of life. It is through accessing these experiences researchers gain understanding of the meanings and perceptions of another person's world (van Manen 1997, Valle et al 1989). Phenomenology does this

primarily through linguistic data as a means of access to consciousness, with the goal of understanding what it is to be human (Keen 2003, van Manen 1997, Wertz 2005).

Phenomenology seeks to explore and clarify the nexus: subject-meeting-object, in an attempt to clarify and see the order of the multi-layered meaningfulness of everyday experience (Bengtsson 2005, Keen 2003, Wertz 1999). Lived experience is revealed through consciousness which is the starting point in building ones knowledge of reality and for phenomenology intentionality is a key feature of consciousness (Koch 1995, Moustakas 1994, Husserl 1970).

Within phenomenology differences arise within the realm of ontology. For example, Husserl's (1936, 1970) descriptive phenomenology focused upon the epistemological question of the relationship between the knower and the object of the study. The main function of the phenomenological description is to serve as a reliable guide to the listeners own actual experience of the phenomena (Spiegelberg 1982). Phenomena are seen to be made up of essences and essential structures and if studied carefully and rigorously can be identified and described (Giorgi and Giorgi 2003, Koch 1996, Giorgi 1994, 1985). Husserl (1936, 1970) posited through bracketing (keeping a distance from ones subjectivity) that it became possible to analyse the experience as it appears to us as a researcher (Polkinghorne 1983). However bracketing raised the spectre of Cartesian mind-body and subject-object dualism, favouring the intellect over experience (Heidegger 1996, 2000). This became a major criticism of Husserl's thought. In this case phenomenology is tending towards a belief in a knowable world with the aim to examine the world 'out there' a more realist perspective (Allen 1995, Koch 1995, Jones 1975). Husserl is not seen as falling exactly within the positivist ontology, as he took exception to the split between mind and body (Jones 1975).

Nonetheless Husserl (1936, 1970) strived for certainty and his emphasis was on making philosophy a rigorous science (Racher and Robinson 2003, Wertz 1999, Valle et al 1989).

Heidegger's (1962) interpretive phenomenology, argues for an existential adjustment to Husserl's writings that interprets essential structures such as basic categories of human experience rather than pure cerebral consciousness (Blattner 2009, Polkinghorne 1983). Heidegger (1962) denied the dichotomy between the world and 'us' and saw existence or being-in-the-world as an integrated whole (Dahlstrom 2005, Heidegger 1996, 2000, Merleau-Ponty 1962). Reality does not exist outside us; we are beings in a world, not disjointed from it. For Heidegger the concept of intentionality stops being expressed in totally epistemological terms and instead, it becomes ontological. Human beings as such are intentionally related to their world (Heidegger 1962, 1996, 2000). For the most part, we are immersed in the world; we are with others and the world in which we live. As such, a person being-in-the-world cannot be separated from the world (Heidegger 1996; 2000; Koch 1995; Munhall 1989). Heidegger (1962) argued that each person will perceive the same phenomenon in a different way (Berger and Luckman 1966).

Heidegger believed that it was impossible to bracket experiences, because we would shed our experience and therefore lose our capacity to understand through shared experience and meaning (Berndtsson et al 2007). But, through reflection we could become aware of our assumptions. This way of being-in-the-world means that researchers cannot help but bring their own involvement and fore-understandings into the research. This is understood as Heidegger's ontological difference and formed the basis of the hermeneutic turn (Cohen 2002, Heidegger 1996, 2000, Kvale 1996). This creates the

possibility for multiple realities, and this is called relativist; which means that realities are 'multiple' (Denzin and Lincoln 1994:110-111). What is real to participants is their experience of SLE and in particular their experience of being. In exploring the everyday world of SLE, the person and the world are seen as inextricable intertwined. Persons actively engage in and with their world. The world is what they perceive and experience it to be and reality can be different for each of them based upon their own unique understanding of their world and their experience of it. This creates the possibility for multiple realities, a relativist perspective. Within their shared experiences, there are no true fixed meanings; truth is purely a matter of perspective (Savin-Baden and Fisher 2002).

3.3 Epistemology

Epistemology concerns the nature of the knowledge to be gained. Within the positivist paradigm, the object of the study is independent of the researcher. Knowledge is discovered and verified through observation or measurement. The data and analysis are value-free and the data does not change because it is observed (Cousins 2002, Coll and Chapman 2000). The inherently reflexive nature of inquiry when humans study humans makes it unsatisfactory to maintain subject-object dualism (Flanagan 1981).

Within qualitative research, epistemology grants the significance of subjective beliefs, values, understandings and context. A person's background, prior experiences and value system are crucial to their interpretation and construction of knowledge. Knowledge therefore cannot be value-free since all incoming information is filtered through the lens of our beliefs (Dobson 2002). Knowledge is created through the reciprocal interactions of researcher and subject (Marion 2002, Howard 1984b). It is through these dynamically constructed

relationships that we are able to extract the detail and depth of understanding which could be difficult to convey quantitatively. Knowledge is relative rather than absolute; it depends 'upon time and place, purpose and interests' (Pratt 1998:23).

Phenomenology is the ideal method when we want to understand an experience as it is understood and lived by those who are experiencing it (Wertz 2005, van Manen 1997). Strauss and Corbin (1990) claim that it can be used to allow new insights, and understanding on phenomena that have been poorly conceptualised or new perspectives on areas already known. It is also appropriate in situations where quantitative measures cannot adequately describe or interpret a situation (Streubert and Carpenter 1995). As yet in-depth knowledge and understanding of the lived experience of SLE is still lacking (Lupus Public Health Services 2001). Few people have heard of it and those who live with it report that 'nobody understands'. Research aims and problems tend to be framed as open-ended questions which aids the discovery of new information (Wertz 2005, Wood 1991). This study asked the question 'what is it like to live with SLE?' to gain rich insights and new perspectives on a phenomenon which remains a mystery. Phenomenology provides the means to seek a deeper understanding and explore the nuances and the intricate multidimensional distinctions within participants' experiences unavailable through quantification (Morse 1989, Kvale 1983, Merleau-Ponty 1968).

Exploring the participants' everyday life world including existential moments can produce rich data. This allows the phenomenon to be described in vivid, deep and powerful ways. The reader can be drawn into the everyday life-world. To imagine, empathise and understand the experience of SLE to a much greater depth than might be the case through more quantitative reports (Green and Thorogood 2004,

Bochner 2000). This allows the world to be seen in new and different ways, which can increase understanding and affect health care delivery (Finlay 2006b). Readers can also gain a better understanding of the experience as the information is conveyed in an accessible and friendly format and in a 'form the reader usually experiences it' (Lincoln and Guba 1985:120). The textual aesthetic emotion and understanding of human experience conveyed through phenomenological reports "may be epistemologically in harmony with the reader's experience" (Stake 1978: 5) and thus more meaningful. The analysis can be presented to the reader as a 'tentative statement opening upon a limitless field of possible interpretations' (Churchill 2000:164, Annells 1996, Caputo 1987).

Within phenomenology, I as the researcher am a central figure who will influence the collection, selection and interpretation of data. The co-constructed interaction between me and the participant will affect the developing meaning and understanding and the data produced (Gadamer 1998, 1990, 1993, Cotterill and Letherby 1993). Each participant brings to bear their lived experience, specific understanding and historical background, assisting to generate inductive knowledge and theory (Koch 1995, Polkinghorne 1983). The interaction must acknowledge that both parties are a significant source of knowledge (Dingwall 1997, Drew 1989). The co-constructed interaction allows covert and hidden meanings to be explored with multiple understandings and interpretations emerging which cannot be construed as truth or reality. Instead the relational unfolding of understanding and interpretation allows ambiguity, descriptive nuances and multidimensionality with multiple voices to be embraced (Stewards 2006, Keen 2003, Allen 1995, Koch 1995). It is acknowledged the experience conveyed by participants can change depending upon their particular perspectives within that time frame,

and the relationship, and interaction with the researcher (Finlay 2006b).

Within phenomenology, the ontology conceptualised will affect the epistemology. For instance, those adopting Husserl's (1936, 1970) descriptive phenomenology with a more realist or subtle realist ontology will probably value research which shows evidence of being systematic and scientific. The researcher would remain objective and provide a transparent methodological account. This would demonstrate a commitment to sustained self reflection in order to reveal personal values and inter-subjective experiences relevant to the phenomenon in question (Osborne 1994, Giorgi 1985).

Researchers involved in Heidegger's (1962) phenomenology for example, with a more relativist ontology, will acknowledge the co-created mutual research relationship between the researcher and participant. The inter-subjective experiences of both parties are a significant source of knowledge (Inwood 2000). Inter-subjectivity acknowledges the experiences, and knowledge the researcher brings to the study has the capacity to enhance the research relationship (Cohn 2002). Being-in-the-world can be understood as the inter-subjectivity of interconnectedness and interdependence of human relationships. This encourages research exploration of holistic experiences, including those of the researcher (Cohn 2002, Hemphill-Pearson and Hunter 1997). Interpretive phenomenology values a reflexive account showing how the researcher's presence and lens of view have influenced the interpretations (Lowes and Prowse 2001, Matelrud 2001). Doucet (2008) uses the appropriate allegory that reflexivity could be conceived as three gossamer walls, where the researcher constructs knowledge from three sets of relationships. These include: (1) the relationship with oneself, our background and

experiences. (2) The relationship with research participants and (3) the relationship with readers and the community.

Within the study, I have discussed the varied voices and perspectives of participants and the way the research is co-constructed. This demonstrated the possibility of multiple understandings and interpretations and the significant sources of knowledge. This account was transparent and open to public scrutiny. The knowledge construction process was shown within the audit trail. Throughout the study, reflexivity was employed, allowing a transparent account enabling readers' insight and a full understanding of the influences upon the whole research process.

The quality of the research report should according to Kvale (1996:252) result in 'knowledge claims that are so powerful and convincing in their own right that they carry the validation with them, like a strong piece of art.   In such cases the research procedures would be transparent and the results evident, and the conclusions of a study intrinsically convincing as true'.

Now with the foundations of the ontology and epistemology laid, the choice of methodology could be considered.

3.4 Methodology

The methodology refers to how I, the researcher, goes about finding out what I believe can be known (Denzin and Lincoln 2000). Phenomenology is an umbrella term encompassing both a philosophical movement and a range of research approaches (Omery 1983, Oiler 1982). Distinct philosophical influences are embedded in each of the phenomenological philosophical positions. Each of these carries different aims; involves different research designs and utilizes

different research methods. Although each has similarities they all have distinct features and 'do not project the same destination' (Audi 2001:664). Rather than a dated philosophy, with no applicable application in today's world, phenomenology can be viewed as an evolving dynamic movement. This is mainly due to our ever developing understanding of the insights granted to us by the great philosophers (Moran 2000, Speigelberg 1960, 1971, 1976).

The phenomenological movement was initiated by Husserl (1936, 1970) who is often referred to as the father of phenomenology, although the term had been used earlier by philosophers such as Kant and Hegel (Moran and Mooney 2002, Koch 1996, Scruton 1995, Polkinghorne 1983). Subsequent theorists have developed phenomenology in a variety of different directions, all with the aim of discovering the world as it is experienced and lived. Heidegger (1962) for example, recast the phenomenological movement elaborating existential and hermeneutic (interpretive) dimensions. Merleau-Ponty (1962) an existential phenomenologist, built upon the writings of Husserl and Heidegger. Hans Gadamer (1998) followed the work of Heidegger and the Utrecht school focused on both descriptive and interpretive phenomenological approaches (Spiegelberg 1982, 1972).

The discussion thus far has identified that the ontological perspective for the study is relativist with the epistemology acknowledging the co-created mutual research relationship. The study sought to explore our ways of being and being-in-the-world, how we exist, act or are involved in the world. To achieve this required the illumination of the everyday existential life-world. The study required openness and a flexible attitude towards the phenomenon of SLE guided by methodological principles that emphasize a reflexive stance (Bengtsson 2005).

The approach needed to allow sensitivity and responsiveness to the elucidation of the phenomenon, as well as maintaining methodological coherence. The aim of methodological coherence is to ensure congruence and cohesiveness between all the intertwining components. To achieve this, the research needed to be based within strong philosophical foundations, but also show the methodological strategies employed throughout, ensuring trustworthiness (Koch 1996, Guba and Lincoln 1989, Ashworth 1987, Sandlowski 1986). As the research unfolds, the process may not be linear, as the phenomenological method is shaped according to the intrinsic demands of the life-world of the human being. This can enhance creativity, flexibility, and allows the fullest possible illumination 'to the things themselves'' to manifest (Husserl 1970a: 252, Holden, 1997).

I also needed to consider the methods employed during the study, including recruitment; data collection; ethical dimensions; reflexivity and analysis. To enable an in-depth exploration that enhanced discovery and illumination of the phenomenon of SLE, a variety of data collection methods were used including unstructured in-depth interviews, drawings, journals and photographs. All these methods required to be compatible with the chosen philosophical position to maintain methodological coherence (Drauker 1999, Koch 1995, 1996).

As the researcher, I can only make an informed and well grounded choice for the methodology when I have an understanding of the philosophical principles and the plurality of methods presented from such a broad phenomenological tradition (Moran 2000, Wertz 1999, Holstein and Gubrium 1994, Moustakas 1990). Husserl's (1936) goals for example were strongly epistemological. He viewed phenomenology as 'a radical beginning, a way to see the world anew as it really is rather than as it is constructed' (Caelli 2000:371, Racher and Robinson 2003). Existential phenomenology rejected Husserl's

idea of the detached consciousness or the ability to turn away from the world.

Philosophical influences on existential phenomenology can be seen in the writings of Heidegger, Gadamer and Merleau-Ponty (Spiegelberg 1976). Existential phenomenology explores the existential, including spatiality, corporeality, and temporality to provide insight into the everyday life-world. The emphasis is directed on holding in abeyance and setting aside suppositions and theories as there is no disengagement with the world (Moustakes 1994). Within interpretive phenomenology, Heidegger and Gadamer's influences acknowledge that researchers bring their pre-understandings into the study. Although attempts are made to identify these and see the phenomenon with 'fresh eyes', it is recognised that meanings can never be fixed. They are emergent, historical and contextual and these will shape our understandings. These pre-understandings can affect the research process and my interpretations. The focus is upon making transparent my values, and background including cultural suppositions (Ahern 1999). This requires me to develop a 'thoughtful, conscious self-awareness' which can result in greater transparency throughout the research process (Finlay 2002: 532, Walters 1995). Hasselkus (1997: 82) however has suggested that pre-understandings 'enables rather than constrains the researcher'.

Interpretive phenomenology emerged from the work of the hermeneutic philosophers such as Heidegger and Gadamer. Interpretation is viewed not as an additional procedure; it is our basic structure of being-in-the-world. All understanding is connected to a given set of fore-structures, including one's historicality that cannot be eliminated. Heidegger (1962) argues that understanding is a reciprocal activity and proposed the concept of 'hermeneutic circle' (Shapiro and Sica 1984, Gadamer 1984, 1989). The hermeneutic

circle is viewed as one between pre-understanding and understanding. According to Heidegger (1993) openness and a flexible approach to the phenomenon relate to processes of understanding and interpretation. One therefore needs to become as aware as possible and account for these interpretive influences (Barclay 1992).

Some of the schools of thought within phenomenology were less interested in theoretical and philosophical phenomenology (Cohen and Omery 1994, Langeveld 1983a, 1983b). The Utrecht school for example shied away from philosophical phenomenological issues. They openly admitted that they were not interested in phenomenology as a reflective method, nor in phenomenology as a rigorous science as a means to build knowledge (van Manen 1997). This could obviously affect the cohesiveness of a study.

Also, careful consideration is required when considering the philosophical positions in relation to the methods employed within the study. Heidegger (1971), Gadamer (1977) and Merleau-Ponty (1964 a, b, c) for example all pointed, in various ways, to the promise of art in revealing understanding as it emerges from the experience of the life-world. Philosophical insights from Heidegger (1971) acknowledge that art offers a showing of human experience in unique ways. Art, changes one's whole way of viewing the world and of finding one's way about in it. 'Art lets truth originate. Art, founding is the spring that leaps to the truth of what is, in the work. Art lets truth leap forth' and using art is one special way of enabling this disclosure (Heidegger 1971: 65-66/77-78, Harries 2009).

3.5 Justification

Within this study, I have a responsibility to be able to discuss the rationale and justification for my choice. To be able to explore the everyday life world of SLE in all its existential existence required thoughtfulness, a heeding and caring attunement about the complexity of living a life (Heidegger 1962). To wonder what is the nature (Being) of this being? What lets this being be what it is? This demands re-learning to look at our world as we meet it in immediate experience. This study wanted to open the window into the everyday world of SLE, with all its existential interlinked fractions (Ashworth and Ashworth 2003, Ashworth 2003a, Finlay 2003). Allowing a fuller more in-depth understanding of what 'lies at the ontological core of our being' to be illuminated (van Manen 1990:13). This study took a holistic perspective to understand each person's broader existence (Hemphill-Pearson and Hunter 1997).

The approach I used in this study was influenced by Heidegger's (1962) philosophical inquiry 'Being and time'. The focus of phenomenology is on illuminating details and seemingly trivial aspects within experience that may be taken for granted in our lives, with a goal of creating meaning and achieving a sense of understanding (Wilson and Hutchinson 1991). Heidegger refers to human persons as Dasein, being-there, because persons cannot exist as persons, and cannot be understood as persons apart from being in a world by which they define and realise themselves (Heidegger 1962, Dahlstrom 2005, Blattner 2009). Heidegger uses the term being-in-the-world, to acknowledge people's physical ties to their world; they think, see, hear, feel and are conscious through their bodies' interaction with the world. The person and the world are inextricably intertwined, humans actively engage in and with their world, and the person exists as a being in and of the world (Heidegger 1962, Merleau-Ponty 1962, Munhall 1989, Koch

1995). The existential provides us with a rich intricate experience of the everyday world or life world, our lived experience and to Heidegger are features of our existence (Blattner 2009). Four aspects are of special interest, lived space, lived body, lived human relation, and lived time. Our 'being-in-the-world' is an interactive integrity. These existential are vital to see the everyday life world of SLE and to understand each person's holistic life experiences and broader existence (Heidegger 2000, Munhall 1994).

Because people are in a world, they think, imagine things, and feel for others, this is the idea of intentionality. In a world of meanings/ interpretations, there are multiple realities beyond a single reality any object is more than a physical object as it has significance and meaning as soon as it is perceived. Each person perceives phenomena in a different way, each bringing their lived experience, their background and their culture (from birth and is handed down, presenting us ways of understanding) (Heidegger 1962). Whenever we understand anything, we do so by grasping in terms of our 'pre-understandings', our advance feel for an object, including its being (Heidegger 1962:37, Gadamer 1975). Meaning is found as we are constructed by the world, while at the same time we are constructing this world from our own background and experience. Interpretation is seen as critical to this process of understanding (Heidegger 1962). Interpretive phenomenology would allow the opportunity to explore 'psychological' and 'social' interpretations within the participant's lived experience to seek to understand each person's broader existence.

Interpretive phenomenology acknowledges that it would be impossible to suspend all beliefs completely and set them aside. My assumptions, interpretations and experiences upon which the research aims are based and interactions with participants during interviews cannot be bracketed in the form of reduction (Annells1996).

Instead, I would bring my own involvement, understandings and background into the research adding another layer of interpretation via the hermeneutic circle. The hermeneutic circle moves between parts of the experience, to the whole of experience and back and forth again and again (Kincheloe and McLaren 2003). Understandings are continuously being modified as I move back and forth, looking at the whole and parts in a dialogue between pre-understandings, interpretations and what is being revealed (Blattner 2009, Heidegger 1962, Hoy 1999, Bohman et al 1991, Kuhn 1991).

Understanding results from a dialogue between my own pre-understandings and the research process, between my own self-interpreted constructions and those of the participant. This 'fusion of horizons' means understanding's (data) from the participants and from myself would be combined to describe the phenomenon in depth and insightful ways (Gadamer 1990, Dingwell 1997, Drew 1989).

A brief résumé

Heideggerian phenomenology was the chosen methodology for this study. Heidegger's (1962) tenets were sympathetic with my own values and beliefs and the aims of the research. These include his ontological philosophy of multiple realities; his emphasis on 'being-in-the-world'; intersubjectivity and his exploration of the existential. Heidegger was one of the first philosophers to consider forms of art as valid expressions.

3.6 Personal philosophy

When embarking upon this research journey, I strove to find ways of working that were compatible with 'who I am'. This includes my underlying beliefs; values; view of reality; philosophies on life and beliefs about how knowledge is known and created. It is important that I make these transparent as far as I can. It also provides honesty and

is ethically correct to allow others insight into the influences these will have had on the whole research process and its outcomes.

My ontological view was vital in understanding the overall perspective from which this study had been designed and carried out. My ontology is relativist. My epistemology is closely intertwined with my ontological perspective. I believe knowledge is co-constructed; this allows knowledge to be created from multiple perspectives. A full reflexivity account should be laid open for public scrutiny, which includes my role as a researcher (Goffman 1959).

These ontological and epistemological perspectives derive from my worldly experiences and are closely intertwined with my philosophical beliefs as an occupational therapist. These beliefs will have been developed, refined and made more explicit and theoretical, through my thirty years of working. This process is ongoing throughout our entire lives as we continue to develop and grow.

I view people as unique, complex whole meaning making beings, with their own values, opinions, backgrounds, agendas, and purposes (Kanny 1993). I am extremely fortunate. My interaction with people is collaborative and holistic, within their normal day to day lives. I endeavour to understand their life world and how they see, feel, orientate and interact with their world (Barris et al 1983). Normal daily activities are used with their potential to promote health, independence, achievement, self image and wellbeing using any media depending upon the person's means of expression (Ede 2008, Creek 2003, Fidler and Fidler 1978). The trusting co-constructed developing relationship is built upon through encouraging freedom, dignity, respect, truth, honesty and caring.

I embrace a collaborative relationship between equals working together in a non-judgemental, empowering, reflective relationship. People will have their own goals, desires, motivations, time conceptualisations and aspirations and can make their own choices as they search for meaning in their lives. They can create who they are, not what I think or society feel they should be. My involvement is to try and understand their world, their meanings. Mattingly (1991) describes how therapists use a phenomenological process to understand individuals meanings, which involve empathy and improvisation to picture clients in terms of past, present and future times, creating stories in order to understand their clients' experiences. This was emphasised as the occupational therapists phenomenological way of thinking (Mattingly and Fleming 1994). To help facilitate this requires empowering optimum growth, having true respect and regard for the uniqueness of the person and their reality.

Each person will construct meanings as they engage within their normal day to day world and each will carry the influences of past experiences, social perspectives and cultural backgrounds which will all affect their present and future possibilities. These influences could be called 'baggage'. The baggage we all have in life. But for some people the baggage from society's expectations, misunderstandings, environmental limitations and the pressures of conforming can have huge influences on their ontological security, their self concept, personal autonomy and sense of agency.

This can affect a human being's ability to grow and have a choice within their life and world. Yerxa (1967:3) related, 'the person is not seen as an object or thing to be made to control or conform, but as a unique individual whose very humanness entitles them to choices in determining their own destiny'. This existential concept that people can create themselves and make their own choices as they search for

meaning in their lives, is pivotal within my profession. So my view is strongly intertwined with the philosophical base of occupational therapy which is essentially humanistic and person-centred (Creek 1996, Hagadorn 1995, Mayers 1990).

The phenomenological approach links well to the humanism espoused in the values of occupational therapy and many other health care professions. As Reed (1993) has argued research methods in occupational therapy should be compatible with the professions humanistic philosophy. The phenomenological paradigm is closely aligned with the traditional epistemologies of health professionals, allowing the phenomenon to be captured through time, 'holistic, engagement is meaningful and dimensions of being' (Omery 1983: 62).

3.6.1 Personal experience and the forming of the research questions

The forming of the research question and aims has been briefly introduced in chapter one and before I continue to explore this area I will offer a brief résumé. My innate curiosity was aroused in 2002 when I was introduced to an unfamiliar world and was diagnosed with SLE. Through the numerous visits to a London hospital, I had ample time to listen, talk, interact, question and observe others with this lived experience. Although I inhabited this unfamiliar terrain, my innate curiosity was stimulated by these absorbing, intimate and private stories.

The impetus for the research study stems from those encounters and my own experience of living with SLE. The study conception was not a spontaneous process, but a slow porous uptake, allowing time to dwell, reflect and contemplate. I still wondered 'what is it like to live with SLE', and what was its significance and meaning for those who have this insider experience. To be a true question means that the answer to what

is the question is not settled (Gadamer 1988: 326). This desire to know, to simply wonder at things being the way they are, a wonder which Merleau-Ponty (1962: vii-xxi) describes as the 'demand for a certain awareness, a kind of attentiveness and will seize the meaning of the world'.

Within the conceptualisation of the study, I was acutely aware that I also have this insider experience. It is an interesting label 'insider' as it implies straight away two mutually exclusive types of researcher, an 'insider' and 'outsider'. Is one viewed better than the other? Or is one more knowledgeable than the other? Is the insider endowed with special insight that cannot be accessed or construed by others? Or is the outsider equated with objectivity, and more ability to remain open to the illumination of the phenomenon? Although I could be viewed as an insider we (people with the experience of SLE) are not all united in the totality of our experiences by a single identifying characteristic. Rather, there exists a plurality of experiences of living with SLE and it is the acknowledgment of the possibility of these multiple positions that leads to the uniqueness of each individual. Although I could be viewed as an insider, my past experiences, background, age, gender, and culture, can all be different to others, and this gives us the complexity of human existence. Respecting the unique difference of the others experience has been important throughout the conceptualisation of this study. This study is aiming to allow the unique differences of individual experiences to come through, while at the same time permitting the essential sameness that unites human beings to be identifiable. No one can truly know the other, no matter what experience we might share and have in common.

However I am also aware that there are 'areas that unite' and I relate to at a deep intimate level, that empathetic understanding of a mutual lived experience. Our common understanding of the experience of

SLE can provide a basis for understanding that perhaps outsiders may not be able to access. This tacit understanding can allow verbal and non-verbal signs to be picked up and drawn upon. This 'tuning-in' can create through the co-created conversation a spiralling depth revealing deeper layers of meaning. Perhaps in one way I could be more open than an outsider to seeing the experience with empathic wonderment, as I would be more sensitive to the communication of the experience shared. Having this insider tacit understanding and knowledge about the phenomenon might in fact enable deeper understanding (Whyte 1992).

I was aware I needed to remain open and broad and attempt to see the world freshly in a different way, a mixture of 'disinterested attentiveness', and empathic wonderment, in the face of the world (Finlay 2008:12). To gain insight into what the phenomenon means and how it is experienced, allowing a 'context of discovery' (Giorgi, 1986: 151) and an 'opening up' and 'keeping open' of possibilities (Gadamer 1975:266). I understood that it would be impossible to separate and exclude my own experiences from the research study. Instead I must acknowledge them, work with them and integrate them, being aware that they can potentially both inform and be intrusive to the whole research process (Rogers and Cowles 1993, Drew 1989, Hutchinson 1986).

Heidegger (1962) suggests researchers interpret according to their own lived experience and historicity. This 'being-in-the-world' means that they need to bring their own involvement, fore-understandings explicitly into the research. It has been suggested that these pre-understandings 'enable' rather than constrain the researcher (Hasselkus 1997:82). Also I understood that human knowledge is co-constructed so any research study must involve some degree of mutual exploration and discovery. To 'document this process in an

open and honest way' was challenging (Walsh 1996: 383). Gadamer (1975) termed prejudices or pre-understandings, those assumptions knowledge's and biases that we bring to the research. To be able to acknowledge these requires reflexivity because without this the research is likely to be compromised. As Bonner (2001: 273) reports 'it would be fundamentally incomplete'.

There are many varied ways reflexivity can be used within the research process. I needed to consider carefully and decide which one of them, if any, would enhance the potential of this study. My adoption and valuing of reflexivity has its roots in a complex mix of occupational therapy philosophy, cultural and social changes (Giddens 1991) and philosophical critique (Gadamer 1975, Heidegger 1962). For some researchers reflexivity has become the primary methodological vehicle for their inquiry. This can be seen within the areas of auto-ethnography, autobiography, heuristic methodologies, narrative inquiry or social poetics (Riessman 2002, Ellis and Bochner 1996, Katz and Shotter 1996, Ellis 1995, Ellis and Flaherty 1992, Moustakas 1990). Auto-ethnography provides a methodology that encourages and legitimizes the inclusion of the researcher's self, and takes into consideration 'the complex interplay of our own personal biography, power, status and interactions with participants and the written word' (Rossman and Sallis 1998: 67, Karma 2003, Etherington 2000, Law 2002, Rees 2001, Cooper 2001, Kneeshaw 2000, Reed-Danahay 1997).

These areas also introduced creative media, such as art and photography which aid the powerful and illuminating stories. These are tangible representations of their experience with which an audience can interact at levels beyond the reach of the written word. Within this expression the art and creative media becomes 'embodied inquiry-sensuous, emotional and intimate' (Bochner and Ellis 2003:

507, Ellis and Bochner 1996, Bochner and Ellis 2002, Ellis 1995, Ronai 1995). Through her book 'illness' Carel (2008) manages to poetically unravel the tension between universality of illness and its intimate private, often lonely nature. She interweaves her own personal experience of living with lymphangioleiomyomatosis (LAM) with insights and reflections drawn from her work as a phenomenological philosopher. She manages to explore the impact of illness upon the person's life, reflecting on the experience of illness as lived. This becomes dramatised by the focus on existential moments in peoples' lives. Toombs (1992, 1995, 2001b) gives us insight into her experience of living with multiple sclerosis over a thirty year period, and Van der Bruggen and Widdershoven (2004) explores the experiences of being a Parkinson's patient by analysing material in autobiographical novels. In her book 'disrupted lives' Becker (1997) employs narratives in her ethnographic research, showing how people create meaning in a chaotic world. The phenomenological approach pulls the reader in to the book to understand the vivid poignant stories of people experiencing disruption.

Researchers have developed reflexivity into many different approaches and styles to complement their own way of working and the studies undertaken. Some of these include; personal introspection; inter-subjective reflection and reflexivity through collaboration (Finlay 1998, 2002a, 2002b, Burns 2002, Toombs 2001, Lynch 2000, Frank 1998, Willott 1998, Ellis et al 1997, Hertz 1997, Heron 1996, Walsh 1995, Richardson 1994, Moustakas 1990, Ashmore 1989, Polkinghorne 1989, Murphy 1987, Tyler 1987). For others reflexivity represents a means of constructing a bridge between research and practice (Etherington 2000, Heron 1996, Reason 1994). With such a variety it is clear that the concept might more appropriately be referred to as reflexivity's (Lynch 2000).

3.6.2 A development of a reflexivity map to find my own direction

Ruth Behar (1996) reminds us that we need to ask where we locate ourselves as researchers; how we reconcile our various roles; how much we expose of ourselves and how we examine the impact of all of these on the whole research process. She invites us to see all the elements intertwined in a deeply problematic way. In doing so we allow for our biases and taken for granted assumptions to be seen, providing the reader with a methodological log of research decisions. This allows the reader the ability to evaluate the research process, and the opportunity to make different assumptions about the data gathered and interpreted. This can add validity and rigour in research. Reflexivity was employed throughout this study to allow for a rigorously well grounded view of the lived experience of SLE. Yes, it provided transparency and rigour, but more importantly it provided honesty. It was a way to 'present the findings that allows them to be evaluated properly' (Madill et al 2000:17).

To achieve reflexivity, within this study, an account was presented to the reader, providing a methodological log. This was under three main headings: Firstly my own personal reflexive responses. Including myself within the study needs to be intentional as a means to an end and not an end in itself and would be expressed within a media of my choice. It was vital that the research was orientated to the experiences of participants; and not a mere reflection of my journey. The second heading 'interactional reflexivity', explored the dynamics and relational interaction between the participant and myself (Rodgers and Cowles 1993). The third heading is a reflexive methodological account of the inquiry. This critically evaluated how my perspectives may have impacted upon all aspects of the methodology including the data collection, analysis and interpretation. This allowed the reader full insight and opened the study to public scrutiny.

The aim of this study was not a quest for a 'true' answer, or to solve a problem. It was purely attempting to make visible in a being something that was not previously seen, by offering a deeper insight and an alternative viewpoint. To achieve this required vividness, emotional connection, and empathy through illumination, imagination and recognition and, an 'untiring effort a sensitive grasp of being itself' (van Manen 1990:132). The offering to the reader is a tentative elucidation of aspects of the life world, opening up a field of possible interpretations. These interpretations allow a further deeper understanding of the lived experience of SLE from the insider perspective.

Descriptions that are powerful have the potential to move others, encouraging the connection to evolve between the reader and the insider's story both emotionally and empathically within the journey. The description of the holistic perspective allows us as human beings to intuitively share in the phenomenon described, drawing us in to their world. Understanding such horizons goes beyond the pure accounts of peoples experiences in their own words as analysis encourages a level of reflection and understanding in which the shared and the unique dimensions of people's experiences are communicated (Churchill and Wertz 2001). This can have implications for person centred health care, changing people's views and ways of working, improving and changing health care delivery. It can provide evidence based recommendations.

The powerful nature of phenomenological research can transform the way we see our taken for granted world, resulting in sensitivity and the questioning of our long held working practices. Such understandings are supported by phenomenological studies that express people's experiences of health and illness, their shared and individual journeys and their interactions with others. Some excellent examples include

Boss (1979), whose life world approach demonstrated how a woman with a long history of gastro-intestinal complaints could only be fully understood with reference to her life projects, her body image, and her spatial and temporal horizons.

Svenaeus (2000) explicates how being ill is essentially characterised as a condition of 'unhomelikeness', alienated from the ways we feel at home in our bodies, with others and in time and space. Van der Berg (1955) discusses being unwell and how the touch of the human hand can reconnect us with a sense of hope that welcomes other possibilities of interpersonal relating beyond illness, or it can make us feel remote. These vivid powerful descriptions can draw us in and show ways of being we had not visualised or conceptualised before. The divided self by Laing (1990), is compelling reading as is the case of 'a different existence' by van den Berg (1972). The dissemination of findings can help deepen professional life world understanding (Mienczakowski et al 2002, Ziebland 2004). Presentations by service users exploring their experiences through stories and arts have been used effectively to increase understanding within health care professionals (Gray 2003, Gallagher 2007).

Interpretive phenomenology provided an ontological and epistemological foundation for informing the methodology for the study and is compatible with my own philosophy and the conceptualisation of the study. The following brief discussion will present an overview of Heidegger's (1962) philosophical inquiry, and its relationship to this study.

3.7 Heidegger's interpretive phenomenology and its relationship to this study

Heidegger's (1962) philosophical inquiry 'Being and time' is the complex fore-structures for an investigation into the meaning of Being.

So as to be able to describe what is there, Heidegger (1962) proposes the phenomenological method. He deliberately tries to exclude any prejudicial theory, ethics or interpretations from his description. He points out the need to always be mindful of the possibility that language may cover up the being of phenomena. Thus phenomenology must always be self-critical and interrogative. If the mode of being within the lived experience of SLE is 'covering-itself-up' then it needs to be uncovered and phenomenology will reveal the full range of modes of being that we face. Heidegger (1962) explains that ontology allows us to move back and forth between articulating some mode of being and seeing the whole of being. He uses down-to-earth-words, which carry no burden of philosophical assumptions. 'To significations, words accrue' (Heidegger 1962: 161). This study will be articulating a down-to-earth account of 'the things themselves' of SLE, using non-committal terms, and to ascertain how SLE has been misinterpreted.

His inquiry begins by choosing the one entity that asks 'what is being?' and whose understanding of being is an essential feature of its being, Dasein 'being-there' (Heidegger 1962, 1996, 2000, Dahlstrom, 2005, Blattner 2009). Only for Dasein is existence (the way of life) a question to be addressed through existing. This feature of Dasein is so crucial that Heidegger used the word 'existential' to mark the basic features of Dasein's being (Heidegger 1962: 44).

He used the term 'being-in-the-world', to acknowledge people's physical ties to their world (Heidegger 1962: 53/78). Our 'Being-in-the-world' is an interactive familiar integrity, a meaningful whole and is our basic constitution. All activities are specific ways of being-in-the-world (Heidegger 1996, 2000). He called it the 'everyday world', the wider world beyond the immediate 'world around us', which is disclosed to us by pre-scientific experiences by 'care, concern and moods'.

Heidegger (1962) claimed Dasein is essentially temporal (Heidegger 2000, Korab-Karowicz 2001, Watts 2001). In our everyday life world the past is revealed to us through our moods. The present is made manifest through language and meaning and the future is projected as indefinite where we run up against the final horizon, death (Watts 2001). Thus temporality illustrates being-in-time as developmental and historical, as well as highlighting the impermanence of our existence. This existential thrust illuminates and reveals our modes-of-being, or our ways-of-being-in-the-world (Boelen 1975). These existential are vital to illuminate the everyday world of SLE and to understand each person's broader existence.

Heidegger analyses Dasein in the mode of 'average everydayness', certain ways of being that are common and necessary in the ways that humans exist as persons. This study will be looking for essential structures within the everyday world. Heidegger felt that objects are connected to human purposes and are implicitly understood. Different entities refer to each other and form a 'significant whole'. These he called 'ready-to-hand' and 'present-to-hand', but they are anchored in Dasein's needs and purposes (Heidegger 1962: 101/71, Heidegger 1993). This study explores the 'ready-to-hand' tools of SLE and the context of significance for these tools. When we encounter equipment to use, we become immersed in what we are doing and pay little attention to the equipment itself. Normally the world and things in the world are inconspicuous. However when equipment goes wrong and malfunctions 'un-ready-to-hand', then tools become conspicuous and can thwart us in our human purposes (Heidegger 1962: 103/73-74). Important insights can be uncovered when tools become an obstacle. Heidegger wants to make apparent what is usually inconspicuous.

Dasein's being-in-the-world means being- with others and mainly they are inconspicuous. Mostly Dasein understands itself from the

perspective of public opinion the 'they' (Heidegger 1962: 126/164). We conform to the expectations and norms of the 'they'. We bow down and try and fit in to 'das man' the 'they' (Heidegger 1962: 126/164). In doing this Dasein loses its own individual self (Boedeker 2001). This in-authenticity can make us prey to 'falling'; described by Heidegger (2000) and Watts (2001) as absorption with the superficiality of the world (Heidegger 1962: 170/214). This includes such things as gossip, trivia, mass media, fashion and consumerism. However in-authenticity can serve as a means of protecting us from existential 'angst' (Heidegger 1962: 186/230). Dasein being-with is basically for the sake of others, which Heidegger calls care, and others mattering to Dasein, caring-for he calls solicitude (Heidegger 2000, Leonard 1994, Watts 2001). Being authentic (which means 'real' or 'proper') is to be one's own person, to do one's own thing, to make up one's own mind and be true to one's own self.

Dasein's moods such as fear, boredom or anxiety can affect engagement with the world. It can disclose the world and reveal things which we are usually unaware of. A mood shows the things that matter and don't matter in the world to Dasein. Attunement discloses our being-in-the-world as a whole. We are always in a type of mood, most often an 'everyday' mood that allows us to perform our everyday tasks. However when we experience heightened moods, such as anxiety through having an illness, then the nature of our being is called into question. This anxiety can allow us to redefine who we are in the world, what relationships and tasks we will sustain and where we devote our time and energy. Anxiety can lead to authenticity, to develop relationships of care for ourselves, for others and the world. The anxiety of running out of possibilities confronts us with the fact that we always face the question of how to live our lives. This is an unpleasant confrontation which we normally seek to avoid, but it can free us to be ourselves. Although 'angst' can be profoundly disturbing

as it reveals the nothingness at the centre of human existence (Heidegger 1962: 186/230). It can also be a way of revealing authenticity. This nothingness centres on the possibility of our own non-being (Watts 2001).

So far a variety of features of Dasein have been discussed. But Dasein must be considered as a whole and Heidegger discusses death (Watts 2001). Heidegger refers to death as the event that ends Dasein's life. Heidegger explains throughout 'Being and time' that Dasein is always ahead of its self, always having possibilities which have not yet been achieved. But, the final possibility for Dasein, which will end all possibilities, is death. Dasein is aware it will die. The 'they' chatter and agree that one dies, but hides the ever ready possibility. The inauthentic Dasein will feel it may happen at some point but not now and it happens to others and not the self. Authentic Dasein on the other hand has an awareness of the possibility of its own death and accepts being towards death and its finitude. This awareness presents Dasein with the possibilities to act now. Live its own life to the full and not be engulfed by the 'they.' Heidegger relates this to resoluteness, which is Dasein's awareness of confronting our being-possible. This opens possibilities of freedom and liberation of 'being true to yourself' and can affect Dasein's future life (Heidegger 2000, Morton 1996). Within the everyday life-world of SLE, death may be concealed and covered up. Our being-towards-death shows us our potential to be, and can make what others believe irrelevant. This can reveal possibilities and the responsibility to act now, living a life that is generally whole and mine.

Heidegger uses the term hermeneutics for the interpretive understanding of Dasein in its existentiality, a fundamental ontology (Heidegger 1962). His analysis is in-depth and rigorous. Heidegger explains throughout 'Being and time' that phenomenology provides

the proper access to an unprejudiced investigation of the things themselves (Packer 1985). The analysis must not let the fore-having, fore-sight and fore-conception be given by tradition, terminology, or popular ideas. The themes developed must be philosophically justifiable 'to the things themselves'. Heidegger does not talk of hermeneutic understanding, since all understanding is interpretation and involves the (hermeneutic) circle. Therefore, all understanding is hermeneutic understanding. Heidegger discusses that this involves all understanding and is not just for the written or the spoken word. Instead hermeneutics is the universal way Dasein is uncovered. For Heidegger the aim of hermeneutics is the correct understanding, of the things themselves in order to reveal hermeneutic truth and being true.

3.8 Implications for the research study

Heidegger's interpretive phenomenology carried with it a number of implications for the research study. These included the methods employed, such as data collection and analysis, but also ethical dimensions, and reflexivity. All of these methods required to be compatible with his philosophical position to maintain methodological coherence (Drauker 1999, Koch 1995, 1996). These will all be explored and discussed within the next section, the methods.

4.0 Chapter 4 - Methodology

The following section will focus upon the methods employed within the research study and includes recruitment of participants; sample size; data collection methods; ethical dimensions; analysis; evaluation procedures and reflexivity. The sampling; data collection methods and analysis have been informed by Frederick Wertz's approach (1982, 1983, 1984, 1985, 1986, 1987, 1988, 1992, 1993, 1994, 1995, 1997, 1998, 1999, 2001, 2003, 2005, 2006). Professor Wertz is Associate Chair for Undergraduate Studies at Lincoln Centre, Fordham University Psychology Department, New York. He practices psychotherapy primarily within a person-centred, existential framework, and heuristically and reflectively within a phenomenological human science orientation. He has conducted research widely within victimisation, depression, abnormality, illness and guilt. Phenomenological analytic reflection was used to grasp and explicate the essential structures of these subject matters.

4.1 Recruitment and Sampling

To be able to achieve an in-depth understanding into the everyday life world of SLE, I needed to firstly gain access to those expert insiders who have the experience in its varieties of different manifestations (Miles and Huberman 1994).

Purposive sampling was used to find participants who have the experience of living with SLE and would be able to provide good personal accounts, that is, they would be 'information rich' and could talk about their experiences (Hycner 1999:156, Sarantakos 2001, Schwandt 1997, Babbie 1995). In purposive sampling, the sample is chosen because of particular characteristics that would enable detailed exploration. Therefore gathering information with depth,

quality and richness with the aim of understanding and illuminating the phenomenon more deeply (Mason 2002, Patton 2002, Denzin and Lincoln 2000).

Phenomenological researchers seek out a varied selection of participants. In this study, these included a wide age range of people with SLE, gender and ethnic backgrounds. Participants of one gender or another were selected because by virtue of their gender, they could provide further insights into the phenomenon of SLE (Dalhberg et al 2008, Wertz 2005, Sadala and Camargo 2002, van Manen 1997, Sandelowski 1995, Polkinghorne 1989). Accordingly, only as many persons of a particular gender were included in the study as is necessary to obtain those insights. Phenomenology does not seek to make comparative statements about different population groups; rather the researcher must formulate the essential themes and structural relations that constitute the phenomenon in general, whilst giving voice to individual difference (Wertz 2005). Giorgi (1966:20) discusses this point, reporting 'it seems that the idea of an essential theme with multiple manifestations is a better model for research than identical repetition or duplication'.

To allow an 'opening up' of possibilities the selection of participants should try and avoid any prior presuppositions about the phenomenon (Gadamer 1975:266). These presuppositions could include for example only choosing participants of one age group or one gender, based upon our understanding of the existing theoretical literature and our pre-understanding of the phenomenon. To allow the fullest illumination of the phenomenon of SLE in all its variety of manifestations, the researcher required not only scientific openness but also to escape from personal prejudices. Gadamer (1975) suggests a solution, which is to question and provoke our pre-understandings about the phenomenon. The answer should be

awaited while maintaining 'relative openness' (Giorgi 1994: 212). By doing this we can come to understand our prejudices and refrain from the 'tyranny of hidden prejudices that make us deaf' to possibilities (Gadamer 1975: 269, Giorgi 2008, Halling et al 2006, Porter 1993, Singleton et al 1988).

4.2 The inclusion criteria for potential participants within this study

- Each participant must have been diagnosed with SLE via the St Thomas Hospital criteria or ACR criteria by a rheumatologist.

- Each participant must have been diagnosed with SLE for more than 12 months. This helps protect those participants who may be coming to terms with being newly diagnosed.

- Participants between the ages of 23 years to 85 years of age were invited to take part. This wide age range helps facilitate the exploration of the varying experiences and perspectives of living with SLE. SLE often appears for the first time in the early twenties (Hughes 2000).

- At least two male participants were included within the study. This allowed insight from their perspective, of what the phenomenon means and how it was experienced. Because the ratio of SLE in females and men is 9:1 (Barwick 2000, Lupus UK 2009) there was a likelihood of a higher response from females than from males.

- The research study included at least two participants from different ethnic backgrounds, to gain insight from their perspectives. SLE is often a more serious condition in a number of different ethnic backgrounds (according to Barwick 2000, particularly West African, Asian and Chinese populations).

4.21 Exclusion criteria

- Participants who could not understand or communicate in English

4.3 Access to participants

To gain access to potential participants with the lived experience of SLE the researcher sought the help of National Lupus UK. At the commencement of the study a full report was sent to Lupus UK asking for their help with access to three lupus support groups and their members. Lupus UK committee members discussed the study and agreed unanimously to support and provide access to three chairs and lupus groups' members upon ethical approval. (Please refer to Appendix.3 Ethical Approval Letter).

National Lupus UK disseminated information regarding the study to each Chair of three lupus support groups, following confirmation of ethical approval. These included Hampshire, Dorset and Devon. The Chair of each group contacted me direct. The study was discussed in-depth, with each chair via phone calls, meetings and e-mails, clarifying any points. Recruitment was initiated with one group at a time to reduce the need to decline participants if potential volunteers were high. Recruitment began with the Hampshire lupus group.

Each member was sent:
1) Participatory sheets with a reply form explaining the study
2) Letter of introduction from the researcher
3) Letter of introduction from the Hampshire Chair, explaining the study and approval from Lupus UK. It also reiterated that

member's personal information would not be disclosed to the researcher.

4) Envelope with the researchers address and stamp (for any reply slips). All information had the researcher's contact details.

All information was placed into envelopes and sealed. A follow up meeting was organised with the Hampshire Chair, and all envelopes were passed over. The Hampshire Chair confidentially put the addresses on the envelopes and disseminated to all members. This meant that I had no knowledge of members' personal information. Interested members then contacted me directly (Please refer to Appendix. 4 Participant Invitation Sheet and Appendix. 5 Participant Sheet).

I also wrote a short article about the study for the Hampshire lupus group newsletter. This was distributed to all members by the Chair. The Chair was thanked for their help. The Hampshire Lupus group membership comprises of, those who have SLE, family members, or interested people. The circulation list covers a vast geographical area including outside the UK, but mainly Hampshire, Wiltshire, Surrey, Dorset, Isle of Wight, and the Channel Islands.

4.4 Sample size

It is not always possible for a researcher to determine the sample size needed to give insights into the phenomenon before conducting the research and carrying out the analysis. There is no simple formula for this dilemma. I needed to constantly reassess the sample size by engaging in a dynamic interplay of critical reflection towards the research interests, the life-world position of the participants, the manifestation of the phenomenon, and the quality of the emerging data (Wertz 2005).

A number of things need to be reflected upon; one of these included the complexity of the study. Because this was an in-depth study about a complex experience, a large amount of data was produced. Therefore the sample size needed to be manageable. If the sample size was too large, there may be insufficient time for the analysis to be truly responsive to the meanings emerging. Similarly if the sample size was too small, insufficient insights in to the phenomenon and research aims might occur. The sample size must also bear a relationship to the researcher's claims about what is being investigated and for what purpose. Wertz (1983) discusses this point, reporting that one case study may be sufficient for the researcher to explore an in-depth experience of particular interest (Firestone 1993, Ragin and Becker 1992, Lincoln and Guba 1985, Simons 1980). However one case will not be sufficient, if the researcher's intention is to describe general insights into the phenomenon (Wertz 1985). This study was aiming for the latter.

Within phenomenology, Cresswell (1998:64) suggests studies should have between 'five to twenty-five participants', while Morse (1994: 225) suggests the sample size should be at 'least six'. Sample size in phenomenological research may refer to the number of participants, but also the number of interviews conducted (Sandelowski 1995). Within this study multiple in-depth interviews were carried out with the same participants and a variety of data collection methods were used. Lee et al (2002) discuss, how studies that utilise more than one method, or use in-depth multiple interviews with the same participants may require fewer participants.

A vital point in any research study is the quality of the data obtained. This can be affected by the interaction within the interview between the participant and researcher. Patton (1990) suggests that the quality

of information obtained is the crucial matter; as opposed to the number of participants per se. Guest et al (2006) reiterates this point.

The sample size in this study was thirty-two participants. This was because; a variety of data collection methods were used to allow insight into this unknown phenomenon. The majority of participants had multiple in-depth interviews, with no time limit. Therefore the data collected required to be manageable. It allowed the unique differences of individual experiences to come through, while at the same time permitting the essential sameness that unites human beings to be identifiable (Wertz 1985). This sample size was manageable within the geographical area.

Masson (2010) discusses that the mean sample size within PhD qualitative research studies using interviews has been 31. This can be more than is required within qualitative research as the aim is concerned with meaning and not generalised hypothesis statements. This point is reiterated because qualitative research is both labour intensive, and the data produced can become repetitive. However with a complex, unknown phenomenon such as SLE it is important to remain open to the different manifestations within such a varied participant group. Only during data analysis can the researcher ascertain to a fuller depth whether or not new themes were emerging. This study also utilised a variety of data collection methods, and this can show varied aspects of the phenomenon that may not become accessible via an interview only. Jette et al (2003) also suggest that expertise within the area can reduce the participant sample size. However within phenomenology, it is important to try and remain open from scientific pre-understandings.

4.5 Response from potential participants

Members contacted the researcher in a variety of ways, including reply slips, phone calls, e-mails, texts and letters. The response was overwhelming with one hundred and sixty-six people wanting to be involved. One hundred and thirty-three people were found to be eligible. The majority of potential participants were females, eight of whom had ethnic backgrounds and twelve were men. The UK geographical area included Hampshire, Wiltshire, Surrey, Dorset, Isle of Wight, and the Channel Islands.

The selection of a sample from this number was difficult. A detailed spread sheet was composed with all the preliminary criteria in colour code. Any additional information obtained via the reply slip or through phone calls was also added to the spread sheet. This included for example whether people worked or had additional conditions associated with their lupus such as psychotic lupus.

From this spread sheet a detailed typology was designed to establish the criteria for selection of the participants (Silverman 2005). This sought to include a varied and diverse sample to ensure primarily the richness of experience and differing perspectives. The sample included a wide variety of varied age ranges, length of time since diagnosis, gender and varied ethnic backgrounds (Dalhberg 2008, Sandelowski 1995). The sample strove also to include some participants who worked or had additional lupus associated conditions and varied geographical areas. When a couple of potential participants had similar age ranges, length of time since diagnosis and gender, the process became random.

The sample size consisted of thirty-two participants. All these people had varying age ranges from twenty-three up to eighty-three years of

age. The length of time since diagnosis ranged from eighteen months up to fifty-four years. Gender included four males and twenty-eight females with five having varied ethnic backgrounds. All had differing perspectives and experiences of living with SLE. (Please refer to Appendix 6 Participant layout). Some people worked, and some had additional lupus associated conditions. They lived in a variety of geographical areas. These thirty-two people were chosen to explore a wide range of experiences of living with SLE.

The Dorset and Devon lupus group Chairs were contacted and informed that their members would not be involved in the study. They were thanked for their help.

4.6 Meeting participants

I informally discussed the study in-depth with all interested participants by phone, giving them time and the opportunity to discuss any concerns or query any aspects about which they were unsure. All aspects of the study were discussed including the data collection methods and all participants agreed verbally to be interviewed. All participants were in control of where and what time they would like to meet, and the data collection methods they would like to be involved in. These initial discussions also assisted participants to feel more confident in 'getting to know' me. The majority of the participants talked for a considerable time about themselves and their interests.

On the first meeting with the participant, I discussed the participant sheets, and any issues or concerns in relation to the study. I endeavoured to make the discussion warm, and friendly displaying real empathy and interest towards each person. All the data collection methods were discussed and how interviews would be audio-taped. All participants agreed to sign the written consent sheets and they

were given a copy. It was understood that they could withdraw at any time. (Please refer to Appendix 8 the Consent Form). During the first meeting I brought all equipment that may be needed by participants for any of the media aspects they may want to be involved with. This included cameras, drawing equipment, journals, pens, and art sheets. I also brought all the audio-tape equipment. This enabled participants to become familiar with its use. Each participant was given the choice of taking part in one interview, and then deciding whether to continue with anymore. Also, they could contribute to one or more media aspects or none at all. Those who declined to be interviewed showed keenness to be involved in the media aspects.

Eighteen participants decided that they wanted to be involved in unstructured in-depth interviews. Seventeen of these participants decided they wanted to also take part in some of the media data collection methods (Please refer to Appendix.7 Media Data Collection Methods). Some of these participants were not sure which media they would like to use, and felt they were not very 'artistic'. On further discussion and reassurance that the media was not to judge their artistic ability, they felt more confident to decide which ones they would like to use to express themselves. I also gave reassurance and discussed other interests of the participants. This helped them decide which media would suit their expression and they would feel confident in using.

During discussions, fourteen participants decided they wanted to be involved in the media data collection methods and then have in-depth interviews discussing and exploring their media. Some participants had formed clear ideas about which ones they wanted to do after reading the participant sheets. This seemed to be especially related to their own interests and ways of expressing themselves, such as through art work, music, photography or collages. Others expressed

that they would like to do ceramics and graphical pictures on a computer.

4.7 The rationale for the choice of data collection methods

Because the phenomenon has been poorly conceptualised, 'is complex', unknown 'and extensive in scope', it was vital that this in-depth study was highly sensitive to both the participants' experiences and to the interconnected co-constructed interactions (Wertz 2005:171). These interactions between the participant and myself during an interview can explore and clarify meanings and understandings to an ever increasing depth. I was seeking maximum depth, with the minimum of structure to obtain rich, thick descriptions of the lived experience.

To be able to fully illuminate the phenomenon involves an open attitude evoking fresh detailed descriptions that capture the everyday world of SLE to reveal aspects not previously considered and enhance our understanding. Because of this, I endeavoured to give the participants their choice of medium through which they feel they can best express their inner selves, their everyday world. As reiterated by Oiler (1982) any artistic expression, such as art, photography, diaries, could be used as sources of experiences that have meaning for the person. It is hoped that the innovation of using multimedia may capture the richness and complexity of this phenomenon as it is concretely lived in its variety of different manifestations.

Participants must feel in control and be able to express sensitive experiences in a trusting empathetic atmosphere. To truly explore this complex area in-depth, flexibility was vital (Bengtsson 2005, Dahlberg et al 2001, van Manen 1990). Priority must be given to the participants' experiences, letting them explore the research area in

their own way and time, thus allowing new meanings and understandings to emerge.

4.8 Data collection methods

In interpretive phenomenology a variety of methods could be used to find meaning and understanding. These could include; unstructured in-depth interviews, journals, art, music and photography (Finlay 2008, Wertz 2005, Jhanji 1985, Cardinal 1981, Friedman and Smith 1965, Langer 1963). This study employed all of these methods, as a means of gaining insight into the person's life-world (Gullemin 2004, Salmon 1993). They have the power of revelation, and allow 'us a deeper insight into the more existential elements', opening-up possible modes (ways) of being (Darbyshire 1999:129). Firstly the unstructured in-depth interview will be discussed followed by the other data collection methods employed throughout the study.

4.8.1 Unstructured in-depth interviews

Audio-taped, unstructured, in-depth interviews were used as the main data collection method, to gain insight and understanding from the viewpoint of the expert insider. This allowed participants the opportunity to explore and describe their lived experience of SLE in their own words and style providing 'information rich' personal accounts (Hycner 1999:156). The in-depth interview is often described as a form of conversation (Lofland and Lofland 1995, Burgess 1984, 1982a), a 'conversation with a purpose' (Webb and Webb 1932:130). Moustakas (1994) and Todres and Holloway (2006:232) report that typically, in the phenomenological investigation, interviewing is the main method used for data collection, because 'an in-depth interview is able to focus on the complexity of the experience, as well as provide a clear focus for exploration' or clarification (Kvale 1983).

The strength of an unstructured in-depth interview is that I can be open to emerging and new insights of the phenomenon, rather than bringing in preconceived ideas or predetermined questions. Wertz (1984) discusses this point, reporting that the phenomenological ideal is listening without prejudice, thereby allowing the participants description of their experience to unfold without interruptions from the researchers' questions and the preconceived ideas these may involve. This facilitates an opening up, and keeping possibilities open rather than premature closure.

The majority of interviews occurred within the participants' home environment. The conversation began by me asking an initial question, opening up the experience to be explored. For example each participant was asked "(name of person) *Can you describe in as much detail as possible your experience of what it is like to live with lupus?"*. The interviews had no specific schedule. It was entirely up to each individual to express their experiences in the way that they wished. Thus they were given control of their interview. As the interviewer, I followed up descriptions with prompts when and if required such as 'what do you mean......?' to clarify the emerging meanings. This enhanced the validity of the findings. An example of part of an interview:

Interviewer: *"Can you describe in as much detail as possible your experience of what it is like to live with lupus?"*

Interviewee: *"Absolutely terrible, to be truthful, because you never know when you're going to be well, you never know when you're going to be ill, um, the flare-ups can be very intense and you feel very ill ((intake of breath)) , um, quite awful. The last two years, before they diagnosed me, I thought I was dying, to be frank, I really thought I was dying",*

Interviewer: *"What you mean you thought you were dying?"*

Interviewee: *"I felt I was going, everything was just going, I couldn't do anything, and I wasn't here anymore, I was somewhere else, but I don't know where (big intake of breath)........"* (Interview continues)
(P8, 1-19)

The conversation throughout is co-created; a genuine human intimate interaction with neither the interviewee nor the interviewer knowing precisely what will be discussed (Holroyd 2007, Gallagher 1992). I listen beyond the overt meanings of the participant's description so that covert and hidden meanings are recognised (Kvale 1996). An inter-subjective depth gradually and sensitively results leading to greater immersion and further spiralling revealing ever deeper layers of meaning (Miller and Glassner 1997). Through this ever descending circle of following up, gentle prompts and clarification, new insights and understandings emerge (Dingwall 1997, Jenks 1995, Streubert 1995, Gallagher 1992, Drew 1989, Gadamer 1989). Both the interviewees' experiences and the interviewers' interactions are reflected within the data. Through this interaction I can develop trust and an intimate rapport aiding interviewees to feel valued and engaged within the research process. The relationship between interviewee and interviewer is a dynamic interplay with the interviewee being leader.

Throughout this 'conversation', it was important that I gained details of the persons lived situation rather than abstract views or interpretations in an effort to gain access to the person's lived experience. As Wertz (2005: 171) states; 'the most outstanding quality of data sought by the phenomenological researcher is concreteness' (Oiler 1982, Valle and King 1978, Geertz 1973, Merleau-Ponty 1962).

Patton (2002: 341) discussed how 'the quality of the information obtained during an interview is largely dependent upon the interviewer'. This rapport will be dependent upon the skill of the interviewer and their interpersonal capacities for connectedness, curiosity, sensitivity and openness which can all lead to successful research (Hudson 2003, Legard et al 2003, Wright and Flemons 2002, Padgett 1998b, Kvale 1996, Koch 1996, Kvale, 1996, Weiss 1994, Riger 1992, May 1991, Fonow and Cook 1991, Neilsen 1990, Aptheker 1989, Polkinghorne 1983, Marcel 1971). Throughout this intimate conversation, I made sure the interviewee was given time to express their experiences in their own way, letting them pause and proceed at their own rate of thinking and speaking, allowing space to talk and time for silence (Rapley 2004, Wertz 2005, 1987a, 1984, 1982, van Manen 1997). The key is flexibility allowing the interviewee's experience to unfold (Rose 1994). The interviewer has an empathic access to the world of the interviewee not only by words, but by tone of voice, expressions and gestures in the natural flow of the conversation. Actively listening, to what is said, but also be aware of what is not said (Noaks and Wincup 2004, Wertz 1984). The interactions between interviewer and interviewee are explored further in reflexivity at the end of this chapter. Throughout the interaction I required being 'in tune' and relaxed with the participant, gently responding, and adapting my approach, establishing a close relationship of trust (Ellis and Berger 2003).

Further follow up in-depth unstructured interviews occurred with the majority of participants. Each participant was in control as to whether they wished to participate in further interviews or not. All eighteen participants wanted to be involved in multiple interviews. Unfortunately one person became very unwell and was unable to continue.

These built upon the previous interviews, allowing clarifications, greater depth and the expression of new experiences. Again the

opening question was used. Often participants shared more sensitive experiences, due to the trust and rapport already established. There were no time limits on any interviews. It was entirely up to the interviewee. Some interviewees stopped after a few hours; others continued to express their experiences for over six hours with breaks in between. Fatigue was carefully monitored.

This time frame could appear long, however it worked extremely well. The majority of participants conveyed full and in-depth experiences, building on ever increasing depth with more and more new things emerging. Some participants repeated earlier experiences, but then built upon what they had conveyed allowing new things to emerge. Other participants with lupus experienced memory and word finding difficulties. This meant that it could take them time to express their experiences and build upon these. With no time restraints, they could express these experiences without feeling pressurised or anxious. They had complete control of how long the interview was resulting in new insights emerging. Passing control of the structure and length of the interview to each participant worked well. If there had been time constraints the depth and illumination of new insights would have been affected. These multiple interviews occurred over an approximately four month period, depending upon the person. The total data collection phase lasted for seventeen to eighteen months.

Due to the susceptibility of researcher bias, criticism has been directed towards this method of data collection. Within interpretive phenomenology I am a central figure who could influence participants' responses, thereby influencing the direction of findings (Finlay 2002). Throughout the entire research study I needed to demonstrate and consequently augment trustworthiness through transparency and openness. Reflexivity helps to bring responses and preconceptions to the fore. To assist a detailed reflective journal was kept, elucidating

thoughts at each stage of the research process. This is an integral part of the interpretive process. Field notes comprised factual details about negotiating access and describing the circumstances of the interview. The subjective notes included personal attitudes, emotional responses, and thoughts about the participants (Hertz 1997, Holstein and Gubrium 1997, Allen 1996, Koch 1994, Cotterill and Letherby 1993, Rodgers and Cowles 1993, Drew 1989).

Within this co-constructed interaction each person will influence the other; as such I as a co-creator can make a unique significant contribution to the research endeavour aiding additional insights (Hammersley and Atkinson 1983). This can enable a deeper understanding of the phenomenon of SLE to emerge, with a potential to add to the richness of data collection and analysis (Dingwall 1997, Jenks 1995, Streubert 1995, Drew 1989). A shared interest between interviewer and interviewee and knowledge of the phenomenon of SLE could be viewed as ultimately strengthening the validity of the research findings, where knowledge is constructed from multiple perspectives (Kvale 1996, Whyte 1992). However I also needed to demonstrate the ability to prioritise the participants' description and interpret from their insider view (Etter-Lewis 1996, Ashworth 1987, Sandelowsi 1986). This is demonstrated by the fidelity to the participants' descriptions, allowing the reader the ability to judge the trustworthiness of the interpretations offered.

Criticism has also been directed towards the flexibility of the interview process. Britten (1997) points out, that interviews need a degree of structure to ensure the data gathered is relevant to the research question. However within Heideggerian phenomenological research, whether any data generated can be viewed as irrelevant is contentious.

4.8.2 Other research studies employing interviews

A growing body of information has become available on the technique and nature of research interviewing (Benner 1994, Gilchrist 1992, Morse 1991, Minichiello et al 1990, Drew 1989, Mischler 1986a, Field and Morse 1985, Walker 1985, Gordon 1980). A number of studies within phenomenology have employed in-depth unstructured interviews (King et al 2008, Finlay 2008, 2004, 2003b, Ranheim 2006, Groenewald 2004). Within Finlay's (1998: 94) study, nine occupational therapists were interviewed to gain insight into their life world. The choice for interviews was justified as the most direct way 'to gain access to the person's meanings'. Davidson et al (2001) studied the difficult problem of recidivism among twelve people with schizophrenia. The interviews encouraged participants to provide their life experiences.

4.8.3 Other data collection methods

Researchers studying first-person lived experiences and employing phenomenology mainly employ word based methods such as interviews (Roulston 2010, Todres and Holloway 2006, van Manen 2006, Dinkins 2005, Moustakas 1994). This is undoubtedly a useful technique, but perhaps this emphasis can limit the multitude of ways the researcher could explore the everyday life-world of the person. John Dewey (2005: 77) suggests that some meanings can only be expressed through visual or auditory media, which have their own 'distinctive existence'. These media can express that which cannot be communicated within the spoken word (Dahlberg et al 2007). These methods have the ability to draw 'on the fabric of brute meaning' (Merleau-Ponty 1998:123) creating a shared empathic understanding of people's experiences (Malinski 2002, Reeder 1993).

Davey (1995: 5) discusses how Heidegger's philosophy shows a concern with the ability of visual art to 'disclose an understanding of both ourselves and our being in the world in an immediate, unique and revelatory manner'. Heidegger (1971, 2001) was one of the first great philosophical thinkers that can be credited for clarifying the phenomena or truths that art can make apparent. He showed great interest in art and poetry. In his most important essay 'The Origin of the Work of Art', Heidegger rejected that art is only concerned with beauty; pleasure and only has an aesthetic value (Harries 2009, Wartenberg 2002, Mallin 1996, Hofstadter 1971). He characterises art as the-setting-itself-to-work of truth (Kearney and Rasmussen 2001). For Heidegger this intimate connection between truth and art is the highest manner in which truth obtains existence for itself (Harries 2009). In 'Being and time' Heidegger understands truth as disclosure and links it to authenticity. The art work opens in its own way the Being of beings (Mallin 1996). This opening up and de-concealing the truth of beings, happens in the work (Harries 2009, Wartenberg 2002, Hofstadter, 1965).

Each of these data collection methods has its own language of expression, they are lived experiences transformed into configurations (shape/form/time). They can enhance our understanding of the phenomenon, revealing dimensions not previously considered (Dengerink Chaplin 2002, Heidegger 1971, 2001, van Manen 1990, Gadamer 1977, Merleau-Ponty 1964a, b, c). The media of expression are as much about the person's history as it is about their present and future (Gullemin 2004, Ricoeur 1981). These artistic media have the ability to re-interpret and re-present the everyday life world of SLE, and to 'extend and alter their being' (Davey 1995: 4, Delancey 2009, Langdridge 2007).

An integrated approach was used combining both a medium of the participant's choice, such as photography or drawings with an in-depth unstructured interview discussing their media. The use of this integrated approach combines not only a visual or sound medium but a word based method. This enables participants to articulate their everyday world in meaningful and creative ways on their own terms (Finley 2008, Veale 2005). They have the advantage of allowing deeper levels of meaning to emerge and assist the clarification and understanding of the multitude of meanings expressed.

Each participant was asked if they would like to use media of their choice to express 'what lupus means to you?' It was entirely up to the participant if they wished to be involved. All equipment, such as cameras, was supplied. For example, a participant who chose photography was asked "(name of participant) *can you photograph what lupus means to you?"* If the participant wished to keep a weekly journal, they were asked to record their experiences of living with lupus. Helpful suggestions were included on a sheet (Appendix, 7). Participants had a few months to reflect and express themselves without feeling pressurized by time constraints (Gauntlett 2005).

Upon completion audio-taped in-depth unstructured interviews occurred. I asked an initial question "(name of participant) *can you describe in as much detail as possible your (media, drawing or photograph) of what lupus means to you?"* I followed up descriptions with prompts when and if required such as 'what do you mean......' and clarifications of the emerging meanings. Through this process participants were able to explore and express the meanings of their particular media in depth. The data collected comprised not only the media, but also the participants' verbal descriptions and interpretations of their media.

Through the media participants were able to give vivid descriptions of their experiences, building upon the peeling layers. These visual and sound media can constitute ways of being-in-the-world in multiple contexts and can offer insights and understandings into the person's lived experiences that may in some instances resist linguistic expression (Pink 2007). This opening up of possibilities allows multifaceted perspectives, on the everyday life world of SLE in illuminating and insightful ways and leads to a much deeper understanding of the complexity of this phenomenon (Berndtsson et al 2007, Leight 2002, Gallagher 1992, Gadamer 1989).

The majority of participants had multiple unstructured in-depth interviews discussing their media. There was no time constraint; it was entirely up to each interviewee. Interviews lasted from a few hours to four hours, with breaks.

4.8.4 Measures taken when employing a variety of data collection methods

These multiple media could be open to the criticism of being too 'broad'. However the justification for their use is a direct response from participants wishing to be able to express their everyday life-world through media of their choice that has meaning for them (Finley 2008, Veale 2005, van Manen 1997). It must be remembered that the phenomenological method is shaped according to the intrinsic demands 'of the things themselves' and allows creative developments of diverse procedures (Heidegger 1962: 58). However the rationale for using all of these data collection methods must be carefully considered and shaped through the analysis process.

Criticism has also been directed at the idea of using images as a way of conveying meaning. Prosser (1998) and Silverman (1993) have

directed criticism at visual methodologies in connection with the use and interpretation and the issue of validity. The interpretation of these images could be open to criticism of being subjective and riddled with ambiguity. However any medium can be viewed as unfinished insofar as it is a source of unfinished possibilities of meanings and interpretations; it is an ever unfolding possibility of meaning. I am purely giving one interpretation and it is up to the reader to judge the validity and credibility of the interpretation. To overcome this criticism a number of important steps were taken to ensure the transparency and openness of this study. Firstly the media should not be 'interpreted' in isolation from the person who has created it. By using an integrated approach it allowed clarification and understanding of the meanings expressed by the participant and deeper levels of meaning to emerge. Rose (2001) reiterates this point, suggesting that the image requires to be explored with the person, to clarify meanings.

Secondly the media should not be analysed on its own. Both the participants' interview about their media and the media itself are analysed. Throughout the analysis I drew upon the transcript of the interview, and the media (Wertz 1983). Thirdly the media must not be altered in any way and needs to be displayed in its original form. If any intervention is necessary I must be honest and declare precisely what has been changed. This must be agreed by the participant and made clear to the reader. With the presentation of the media are descriptions and direct quotes from participants. This provides readers with an opportunity to form their own interpretation and at the same time permits verification of the analysis presented (Patton 2002). Rose (2001) also suggests that the media should be presented unaltered.

Fourthly the variety of different media used, and descriptions from participants allows the opportunity for the researcher to clarify, verify and elaborate, bringing to life the phenomenological experience. The

researcher can look for any inconsistencies or contradictions of the images with the other data collected, giving voice to differences (Wertz 2005, 1983, van Maanen 1983).

4.8.5 Other research studies employing a variety of data collection methods

A number of research studies have employed drawings. A distinctive study researching menopause and heart disease, using a similar integrated approach that combined drawings and an interview is by Guillemin (2004). However within this study, Guillemin (2004) initially interviewed participants. Then, the participants were asked to draw how they understood their condition and then asked to describe their image. Nowicka-Sauer (2007) explored the experiences and illness perception of SLE through drawing. This study consisted of thirty-eight women who attended a 'my life' course and were asked to draw their disease. The women provided comments on their pictures. The experiences of women with HIV have been explored by Salmon (1993) using life history and drawing methods. Participants were given instructions on how they should draw based upon Fleming and Cox (1989) which encourages depiction of physical concerns. The approach of Fleming and Cox (1989) is directional. They give quite specific instructions on what the person should do, specifying the size of the paper and how the drawing should be laid out. They gave suggestions for prompts when discussing the pictures. These include for example; do you see any connections? Do the drawings suggest any relationship between your physical problems and your feelings?

Drawings have been utilised within chronic, life-threatening and terminal conditions, revealing attitudes and beliefs about the illness (Tate 1989, Williams 1988, Siegel 1986, Furth 1981, Gordon 1978, Perkins 1976, Bach 1966). Martin's (1994) study 'Flexible bodies'

involved conversations with different community groups about how they understood their immune system. Participants were asked to comment on media images of the immune system to give insights in to how adults view health and illness experiences. Wertz's (1987a) study asked 'what is abnormality in everyday life?' and involved one hundred and twenty people. Participants explored this question by using drawings, written summaries or interviews. Participants given the task of drawing could write a summary to clarify their picture. Data was analysed using Wertz's (1983) method.

The emphasis on the elicitation of participants' own meanings and experiences has prompted researchers to hand participant's cameras to take pictures. This method is called auto-driving (Heisley and Levy 1991). This allows ownership of the dialogue through the selection of their photographs and increases empowerment, (Lassetter et al 2007, Oliffe and Bottorff 2007, Quinn et al 2006, Hurworth 2003). The autobiography of illness 'the invading body' combines literacy and pictorial accounts (Avrahami 2007).

Music has been studied in relation to the body, time and space with adults with chronic illness (Jonas-Simpson 2007, Nicol 2004, Ruud 1997, Schorr 1993, Sacks 1984). The combination of diaries and interviews in phenomenological research assists people to reflect on aspects of their past and present life (Clarke and Iphofen 2006, Miller 1999, Dyck and Forwell 1997, Lauterbach 1992, Van Manen 1990).

4.9 Ethics

When undertaking interpretive phenomenology, data is collected from participants in a variety of ways, the interactions are co-created, participants are actively involved within the research and mutual openness and sharing will occur. Participants can disclose very

personal information, may become upset and share intimate experiences that have been reawakened. These possibly painful experiences may not have been shared with anyone else (Hudson 2003, May 1991). Yet, I as a researcher am asking participants to bare all and expose themselves.

This obviously raises questions about how participants are viewed and treated. It was important that I not only safeguarded and protected the participants but also endeavour to make the process a positive one. To achieve this, a number of measures can be taken in terms of informed consent, confidentiality, respect, and protecting each individual participant. I was aided in this process by the ethics committees. This study received approval from the Oxford Brookes School of Health and Social Care Research Ethics Committee and the Oxford Brookes University Research Ethics Committee.

The following discussion focuses on three areas, informed consent, confidentiality, and protecting participants.

4.9.1 Informed consent

Informed consent was obtained on an ongoing basis throughout the study in several ways. The Chairperson of the Hampshire lupus group disseminated information to all members; part of this information was the participant information sheet. These sheets discussed the purpose of the study, confidentiality and what participants would be asked to be involved in. The information allowed potential participants the opportunity to decide whether they would be interested in taking part, or not. My contact details also ensured interested people could obtain more information before deciding whether to be involved.

Those interested returned the reply slip or contacted me by other means. I informally discussed the study with all interested participants by phone, giving them time and the opportunity to discuss any concerns or query any aspect that they were unsure about. All participants agreed verbally to be interviewed.

Prior to obtaining written consent face-to-face discussions occurred between myself and the participant. This allowed time to go through the participant sheets and discuss any concerns or issues raised in relation to the study. All participants understood they could withdraw from the research study at any time.

All participants consented to being audio-taped. Participants were encouraged to be in control of the interview structure and process. Before any interview all participants signed a consent form and received a copy. Consent was always re-sought and reiterated at subsequent interviews. Consent was obtained for any media aspects which they decided to submit with guaranteed anonymity. Participants were aware and gave consent for their data to be used on more than one occasion, such as for publication purposes.

4.9.2 Confidentiality

All the participants understood that information they gave would be confidential and anonymous. Any details which could identify them, such as names, addresses, were changed. Transcripts were given to those participants who wanted a copy. On follow up interviews, participants were shown their anonymous transcripts, to establish that they were happy with the confidentiality. All information about participants was securely and safely stored.

4.9.3 Protecting the participant

Throughout the study I endeavoured to make sure that participants felt included, important, valuable, respected and in control. To facilitate this, a warm interpersonal connection is vital. Participants were always in control of where and what time they wanted to meet and the structure and the length of the interview. Time was given before and after the interview to discuss anything in relation to the study. All participants were offered a copy of the transcript; the majority of people accepted these and gave feedback, acknowledging that they were happy. Initial emerging themes were shared with some participants who wanted to be involved.

Some people with SLE experience difficulties in communicating related to muscular problems in their mouth and throat or difficulties with memory or word-finding. This could cause difficulties in relation to articulation, and the ability to express their experiences. No participant was excluded from the study due to any difficulties they felt they had with their communication. Any concerns they had were discussed. I ensured that the participant's welfare was of top priority and that they were acknowledged for their information rich experiences.

The whole process was made as positive as possible. Participants were given time to facilitate the expression of their often painful experiences in a safe, non-judgemental and empowering way. Ultimately it is my responsibility to maintain the professionalism and integrity for all aspects of my research study (Ezzy 2002, Kellehear 1993).

5.0 Chapter 5 - Analysis

5.1 Rationale for the choice of analysis

As analysis is pivotal to draw sound insights and conclusions, the data analysis is possibly the most important phase of this research. This in-depth exploration of the lived experience of SLE required the analysis to be sensitive and responsive to the multitude of intertwining meanings within the participants' lived situations. Also, the congruence between the philosophical underpinnings of interpretive phenomenology and the analysis had to be ensured. Thus, the fidelity was maintained and allowed the reader to judge the methodological coherence of the study.

I must ensure that the analysis is rigorous, open and transparent, thus allowing readers the opportunity to follow a) my decision making processes b) judgement of the soundness and validity of the interpretations. Proposed interpretations must be supported by the evidence of participants' descriptions to maintain fidelity to the interview transcripts. Readers may disagree with the interpretations offered, however interpretations are only viewed as tentative, opening up a field of possible interpretations c) a clear audit trail, showing the data analysis process d) my reflexivity, allowing honest insight into the analysis, interpretations and decisions.

Also the analysis required to be compatible with a variety of different data collected including; interviews; journals; art; music and photographs, and that the analysis required to have been previously used with some of these media. Thus it was a well recognised method, but had the potential to be developed further.

Therefore the analysis of choice required to be rigorous, systematic, open, transparent and robust, with a 'good pedigree' that is, to have been reliably trialled. It also required to have flexibility, creativity, and to be sensitive to the phenomenon of SLE.

5.2 The choice of analysis

Heidegger gave many important philosophical insights, which can assist within the analysis phase. But he did not develop any research methods as such. With this in mind, I was required to consider the suitability and compatibility of a variety of different methods of analysis, so as to establish which is the most appropriate. The following discussion will briefly focus upon a few examples that could be used. These include the methods of Benner (1984), Diekelmann et al (1989), Colaizzi (1978) and Giorgi and Giorgi (2003). Consideration was given to their use, but also their feasibility for this study.

5.3 Suitability and compatibility of different methods of analysis

Within the interpretive phenomenological approach, analysis methods have been developed by researchers such as Benner (1984), Benner and Wrubel (1989) and Diekelmann et al (1989). Nursing theory has been advanced considerably by Benner's (1984) theory of 'novice to expert'. Benner (1984) used a method of analysis, consisting of three interrelated processes; including; thematic analysis, analysis of exemplars and paradigm cases. Benner's (1984) method has been criticised by Caelli (2000) and Crotty (1996) who suggest, that it synthesizes themes to express a general level description, rather than gain access to the phenomenon. Diekelmann et al (1989) has a seven-stage process of data analysis that involves a team of researchers in a collaborative effort to describe common meanings and shared practices.

Colaizzi's (1978) analysis has been widely used by nurse researchers and has been utilised for phenomenological research but also interpretive phenomenological research (Scannell-Desch 2005, Thomas 2005, Perreault et al 2004, Fleming et al 2003, Priest, 2002, Hodges et al 2001). The analysis has been used for varied lived experiences, in different age groups (Pratt 2006, Iaquinta and Larrabee 2004, Baillie 1996, Beck 1992, Coward 1990). Even though his involvement in phenomenological research has declined, the method is still widely used (Thomas 2005). Each of these researchers has developed techniques especially suited to understand their particular experiential phenomenon.

After careful consideration, the following examples of methods of analysis including Benner (1984), Diekelmann et al (1989) and Colaizzi (1978) were dismissed from this study for the following reasons. There appeared to be a lack of clarity regarding the inclusion of additional data, such as photographs and journals within the analysis, and if these data could be included how they would be analysed. The analysis required a research team to be involved.

As a novice researcher, I felt these methods also appeared to be presented as rather neutral, abstract, and disembodied techniques that were applied to the data. This may have been due to the way they were presented, or the lack of clarity of the analysis procedures. This gave the impression that I, the method and the data were all separate entities rather than reflexively interconnected and interdependent. Inherent in the phenomenological attitude is the understanding that I will inevitably influence the form and content of their findings (Fisher and Wertz, 1979). The analysis procedures are therefore not simply neutral techniques because they carry my ontological and epistemological assumptions (Alvesson and Skoldberg 2000). I cannot 'eliminate' my experience, which will be inextricably linked to

interpretations (Thompson 1990:246). These horizons that I bring to the study are influential and require reflection (Gadamer 1976).

This study was seeking depth, to understand the lived experience of SLE in its many manifestations. To achieve this required an analysis that sought to explicate the holistic human experience through disciplined reflection. Reflection involves meaningfully integrating the whole experience, including existential dimensions and re-engaging with the lived experience in a new light (Wertz 1999, Ricoeur 1985). Wertz (1983: 204) discusses 'we cannot be spectators but must experience the joys and pains of our participants in full detail and in our very depths, if we are to faithfully know them' (Burnard 1991, Steiner 1978). Within interpretive phenomenology Heidegger (1962) describes that the analysis involves a prolonged period of reflection on both parts of the data and the whole, in order to situate the meanings derived. This involves 'being-with' rather than doing-to. It involves being 'fascinated with' and immersed in the other, and it involves 'spontaneous upsurges of empathy and intuition' combined with intense reflective concentration and reflexive awareness (Finlay 2006: 2). As Heidegger (1962: 206) suggests: 'Listening to, is Dasein's existential way of Being-open as Being-with for others, As a Being-in-the-world with Others, Dasein is in thrall'. Only through deep penetrative reflection could the understanding of the phenomenon of SLE be enhanced.

This study also required the ability to be able to show reader's all stages of the analysis and how the interpretations were developed. There can be tendency to simplify the complex process of representing the voices of participants as though these speak for themselves rather than through me, as I will inevitably make the 'choices about how to interpret these voices and which transcript extracts to present as evidence' (Reinharz 1992: 267, Frith and

Kitzinger 1998). Readers as interpreters themselves, participate in the process of interpretation by bringing their own horizons to the work (Gadamer 1990, Bollnow 1966). Critically although readers may not share the authors' interpretations, they must be given the framework that led to the interpretation given (Benner 1994). I still required a method of analysis that would respond faithfully and as comprehensively as possible to the whole phenomenon of SLE (Sardello 1971, Giorgi 1971).

The Dusquesne University situated in Pittsburgh Pennsylvania USA, has developed methods for carrying out existential phenomenological research. Existential phenomenology blends the philosophy of existentialism with the methods of phenomenology (Valle and King 1978). This results in contextually based, holistic psychology that views human beings in non-dualistic terms and seeks to attain a first person description of experience (Giorgi 1983). The philosophy underlying existential-phenomenology is associated with the works of Heidegger (1962) and Merleau-Ponty (1962). It requires seeing the world from a new perspective, and the being is a being-in-the-world (Heidegger 1962). The Dusquesne University psychology department emphasises qualitative research that explores questions regarding meaning and experience with the pursuit of psychology as a human science. It explores hermeneutics, psychoanalysis, existential and phenomenological approaches and has a worldwide reputation for outstanding research.

The Dusquesne University has influenced many researchers in their quest to establish and develop reliable methods of analysis. Amedeo Giorgi (1970) with the Dusquesne circle including such researchers as William Fisher, Von Eckartsberg and Constance Fisher can be credited with the development of phenomenological research during the 1960's to 1970's (von Eckartsberg 1971, Fisher 1974, Fisher and

Wertz 1979, Wertz 2005, Cloonan 1995). The aim of the Dusquesne University was to develop phenomenological psychology with the investigation of phenomena being methodical, systematic and rigorous, drawing on descriptions from participants and philosophical insights of phenomenology. In other words for 'scientific research' to be carried out the informative philosophical insights and principles need to be translated (Giorgi 2000a:4).

A variety of different methods have been developed within the Dusquesne University, including, forms of expression and analysis, depending upon individual researchers and their studies phenomenon. Giorgi (1985, 1975) and Giorgi and Giorgi (2003) determined four steps that are involved in all phenomenological orientated psychological research (Wertz 1983). These include, 1) reading the entire description to gain an overall sense of the whole 2) demarcating 'meaning units' to reveal the phenomenon 3) reflection on each meaning unit to try to reveal the phenomenon and 4) the expressions and insights are combined to express the experience.

Wertz (1983:197) comments that Giorgi's steps 'are particularly interesting, useful and powerful, as they appear to be present even if implicit in all phenomenological orientated psychological research' allowing the researcher to proceed rigorously and systematically. However, for a novice researcher Giorgi's (1975), steps may require clarification, to ascertain precisely what the reflection activities involve, as this is not specified. This is reiterated by Wertz (1983: 198) who discusses that the one limitation of Giorgi's (1975, a, b,) method is it's 'lack of a detailed elaboration of the procedures undertaken, particularly the reflection activities'. The following discussion outlines a brief introduction into the development of Wertz's (1983) method of analysis and then phenomenological research studies employing Wertz (1983) method.

5.4 The development of Wertz's (1983) method of analysis

In 1978, Wertz, an existential phenomenological researcher, reviewed all completed dissertations from the Dusquesne University, aiming to clarify, develop and increase understanding of the procedures of a research study including the analysis. Wertz was particularly interested in how researchers were carrying out part three of Giorgi's (1975, a, b) phenomenological analysis, the reflection phase (Wertz 1983a, 1985).

This phase had remained opaque, mainly due to the complex multiple reasoning, comprehension, understanding, and sense making operations (Wertz 1983). After reviewing the dissertations, Wertz started to consider all the many interrelated phases researchers were using. In trying to ascertain the processes involved, Wertz carried out a research study 'being criminally victimised' (1983) to allow increased insights into these reflective activities, and the multiple modes of understanding researchers were using. From this research study, Wertz's (1983) developed a method of analysis that follows on from Giorgi's (1975 a, b) general outline, allowing fuller insight and understanding into the steps of the attitude of the researcher and the analysis process including the psychological reflection activities.

But, most importantly, and this cannot be over emphasised, interpretative phenomenology cannot be reduced to a set of procedural steps. Wertz, himself, had reservations that his method of analysis would be used "as a kind of cookbook". The procedures are there to enhance interpretation so that the reflection activities can be 'spontaneous, free-wheeling and risky' (Wertz 1983:199).

This is especially pertinent, as the analysis chosen for this study is required to be sensitive and responsive to the phenomenon of SLE,

allowing flexibility, and creativity. This is reiterated by Giorgi (1971a) who expresses the concern that, no method should be imposed that might do an injustice to the phenomena; the method adopted by the researcher should arise out of the data.

5.5 Phenomenological research studies employing Wertz's (1983) method

There are a number of interpretive and phenomenological research studies which have employed Wertz's (1983) method of analysis. Finlay's (1998) interpretive phenomenological study captured 'the lifeworld of the occupational therapist'. Her study involved interviews and observations with twelve occupational therapists. She does not include sample analyses that illustrate in any depth the procedures of her interpretations. Nevertheless Finlay (1998:139) experienced 'the emergent, ever-shifting nature of my data and the complex analysis offered a strange security. Perhaps I was liberated from having to produce a 'right' or 'definitive answer'. Francis-Wright (2007) also utilized Wertz's (1983) analysis in his interpretive phenomenological study of 'living with Dyslexia'. He used multiple data gathering methods, including interviews, audio taped journals and documentary sources from eight participants. No sample analyses were included. Francis-Wright (2007:109) reported that Wertz's analysis was, "difficult to follow", and aspects of the process "remained rather too difficult to apply". Nevertheless both Finlay's (1998) and Francis-Wright's (2007) studies are rigorous in their reflexivity, interpretations and conclusions.

A significant body of interpretive and phenomenological research has employed a method of analysis which combines the work of Wertz (1983) and Giorgi (1985). Responding to the need for investigation into consumer credit problems, Hill (1994) selected the analyses of Giorgi and Wertz to uncover the nuances and emotional tone of fifteen

debtors. Quail et al (1994) studied a client's experience in art therapy, using verbal descriptions from the participant reflecting on their art work. Ashworth et al (1997) investigated students' perceptions of cheating and plagiarism with nineteen participants, involving several authors to aid the formidable task of analysing this number of participants. Other studies which have trialled Giorgi and Wertz analyses include Ashworth and Lucus (2000), Milligan (2001) and Finlay (2001).

Although there is a lack of precise data analyses and samples analysis in the literature above, McCraken (1988:41) argues that 'the exact manner in which the investigator will travel the path from data to observations, conclusions and scholarly assertion cannot and should not be fully specified'. However, a study can only achieve transparency, validity and openness by a description of the components of the analysis and providing sample analyses. These provide readers an opportunity to follow and judge the soundness of interpretations and conclusions (Wertz 2005). Sandelowski (2000:336) endorses this view, 'Wertz's (1983) analysis of the 'moments' of a phenomenological study is an excellent demonstration of the successive transformations from a participants description of an event to a researchers phenomenological description of that event'.

5.6 Summary regarding the choice of analysis

Wertz's (1983) method is methodical, systematic and rigorous; it is also responsive to the phenomenon, allowing creativity and flexibility. It is sensitive to the 'lifeworld existential' such as corporality and temporality (van Manen 1990:101). When embarking on such existential descriptions I must go beyond just the words and descriptions, and read into, between and beyond them.

Methodological coherence can be ensured and alternative data, such as drawings can be utilized within his analysis. The key question concerning the use of these 'artistic media is how to use them in a way that is genuinely psychologically revelatory' (Wertz 1999:154). These media reveal meanings that are found within the person's human experience, and provide insight and understanding of their life world. This is what makes their inclusion psychological and justifies the use of artistic media (Sass 1992, Freud 1916-7, Yancar and Slife 1997a, Yanchar 1997b). Although not all the alternative data, such as photographs and music have been trialled using this method, I can build on the preliminary ground work.

Sample analysis and procedures can be demonstrated allowing transparency and openness and establishing an audit trail. This would allow readers the opportunity to judge the interpretations and validity of insights themselves. Incorporated within the analysis procedures are my reflections adding another layer of interpretation and aiding transparency. Wertz's (1983) method of analysis would allow the voices of participants to be heard, and allow for variation. It will focus on the individual, whilst exploring and eliciting the collective experience. Wertz's (1983) method can also be evaluated throughout. The complexity of human meaning demands a method that is multidimensional with the holistic interrogation of the entire field in which it resides (Wertz 1987d, Freud 1900). Wertz's (1983) method allows this holistic, 'relationally attuned insight, which is the basis for establishing psychological knowledge' (Wertz 1999: 150). This allows a return to the 'primacy of existence itself the life world, with all its multifaceted ambiguity and mystery' (Wertz 1999:151).

Wertz's (1983) method is particularly attractive because of the clarity of the reflection activities, and its ability to communicate powerful insights acknowledging the multi-intertwining reasoning that occurs.

This way of reasoning has similarities to how therapists work (Mattingly 1991). The analysis emphatically draws you in, tuning-in to the dimensions. This in itself is a total immersion, allowing a slow porous uptake, reflecting upon every aspect and refocusing on the experience in a new way (Anderson 1998, Moustakas 1990).

Another important part of the data analysis process involves sorting, organising and indexing data (Mason 1996). To begin with I tried to use the qualitative package 'NVivo'. Unfortunately, after trying 'NVivo', I felt it did not suit my way of working. I then used word files and media files on the computer for saving photographs, and additional information. It is very important that all files and media aspects are saved, so as to help manage the data, and ensure that a full, clear audit trail is established and recorded (Dickson-swift 2004).

This study used Wertz's (1983) method of analysis. The following discussion will explore Wertz's (1983) steps of analysis. Beginning with the preparatory phase, then moving on to the psychological analysis of the individual. Included are the reflection activities, and finally the psychological analysis of the general.

5.7 Steps of analysis

5.7.1 The preparatory phase

Wertz's (1983) method of analysis begins with a preparatory phase. Its primary purpose is to organise the interview data into a manageable written description, which is expressed in the participant's own language.

I listened to the participant's audiotape, with an open attitude gaining an overall sense of the experience and the expressions and meanings

used. The interview was saved on to the computer under a password sensitive key. This is the start of the audit trail for the analysis.

The interview is transcribed, and the transcript is read while still listening to the participants' interview, assisting the initial immersion. Participants checked their transcripts, to ensure they felt they were accurate records. The transcript was then saved on the computer under specific titles, continuing the audit trail.

The transcript was read a number of times, with an open attitude. The parts of the interview data can never be understood outside their context and relations to the whole. Distinguishable moments in the experience, or phases which express a distinct content, started to develop. These meaning units were named for example, 'before being diagnosed with lupus', 'living with lupus'. These general themes helped with the organisation of the data for the analysis, as descriptions may be complex and lengthy.

The transcript could then be re-ordered into a temporal order or interweaving themes to assist with the analysis. The preparatory phase resulted in an individual description which was named for example, 'Joanne's lived experience of lupus' which was saved within 'a window file. Wertz's (1983b, 2005:172) calls the result of this phase an 'individual phenomenal description'. The analysis now moved on to the 'psychological analysis of the individual' (Wertz's 1983: 203).

5.7.2 Psychological analysis of the individual

The psychological analysis of the individual requires five steps of the researcher's basic stance and eleven active operations of understanding come into play through reflection (Wertz 1983, 1983a, 1987b, 1993). The phenomenological stance is one of 'openness' and empathetic wonderment, requiring sensitivity, observance and

attentiveness to the lived experience, striving to be able to see things in a new way (Dahlberg et al 2001:97, Giorgi 1970, Finlay 2008). The steps of the researcher's stance are all seamlessly moved through on the many readings. The following steps are expressed within an orderly fashion, however in reality they were all so intertwined, and interconnected that ultimately the steps appear inseparable.

According to Wertz (1983) method the five steps include:

(1) Empathic immersion in the world of description.

I require an attitude of 'openness' that is highly empathic, reading the written transcript many times, immersing myself, experiencing the joys and pains of the participant in full detail. Each reading brings new meanings, allowing fuller access to the situation as it was lived; care is taken to gain a sense of the whole.

(2) Slowing down and dwelling

I must not pass over details of the description as if they are already understood. Instead, I must make room for the description and give it time. I must slow down and linger, dwell and let the sense emerge.

(3) Magnification and amplification of the situation

When slowing down and lingering, its significance becomes magnified. To a casual observer that which appears a 'little thing' becomes important to me.

(4) Suspension of belief and employment of intense interest

I must now step back and review and reflect on the situation. To begin to think interestedly about where the participant is, how they got there and what it means to be there, and to see the relations and overall structure.

(5) The turn from objects to their meaning

I turn my attention from the facts to the meanings. Focusing on the way the situation appears to the participant, the meaning of objects and events for them and the participation in terms of which such meanings arise. This delivers me to the situation precisely as experienced, as meant by the participant.

5.7.3 Activities of reflection

While being absorbed in the above stance the reflection activities are simultaneously performed. These are used to comprehend the precise meaning and sense of the situation in which the participant participates, occurring one at a time or in a continuous flow.

Activities of reflection include:

(1) Utilization of an 'existential baseline'

A typical day to day life is contemplated in which the phenomenon under study is not profoundly present. This serves as a foundation upon which the phenomenon under study stands out and is identified.

(2) Reflection on judgement

When I judge descriptive material to be relevant, I must reflect on my judgement. "What does this statement reveal about the phenomenon?"

(3) Grasping implicit meanings

Once I am firmly situated in the participant's world, I can reflect upon things not mentioned in the description but which are demonstrably present in the subject's life.

(4) Making distinctions

Each aspect of the situation is questioned, its relationship with each other, and its place and contribution in the whole. Each statement is asked, 'what it expresses that is different from the others', being sensitive to different aspects of a single situation (e.g. temporal moments, spatial constituents).

(5) Identification of relationship between themes

In thinking through the relations (e.g. spatial, temporal, social) of themes, I begin to see relative priorities, asking questions such as; what has this to do with that and that? What has this to do with the whole?

(6) Identification of recurrent meanings

This is closely related to the previous procedure. I am finding recurrent themes.

(7) Persistence in perplexing areas ('Interrogation of opacity')

There are always vague areas that are perplexing. Often sense is found by dwelling with special persistence on these areas and questioning their context.

(8) Imaginative variation and seeing the essence of the case:

I ask all themes if they could be different or even absent while still presenting the individuals psychological reality. For example: would it be the same if there was no illness? The essential characteristics could be grasped.

(9) Expressing the sense in the researcher's own words

Themes, phases, distinctions, relations are all named. This is now expressed in my own language, using appropriate words utilized in everyday language.

(10) Verification, modification and reformulation

I constantly return to the original transcript in order to verify my emerging reflections. "Is everything I am saying there? Is everything in the description reflected in the writing?"

(11) Using existential phenomenological concepts to guide reflection

I use existential phenomenological concepts to guide reflection: for example, temporality, corporeality and spatiality.

In the concluding stages of the analysis, I question the situation in view of previously held beliefs and presuppositions that may reveal aspects of the material that were not yet previously evident. Other data sources were combined, such as art forms and journals with my

reflections (Wertz 1977, 1982, 1985, 2005). The final stage of the individual analysis involves writing an in-depth summary of key themes and sub-themes with illustrative quotes and saving files on a computer maintaining a clear audit trail.

The psychological analysis of the general is the last phase, and this helps develop general insights into the phenomenon of SLE (Wertz 1985).

5.7.4 The psychological analysis of the general

Wertz (1983) explains that this phase involves four additional steps; these build upon and are simultaneously carried out with all the steps from the psychological analysis of the individual for the achievement of general psychological insights. Some statements may be more evident in more than one case and are therefore general but not true in all cases. This may show insights into the typical variations within the subject matter (Wertz 1983, 2005).

(1) Identification of general features of individual structures

I must determine which features of individual structures display a general truth and which features refer to that particular case.

(2) Comparisons of individual descriptions

I compare the analyses across all the individual studies to establish commonalities and differences. This requires reflection on all the phenomenological structures of the individual descriptions, identifying further meanings that may have remained hidden or obscured. My reflections and additional data can be used. While remembering,

imagining and collecting new data I remain alert for instances of the phenomenon that throw a different light on the study.

(3) Imaginative variation

I imagine different possibilities any and all possible variations of living with lupus and to see what is necessary for the phenomenon to qualify as an instance of it appearing.

(4) Explicit formulation of generality

The essential themes and structural relations that constitute this phenomenon in general are formulated, whilst giving voice to individual differences. I need to verify and elaborate on themes and sub-themes 'bringing to life' and expressing the phenomenological experience.

The psychological analysis of the general results in illustrative themes with quotes from participants, achieving general psychological insights. The structure must include all constituents of the phenomenon and be cohesive. Points of variation should be savoured and delved further. All general themes must be borne out in the description. These were recorded on a computer.

5.8 Presentation of results and extension of findings

The research required an account of methods used in organising and analysing the data. The validity of these procedures was established by demonstrating their fidelity to the phenomenon under study in its life-world presence, 'to the things themselves'. Sample analysis with descriptions and participants' quotes with also an account of procedures were shown, providing readers with an opportunity to

follow and judge the soundness and development of the conclusion. Findings were presented in many forms with photographs, drawings and illustrations (Wertz 2005) and discussed in relation to their impact on, theoretical knowledge, practical applications and the impact on participants. The psychological general insights were extended further by relating the findings to the life-world at large. This included the general public, the larger community, health professionals and the development of care services.

5.8.1 Sample analyses

The following discussion will explore two sample analyses, allowing readers an opportunity to follow and judge the soundness of the conclusion and insight into the procedures.

5.8.2 Peter's interview

The psychological analysis of the individual will be discussed (Wertz 1983).

Sub-theme 'Role, gender and identity'

As Peter expresses

"But as a man that's always been involved with lots of things and his work was part of who he is I'm now in a different place, I'm not that person anymore" (Pg 30, 647-650 T1)

Psychological analysis of the individual

Empathic immersion in the world of description is involved throughout. For Peter's description, as a researcher I had to place

myself in his position as a man who has experienced lupus for about 11 years. I placed myself in his situation being dependent and feel his sense of loss, isolation and loneliness. As I struggle with my day and remember how I used to be, I must wonder what the point of my life is now, I must think 'why me?' and feel the desolation over a life ruined. I am alone and vulnerable and think is life worth living?

I entered, **slow down and dwell**, letting the sense emerge. I needed to consider, what work means to Peter? What does Peter need from this? And what is he getting now? I put myself in Peter's situation of not being able to work, of a life now without purpose, or achievement, and where nothing makes sense. I feel his sense of anxiety, loneliness, and exclusion. I must wonder what the point of my life is. I search for meaning and yet can find none and I feel his sense of failure, disablement, and inability to provide, to be a man. I feel his worry about how others will see me, now I receive state help. I feel his sense of being lost, and wondering who he is, of feeling unease, and restless, in my constant quest to find where I have gone.

I now lingered, probing what is being said, and how it is being said. I enter **magnifies and amplifies**, and reflect on *'but as a man'*, what does Peter mean as a man? And what does he think he is now? Does Peter feel unable to be a man, a protector, lover, supporter, and strong in control? I reflected on the situation, to think about where Peter is, how he got there. I looked for relations and try to gain an overall structure.

To be able to reflect further I stepped back and entered **suspend belief and employ intense interest**. Where is Peter at this moment? How do you get to that point? What does it actually mean to be at that point in his life? I reflected on what 51 year old men do at this point in their lives? I placed myself in his position of evaluating his life, and

feel the intense pain of knowing what I have lost. Of wondering where my life has gone, all the wasted time and I must feel the intense loss of missed opportunities, a life wrecked. Of wondering what my future now holds, now that my future holds no guarantees and all the dreams I did have gone.

I turned from **objects to their meanings**. How does the situation appear to Peter? What are the meanings of his objects, what are the meanings of his events? I position myself in Peter's situation, being dependent on my wife, and how she exposes my weaknesses, and inabilities to fulfil my male role. The loving intimacy now changed, to dependency and the intense guilt as she goes off to work to support my family. I feel the constant pressures to try and do, yet never being able to achieve. I feel the intense expectation to carry on as if nothing has changed, yet being unable to fulfil.

Through every part are the intertwining **reflection activities**, the **utilization of an existential baseline**. I **reflected on judgement** "*I'm now in a different place*" Is this how Peter sees himself 'after lupus', where is he now, and what is this place like? I used the description to penetrate deeper to the implicit horizons. He does not express how a man should be, but all may be implicit significations that assist the fuller sense. I needed to consider **distinctions**. Closely attached to this is **relating of constituents**, for example; "*but as a man*", is closely related to "*I'm not that person any more*". Throughout the reflection activities I needed to question the **opacity and vagueness** of the description. What does Peter mean he is in a different place, what does this place mean to him. Through questioning I began to gain insights into where Peter is at this point in his life.

I moved into **imaginative variation** and see the essence of the situation. Would Peter's psychological structure be the same if he had

lost his job? No, because he could still be involved in lots of things and could work doing something else. If Peter had a different chronic illness would the psychological structure be the same? Well yes it could be it depends upon the illness, and therefore I would need to probe this further.

Throughout all these different activities I started to express themes, phases, and relations in my **language**. I then returned to the transcript in order to **verify** all the emerging reflections. Is everything I am saying there? Is everything in the description reflected in writing? Using the **existential phenomenological concepts** to guide reflection, I looked at self-world-other and how they all relate. Temporality, projects, selfhood, embodiment and Peters gender, how he relates to others in his life and his world around him. I continued to question aspects, what does it mean to be this person? What are their goals? What do they think about? Where do they experience their day? How do they experience their day? Is it pressured, slow, and discontinuous? Then I wrote the psychological reflection of the theme or sub-theme.

Psychological reflection:

Sub-theme 'Role', gender and identity

As Peter expresses

"But as a man that's always been involved with lots of things and his work was part of who he is I'm now in a different place, I'm not that person anymore" (Pg 30, 647-650 T1)

I placed myself in Peter's position where his world is now strange, desolation and a struggle to cope with anything. I feel his unease as

he doesn't know where he is, or who he is, or what he is supposed to be. However hard he tries, his life seems without purpose and makes no sense. I feel his guilt watching others perform his previous roles, and his frustration, anguish, and despair, remembering how he used to be. I feel his isolation an unbearable place to be. As he looks around at his previous life and his abilities to be, it shows him all too clearly his disabilities. I feel his desperate struggle to find who he is, and to try and regain who he was. He is left in this awful place of trying to be how he was, yet never being able to fulfil, stuck and yet unable to escape.

The second theme is from an interview with Joanne discussing her additional data in this case photographs. The principles of analysis are similar for any media.

5.8.3 Joanne's interview

I start on **psychological analysis of the individual,** I begin by focusing on the transcript, and then the photographs are reflected upon later in the analysis.

Sub-theme 'Who am I?' Loss of identity

As Joanne expresses

"All I wanted was to be a mum, to have a family... didn't I, is that so much to ask for, and now I don't feel I have anything.... I don't have anything really (deep sigh) I feel like...umm, I am like a pebble being drowned by lupus and it's eroding me; soon I won't exist...I will have just gone completely disappeared in to nothing" (Pg 19, 398-402 T2.2)

Empathic immersion for Joanne's description, I had to place myself in her position as a female who has experienced lupus for about eight years. I placed myself in her position of being dependent and feel her loss, anger and frustration, of being unable to fulfil her purpose, to be a woman. As I struggle to cope with each day and try to look after Tim, I must wonder if it will ever end. I must think 'why me?' and feel utter despair and anger at being cheated. As I look at my son, and reflect on what should have been, I feel her anger, it's so strong it's overwhelming.

I **slow down and dwell**, I needed to consider what 'to be a mum' means to Joanne? What does Joanne need from this? And what is she getting now? I placed myself in her situation, fulfilling the deep burning womanly longing to have a child, her lifetime dream. I placed myself in Joanne's position; feeling devastated; so angry at my loss and not able to fulfil my innate womanly desire. I am left with a deep longing, never to be extinguished, and each time I see Tim I see my intense loss. My lost future, dreams faded into despair and intense anger at my life, and bitterness at those around.

I lingered, probing what is being said, and how it is being said entering **magnifies and amplifies.** I stepped back and reflect further entering **suspend belief and employ intense interest**. What does it actually mean to be at that point in her life? Joanne is 29 years of age. I placed myself in her position being dependent; I feel her anger at her missed life of being a mum, the extreme tiredness and the hopelessness of my day. I struggle to carry on, but question what the point is; and yet I survive for Tim. I am so angry at my life, with the never ending longing of what should have been. I struggle on for Tim; I put on a front for him so he will not see my pain.

Now I turned from **objects to their meanings**. How does the situation appear to Joanne? I began with her theme, and then the photographs come into play. I put myself in Joanne's position, where I struggle being swamped by life demands, each day is a battle. I feel her always looking on yet never feeling a part. I feel her watch her mum look after Tim, and being so bitter that her mother can still do, while she cannot. I feel the guilt, intense despair, when I see other mums with their children, having a normal life, being true women. I feel her pain when I see my loving son, and hiding my pain tightly away, but when I see him I see my loss, and his future gone away. I feel her watching him from afar. Then I included the pictures.

I reflected deeper *"I am like a pebble"*. I placed myself in Joanne's position, of feeling completely detached from everything, shut within myself, of no concern just watching. *"Being drowned by lupus"*; I feel her lupus swamping me, engulfing me, as the waves keep coming in. I feel her drowning, gasping for breath, alone and sinking deeper and deeper as I loose myself, desperately trying to hang on to me. *"Eroding me"*; I feel her disappearing, slowly bit by bit. I feel the anxiety of completely disappearing, as she desperately fights to hang on to herself.

Figure 1 Joanne's photographs

I moved on to the **intertwining reflection activities**, consisting of the **utilization of an existential baseline**. I reflected on **judgement.** I used the description to penetrate deeper to the **implicit horizons.** I needed to consider **distinctions.** Throughout the reflection activities I question the **opacity and vagueness** of the description. What does Joanne mean *"I am like a pebble being drowned by lupus"* what does it feel like for Joanne to be drowned.

I involved **imaginative variation.** Would Joanne's psychological structure be the same if she couldn't have children? No, because she could maintain her other roles, such as a wife, worker, but her main goal in life would never be achieved, and this would cause her great despair.

I expressed in my **language** and returned to the transcript in order to **verify** all the merging reflections. Is everything in the description reflected in writing, and the photographs? I used the **existential phenomenological concepts** to guide reflection, looking at self-world-other and how they all relate. I continually returned to the

transcript as a whole, re-reading. I then wrote the psychological reflection of the theme or sub-theme.

Psychological reflection

Sub-theme 'Who am I?' Loss of identity

As Joanne expresses –

"All I wanted was to be a mum, to have a family... didn't I, is that so much to ask for, and now I don't feel I have anything.... I don't have anything really (deep sigh) I feel like...umm, I am like a pebble being drowned by lupus and it's eroding me; soon I won't exist...I will have just gone completely... disappeared, into nothing"(Pg 19, 398-402 T2.2)

Figure 1 Joanne's photographs
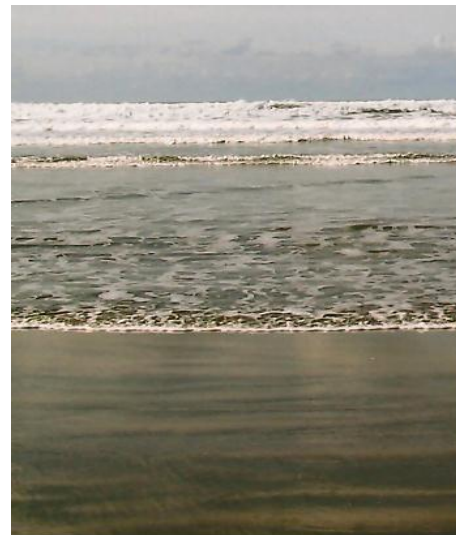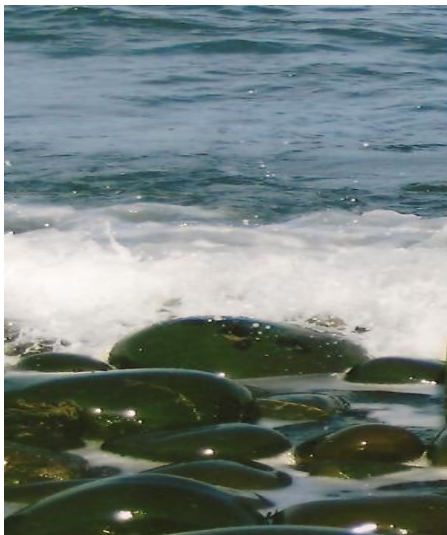
I placed myself in Joanne's position, of the intense burning womanly innate desire to be a mother, a longing so deep, but then lupus came with Tim. I placed myself in her position of being dependent, disabled,

looking in from afar, and so angry at life. I feel her frustration and anger watching others look after Tim, with the constant feeling she is losing herself. I feel her anguish at her constant battle against the lupus waves, of being so washed up and battered day after day, and still the waves wash over her, submerging her still further and taking her away. I feel her struggle and fight so hard against the powerful waves and her intense fear that she will submerge to such a depth, never to come up again. I feel her desperate gasps for breath, to try and keep her, but each wave takes a part of her out of sight and away. I feel her dread at her future, and her loss of seeing Tim, her endless struggle to keep herself from beneath the destroyer of the lupus sea.

5.9 Criteria for evaluation

An important part for any phenomenological researcher is how to ensure and show the reader the quality and trustworthiness of the study. The following brief discussion will give an overview of aspects within this study to maintain and show trustworthiness.

Guba and Lincoln (1996) suggest two sets of criteria to judge the quality of any qualitative research investigation, trustworthiness and authenticity. Trustworthiness embraces the criteria of credibility, transferability and dependability. And authenticity can be understood as relating to the degree in which the research enhances growth, understanding and future action. The use of these explicit criteria allows a researcher to highlight the strengths and limitations within their study. To aid transparency, this needs to be communicated to the reader clearly so that they can judge the trustworthiness of the study.

Guba and Lincoln (1996) argue that ensuring credibility is one of the most important factors in establishing trustworthiness. Credibility refers to the degree to which findings make sense, rather than establish 'truth'. The researcher needs to convey explicitly the procedures employed throughout the study, and whether these were appropriate and are well recognised methods. I discussed the justification for the well recognised data collection methods and the techniques employed. The use of a variety of methods can compensate for their individual limitations. Using such methods can enhance the study's ability to check out bits of information and negative cases (van Maanen 1983). Data collection was carried out over a period of seventeen to eighteen months, which was a fairly prolonged engagement.

A key component was the reflexivity journal which aided me not only to evaluate the study's progression, but also to record thoughts and reflections after each interview. The reflexivity journal has been used throughout the study. Participants have checked the accuracy of the transcripts (member checks), and have also been involved in discussing emerging themes. The feedback was reassuring and themes were explored as a result of participants' interest and it opened up additional insights, rather than validation as such which implies one truth.

Within the results detailed descriptions of the phenomenon are conveyed. Throughout the study's progression regular supervisory sessions, have allowed monitoring of methodological trustworthiness, discussion of issues, changes within direction, analysis and transcripts. This allowed a full open discussion regarding the interpretations, and different viewpoints, enabling the analysis to become enriched and continued skill development.

5.9.1 Reflexivity

The following brief discussion will explore a few of the reflexivity areas within the methodology. When embarking upon this research journey, the first hurdle to overcome was the philosophy and terminology within phenomenology. I was plunged into a quagmire of confusion as I battled to try and understand the alternative terms, and descriptions which often appeared vague and ambiguous. The term phenomenology was frequently used but there appeared to be confusion around its nature and meaning. This was particularly prominent within research articles where authors stated they were using a particular philosophy such as 'interpretive', 'hermeneutic', or 'descriptive' yet appeared to be using a completely different method or interchanging terminology. The rationale established for such studies evokes the names of the philosophers as justification, yet it could be noted that researchers offer no more than an over-view of the theoretical aspects of studies without explicitly defining the philosophical framework.

Researchers such as Paley (1997), Crotty (1996) and Kosh (1995) have directed the majority of criticisms towards nursing research, focusing on its subjectivity and lack of critique, and not following the original intentions of the phenomenological philosophers. Crotty (1996) refers to these researchers embracing what he calls 'new phenomenology' a hybrid American form of phenomenology.

However different forms of phenomenology may have developed due to the phenomenon under investigation and the knowledge the researcher seeks or the approach is being used for research and not philosophy (Caelli 2000). The phenomenological philosophers offered many eloquent insights, but little assistance regarding research methods and this can result in a multitude of interpretations and

understandings on how to apply their ideas (Lowenberg 1993). Garza (2007: 338) discusses 'the flexibility of phenomenological research and the adaptability of its methods to ever widening arcs of inquiry is one of its greatest strengths'. Perhaps it all comes down to how phenomenology is interpreted. As Caelli (2000:373) argues 'thoughtful, reflective descriptions of experience by research participants provide a broad canvas on which to paint a description of a phenomenon than is provided by traditional phenomenology'.

In my endeavour to understand I returned to the original philosophical insights reading Husserl, Heidegger, and Merleau-Ponty. I embraced the idea that phenomenology gave 'insights', but not necessarily answers or truths. Slowly I started to understand, to see the philosophical underpinnings and variations. From my original despair, came the pleasure of questioning at a deeper level, and enjoying reading contradictory thoughts.

Once I had established as far as I could the underpinnings of the different philosophies, my attraction was eventually directed towards interpretive phenomenology. Heidegger's (1962) philosophy was harmonious with the studies conception and aims but also my own ontological view. I carried on to ascertain that the philosophical underpinnings were compatible with the methods including data collection and analysis. I discussed all areas with my supervisory team, who aided further thinking and nurtured my progressive growth. They encouraged new reading, the expansion of my thinking, justification of my developing ideas, and to build upon these foundations. It began to make more sense and fitted together like a giant puzzle. The process of striving to understand phenomenology still continues and will never cease. But I will never reach a conclusion, because there is not one. The more I read, the more I realise just how little I know, and the more I understand the more my

interpretations and understandings will develop. This is what makes phenomenology never ending, exciting and stimulating.

5.9.2 Data collection methods:

Through the conception of the study, I decided that to explore this area required a variety of data collection methods and not to limit expression to only verbal descriptions. This stems mainly from my experience as an occupational therapist, and ways of evoking meanings and expressions in people on their own terms. I do not view using these as unusual, for me they are quite normal practices. I have learnt how powerful visual descriptions can be showing the brute meaning of an experience in stark dramatic clear ways. They also evoke new ways of seeing our taken for granted world, which can be intense. I was highly aware that I needed to reflect vigorously on my data collection phase. Wertz (1984:39) reminds us as researchers 'whose presence, for example in interviews can be responsible for omissions and even fabrications which are mistaken as valid data'. Also I was aware that my relationship with the participant would be crucial.

5.9.3 Including myself: and interactional reflexivity

I decided during the conceptualisation of the study, I would not say I had lupus on the participatory sheets. But if I was asked by any participant, then I would be honest. There were a number of reasons for this decision. Firstly 'the exposure of self, who is also a spectator, has to take us somewhere we couldn't otherwise get to. It requires being essential to the argument, not a decorative flourish, not exposure for its sake' (Behar 1996:14). What purpose would it serve to expose this? Would it be exposure for its sake? Or is it a safeguard for me?

Of course exposure may encourage some participants to feel they could talk to somebody who perhaps has a better understanding than most. But it could also confuse, cause ambiguity and distract from the importance of their experiences. Already I came under the heading of being a researcher and an occupational therapist. It was vital participants could report their experiences, without feeling intruded upon by a researcher who also has a similarities in experience. It could result in the closing down of the shared experience, rather than opening up of deeper more intimate layers. I wanted to remain open and focused on their experiences and not a mere reflection of mine. I also needed to be careful not to assume, or take for granted similarities of experience, and the shared understandings these may involve.

Also my past experiences helped guide me within this decision. From talking to people in clinics, I realised quickly they wanted somebody to listen to them, to be interested in their experiences, and to be able to convey their experiences maybe for the first time in a safe non-judgemental way. It should be their time to express intimate things with somebody who really wants to listen, to try and understand. Their condition remains hidden, dismissed, ignored or silenced by apathy towards others non understanding. This is their time to express their obscured experience, to be allowed to express what others try and shut away (Houston and Kramarae 1991).

Of course my own self disclosure could produce more in-depth data, to get to the real experience. But to get to the real experience may not necessarily involve this self disclosure. The advantage of having this insider experience is the ability to prompt and clarify not only at the right time, but open up their conversation and experiences further to a much greater intimate depth. Oakley (1981:49) discusses that 'there is no intimacy without reciprocity', but reciprocity can be achieved

through these interactions, it's the being-with, the feel from the other, the ability to seek deeper experiences in the right places, and the ability to fully explore the experience, where those without the insider experience may never tread.

The intimate deep connection established with participants could be built through the strong interaction of a mutual experience, where I can feel the other, resulting in empathic tuning-in. Where the participants not only feel truly listened to, but where clarifications and prompts are built upon through this mutual empathy. This can lead to participants feeling really understood. Somebody is really interested and wants to understand what their experience is like.

Of course as a researcher I am included in the interaction, the conversation, assisting the facilitation of this mutual intimate deeper connection. But through this interaction I strive for equality, without power over the other, or the need to take over and report my experiences or to reduce the control of the other in any way for the other is always in control. I have areas that unite, which I can relate to at a deeper intimate level. This is the empathic understanding of a mutual experience, an access to their world. But to never assume, for no one can ever truly know the other.

Empathy can be described as openness, a process of gently feeling into and the ability to be highly sensitive to the other (Rogers 1975, Gendlin 1962). It involves being totally drawn into the others world, to sense and feel their intricate reactions, but also being highly aware of my own, never judging. Checking out regularly that the senses and feelings I am experiencing are in-tune with the other, and being guided by the responses that I am receiving. My whole being is drawn into the other as I pick up on their feelings, expressions, non-verbal's, anxieties and fears experiencing the unified whole (Stein 1989,

Toombs 1993). Merleau-Ponty (1960/1964:172) describes powerfully 'It is through his body that the other person's soul is soul in my eyes'. I feel the other in a total subconscious reactive way, but are still able to feel and respond to my own reactions throughout, constantly adapting every part of me to each person's response. The strong unified tacit feelings that I feel from the other are enhanced by my empathic tuning-in, sensitive to all their minute signs, and the experiences they convey.

Being aware of when to clarify and letting the other move on, expanding on their expressed meanings and when silence is needed, a time for humour, and embodied empathy. Mutual empathy demands of me, an active memory, imagination, total awareness, sensitivity and an innate regard for the other (Davidson 2003). This results in a strong intimate connection between me and the other, allowing their experiences to unfold in a safe trusting relationship, within shared meanings (Hycner 1991). This interaction is extremely powerful, and my body and soul are absorbed with the other (Stein 1989). This joint relationship forms a connection that both fluctuates closeness and distance in an oscillating way (Todres 1990). Creating a strong intimate empathy and understanding of the other and it is this 'intersubjective horizon of experience that allows access to the experiences of others' (Wertz 2005:168). This oscillation draws me into 'a new space over everything and into everything' (Heidegger 1987:30). This enables empathy which is both the understanding of the other and self understanding, a true being-with. The data produced from this interaction can be full, and deep, with clarity of meanings expressed. These skills I have developed not as a researcher but through my many years of working, of being highly sensitive to the other and being-with. But these skills are aided by the mutual experience, empathic tuning-in, which enables sensitivity, intuition, and tacit understanding.

During all the interviews only three people asked me if I also had lupus. Interestingly they asked me after the interviews had finished, and didn't follow this up with any particular interest. I did ask why they had asked me. All reported they thought it was unusual for somebody to research this area unless they might have the condition or worked within the area. I do not feel that not exposing this mutual connection impacted upon the interaction achieved, in fact I think it aided the process. They were keen to convey their experiences to somebody who was interested in them. They wanted someone to hear and understand their perspective and in a way did not want to listen to somebody else's experiences of something they live with everyday. It was their time. I feel my initial feelings about this were correct.

I really enjoyed meeting each participant and hearing their experiences, I endeavoured to make the interaction enjoyable, relaxing and a positive one for them. It can cause some anxiety when a so called 'researcher' is visiting you, particularly as the term researcher will have already conjured up preconceptions. I suppose my background helped, dressing appropriately, and reducing anxiety through adapting my approach and being genuinely really pleased to meet them. I have been extremely privileged that they have allowed me into their world, and shared intimate painful experiences.

6.0 Chapter 6 - The Findings and Discussion Chapters

6.1 Introduction to the findings and discussion chapters

Three dominant themes emerged from the participant's everyday experiences of living with lupus. Self-doubt and doubt explores the participant's ongoing uncertainty about their symptoms, embodiment and illness and the continual doubts which they experienced from others regarding the reality of their illness experience, engendered by the perception of lupus being physically, socially, culturally and medically invisible.

Entrapment explores some of the multiple ways in which the participants felt entrapped within their situation. Lupus brought many barriers, restrictions and limitations and is perceived as closing down their potential and existential possibilities to engage in being-in-the-world, the future and their ability to be. The participant's situation feels uncontrollable, unremitting and inescapable as they were being forced to live a very different everyday life to one which they had experienced in health.

Coping and regaining resilience explores the varied and diverse ways the participants learnt to live with lupus and overcome adversity. They were learning to adapt and change in response to their circumstances and live forward actualising their possibilities.

Respecting the unique difference of the others' experience has been important throughout this study. I have therefore aimed throughout the findings to enable the thirty-two voices of the participants to be heard and allow the unique differences of individual experiences to come through, while at the same time permitting the essential sameness that unites human beings to be identifiable through exploring and

eliciting the collective experience. In this light, Wertz's (1983) method of analysis has allowed the voices of participants to be heard, and has also allowed for variation, focusing on the individual, whilst exploring and eliciting the collective experience. This has allowed a holistic perspective of the shared and unique dimensions of people's experiences to be obtained. Only through deep penetrative reflection could a window be opened into the everyday world of the person with SLE with all its existential interlinked fractions and the understanding of the phenomenon of SLE be gleamed. The findings and discussion are presented to the reader as a 'tentative statement opening upon a limitless field of possible interpretations' (Churchill 2000:164).

Each of these findings will be discussed in turn beginning with self-doubt and doubt.

6.2 **Self-Doubt and Doubt**

6.2.1 Introduction to self-doubt and doubt

Doubt was a pervasive phenomenon throughout the participants' everyday experiences of living with lupus and took on many forms. The participants all experienced ongoing self-doubts and uncertainty about their symptoms, embodiment and illness, and also experienced continual doubts from others regarding their illness experience. The self-doubts and doubts the participants experienced were heightened because they are living with a relatively rare and unknown condition, which is generally physically, socially and medically invisible.

The Chambers Dictionary of Etymology (2006) reports that the word doubt stems back to 1280, and means to be afraid of, dread, to waiver in opinion, and dubious. The concept of doubt is to be, in uncertainty about the truth, or to be apprehensive, or undecided about, or distrust,

and an inclination to disbelieve (Cassell Concise English Dictionary 1995). Other meanings of doubt include confusion, bewilderment, dilemma, lack of confidence and scepticism (Collins Thesaurus 2002).

This chapter explores a number of areas including the participants' pre-diagnosis experiences and increased self doubts regarding symptoms, the dismissal of their embodied knowledge and the effect of having no biomedical evidence, or visible proof of a disease. The delay in obtaining a diagnosis and its devastating effect on all the participants is conveyed through their experiences.

Diagnosis experiences are explored including feelings of relief, validation, and utter confusion regarding autoimmunity, the condition and what it all means. The participants once planned for future had been thrown into doubt.

The participants' experiences of interactions with health professionals and general practitioners are explored. There appeared to be a gulf between the participants' expectations and reality of their situation. Trust and confidence is lost, when health professionals are perceived to have limited understanding of their experience, condition and needs and past experiences of not being believed and supported are rekindled.

The chapter then progresses on to explore self-doubt and doubt during social interactions with others and how the participants' experience is continually challenged by societies common expectations about how sickness and health should be represented. Feelings of isolation, rejection, loneliness and vulnerability were fostered by social rejection, stigma, and trivialisation, lack of care and questions of legitimisation primarily fostered by the invisibility of lupus. Lupus can present as physically, medically, socially and politically

invisible. This chapter finishes with a conclusion that discusses the results in relation to the literature.

The discussion begins with the participants' experiences of self-doubt and doubt prior to receiving a diagnosis of lupus.

6.3 Pre-diagnosis experiences of self-doubt and doubt

6.3.1 Something's wrong

All the participants vividly recalled prior experiences of when they first knew 'something was wrong'. Only in hindsight could they identify that this was the start of their passage into lupus, and the time when everything they cared about in their everyday lives started to change.

From early adolescence, many of the participants, such as Angie were certain that there was 'something wrong'. From an early age, she felt very tired.

"From about the age of 11 I was very tired and my parents used to call me lazy. I had two sisters and they always seemed to be able to do much more than I could do. And, I used to get dragged along on these long walks through the countryside and just struggle all the way" (Pg 1-2, 21-28, T 21)

"Dragged along" epitomises Angie's painful recollections, when she was struggling with normal activities, while her siblings could to do far more. In comparison to her siblings, she was not conforming to the socially accepted idea of what is considered to be a normal ability for activities (Johansson et al 1999).

Her parents interpreted her 'lack of energy' as "laziness", implying, workshy, and lethargic. They disbelieved there was anything physically wrong. Angie looked well and could provide no evidence for her invisible "tired" embodied experience. Her family believed, that the appearance of the body reflects ones state of health. To look good means you 'feel good' (Nettleton 1995: 50). Angie was not showing 'a syndrome' of typical experiences, or a set of words, or feelings which typically 'run together' for members of her family to understand and recognise as real illness (Good 1977: 27, Good and Good 1982).

Through Angie's interactions and relations with her family, the credible claims-makers, she came to believe that what they said must be true and real. Angie's embodied invisibility with the subsequent lack of evidence threatened her identity as a credible person. She needed to 'work harder'. She was being stereotyped and 'labelled' (Link et al 1987, 1989). Angie started to believe she was lazy, not the same as others, and deviant from the norm of society (Miall 1987). Angie had internalised the lower status "lazy" given by society and had carried that label with her through her life.

Angie's words reveal the origin of a theme which permeates the experiences of all the participants, that of being disbelieved. Many participants had no visible signs or indicators of illness and therefore could not prove their illness experience to others.

6.3.2 Increased symptoms and spiralling self-doubts

All the participants described this prior time as a period of ever increasing self-doubt. Various bizarre symptoms developed such as skin rashes, fatigue, weakness, flu-like symptoms, hair loss, tremors, and pain. Some of these would vanish, only for other strange symptoms to appear. Initially the participants put these down to

182

general illnesses they had previously experienced, such as flu, or rheumatic fever but these symptoms bore no resemblance to the illnesses of their past. What the participants were experiencing was something unfamiliar, and strange. Intuitively David felt 'something wasn't right'. His body was disclosing something to him.

"I can recall the feeling something not being right, something… some, not sixth sense, but like a… I can feel something's different, something is, um… difficult to describe" (Pg 29, 586-590, T 27)

His embodied past knowledge of how he felt in health, gave him a mirror to compare with his present condition. He felt different, but it was difficult to describe because it was beyond his previous experiences. He sensed something was wrong, but he could not identify or understand what was happening. His self-doubts increased not knowing what it meant.

Sometimes things 'just don't feel right'. The world appears uncanny with a sense of estrangement and disconnection from it. Heidegger (1962) called this anxiety (Angst). Anxiety is a complete loss of everyday practical familiarity; an absence of any sense of connectedness to things. David's' world does not feel right; there is a sense of unfamiliarity.

Abigail's being-in-the-world has been transformed in a way that worries and concerns her. She felt "awful" and her symptoms were "so varied" and "strange". She, could never regain her health or normal life, and "get back on her feet".

"It was so varied and strange and I just felt awful and I couldn't get back on my feet...it went on" (Pg 38, 750-752, T28.1)

Her 'body, was manifesting itself as an independent creature, resisting her will and understanding' (Leder 1990: 69). Her once taken-for-granted activities performed with ease, had become hard, and she could not understand what was going on, increasing self-doubts about her body.

Heidegger (1962) discussed how, certain phenomena experienced in life can resist meaning, he gave an example of environmental disasters, but it could also apply to illnesses such as lupus. These can 'break in on us and destroy us' (Heidegger 1962, 2000:152/193) as they 'strike against us as something totally unfamiliar and uncontrollable which threatens our existence' (Svenaeus 2000:142). Abigail is experiencing something not only 'unmeaningful' but also 'absurd' (Heidegger 1962, 2000:152/193).

Abigail's openness towards the world is gradually becoming obstructed by her varied and strange symptoms. Her being-in-the-world is not offering her any comprehensibility, sense of order and meaningfulness' (Heidegger 1996:151-152). Her being-in-the-world has become unhomelike. The lasting character of Abigail's symptoms increases her unhomelike attunement further.

Svenaeus (2011: 333) suggests that a 'phenomenology of illness can be carried out through highlighting the concepts of otherness in relation to meaningfulness. Otherness can be understood as a foreignness that permeates the ill person's life when their own lived body takes on alien qualities. A further specification of this kind of otherness can be found with the concept of unhomelike being-in-the-world. Health, in contrast to this frustrating unhomelikeness, is a homelike being-in-the-world in which the lived body in most cases has a transparent quality as the point of access to the world in understanding activities'.

6.3.3 Seeking medical assistance and the experience of being doubted

Facing such an array of strange and unfamiliar symptoms, all the participants sought medical assistance (Jutel 2011). Doctors through their medical knowledge and professional role are viewed as experts by society, and are held in high esteem. Integral to the medical system is the diagnostic process, which is embedded in the style of their everyday practices (Johnson 1991, Register 1987). The participants anticipated that the doctor would identify what was wrong and know what to do in the face of their illness, distress and discomfort (Dumit 2006, Nettleton 2006, Stockl 2007).

Rebecca's felt out of rhythm with expectations of what her once normal body should feel like. Her ongoing symptoms 'signify and reveal sickness as her immediate reality' (Foucault 1966: 136).

"I mean it was awful because I just didn't know what on earth I was dealing with, it was so confusing. And I said to them, "There's definitely something not quite right." But, it was hard to describe, and I could only say how I felt but they wouldn't listen. They dismissed it..., and kept saying was there was nothing wrong" (Pg 16, 296-299, T 20).

Through her many consultations Rebecca expected the doctors to fulfil their purpose and uncover the medical reasons for her illness. She had sought reassurance to relieve her fears and a diagnosis.

Rebecca "could only say how she felt", but, the doctors were paying no heed to her description. She was being "dismissed" and told "nothing's wrong". Her illness experience was being trivialised and her integrity and self identity were being affronted. She was being

evaluated on how others interpreted her words and behaviour. Instead of experiencing the medical encounter as one which would shed light on her illness, she came out feeling even more uncertain.

She was being evaluated and categorized according to established criteria, where the normal is shaped and maintained through the establishment and definition of the abnormal (Foucault 1988a). Compared to the normal clinical data Rebecca's strange assortment of symptoms did not fit any standard classification for diseases. Without a diagnosis she was left to manage her uncertainty, stress and chaos alone.

Lisa's embodied intuition disclosed that she was physically ill, yet her embodied knowledge was being discounted and doubted. Instead of being believed and encouraged to listen and trust her intuition, her experience was being disregarded and discredited.

"There's nothing worse than having lots of strange symptoms and having the suspense and fear of not knowing what it is, and them saying, "It's nothing", because I wasn't throwing up the right blood tests. The doctors were actually working along the lines of that being um a psychological disorder and, again, I knew it wasn't, I knew I was ill, I knew that I was physically ill" (Pg 8-9, 164-174, T9)

Lisa, "wasn't throwing up" any positive results. Rather than being an embodied person, she became a collection of test results derived from medical technology. The medical gaze had become blinkered, with the resulting exclusion of her experience of the illness (Toombs 1993). Her symptoms, the pain and fatigue were medically invisible and therefore an illness did not exist.

Kirmayer et al (2004:663) discussed, that 'the lack of explanation reflects the limits of medical knowledge, available technology and the epistemological difficulties of assigning a clear cause to subjective complaints like fatigue and pain, which have no objectively measurable correlates and may change rapidly over time in quality and intensity'. Without objective results she was being left with continual doubts, uncertainty, and fear about her embodied pain and symptoms.

Without positive blood tests, Lora hoped she could show her GP something "really big" to prove her illness really existed. But with her health and symptoms being so unpredictable any visible signs of illness had faded complicating medical consultations.

"Of course the day I go to see my GP, my rashes and sores had gone, and although I felt awful I had nothing really big to show her which is what I needed. And, I could tell she thought I was a fraud and doubted I was even ill" (Pg 6, 109-113, T 11)

Lora wanted to be able to show some visible sign, to "prove" that what she reported was true and real (Kirmayer 1994). But, the truth of her illness lies within her own senses; she could not prove that it existed. Lora felt she was being seen as a fraud, and suffered continuous disappointment, and frustration.

Michael felt he was powerless to defend himself. He could not control or influence the encounter.

"I was going to hospital and explaining all this every time, but nothing was happening, so…, it was out of my hands really. I could only tell them how I felt. Um, I think half of them thought I needed a shoulder to cry on, know what I mean?" (Pg 29, 574-578, T5)

He was being evaluated on how others interpreted his words and behaviour. Michael felt he was not being seen nor heard, and had no control or power to change his situation. Power structured his 'possible course of actions' (Foucault 1983:194). He had lost his ability to act. It had in a sense been taken from him and he was powerless.

Rachel had described "all these different things", but she was also being judged medically on her words and behaviour. Instead of finding an answerer, she was being seen as a "crackpot" and labelled a "hypochondriac". Her experience was not believed, she was being undermined and devalued.

"I'd gone to the doctor with this list of all these different things and I think he just thought I was a crackpot, you know, there's… you're some kind of hypochondriac or something" (Pg 6, 102-105, T 17)

The label "hypochondriac" insinuates Rachel was imagining her symptoms and was preoccupied with health concerns. She was perceived as being 'abnormal' and anxious.

Rachel's experience did not fit the norm criteria for any disease and her behaviour was deemed as 'a maladaptive way of experiencing one's own state of health' (Pilowsky 1994:567). The doctor can perceive maladaptive behaviour as the patient complaining about seemly unjustified symptoms. The doctor's inability to find a definite cause through symptoms or objective tests shifts responsibility away from the doctor to the patient suggesting that the cause of the problem is the patient.

6.3.4 Spiralling self-doubts

The participants struggled with continual doubts and fears about what was happening. They described their experiences while on the 'diagnostic trail' as one of uncertainty, dark thoughts and fear which they locked up inside themselves. Rebecca's doubts spiralled, thinking what it could be, nothing was certain and nothing was being resolved.

"Everything was going through my head. You know, to… cancer to a stroke or whatever, you know" (Pg 16, 305-306, T 20)

Rebecca was being left in continual uncertainty, and instability, fearing the worst. Medical invisibility with the failure of biomedical tests increased the uncertainty about the illness, its course, its consequences, the future and its threat to one's life (Johansson et al 1999, Kleinman 1988).

Liz felt she had a threat to her life; 'her life was draining away'. Her focus changed from considering death as a someday actuality to considering death as a possibility today. She was Being-towards-death and was no longer able to go forward.

"Each bit of my body was getting weaker and I hurt so much and… it's… it's hard to explain how I felt, knowing there was something wrong and that something was draining the life out of me and at any minute I'm going to be gone. To be frank, I really thought I was dying" (Pg 27, 533-538, T 14.1)

Adamson (1997: 134) discussed 'idiopathic diseases' can cause existential uncertainty, as they can arise 'spontaneously and from an obscure or unknown cause'. With these diseases patients experience

some kind of private existential uncertainty because they realise that their 'future life of his or her mind, body and self is in jeopardy' Adamson (1997: 134).

With, no hard biomedical evidence, or any visible proof, the participants self doubts spiralled (Ware 1992). Nadine tried to hang on to the authenticity of her illness, "knowing she was ill" (Peters et al 1998). But she was experiencing debilitating symptoms for which she had no explanation, diagnosis, prognosis or treatment and her illness reality was being repeatedly disconfirmed. Her self-doubts intensified and she questioned whether her experience was real or a figment of her imagination. She was haunted by the idea that she may be "cracking up". She endured a significant degree of 'embodied doubt and uncertainty' (Nettleton 2006: 1167).

"When they didn't know what was going on I thought, right, am I making all this up in my head? Because that's what I felt like I was doing, right? You know, I'm ill but I can't explain it to people. And I wasn't getting no answers from the hospitals because nothing was showing up, so I thought is it all in my head? I did go through stage of thinking, am I cracking up here?" (Pg 29, 567-573, T 24).

Embodied doubt can be conceived as the convergence of 'symptomatic, physical, clinical and technological uncertainty' (Price and Walker 2013: 15). Nettleton (2006) goes on to argue that embodied doubt is a feature of late-modernity and that people with unexplained syndromes are just the tip of the iceberg of what it means to live in late modern societies. 'The relatively marginalised and neglected sets of people who live with medically unexplained symptoms comprise an extreme example of the lives of the majority of people in the 'risk society'. Although positioned on the edge of society,

they might also be considered as emblematic of the mainstream' (Nettleton 2006: 1169).

Barbara had endured 30 years of being medically invisible, living with perpetual uncertainty, receiving no legitimisation, authentication and credibility of her experience. She had fallen outside the boundary of medical knowledge; none of the objective medical tests had identified her condition (Aronowitz 2001).

"I felt so ill, but it was never diagnosed and nobody took it on board how serious it was. And for 30 years everybody doubted me and I could not prove my experience was real. Everything I had known had gone, and it was all in question, my life, my future everything.... It was like being shut in a padded cell screaming for help wanting somebody to listen and understand what I was going through but nobody could hear my pain. I was stuck ... in a no-man's land, a different world, a limbo, thinking it was part of my makeup and going mad" (Pg 2, 29-41, T 10.2)

She had lived with continual self-doubt, uncertainly, and suspense, knowing something was wrong, but in the absence of truth, her reality did not exist. The doctors 'who construct reality' with the expert knowledge (Scheurich 2000: 461) had "doubted" her experience (Delvecchio-Good et al 1994, Kralik et al 2001). She was not a healthy person, but neither, was she identified as sick.

Barbara's picture (Figure 2) conveys the sense of her mental anguish and suffering from this past time. When she became unwell she was thrown into a world of anxiety, despair, and emotional distress which may 'be perhaps the most intractable pain of all' (Saunders 1963:197).

Figure 2.Barbara's Experience of Pre-Diagnosis.
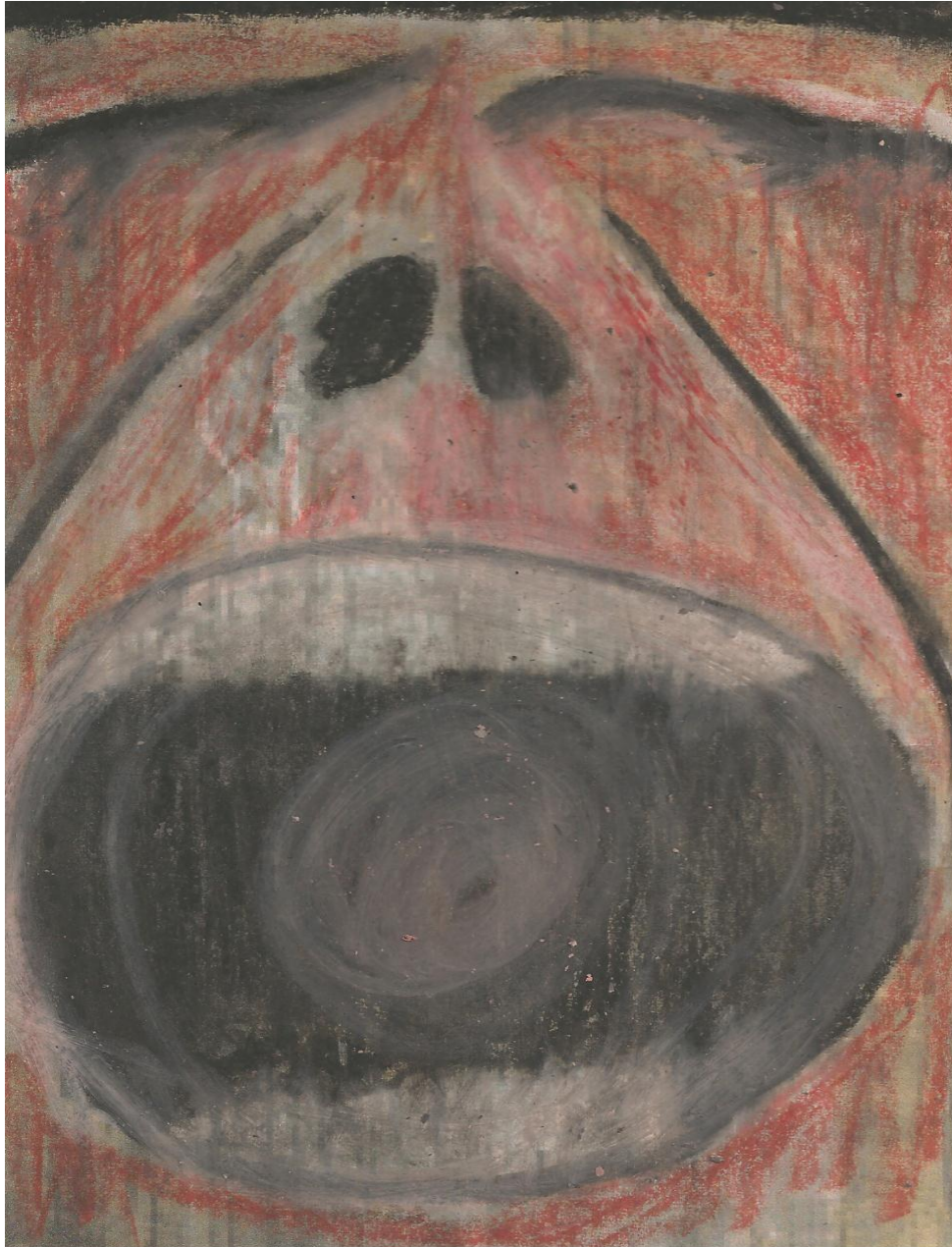
Barbara's experience had provoked endless self-doubts regarding what was previously implicitly assumed, and a questioning of her once taken for granted prior assumptions. Her experience was marked by uncertainty, an uncertain framing of her illness experience, an

uncertain understanding of herself, and an uncertain present and future (Adamson 1997, Stockl 2007). She had searched for a closure, which in itself forms a further cruelty she had to negotiate. Her life had been under a condition of uncertainty, which had seemed permanent and irreducible (Bauman 1997: 21).

Heidegger (1962) suggests being in the world is fundamental and it is on this basis that Dasein exists and reality is encountered (Heidegger 1962: 246). Barbara had experienced a "no man's land", "a different" Being-in-the-world and had been desperate as she had nobody she could turn to. Stanghellini (2004: 69) discussed the sense of reality is an 'experience of belonging'. Barbara's sense of reality and a feeling of rootedness or connectedness in the social world at that time had changed. That world was strangely uncanny and frightening as her sense of reality has been thrown into doubt.

Perhaps Barbara's sense of using the world no-man's land follows the English playwright Harold Pinter (1975) 'no-man's land'. The term applies to the search for meaning, in which nothing is certain and nothing is resolved and the lines between reality and imagination, past and present are blurred. This is where time does not advance towards a future and is neither here, nor there. She was in "no-man's' land", lost, no longer knowing who she was and not being able to be anything. She was caught in a mysterious limbo, a twilight zone, between life and death, between a world of brute reality and one of fluid doubt and uncertainty, stress, instability, and chaos (Pinter 1975). She was of an 'indeterminate status', a luminal being, 'neither wholly self nor wholly other', which was deeply disturbing (Shildrick 2002:3).

6.4 Diagnosis Experiences of Self-Doubt and Doubt

Receiving a diagnosis had been a memorable event in all the participants' lives. For the majority of participants a gamut of emotions were brought to the surface. Initially many experienced huge relief.

"Everything had been going through Rebecca's head". She had wanted to know what was wrong and to have a name for her suffering, but feared what it may be. She had imagined the worst scenarios. At times she had doubted the medical fraternity would ever find an answer or give her a release from her plight. She had envisaged never knowing, and always worrying.

"Everything was going through my head. When they did diagnose it, it was a relief to think, well, at least they've found out what it is, that's the main thing and to be able to treat it as well" (Pg 16, 305-307, T 20)

Receiving a diagnosis brought Rebecca immense relief from her endless doubts, dark thoughts and imagined scenarios. Finally her illness had been taken seriously; she had escaped chaos, and had been officially recognised. It was a time of hope, as it could be treated and she was on the road to recovery and finding a way back to normality.

Mendelson (2009) emphasises the importance of the sense of legitimacy that comes with a named diagnosis. In addition, it provides access to professional support. Lora, felt it made a "tremendous difference" as she had something "official" to put on forms. She could at last share how she felt with others, and they would no longer doubt her experience, because she had a name to prove it. She would be socially accepted.

"To be diagnosed, and finally you've got something to put on the forms and stuff. And when people go; "Well, what exactly is wrong with you?" And you're going, "Well, I've got lupus and I've got this, you know", whereas before it was like well, "I'm feeling very unwell" and they're like, "Oh God", you know. Yeah, it makes a tremendous difference being diagnosed" (Pg 30, 588- 601, T 11)

For Peggy diagnosis brought anger to the surface, directed at those who had dismissed her experience, embodied intuition and knowledge. She had lost faith and trust in the medical profession.

"At last I'd got a diagnosis, but this was 16 years on. So for 16 years I I'd been fighting all of them, so I have lost trust in them" (Pg 11, 219-220, T18.2).

Penny questioned why she had not been diagnosed earlier and whether this had resulted in further damage to her body. She lived with continual doubts.

"But apparently it had got to my kidneys already. So I do question if I had been diagnosed earlier whether things would have been different, and I think about that a lot" (Pg 3, 54-57, T 22.1).

For many of the participants, the diagnosis had been a shock. Amy had lived an emotional rollercoaster journey, longing "to know" what was wrong. Then it could be sorted out, she could be cured and return to normality. She had expected "something so easy to get over" so she could get on with her future planned life. But, the diagnosis had been a shock, she "didn't expect" something so "severe". Her dreams and hopes of a cure and re-entering the real world quickly faded. Her once planned future had been thrown into doubt.

"All these years I've wanted to know what was wrong and yet as soon as I knew, I didn't want to know, but I, I suppose I didn't expect it to be that, or so severe, I'd thought it was going to be something so easy to get over, you know" (Pg 6, 122-125 T3)

Amy had been thrown into even greater uncertainty; everything had changed. Her hopes had been destroyed, now the reality of her situation hit home. Instead of what she had expected, she knew she would be living with something "severe" and long term. Her past had to be redefined, and different ideas about the future had to be made (Adamson 1997, Kralik et al 2001). Becker (1997: 4) discussed how 'meaning is assigned to specific life events and the roles that accompany them. When expectations about the course of life are not met, people experience inner chaos and disruption'. Amy "didn't want to know" anymore, because she feared that unknown. She was trying to come to terms with finding new meanings in her relationship between her familiar self and her new identity as a person with lupus.

A diagnosis has to make sense in order to be meaningful for the patient (Good 1994, Madden and Sim 2006, Nettleton 2006). Many participants were swiftly thrown into confusion, as the diagnosis was meaningless. Lorraine was presented with a strange sounding name; 'systemic lupus erythematosus', an unheard-of and incomprehensible condition. She had no idea "what it was" or what it meant.

"And I'm thinking, "Right, okay, but what does this actually mean?" You know? I had never heard of it" (Pg 23, 429-430, T29.1)

Uncertainty and doubts dominated Angie's thoughts.

(The consultant) "Said, "Right, you have got something called systemic lupus erythematosus." And I thought, "Okay, that sounds like

something a rabbit might have," You know, the whole myxomatosis thing at the end. I had no idea what it was" (Pg 3, 58-61, T 21).

Angie could not relate the name to any context of her pre-existing knowledge of diseases, and how it would impact upon her life. Lupus was an unknown; she had no social construction to work with or anything to compare it to. The only thing she could relate it to was "something a rabbit might have".

Goodman et al (2005) has shown that when individuals receive a diagnosis, they generate representations of that illness based on their generalised pool of illness information. Wiginton (1999) has discussed that individuals will then modify their response to a diagnosis by using their prior concepts about the illness to fit in within the context of their lives. If individuals have no prior concepts then this may affect their ability to develop appropriate coping strategies.

For the majority of participants, the condition was not clearly explained. Phoebe was left in completely confusion. The doctors were talking about, "autoimmunity" which was a mystery. The only social construction she could relate to was AIDS.

"I had about six doctors and they were all talking over me, and they were talking about this disease and I said, "Hang on a minute, what are you talking about?" And I hadn't a clue what they were talking about, and I thought they were talking about AIDS or something, because they were talking about autoimmunity" (Pg 4, 69-73, T 12).

Phoebe "hadn't got a clue", "what they were talking about". "Autoimmunity", can conjure up powerful images of warfare, battles, and societies negative stigmatising connotations regarding certain conditions. Phoebe could only think of AIDS associated in society

with deviant behaviours, linked to the gay population, drug users or sex workers. Having AIDS implies personal responsibility and a moral fault (Sontag 1988).

For the majority of participants, there was no information forthcoming as to the rarity of SLE. The professionals probably daunted by its complexity lacked what participants described as the 'desire' or 'ability' to embark on an understandable explanation. These findings are confirmed by Waldron et al (2011), who found information was inadequate at diagnosis.

Without good and effective information or professionals taking the time to talk about the diagnosis, many participants felt confused and scared.

6.5 Interactions with Health Professionals and the Experience of Self-Doubt and Doubt

Once diagnosed, a normal part of the participant's everyday life had become attending clinic appointments, blood tests and coping with medication. For the majority of participants appointments caused ongoing anxiety. Angie was always "concerned about her appointments". It was the on-going uncertainty about test results, if there were any changes in her condition and "what he's going to come up with", in relation to possible medication changes.

"I'm perhaps more concerned about my appointments. I'm never quite sure what he's going to come up with" (Pg 26, 566-568, T 21).

Amy got "very het up" when she had her blood test. It wasn't the procedure that bothered her, but rather what would be shown. Each time it was going into the "unknown" of "is it going be worse, is it going

to be okay, are they going to change things". Her apprehension would spiral, thinking the worst causing a build-up of anxiety reaching a climax on the appointment day.

"As soon as I have those blood tests I think, oh, my God, now what, you know, is it going be worse, is it going to be okay, are they going to change things. I hate that it's like you're going into the unknown, because you just don't know what one blood test from another blood test is going to reveal, it can be so different from a couple of months your levels can go so drastic and every time I've been it's been more medication, more medication, and you think, oh, not again. So you… I do worry; I do get very het up, where normally nothing really bothers me like that" (Pg 45-46, 913-928, T3)

The blood test reinforced Amy's feeling of never being in control and the fear it was still there and getting worse. She would have to cope with "oh, not again", where the doctors would decide her fate, her medication would be increased and it would be the endless cycle of lost hope of not regaining stability and a normal life. She interpreted the amount of medication as a symbol of how well she was doing. An increase in medication following the appointment indicated a decline in her health.

She would "panic" about her medication when it came to appointment time. Amy was familiar with her current medication and had got into a routine of taking it and its effects. So, attending an appointment meant "here we go again", as she would be plunged into apprehension and uncertainty about what medication they would give her this time.

"The only time I really panic about the medication side of things is when I go for my appointment. And I think here we go again, what am

I going to come back with this time?" It is a double edged sword really" (Pg 24, 465-467, T 3.3).

For Amy medication was "a double edged sword". On the one side she realised the importance of her medication to remain stable, but, on the other side she hated the procedure and the side effects. A change in medication would mean, coping with a changed routine, the uncertainty about side effects and adjustments to new effects.

The participants all had high expectations that these doctors with specialist knowledge of lupus would understand their experience and be able to explain their condition to them to reduce on-going doubts. However, for the majority of participants there appeared to be a great gulf between expectations and reality. This clash arouses feelings of mistrust, uncertainty, neglect, dissatisfaction and frustration. A sense of anticlimax pervaded the majority of the participants' experiences.

Jane wanted to ask questions, so the doctors could reassure and explain her condition to aid her understanding. But, she understood they "don't have time to talk" they were "busy". She kept her doubts and concerns to herself and continued to worry quietly, alone.

"It goes in my mind to ask. I don't think they'd have time to talk about it, really. They're busy. They do their best, but, no. I don't feel I can talk…" (Pg 9, 180-181, T7)

Jane had on-going misgivings and fears about what her future may hold. She had a desire for more knowledge about her enigmatic condition. With her condition constantly changing both in symptoms and intensity, she wanted to establish a trusting relationship with familiar doctors. But, she related "I don't feel I can talk", she knew they were in a rush and there was insufficient time for her to express her

concerns during the consultation. Jane had nothing to hang on to which would give her hope that her fears would never become reality. For her, the long term effects were an unknown, which left her, in a very unsettling and anxious place.

"Oh, I just wonder how… where is it going to take me next? What is the next thing? Because I don't really know the progression of this… of this disease, so it's just wondering what's going to happen next" (Pg 8, 145-148, T7)

She had imagined what her future might bring, and her inner doubts and demons conjured up the worst scenarios. She often thought about a patient she had met with lupus. It was a strong image recalled and revisited, a dark thought which haunted her from time to time.

"I always think of her… it was the way she was doing it, like she was a lady in a wheelchair. And I didn't nurse her for long. That's the only person I met… I've met with Lupus. I just remember her being in a wheelchair. Even wheeling her to the bathroom" (Pg 33, 621-625, T7)

"Just putting myself in her shoes that maybe one day I'll be like that. I don't know, but it worries me, I couldn't cope with that" (Pg 33, 628-629, T7).

That patient was only other "person she had met with lupus" and Jane recalled every moment of that encounter. The image was etched upon her mind as she felt it could be her at some point in time. The reality of what could be her future hit home and hit hard. Jane could not brush that thought aside. She envisaged her future as that woman and it brought immense fear it would be her fate. She doubted she would ever be able to cope if she was in her place.

An important element for all the participants was having enough time to talk about their concerns and fears during the consultation. Without this, many were left with continual doubts about their future and the progression of their condition.

According to Heidegger (2001:141), modern medicine, 'is pushing us towards uncanny developments, in which one no longer asks how the (human being) patient is'. The speed of consultations provides limited time for an understandable interaction with-others, and this impacts on the participant's self-understanding and identity.

For the majority of the participants the appointment experience was a disappointment and one of anti-climax. Phoebe wanted the consultation to be worthwhile and useful. But, she was left with-doubts feeling they "don't help very much"; as the appointment centred purely on tests without ever knowing the results.

"They don't help me very much; I don't push it at all. I mean a lot of the time they just do the tests and they don't even tell me what the results are. And they don't give me any help in coping with anything. And it just takes a lot out of me, going to these appointments. Sometimes, I do have misgiving and am in too minds about going, but they are the experts, you know who will look after me and keep me stable" (Pg 57, 1090-1097, T 12)

She wanted more practical help with ways of coping with lupus. Although she had many misgivings especially as the appointments took their toll leaving her exhausted, she would always go, but never "pushed it at all". They were the experts who would monitor, keep her well, and were her security blanket, her life-line, so she could carry on living her normal everyday life.

Joanne also experienced doubts and reservations about her appointments. She had high expectations that the lupus doctor 'an expert' would really understand her experience. But, instead she felt her experience and hard-learnt embodied knowledge was being demeaned and not taken seriously. Her present experience rekindled past experiences evoking further uncertainty and self-doubts. She was losing faith and trust in her doctors.

"I say to her, "Well this is happening", "Oh well it could be the dermatomyositis or it could be the lupus but we'll see how you go", "fine, okay. See you in a couple of months then". And you go away and you think, "Does she just think I'm just saying that because I want something to say and I want sympathy or I what?" (Pg 65, 1190-1195, T2).

The doctor was not fulfilling any of her expectations and Joanne began to' shut off'. As far as she was concerned the doctor doubted her experience, and thought she just wanted "sympathy or I what". They were not interested, or listening. Joanne started to experience reservations about any medical suggestions. Without a good interaction, Joanne became disillusioned about her appointments.

Some participants were seen by the lupus nurse, rather than the doctor. Nadine viewed this as being "stuck with a nurse" which caused her doubts, because "it's just not the Dr is it". Her expectations of being "monitored right" and supported by an expert doctor were not being fulfilled, leaving her feeling insecure. She felt rejected and insignificant as the doctors obviously "don't care", and were "not interested" in her. Her confidence and trust dwindled, and she began questioning "why she was here". Her past experiences of not being managed appropriately came to the fore.

"You've got the nurses, they're lovely, but it's just not the Dr is it, but I haven't seen him for the last couple of times I've been there, they've stuck me with a nurse. So… And I always feel like, well they don't care; they're not interested in me. I'm not monitored right so it does make me anxious... and I think to myself so ... why am I here? I do, that's how I feel every time; I …you know, and I think to myself, oh, I just can't be arsed with it" (Pg 39, 765-776, T 24)

Even though the majority of the female participant's expectations of the consultation were disappointment, they wanted to see a "doctor" in preference to a specialist lupus nurse. This is interesting as a specialist nurse, could supply them with more time and intense interactions focusing on how they are coping, rather than purely the medical aspects. Interestingly, none of the men expressed similar concerns regarding wanting to see a doctor in preference to a specialist lupus nurse.

However much the participants criticised their medical care, and were in two minds about whether the consultations were worthwhile, relating "I can't be arsed with it" and appearing indifferent, they ultimately attached value to their appointments and seeing the doctor. The doctors were viewed as all important, and signified knowledgeable experts of lupus, who could provide assistance, and offer specialist on-going medical treatment. They were as some participants described "my only hope", and "all that I have" to "keep me alive". The doctors were the participant's only life-line and safety-net for continued stability, and provided them some security which was sadly lacking in every aspect of their lives.

Gore and Ogden (1998), and Pandhi et al (2007) discussed patient loyalty and how this can be measured in terms of the patient's tolerance of unsatisfactory care. Lings et al (2003) called this

satisfaction paradox, where patients express dissatisfaction with certain aspects, but continued to maintain a relationship and attend appointments (Gabel and Lucas 1993).

Lisa would always attend her appointments. She described this as having "a foot in the door", so she could "stay on their books". It was her back-up and security blanket 'just in case' she became unwell and unstable.

"I mean really all I'm doing is turning up every six months so they can keep me on their books. I'm not sure that there's any benefit to me going. Of course if I suddenly develop some other symptom and, you know, then obviously I've got a foot in the door" (Pg 48, 972-978, T9)

Uncertainty and insecurity haunted Karen at each clinic appointment, as she questioned whether it would be the last. She was "afraid" that she would be discharged from the clinic. Then her lifeline to expert monitoring, assessment and support would be terminated. Being left in the care of her general practitioner or local hospital revived her prior horrible memories of her diagnosis experiences.

"What I'm a little bit afraid of is when eventually, they decide that they won't treat me, you know, and whether they say you have to go back to your local hospital, and I'm not sure that they are really geared enough for that" (Pg 25, 493-499, T 19)

The deep insecurity experienced by the participants may stem back to their prior experiences, of being abandoned, not believed, not supported and rejected. But, they were also trying to live with a condition that was totally unpredictable with medical and 'social ambiguity which engendered existential uncertainty' (Napier 2003: 81). The fear engendered by not seeing the doctor, or being

discharged and therefore losing what limited security they had, could as Schmidt et al (2002) suggested lead to the perception of an insecure attachment. This predisposes patients to be fearful, and occupied with rejection, abandonment and distrust.

One interesting hypothesis tested out in Bennett et al (2011) SLE study, is patients' attachment styles and whether this would predict satisfaction. The term attachment styles relates to the working model of the self and others that provides the prototype for social relations (Bowlby 1973, 1980, 1982). The dimension of attachment includes 'fears of rejection and preoccupation with abandonment' (Bennett et al 2011:54). In a secure attachment, anxiety and avoidance are managed in order for the person to experience security in a relationship. Bennett et al (2011) concluded attachment can impact on the patient's ability to engage in a fruitful working alliance with their doctors to manage their SLE.

6.5.1 General Practitioners and the Participants Experience of Self-Doubt and Doubt

The participants also expressed doubts and a lack of confidence in their general practitioners. Consultants at lupus clinics update and notify GP's as to prescription changes for medication and instructions for further medical examinations. General practitioners are therefore vital for providing prompt care for the continued well being of those with lupus.

Phoebe's trust and confidence in a GP firstly depended upon whether she felt they knew anything about lupus. Then, if they actually did what she wanted and offered appropriate treatment and care. If she found a good one, she felt very fortunate. If she felt the GP's

knowledge base of lupus was wanting, her doubts would spiral. She viewed her current GP as "dangerous" and to "be avoided".

"I really rely on good GP and if I can't find one it's very, very hard. The doctor I had at my last place had a mother with lupus and so it was a lot easier, I didn't have to explain things to her. But, now my doctor doesn't know anything about lupus. He doesn't read my notes or do anyway I want him to do, so I don't trust him and to me he is not only dangerous but should be avoided. He doesn't seem to have any comprehension about lupus, and he dismisses what I say because he thinks he knows best. So as far as lupus goes it's the doctors really that need educating, because I have to battle with him all the time as well as with my disease, and that's really hard going" (Pg 2-3, 40-49, T 12).

Phoebe originally had a good GP, who understood lupus and who she had confidence in and could trust. But her experience since, had been one of disappointment, with the underlying feeling "he" does not understand, or do anything to help. Her interaction with him was described as a "battle", because "he knows best", discounting her embodied and extensive knowledge.

Her interactions with the GP were "hard going"; he was being unhelpful and "dismissive". This rekindled her past negative experiences with GP's, and her experience of being disbelieved and trivialised. Phoebe distrusted him, and was uncertain that he would do what she wanted. This meant she needed to be extra vigilant and in charge of her own health care. Phoebe needed to constantly remind him, follow things up, check what he had done, make sure the medication he had prescribed was suitable for her needs and make sure he had understood what he needs to do. But, being in charge of

her own health needs was an extra strain and burden when she is unwell. In fact he made her life harder.

The participants all had ongoing circles of self-doubts that actually one day it could be something else that was seriously wrong with them, rather than "Lupus". Lisa was left with doubts, and concerns about "missing something one day". She was sceptical that her GP would ever pick up on any other health issues or illnesses, because everything she had was automatically blamed on her lupus.

"The danger is that I'll miss something one day because everything tends to get blamed on the lupus and when I go to the GP they always say its lupus" (Pg 50, 1009-1010, T9)

6.6 Social Interactions and the Participants Experience of Self-Doubt and Doubt

Once diagnosed with a named condition, the participants had all held high hopes and assumed that society's scepticism about their illness experience would be a thing of their past. However, the majority of participants were living with a physically invisible condition, and they still faced the flawed notion of society, namely that if you looked well, you must be well. They were also living with a rare condition which was socially invisible and meaningless. Their high hopes of being believed, supported and understood quickly faded. Their illness experience was still doubted and they were being viewed as suspicious by others.

The participant's experience was continually challenged, by society's common 'expectations about how sickness and health should be represented' (Napier 2003: 86). The majority of participants had nothing visible to show and prove they were ill. Although Peter could

tell others he had a legitimate illness, he continued to be judged by society because he "looked fine" and therefore "there's nothing wrong with you".

"I haven't got a broken leg; I'm not a paraplegic so at least you could understand if I was in a wheelchair whether it's right or wrong they could understand what my condition is. And when they see me, they say "Oh well, I don't understand, you look fine to me; there's nothing wrong with you" (Pg 26, 551-558, T1).

The 'most profound social doubts can derive from the misreading' of those with SLE by others who are using 'other illnesses as models of pain and hardship' (Napier 2003:87). Peter displayed no real outside presentations to signify his internal suffering; his symptoms of fatigue and pain were invisible. He looked really healthy despite huge changes in his body. He used no symbols, such as a wheelchair, which would indicate any sign of illness or disability to society. Peter therefore did not present any of the typical and normal cultural signs which others could recognise as a condition or disability. He conformed to the socially accepted idea about a healthy body, his lupus was physically invisible. He had a 'condition that was not perceptible, not noticeable, not evident, and unseen by others' (Vickers 1997: 241).

As well as the issues caused by being physically invisible, the participants also had to contend with lupus being a relatively rare condition, and as such due to the lack of public awareness, it is usually greeted in the main by social ignorance. The social construction of illness implies a sort of pecking order. Lupus is not socially well established, and therefore is not considered to be as important as some other conditions. There are for example certain conditions which are considered to be really important, severe and

taken very seriously such as cancer, AIDS, and MS. Then further down the pecking order are the so called rarer more neglected conditions, such as lupus which have a low prevalence and cause social ignorance.

Initially, Peter tried to "get others to understand" but, others had never heard of his condition. Lupus was never mentioned like other conditions; it was an unknown thing and was not in the same league as cancer or MS, which society had "a broad understanding of".

"Trying to get other people to understand it because it's, not cancer, you know, it's not MS, it's not something that people have a broad understanding of" (Pg 25-26, 544-547, T1)

"Lupus is a secret condition I suppose because nobody understands what it's like" (Pg 26, 551-553, T1).

Peter's lupus was a "secret condition"; others had never heard of and had no idea what it was. Peter was experiencing social rejection, which leads to a continuation of his social invisibility, as the consequence of disbelief in his known illness situation.

Unless somebody knows someone with lupus the usual response to it being mentioned is "what's that?" Joanne felt she would like to say she had "cancer", rather than lupus because at least then others would think "Oh God" and she would get a positive and supportive response.

"Sometimes I feel like saying…, "Well what have you got?" I just say, "I've got Cancer" (Pg 53, 978- 981, T2)

"Then they'll think, "Oh God, you've got Cancer. Oh dear", you say Lupus, "Oh, right. What's that then?" Autoimmune disease, what does that mean? It just means I don't feel very well" (Pg 53, 983-986, T2).

But saying she had lupus meant social ignorance, as her condition had no social currency, or culturally recognised value. Her condition is completely socially meaningless and as such causes others suspicion, confusion and doubts.

At clinics, Joanne talked, scrutinised and watched, carefully comparing herself to others. She was suspicious as they "looked healthy" and their experience bore no similarity to her own. She doubted that they were as bad as her, and felt she must have a worse "case of Lupus".

"I go to the Lupus Clinic……and I wouldn't think anything was wrong with them. They walk fine, they look healthy. They may well suffer, but why can't I be like that then? Why do I feel like I do and look like I do? Like I haven't slept for a week and is it because… I've got a worse case of Lupus?" (Pg 55-56, 1014- 1028, T2)

Lupus patients often find they have less in common with their fellow patients than with others suffering from unrelated illness. Joanne felt socially isolated and was unsure how she was supposed to be or whether her experience was normal for lupus. She wanted reassurance and sought a 'standard experience', which does not exist. This left her even more confused, bitter, and anxious. The difference between her insider experience and what she could see in others with lupus was incompatible. She was aware of their illness situation, but was suspicious because there is no standardised suffering for any one person.

Amy felt if she really said what it was like; she would be viewed with suspicion, and would be doubted. She would be perceived as "exaggerating". She knew from past experience "to stay quiet and say nothing" that way she could 'fit in' and be the same as everyone else.

"They sort of looked at me and I think sometimes they thought ((pause)) you're exaggerating, is it really that bad, can anyone have all those illnesses and be walking down the street? I've learnt to stay quiet and say nothing" (Pg 63, 1222-1229, T3.2)

Amy did not want her past experiences remerging and to be labelled a hypochondriac again. To fit in to society there is a way of doing things, and for the most part Amy did the same as everyone else. She had learnt to censor what she said, not to talk about her condition, to stay quiet so she could fit in with others and not be seen as being different.

She obeyed the social patters and the norms of society. Amy 'took pleasure and enjoyed herself as one takes pleasure, likewise she shrank back from the 'great mass' as one shrinks back, and she found shocking what one finds shocking' (Heidegger 1962: 164/ 126-127). The Anyone, which is nothing definite and which we all are, prescribes the kind of being of everydayness.

Like all the participants, Amy, had quickly learnt, that sharing how she felt made her presence obtrusive. She stood out and her behaviour required interpretation. This disturbed others, because her behaviour was perceived as deviance from averageness. Amy learnt to suppress anything which could be perceived as deviance, and conform to the social norms of everyone, which dictates, 'what she should say and do'. She abided by the social patterns and expectations of the way 'one does things', to 'fit in'. Amy suppressed anything which may be

perceived as deviance, so she would not be seen as 'abnormal', or 'conspicuous'.

Heidegger (1962: 164/126) discussed, 'But this distantiality which belongs to being-with is such that Dasein, as everyday being-with-one-another, stands in subjection to Others'. It itself is not, it's Being has been taken away by Others. Dasein's everyday possibilities of Being are for Others to dispose of as they please'.

6.6.1 Self-doubt and doubt in everyday life

Being both physically and socially invisible caused all the participants ongoing issues and frustrations in every aspect of their everyday lives. Nadine on first impressions looked healthy and normal.

"My social services… OT, he came round. And he said, "We're going to register you disabled and we're going to give you a parking space out the front," And since I had that put in I've had nothing but hell and trouble off the neighbour. He don't think I have anything wrong with me, so I told him I've got lupus, but he thinks I'm making it up just to get a parking spot. And I do have problems you know, it's legitimate, so, it's been hell really" (Pg 40-41, 799-803, T 24).

Nadine had informed the neighbour she had a legitimate condition, but, he had never heard of it and doubted its existence. He made his judgement based upon her body which 'is the medium for others perceptions' (Grytten and Maseide 2005:232). Nadine was viewed as a fraud and did not deserve a car parking space, as that privilege is only given to those with a real disability that can be seen.

Nadine found the situation very difficult, she felt misunderstood and not accepted. She was in an ambiguous situation. She had attempted

to hide any signs of being different and had not used her walking sticks in order to appear normal. But, she also desired understanding, support and to be given some allowances for her condition in-order-to make her everyday life a little easier. When her condition was misunderstood and was not accepted, it caused her to feel real resentment towards her neighbour. Burke et al (1976), Druley et al (1997), Mendelson (2009) and Pettersson et al (2010) have also investigated these experiences. As a result of the issues with the neighbours, Nadine started to exaggerate her walking difficulties and used her sticks which symbolised disability to society.

"So I thought what the hell, if he's going to be a miserable old sod then I'll show him I've got problems. So I use my walking sticks even though I hate it, to show him its true, I've got a condition, and I do need the parking space, so he can get off my back" (Pg 41, 816-823, T 24)

Grytten and Maseide (2005:233) have argued that people who suffer from chronic illness can manipulate their identity and act differently in various social situations. Taylor (2005:745) related, 'bodies are something that we do and do in multiple ways'. Nadine had visualised her illness to receive recognition. Her walking sticks and posture were a symbol in-order-to show she had a genuine and real illness and deserved a parking space.

6.6.2 Self-doubt and doubt experienced at work

Many of the participants experienced issues at work, as they were being perceived as healthy, yet having time off sick. Karen had wanted to control her self-identity and not experience any social stigma from colleagues because she had an illness, which carries no social status (Masana 2008). She had feared being socially rejected

and excluded and did not want to feel humiliated or vulnerable. So, originally Karen had hidden her condition, to pass as normal and healthy (Hay 2010, Miles et al 2005).

But, Karen had received negative reactions from her colleagues for her times off with sickness. She had eventually plucked up courage to tell them she had lupus in the hope they would believe her and their scepticism would cease, but the situation deteriorated further. She had to change jobs in the end, because her life had become "hell".

"Colleagues had made some really nasty remarks about my sickness; you know "did you have a nice rest". I mean I was ill it wasn't a holiday. So, in the end I got so fed up I told them I had lupus. I suppose at the time I thought it would help, but it made things even worse. They continually implied I was malingering and not up to the job; it made my life hell" (Pg 10, 191-204, T 19)

Karen experienced numerous issues from colleagues, who demonstrated 'hostility and knowledge based stigma' about her condition, with the associated perception of "malingering" (Falvo et al 1982: 5). She was left in a position of feeling vulnerable and stressed, which obviously aggravated her ongoing health issues. Vickers (1997a, 1999a, 2001, 2000) carried out extensive studies on invisible chronic illness in the work place. One of the areas she identified was issues with colleagues, and how they can make judgements, regarding 'long vacations', instead of perceiving a period of sickness as time to recover. Karen had received stigma, based on a condition her workmates disbelieved and did not understand.

215

6.6.3 Self-doubt and doubt experienced in the benefits system

Now the majority of participants could no longer work, they had to start to apply for benefits. They faced a bureaucratic hurdle, and quickly learnt that Agencies had little or no knowledge of lupus and doubted the validity of their claims. The participants all had the disadvantage of having a relatively unknown and rare condition, which the benefits system does not seem to acknowledge, recognise or understand.   On top of this the majority of participants have an invisible condition and display no outward sign of illness, or disability. This made them particularly susceptible to being labelled 'scroungers'. The participants in this study found it very hard to prove they had a valid claim to receive benefits.

Abbey's condition was not being recognised. She resented deeply the idea that she was being classed as "putting it all on" implying she was a scrounger.

"The benefits agencies seem to have the impression that lupus is similar to influenza, and I will make a full recovery soon. They don't understand it's for life; I'm not putting it on to receive benefits. It does drive me insane that, nobody ever believes it's real" (Pg 22, 438-401, T32.1).

The benefits agency rekindled her prior experiences of never being believed, which was "driving her insane".   However much she explained, and provided documentary proof, her condition was not being recognised. The benefits agency insisted she would make a full recovery, and therefore did not meet their criteria. But, how was she supposed to survive without benefits. She was visited by "officials" and "checked out" to see if she was legitimate and could really prove her illness. Throughout her ordeal, she sensed the officials doubted

her condition and she needed to constantly justify and prove her illness. She felt they thought she was undeserving, and were 'suspicious about her entitlement to the benefits' (Finn et al 2008:45-46). She did not have a social or politically correct condition and as such she found it very hard to prove she had a valid claim.

6.6.4 Self-doubt and doubt experienced from family and friends

It was bad enough that society doubted the participant's experience, but worse still was the indignity of having family and friends view their illness with suspicion. This continuous conflict between how the participants felt, and how they appeared, affected the amount of support they were offered. Many participants felt let down by those they thought they could trust, rely on and the only ones who would understand.

Dawn was angry and indignant at her family's misunderstanding and the manner in which she had to justify when she was ill. She felt they still doubted the authenticity of her illness, although they knew she had lupus. Her family were implying her experience was not as bad as she was making out.

"When I'm bad I can't do some things and I get anger at my family because they don't help or understand. And I think outwardly I don't look as though there's anything wrong. So they think, well is she really ill, does she really need help or, you know, is she just saying it? And you want to get hold of them and say (sound of shaking them) "it is, you know, it's real" (Pg 4, 72-78, T 25)

Dawn was experiencing rejection, as the consequences of disbelief in her illness situation. Her families disbelief in or non acceptance of her lupus, either because of her apparently healthy appearance or

because of the type of illness lead to Dawns further social rejection and continued social invisibility. She was left angry wanting them to believe "it's real", yet receiving no help, support or understanding. Her condition was not being seen, or recognised, or accepted. The continual rebuffs and disbelief made Dawn question whether her family really believed or cared about her.

6.7 Conclusion of Self-Doubt and Doubt

From the participants experience they were assaulted by doubts. There were the doubts arising within themselves and those engendered by the perceptions of lupus as being physically, socially, culturally, and medically invisible.

Continual self-doubts developed because of the challenges of living in an ever-changing body. The participant's experiences are out of sight, invisible to family, friends, medical professionals and bureaucracy. There is a strong linkage between these doubts and the invisibility which opens out a wide field for reflection.

The participants needed support, understanding, and somebody to listen and believe in their experience. But on the whole they were being denied acceptance of their condition. Those around them did not see and so did not believe.

In society's construction, an illness must be socially, culturally and medically accepted and must appear clearly to exist and be unfeigned to be considered authentic. Then it can be accepted as legitimate. The social construction of illness happens through cultural meanings and beliefs (Ware and Kleinman 1992). This sort of classification brings a socio-cultural status of the condition, that is recognition and

acceptance, or rejection, and legitimation or delegitimation of the condition.

Delegitimation can be conceived as 'having ones perceptions of an illness systematically disconfirmed' (Ware 1992: 347). Masana (2010) discussed how the concept of delegitimation can be used to refer to the loss of a legitimate word, which Kleinman, (1992) reports implies cultural values and rules about what is considered to be normal. Any illness must be recognised socially and culturally in order for it to exist (Comelles and Martinez 1993, Comelles and Perdiguero 2000). One of the effects of not having one's illness experience believed is to feel stigmatized. A key father of sociology, Erving Geoffman, describes stigma as essentially the possession of 'an attribute that is deeply discrediting' (Geoffman 1963:13).

Ware (1992) conducted interviews with 50 Americans experiencing chronic fatigue syndrome (CFS) and highlighted examples of how others can render an individual's symptoms as trivial or psychological. Having your symptoms minimized or dismissed by others, can cause humiliation and shame. Ware (1992: 354) wrote their shame 'is the shame of being wrong about the nature of reality'. Trivialization of symptoms can increase the person's self-doubt and self-blaming (Dumit 2006, Johansson et al 1999) and this can generate increased anxiety and suffering (Kleinman and Benson 2004).

In a similar study, Dickson et al (2007) undertook 14 interviews in a UK sample of CFS sufferers. Their participants described feelings of rejections and isolation following such challenges.

The common theme of being disbelieved arose in the participants experience before diagnosis due to physical and medical invisibility and their embodied experience. The participants had all sought expert

advice from doctors who hold the power and cultural authority to legitimize; authenticate and give credibility to the patients experience (Blumer 1971).

Firstly, the patient attempts to describe the atypicality of their experience in terms of deviation from typical ways of being, while the physician tries to grasp the naive way prior to interpreting it in light of scientific knowledge. The doctor's clinical gaze has the ability to see, understand and bring to light illness, by decoding the symptoms. The arrangement and configuration of the participants symptoms the tiredness, pain, and weight loss "become essential symptoms" which provide clarity and insight into disease (Foucault 1963: 89). The collection of symptoms, will point the doctor in a specific direction for finding a diagnosis (Croskerry 2002, Leder 1990, Freidson 1972).

However, lupus can be extremely problematic in this respect as. Stocki (2007) described clinicians can encounter numerous difficulties in diagnosing SLE which has an overabundance of symptoms which do not match diagnostic criteria.

Virginia Woolf, in her essay on being ill, emphasised the difficulty in describing our bodily experience and its neglect in literature. 'English, which can express the thoughts of Hamlet and the tragedy of Lear', have no words to describe some symptoms (2002: 6). The participant's felt they were not being 'seen nor heard', and they could not control or influence the encounter. They were being marginalised by their inability to suggest an illness that the doctor could recognise (Balint 1964). They 'could only say how they felt', but, often the participants were conveying a different styled presentation of symptoms. Their subjective experience was being viewed as unreliable and their embodied knowledge was being discounted. The

reality of their experience was not being believed, and they were being 'dismissed' and told 'nothing's wrong'.

The participants were being viewed as unworthy of serious consideration and their illness experience was being 'systematically disconfirmed' (Ware 1992: 347). They had become powerless. Power had structured their 'possible course of actions' (Foucault 1983:194).

Secondly to identify an illness the medical profession rely on objective measures. Medicine generally operates from the reductionist viewpoint, 'dominated by the mechanistic values of objectivity, precision and standardization' (Mc Whinney' 1978: 299). Engelhardt (1989) points out; scientific medicine exemplifies the notion that the sciences are understood as telling the truth and presenting what reality is the case. Therefore to be truly 'sick' the illness must have a proven biological origin (Richman et al 2000).

The doctor's trained medical eye and the advanced medical tests (technology) could not see their illness (Schwartz and Wiggins 1985, Baron 1985). Diagnostic judgements based on subjective evidence; are replaced by objective evidence provided by laboratory procedures and technology (Ledger 1990, Reiser, 1978). Medicine reinforces the perception that the 'truth' of human existence lies concealed within the confines of tests tubes and bodies, a terrain our own senses could never comprehend (Comaroff 1982:59). Dumit (2006: 580) discussed 'One must have laboratory signs in order to be suffering, one must suffer in code (ICD) in order for it to be recognised to be suffering, or one does not suffer at all'.

Hatfield-Timajchy (2007) determined that diagnostic delays in lupus were widespread and that clinicians placed too much reliance on

objective results and disregarded subjective experience. Lupus is interesting because there are clinical diagnostic criteria and biological markers that are indicative for a diagnosis. These include the existence of anti-nuclear antibodies, anti-DNA antibody and a range of extractable nuclear antigens. However, these are not always exhibited by people with lupus, leading to misdiagnosis and considerable time delays. The participants are physically invisible and also medically invisible. The participants were not 'throwing up' any positive test results.

Heidegger warns us about the current problems and the use of objective measurements, 'We can use technical devices as they ought to be used and also deny them the right to dominate us, and so warp, and confuse' (Heidegger 1959:54). For Heidegger the greatest danger with technology is that it can lead towards the elimination of all marginal practices.

Perhaps in considering marginal practices, an exemplar of practice in lupus can be gleaned from the work of Graham Hughes. Hughes (1997) warns the medical profession not to be restrictive in the classification of lupus, but instead to have scope for lateral thinking. He put together an alternative list for diagnosis and not pure classification. His list comprises ten clinical and four investigative criteria that has no statistical basis but is based on his vast clinical experience and expertise within lupus.

Medically lupus symptoms, of pain and fatigue are invisible. Kirmayer et al (2004:663) discussed, that 'the lack of explanation reflects the limits of medical knowledge, available technology and the epistemological difficulties of assigning a clear cause to subjective complaints like fatigue and pain, which have no objectively

measurable correlates and may change rapidly over time in quality and intensity'.

Often the participant's experience did not fit the normal criteria for any disease and their behaviour was deemed as 'a maladaptive way of experiencing one's own state of health' (Pilowsky 1994:567). The doctor can perceive maladaptive behaviour as the patient complaining about seemly unjustified symptoms. The doctor's inability to find a definite cause through symptoms or objective tests shifts responsibility away from the doctor to the patient suggesting that the cause of the problem is the patient.

The problem occurs because modern medicine strives to create order, and control through classifying, naming and categorising. The more advanced we become with medical technologies the less able we are to tolerate clinical uncertainties (Fox 1980). This can as Stockl, (2007:1150) discusses generate more 'epistemological disorder' and chaos rather than reducing it. Crawford (2004:506) has argued that the continuing expansion of medical knowledge and technologies 'aggravate the very insecurities they are designed to quell'.

Heidegger and Foucault open a space for critical questioning by showing that our 'understanding of reality need not be defined by techno/bio power, and that we need not be dominated by the drive to order and optimize everything' (Dreyfus and Dreyfus1996:15).

Biomedical failure left the participants feeling betrayed and neglected (Kleinman 1988, 1995) and with no means of coping (Ware 1992). Individuals come to depend extensively on health professionals to cure and care about their sufferings. The failure of these high expectations can be seen as a betrayal and neglect from those that should be taking care of their health.

For the participants the label of a psychological disorder brings stigma and shame. It implies it is their fault, suggesting they have the ability to control and reverse their physical symptoms. Stone et al (2002:1149) suggested 'some diagnostic labels, particularly those that sound 'psychological' can be perceived by patients as offensive by implying that the patients are 'putting on' or imagining their symptoms or that they are mad' (Dumit 2006, Nettleton et al 2004). This was demonstrated clearly by the participant's accounts in this study.

The unpredictable nature of lupus meant that participants could not always show some visible signs, to 'prove' that what they reported was true and real (Kirmayer 1994). Society believes that if you look well, you must be well (Nettleton 1995).

Vickers (1997:241) discussed how invisibility can mean 'few will be understood by relatives, friends or colleagues, or health professionals simply because the symptoms cannot be seen'. This leads to delegitimation and additional mental pain. The participants are assumed to be well, until they are proven sick. Both medical and social diagnoses apparently rely upon one's ability to see illness (Vickers 1999c). Some participants became fearful to share their experience in-case of rebuff, and denial of their experience. Participants were surrounded by doubt, in an effort to protect self; others were viewed with some distrust.

Nettleton (2006:1167) discussed, 'society does not readily give people permission to be ill, in the absence of an 'accepted' abnormal pathology or physiology'. Western perceptions of the reality of illness rely upon the sanction of the medical profession. If it is not diagnosed it does not exist (Vickers 1999c). Medical sanction is a requisite for society to permit the individual to assume the benefits of the 'sick role' (Parsons 1951, Veatch 1981:527).

Medical invisibility with the failure of biomedical tests increases uncertainty about the illness, its course, its consequences, the future and its threat to one's life (Johansson et al 1999, Kleinman 1988). Adamson (1997:134) discussed 'idiopathic diseases' can cause existential uncertainty, as they can arise 'spontaneously and from an obscure or unknown cause'. With these diseases, patients experience some kind of private existential uncertainty because they realise that their 'future life of his or her mind, body and self is in jeopardy'.

With, no hard biomedical evidence, or any visible proof, the participants started to experience self doubts (Ware 1992). Embodied doubt can be conceived as the convergence of 'symptomatic, physical, clinical and technological uncertainty' (Price and Walker 2013: 15). Nettleton (2006) goes on to argue that embodied doubt is a feature of late-modernity and that people with unexplained syndromes are just the tip of the iceberg of what it means to live in late modern societies. 'The relatively marginalised and neglected sets of people who live with medically unexplained symptoms comprise an extreme example of the lives of the majority of people in the 'risk society'. Although positioned on the edge of society, they might also be considered as emblematic of the mainstream' (Nettleton 2006: 1169).

Chapter seven, the findings and discussion chapter discusses the second theme, entrapment and explores the multiple constraints and barriers the participants experience in everyday life, as well as the constraints imposed on the participants from health services, and organisations.

7.0 Chapter 7 - Entrapment

7.1 Introduction to Entrapment

This chapter explores some of the multiple ways in which lupus brought the feeling of entrapment into the participants' lives. All the participants reported the feeling of 'entrapment' and longed for the freedom of the former self. The word entrapment has many different meanings and does encompass the participants' varied experiences. Referring to the Collins Thesaurus (2003) the noun of entrap means to trick, seduce, entice, entangle, trap, and enmesh; while the verb signifies capture, detain, confine, hindrance, barrier, restraint, drag, and resistance.

The participants were being forced to live a very different everyday life to the one they had experienced in health. They have lupus with its many barriers, restrictions and limitations and this places a drag on their forward trajectory; it situates them and makes them feel that lupus is keeping them tied to their context. Their situation is perceived as uncontrollable, unremitting, and inescapable and the participants feel they are being 'held fast', powerless to alter their situation (Gilbert and Gilbert 2003, Williams 1997).

They experience a lonely and daunting process, living in a narrowing world. The participants' sense of entrapment is diverse and is associated with many different things. The multiple constraints and barriers brought through their condition, as well as from being-with others, and the effect of living with a demanding condition.

The chapter begins with the participants feeling of being detained within their circumstances and progresses on to explore the betrayal of their body through loss of control, continual demands, unpredictable

nature and how a changed body affects the participants' relationship between self, being-with and being-in-the-world. The participants' experience a body that has become strangely foreign and the otherness of one's body are explored.

The chapter also explores the participants' experiences of entrapment through barriers including susceptibility to infections and environmental factors, the sense of distance and detachment and the transformation in their space of possibilities.

The section on continual change and disruption discusses the participants' experiences of uncertainty, new restrictions and losing important aspects of their lives. This leads on to feelings of entrapment through a sense of self-being diminished which includes work, parenting, obstacles to pregnancy, genetic inheritance and the effect lupus has on their children. Not receiving the support they need and problematic support is explored, as well as entrapment through the anxiety of experiencing a flare and additional health issues.

The section on barriers to future progression from health services explores the experience of appointments, not receiving a consistent approach and the effect on their life from health professionals not understanding the condition. Entrapment through autoimmunity explores the participants' experiences of losing themselves.

The discussion begins with the participants' experiences of entrapment through circumstances.

7.2 Entrapment through 'being held fast by circumstances'

SLE with its lack of a curative treatment, and unknown cause fostered the participant's feelings of being held fast and detained within their circumstances. The affect of lupus on Nadine was absolute it was "a waste of her life".

"It's a waste of my life, that's how I feel about this illness. I'd rather I had cancer, because at least the majorities of cancer they can treat. And I think it's a bit cruel really, isn't it, to make me suffer when… there's a lot of illnesses they can treat. And I've got this and lupus has taken my life away. You know, why the hell have I got this, I must have done something really bad and this is Gods retribution" (Pg 26, 509-516, T 24)

Nadine's illness generates questions, she searches for an explanation, 'why me? And what can be done?' and the answers to these questions reach beyond a search for causes and become a search for meaning in an attempt to reconstruct coherence in her life (Pierret 2003, Zempleni 1988). Nadine could find no reason except that it must be a retribution and punishment from God for some wrongdoing. Even if Nadine perceives her illness is the result of a transgression, it cannot be changed or undone. She is acutely aware of her loss of control over the situation.

As far as Nadine was concerned, that was it, there is no cure and her situation was never going to change. All the things she been doing and could have done have been stopped. Her life had been taken from her and thrown away. It was not only that there was a loss of the future through the loss of her future goals, but that lupus engendered a simultaneous loss of the actual present. The present has been forfeited and changed into an imagined future.

Nadine had expected that modern medicine with the power of technology would provide a complete restoration of her health. Science and medical interventions had been extremely successful in "the majorities of cancer", and many other conditions and diseases which can be cured. But, the cruel thing with lupus that was causing Nadine anguish and suffering was there is no cure; she would never be restored or regain her former self and life.

Engelhardt (1982:146) pointed out that illness is experienced not simple as suffering but 'as a suffering with a particular portent and meaning, as a suffering of a specific kind'. For Nadine, the significance and meaning of lupus depends upon her unique biographical situation, her individual life history, as well as determined by social meaning (Cassell 1979: 2003, Kleinman 1988).

Nadine's sense of entrapment is associated with the chronic ongoing nature of lupus. She perceives her situation to be inescapable, as there is no likelihood of rescue through either her personal volition or from others. She has lost her former life, lupus has taken it away, and she is trapped in a situation she is powerless to change struggling to find any meaning.

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Sacks' (1983) makes the point that this sense of what is lost, and what must be found, is essentially a metaphysical one. If we asked patients what it is that they wish or seek, they may answer 'my lost health', my former condition', 'feeling fully alive'. They long for a change, for everyday to be alright once again, unblemished, the way it was (Sacks 1983: 27).

Napier (2003: 80) discussed that 'we know less about the causes of SLE than we do with AIDS or certain forms of cancer'. So 'the reasons for contracting SLE frequently involve' some blame. Taieb et al (2010)

and Goodman et al (2005) confirm this in their studies discussing the beliefs about the causes of SLE, which include autoimmunity, psychological and familial causes, heredity, religious, guilt, punishment and infectious causes.

7.3 Entrapment through the betrayal of one's body

One of the major ways the participants all felt entrapped, was to be detained within an unpredictable, inescapable, strange and very restricting body. Napier (2003: 80) discussed 'lupus diversity is its major attribute, enough so that the 'pain' in this illness may be defined by an enormous range of symptoms' and bodily changes.

Heidegger (2011:157) discussed how the phenomena of the body cannot be dealt with without a 'sufficient elaboration of the fundamentals of existential being-in-the-world'. All bodily nature can be called the determination of the unfolding essence of Dasein.

In discussing phenomena, Heidegger (1962: 29/52) gave an example of disease appearing by way of its symptoms, 'occurrences in the body'. He noted that, rather, than reducing symptoms to elements, it is important to describe 'what is there', 'that which shows itself in itself, the manifest' (Heidegger 1962: 51/28).

The unpredictable course of lupus with its erratic changes and myriad of symptoms fostered feelings of entrapment and caused all the participants immense anxiety, uncertainty and concerns about their future. Lupus brings a devastating and frightening message; the body has a mind of its own. Intrinsic to Amy's experience of lupus is the total loss of control that she felt over her own body.

"One of the most disturbing things about living with lupus is… is the lack of control that I feel over my own body, it just all seems to go haywire and I never know how my body is going to be" (Pg 44, 871-889 T3)

Fig. 3 The Haywire Body

Amy chooses the very apt word "haywire" to signify the uncontrollable nature of her lupus body. Referring to the Chambers Dictionary of Etymology (2006), haywire refers to a term used among American English loggers for poorly equipped or, inefficient logging equipment, repaired with soft wire for binding bales of hay. The sense of out of order, tangled or wrong in reference to the springy and uncontrollable nature of haywire, was first recorded in the phase go haywire (1929). The extended sense of crazy or mad is founded in John O' Hara's Appointment in Samarra (2013).

Amy's picture signifies the precarious position she is in, one of, instability and fear with the sense of nothing being safe, certain or secure as she is subjected to endless unpredictable happenings and inconsistencies.   Her position is not one of fluidity, but constant sometimes violent changes with no anticipation of what might be coming or what is looming ahead. She is at the mercy of her "haywire" body and has absolutely no control of her situation or fate. Uncertainty surrounds everything as her body can no longer be trusted.

Silberman (1991:13) discussed 'sickness....shatters the web of assumptions on which our lives are based. We take it for granted that our arms, legs, fingers, feet and other organs will respond to our commands. When they do not, when we cannot move as we wish, or, become unstable, we discover how much of our sense of self is bound up with our body and how disorientated we become when the body turns into our enemy rather than an ally'.

Amy's body had once been her anchor in the world and alley, but with lupus her body is an enemy, out of order and disrupts every aspect of her life and self (Bury 2001). Amy's body can no longer be taken for granted and she can no longer assume that things will continue in a similar manner as they had in health. Her way of being depends upon

"her haywire body" and the unpredictable demands of her body dictate the terms she lives her daily life. Amy is not free to do whatever she will. She must always take into account "my body".

Binswanger (1975) discussed, 'experience is that in which our existence moves not only unreflectively, but also unproblematically and unobtrusively, as smoothly as a natural chain of events. When this breaks down, a person can no longer live serenely in relation to things, the world is turbulent. The consistent grounding' Amy requires to embark upon any of her 'projects is lacking' (Binswanger 1975: 251-252).

Her change in existential orientation is experienced as something bodily, but it is also the way in which things in her world appear. Her world is "haywire", turbulent, and chaos. The word chaos is derived from Greek, meaning gaping void, nothingness (Hamilton 1998). Her prior feelings of being secure and the comforting sense of belonging to a familiar and dependable world have gone. Her life is filled with dread, uncertainty, and unsettledness, where nothing is taken for granted and what remains is an all embracing awareness of a continual threat. Adamson (1997:134) discussed how 'patients experience some kind of private existential uncertainty because they realise that their future life, their mind, body and self are in jeopardy'. Amy is entrapped within her uncontrollable, turbulent situation and is unable to regain any stability, balance or 'equilibrium' (Gadamer 1993: 144-145).

The participant's unpredictable haywire body is demanding 'calling them back from their world and projects' (Pollio et al 1997: 79). May's body cries out for attention, disrupting and stopping her everyday life.

"The symptoms are so varied and relentless, I mean how can I do anything with this, it continually distracts and breaks my concentration and I'm pulled back to this body and it never stops or goes away" (Pg 14-15, 313-315, T 31.1).

May tried hard to forget about her "symptoms", and let them 'slip away'. She tries to 'turns away from herself and towards the things with which she was concerned' (Stone and Papadimitriou 2010: 141) by 'occupying herself' more and more with' her meaningful everyday activities' (Heidegger 2011: 161). Yet, her symptoms do not slip away; they remain and "pull her back to this body". She is no longer comfortable immersed in activity and the world no longer reflects the same kinds of possibility. Her body signifies a relentless obstacle, an enemy that thwarts every aspect of the unfolding of her life and closes down for-the-sake-of-which she exists, her projections to be a mother and wife. May's body had become strangely foreign, a defective tool, that never goes away, and the otherness of her body comes to the fore (Svenaeus 2011: 337).

This is stark contrast to how her body had been in-health, when it had been reliable, and a homely ground, taken for granted, as it effortlessly determined her comportment. Then, 'when she was absorbed in something her body was not present', her body had silently and quietly performed its functions without compelling moment-to-moment awareness (Heidegger 2011:85). Her 'body had stayed out of the way so she could get on with the task' and she had been effortlessly situated in a context of activity where the world was seen as a realm of salient opportunities for her many projects (Gallagher and Zahavi 2008: 143).

The participants' experience their lupus body as a constant inescapable presence. Christine lived with continuous fatigue and with

it came the perpetual feeling she was losing herself. Her body signified a heavy weight that brings endless limitations and dominates her life.

"The fatigue never goes away somebody is turning a dial and draining me like a battery until I'm nothing …. And I find my body is too heavy, everything is too heavy and I can never free myself from its constraints. And I never feel fully alive, my flame has dulled it keeps flickering and dying and that's me, I am empty nothing. Lupus has trapped me in a body that dominates my life" (Pg 44, 947-955, T 15)

Fig. 4 Loss Of Self Due To Fatigue

Tiredness 'belongs to healthy life as a phenomenon occurring daily that frames our being-in-the-world' (Svenaeous 2000: 12). Tiredness is a 'universal sensation, expected to occur normally at certain times of the day' usually after exertion, or lack of sleep and has a transient nature (Piper 1993: 279). Following rest the tiredness goes, and with it comes the taken for granted assumption of the return of vitality.

Christine's experience is completely different to that of tiredness experienced in health. She experienced no transient nature or times of rest from that heavy burden and restraint and she had no choice in the matter. She does not 'have' a body, she said "my body", the body is in each case 'my' body, the 'my' referring to myself (Heidegger 2011:113). Christine's bodily spheres of existing are not set free from her, rather they remain, and belong to her as long as she lives.

Gronda (2002:11-12) discussed 'I am just alive and existing...Dasein always exists in the world. Three terms facticity, throwness and state-of-mind help to describe the process of trying to dance with the body I have. Facticity designates the irreducible specificity and always alreadyness of Dasein's being-in-the-world. The body 'Christine has' is always unavoidable and specifically mine. The concept of facticity also implies that Dasein is meaningfully bound to the conditions of its existence and the entities it encounters. The specifics of my 'there' mean something to me. Whether, 'I have lupus' or red hair or yellow skin are not random, objective facts; they are important to me and to others, but I don't get to choose them. I think the 'there' of my existence is always and most proximally, my body. My bodily particularities are part of my facticity, they constitute the mineness of my existence; it is the inheritance which I do not choose' (Gronda 2002:11-12).

Christine is defined by the past, all the facts about herself and the world, the actualities and possibilities that are 'there' as a product of the past which she has no power to change. This 'there' is her situation, the part of her being a person into which she has been thrown. Thoibisana (2008) discussed how Heidegger (1962: 2) uses the 'evocative term throwness to signify this inescapable submission to existence itself'. Dasein is always and already 'delivered over to the Being which, in existing, it has to be' (Heidegger 1962: 173).

Christine's embodiment dominates her life and gives her a sense of inescapability and limitations. 'In certain ways and whether I like it or not, there are some activities, postures, gestures, and sensory encounters which are just not within my bodily scope' (Zaner 1981:51). The limit of Christine's bodying forth is the horizon of being within which she dwells. 'The bodying forth of the body is determined by the way of my being and therefore is a way of Dasein's being' (Heidegger 2011:113). Christine's once healthy dwelling place extended wide into the world. But, with lupus she is weighed down and the taken-for-grantedness and the transparency of her once normal activities have changed. Her life offers continuous severe resistance, she never "feels fully alive"; her flame has dulled and her energy is incessantly draining away until she is left with "nothing". In a sense she has become powerless. She has lost independence and freedom and has no energy to work, look after the children or be a housewife. Her experience means a lasting, never-ending tiredness, 'transformed into unhomelike, and alien attunement, which has gone out of rhythm' (Svenaeous 2000: 12).

Due to the unpredictable nature of lupus the participant's traitorous body can quickly change, 'out of the blue', and they can be imprisoned, and restrained. Ann dwelled in a body that violently "out of the blue" "erupted".

"Then suddenly out of the blue a volcano erupted inside me for no reason. I had symptoms appearing from nowhere, this awful pain in one leg and then all of a sudden it jumps wherever it wants to and it explodes and that's it, my life gets blown away and stopped" (Pg 8, 145-148, T 30.1)

Fig. 5 The Eruption Of My Body

Ann felt betrayed in a dramatic way. She had experienced some good days, with some progression only for it all to be taken away. Her symptoms appeared without warning, carrying danger and 'threatens her existence' (Svenaeus 2000:142). Her life had suddenly been

curtailed, "blown away" and "stopped" and she is powerless to change that situation. Her powerful image a "volcano erupting" signified the force, violence, fear, uncertainty and the utter devastation inflicted upon her by lupus. She is aware of just how uncontrollable her life has become, its fragile nature and how quickly it can all be shattered.

Amy was being violently restrained; her picture signifies the fear and strangeness of her experience.
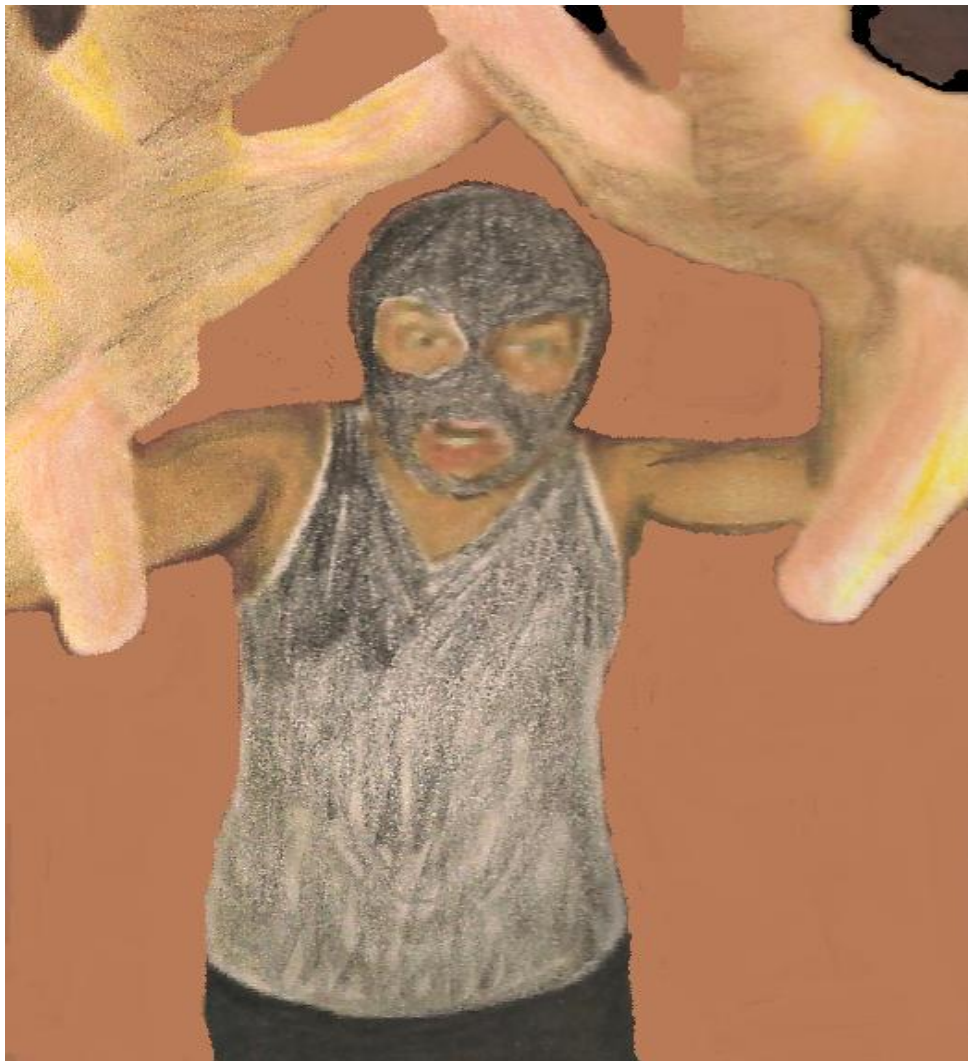
Fig. 6 Being Held Down

An intruder had invaded and "someone" was holding her down.

"I find that hard, very hard. My body just won't let me, full stop. Someone is forcefully holding me down, and in my mind I feel, I really want to do that, and I want to do this, and … I can't, I am being held down" (Pg 14-15, 290-294 T3).

Amy's body had manifested itself suddenly and without warning into a forceful 'essentially alien presence which has its own nature', and which 'I am at its disposal' (Zaner 1981: 52-53). She wanted "to do that, and do this" but however much it mattered to her, she could not resist the forceful attack. She is being held captive and all her possibilities have ceased in an 'obstructive and merciless way' (Svenaeus 2001:111).

Lora is suddenly "imprisoned" within an existence of pain closing down any possibilities to be anything.

"It's this nerve pain and that really kills me. I literally hurt from my head to… to my toes, I've been stabbed with sharp spears and I can't move or if I'm touched I scream, literally just being brushed against is agony and I'm imprisoned in pain, nothing" (Pg 11, 229-230, T 11)

Lora's picture conveys the sense of her pain radiating out 'to fill her entire universe' (Scarry 1985:35).

Fig. 7 Lora's World Was An Existence of Pain.

Lora reverted to a battle image, reporting that the lines directed at her body symbolised "sharp spears" piercing her skin. It could also symbolise the unexplainable violent attack inflicted upon her body by lupus. Lora could find no comfort. Her pain is so intense she can't

stretch, move or lie, and the pressure from her clothes, being-with, light, or sound was unbearable. Her pain 'resisted' and 'destroyed' language (Scarry 1985:4). Her picture shows her curled up, immobile, still, barely alive; the careful divide between being, being-towards-death and no longer being at all.

When we look at her picture, we may wonder whether she is trying to retreat deep inside, maybe even disappear in an effort to escape the pain, but, she can find no hope of sanctuary. Her wounds and scars run too deep, and they are something which is always carried with her and from which she could never escape. She finds herself bound to her particular embodiment and is irrevocably bound to suffer whatever her body suffers. There is a strong sense of Lora being restricted, pinned down, and having no power or control over her situation. Lora has been thrown into the world and is delivered over to situations of possibility and choice which she did not choose, and does not control. She is imprisoned in pain and cannot escape or retreat. Time is running out and annihilation appears close. For this time she has lost her usual sense of existing, of being-in-the-world and being-with and is experiencing "nothing", or non-existence, 'everything is obliterated' accept pain (Scarry 1985: 30).

Van den Berg (1966) discussed, the possibilities the world offers are much more restricted. 'I have ceased to belong; I have no part of it' (1966: 26-27).

Lora's pain is probably the pain that Emanuel Levinas (2005) was referring to; when he discussed that severe forms of suffering subjugate the self, fully. The acuity of suffering lies in the "impossibility of retreat" (Levinas 2005: 238). I am "held fast" in pain (Levinas 1981:52). The self "becomes" pain (Bullington 2009:109).

Hatfield-Timajchy (2007) explored the meaning of pain for SLE patients. The participants drew on a picture of a human body, their current pain experience including its position and intensity. The participants explained that they experienced pain 'everywhere'.

Patients with SLE can experience additional autoimmune conditions such as fibromyalgia (FM), or they can experience symptoms on the spectrum of that autoimmune condition. Wolfe et al (2009) used the term 'Fibromyalgia-ness' to refer to the prevalence and intensity of FM-related symptoms that might exist as a continuum across all rheumatic disease (Wolfe and Rasker 2006). Fibromyalgia (FM) is a syndrome of autoimmune origin, which increases sensitivity to pain. The majority of those with fibromyalgia experience constant pain throughout their body (Bennett 1995). Patients with SLE and FM (Atzeni et al 2011) have described how their pain is everywhere. Further insights into SLE pain experience may be obtained by referring to qualitative studies on fibromyalgia.

Research into fibromyalgia has explored a world fundamentally altered by a body in pain (Juuso et al 2011, Mease 2005, Solitar 2010, Cunningham and Gillings 2006, Raheim and Haland 2006). Juuso et al (2011) study entitled "Living with a Double Burden", aimed to elucidate meanings of pain for fifteen females with FM. Each was individually interviewed and encouraged to talk freely, from between 45-115 minutes. A phenomenological hermeneutic interpretation was used to analyse the texts. Findings revealed that the pain was ever present. It was felt throughout the body and overwhelmed and dominated daily life. The pain was invisible and their suffering was increased by being doubted. They had come to understand that they had to reconcile themselves to pain being part of their lives. The strength of this study was in the choice of a comprehensive sample and the depth of analysis.

With a changed body the participant's intimate relationship between self, being-with and being-in-the-world alters and this affects how all of these are experienced. Jenny's bodily sense felt as if it radiated out to fill her whole world.

Fig. 8 Jenny's Whole World Vibrated

"My body continually moves and the vibration goes straight through me. And I sit on the floor and try and touch something that isn't vibrating...but, nothing is how it should be, it's sort of unreal, out of touch, weird like my world is collapsing around me....And it's very

frightening, it's just not right, nothing feels right,...and it never stops" (Pg 48, 939-955, T 13).

Jenny feels trapped engulfed in movement and her world feels as if it is "collapsing". Her way of finding herself feels "frightening", "unsettling" and "nothing feels right". Van den Berg (1972:56) discussed, 'His world is collapsing. Is he not saying the same thing when he states that his legs are failing him and he feels he is losing his sense of equilibrium! World and body are interrelated'.

In-order-to regain a sense of being situated in the world, rather than being cut-off, Jenny engages with her world in a way that is given meaning. Ihde (1983) discussed how "touch" is integral to a sense of connectedness between self and world, of belonging to the world: 'through touch, I am constantly 'in touch' with that which surrounds me' (Ihde 1983:99). But, rather than regaining a sense of familiarity, and connection, Jenny's way of being-in-the-world felt "out of touch" and "unreal".

One form of anxiety is 'the awareness that' one feels 'in an unreal world in which things (are not) what they seem to be and in which attempts to connect fail' (Glas 2003:238). Jenny feels "nothing is how it should be" her background sense of belonging is missing. She does not feel in touch with the world. Her experience is structured by an absence of practical belonging and her activities are disturbed.

Heidegger (1962) suggests that moods constitute a sense of belonging to the world and this belonging can breakdown to varying degrees. Sometimes things 'just don't feel right'. The world appears uncanny with a sense of estrangement and disconnection from it. Heidegger called this anxiety, Angst. Anxiety is a complete loss of

everyday practical familiarity an absence of any sense of connectedness to things.

'Here the totality of involvements of the ready-to-hand or present-to-hand discovered within-the-world is, as such, of no consequence; it collapses into itself; the world has the character of completely lacking significance' (Heidegger 1962: 231).

The mood that binds Jenny to the world breaks down and this gives her the sense of complete unfamiliarity, a "'nothing". Heidegger (1978a) explains that this 'nothing' is a disintegration of everyday belonging, the total absence of significance. One is no longer there anymore and all that remains is the feeling of having 'no hold' on anything (Heidegger 1978a:101).

Jenny cannot disappear into a particular pattern of practical activity if all of her experience is structured by an absence of practical belonging, if she does not feel in touch with the world. The things she engages with feel unfamiliar, perhaps even threatening and alien.

The participants' lupus body had changed and become strangely foreign, with a sense of estrangement. Their body could no longer be relied upon or trusted, it signified a threat. Vivian is faced with her inherent vulnerability and dependence upon her body.

"Even though I try and adopt a positive attitude and I try to do as much as I can to overcome lupus, the barriers are still there and I cannot do what I want to do. And I find that deeply frustrating. I...I never realised how much I relied on my body until it went wrong, now I am held back in everything I do" (Pg 44-45 , 891-898, T16.1)

Vivian's body had become a saboteur shutting down possibilities rather than an enabler for her everyday life. She is not free to do whatever she will. She must always take into account "my body". Her lived body has been reduced to a body that has gone "wrong" and cannot be corrected.

Heidegger (1962) gave a useful analogy when he was discussing tools, and how when they break down they become the centre of our attention. When Vivian's taken-for-granted way of being-in-the-world 'breaks down', when her equipment 'her body' malfunctions and resists, it forces her to focus upon her body rather than on the work to be accomplished. It is at these times of breakdown that the taken-for-grantedness of everyday life is exposed and becomes visible (Heidegger 1962).

Heidegger (1962: 73/102-103) discussed, 'When its usability is discovered, equipment becomes conspicuous. This conspicuousness presents the ready-to-hand equipment as a certain unreadiness-to-hand'.

Heidegger (1962) goes on to say, 'When we notice what is unready-to-hand that which is ready-to-hand enters the mode of obstructiveness. The more urgently we need what is missing and the more authentically it is encountered in its unreadiness-to-hand, all the more obtrusive does that which is ready-to-hand become-so much so, indeed, that it seems to lose its character of readiness-to-hand. It reveals itself as something just present-at-hand and no more, which cannot be budged without the thing that is missing. The helpless way in which we stand before it is a deficient mode of concern and as such it uncovers the being-just-present-at-hand-and-no-more something ready-to-hand' (Heidegger 1962:73/103).

The failure of a piece of equipment, 'Vivian's body' disrupts her normal everyday life and forces her to confront the question of what her body does in her life. This is not something she would normally do in health when her body was 'working'. She is confronted with her reliance on her body to achieve her future possibilities.

Heidegger expressed 'Das Leiben des Leibes' (1994:113). Existence is a 'bodying forth' in the meaning structures of the world. The bodying forth of the human beings body co-determines the human beings being-in-the-world, 'We must characterise all comportment of the human being as being-in-the-world, determined by the bodying forth of the body' (Heidegger 2011: 90-91).

Human embodiment and embodied human practices are not just contingently implicated' in our possibilities, 'but are central to the character of those possibilities as possible' (Stone and Papadimitriou 2010: 150). Bodily being co-determines Dasein's existence as being-in-the-world and belongs essentially to existence (Heidegger 2011: 122). All bodily nature can be called the determination of the unfolding essence of Dasein.

Vivian wakes up to the realisation that her body is needed for her purposes and the implicit purpose of her body comes to the foreground. Without a body that works, "I am held back in everything I do". Vivian's body has gone "wrong" and she is no longer comfortable immersed in activity, and the world no longer reflects the same kinds of possibility. Her unfolding essence is being thwarted. She is embodied in a body that had become a real and deadly threat to her continued existence.

Although the analogy of the sick body as a broken tool, may reflect Vivian's experience, Marcum (2004: 125-137) points out 'that it would be wrong to call the body parts tools, since they are also part of Dasein itself. They are not only a part of the totality of tools, but also as lived (leibliche), they belong to the projective power of the self' and is subsequently united 'to the most intimate and irreplaceable parts of being-in-the-world of the person' (Svenaeus 2000:134). Heidegger (2011:232) discussed, 'In contrast to a tool, the bodily spheres of existing are not set free from being-human. They cannot be cared for in a tool box. Rather they remain in the sway of being human, held in it, and belonging to it so long as the human being lives'.

The participant's feelings of entrapment intensify; they felt trapped in another's body. The 'otherness of Amy's own body comes to the fore'.

"I'm in someone else's body, a stranger has moved in and taken over, or they've put somebody else's body on me and … it doesn't belong...I'm confined and trapped in this thing and it isn't me, what the hell is happening and I can't escape … and to me it's not right" (Pg 43, 866- 870, T 3.3).

Amy's body no longer felt her own; she experienced the sense of being taken over, controlled and confined in something other than herself. A "stranger", who "doesn't belong" had moved in and has removed her from her own homely context and dwelling place.

<u>Fig. 9 It's Somebody Else</u>

Amy's picture conveys the sense of her bewilderment. She can no longer see her own reflection in the mirror; instead she is confronted by an unfamiliar and utterly alien thing looking back at her, which offers her no possibilities. In a sense she has been ravaged by the alien encounter and has become so close to the otherness, there is no normal self, and therefore there is no possibility of her own reflection.

She experiences her own body as other, uncanny (unheimlich) and has 'a profound sense of alienation from her body' (Svenaeus

2001:337). The alienation Amy feels attunes her being-in-the-world in an unhomelike way (Heidegger 1962: 189). The unhomelike attunement colours and determines her transcendence, 'the act of going outside of itself and into the world, performed by Dasein' (Heidegger 1996: 363-364).

Heidegger (1962) discussed 'uncanny' in relation to anxiety where one has an 'uncanny' feeling. For Heidegger, the uncanny comes from nothing and nowhere. Uncanniness means at the same time 'not-being-at-home' (Heidegger 1996:188/233, Svenaeus 2000:7). Anxiety is the most extreme form of the uncanny, a disintegration of background existential orientation that amounts to the 'complete negation of the totality of beings' (Heidegger 1978a:98). The unfamiliarity in the uncanny is not the absence of familiarity but a feeling of unfamiliarity, the awareness something is "not right", and something is missing. In anxiety everything in the world reveals itself as empty against a backdrop of a basic meaninglessness, a homelessness of life. Freud (2003:123) suggests uncanny belongs to the 'realm of the frightening', an all encompassing sense of "weirdness", 'fatefulness' and 'inescapability' and can involve a feeling of helplessness (Freud 2003:144).

Svenaeus (2000) discussed how 'Illness can be conceived as an unfamiliarity within the world, that world that is part of my own being as being-in-the-world'. The 'phenomenology of illness can be carried out by highlighting the concept of otherness, in relation to meaningfulness, where the Otherness is to be understood here as a foreignness that permeates the ill life when the lived body takes on alien qualities. A further specification of this kind of otherness can be found with the concept of unhomelike being-in-the-world' (Svenaeus 2011: 333).

7.4 Entrapment through barriers

Lupus brings barriers and invisible walls through the betrayal that occurs in one's body. Rebecca's fragile body signified a barrier to her world and being-with. Her body was highly "susceptible to infections" and environmental factors, such as sunlight, ultra violet light, noise, space, smells, and changes in temperature. The effect upon her was absolute. The world and being-with made her physically unwell and she could no longer "be in it". "Lupus has barred me from the world". Rebecca's picture conveys the sense of her lonely existence.
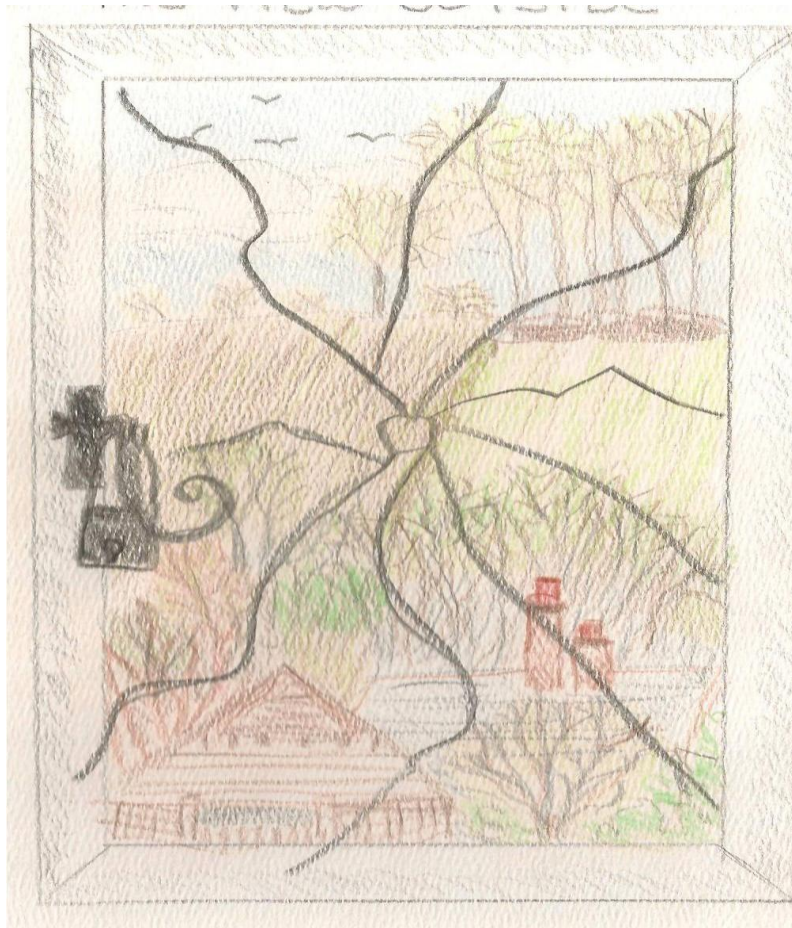
Fig. 10 Unable To Be On The Outside

"I feel I've gone through a complete character change, one I did not want and I'm a different person out of kilter with my old world. Lupus has made me allergic to so many things, I mean I used to love socialising, but my body is fragile and I'm very susceptible to infections so I can't be in any crowded areas. I can't tolerate any environments that have bright lighting or are noisy or large because it makes me ill and even being near people is horrendous. I can't be in the sun, if it hits my body it just burns and I'm in agony. I mean Lupus has barred me from the world and I am forced to live this very lonely existence. I do feel excluded, vulnerable and very remote and...However much I want to be in it, I can't it's too lethal (Pg 3, 61-79, T 20.1)

In health Rebecca had taken for granted her ability to dwell widely and mix freely being-in-the-world, being-with others. She was being-in, engaged in activities participating in a world shared with others being absorbed and immersed in the world. She had grasped her ready-to-hands object, in relation to her own possibilities for being. She had the opportunity to enact choice and assert control over her occupations and aspirations and her world was a field of endeavour for her many possibilities. Her world, saturated with cultural and historical meaning had been familiar, a homely ground, and she had not been a stranger in her worldly dwelling place and her world was not alien.

Heidegger describes being-in-the-world as our basic constitution we are familiar with the world. 'I reside or dwell amidst the world as that which is familiar to me' (1962: 80/54). And 'I am delivered to the world (geworfen) with other people and being together with them (Mitdasein) is part of my own being' (Heidegger 1962:117).

Rebecca is acutely aware of her previously taken-for-granted life and how she and her life had altered. She had become a different person and had no choice in the matter. Rebecca had been thrown into a world that is strangely unfamiliar and unhomelike and was now a 'dweller in a foreign place' (Thoibisana 2008:3).

The world of lupus, impinged upon her senses in a qualitatively different manner than it had in-health. The world had become intolerable, overwhelming, too bright, "noisy", and "crowded". Her vulnerable and fragile body had let her down, and the world and being-with had taken on a new and deadly meaning. They were invasive and potential destroyers of her fragile self.

Every aspect of her life has changed and she is being forced to live a very different existence. She could not meet up with friends or be in crowded areas due to the high risk of infections and environmental factors exacerbated lupus. She had become "out of kilter" with her old familiar world and her field of endeavour to realise her possibilities had constricted. Lupus demanded that she lived a lonely existence, in solitary confinement. However much her life projects matter to her, she is cut off and barred from being-in-the-world and from being-with others which compound her feels of isolation, and alienation.

The symptomology of increased sensitivity for those with SLE has been reported in the literature. Mattsson et al (2012) mentioned that light sensitivity can be associated with SLE. Danoff-Burg and Friedberg (2009) reported that those with SLE require help regarding sensitivity to bright light, sun exposure and coping with hot and cold temperatures. Robinson et al (2010) relates that skin sensitivity and cutaneous manifestations are significant disease-related issues with SLE.

Abigail experiences a different sort of barrier; she experiences the sense of being distanced from her familiar being-in-the-world and being-with. Abigail's picture gives us an insight into her very lonely existence, and the sense of distance, detachment, of things being strange, and not real. They show us an "in-between world", a world which 'we don't normally see' and even if we cannot experience it, through her picture 'we can sense it, and become sensitive to things which one oblivious before' (Klee 1956: 301).
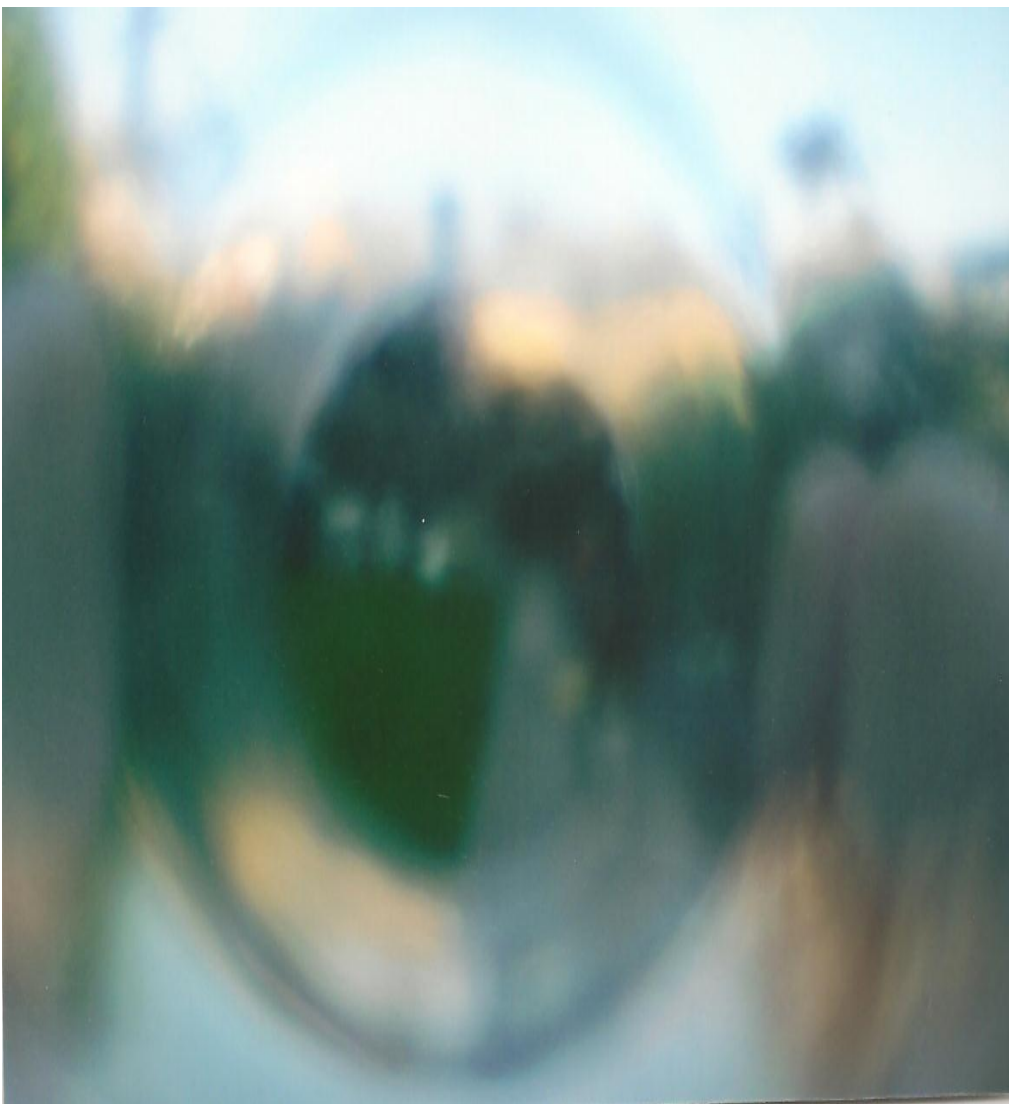
Fig.11 An In-Between World

"Things are happening out there and I… I want to go and join in and do things… but it's on the other side of the window and I can't get through, I'm trapped behind a barrier. It all seems a long way away... and I'm cut off in a different world... an in-between world where I'm there, but not there.....if that makes sense. I'm watching from a distance but can't join in and it doesn't feel like it's me, it feels unreal. It's like I'm detached from everything it's very strange...and frightening. It's like torment that never ends... (Sigh) nothingness in a way" (Pg 15-16, 310- 349, T 28.1)

Abigail experiences the strange sensation of looking on from afar, as if being a spectator watching a scene being played out, but not being able to join in. She is physically "there, but not there", a sense of detachment, of not being part of a situation or belonging as if it's not her at all.   Her bodily feeling is experienced as an altered space of possibilities, where possibilities for social and other activities drop out of her world.

She has been thrown into "a different world... an in-between world" and has lost her familiar being-in-the-world and her once ordinariness, and averageness of life and has become marooned in a very uncomfortable and frightening place, 'a form of torment so alien to everyday experience' (Styron 2001: 14-15).

Medford et al (2005: 93) discussed the feeling of 'everyone is acting out a role on stage, and I am just a spectator' and things 'appear detached from me', 'living in a tunnel' and as the participants described "it's the other side of the window" feeling "nothingness" point to an intimate connection between changed bodily feelings and how the world is experienced. While Radovic and Radovic (2002) related that a sense of unreality is closely associated with feeling 'cut off' from things, which seem remote or detached.   Radovic and

Radovic (2002) draw together various autobiographical descriptions, which include feeling detached from body and world, feeling like a spectator, feeling of unreality and strangeness.

The resultant transformation in the space of possibilities is often referred to in autobiographies and works of literature as a prison, glass wall or container from which escape is impossible.   There were numerous similar comments within this study, such as "there is a wall, between me and the outer world", and "I am imprisoned in a diving suit, looking through its glass plate". William James (1890:178) described it as like being 'sheathed in India-rubber'.

The healthy person can venture freely in the world, engaging in their familiar life. But, for those with lupus that tempting 'vibrant world out there' with its vast range of possibilities is often out of reach. The lives the participants lead are narrow and constricted, contrasting sharply with the lives of others around. They no longer had the energy to socialise and never knew how they would be. They could no longer fulfil obligations that were implicit in their past relationships in health. They have become separated, travelling alone, in a barren, alien and unknown place. Lupus can feed and amplify loneliness until it becomes tortuous.

Ann felt increasingly estranged and disconnected from the world in which she had previously been immersed. She had entered a parallel universe, far away from the world she wanted to be in.

"I've been catapulted into a parallel universe far away from the world I want to be in. My world spins out of control, moving further into space, while everybody else's world carries on normally. I see their vibrant world, while mine is remote, their world is moving on without me and it makes me feel very lonely" (Pg 40, 769-779, T 30.1)

Ann's world spins out of control, an endless daily struggle to preserve her daily life as best as she could, being a wife and mother. Her world had become illness, fear, confusion, a completely different reality to those around her. They carried on as if everything was normal, in their familiar and comfortable world, while her world had become isolation and loneliness.

The isolation she feels is even more acute because the familiar world is "moving on" without her, and she is being left behind, giving her a feeling of non-participation. She still appreciates that all the shared routines she used to take part in still carry on much the same as before, and her sense of a practically significant world remains intact, but, the possibilities are no longer her own. 'I have ceased to belong; I have no part of it' (Van den Berg 1966: 26-27). 'What prevails is a tormenting feeling of distance, the awareness of an unbridgeable gap, and attempts to connect fail' (Glas 2003:238).

An excellent example showing how certain existential feelings can constitute insurmountable isolation from others is Sylvia Plath's (1966) semi-autobiographical novel 'The Bell Jar' charting the progressive estrangement of Esther. Plath (1966: 178) wrote 'wherever I sat, on the deck of a ship or a street cafe in Paris, I would be sitting under the same glass bell, and stewing in my own sour air'. She is physically in the room but she is not in a shared social situation. Plath is able to convey the result of 'estrangement from the social world' the sense of detachment, of not belonging, and not being part of a situation (Ratcliffe 2008:67-68).

Karen had family members around but she still experienced a distance, and loneliness.

"They don't understand what it's like, I mean I try to say how I am but they don't appear to be interested, they just change the subject and there's a growing distance and I feel cut off, and very, very lonely" (Pg 7, 129-131, T7).
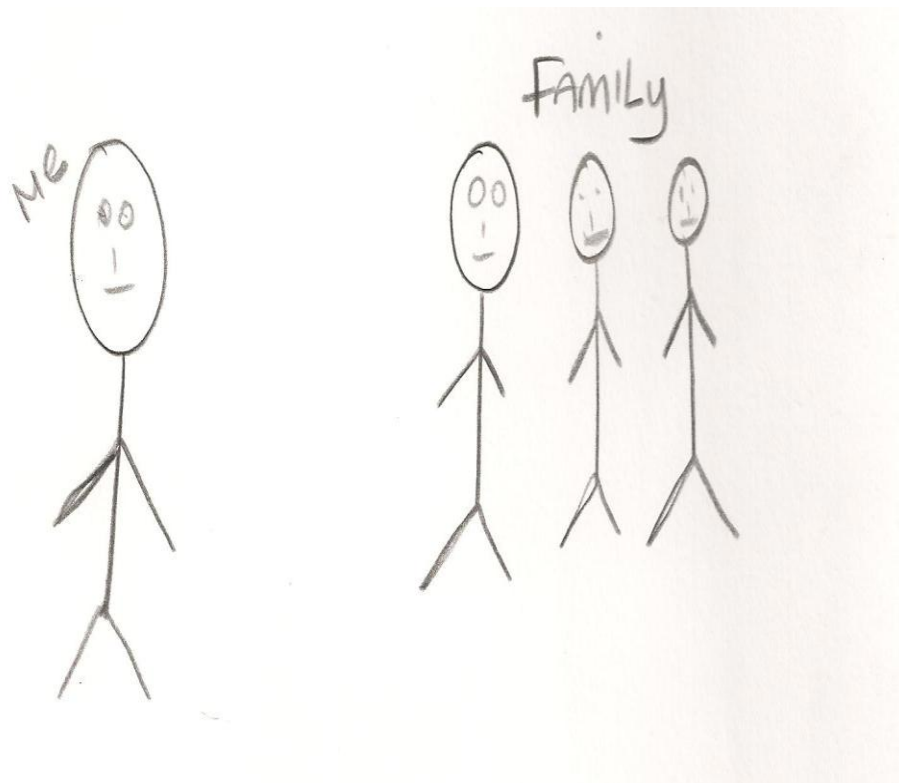
Fig. 12 A Growing Distance With My Family

Being able to care or not care, or being variously concerned or indifferent is always a matter of attaching value to facts. Karen engaged with her family in a way that matters to her, she wants them to care, to acknowledge she is still alive, and is still here. Laing (1960:125) comments 'it extends to the need to have ones presence endorsed or confirmed by others, the need for ones total existence to be recognized, the need to be loved'. Her families disinterest hurt. She

felt rejected and completely alone. Her situation seemed to be of no concern to her family. This increased her feelings of a growing distance, alienation and feeling alone trapped in her situation.

Van der Berg (1966) discussed how a feeling of alienation can be exacerbated by the orientations that others continue to take for granted and that which the patient has come to inhabit.   'The ill person is certainly hurt when his wishes to discuss the state of being ill as a form of life which is hard or impossible to bear, is declined with trivial remark' (Van der Berg 1966: 45).

Other people pursue their activities much as they have in the past and although lupus had affected the totality of Karen's own experience, it was only on the periphery of others.

7.5 Entrapment through continual change and disruption

Lupus caused huge changes and at times obliterated everything within the participant's life, while smaller changes gradually eroded in particular ways. Living with lupus means unpredictability, continual change, disruption, uncertainty, compromises, and anxiety. Phoebe's world had been "turned upside down". She had lost any firm foundations and was on "shifting sand" unable to get a "foot hold" to regain any stability for progression.

Every aspect of her life kept altering, nothing remained the same and with every change she became unsettled and anxious. The context of Phoebe's daily life is framed by "endless" uncertainty; and a continual need to modify her roles and expectations about what she could do.

She suffered continued disruption in every aspect of her life and self, including the imbalance and psychological turmoil from loss of control,

continual lifestyle changes and the losses of roles, status, social engagement and independence.

"Well I think it's changed my life completely. I… I never thought… that I would have such an upheaval. I didn't, realise I would have to change absolutely every aspect of my life. Physically I thought it would just mean that I wouldn't be able to do quite so much, but that's not the case at all, it's ever shifting sand with continual change and never getting a foot hold" (Pg 1, 6-11, T 12)

"I get more, disability and illness, and further barriers and I have to try and adjust to it again. So it's not one change, its continuous endless change and I find that very hard. It's always giving up something, driving, work, relationships, and friends and I'm sinking further and further into sand, disappearing slowly forced to live a very restrictive life dying inside and there is no way out" (Pg 1, 13-18, T 12)

Each change brought new restrictions, illness, disability, and the "giving up" of something important that gave her life meaning. With each change, she experiences a sense of disorder, and loss and has to try to rework her identity and adjust to a new way of being-in-the-world.   Each time she had tried to adjust to her present situation, she had to adjust again. Phoebe's ever changing sense of possibilities means she has to continually modify her roles and expectations, and experiences an ever-changing sense of identity. With each change came uncertainties about what it all means, and what her future may hold.

Fig.13 Ever Shifting Sand Sinking Deeper

Phoebe's picture shows her precarious position. She has no expectation of a return to normal function. She was scared about how much of her would be left. Lupus brings the threat of increased disability, illness, and restrictions with the loss of present and future possibilities and that means facing the destruction of life itself. With

each change there is a sense of self-being diminished by the loss of her many precious role identities. She is losing herself "sinking" further into sand, and "disappearing slowly" and "dying inside" and she could see no way out, increasing her feeling of entrapment.

Jaspers (1962) discussed how the sense of feeling you are dying is related to the feeling of there is no possibility of escape, a non-existence. 'The world has escaped them. Nothing remains. They are alone in terrible isolation, suspended between infinities. They themselves no longer exist; their body is dead. Only this fake-existence remains as their horrible fate' (Jaspers 1962: 63).

Jaspers (1962) talks about fake-existence, while Heidegger (1962) discussed 'existential death', when we cease to exist as a person but continue to live as a human. What he may mean by this is a situation in which the person 'gives up' on existence. It is not a matter of no longer wanting to go forward but of not being able to go forward. Lupus has set limitations and restrictions on her life; and Phoebe is running-out of possibilities. The possibility of running out of possibilities confronts her with the fact that she will always face the question of how she lives her life. She is condemned or delivered over to confronting the question of her identity, which is embodied in how she lives her life. Heidegger (1962) used the term throwness, which for Phoebe means she is subject to life and it burdens her in the sense that she cannot remove herself from caring about it.

Svenaeus (2002:13) discussed how the threat of ceasing to be or of getting worse is experienced in lived time, and 'this very threat brings unhomelikeness with it as a constant eclipse of the future'. Phoebe can never reach a transcendence 'the act of going outside of itself and into the world performed by human being-there (Dasein)' (Heidegger 1962: 363-364) that enables her to perform her activities in a way that

makes sense to her. It is not possible to compensate for this so she can lead a normal life. This attunes her whole being in the world, in an unhomelike way and she 'experiences a constant sense of obtrusive unhomelikeness in being-in-the-world' (Svenaeous 2000: 10).

This unpredictability is widely reported in the lupus literature. Mattsson et al (2012:1) refer to the experience as 'multifaceted uncertainty'. This is an apt and comprehensive term as it includes not only the physical aspects but also the emotions arising as a result, namely; anger, powerlessness, fear, sorrow and despair. These unseen emotions impinge on the participant's lives when they are attempting to work and live social and family life. Within the lupus research similar findings have been found by Archenholtz et al (1999), Bauernfeind et al (2009), Mendelson (2006), Wiginton (1999) and Schattner et al (2010).

Lupus with its emotional "roller coaster ride of up's and down's" presents a very daunting challenge to psychological coping.

Peter felt despaired and trapped within his present situation.

"I'm trying to build a fence outside and the day before last I was cracking on quite well, I have to stop every so often and sit down because of the tiredness, but it was going on well, so psychologically, I was quite buoyed up" (Pg 33, 708-713, T1)

"And then the next day I was wiped out, I wanted to get on and finish it but I couldn't, I had to stay in bed and that's how lupus has affected me. And it is an endless spiral, a roller coaster ride of up's and down's, with one step forward and then dragged back two and it's a roller coaster ride of the despair and a psychological barrier to get across" (Pg 33, 713-725, T1)

264
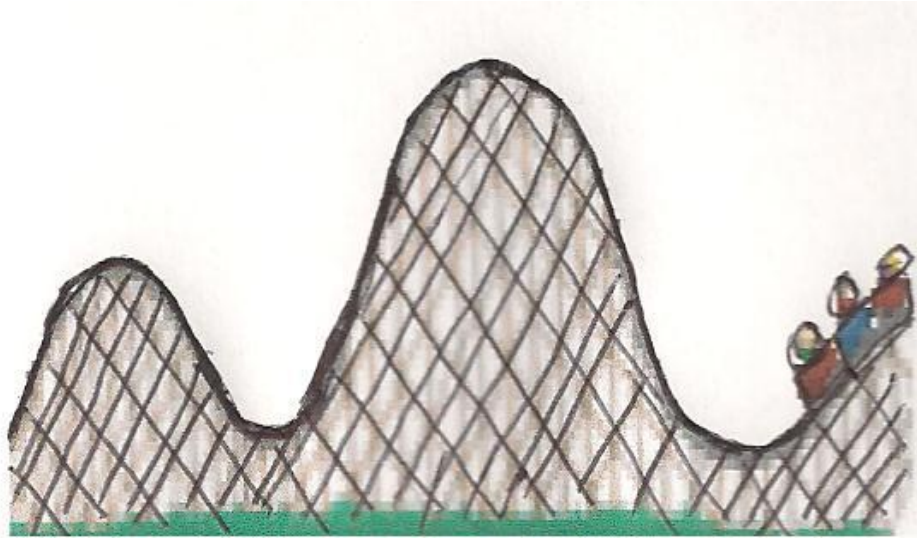
Fig. 14 Roller Coaster Ride

At times Peter felt psychologically 'buoyed up'. He had experienced a glimpse of his former self and his everyday life flowed a little easier. He grasped the ready-to-hand objects, the hammer, nails, fence, in relation to his own possibilities for being. He had possibilities and was achieving something.

The next day, it was all taken away, Peter could not proceed. He was physically exhausted and his body had thwarted any progression. Psychologically Peter felt 'wiped out', frustrated and despaired. He could not progress, finish or complete the task. His life had become an 'endless spiral' of hope at being able to do, and despair at being thwarted and "dragged back". He had experienced a glimpse of his former self and this heightens his awareness of just how much his life had become restricted.

Peter wants to progress; it matters to him that he can do his for-the-sake-of-which he existed. He wants to be the capable man who can

do the physical practical jobs. But, he is being constrained, lupus "dragged him back" and kept him confined within his present situation. Feelings of despair and frustration come to fore as he cannot finish the task. Peter had 'lost the possibility of hope'; he is powerless to change his situation (Steinbock 2007: 446).

He is perhaps 'stuck in a situation, losing grip, sinking into a narrow existence, focusing on impossibility and losing the future' (Kylma 2005: 813). Peter's openness towards the future in developing possibilities is being eroded and constrained. His Being-already in, the giveness of his situation, is due to his present states of affairs being fixed by past events which he cannot change. His throwness, dictates his possibilities. Heidegger (1962) used the term throwness, which means Peter is subject to life and it burdens him in the sense that he cannot remove himself from caring about it. It had become a "psychological barrier" to cross each day which caused additional stress which made his lupus worse. It had all become a 'vicious circle'.

7.5.1 Entrapment through a sense of self-being diminished

The participants try to carry on with everyday tasks, with life rotating around how they are going to be. They still take the external world as their point of reference despite the encroachment lupus makes upon them. They are still a parent, father, mother and wife and they try to fulfil their roles. They have to reconstruct their lives around illness. Times of illness and times of relative health define their pursuits.

Angela fights to keep her independence, but that had consequences on her health. She was no longer being who she used to be a mother, wife and parent, because she could no longer do those former things.

She hated the feeling she was not fulfilling her purpose, or her own expectation of herself.

"I'm an independent person… and that is where my difficulty lies. I will fight. And I think that is why I get the really bad days. I hate him having to clean up. I hate relying on people. I have always been the strong one in the family, the one that everybody else relies upon. And I know I can't do it and I can't change that situation" (Pg 15-16,299-306, T 23)

Angela had been the reliable, dependable, wife, worker, mother, and confidant. The 'strong one' behind the scene, who did all the household tasks, who cared for other's needs, and held the family together. But, now she was in a different place. Lupus, with its tangible restrictions the fatigue, pain, illness, poor concentration affected her daily performance and her competence to fulfil her former tasks. She hated relying on others and watching them do the things she had always done. The loss of her role identities challenges her sense of identity, and her feelings of worth and value had declined (George 2009).

A theme that runs through the participant's accounts is of sadness and despair arising from diminished sense of self and the loss of valued selves (Mead 1934).

Amy has been displaced from being a wife, and mother; she had lost her purpose, and meaning in life. Her feelings of guilt, despair, and responsibility made her feel an "extra pressure" and "burden" on her family. Her situation was never going to change and she had nothing left to offer. Her intense feelings of desperation led her to contemplate suicide.

"I should be doing it for them that is my purpose in life. And all I see now is that I'm an extra pressure and burden on them. I have nothing I can give them it would be better if I committed suicide" (Pg 30, 609-610, T 3.3).

Her narrative reflects the sense of depression and sadness arising from a sense of self-being diminished by the loss of precious role identities. Amy's experience illustrates what Beckerman (2011) identified, that a major challenge of living with lupus was the diminution of role, resulting in a high vulnerability to depression.

The sense of 'becoming a burden' is closely aligned with loss of hope, and despair at not being able to recapture positive images of the past. Havens and Ghaemi (2007: 111) suggested despair was a 'complete loss of hope for the future and a loss of any grounding in the world', while Beck et al (2003) felt despair was a place of profound loneliness and alienation. Charmaz (1983: 188) discussed how the person can no longer claim identities based upon prior external interests and social interactions, which can lead to feelings of being a burden.

7.5.2 Entrapment through not being able to be the best parent I can be

Being a parent is an exhausting and demanding role, even in health. So, to be a parent of a family and have your energy sapped away by lupus is, as some participants described, 'The cruellest of experiences'. As a parent, the participants' oriented themselves fully to their children's needs, and take part in their being-in-the-world, being absorbed in their children's comportment. They as 'being-with, is essentially for-the-sake-of others' (Heidegger 1962: 160/123).

The participants lived daily with the competing demand of lupus and being a parent. They were continually torn between wanting to be the 'best parent they could be', and feeling 'inadequate' and 'guilty' that they could not fulfil aspects of their parenting roles. How well the participants felt they were fulfilling their role was influenced by the perceived needs and the demands of their children. Babies and young children required more physical assistance. Nadine's treacherous body brought physical limitations resulting in more challenges. She had the feeling of continually struggling.

"It was awful, I couldn't dress them; hold or feel them, I couldn't carry them up the stairs or wash them. The worst thing was I couldn't feel their skin, or do anything with them ...I felt a complete failure as a mother" (Pg 2, 23-25, T 24)

Nadine could no longer dress, carry, feel her children's skin, or judge whether she was holding them too tight. Her intimate bond, the sense of 'belongingness and being-together-ness' (Heidegger 2011: 324), and the emphatic embodiment between her and her children felt diluted. Nadine felt she could no longer give them the bond they needed and could not do everything a mother should be able to do, which signified being a "failure as a mother". She had let her children down. Thurer (1995) discussed how this feeling of being a failure is probably felt more intensely due to society's belief that the wellbeing of the child depends entirely upon the essential bond between mother and child. Nadine could never live up to that belief.

Jenny had bitter feelings towards lupus. She had been "deprived" of the possibility of being the mother she had wanted to be.

"I mean I think my main problem is, not being able to… feel that I've been the best mum that I could have been. All the things that I would have naturally been, I couldn't be" (Pg 16, 364- 367, T 13)

"I'm very wobbly if there's anything going on that I feel I should be able to help them with but I can't because I'm not well. And I do...feel very low and guilty, because it's just being in an awful place, and not being able to do what I would do, if I was able. And I look at other mothers who are able and I do feel inferior, useless and inadequate. And I feel sad that lupus has deprived me of the opportunity of being a good mother" (Pg 33, 765-778, T 13)

Jenny felt she would have naturally been a good mother, if lupus had not constrained that possibility. Her illness had got in the way and she was not "able" to provide the solicitude' her children needed. Solicitude, literally means caring-for, and is a term for the way others matter, simply in so far as Jenny leads her life. In living for-the-sake-of-being-a-mother, Jenny lived for the sake of her children. Her children mattered; she cared-for 'solicitude' them deeply (Heidegger 1962: 160/123).   She wanted to be able to be-with her children, to provide the comfort and support they needed, it was her purpose in life, yet she felt inadequate in that role.

Jenny could not always commit to her children's projects or meet their needs. She sensed a growing distance to her children. She was in an awful place; she was never wholly separate from being-with-them, but neither did she feel a part of her children's world. She perceived herself as useless, a hindrance more than a support and compared to other mothers she was an "inferior and inadequate". She had experienced the constriction of the possibility to be a "mother" she should have been.

The way in which her being matters to her is disclosed in mood.

According to Heidegger (1962) moods play an important role in our experience 'a mood assails us. It comes neither from outside nor from inside, but arises out of being-in-the-world as a way of such being' (Heidegger 1962:176/136). A mood is in each case already there, like an atmosphere in which we immerse ourselves and then attunes us. Jenny's mood forms the way she understands and articulates the phenomena in the world, and also the way she understands herself and others. 'Mood has always already disclosed being-in-the-world as a whole' and this makes it possible to direct ourselves towards something (Heidegger 1996: 137/176). Jenny's mood reveals how she is faring and doing.

She wants to fulfil her obligations to be a good mother, but lupus has constrained this realisation. Feelings of uselessness and guilt come to the fore as she is "letting others down", but she is powerless and helpless to change her situation.

Being a parent with lupus meant constraints, compromises, loss, guilt, missing out and feeling excluded from their children's life. With it came the awful feeling they were never good enough and were letting their children down. They were struggling with lupus as well as society's expectations about how a good parent should be. Marchant (2004) and Rothman (2000), discussed that there is an expectation that a good mother should be able to look after their children themselves and not expect their husband to share responsibility. Small et al (1997) discussed how 'good mothers' must always be with their children. For many participants they could never live up to society expectations leaving them feeling guilty and useless.

Within the lupus literature studies have identified, feelings of inadequacy as mother (Wiginton 1999, Backman et al 2007); difficulties carrying out parenting roles (Porter 2000, Shortall et al 1995) and missing out on their children's lives (Jones 2003).

7.5.3 Entrapment through loss of work

Work is one of the most normative activities, bringing financial autonomy, purpose, routine, structure, and social contacts and is probably one of the main aspects of an individual's identity and primary contributor to finding meaning in life (Samson 2006, Riverin-Simard 2002). So the deprivation of the ability to work represented a major challenge for the participant's identity. Peter had been at the pinnacle of his career as a professional draftsman when he was diagnosed with lupus. The loss of his aspirations and income had a marked affect upon his everyday life.

"I'd like to get out of this situation by being able to work and that's partly, a pride thing, I want to support my family, I want to be where I was before, successful with a good career" (Pg 30, 621-635, T1)

Peter desperately wanted to be that former person, the hardworking, successful, reliable, energetic man who fulfilled his responsibilities as the breadwinner supporting his family. He desperately wanted to regain his identity, his masculine "pride", and "status".

"I just kept telling myself that it wasn't going to be forever …but it never happened. Lupus is a real barrier, I just can't work with this, I mean what with the symptoms, unpredictability, medication. But, you see work is who I am, it's not something I do, it's always been part of who I am, so I wonder who I am now, because I've changed" (Pg 14, 289-293, T1.1)

For Peter work signified "who I am" and he struggles with illness and the huge limitations it has placed upon his life.

Peter is condemned or delivered over to confronting the question of his identity. The answer to his question is embodied in how he lives his life. Peter is disclosed to himself in so far as it matters to him who he is. His being is an issue for him, an issue he is constantly addressing by living forward into a life that matters to him. But Peter cannot move forward into a life that matters to him. Lupus had given him restrictions and has limited his choices.

He had been someone, but now who was he. He stayed at home and watched his wife go out to work and was in a completely different place from how he had been. His sense of identity and competence had been sustained through valued social roles as provider, husband and parent within the family (Thoits 1991). The loss of his job disrupted household roles and relationships, including coping with financial issues (Menaghan 1991, Broman et al 1990). Shifts in authority and status within the family can lead to feelings of loss and conflicts (Atkinson et al 1986). He had to rethink many facets of his life. Corbin and Strauss (1987) suggested that illness leads to an inability to perform valued activities of everyday life and this may lead to a loss of certain aspects of the self such as perceptions of competence, self-worth and identity.

7.5.4 Entrapment through an expectation to work

Dawn was being expected to work and do her bit, but she was struggling to cope with her many roles as a worker and a wife.

"I struggle working, managing the house and I would love to stop working but my husband's feels that would put a lot more on him, and

I can't be that selfish. I've asked him for more help around the home but he says that's my role. And I know I'm doing too much but there nothing I can do" (Pg 44, 912-914, T 25).

Dawn was under constant pressure, she was being expected to continue to work to reduce the pressure on her husband, and fulfil her duties as wife. Enns (1994:128) and Burgess-Limerick (1993:356) referred to this as the 'work-home mesh'. Hochschild (1997:6) referred to this as the 'second shift', where a woman is expected to be everything to everybody (Hochschild 1989, Alway et al 1998, Braiker 1986). Dawn was 'struggling' and doing too much and that was 'detrimental to her health' (Nettleton 1995: 181).

Dawn was in a difficult situation; she cared about her husband and could not let him down. She felt she had no choice in the matter. Dawn interpreted her own nature in terms of behaving like a women, and a wife does, and put his needs before her own. Gherardi (1995:15), discusses how the attributes of femininity are ingrained in the subordination relationship through notions of caring, compassion, sensitivity, nurturing, willingness to please others, generosity, and emotionality. Dawn carries on being a wife, and working, fulfilling her husband's expectations at the expense of knowingly choosing which possibilities to actualise in the definition of who she is. She was being-with her husband and this affected not only her way of life but also dominates her possibilities. She does this because she lives with the assumptions, beliefs and attitudes of society, the, everyone which dictates her being-in-the-world in ways which to an extent she is not normally aware. It becomes a way of not noticing the world, its assumptions obscure what is really going on and she confuses familiarity with the way of doing things with some kind of truth. Her who she is becomes 'anyone' as she lets her gender and occupation define her way of thinking and way of life. Her essence is a kind of

second hand averageness, everyone becomes 'how things are'. Her everyone informs her selfhood, and she is lost in publicness, absorbed in the world and adopts roles and values of everyone. The world and herself is as everyone dictates.

7.6 Entrapment through Obstacles to Pregnancy

Life with SLE means facing many obstacles, one of the hardest of which is whether to risk having children. The younger female participant's within this study had always assumed they would have children 'at some time in their lives'. But, when they were diagnosed with lupus, no longer was having children something to be taken for granted. Becoming pregnant needed to be revaluated carefully. They were torn between the desire for a family life and the inherent serious problems this could cause.

Abbey felt it was her "maternal instinct" and an inherent trait as a woman to be a mother; she had always taken it for granted.

"I've always seen myself as a mother... it's in my makeup and we had planned to have children in a few years. But when I was diagnosed, well it all changed. We've done a lot of research and there are so many complications and risks...but I do desperately want a family" (pg 48, 958-964, T 32.1)

Abbey was confronting the inherent risks and her choices. She had searched the web and read information. She and her husband had become fully aware of the dangers involved, namely; difficult pregnancies and births, the risk of adverse effects on the baby, and the chances of lupus being inherited by her children. But, she perceived motherhood as a natural blissful thing, which would 'complete' her life and she desperately wanted children. She was in

the process of grappling with her options, and weighing up the consequences of her decision.

Francis-Connolly (2000) discussed how motherhood is a major role for many women, one which is valued, respected and is historically taken for granted because it is so common. Women can feel under social pressure to conform, and this could be attributed to the assumption that motherhood is an inherent trait in all women.

The following SLE studies, McElhone et al (2010), Karlen (1997), Taieb et al (2010), Porter (2000), Backman et al (2007), Baker and Wiginton (1997), Mendelson (2006) and Wittmann et al (2009) have discussed postponing parenthood, due to the risks and complications involved.   Many participants within this study were working out their options trying to make a difficult decision.

May had been left in a positioning of always wondering. She reflected on her prior experiences in the 1950's when she had sought expert advice from consultants. She had desperately wanted to become pregnant, but had been advised not to.

"We had spoken to a number of consultants who had said "Don't it's too risky". My kidneys were failing... and I was unstable, so we didn't really think we had a choice. Of course they didn't really know about lupus then... or have the medication they do now... we didn't risk it, but it was a great loss to us both" (Pg 12, 228-237, T 31.1).

In the 1950's lupus and pregnancy was relatively unknown. It carried considerable risks as there were not the medical advances that are available today. May only had the options available for that time. Her chance of being a mother had been dictated by past events which she did not choose and over which she had little or no control. The

historical context constrained her realisation. Her throwness dictated her possibilities. That choice had been taken from her because of her circumstance.

May had revisited that lost opportunity numerous times. She questioned whether she should have ignored the advice and "risked it". But at that time, she felt she had no choice in the matter and had closed off the realisation of that possibility.

Heidegger (1962: 331/285) discussed, Dasein must act and choose; it must annihilate some possibilities while actualizing others. 'The nullity we have in mind belongs to Daseins being-free for its existentiell possibilities. Freedom, however, is only in the choice of one possibility- that is, tolerating not having chosen the others and not being able to choose them'.

May's choice involved matters of life and death, and she had to choose one alternative. She had to choose on advice she never fully grasped, yet for those consequences she is fully responsible. She regretted she had given responsibility away, but she was also aware that if she had taken that risk she and the baby could have been dead. She had gone through life feeling different and felt she had let her husband down.

"I've gone through life feeling a bit of an outsider when I'm with other women. There was always the feeling....why didn't you have any children?" (Pg 12-13, 248-251, T 31.1)

Motherhood grants women access to 'a world of female knowledge and experience and enables them to share a common identity' (Woollett 1991:55). May had longed for that, but she had gone through life with the silent implication she was different. She did not

have children and had lived with the implication she was not fulfilling her purpose. She felt she was viewed with some pity by society.

7.6.1 Entrapment through genetic inheritance and the affects of lupus on my children

Daphne already had a family before she had been diagnosed with lupus. It was only years later did she realise she had passed lupus on to her daughter.

"And I said to her (daughter), "But I feel so guilty," And she said "Well it's not your fault mum," she said, "somebody give it to you, it's in the genes and that's it" (Pg 56-57, 1217-1220, T4)

Daphne had not known her genetic inheritance would affect her daughter. Daphne felt intense guilt, and her mood discloses her throwness. Heidegger (1962: 174/135) discussed, 'The expression 'throwness' is meant to suggest the facticity of its being delivered over. The 'that it is and has to be' which is disclosed in Dasein's affectedness'.

The Being-already in, of Daphne's situation is due to the present states of affairs being fixed by past events. Her facticity is a function of her past, her being-already-in and the 'giveness' of her situation. This refers to those aspects of herself, such as her genetic inheritance being pasted on with an increased risk of lupus, that through being defined by a past she had no power to change and lie beyond the scope of freedom.

Heidegger (1962) offered an existential account of Schuld, which means guilt, indebtedness and responsibility. Everyday guilt arises because Dasein, to cover up its unsettledness, takes over the cultural

mores as bind. Heidegger (1962) discussed, Being-the-basis in the ordinary sense is being responsible for something; 'being the cause or author of something, even being the occasion for something' (Heidegger 1962: 282).

'We fine the formal existential idea of the "Guilty!" as "being-the-basis for a being which has been defined by a 'not'"...as being, Dasein is something that has been thrown; it has been brought into its "there", but not of its own accord (Heidegger 1962: 169).

Daphne understood it was not her fault, but she still felt guilty for the matter of being responsible for some deprivation in the life of another. But there was nothing she could do to alter that situation.

7.7 Entrapment through not receiving the support I need

The participants were living with the psychosocial consequences of having an unpredictable and potentially fatal condition with a diversity of symptoms resulting in multiple restrictions on everyday life, and the side-effects of medications. The participants strove to maintain their independence, but coping daily with lupus was daunting. They relied on family members and close others to provide them with the consistent emotional and physical support which they needed for day to day living. This has been confirmed in the SLE literature by Sarason et al (1983), Revenson (1993) and Mendelson (2003).

Without this vital support, many participants related feelings of entrapment and could see no way out. They were struggling alone, trying to fulfil their former roles, which had a marked affect on their continued health and quality of life.

At first, Abbey's family rallied around and supported her in every way. But as time progressed and her illness remained they 'got fed up' and 'irritated', by continual illness. They had lost patience and offers of help once freely given dwindled and finally stopped altogether.

"It's not a highly understood illness and my family just doesn't have the patience I find with something that drags on. And not a day goes by that there's not something and they always say, "But you must be better by now". And I'm sick of trying to explain and their disappointment I can't do things, but they won't support me and I'm left struggling" (Pg 9, 162-170, T 32.1).

Abbey desperately needed her family's support and understanding, but they were not offering up any possibilities of help, concern, or compassion. They had assumed lupus was like an acute illness and she should be over it by now. Abbey was not being what she had always been a mother and wife, and was not fulfilling her purpose. She sensed the family's growing impatience and disappointment and she tried to explain her condition, but they did not understand and she was left struggling.

Each time Lisa had asked for help the requests caused increased family tension. The continual negative responses became too much, she felt under-attack and vulnerable and withdrew further into herself "battling on" alone. But, this had huge consequences on her emotionally and physically.

"Even when I am desperately ill I say nothing and I'm having to run the house, cook the meals but I won't ask for help because of the negative comments. They definitely don't understand so what's the point? It upsets me and I can't have stress so I try and keep out of their way to reduce the tension and I'm left to battle on alone which

wrecks me emotionally and physically. And I can't do lots of things because they won't help, so it's a vicious cycle" (Pg 16 327-30, T 9).

The negatives responses increased her distress and feelings of rejection and to reduce the tension she withdrew further into herself, and said "nothing" keeping "out of their way". But not being able to ask for help "wrecked her" "emotionally and physically" it had become "a vicious cycle". There is a sense of her self-being diminished by the loss of precious role identities due to not receiving sufficient support and understanding from family members. A gulf had developed between her and family members and she had been pushed further into isolation.

Lupus is particularly challenging for family members to understand because it is a relatively unknown condition (Waldron et al 2012, McElhone et al 2010). Misunderstands can arise from its chronic nature, as well as the unpredictability and hidden symptoms. It was noted in a study by Danoff-Burg and Friedberg (2009) that patients were worried that family members would not have the understanding to help them cope with their fluctuating levels of needs.

The participants in this study reported feeling isolated because of being misunderstood and tired of trying to explain their condition to family members (Robinson et al 2010). There was a fear that loved ones had become fatigued from hearing about the complaints. This lack of understanding from significant others can appear to compound feelings of isolation (Johnson et al 1995, Hale et al 2006, Danoff-Burg and Revenson 2005). Increased interpersonal conflicts and stress resulted from expressions of disappointment and anger directed at the participants for not fulfilling their purpose (Mattje and Turato 2006, Moss and Dyck 2002). There was a sense of the participants self being diminished by the loss of precious role identities due to not

receiving sufficient support and understanding from family members. Neville (2003), Paterson et al (2003) and Gottlieb and Wagner (1991) discussed how the feeling of isolation from family members can lead to lower self-esteem.

Many of the female participants within this study decided it was better to say "nothing" and "battle on" alone because of their family's response. A negative response or a refusal increased distress leading to feelings of isolation, alienation and rejection by others (Dunkel-Schetter and Wortman 1982).

Lyons et al (1995) and Pennebaker et al (1988) reported that not being able to share an illness experience has a detrimental effect on health and well being. Frattaroli (2006) noted that keeping the experience to themselves denies the person the opportunity to make sense of their experience through its retelling and to diminish the experiences negativity through its repeated exposure. This may also deprive the person of much needed social support, as family members will perceive them as being well and therefore reduce support further. Danoff-Burg and Revenson (2005), Pennebaker et al (1988) and Jorgensen and Gaudy (1980) have discussed how sharing an illness experience is conducive to enhanced health and personal relationships.

7.7.1 Entrapment through Problematic support

All the participants strived to remain independent and to regain some control over their life. But they and their life had altered. Many of the participants related how family members could "interfere", leap in and close down possibilities, reducing their independence further.

Heidegger (1962) lays out the basic mode of togetherness (Mitdasein) of being-in-the-world, and used the word 'solicitude' (Fursorge) to describe caring for another (Heidegger 1962:158). Leaping in for them, can, so to speak, take the others 'care' away from them. 'This kind of solicitude takes over for the other that which he is to concern himself. The other is thus thrown out of his position. In such solicitude the Other can become one who is dominated and dependent, even if this domination is a tacit one and remains hidden from him' (Heidegger 1962: 158-159).

When Lora became ill, like many of the younger participants, she had to move back home to live with her parents. It was a shock after all the freedom and independence she had experienced at university. Now, she was back under their roof, she had regressed to being that child again.

"It's very hard to go back to live with my parents, very hard because I've lost all my independence and freedom completely" (Pg 8, 152-153, T 11)

"I mean at the end of the day it's their house, they tell me what to do, I don't have an opinion or a choice in the matter. I'm expected to eat when they eat, go to bed when I'm told and it's intense. They try and do everything for me and they wrap me up and protect me so tight I can't breathe. I feel like I'm a child again, or something ridiculous like that, because that's how I'm treated which is, really hard. They have taken my independence away and made me that little child again" (Pg 40-41, 799-803, T 11)

Moving back home to her parents home should have provided support, comfort, understanding and time for recovery to aid her independence. Instead it had become "intense". Her life was being

taken over, she had been smothered and her independence removed. Her loss of independence challenged her sense of identity; she was no longer an adult, who had an opinion and a choice.

Her parents had taken over and taken her independence from her. They were keeping her safe and under-wraps and had closed down all her possibilities to be. Lora was unable to be herself, instead she had "regressed" to being their "child again". Her parents had leaped in to care for her needs and she had lost any control over her situation. Lora experienced being re-positioned as a child, and was a no longer a young independent woman. She retreated to her bedroom away from her parents, desperately protecting what remained of her fragile self. She could see no way out. She longed to rebel and move out, but how would she cope, she was dependent upon their support.

7.8 Entrapment through anxiety

Increased symptoms caused all the participants anxiety. Margaret was trapped within, the uncertainty "it'll click back in", and there was nothing she could do, she is vulnerable and terrified.

"It rules my life, every day I'm on a tightrope over an abyss waiting to fall and that's terrifying. I know it's going to happen, it'll click back in,.... and then ... it's doing its attacking job...my organs will be affected...I will get worse, more disabled and be back to square one, in a vacuum devoid of life, just nothing.... and its raising medication and it all takes forever and I may never stabilise, I may even die" (Pg 31, 606-607, T 26.2)
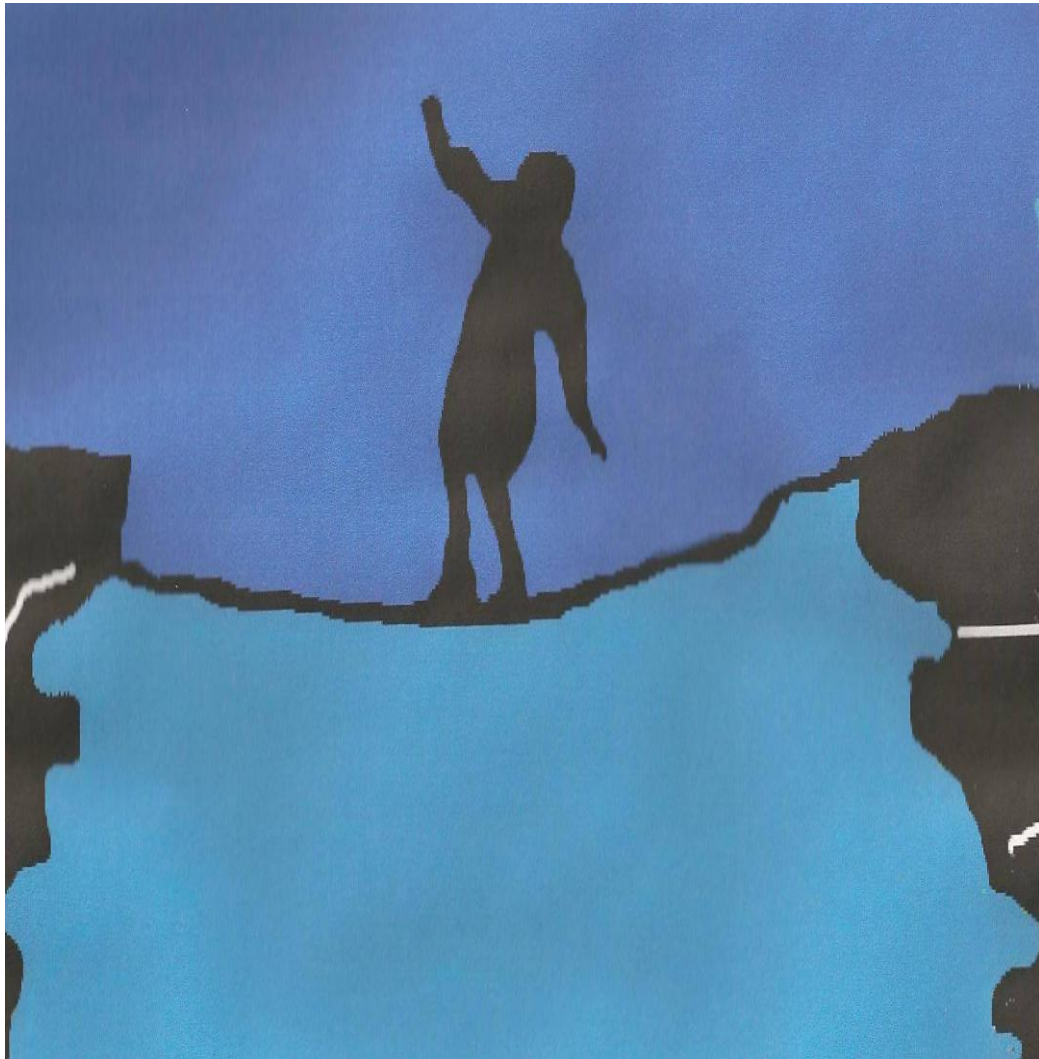
Fig.15 On A Tightrope Over An Abyss

Margaret lived in suspense, waiting for "it'll click back in". Then it would mean serious illness, loss of independence, and the removal of possibilities. She would go "back to square one", with numerous appointments, changes in medication, and time delays. She is terrified it may never stabilise and she will become more disabled or even die. Heidegger (1962: 180) discussed fear as 'a slumbering possibility of Being-in-the-world' which 'has already disclosed the world, in that out of it something like the fearsome may come close'. He explained that

'only a being capable of being threatened, a being whose own being matters to it, can be afraid' (Ratcliffe 2008: 49).

The significance of her past flares hung over her as a continuous threat which pervaded her present. Solomon (1993: 137) discussed that every emotion 'presupposes the entire body of previous emotional judgements to supply its context and its history'.

Everyday Margaret perceived her destruction as an imminent possibility. The possibility of plummeting into "an abyss" and being confined in "a vacuum devoid of life" estranged inhabiting a different existence, one of nothingness or non-existence.

She lived with 'the full terror of the world as liable at any moment to crash in and obliterate' her, 'as a gas will rush in and obliterate a vacuum' (Laing 1960: 47).

Margaret's experience has similarities to Frank (1991) example of a heart attack (Toombs 1993: 69). Frank (1991: 16) discussed 'having a heart attack is falling over the edge of a chasm and then being pulled back. Afterwards I felt always at risk of one false step, or heartbeat, plunging me over the side again. I will never lose that immanence of nothingness, the certainty of mortality. Once the body has known death, it never lives the same again'.

Margaret had experienced 'nothingness', and nearness to death. She stopped many of her roles restricting her lifestyle to reduce the likelihood of it clicking back in.

"I have to be very careful, I daren't do too much in case I aggravate it, so that's restricted my life even further" (Pg 35, 685-688, T 26.2)

In trying to regain some control over her situation she had lost more independence and freedom and pushed herself further into entrapment and isolation. Charmaz (1983:175) discussed how people will voluntarily restrict their lives if they experience loss of control, and this can increase loneliness and boredom. People can become more focused on bodily changes and symptoms fearing the worst.

Even with implementing self restrictions and following advice the unpredictable nature of lupus exerted a strong influence over Angie's life.

"I mean even though I have followed all the advice and been careful I don't have any control over it … So there's always that anxiety" (Pg 14, 299-305, T 21)

Angie had followed the advice, altered her lifestyle and imposed restrictions but she could not control her haywire body. She experienced ongoing anxiety from the continual threat. Svenaeus (2002:13) discussed how the 'threat of getting worse or ceasing to be brings unhomelikeness with it as a constant eclipse of the future'.

7.8.1 Entrapment through its systemic nature

The systemic nature of lupus, meant at any time additional unpredictable serious health conditions could develop. Through personal experience the majority of the participants had learnt that lupus had a 'sting in its tail and could bite'. It could always throw something else.

"Your kidneys are failing, brilliant, you know? What else can it throw at me? … This is happening to somebody else and I'm just there standing by watching. And it is very much the skeleton in my closet

that I can never sweep away, lupus always has a string in its tail and can bite" (Pg 27, 499-510, T8).

Meg experienced yet more improbable, shattering events, carrying immense danger as she lurched from one health crisis to another. She questioned, what else can it throw at me? The event seems surreal and unreal and she is vulnerable. Her life had become a nightmare and she felt a distance to the unfolding event. She had been catapulted into another reality, the dual reality of the world she had been in and had been trying to adjust to and the present one, the crises.

Charmaz (1991: 31) discussed 'Like Dorothy in The wizard of Oz'; Meg 'can feel thrown into an alien world in which events remain dissociated from' her. She waits to get through the present so that real life can go on into the future just around the corner. Since the present seems so improbable, she waits for it to end'. Meg could see no end or release from her situation. Her crisis with the threat of increased illness was like being-towards-death, the death of how she used to be and her present and future possibilities. The loss of present and future possibilities means facing the destruction of life itself. She lives with disruption, and immediacy, and each time the crisis severs the present from the past and shatters the future. She is immersed in an uncontrollable present and an uncertain future.

7.9 Barriers to future progression from health services

The participants face a lifetime of monitoring at lupus clinics. Vivian felt her ambitions were being thwarted by these constant interruptions.

"I'm an aspiring writer I'd like to research for a book, that is what I would like to do. But what I find is a barrier is I rarely get days when I

don't have something going on medically so I can never start writing. It's the same thing repeating itself and I never feel my life moves forward, it feels static" (Pg 14, 305-313, T 16).

Vivian has to structure her routine and life around medical appointments. These continual interruptions stopped her being able to achieve her for-the-sake-of-which she exists, being an author. Appointments signified the continuous demands placed upon her by lupus; it was yet another thing she had to do. The lost opportunities and the feeling of being held back meant she could not move on or progress with her life.

Vivian is confined in a shrunken world with few opportunities to create herself and she is acutely aware that this lost opportunity results in the further loss of herself. This gives her the sense of her life being static; an endless cycle of medical appointments, doing the same thing over and over again with no achievement or progression. Her experience leads to a sense of unchanging time, with no movement forward towards her possibilities. Calkins (1970) discussed how an immersion in routines can lead to a sense of unchanging time. Thomas Mann (1924: 183-184) described 'all the days are nothing, but the same day repeating itself or rather as it is the same day, it is incorrect to speak of repletion, an everlastingness sameness'.

Lora felt the specialists at the lupus clinic were not fulfilling their purpose. She wanted advice so she could learn how to manage the condition.

"I thought the specialist's job was to not only dole out the medication but also advise me of all things to avoid and ways to cope but they never do any of that. I feel I really need that to be able to manage this

and it would help a lot, and it's very disappointing they don't" (Pg 44-45, 875-883, T 11)

Lora wanted to gain more control over her condition, but she lacked the strategies and support she needed to be able to implement any changes in her life. The health team were not offering up any possibilities of help and she could not change the situation by herself. Lora lacked the skills to effect changes in her life in order for her to be able to move on. Not having the skills was a barrier to her future progression.

Barbara wanted to be actively involved and regain control of her own health. Instead of offering opportunities the appointment was one of disappointment and anti-climax. The interaction made her feel passive in relation to her condition and treatment.

"I mean a lot of the time they just do the tests and that's it, they never tell me what the results are. And they don't give me any help in coping" (Pg 57, 1090-1097, T 10.1)

In order to fit in Liz adopted the role of a 'good patient' acting according to expectations, and complying with treatment. She could never be honest or disagree. She was dependent upon their expertise.

"I don't want to get the reputation of being a difficult patient who refuses to accept advice on treatment, it leaves me feeling very insecure which is a sore spot because of what went on in the early days. I've got to keep them onside and happy. I can't be honest or question their opinion. I mean I'm dependent on these people" (Pg 9, 169-171, T 14.2)

Lisa wanted to know where she stood, she wanted a consistent approach.

"I'd been to the clinic and I ended up angry, frustrated, feeling powerless, every time I go I see a different person and they're assessing me, my lifestyle, and each one has a different idea. They alter medication, don't know my background history and there is nothing I can do to alter it, its hopeless" (Pg 4, 74-77, T 9.2).

Lisa kept seeing different doctors and could never anticipate how they would react or what ideas they would come up with next. The doctors never knew her past medical history, so each time she would have to repeat it, and then she never had time to discuss her important health issues. Each doctor had a different idea about her treatment and would alter her medication, and each time her medication was altered it caused disruption and increased side effects. She was never able to establish a trusting familiar relationship, or experience security, or consistency in her care.

Lisa felt her situation was 'hopeless'. The feeling of entrapment can be perceived through the feeling of powerlessness or the person lack capacity to change the situation (Taylor et al 2009). She was not receiving longitudinal care which would have provided her with consistency and security (Tarrant et al 2003, Roberge et al 2001). Worse outcomes in lupus have been identified, if patients never have the same doctor, and there is insufficient time during consultations, and irregular follow-ups and treatment (Uribe et al 2004, Alarcon et al 2002).

Ann felt her concerns were never being addressed, the consultation was rushed. Time appeared to be an important controlling factor.

"There's that pressure where I feel I'm being rushed all the time and it's sort of ten minutes stuck on a conveyer belt where I don't even get time to sit down, before I'm moved back out of the door. One in, one out, a stream and 10 minutes is not much time, I don't have time to say the important things. And they don't even know my name; I'm not a person but a number, an object on a conveyer belt" (Pg 44,897-916, T30.1)
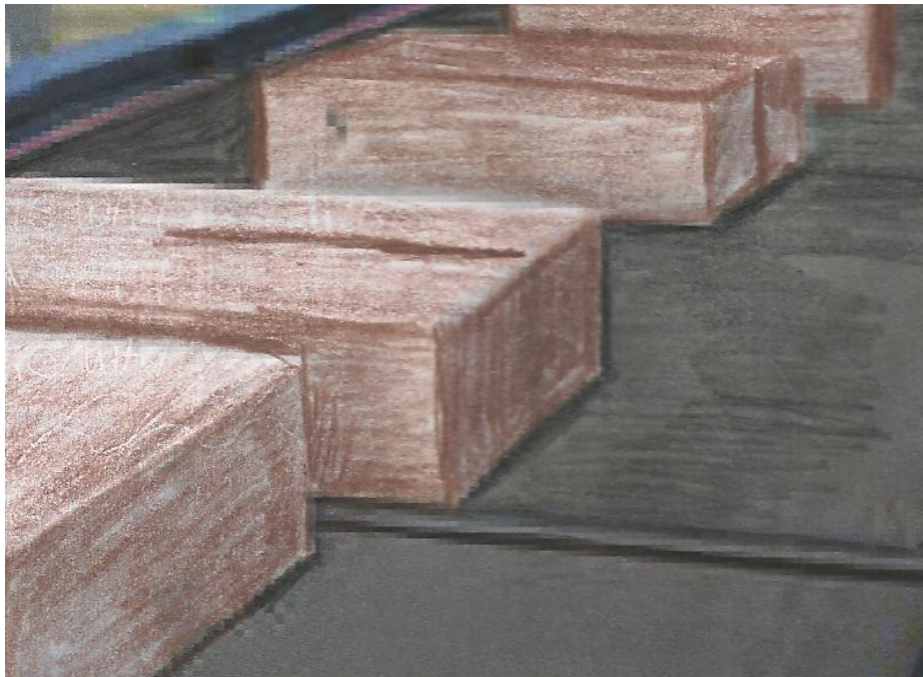
Fig.16. An Object On A Conveyer Belt

Ann had ten minutes to discuss her health issues. By the time the doctors had asked her questions, decided what medication she should be on her time was up, and she was automatically moved out the door. Her important issues were never being addressed. She wanted the consultation to be worthwhile and useful; she would not be attending another appointment for months, so it was her one chance to discuss the important issues. There was no time for saying (discourse) anything or a showing of something.

Heidegger discussed 'There is the highest need for doctors who think and who do not wish to leave the field entirely too scientific technicians' (Heidegger 2001:103). Heidegger (1966) foretold the consequences of humans becoming like objects, attempting to fit into technological system, where progress is measured by speed. Modern technology can objectify the patient, and poses a threat to the essence of medicine. 'The human being is conceived of beforehand from the background of the technical manipulatability of the world' (Heidegger 2001:141).

Instead of viewing the human person holistically and standing back and letting the other human being be, the person is reduced to an object, a body, a disappearing person, and the being human and the being-with are lost. Instead of watching, listening, and feeling the patient, the stethoscope, blood results, and medical machines provide the objective measures.

Foucault (1973) extended this concept of alienation to describe how depersonalising and even dehumanising the effect of technology could be, in medical practice. Frank (1995) warned of how advancing technology could overshadow holistic caring. Todres (2003) wrote of how this situation presents a huge challenge to both patients and clinical staff. Ann's experience was a long way from the philosophy and desirability of life-world care.

Heidegger (2011: 210-211) discussed, 'when I give quinine to someone suffering from malaria, I am merely the occasion for the quinine killing the amoebas. The patient's body (as cause) then heal him. If the physician understands his role as merely being-with-the-occasion, then it is indeed still possible that the being-with (the patient) can continue. But if the physician were to understand himself in such a way that he has brought about (caused) the healing of the

293

patient as an 'object', then the being human and the being-with are lost'.

'As a physician one must as it were, stand back and let the other human being be. These (dealings with the patient as 'being-with' or an 'object') are entirely different modes of comportment, which cannot be distinguished from outside at all. Herein lies the existential difference between a family doctor and a specialist clinic. It is characteristic that family doctors are a dying breed' (Heidegger 2011: 210-211).

The participants experienced issues with specialist lupus clinics, but they also experienced issues with their General Practitioners.

The majority of participants expressed concern and anxiety about not receiving prompt and correct treatment from their GP for infections. This resulted in "an extended illness" and an increase in lupus symptoms which had a detrimental effect on the participants' physical health and caused psychological distress.

Jenny feared the "confrontation and battle" with the GP in-order-to receive the treatment she needed.

"I just try so hard, not to get infections or… I mean it's impossible but I tend to put a box round myself so that I don't get ill, so I don't have to go through those… situations. Which is an awful way to live, but it's what I've done, in order to try and not have to, get the treatment that I need. I think that's probably the worst part of it in many ways, is… trying not to get, anything wrong because unless I do get that treatment straightaway, I'm really very ill and … another bit of my life's sort of wrecked again" (Pg 24, 544- 553, T 13)

Jenny could become very unwell quickly. Her life-line was medication and it caused intense anxiety, when she was denied the treatment that would literally save her life. She had explained her condition numerous times and given the surgery information, but, they still did not respond and give prompt and efficient treatment when needed. The surgery seemed to have no understanding of her condition and the serious implications of an infection on her health.

Being-with the GP affected her way of life, but also dominates her possibilities which affected her way of being. Jenny had restricted every aspect of her life so she would not get an infection. She had put a "box round" herself in-order-to reduce "those situations". She had lost being-in-the-world and being-with others; independence, and freedom, in-order-to protect herself so she would not have to "battle" with the GP. It had become an "awful way to live".

7.10 Entrapment through autoimmunity and losing themselves

Daphne felt she was involved in a daily battle that she was losing. However hard she fought, lupus always had the upper hand. She had no power over her circumstances. Illness as Pellegrino (1982:159) has noted 'moves us towards the absorption of man by circumstance'.

"I'm losing a fighting battle, no matter what I try, my body's turned on itself and is committing suicide and it says, no, I'm not going to stop, you're not going to join together; you're going to stay like this and that's it … and there is literally nothing I can do. It holds me so tight, I feel it suffocating me and I have nothing left I have no control, it wants to die. I am killing myself slowly and will end up as nothing" (Pg 28, 597-600, T4)

Daphne's photograph symbolised her sense of being held tight, suffocated and having nothing left. It is a quite disturbing picture which conveys her feelings about 'what lupus meant to her'.

Fig 17 I Feel I Am Suffocating

Daphne's being is one of being towards possibilities, which is part of her potentiality for being. But with lupus, she has been forced to surrender her most cherished assumption; the assumption of personal indestructibility. 'We taken it for granted...that life is predictable and we are immortal and that we can, therefore control our own

fate...Illness destroys this primordial sense of invulnerability, forcing us to acknowledge our impotence and our own mortality' (Silberman 1991:13).

For Daphne, lupus had brought a continuous threat, the threat of being-towards-death and the prospect of running out of possibilities.

Daphne's experience of lupus is intimately tied with her body. Her body felt fragmented, the awful sense of not being 'joined together', where her body felt alien, but at the same time herself. Her body could not recognise its self and felt other than herself, something which has its own ways and must be regulated if she is to survive. But, whatever Daphne tried, she was losing the "battle", her body was determined to "commit suicide", and she had no control over her body or her situation.

Burnet (1969: vii) discussed how 'the capacity to distinguish between what is acceptable as self and what must be rejected as alien is the evolutionary basis of immunology'. Lupus as an autoimmune illness seems to manifest the 'paradoxical and deadly proposition that the body/self both is at not itself' (Cohen 2004: 8).

Daphne's malfunctioning body discloses itself as a hidden and alien presence which is beyond her control, and where a sense of otherness is acutely felt. Richard Zaner (1981: 48-55) in The Context of Self investigated the different ways in which the body announces itself as uncanny in illness. 'My body is not just any tool that I use or a dwelling I live in, which is the basic mistake in dualism. It is instead me, I am my body', yet as Zaner (1981) remarks it also has a life of its own.

'If there is a sense in which my own-body is 'intimately mine', there is furthermore, an equally decisive sense in which I belong to it- in which I am at its disposal or mercy, if you will. My body, like the world in which I live, has its own nature, functions, structures and biological conditions; since it embodies me. I thus experience myself as implicated by my body and these various conditions, functions, etc I am exposed to whatever can influence, threaten, inhibit or benefit my biological organism' (Zaner 1981: 52).

Daphne's experience of lupus is fundamentally a loss of wholeness, certainty, and a loss of control. Her loss of wholeness manifests itself in the awareness of symptoms, the bodily disruption and a loss of bodily integrity. Her body can no longer be taken for granted; it has become an opposing will of its own, that is beyond her control and cannot be ignored. Rather than functioning effectively Daphne's "body" has "turned on itself", and malfunctions, thwarts plans, impedes choices, and ends actions. She perceived her destruction as an imminent possibility, the state of being cut off from being in the world, on her own, with the possibility of "nothing", of no live possibilities before her. The "nothing" Daphne feels, Heidegger (1962) explains is a disintegration of everyday belonging, the total absence of significance.

Lupus has disrupted the unity between the body, self and being-in-the-world. Cassell (1982) notes; 'diseases can so alter relations with one's body that the body is no longer seen as a friend but rather as an untrustworthy enemy. This is intensified if the illness comes on without warning and as illness persists, the person may feel increasingly vulnerable (Cassell 1982: 640).

This sense of fragmentation can be seen in Lora's experience of being "shattered beyond repair". She like Daphne had the sense of perpetually 'losing herself'.

"It's the mental pain of knowing my body has betrayed me, it's out of control and something inside which is part of me is attacking and destroying me bit by bit. And I am shattered beyond repair... it's a hopeless situation really because I am killing myself and losing myself. And I'm exhausted; a husk of my former self, not being anything disappearing into the unknown. I mean it's taken over my body, life and everything, so its continual suffering really; do you know what I mean?" (Pg 47, 944-955 T 11)

Fig. 18 A Husk Of My Former Self

Like Daphne, Lora uses a number of metaphors to describe the assault and perpetual threat, "attacking", "destroying me bit by bit", "shattered beyond repair". Her picture signified disappearing into the unknown. Hawkins (1999) discussed how being assaulted by illness and doing battle with it are components of a metaphor used for managing illness and this can be construed as reflecting an assault on, or violation of the persons former self. Lora related she was a "husk", that was all that remained of her. All the important parts of Identity and self had gone.

Lora perceived a perpetual threat to her existence and with it, came the awful realisation she was "killing" herself and had no choice in the matter. She had lost everything important in her life, a husk of her former self disappearing into the unknown. She could see no end to her plight; she viewed her situation as "hopeless". Viktor Frankl (2004, 2006) discussed how suffering can cease to be suffering, at the moment it finds a meaning. But, Lora can find no meaning in her life, she was losing her sense of being 'myself'; and cannot understand what is happening or why her body is attacking herself (Frank 2001). Lora is left in a position of existential instability, a feeling of "fighting" for survival. George (2009) relates that suffering results from an attack on integrity and sense of self or otherness.

Cassell (1991) argues that suffering occurs when the impending destruction of the person is perceived. Cassell (1982) stressed that in suffering, the extent of suffering is determined not by the illness itself, but by the meaning for that individual of the threat to his or her 'personhood'. Personhood as Cassell means refers to the individuals' body, life experiences, range of activities and relationships.

Lora perceived her destruction as an imminent possibility, the possibility of "losing myself". Heidegger (1962) discussed how death is

the ever present possibility of the impossibility of personhood when we run out of possibilities.

Heidegger (1962) also discussed demise, an existential death, an intermediate state between dying and death. For Lora It is not a matter of no longer wanting to go forward, more she is unable to go forward and this means she has ceased to exist as a person but continues to live as a human. The end of all possibilities impedes upon Lora as an ever present possibility. She has the continual feeling of losing herself, causing intense "mental pain" and "continual suffering".

Chapter eight, findings and discussion discusses the third theme, coping and regaining resilience and explores the wealth of coping strategies used within the participants' everyday lives and the ways they have been able to overcome adversity and find ways of moving forward regaining resilience.

8.0 Chapter 8 - Coping and Regaining Resilience

8.1 Coping skills and regaining resilience

This chapter explores some of the varied, diverse and complex ways the participants learnt to cope with lupus. Living with a condition that continually changes and brings numerous challenges to everyday life is extremely demanding both emotionally and physically. For the participants to be able to learn to adapt, and become accustomed to lupus, involved great resilience, strength, and determination.

Resilience can be defined as 'reduced vulnerability and the overcoming of adversity' (Rutter 2012:336, 2006). The concept of resilience refers to the ability 'to recoil or spring back into shape after bending, stretching, or being compressed, or an ability to recover quickly from physical illness' (Cassel Concise English Dictionary, 1995). The word originated in 1626 formed in English from the Latin, resilire to rebound (Chamber Dictionary of Etymology 2006).

Learning to live with lupus was a slow laborious process that took the participants' time. Each participant's way of coping and 'of being able to contend successfully with, and manage successfully' was unique to them (Cassel Concise English Dictionary 1995). There was no predictable trajectory or a final static point. Rather, it was an on-going process where skills were developed, altered, refined and adapted further depending upon the participants' changing needs. Such needs include variations in condition, new demands and changes within the participant's way of life.

In time, with increased understanding and knowledge and by trial and error through experience, the majority of participants had learnt, developed and built-up a vast array of coping strategies that they

could use to assist them in everyday life. This chapter explores the participants many ways of coping including the way they adapted tasks, paced themselves, listened to their body, trusted themselves and managed a complex medication regime. The participant's engaged in problem solving, and maintained optimism, using their mental strength and determination, to push on with daily life. Participants worked on 'themselves' in various ways and obtained enabling equipment that would increase independence in everyday life. They sought support from family, friends, and health professionals, and lupus support groups. The participants re-evaluated their life, took opportunities and lived with the possibilities that are there. They were learning to live with what was possible in spite of their restrictions and accept themselves as they are in the present and their potential for living forward.

The chapter begins with exploring the participants' everyday management.

8.2 Everyday management

8.2.1 Learning about lupus

The majority of participant's learnt as much as they could about lupus, gradually building up their knowledge and understanding by researching books, articles, using the internet, talking to health professionals and lupus group members. Baker and Wiginton (1997), Chute (1999), Goodman et al (2005), Hale et al (2006), Hatfield-Timajchy (2007), and Beckerman (2011) all discussed seeking information and advice from professionals as avenues for coping used by those with lupus.

Provoked by her situation, Rachel searched for new meaning.

"I read up on it and realised why I was getting all these different things, then it made sense and I thought, well, if it's an incurable disease I've got to just live with it, and it's up to me to make the best of… of what I've got" (Pg 1, 10-15, T 17)

Rachel "read up" and the more she read the more it made sense. She understood her condition was incurable and would remain with her for the rest of her life. She drew upon her new knowledge, her past experiences, attitudes, and creative strategies to try to positively reframe her condition and see it in a different light.

She had come to terms with the reality of her situation and accepted her circumstances. Rachel made the decision to live with it, make the "best of what she had got" and take responsibility for it. No one else would take up that responsibility for her, "it' was up to her". Her new understanding discloses things to her and also discloses herself as a potentiality for being. This made her existence 'mine' instead of anybody else's (Heidegger 1962:67). In a world of things she cannot change, she is responsible for being who she makes herself to be through the changes she can make. To regain more control within her life she needed to be proactive and start managing her condition herself. She had taken responsibility for her situation and had a sense of purpose and direction in the course of the actions she had decided to take.

Phoebe had contacted a lupus group in America in-order to find out more information.

"I didn't know anything about it, it was very confusing so I contacted a lupus unit in New York and they sent me some books and they did explain a lot. And, they put me in touch with, this lady who had lupus

herself, and she told me lots of things that had helped her. I tried the suggestions, but they didn't work for me. So I've learnt I'm on my own, it's a challenge and I have to find my own way and get on with it. I always look out for new information but most of it isn't very useful" (Pg 4-5, 81-85, T 12)

The information Phoebe had gained had given her more insight and understanding into lupus. She used the information and put these ideas into practice, but some of the suggestions had been ineffective or problematic. She realised she would need to develop her own individual coping strategies that would work for her. In increasing her understanding of lupus, she could work out ways of adapting and changing her lifestyle.

Phoebe was evaluating her personal resources and alternatives in-order-to deal with the demands and restrictions lupus imposed upon her life. She viewed lupus as a "challenge" which could be overcome and this mobilised her efforts to initiate the adaptation process which gave her a new sense of purpose in her life. She never stopped searching for strategies that may give her more control over lupus and her life. For Phoebe it was an ongoing process keeping up to date with new developments. She remained open and receptive to new ideas, knowledge and understandings.

Following diagnosis the majority of the participants had an extremely fragmented understanding of lupus. They had received little if any information and the majority of participants had no idea what SLE was, or any understanding that it was a chronic long term condition that could not be cured, only treated.   With increased understanding the participants could begin the process of making sense of their experience and start to come to terms with accepting it. Heidegger (1962) discussed how understanding is the development of attaining

meaningfulness. This allows explanations of events and through the new understandings developed; attempts to change the situation can be made (Svenaeus 2010: 34).

Rachel and Phoebe were questioning and searching for a meaning; some purpose for what they were going through. The possibility that stressful life events, such as lupus may provoke trying to find a meaning from the experience has been recognised in research on recovery from trauma (Affleck and Tennen 1996, Ickovics and Park 1998, Janoff-Bulman and McPherson Frantz 1997). Finding meaning is often cited as part of the process of positive adaptation to threatening events (Taylor 1983). There is also substantial evidence in the research that the ability to find meaning in a traumatic or stressful event, in this case serious illness, is often psychologically adaptive (Mendola et al 1990, Schwartzberg 1993, Thompson 1991). The search for new meaning provoked the quest for redefinition of the illness situation from a threat to a possibility of dwelling upon and finding new meaning.

The participants were taking responsibility for themselves and understood they had to develop their own way of learning to live and cope with lupus. Through the increased knowledge they had gained, they were starting the process of becoming more empowered over their situation.

8.2.2 Adapting activities

Pacing was the most frequent coping mechanism used by all the participants in everyday life. The term 'pace' can be related to the speed or rate something is done, or to do something at a slow and steady rate in order to avoid over exertion (Cassel Concise English Dictionary 1995).

Lora had accepted she could not change her situation. She had learnt to take her time and see what she could achieve.

"So, I almost find it better now to say this is the thing I'm living with, it's my body and there's nothing I can do about it. It's almost and then you think okay, well I'll take my time today and see what I can get through and see what I can get done" (Pg 31-32, 621-629, T 11)

Lora accepted "it's my body and there's nothing I can do about it". She is defined by the past which she has no power to change. Her 'bodily particularities are part of her facticity and constitute the 'mineness' of her existence' (Gronda 2002:11-12).

Lora had grasped her throwness, and inhabits the possibilities of her 'there' and 'danced with' the body I have' (Gronda 2002: 13). Lora has learnt to 'dance with the body I have', dwell in her body, and do as much as she can with her limitations. She had accepted her situation and was "taking her time", seeing what could be accomplished that day. She has learnt to remake her life, to be flexible, pace herself, and accept she has to make compromises and tradeoffs.

Nadine had learnt not to push too hard or rush around, as that had consequences on her health. She "pottered" but always strived to achieve something, however small during her day.

"That's what I do, I potter, nothing… in a rush. It's like my body's just slowed right down, because if I rush I'm just ill. I do things in bite sized bits and I think I've learn to get it under control in a sense by going at my pace" (Pg 56, 1187-1191, T 24)

Nadine had slowed down, and loosened schedules, doing things at her 'own pace' in 'bite sized bits'. She had learnt to simplify tasks,

and do one thing at a time. She sensed her situation had got better, she had learnt to regain more control. She was more confident in her abilities and her success made her even more resilient.

Margaret had learnt to conserve energy and balance her day.

"I wake up early, and from six until sort of 11, 12 is my most energetic time. Then in the afternoon I need to rest and take things slower. If I can I will cook a dinner, but if I'm too tired he will do it" (Pg 7-8, 143-150, T 26.1)

Margaret had learnt when her optimum times were and used these to the full to do 'important things'. These were times when she had the most energy. Later in the day when she was tired and fatigued, she rested. She had learnt to make tradeoffs and accepted that periods of rest were necessary. In pacing and balancing, Margaret was able to continue doing her valued activities.

Many of the participants had learnt to slow down, not rush, or do lots of things during the day; they took their time and had regular times of rest.

8.2.3 Maintaining a positive attitude

The participants worked hard to maintain a positive attitude and pushed themselves everyday to do as much as they could. Phoebe felt to be able to manage lupus she needed to have a "positive attitude to life", "determination", and "stubbornness" and the will to struggle on.

"It demands hard work, commitment and real stubbornness and I've got to have that mindset to want to do it, because it's not easy. I have to be determined and force myself to do things. I'm quite hard on

myself really. I think, well I can do that. I'm not going to put it off. And of course I feel really good when I do something. That's quite a boost, it gives me more confidence" (Pg 56, 1065-1073, T 12)

Phoebe had a strong mental attitude and "forced" herself to do tasks. She had the right "mindset" pushing herself daily, being committed and determined; she was not going to be beaten. She had learnt to be hard on herself, use positive thinking and when she succeeded it gave her a real confidence boost. Her positive sense of achievement reinforced her determination to keeping going. It became her personal daily battle to cope with it and carry on.

Similar findings regarding maintain a positive attitude was found in a lupus study by Mattsson et al (2012). Lo and MacLean (2001) and Meyerson (2001) pointed out how determination has been identified as important for better adjustment to chronic illness and can bolster resilience. Robinson (1993) explored the tactics employed by those with chronic illnesses in attempts at normality. These included pacing and doing things at substantial cost to themselves and having a positive attitude.

Rebecca pushed herself to do things however she felt. She was not going to be a "cabbage"; she wanted control over her life.

"I make myself do things because if I don't I'm going to be a cabbage and stay indoors. It's no good saying I'm really ill and sitting down, thinking "Oh, I wish I could do that or I wish I had done that," well that's no good. That doesn't do anything. I've got to get up and do it and push through it, whether it hurts my knees or my head or whatever, do it, otherwise I just won't" (Pg 18, 328-342, T 20)

Rebecca was not going to blame her situation on lupus and say, "Oh, I wish I could do that or I wish I had done that". She lived with what was

there and seized her opportunities while she could, rather than wait for better opportunities to arise, and regret the possibilities that are not there. She was determined and motivated and "pushed through it", forcing herself to get up and do something purposeful every day. She grasped her possibilities to do the important things in her life of, being a mother and a wife.

<u>8.2.4 Embodied knowledge</u>

In time and with experience the majority of the participants had learnt to listen to their body and feel more in-tune with its different needs. Mattsson et al (2012) confirmed this in their lupus study.

Angie had learnt through hard experience that if she did not listen to her body, there would be "repercussions". Through trial and error she had become actively attuned to her body's reactions so she could understand and manage her illness. She had learnt to become patient and sensitive to her body's changes and in doing so felt more in control.

"I've just have to be thoughtful and listen to my body symptoms, and I mean I've gone through stages, having lupus for 33 years, I've gone through stages of not being patient, in the early days and pushing myself too far and then–having repercussions on doing that" (Pg 1, 9-13, T 21)

Through time Angie had learnt about her body and its tolerance levels for different activities. She had learnt about things which could make her symptoms worse, such as certain foods and physical environments. She acknowledged her body, listened to its signs and reactions and altered her everyday life accordingly. She had

established a new and worthwhile relationship with her body. She had become an expert in her embodied knowledge and understanding.

For years, Lisa's embodied knowledge had been questioned and dismissed by family and health professionals. She had remained "strong" and had learnt to "trust" her own instincts and embodied knowledge. She regarded her knowledge as the most valuable coping resource she had.

"For 20 years my bodily knowledge has been denied and questioned by family and health professionals. They've accused me of being a hypochondriac and making it all up. I've had to learn to keep quiet, to be strong and trust my own instincts. I mean it is my body and only I know my body so I'm in tune with that and I listen to what it tells me and that has really helped me cope. I'm really good at listening to my body and recognising those signs and I have adjusted my life so much that it's difficult for me to say what adjustments I've made, this has …become normal to me" (Pg 3-4, 63-77, T9)

Slowly and gradually over 20 years, Lisa's sense of how to live and dwell in her body had been refined, integrated and expanded constituting an important basis for her being able to cope with lupus. She had learnt she was on her own and could not discuss her embodied knowledge with family or health professionals.

She had remained strong, trusted her bodily instincts and had learnt to observe, listen, interpret and be in-tune with her bodily reactions. Her embodied knowledge had been internalised, and she had gained an automatic insight, and was able to adapt her medication and alter her activities accordingly. Through her vast experience, she had become an expert in understanding and adapting her everyday life. The

process had become embedded in her experience of managing her condition.

"Automatically somehow I seem to know without having to think about it what I'm capable of doing that day or that hour or however long. That seems to …come with living with it for so long" (Pg 40-41, 818-822, T9)

Lupus had gradually become a "normal" part of her everyday life; she adjusted to things sub-consciously without really thinking about the changes she was making.   Deatrick (1988), Knafl and Deatrick (1986) and Riding (1997) discussed how normalisation is a process by which the individual learns to cope with chronic illness. The person will describe their life as normal despite disruption and illness. This depends upon their cognitive reframing of life challenges into one that is manageable and normal and supports hope.

8.2.5 Medication

For all the participants, everyday life revolved around the demands of their condition. Medication had become an essential item that helped them control lupus.   Each day James awoke and began the ritual of sorting out his medication for that day.

"Medication is vital for me it has to be my top priority, whatever I'm doing. I have to make sure I have enough, and when to order more. Each day it has to be carefully counted out in order and marked. I have to make sure, its right, if I think I'm going to be out late tonight, I've got to take everything I need, because I can't chance it, you see. So I've got to think all the time of them, I can't be without my medication, I mean I'd be nothing, so I've got to take it with me" (Pg 22-23, 450-455, T6)

James took great care, paying particular attention to the task at hand; he took his time, being aware of how important it was to get "it right". James always thought ahead, planned for the unexpected and never left anything to chance. Always to be prepared, gave him some control and reassurance. He grasped the ready-to-hand objects, the prescriptions, the box, the pills, and his medication box in relation to his possibilities for being. It was his top priority, his life-line and without it he "can't be", he would be "nothing" and could not carry on in his everyday life.

Medication symbolised his main way of being able to cope; it was something proactive he could do to control his situation. Medication helped reduce his symptoms and illness and offered him some normality and the possibility of being able to continue to work, and carry on with his everyday tasks. With time medication had become familiar, and integrated into his life; he had become an expert.

Peter had gained considerable knowledge of medication. He took great 'pride' in knowing every aspect of his medication, the amounts, side effects, costs and what was best for him.

"I'm very interested in the mechanism of what is prescribed, so I want to know about them, what the side effects are going to be and the positives. I know all the different medications I'm on and I take over 50 tablets a week, and I know what's good, what won't work and that's really important, in fact I know more than the doctors do so in a way I am teaching them" (Pg19, 400-403, T1)

Peter's knowledge of medication was his main way of feeling more in control of his situation. With increased knowledge came increased power. He was being proactive, and was able to question health professional's decisions, and discuss the best medication for him. He

had become an expert and was able to argue his case fluently, feeling he knew more about medication than the doctors.

Having that knowledge had given him a new purpose in his life. He kept busy researching and finding out the latest information making sure he knew more than the doctors. Peter also helped others, and passed his knowledge on to lupus group members, who respected him for his wisdom.

Being able to contribute to the lupus groups was very important; it fostered Peter's sense of value and competence which increased his feelings of self-worth (Pentland et al 2002, Rebeiro 2004, Reynolds 2003, Waldie 2002, Hammell 2004). The resilience literature written by Yi Vitaliano et al (2008) and Kralik et al (2006) recognise the importance of people viewing themselves as contributing to relationships, society and feeling worthwhile.

8.2.6 Taking control

Many of the participants worked on themselves everyday in various ways. Vivian had become her "own project". It was not something she wanted to do, but felt she had to do. She realised she had to take responsibility for herself. She kept abreast with all health issues and test results and followed up medication, prescriptions, and appointments at lupus clinics and with other consultants.

"I've become my own project. And that's not what I wanted to do. That's not my natural inclination. It is my natural inclination to get things sorted out and get to the bottom of things, which is why I was a good research scientist. On a day to day basis I make sure that I'm up with all my blood tests, I like to see everything, I like to engage with everything. I also work on myself in various ways, I do Tai Chi,

meditation and I make sure I eat fresh food with no additives and I find this is an essential part of living with lupus is the work that I do on myself" (Pg 3-4, 63-81, T 16)

Vivian felt it was important to change her lifestyle and find new activities to do. To help her lung function, she enjoyed singing in a choir; it gave her a great sense of fulfilment. She did physical activities and had learnt techniques to help her relax and started doing creative art as a way to express her feelings. It made Vivian feel more in control of her emotions and anxieties and therefore reduced her stress and the effect this could have on her lupus.   Participating in meaningful activities gave her a chance to be creative, to make choices, judgements, and to make friendships, which are all important in giving her a sense of meaning in her life. Cochran and Laub (1994: 91) discussed how 'having things to do that are meaningful fills life with purpose'. All her energies went into getting "to the bottom of things", to find a solution, a way forward and to be in a better place than she was at this time.

8.2.7 Adapting coping strategies around everyday life

Haan (1977) discussed coping, as an open dynamic process that permits new information to be used and behaviour modified in light of new insights.   Being told and reading information increased the participants understanding of lupus, but for many it was not always possible to follow all the advice all of the time.   The participants were making their own individual choices about what worked and what did not work for them. They were adapting and developing their own coping strategies around their specific needs.

8.2.8 'Caution versus the real world'

Peter felt it would be impossible to avoid all the triggers for lupus and live in the real world. He wanted to live, not 'bury himself' away and have no life or purpose. He had to find a realistic balance which worked for him.

"Shall I go and bury myself in the garden because I don't think I can do that really, that's not the way I am, I have to get on with my life. It may not be sensible to have an open top car when my consultant says "Well, you ought to stay out of the sun" and I say "Well, I ought to, to do lots of things, but, in the real world, I've got to do these things" (Pg 27, 577-589, T1)

Peter knew he could not give up his sports car; it was the one thing which gave his life meaning. His sports car was pivotal in his life, and signified a 'bolt hole', a 'life-line'. It was 'hugely important in carrying on' and supplied him, with 'everything I want'. He was not going to forsake his sports car in-order-to avoid sunlight.

"If I'm feeling really ill and really rubbish and psychologically not really with it, my main drug is the car outside, I just get in my little roller skate with the roof down, whatever the weather and I go for a drive. It's the one thing that gives me a feeling of achievement, and is hugely important in carrying on; it supplies me with everything I want" (Pg 22-23, 480-483, T1).

Since having lupus, it was a rarity for Peter to experience the feeling of achievement and satisfaction. Many of his previous roles had diminished and he was struggling to find a way forward. Peter is experiencing a common theme, which runs through the literature, that of depression, resulting from a sense of diminution from loss of

precious role identities (Perry 1987, Karasz and Quellette 1995, Beckerman 2011).

Peter wanted to regain a glimpse of his former self, his independence and freedom, and not be shut away and protected from the world and being-with. He wanted to regain some purpose in his life; otherwise 'what was the point'.

Driving was Peter's "main drug"; it kept him alive and stable and reinstated his identity as a man who could still do. He had regained the feeling of control and psychological well being. For that time, he could be free, escape lupus, illness and be who he used to be and normality had returned. He had regained some meaning and purpose in his life. His sports car was his way of coping with lupus.

8.2.9 Altering and increasing medication

Many of the female participants began to regain personal control, which they so badly desired and became managers of their treatment regime altering their medication to their own individual needs and situation. This appeared to be one way many of the female participants gained more personal control over a condition that at times appeared to be completely beyond control. There were a number of reasons why the female participants modified their medication.

Christine felt the prescribed medication was incorrect for her bodily needs. She wanted more "equilibrium". She felt she was in a better place to judge what was suitable and experimented with the dosages listening to her bodily responses.

"I realise I probably should stop playing around with my drugs. But it would be nice if I got it right as far as I can get it to how my body feels and have more equilibrium" (Pg 10, 219- 221, T 15)

Christine had a wealth of embodied knowledge and she instinctively felt the prescribed medication was not right for her bodily needs. She was altering amounts, listening to her body's response and fine tuning the process to achieve more balance for her daily needs.

Lisa had learnt the beneficial effects of medications, and at times she would change the amounts and times of medication in order to facilitate more control over her situation.   She succumbed to the temptation of increasing her steroid dosage in line with increased demands within her life.

"I put the steroids up when I need to, if I have more commitments or I have to do more. Of course it's not the right thing to do, but I feel so good, sort of high and alive and it gives me some sort of sense of achievement because I can do more and that's not something that I get very often" (Pg 5, 104-107, T9).

At times, when Lisa experienced extra demands, attending a parent evening, or preparing a meal for her husband's work colleagues she increased her medication. Increased steroids meant she experienced a sense of her former self, feeling "alive", and regained a sense of normality, being able to do and achieve more things. She had renewed confidence in herself; she would not let her family down and would be able to cope fulfilling her purpose as a wife and mother. In a sense Lisa needed a fix, to be able to cope with the increased demands in her life.

8.3 Coping with infections

The participants developed their own way of managing their susceptibility to infections. Peggy was determined the increased risk of infections was not going to control her life. Being-with others had become a definite threat, but, she was realistic about her situation and understood she could get an infection at anytime.

"If I know it's something quite nasty then that's the only time I stop and think. But everything else, it's…. I mean I could think, oh don't come near me … you might give me an illness. How the hell can I live life like that? Then it's controlling me a lot more than the illness really is, because I'm frightened of an illness on top of lupus. I'm just one of those.... well if I'm going to get it I'll get it" (Pg 50, 999-1006, T 18.1)

Although the thought of getting an infection caused Peggy some apprehension, she was determined she would not become a recluse, or hideaway from being-with other people. Peggy understood the risks and at times, she would be more careful. But, "hiding away" and excluding herself would mean lupus had the upper hand and controlled her. She was not going to let it rule and ruin her life by succumbing to the fear of continual illness and infections.

Peggy had accepted her situation, and taken responsibility for her decision. She would carry on being-in-the-world and being-with others maintaining her independence and freedom. In making that decision, Peggy felt she had regained more control over her situation.

8.4 Adapting to daily change

Some participants, who had limited experience of living with lupus, found adapting to daily change extremely difficult. Ann was struggling to find a way that worked for her.

"It's very, very hard to try and live with lupus, it's the unpredictability, things happen so quickly, then my body suddenly changes again. I don't know how anybody can live with this; I'm struggling and it doesn't get any easier" (Pg 15, 302-310, T 30.1)

Ann had only been diagnosed for a few years and was struggling to adapt to the continual change and develop strategies that would help her. She is a relative novice, and has a merely positive understanding of some skills and tools she can use and has not yet be able to see what is genuinely possible. Dreyfus and Dreyfus (1986) emphasised the 'way in which an experienced and expert practitioner of a skill will just see and respond to situations that baffle or defeat a novice. It is important however to recognise that this kind of intuitive expertise is not just a matter of doing what is appropriate or called for but rather it enables creative and flexible responses to situations' (Blatter 2009: 137, Drefus and Dreyfus 1986).

May had a wealth of experience which she brought to the fore and had learnt to adapt quickly to her situation. She is experienced; an expert who will just see and respond to situations that can baffle or defeat a novice. As an expert May will have developed creative and flexible responses to situations.

"I have to adapt quickly. My disease makes me do that. And if something happens for, a week or so, I have to adapt, and then I have to adapt again. I do adapt to things and find ways of getting around it.

I'm creative and I know I can do it, I trust my abilities, I stay strong and positive and don't give in" (Pg 39, 752-755, T 31.2)

May had self-confidence and belief and trusted her abilities to be able to adapt and overcome lupus. She solved problems quickly by working through issues, trying different ways of doing things and identifying what worked for her. She never 'gave in' and remained strong, determined and positive, being optimistic that she would find a solution to overcome daily issues. She utilized her past experience to help her adapt and refine ways of doing things.

To adapt, means to move towards a suitable outcome or resolution. May's successful adaptation meant restoring a sense of normality to her everyday life. Samson (2006), Core et al (2003), and Core (1992) discussed how the adaptation to change is achieved by accomplishing a series of adaptation tasks. Corr (1992: 83) defines tasks 'as work that may be undertaken by those who are coping'. In other words, 'tasks can be understood' as the efforts a person 'undertakes to reconstruct one or many aspects' of their life that has been affected by illness (Samson and Siam 2011: 244, Samson 2006).

8.4.1 Opening up possibilities for increased independence

Due to symptoms and the limitations imposed upon them by lupus, the majority of the participants' everyday taken for granted activities had broken down. At, times of breakdown 'the normalcy of everyday life is disrupted' (Sloan 2002:159). It is at these times of breakdown that the taken-for-grantedness of everyday life is exposed and becomes visible (Heidegger 2007). None of the participants felt they were as independent "as I would like to be" and had instigated and "researched" enabling equipment themselves using the internet,

magazines and mobility shops. They had sought ways of regaining independence, and a better quality of life.

Heidegger's (1977) proposes a radical way of thinking about technology (enabling equipment). He moves us beyond the idea of technology as a 'means to an end'; and calls us to question 'technology's essence of revealing' (Zitzelsberger 2004:242). Heidegger is calling for us to consider the threat and promise of technology in our relationships with it. The equipment (technology) that was purchased by the participants in this study is more than a 'means to an end'. It can impact upon the participants' lives in both 'positive' and 'negative' ways. The 'promise' of this technology, was related by the participants reporting the significant benefits it had brought into their lives (Wrathall 2005).

Angie's mobility difficulties made her feel "imprisoned" within a body that could never keep up with her family or be a part of family life. She felt a distance to her being-with her family and being-in-the-world which had affected relationships and her quality of life. With the help of her father, she purchased a mobility scooter.

"There are times when it gets me down and there's times when I… want to do something and I know I can't and that's when I feel so imprisoned in this body. I've had to adapt things in my life, like I've got a scooter, I got so fed up of being left behind when the family went for a walk, they'd be, "There's the first bench, that's where mum stays. We all go on and come back for mum." You know, no, I'm not having that I want to be there the whole way. So, I got a… my dad really was kind and he bought me a scooter and so that's good" (Pg 18-19, 393-400, T 21)

The mobility scooter became a symbol of 'togetherness and increased freedom' and was an essential item she relied upon in her life. The mobility scooter (technology) was more than a 'means to an end'; it impacted upon her life in positive ways. A barrier had been removed; her situation had been changed and her world had opened up new possibilities. She had re-gained more independence and rejoined being-with and being-in-the-world. She could dwell widely, and had freedom to be-involved in shared activities with her family. She was being-with close-others she cared about and who had relevance in her activity. She experienced a sense of being connected, in a shared space of possibilities, which increased her self-confidence so that she could maintain her purpose within the family. Toombs (1995:11) in her autobiographical discussion of living with multiple sclerosis spoke about equipment in terms of access. She described being "imprisoned" by her body if she had not had the funds to pay for an electronic wheelchair.

Although having a mobility scooter had aided Angie's independence, she still had to rely on her husband to "put it in and get it out" of the car. This meant that when she went out, he had to come as well. She was still dependent upon him and only felt 'partly independent' as she related. She still had the constraint that her life had to be planned around his schedule. She still could not experience spontaneity and did not have the freedom or independence she had experienced in-health. But, when his back went, Angie's situation changed and new possibilities opened up.

"Then my husband had a back problem so in the last two years we've had to get a hoist fitted in the car so he doesn't have to lift the scooter for me. But, um… so I mean that's even better because I'm even more independent, I don't need him at all now, to go out shopping or

whatever, I have some spontaneity around my needs" (Pg 18-19, 400-405, T 21)

Angie had regained "more independence" and experienced the freedom of being able to go out on her own for the first time in eight years. She had possibilities to do whatever she wanted to do, whenever she wanted to do it. The mobility scooter had offered her many different things, but most of all it increased her self-worth, and confidence. She had got, "even more independent" and had regained possibilities for being a person who could 'do and be'. She was living again and it had become essential for helping her to lead a longed for more normal life.

The 'promise' of this technology exceeded her expectations. Enabling equipment can have a huge impact on quality of life (Sainty et al 2009). It can open up new opportunities, offer the person increased privacy, dignity, independence, and freedom. Equipment success may be due to perceived gains when people accomplish the task themselves, and re-gain independence and an increased quality of life (Verbrugge et al 1997). Retaining maximum independence is a hallmark of resilience (Nygren et al 2005, Morse and Johnson 1991).

8.4.2 Staying strong for my children

The participants conveyed how being-with their children gave them a sense of meaning in their lives. The participants as 'being-with, is essentially for-the-sake-of others' (Heidegger 1962: 160/123). Simply in so far as Dasein is being-in-the-world, it is also being-with, and simply in so far as its own life matters to it, the lives of others matter to it. Caring about others is the norm; Heidegger (1962:158) used the word 'solicitude' (Fursorge) to describe caring for another.

Joanne felt being-with, caring-for, being part of her son's being-in-the-world and comportment gave her a sense of meaning in her life. Without her son, Joanne felt she had "nothing" and there would be no point in carrying on with her life. She had to keep going for him and he gave her the motivation and incentive to stay strong, and push hard. Her son had given her a reason to live.

"If it wasn't for (son's name) my life would not be worth living, there would be nothing and no point I would have given up. I would have said, "Sod it, I'll die or stay in my wheelchair". He gives me the strength to carry on, I've got to be strong for my son because I have to keep going for him, I can't let him down" (Pg 31, 521-528, T2)

Many of Joanne's future aspirations had been thwarted and her roles had diminished, but, she held on to being for-the-sake-of-which she exists, a mother. She felt responsible for protecting, nurturing and caring for her son (Ingram 1996, Ingram and Hutchinson 1999).

Joanne's life revolved around her son. He gave her life meaning and having meaningfulness in her life provided her with self-worth and a reason to live (Somner and Baumeister 1998). He gave her the inner strength to carry on fighting and cope with her illness. At times, Joanne had accepted gruelling medical treatments because she needed to 'get back on her feet' to fulfil her purpose as a mum. Joanne wanted to be with him, have time with him, enjoy seeing her son develop, and this gave her a focus in her life and a reason to live. Caring for ones child, simple being-with them, expressing love is an expression through occupation (time, energy and interest) of something very important, of a connection and of sharing of oneself and that gave her the motivation to carry on living. She had worked hard to maintain her wellbeing for the sake of her son, and kept a

positive attitude looking after herself which enabled her to be able to continue to look after her son.

Existential philosophers content that meaning, purpose and choice are fundamentally important to the experience of a life worth living (Lavine 1984, Plahuta et al 2002). Joanne was 'doing, being and becoming' (Wilcock 1998a: 341) and that perceived meaningfulness of her life affects her 'will to live' (Carmel 2001:956).

Similar findings regarding the motivation of parents to keep well for their children have been reported in studies of women with HIV, (Ciambrone 2001, Van Loon 2000, Sandelowski and Barroso 2003a, 2003b). Studies into illness particularly again HIV have explored reasons to carry on living (Ingram and Hutchinson 1999).

8.4.3 Receiving the right support

For the participants to be able to cope with lupus, it was vital that they had a fulfilling network of interpersonal relationships which they could count on to provide both emotional and practical support. Support, can be understood as the existence or availability of people on whom the participants can rely, and who will value, care and love them (Sarason et al 1983). The majority of participants relied on close family and friends being there for them.

Heidegger (1962) lays out the basic mode of togetherness (Mitdasein) of being-in-the-world, and used the word 'solicitude' (Fursorge) to describe caring for another (Heidegger 1962:158). Solicitude has two extreme possibilities. The first one is 'leaping in'. Leaping in for them, can, so to speak, take the others 'care' away from them. This kind of solicitude takes over for the other that which he is to concern himself. The other is thus thrown out of his position. In such solicitude the

Other can become one who is dominated and dependent, even if this domination is a tacit one and remains hidden from him (Heidegger 1962: 158-159)

The second kind of Solicitude, is the possibility of a kind of solicitude which does not so much leap in for the other as leap ahead of him (ihm vorausspringf) in his existential potentiality-for-Being, not in order to take away his 'care' but rather to give it back to him authentically as such for the first time (Heidegger 1962: 158-159).

Penny relied on her mother, to 'step in to' the breach and support her when she was ill.

"My mum's been brilliant. I mean she's always stepped in, you know, and helped me when… when I haven't been well. The first sign of illness she's straight round looking after my children and doing everything for me" (Pg 15, 327-330, T 22).

Penny was able to totally rely on her mother who would respond quickly and arrive to offer affective emotional and physical support. Her mother would seamlessly 'step into her shoes' and take over supporting and caring for the children and all the household tasks. Her mother also offered Penny much needed emotional support, the comfort, love, understanding and attention she needed to help her cope with illness and remain strong. Her mother offered her the right sort of support, one which was flexible responding and changing to Penny's own varying needs.

The solicitude that Penny is describing was 'leap ahead caring', which enabled her to still care for herself. At other times when Penny was very unwell solicitude was directed towards doing what she could no longer do for herself, washing, feeding, going to the toilet, and her

mother provided 'leap in caring' by taking her care from her. This care was only for the time Penny was very ill. When Penny started to get better 'leap ahead' care stepped in, a 'helping-togetherness', where Penny did things for herself (Svenaeus 2001:160). Her mother had the right balance which increased Penny's feeling of control over the situation, aiding her independence and self-esteem.

At times Joanne's experience made her question her own mental soundness. The emotional support she received from her mother was vital in helping her feel she could cope with lupus.

"Mum's always been supportive; she has never doubted me or anything like that" (Pg 18, 371-372, T 2)

Her mother was the one person Joanne could rely on and trusted. She was 'being-with-her-mum' who had always believed in the authenticity of her illness. She was being-with someone who cared, listened, comforted, loved and accepted her for who she was. Her mum was being there when Joanne was down and brought her out of consuming illness and despair by picking her up emotionally and helping to find a way forward. She kept her feet on the ground, gave her a different perspective, and offered reassurance and encouragement never letting her down.

"If I hadn't had my mother, I would have been in a mental institution" (Pg 28, 518, T2)

Her mother signified her life-line, a rock, her mainstay and the one person who kept her sane. She had been "with-her" all the way. Her mother was the one stable influence who believed and understood. She was her witness to her illness, her confidant, sounding board and

the one person who had stood up, supported and shouted for her. She was vital for Joanne's continual survival and well being.

The emotional support she received from her mother helped her maintain the strength to carry on and reduced her feelings of depression and of not being able to cope.

8.4.4 The right support from health professionals

Many of the participants felt they were receiving very good support from health professionals. A number of lupus clinics have improved their services by making phone consultations possible with a lupus nurse. James found this really helpful. It was his lifeline. He could discuss his concerns and worries as they arose, giving him confidence.

"I like to have someone on the end of the phone if I get a problem (clears throat) I can ring up and they give me advice or help me, like this nurse practitioner I have" (Pg 12-13, 247-249, T6)

Instead of having to wait for an appointment, James felt confident he could phone and talk through issues then and there. It was everything he needed. The lupus nurse was fulfilling his purpose and providing immediate support to reduce his anxieties increasing his confidence and feelings of security.

Peter felt he received really good treatment from the top man, who was "really interested in him".

"I was under two consultants; a rheumatology consultant and a respiratory consultant and both of those are great because I can talk to them. The respiratory consultant who was the senior consultant in

the hospital, he spent about 20 minutes with me, and he was really interested in me" (Pg 11, 233-237, T1)

Peter's expectations were being met. He felt he was getting the best treatment and was actively involved, listened-to, and given lots of time to discuss his issues. Peter also had a good trusting relationship with his GP.

"He's great, I get on very, very well with him, he listens to what I say and it's a management thing really. We sort of have a discussion, and it's exactly what I would want to do with any instance I just want to be fixed with the least possible problems" (Pg 8, 169-178, T1)

They were working together focusing on the task at hand to solve a problem. The GP was enabling Peter and he felt an active partner in the management process. He was being involved in all decisions, and respected as an equal being-supported.

Health professionals play a vital part through giving information, increasing understanding of the condition, listening, offering encouragement, and working with the person in enabling personal transformation through the process of increasing their feeling of empowerment over their situation. McWilliam et al (1997) related that the empowerment process starts to occur while the patient tells their story and the health professional facilitates the understanding they both gain from the patient's situation adding and creating meaning to the patient experience. The main focuses of this empowerment relationship is the continuity of care, patient centeredness, mutual acknowledgement and relatedness. Other attitudes contributing to the empowerment process include a positive atmosphere, demonstrating interest, positive regard, paying attention to the patient's priorities, active listening, and encouraging patients to be actively involved in the

consultation, provide emotional support, and giving patients time (McWilliam et al 1997, Skelton 1997).

In Andersons et al (1995) study, patients expressed that as a result of their empowerment process they felt they understood their disease and became more positive and comfortable in asking questions to their doctor. Empowerment results in people becoming more competent in relating to self and others and dealing with their condition, life and environment. It suggests a tendency towards self-growth, or self actualisation (Rogers 1951).

Research into the SLE patient-doctor relationships has demonstrated the presence of intangible interpersonal qualities such as trust; communication and cooperation and how these correlate significantly with fewer side effects and better global health (Berrios-Rivera et al 2006). Yen et al (1999) discussed how lupus patient satisfaction is very important as it gives a projection of how patients will comply with future interventions. Patients who are dissatisfied with their medical care are less likely than other patients to comply with treatment recommendations (DiMatteo et al 1982, Gerber and Nehemkis 1986, Ley 1988, Bennett et al 2011).

8.4.5 The right support through work

The majority of participants were no longer able to work. In-order-for David to continue to work, he relied on a supportive boss who understood his illness, and needs. David was given flexibility, which aided his ability to hold down a job, and continue to work full time.

"I'd been off for a long time because of lupus and I thought that would be it... I won't be able to cope. But my boss has been brilliant, I can talk openly to him, he is human and he understands lupus and my

needs. He has been very supportive letting me have time off if I'm ill or have appointments and he never questions it. He's made sure my job is manageable and not too stressful, and I'm home-based most days. I only have to go to head office when required and most of my clients see me here (at home)" (Pg 8, 160-169, T 27.1)

David was being-with his boss who understood his health needs and was being supported during times of sickness or appointments. David's boss listened and was "human" offering compassion, understanding, support and strategies to aid his coping. In having flexibility David was able to be for-the-sake-of-which he exists, a working man, supporting his family. This gave his life meaning and an opportunity to contribute to the company, society, and expand his social networks, and regain a sense of normality in his life.

His job restored meaning in his life which led to feelings of increased self-esteem, and self-efficacy. He was financially independent supporting his family which increased his sense of security, and the feeling of being capable. This is confirmed in the SLE literature by Archenholt et al (1999).

8.5 Support through Lupus Groups

Peter attended a lupus support group; he felt the group offered him "everything he needed". He felt accepted, included, and was not alone being with others who were like him. It was the one place he felt he fitted in.

"Through a group I can feel comfortable that, actually, I'm not alone and I'm not the only one and I can be honest and say how I feel. And the information they provide is pretty good. And to be able to be part of it, to help, is important in my life" (Pg 60, 1272-1283 T1)

Going to a support group allowed Peter to share his experiences "honestly" being-with others who understood. This was viewed as especially important because of the misconceptions of lupus by society and family members. Mendelson's (2003) study entitled 'Gentle Hugs' also identified this point. Peter could access information and gain useful advice from members on ways to help him cope.

The group offered him an identity and a purpose. He wanted to become actively involved. Riessman (1965) takes up this point and proposed that self-esteem is enhanced, not only by sharing experiences and the feeling of being with others in a similar situation, but also having the opportunity to help others and not just focussing on themselves. The group had given Peter a new purpose, focus and an achievement in his life.

Matthews (2000) discussed how support groups are a source of constructive socially embedded help. They reduce distress, the sense of isolation and provide the sense of being able to share experiences in a safe, supportive environment, as well as provide information about the disease, and its treatment.

Some participants attended regular lupus group support meetings finding them beneficial and supportive. They brought people together and provide a sense of common predicament and prompts feelings of mutuality and community (Williams 1989). By the creation of a common predicament, social distance can be reduced along with feelings of vulnerability. Support group participation has been found to be associated with decreased levels of depression and anxiety among women with lupus (Bitter 1986). Support groups could provide much needed informal support, the sharing of information, and socializing with others in the same situation. Virtual support groups, through the

internet, were very important for those who found it physically difficult to attend meetings.

8.6 Re-evaluation of life

For all the participants' the stark reality 'actually I'm not going to live forever' had come to the fore. Due to the unpredictable nature of lupus, with its additional serious health issues, infections and organ damage, death was a real possibility 'now' and not sometime in the future which could be covered up and ignored. The participants had all reflected on and considered death and for the majority of participants' time had taken on a new importance and a different meaning. Time had become a precious commodity to be used wisely and to the full now.

Penny had firsthand experience of the unpredictability of lupus. Her sister had died suddenly of lupus.

"My sister died of lupus at 41 of pneumonia. With no warning, slight cold, didn't feel too good, put the kids to bed, and just died suddenly in the night, it was very unexpected. I don't look at the long term picture. … I'm very aware of my mortality with lupus … So … anything I want to do, I'm doing it right now, that's the way I am" (Pg 13, 263-269, T 22)

The reality of her sister's death hit Penny hard. Death was no longer an abstract remote notion, she realised she could die from lupus at any time. Penny revaluated her priorities and took stock of what was important within her life.

'It is through the act of understanding the nearness of the possibility of one's own death that new possibilities for being emerge' (Gullickson 1993:388)

With death as an ever-ready possibility Penny had no time to waste. Every moment was unique and she must take responsibility for how she lives. She was determined to live her life "right now" and do all the things she wanted to do before it was too late. Penny thought less about her future and her in-health past, and lived dwelling in the present moment savouring every aspect of her life.

Lupus had changed Phoebe's priorities and new possibilities were emerging. When Phoebe was well she grabbed possibilities and lived "life now" and did as much as she could. For tomorrow it could all be taken away.

"I mean something else could go wrong to my internal organs and I can't do anything, so now, while I'm as fit as I can be I live life now and enjoy myself. I've not got the time… to waste. Because I don't know what's round the corner. A lot of people wait until they retire before they go anywhere. I just couldn't even think of doing that. And it's completely different; I have to do things when I'm well" (Pg 31, 592-599, T 12)

"If I get the chance I'll do it. I do things that other people won't do. I mean I sky dived and went diving with sharks; a lot of people won't dive with sharks. I'm not afraid of them… a shark has never attacked me. This is my life and whatever I want to do, if I want to go on holiday or spend money, I will, I live my life now" (Pg 35, 673-679, T 12)

Phoebe was acutely aware of the possibility of death. She understood her own capabilities, and fulfilling her potentiality for being is what

motivates and informed her existence. When Phoebe was "well", she seized her possibilities "to do things" and anticipated the future right now. Life had become precious and not to be wasted. Urgency had crept into her life.

She did not have time to procrastinate or delay, or wait for someday later in the future, letting herself be defined by what she is already. She took her opportunities now and lived with the possibilities that are there, rather than regretting the possibilities that are not there.

Lupus had brought limitations, but it had also opened up new possibilities within her life. Things which she had wanted to do 'at some time' she did now, she 'sky dived with a buddy and swam with sharks'. She spent money on holidays and did not feel guilty; there was no point saving it for a rainy day. Phoebe is exposed to so much uncertainty that she had found a way of not worrying about things too much. She had learnt to dwell in the present and had stopped thinking about the future.

Death is not the end of life but rather an 'authentic' possibility for understanding the meaningfulness of life and its relation to time. 'The next moment could be my last and death as this overreaching possibility affects our way of receiving meaning from and giving meaning to our existence, which is thus a being-towards-death' (Heidegger 1996: 247).

One thing stands out from both Penny's and Phoebe's narrative, a focus on the present amidst a shrinking away of the past and the future. Svenous (2011:339) proposed that the 'temporal structures of illness can be conceptualised as an alienation of past and future, where my past and future appear alien to me, compared to the case before illness.

Narratives make it possible to give meaning to events that have disrupted and changed the course of one life (Williams 1984). Frank (1995: 76) proposed that three types of narrative exist, the 'restitution, chaos and quest narratives'. In the 'quest narrative', the individual accepts illness and it is seen as a challenge and an impetus for change (Frank 1995: 166).

The ability to find meaning in the case of serious illness is often psychologically adaptive (Mendola et al 1990, Schwartzberg 1993, Thompson 1991). This can be likened to Frankl's (1959:114) belief that, 'suffering ceases to be suffering in some way at the moment it finds a meaning...And one is given a last chance to actualise the highest value, to fulfil the deepest meaning'. It is a search for new meaning provoked by lupus that involves redefinition of the illness situation from a threat to a possibility of dwelling upon and finding new meaning in life. It attempts to change the situation through the new understandings developed in the story.

According to Mishel (1990) the theoretical model of uncertainty in illness, uncertainty occurs when a person is unable to determine the meaning of illness-related events and or fails to predict outcomes when adequate cues are missing (Mishel 1988). Uncertainty can be experienced both as a threat and an opportunity during the course of a disease (Mishel 1990). When uncertainty is accepted as a natural part of life, consideration of numerous possibilities and re-evaluation of what is important in life can take place (Mishel 1990).

Many participants in this study related positive consequences of living with lupus. A few studies have exhibited similar results including; enriched experience of life (Bauernfeind et al 2009, Stamm et al 2007), positive consequences of living with SLE (Goodman et al 2005), and personal growth (Wittmann et al 2009). Lupus made the

participants question what was really important in their life. Those who gained insight into the meaning and course of their life talked about new possibilities through changing jobs, and moderating career aspirations. Many participants redefined their relationship with being-with others and had learnt to say "no". The participants were developing new opportunities and some of these experiences will be explored next.

Angela was not going to be a "people pleaser" anymore. She did not have enough time or energy to waste. She was going to do what she wanted to do now, rather than having to fit into what everyone else expected.

"I used to be a people pleaser years ago. People would invite me to things and I didn't really want to go but I felt I had to go because it's expected. Now, if I don't want to do something I don't do it. If someone invites me to something I'll say, "No". It's given me a cop-out and I don't care about what they think; I haven't got enough time or energy for that, I have to do the things I want to do now. So, now I can do what I like more or less. And that is a freedom, but my limitations tie me down a lot. I do try and do as much as I can when I can. I don't waste any time that I am able to get around and do things" (Pg 15, 282-296, T 23.1)

Angela used to be busy conforming and fitting in with everyone else. Lupus forced her to confront her situation and she had taken a stand on 'who she is'. In a world of things she cannot change, she is responsible for being who she makes herself to be, through the changes she can make. She takes responsibility for herself and understands she has not got enough time or energy to waste doing things she "doesn't want to do".

She learns to say "no" and does not worry about what people think. She chooses to live a life of a person rather than fitting in with everyone and takes responsibility for living a life that is generally whole and generally 'mine'. She is keeping to her convictions and is honestly facing her changes, by, disclosing what she really wants, rather than what she has always been conditioned to do. She is being responsible for herself and her actions (certainty and conviction) and the combination of understanding, acceptance, responsibility and reticent determination is resoluteness.

Angela was not going to be carried along with the herd. She was being liberated to live now, and was being her own person, doing her own thing and making up her own mind. She experiences a new freedom in one way, but is aware her "limitations tie her down".

Heidegger (1962) describes existence as thrown projection. Angela is thrown into a world, a historical and political period, race, gender, family, genetic background, over which she has no control. In this sense, her past is something into which she has been thrown. But, she is also constantly projecting forward into the future, choosing what possibilities to pursue and which ones to let go. Thrown projection expresses the fact that the freedom to shape her future is not unbounded. It is limited by the past and a finite future. Angela's ability to choose is within limitations, she has bound or finite freedom.

Ricoeur (1975) described freedom and constraint as un-separated poles with in-between degrees of what is free and less free, what is constrained and less constrained. Freedom is therefore experienced in varying degrees. According to Frankl (1993) a person's freedom lies between the possibilities to approach the different situations in life in a certain attitude, and it is possible to experience freedom despite restraint in life.

At one time Meg had been keen to make money and have status as a professional person but that was no longer important. She wanted to do something worthwhile and make a difference to others. She had other priorities in her life of far more importance than money or status.

"I accepted pretty quickly that I was only going to be able to work part time only two days a week. Lupus has been responsible for that, because of my limitations so I've changed direction and I love it I feel useful and its worthwhile and also other things are more important now" (Pg 4, 73-80, T8).

Meg had given up her full time high powered job and changed direction completely. Her once important career ambitions were no longer important. Her priorities had changed. She loved her new job, and felt she was at last being "useful". She had a new purpose in her life and had some responsibility but without the pressure. This different direction gave her a new identity and a new future doing something she loved.

Rachel had taken up running to help with the osteoporosis, and this had given her a whole new sense of meaning and purpose in her life. She was looking at lupus in a positive way; her lupus was her 'wolf running buddy', and lupus had turned from an enemy into a running companion.

"Actually Lupus had done me a favour, because I've become a runner. So the way I see it is instead of having the wolf as my enemy he's my training buddy keeping me fit because he's running behind me, chasing me, so I can't let him catch me so I've got to keep going. And that's almost how I see my exercise, running from the wolf" (Pg 2-3, 37-43, T 17)

Fig.19 Running From The Wolf.

Her running opened up other directions within her life. She ran marathons, met new people, told people about lupus and spoke about her experiences.

8.7 Conclusion of Coping and Regaining Resilience

This chapter has explored a few of the multiple coping strategies which the participants used and the ways they have developed resilience. The participants had learnt to adapt tasks, listened to their body, trusted themselves, and used mental strength and determination to 'push on'. They had developed, 'good psychosocial

capacities such as competence, coping, creativity, and confidence' (Anthony and Choler 1987:3-48). They maintained a sense of optimism and perspective, not wasting energy or time and used flexible coping responses, being persistent in face of their challenges. They participated in purposeful activities and contributed to relationships and society and through this developed new self-esteem, purpose and meaning in life. They strived to maintain their independence, and actively sought support when needed. They accepted limitations and developed new possibilities and opportunities for personal growth demonstrating resilience. The participants had as Demos (1989:5) suggested in its most developed state, such buoyancy requires 'an active stance, persistence, and the application of a variety of skills and strategies over a wide range of situations and problems and flexibility to know when to use what'.

Many participants had developed a new relationship with lupus. Lora had in time come to accept lupus, and decided to work alongside it and make it a friend.

"I see my lupus as something that's tied to me this hurricane that moves in and out of me at its own free will and some days it's a bigger and other days it's smaller and more manageable. It was impossible in the beginning ... it knocked me off my feet, crushed everything in its path but I've learnt to bend in the wind, take protective clothes and be prepared for all conditions taking shelter when needed. I've accepted its part of me; I learnt to be strong, flexible and live now, appreciating life to the full. And I decided to make a friend of it and I thought well it can either beat me or I can try and work alongside it" (Pg 47, 919-929 T 11)

Fig.20 It's Part Of Me

In time lupus had become "a part of her"; she had learnt to bend in the wind, be flexible, and be prepared to use her "protective clothing and take shelter". She had learnt numerous ways of coping and dwelling in the present and stopped thinking about the future. Lora cannot change the past, and her future has not happened yet, so she cannot command it. She had no weather forecasts to help her predict what the future may hold, so there was no point worrying. She focused on,

being here and now, and "appreciating life to the full". Her attitude to time had changed and her energies are focused into now.

Carel (2008: 134) discussed how 'focusing on present abilities, joys and experiences instead of worrying about a no-longer-existing past and a not-yet existing future is a way of avoiding some of the suffering caused by illness'. In time and with great inner strength, many participants in this study overcame adversity and found a way forward, being able to find a new and different way of being-in-the-world, from the one they had experienced before lupus, which was a more homelike being-in-the-world (Rutter 2006, Svenaeus 2011). They were developing growth and new opportunities.

For all the participants, the development of their embodied knowledge was vital for assisting them to feel more in control and better equipped to adapt and regulate their activities, medication and lifestyle. This is perhaps not surprising considering the unpredictability of lupus and the limitations the lupus body can impose upon the lives of the participants. Embodied knowledge is therefore an extremely important resource within lupus which should be embraced and used. Benner and Wrubel (1989:161) point out a 'coherent and resilient form of health and healing comes from restoring the sense that the world and the body are trustworthy and capable'.

Yet rather than being embraced lupus embodied knowledge appears to be rarely acknowledged by health professionals. The majority of participants related how health professionals and family members often ignored or denied their embodied knowledge. This was demonstrated in Lisa's experience of being accused of being hypochondriac.

Liang et al (1984:18) discussed 'given the multiplicity of symptoms possible...and the continuous need for self-monitoring and adjustment of activities, one hesitates to label hypochondriacal symptoms (exaggerated concern about health or bodily or mental sensations) as dysfunctional. Likewise, hysteria, the conversion of anxiety into somatic symptoms, is more likely to occur in the setting of an existing organic disease. In these patients, hysterical symptoms may help re-channel anxiety released by the uncertain, potentially disabling, life-threatening aspects of these diseases'.

Liang et al (1984) is making the point that these symptoms may well be an appropriate adaptive strategy given the nature of lupus. Napier (2003) points out, that to what extent can a response be called 'unhealthy' when it is appropriate? Those with lupus may appear to family and health professionals as obsessed with their body, but these responses may be normal and healthy for someone with lupus. The participants had to become acutely aware, listen and be in tune with their bodily variations in order to be able to adapt their medication and lifestyle to their body's changes.

As this is a vital resource for adding adaption and the ability to cope with lupus, patients should be encouraged to learn, listen, become sensitive to, trust their bodily experience and be able to communicate this to others. It was unfortunate that the participants within this study were being discouraged to talk, or even admit their embodied knowledge aloud. One could question why this might be.

The need for re-establishing habitual knowledge as part of recovery has been described by Benner (1989), Leder (1992), Toombs (1993, 1988), and Morse (1997). According to Merleau-Ponty (1996), human perception is embodied. Therefore, a changing body leads to an unfamiliar daily life. When a person adapts so that their world no

longer seems so unfamiliar and unhomelike, they can regain some meaning in their life, and experience a more homelike being-in-the-world.

There is considerable research on the embodied experience of chronic illness (Corbin and Strauss 1988, 1992, Anderson and Bury 1988, Toombs 1988, 1993, Ledger 1992, Frank 1995, Thorne et al 2000, 2003, Corbin 2003).   The practical knowledge established by the experience of living with a condition over time has been described as the increased development of bodily intelligence, the skilful body, and embodied knowledge (Merleau-Ponty 1994, Benner 1994, Benner and Wrubel 1989 and Corbin 2003).

The importance of embodied knowledge for the persons well being has been explored by Morse (1997) who related how patients diagnosed with illness, experience bodily changes through stages of uncertainty and they strive to regain self. This process helps the person endure suffering. Gullick and Stainton (2008) discussed how lung patients experience a shrinking life-world shaped by breathlessness. Patients developed strategies of conscious body management to facilitate breathing, mobility and task completion. While Price (1993) explored health and self management in patients with asthma and diabetes and found that they used 'body listening' to aid them control the illness and to avoid getting into situations where activities and goals could be restricted.   Ingadottir and Halldorsdottir (2008) described body listening as an important process, the guiding light in an attempt to find a comfortable and safe condition in diabetes.

Heggdal (2008) explored Bodyknowledging and how the persons embodied knowledge is developed as a resource for health through a dynamic, nonlinear process of interaction with the environment. 'Bodyknowledging' can be defined as 'a fundamental process for the

development of personal knowledge about one's own body, coping skills, health and wellbeing' (Heggdal 2008: 34). The study found stages denoting health promoting process, listening and understanding the body's signs and integrating embodied knowledge into new possibilities for well being and health. Heggdal (2013) used a grounded theory methodology that informed data collection and analysis. In depth interviews were conducted with 56 men and women diagnosed with chronic obstructive pulmonary disease, inflammatory bowel disease or a stroke.

For those who had lived with lupus for many years, their embodied knowledge had become a "normal" part of their everyday lives. Many adjusted to things "sub-consciously" without really thinking about the changes that they were making. They had become experts at understanding and listening to their body and had gained an automatic insight, being able to adapt accordingly medication and their activities. They had established a new and worthwhile relationship with lupus. Instead of an enemy their body and lupus had become a friend and a travelling companion. Wilde's (2003) research on embodiment showed how some people diagnosed with chronic illness approach their body as if it is a friend or a silent informant.

Chapter nine discusses some aspects of the findings and discussion chapters, and the lupus literature, and also the strengths and limitations of the study and the disengagement process.

9.0 Chapter 9 - A Summary of the Findings and Discussion Chapters

This chapter will briefly discuss some aspects of the findings and discussion chapters and the lupus literature. The chapter will also discuss the strengths and limitations of the study and the disengagement process.

The participants' self-doubts were escalated through the challenges lupus brings of living with an ever-changing body, its strange atypical presentations, incomprehensible origins that followed no 'normal' disease course, the invisibility of the condition, its relative rarity and lack of public awareness. The participants needed support, understanding and somebody to listen and believe in their experience. Instead they were greeted with misunderstandings, doubts, suspicions, and the pain of having their experience trivialised, ignored and not understood.

An underlying feeling that runs through all the findings and discussion chapters is the influence on the participants of their pre-diagnosis experiences. These experiences created a lasting negative effect that could be rekindled, evoking insecurities, and uncertainty and for many participants tarnished their perceptions, interactions and trust in health professionals and the medical system.

A common theme in the participant's pre-diagnosis experiences was that of being disbelieved due to the physical and medical invisibility of their embodied experience. The participants had sought medical help with the reasonable expectation that health professionals would be able to uncover the clinical reasons for their illness (Stockl 2007). They had the expectation that the health interaction would shed light

on their illness experience and offer support, understanding and a trusting relationship, instead it generated more uncertainty.

Throughout this time, their integrity, sense of self and personal identity had been challenged in numerous ways by detrimental interactions with health professionals. Most participants reported how their experience had been trivialised and dismissed, and they received no acknowledgement that their experience existed. Their bodily intuition and knowledge had been ignored and they were disempowered, misdiagnosed and labelled. Many participants through ongoing poor health management were extremely unwell by the time they received a diagnosis.

The pre-diagnosis experiences identified in this study have been collaborated by other qualitative lupus studies (Hale et al 2006, Hatfield-Timajchy 2007, Waldron and Brown 2007, Stockl 2007, Waldron et al 2012, Price and Walker 2014). Mendelson (2003, 2006, 2009) in an extensive and detailed body of work, discusses this protracted period prior to diagnosis, using the term 'the luminal state' (Mendelson 2009:390). It is the period when the patient is self-aware that something is wrong, but has not yet received a formal diagnosis of lupus. The person has lost their familiar identity of being healthy but is not able to be sick as they have no recognised diagnosis. Patients in these luminal states are neither one thing nor the other; they are 'betwixt and between' (Turner 1997: 96-102). Patients are trying to cope with an uncertain present and future (Adamson 1997, Stockl 2007). Price and Walker (2013:1) called it 'diagnostic vertigo', referring to a condition that is at odds with any biomedical order anticipated in the diagnostic process.

This study has built on previous research, identifying that for many participants' interactions with health professionals during this time

caused real harm and suffering and this has had a huge detrimental effect on their lives. Many participants had been left in a condition of extreme uncertainty, full of doubt where nothing was certain and nothing was resolved as they could find no closure. These experiences have nurtured ongoing insecurities, feelings of vulnerability and being abandoned with their health concerns.

The central moral obligation of the medical profession is the healing act measured by the fullness with which the health professional supports, cares, and develops collaboration and a trusting relationship decreasing the afflicted state that illness has created. This means reducing suffering, uncertainty and chaos. It is vital that health professionals have a greater understanding of the patient's experience during this pre-diagnosis time and listen to the patient's narratives. Pellegrino (1982) discussed how the take-home lesson for health professionals should be that the meaning of illness can only be fully understood by exploring the lived experience of patients. Health professionals need to open up dialogues, and allow patients the time to tell their stories, because in telling the story the patient can be helped brought back into medicine and find a way of gaining meaning and healing.

In the absence of a diagnosis patients need to be managed sympathetically and should be supported by health services. In this study the length of time for diagnosis ranged from 13 months to 54 years, with the average length of time being 11 years. It should be noted that, during the recruitment of participants out of the thirty-three people not eligible, twenty-eight had not yet received a definite diagnosis, although they were all convinced they had lupus. One could therefore question whether these individuals were stuck in 'no man's land', waiting to secure a diagnosis and experiencing the long desperate journey conveyed in the participants' accounts. Living with

an illness that has not been diagnosed, being surrounded by doubt, uncertainty and abandoned, is perhaps, one of the worst experiences of all.

With diagnosis, came legitimisation and eligibility for professional care. Every lupus patient needs, what is unavailable, namely a viable support system. Receiving a diagnosis after such a long journey brought relief, but also uncertainty. Many participants had the expectation that medicine would cure their illness and that they would be supported by knowledgeable experts, who would give them the skills to return to normality. But instead of achieving these expectations, the participants were thrown into confusion.

For the majority of participants the diagnosis was delivered in a way, which left them questioning what it all meant. Their diagnosis made no sense and was meaninglessness. Such communication can have a lasting negative effect (Thorne 2006).

The participants' questions, anxieties and concerns were not addressed and they were being left in the dark. A few participants did receive a NHS leaflet, but this did not explain the condition in any depth. This study corroborates that of Waldron et al (2012) and Hale et al (2006), and the deeply felt dissatisfaction of the lack of information and NHS leaflets in which there is a disregard of lived experiences.

The participants in this study received no reassurance or explanation of their condition to aid their understanding. They were left with an extremely fragmented understanding of lupus, having no idea what it was, or that it was a chronic long term condition that could not be cured, only treated. They received no guidance on how to manage lupus when they needed it most. This left the participants feeling

unsupported. Becker (1997: 4) discussed how 'meaning is assigned to specific life events. When expectations about the course of life are not met, people experience inner chaos and disruption'.

The participants were not being offered the skills they needed to help them find a way forward and find new meaning to manage the condition. This left them foundering and confused. These findings are confirmed by Waldron et al (2011) who found information was inadequate at diagnosis.

Because the participants felt in the dark about what it all meant, and what they should do next they sought information for themselves. If this knowledge is largely based on medical facts and the medical model, it may limit their existential understanding of their condition. This can increase anxiety, uncertainty, and confusion escalating the feeling of being lost and alone. Mishel (1988) defined uncertainty as when a person is unable to determine the meaning of illness related events and/ or fails to predict outcomes when adequate clues are missing. Uncertainty can be conceived as a subjective perception which can manifest itself in 'lack of absolute knowledge or understanding, or difficulty in interpretation' (Cleanthous et al 2013: 184, Johnson et al 2006). The participants in this study craved reassurance, understanding, stability and ways to manage their condition. Chuang et al (2010) showed that the greater the uncertainty, the more negative affects it had on the individual's quality of life and on their ability to manage illness.

Diagnosis is a pivotal moment in lupus where either further harm and damage can occur or benefit and growth can be regained (Clarke et al 1995, Simson et al 1991). Thorne (2006) refers to a window of opportunity when health care communication is of prime importance in

promoting coping strategies and optimum quality of life or damaging those ideals and determining ill-disposed patient attitudes.

Once diagnosed, a normal part of the participant's everyday life had become attending ongoing clinics. For the majority of participants the clinic appointments caused uncertainty, they were going into the unknown which resulted in apprehension and anxiety. The appointments reinforced the participant's sense of powerlessness.

Time constraints were a major barrier for developing caring health communication that would foster the growth of the participants. Health professionals were viewed as not interested, disrespectful, and participants were not active partners in the medical management of their disease. Danoff-Burg and Friedberg (2009) and Whitehead and Williams (2001) collaborates this finding. Many participants experienced inconsistency in their care and the interaction focused on symptoms and medication without taking their experience, background or previous history into account. They were being treated as a case, and not a person. Concerns around the impact the illness on their lives, changes in treatment regimes and the possible future course of the disease were never addressed. Lupus threatened and affected their whole life, but the health interaction only focused on symptoms and medication.

The participants saw themselves as an object on a conveyer belt; part of a machine, a number and their condition and treatment does not make sense. With the evolution of modern medicine, narratives have become increasingly neglected with emphasis placed on facts, findings, time, and efficiency. Narratives make it possible to give meaning to events that have disrupted and changed the course of one's life (Williams 1984). It is a search for new meaning provoked by

lupus that involves redefinition of the illness situation from a threat to a possibility of dwelling upon and finding new meaning in life.

Many general practitioners had poor knowledge of SLE, Hale et al (2006) and Sansom (2010) collaborated this finding. General Practitioners did not provide medication or provide joined up care by liaising with the consultants. This had a huge detrimental effect on the participant's lives, causing unnecessary anxiety and stress. Primary care services need far more understanding of lupus patients needs. One-sided, traditional medical education should be modified to acknowledge lived experiences (Thesen 2005). General practitioners were causing additional barriers and affecting the participant's way of life

Coping and regaining resilience explored how health professionals offered the right support through giving information, increasing understanding of the condition, listening, and offering encouragement. The main focuses of this relationship was patient centeredness, mutual acknowledgement and relatedness and the development of attunement between patient and health provider (Fox and Chesla 2008).

The findings and discussion explored aspects of how the participant's experience is continually challenged by society's common 'expectations about how sickness and health should be represented' (Napier 2003: 86). The majority of participants looked well and healthy. As such, the participants were greeted with 'there's nothing wrong with you?' and these comments became a depressing endless cycle with others assuming they looked well, so they must be well. The 'most profound social doubts can derive from the misreading' of those with SLE by others who are using 'other illnesses as models of pain and hardship' (Napier 2003: 87).

The suffering which lupus gives rise to is 'atypical' and does not conform to conventional moulds. The suspicions of others are based on the fact that those with lupus do not subscribe to the socially acceptable paradigm of those that are ill appearing as 'emaciated fighters' (Napier 2003:82). The invisibility of their condition meant relatives, friends, and colleagues could not see their symptoms and suffering and did not understand their experience.

As well as the issues caused by being physically invisible, the participants also had to contend with lupus being a relatively rare unknown condition and as such due to the lack of public awareness, it is usually greeted in the main by social ignorance. The social construction of illness implies a sort of social standing. Masana (2010:130) presents an interesting debate as to what constitutes an invisible disease. It is argued that illness visibility or invisibility does not rely on observable evidence but on a social look formed by illness cultural meanings and beliefs. Within this debate, a classification exercise of chronic diseases is constructed on the basis of social and biomedical perception. Lupus would seem to fall within the 'unknown and neglected ones....whose low prevalence causes social ignorance and public policies overlook' (Masana 2010:130). With a well known and understood disease, others will often respond with empathy and understanding. However, with lupus, others can respond with lack of interest, disbelief and rejection. This generated many challenges for the participants. The combination of invisibility and the disease being relatively unknown impacted on the response and the amount of support they received from those around.

Lupus patients have no social model of the disease to refer to when describing their experiences to others who are accustomed to the progression of conventional illnesses. The participants struggled not knowing how to describe their experience. For some sharing their

illness experience, broke the cultural taboo. Talking about illness was perceived by others negatively, symbolising moaning or complaining (Album 1996). Many participants were tired of trying to describe and explain their health situation and said nothing.

Heidegger (1962) discusses that our sense of identity, cannot be disentangled from the world around us (Aho 2005: 4-5). The self is understood as acquiring its meaning and identity by way of being-in-the-world, being-with others. Our public way of being is understood in terms of going about daily life, talking to people and others assign meaning to our goals and how we present ourselves. 'They' make us 'who we are' (Aho 2005: 5). In everyday activities, we are always being-with-others and the 'they' have determined our own bodily perceptions, which are always saturated with cultural and historical meaning. 'They or Anyone' determines the possible ways that we can understand ourselves and make sense of things (Heidegger 1962: 126).

Being-with others affected each participant's way of life and also dominated their possibilities and way of being. Feelings of isolation, rejection, loneliness and vulnerability were fostered by the continual social rejection, stigma, and trivialisation, and questions of legitimisation primarily fostered by the invisibility of lupus. This discrediting communication had a lasting negative effect and completely demoralised the participants, damaging and compromising their self identity and sapping their limited resources and inner strength. It was a constant torment, which constrained everyday life, interactions with others and fostered an escalation in self-doubts, differences and 'unhomelikeness' being-in-the-world.

Lupus is one of those invisible unknown diseases which do not seem to enter official statistics in sufficient numbers and so do not receive

equality in care, social services and benefits (Dumit 2006). It is politically invisible. When knowledge about lupus is virtually unknown, services cannot interpret its invisibility and it is assumed that to look well is to be well. This brings several consequences for patients such as discrimination, issues with organisations and isolation. Lupus imposes barriers, through the invisibility and social ambiguity surrounding the disease and presents as physically, medically, socially and politically invisible.

Aspects of this study have been collaborated by Schattner et al (2008), Hatfield-Timajchy (2007), Goodman et al (2005), Mattsson et al (2012), Baker and Wiginton (1997), Archenholtz et al (1999), Beckerman (2011), Moses et al (2008), Waldron et al (2011), (2012) and McElhone et al (2010) who have related how difficult it was for other people to understand what it is like to have SLE. Mattje and Turato (2006) discussed how lupus was seen as something cloudy without a recognisable identity. This may be due to the condition being relatively rare and unknown within the Brazilian population. de Barros et al (2012) related how others lack of familiarity with the disease brought several consequences for patients such as isolation as they are thought to be contagious. Porter (2000) discussed that family and others who did not understand their symptoms were not much help with daily tasks.

Throughout the findings and discussion chapters the participants' narratives revealed a rich range of illness dimensions, perceptions and diversity of metaphoric constructions. Metaphors (indirect comparisons), similes (direct comparisons) or analogies (resemblances, parallels, and functional similarities) are an important means of explaining the complexities of their illness experience.

Some participants related the metaphors used in immunology, battle, and defending, recruiting, killing, and self destruction. For some participants it was difficult for them to come to terms with the paradox of 'their self' reacting to 'their self', which is easily construed as their body committing suicide or the idea of a body at war with itself, and this concept can evoke causal blame. This is increased and inflamed by the clinical and social ambiguity of lupus in which psychological factors may be unfairly brought forward by family, and friends which fuel existing feelings of guilt, blame or self-doubt. Hawkins (1999) discussed how being assaulted by illness and doing battle with it are components of a metaphor used for managing illness and this can be construed as reflecting an assault on, or violation of the person's former self.

Other participants followed more socially embedded metaphors and these may well keep those with lupus in existing culturally defined scenarios. Those with lupus cannot fail to notice the pictures on book covers, in the literature and web pages, of butterflies and the more sinister wolves. The participants' confusion was reinforced by having a disease named after the Latin for wolf and with one atypically associated with animal symbols. Three main metaphors that appear within lupus include the wolf, the monster Hydra and the butterfly. The butterfly means hope and the wolf a challenge to overcome this disease. These metaphors may assist participants to employ meaning, and fight and move forward. But, the older entrenched concepts linger and serve to increase the confusion and loneliness of patients.

Metaphors consistently emerge as the major vehicle for creating new meaning and can show us illness representations as well as making something visible that was not seen before. They embellish difficult concepts. For a disease, such as lupus, Hawkins (1999) relates that

these figurative expressions are an important means of translating the diverse complexities and subtleties of illness experience.

Examples of ways the participants conveyed their experience include a 'husk' all the important parts of their identity and self had gone; 'my flame is flickering and dying', 'I'm extinguished'. Others expressed instability; 'tightrope over an abyss waiting to fall', and 'shifting sand', or revert to battle images; 'stabbed by sharp spears' relating to the pain or the fear of annihilation, like 'a pebble being drowned'. The participants tried to convey the difficult concept of lupus generating the feeling of 'nothing', the underlying insecurity of the continual feeling of losing themselves.

Lupus brings uncertainty, and has set limitations and restrictions on their life, and they are running-out of possibilities. Heidegger (1978a) explains that this 'nothing' is a disintegration of everyday belonging, the total absence of significance. Anxiety is the most extreme form of the uncanny, a disintegration of background existential orientation. The uncanny comes from nothing and nowhere and means at the same time 'not-being-at-home' (Heidegger 1996:188, Svenaeus 2000:7).

Crofts and D'Cruz (1997) and Danoff-Burg and Freidberg (2009) reported that the vast majority of their patients acknowledged at least some unmet psychological needs relating to help dealing with fears about SLE getting worse, anxiety, stress or feeling down or depressed. Mattsson et al (2012:1) refers to the experience as 'multifaceted uncertainty'. This is a comprehensive term as it includes not only the physical aspects but also the emotions arising as a result, namely; anger, powerlessness, fear, sorrow and despair. These unseen emotions impinge on the participants' lives when they are attempting to work and live social and family life. Similar findings have

been found by Archenholtz et al (1999), Bauernfeind et al (2009), Mendelson (2006), Wiginton (1999) and Schattner et al (2010).

Within this study the participants' narratives reflect the sense of depression and sadness arising from a sense of self-being diminished by the loss of precious role identities. The participants' life roles were the foundations of their self and they still try to fulfil their roles of a parent, father, mother and wife. They have to reconstruct their lives around illness. At times they glimpse their former self, only for all it all to be taken away. Times of illness and times of relative health define their pursuits. All the participants gave compelling accounts of the devaluation of self, and their reduced roles in life. They related the complex situation which locked them into a spiral of self-being diminished as they suffered continual disruption in every aspect of their life and self.

Their lives became more restricted, and they experience discredited feelings, developing weakening bonds with others and heightened anxiety. The participants experience a fading away of their contributions to everyday life and to social interactions. Many participants were forced to stop working, and those who continued working part-time struggled with other aspects of their lives due to energy levels. Participants within Robinson et al's (2010) study commented upon their decline in activities of daily living over time. Similar results have been identified in studies carried out in the USA and Europe (Leong et al 2005, McElhone et al 2007, Laouri et al 2006, Katz et al 2008, Bauernfeind et al 2009).

Beckerman (2011) identified, that a major challenge of living with lupus was the diminution of role, resulting in a high vulnerability to depression. This was seen within this study's findings. When the structure of lives is disrupted, uncertainty will be experienced by all

family members (Horn et al 1995). This uncertainty is a continuous accomplishment with lupus, acting as a stress stimulus affecting the normal function of all concerned. The participants hated relying on others and watching them do the things they had always done. The loss of their role identities challenges their sense of identity, and their feelings of worth and value had declined (George 2009). The participants were deeply concerned with becoming a burden to others, particularly their children. When, as parents their roles should have been protective, they observed their children shouldering family responsibilities.   The sense of 'becoming a burden' is closely aligned with loss of hope, and despair at not being able to recapture positive images of the past. McElhone et al (2010), Wittmann et al (2009), Mendelson (2006), Goodman et al (2005) and Stamm et al (2007) have mentioned concerns about being a burden to the family.

Bray (1998) reported that the depressive symptoms may be symptoms of chronic sorrow, the emotional pain associated with losses and trying to live with a long term condition. Wachtel (1987) related that depression in females may be due to complex role strain. SLE affects the persons psychological health in a variety of ways, one of which (Perry 1987) terms 'chronic exacerbation' of difficulties carrying out their normal activities of daily life. Pain, fatigue and cognitive difficulties such as poor concentration can all affect competence in fulfilling tasks, thus damaging self-esteem. Karasz and Ouellette (1995) discussed how SLE patients are often advised to reduce their roles and activities during times of heightened disease severity in order to avoid stress. Yet in reducing roles the person can feel even more worthless, isolated and alone which can heighten their psychological distress.

Anecdotal accounts suggest that a high degree of emotional adjustment is required to adapt to SLE (Aladjem 1982, Lee 1986,

Regan-Gavin 1988). Potts (1992: ix-x) described her experience of SLE as a 'three-edged sword'. She explained that the first edge of the sword involved the acceptance of both physical and psychological aspects of the disease. Intermixed with the physical symptoms, of fatigue, and pain was the endless psychological blows. These included depression, fear, anxiety, loneliness, isolation and loss of self esteem through dependency on others. The second edge of the sword was society and how society seemed to accept some diseases but found it difficult to accept SLE. The third edge of the sword was the medical profession, and their perceptions.

Even with these multiple constraints and barriers, the participants have been able to overcome adversity and find ways of moving forward regaining resilience. They have used creative strategies and adapted, discovered new ways of doing things and developed a vast array of coping strategies. Slowly the participants came to accept that their care was dependent upon them, alone. Sooner or later, they had to discover coping methods which worked for them. The participants experience a long process of developing a different self. They sought information and learnt as much as they could, and acknowledged their body, listened to its signs and reactions and altering their everyday life accordingly. They established a new and worthwhile relationship with their body and had become experts in their embodied knowledge and understanding. They began to establish a new relation with their self and being-in-the-world and being-with. Their lupus self became more habitual. Building their personal routines restored some self-worth.

They worked hard to maintain a positive attitude and pushed themselves everyday to do as much as they could. They engaged in problem solving, and maintained optimism, using their mental strength and determination, to push on with daily life. Pettersson et al (2010) identified the importance of an optimistic attitude. Mattje and Turato

(2006) reported of patient's attempts to rebuild their relationship with their own strengths. Mattsson et al (2012) discussed how patients had learnt the importance of mental well being; they set priorities, and lived for the present moment.

The participants in this study were learning to live with what was possible in spite of their restrictions and accept themselves as they are in the present and their potential for living forward. The participants were able to transcend their determined circumstance in some sense. Heidegger (1962) discussed that the essence of a person is defined on an ongoing basis by how they live their lives. People choose among possibilities, their existence is always pointed towards the future as well as rooted in the present that is defined by the past. So, people choose among various but limited real possibilities. The essence of a person is continually invented and re-invent in the process of living their lives. So being human is always in process and never finished. This means a certain openness to the ways people respond and change in response to their journey's circumstance.

This study has explored the multiple ways the participants have felt constrained and stuck within their present situation, and the ways in which they were able to actualise their potential for living forward by achieving personal growth through adapting, coping and regaining resilience. To be able to help them regain a more homelike being-in-the-world these constraints need to be reduced.

9.1 Strength and limitations of the study

Within this section, I will be discussing the criteria for evaluation of the study and identifying some of the strengths and limitations. Guba and Lincoln (1996) suggest two sets of criteria to judge the quality of any

qualitative research investigation, trustworthiness and authenticity. Trustworthiness embraces the criteria of credibility, transferability and dependability, while authenticity can be understood as relating to the degree in which the research enhances growth, understanding and future action. These will assist me to highlight both the strengths and limitations within this study.

This comprehensive study asked 'what is it like to live with lupus' from the insider perspective in order to explore the meanings and interpretations people ascribe to it, to gain a deeper and fuller understanding of the lived experience of SLE. Throughout the study, I have aimed to give the participants a louder voice by attempting to reveal a glimpse of this lived experience.

One of the major strengths of this study was the response from the participants, who were all important. They committed wholeheartedly and shared their experiences willingly, eager to be involved in the variety of data collection methods. Their motive was altruistic, in the hope that knowledge of this disease and its effects could be increased and become more widespread.

The approach for this study allowed sensitivity and responsiveness, as well as maintaining methodological coherence. Through the audit trail I have discussed my choices and decisions clearly and honestly, including reflecting upon my pathway through the philosophical stances, my decision making process in regards to the approach and methods employed including the recruitment of participants, sample, data collection methods, ethical dimensions, analysis, reflexive process and presentation of the findings ensuring trustworthiness (Guba and Lincoln 1989).

I have also been flexible in my approach as the phenomenological method is shaped according to the intrinsic demands of the everyday world of the human being and requires creativity and flexibility, to allow the fullest possible illumination 'to the things themselves" to manifest (Husserl 1970a: 252).

The research methods I have used are well established. This study employed unstructured in-depth interviews, journals, art, music and photography. Audio-taped, unstructured, in-depth interviews were the main data collection method. The strength of the unstructured in-depth interview is the detailed contextual information it produces, which aids the understanding of the meanings of the participants. Due to its unstructured nature I was able to be open to the emerging new insights of the phenomenon, rather than bringing preconceived ideas or predetermined questions. The interviews allowed flexibility and had no time limits; it was entirely up to the participants. Multiple in-depth, unstructured interviews were carried out with the majority of participants and this allowed clarifications, greater depth, and the expression of new experiences.

Participants also chose a variety of methods journals, art; music and photography, that they felt they could best express their inner selves, their everyday world. Oiler (1982) related that, any artistic expression could be used as sources of experiences that have meaning for the person. An integrated approach was used which combined both a media of the participant's choice, such as photography with an in-depth unstructured interview discussing their media. Upon completion the majority of participants had multiple unstructured in-depth interviews discussing their media. There was no time constraint; it was entirely up to each interviewee.

Participants were encouraged to be in control of the audio-tape, the interview structure and process and where and what time they wanted to meet and the length of the interview. They decided which aspects of the methods of data collection they wanted to be involved in, if any. I encouraged their own creative ideas and they had a free hand to explore their experience in their own multiple ways. They decided where the interview would take place.

A major strength of this study has been these data collection methods. The participants voluntarily provided pictures, photographs, journals and music to facilitate the communication and expression of their experiences, which at times can be difficult to communicate solely through the spoken word. These have enabled the participants to describe their experience in new, varied and different ways and in more detail than, to the best of my knowledge has been previously captured in the lupus literature so far. The participants enjoyed using these various methods and developed folders of varied artwork, photographs and kept journals as a means of describing their experience. In using these methods, this study has build upon current knowledge of the methodology being utilised and pushed its boundaries further.

The data collection was carried out over a 17 to 18 month period, which was a reasonably prolonged engagement. Through my interaction and engagement with the participants I was able to develop trust and an intimate rapport aiding them to feel valued and engaged within the research process and this allowed them to share new and more sensitive experiences. During this time a total of 115 in-depth unstructured interviews were carried out.

Within the thesis I have explained my rationale and justification for choosing Wertz's (1983) method of analysis. Methodological

coherence was ensured as alternative data, such as photographs and art work could be utilized within the analysis. Sample analysis and procedures demonstrated Wertz's (1983) method of analysis which allowed the voices of participants to be heard, and allowed for variation. It focused on the individual, whilst exploring and eliciting the collective experience. The interpretations were supported by the evidence of participants' descriptions and maintainance of fidelity to the interview transcripts. This allowed readers the opportunity to follow and judge the soundness and rigour of the analysis and shows a clear audit trail.

My reflections incorporated within the analysis, added another layer of interpretation aiding transparency and openness. I acknowledged that the experience conveyed by the participants can change depending upon their particular perspectives within that time frame, and their interaction with me.

The interpretation of the visual images could be open to criticism of being subjective. However any medium can be viewed as unfinished insofar as it is a source of unfinished possibilities of meanings and interpretations. I am purely giving one interpretation and it is up to the reader to judge the validity and credibility of the interpretation. To overcome possible criticism a number of important steps were taken to ensure the transparency and openness in the study and these were discussed at length and in detail. With the presentation of the media are descriptions and direct quotes from participants. This provides readers with an opportunity to form their own interpretation and at the same time permits verification of the analysis presented.

One issue that emerged in this study was the amount of data produced and the analysis took over a year to complete. The sample size, together with the participants' enthusiastic responses led to a

formidable, comprehensive and challenging body of data. I have reflected in hindsight, whether a smaller sample would have sufficed and made analysis easier. However a smaller sample would not have provided all the insights that this study has shown, or the varied perspectives and experiences that emerged. Perhaps the issues I experienced were down to my own inexperience as a researcher, and my slowness with the analysis.

The use of a variety of methods (triangulation) enhanced the study's ability to check out bits of information and negative cases (van Maanen 1983). This can help compensate for their individual limitations and exploits their respective benefits. The variety of different media used, and descriptions from participants allowed me the opportunity to clarify, verify and elaborate, bringing to life the phenomenological experience. I was able to look for any inconsistencies or contradictions of the images with the other data collected, giving voice to differences, and allowing the voices of the participants to be heard.

One of the strengths of this study has been the reflexivity, which has been employed throughout the study to allow for a rigorously well grounded theory of the lived experience of SLE. Yes, it provided transparency and rigour, but more importantly it provided honesty. I understood that it would be impossible to separate and exclude my own experiences from the research study. Instead I had to acknowledge them, work with them and integrate them, being aware that they can potentially both inform and be intrusive to the whole research process (Rogers and Cowles 1993). I have discussed openly and transparently the processes, by which the data has been collected, analysed and presented.

Conformability and dependability can be established through my reflexive journal. This has been a key component aiding my ability to evaluate the study's progression, record thoughts, feelings and reflections after each interview, the techniques used, initial impressions of each data collection session, length of interviews, the patterns appearing, and thoughts generated. It helped me reflect on areas I was not sure about and at times could not see. With such a comprehensive body of data, there were exceptions to general themes, divergent patterns, and some statements were more evident in more than one case and were therefore general but not true in all cases. Difference in experiences was savoured and reflections about these were a challenge to deeper thought, but also an indicator of trustworthiness.

One reference in the reflexivity journal, discusses the analysis

'The analysis causes me endless searching and questioning. Wertz's analysis is complex, yet strangely supportive in its ability to assist my reflections on the experiences. But I continually question, could I do it better? Am I missing things? Or will it become spoiled, like a painting overworked that misses the essential phenomenon and becomes diluted by too much thought. My concerns centre on being able to do the participants experience justice. Perhaps I will learn to feel when it is right and no there is no 'right' or 'definitive answer'. But at this time, it fills my mind with questions and uncertainties'.

A reflection following an interview

'It's interesting how within each interview the person has begun their story expressing chaos, the chaos of no diagnosis, no reason, no meaning and no end. The emotional torment and harm this has caused goes with them. I wonder if health professionals understand

the significance of this time, and the destructive and detrimental affect it has had on their well being'.

The study has also discussed my background, personal and professional, the initial impetus for the research, my qualifications and experience and credibility. This is important because I am the person who is the major instrument of data collection and analysis and therefore my personal experiences and knowledge could unintentionally lead to biases (De Lyser 2001).

All the participants had the opportunity to have a copy of their transcript and have checked the accuracy of their transcripts (member checks), to confirm that is what they said, but also that their words match what they actually intended to say. They have also been involved in discussing emerging themes. This opened up additional insights, rather than validation as such which implies one truth.

Throughout the thesis I have provided sufficient detail of the context of the fieldwork for a reader to be able to decide whether the prevailing environment is similar to their situation and whether the findings can justifiably be applied to other setting. I have discussed the research design, methods, and reflexivity in detail, and this would allow another researcher to use the same methods, even if they do not gain the same results.

Within the findings and discussion chapter's thick detailed descriptions of the phenomenon are related to help convey the situation and the content. Without this it is difficult for the reader to judge whether the findings run true. The participants' everyday worlds including existential moments have produced rich data. The validity of these procedures was established by demonstrating their fidelity to the

phenomenon under study in its life-world presence, 'to the things themselves'.

The study has demonstrated the examination of previous findings, to assess the degree in which the present findings are congruent with past studies. The findings and discussion were presented in many forms with narratives, photographs, drawings and illustrations (Wertz 2005) and discussed in relation to their congruency with other lupus studies, the impact on the participants, and theoretical knowledge. The practical applications were discussed within chapter 10 the conclusion. The psychological general insights were extended further by relating the findings to the everyday life-world at large. This included recommendations for health services, and the development of care services and society.

I have been fortunate to have opportunities to discuss the study with colleagues, peers and academics. This has allowed others to challenge my assumptions, which has assisted me to stand back, view it from a distance, and think again. Feedback has resulted in different directions and thoughts and increased quality. Regular supervisory sessions, has allowed a sounding board for a full and open discussion regarding the research process, its development, possible issues and limitations, new ideas and changes in direction.

To ensure primarily the richness of experience and differing perspectives, a purposive sampling strategy was used which sought a varied and diverse sample of participants. This allowed multiple voices to be heard, differing experiences and a greater knowledge of the wider group. The purposive sampling in this study covered a wide range of variations except for the geographical area (Hampshire, Wiltshire, Surrey, Dorset, the Channel Islands and the Isle of Wight) and this is a limitation within this study.

As such the findings cannot be generalised across other regions. Another limitation within the study is that the sample was recruited from one source the Hampshire lupus circulation list. People, who sign up to receive lupus information, may not necessarily represent the lupus population as a whole. As all the participants were drawn from one lupus association, this may reflect a bias in terms of associated member characteristics which makes generalisations difficult. Members may either have higher levels of needs or in contrast may be more active and successful in seeking help. However, it should be noted that being a member of lupus UK means members receive a lupus magazine, but they will not necessarily attend a support group or participate in any other aspects.

9.2 Future research

Within the study the male participants showed differing experiences to the female participants in a number of areas, such as to medication, appointments, interactions with health professionals, perceptions and mental representations of lupus as well as coping skills employed. It would be very interesting to explore these and new areas further. There is a noticeable lack of research focusing purely on male experiences in lupus and this offers exciting future possibilities for further research.

An absorbing project would be to attempt to capture the experiences of this study's cohort in a longitudinal study, to gain further insight into experience and change over time and the development of coping skills. A longitudinal study may elicit patterns of change.

The use of the varied media, artwork, photography, music to help the expression of experiences is an interesting area which needs far more research. It offers existing possibilities for helping patients to describe

and covey their experiences to health professionals, and others offering further insights into the meaning of the condition and their world.

These media, artwork, photography can offer people ways to express their experiences which often remain locked within because they are too difficult to express. This could open up further research to see how effective this is to help people find meaning and move forward in their lives.

This study has collected a wealth and depth of information, both verbal through interviews, visual through artwork, photographs and sound through music on the experience of living with lupus. Although this study has given important insights into the experience of living with lupus, it feels as if I have only given 'a small touch of the toe in the water', due to the limitations of a thesis. The large amount of material collected reveals fascinating aspects, undercurrents of differing themes and discrepancies that must be explored further and this has potential for further research.

Representations of lupus and autoimmunity through visual methods and metaphors would offer interesting research. The representations of lupus found in this study were interesting because of the diversity in the ways people visually and metaphorically perceived the condition. This can uncover further aspects about this lived experience.

9.3 The disengagement with participants

From the start of this study including planning, access to participants, the first meeting, and interviewing, I carefully considered both the engagement and the disengagement process. For me these run in

parallel and need to be worked on simultaneously throughout the whole data collection phase.

Throughout the multiple interviews I tried to facilitate a warm interpersonal connection that aided the participants to feel valued, included, respected, important and in control. I used myself to establish connectedness, sensitivity, openness, empathy, and warmth and this helped them feel able to express their experiences in their own way and in their own time. Through the interviews a close connection was developed and this is important for being able to gain 'deep in-depth data' which is what a researcher is after. However, it is equally important that I have been preparing them for the end of this interaction and that for them the disengagement process is managed successfully.

To achieve this I had been gently preparing them by reiterating some of the more formal aspects of the research study and our interactions. Throughout I have thanked them for their help and the valuable contribution they have made, as well as discussing and reflecting on their feelings about the interview process, the other data collection methods and their involvement in the study.

The participants were all prepared for their last interview, and after this each of them was sent a personal letter and a thank you card wishing them well in the future. They were all aware that on the completion of this study I would send them a concise version of the findings. The study will also be written up for the lupus UK magazine, which they all have access to.

Following disengagement, some of the participants have written and sent e-mails. I have always responded, but have never opened up the

possibility of further interactions. I have made my responses caring, yet formal and have always wished them well in their future.

Throughout my journey being-with the participants, I experienced their humour and have felt their pain, confusion, lost hopes and possibilities, as well as their determination, strength, and resilience. Their honesty, and openness, has been amazing. After each interview, I have asked them how they felt about the interview, and whether there was anything I could have done better. Many of the participants fed back.

Meg felt,

"It's very therapeutic to be able to talk about it cathartic really.... and I have never shared those things with anyone before, it does bring back lots of strong memories the diagnosis and that... but I feel it's really helped me" (Pg 55, 1179-1183, T 8.1)

Michael related,

"I'm not very good at talking about things, to be honest; I find it hard. And I've never done anything like this before. I thought I wouldn't be able to do it, you know, you would stop, say that's no good, or not be interested like everybody else, but no, I did it, I actually did it. I mean that was a first for me, I've been talking and talking for hours, I've never talked that much....It was strangely calming" (Pg 43, 845-847, T5.1)

The other data collection methods evoked lots of feedback. Phoebe related,

"I have loved doing this it's given me a real purpose and I will carry on. It's been really cathartic, I have been able to say how I feel for the first time and that's wonderful, it's a relief because it's been impossible...and I can and that's been really important for me" (Pg 57, 1090-1097, T 12. 3)

A theme that runs through all their feedback was one of being able to express what they have not been able to express before. This had been possible because they found a method which aided and suited their own individual preferences. It was a chance for them to convey what this experience was like, and what it meant to them. They shared deep aspects that had remained hidden, protected and shut away and rather than being silent they had a voice and were not being ignored. The experience was seen as cathartic, calming, sense making and a way to release what remained in side in silence yet bubbling away. They enjoyed being given the chance to talk and share their experiences with someone who was interested, who listened, acknowledged them and did not criticise, judge, or tell them what their experience was like.

They appreciated my flexibility, changing appointments to suit them, they liked being in charge of the Audi-tape equipment and having the media, art books, pens, colouring items, cameras to work with. They liked coming up with their own ideas, and finding something that worked for them using their own creativity. Many produced files and journals recording aspects and experiences that were important to them. Many will continue with this as it has given them an interest, a purpose and is something they can develop.

These visual, word and sound media can constitute ways of being-in-the-world in multiple contexts and can offer insights and understandings into the person's lived experiences that may in some

instances resist linguistic expression (Pink 2007). Heidegger (2002) recognised that art could reveal that which could not otherwise be revealed. He wrote that 'art brings forth possibilities of existence that could not be understood and established in any other way' (Heidegger 2002: 38-39). Klee (1968:296) believed that art makes visible not just that it shows us to see, but there is another role, to perceive things which had not been revealed. 'It attunes us in a different way' (Klee 1968:296).

The participant's art, music, photography, lets what is revealed by the art develop and expand. It lets us see things in a completely different way, a way we had never thought about and conveys these experiences in all their brute meaning. These aspects have generated new meaning and opened up new possibilities beyond the existing meaning, they are an ever unfolding possibility of meaning which expresses originality.

The next chapter is the conclusion and this will discuss the empirical findings and the recommendations and dissemination plan.

10.0 Chapter 10 - Conclusion

The main findings are chapter specific and were summarized within the respective chapters, self-doubt and doubt, entrapment and coping and regaining resilience. This section will synthesize the empirical findings to answer the study's research question and discuss the recommendations and dissemination plan.

This study affirms that lupus is a 'nothing disease', for most, physically unseen, politically neglected, socially unknown, doubted and discredited. Yet, it is manifestly evident that the lived experience of lupus is one of existential uncertainty. An underlying theme running through the findings is of the participants feeling like 'nothing'. It is interesting that outsiders could possible identify lupus as a nothing disease and that the participants themselves, regarded their condition as being 'nothing'.

For the participants' lupus engenders the sense of nothing being safe, certain or secure, caused by the unpredictable course of the disease, the uncontrollable changes and the myriad of symptoms. The anxiety and uncertainty accentuates this feeling of nothingness. The participants struggled with their own self doubts and those of others and they contend with pain, flares, instability, autoimmunity, heredity fears, family tensions, misunderstandings and the inability to plan. Continuous fatigue brought the feeling of never being connected, belonging or fully alive. Their energy is continually drained until they are left with nothing and are in a sense powerless. The lived experience revealed that everything has changed and their world is unfamiliar, chaos and nothingness as their relationship to self; being-with and being-in-the-world has changed. They live with the threat of increased illness, disability, limitations and the loss of present and future possibilities and they fear how much of themselves would be

left. They are living with an unknown entity and as such are left in a very precarious position. They know they can fall at any time and there is nothing they can do to change the situation. They are embodied in a body that is a threat and they perceived being cut off from being in the world, being-with and the possibility of nothing. The existential anxiety they experience is immense and this gives rise to a feeling of losing themselves.

Lupus can present a daunting challenge to psychological coping. The uncertainty and unknown course of their SLE was a constant source of anxiety and depression. They needed support and understanding to help them with underlying existential needs relating to their fears about SLE getting worse, anxiety and stress. But, underlying existential concerns were rarely addressed by health professionals. This increased underlying anxieties in relation to their condition and treatment.

The participants wanted to be involved in the health interaction, learn how to live and cope with lupus and regain more control over their own health situation. Health interactions were not offering up any possibilities of strategies or support for them to be able to implement changes in their life. Health professionals were holding the participants back and making their experience even more difficult and disempowering.

Due to society's common 'expectations about how sickness and health should be represented' (Napier 2003: 86) as well as lupus being relatively unknown, it is important that understandings about this disease is increased. There is a wide gap which needs to be bridged between those without the disease and those that live in a parallel universe with lupus. Family and friends can offer vital support for everyday life and coping with lupus and they need to be actively

involved and have information that would increase their understanding of the disease. Organisations such as the benefits agency need information and help to understand this condition and the needs of those with SLE. Many of the participants struggled to convey their experience and felt it was easier to say nothing. Lupus patients need support to feel more confident in interactions with others and feel they are able to ask others for support.

Past experiences of health interactions were not buried or forgotten by the participants; they were raw, full of brute meaning and significance and could emerge with vehemence. The majority of participants in this study had endured a long and psychologically distressing journey characterised by uncertainty, chaos, frustration, insecurity and for many suffering, before eventually securing a diagnosis. Most participants reported encountering disrespectful, discrediting and distressing healthcare communications. Power and control were important aspects throughout this time in which collaboration and support was not present, resulting in alienation, powerlessness and a loss of sense of control over their lives. An important area identified in this study has been throughout this time the participants had searched for a closure but were unable to find it, which in itself was a further cruelty they had to negotiate. These pre-diagnosis experiences can have a huge impact on how patients understand and manage their lupus and affects their future interactions with health professionals. Patients need to be managed sympathetically and should be supported by health services.

After a long and anxious pre-diagnosis, many of the participants had lost trust in their medical care. The majority of participants at diagnosis were left with just a name 'SLE' which made no sense and was meaninglessness. They were confused and received no understanding or explanation to aid their understanding. Due to time

constraints and the manner in which the diagnosis was delivered, underlying existential concerns about what it meant, and the possible future course of the disease could never be addressed. They were faced with a struggle to gain comprehension themselves.

Diagnosis offers a window of opportunity that offers possibilities for building long term relationships of trust, and respect and acknowledging their embodied experience. Health professionals must be attentive to the patient's narrative as well as develop attunement between patient and the health practitioner. If this window of opportunity is missed it will affect how patients adjust to their diagnosis and the future management of their lupus.

Health systems severely restrict the time available for establishing a relationship and patients are then left to try and figure it out for themselves. As such it is necessary to challenge the conventional care models and build on the elements that hold potential to set patients on a suitable course of action. Professionals can show the patient the way home, back from an uncanny experience by having time to involve the patient in a dialogue about what it means. Professionals need to listen to their patient's story and help them create meaning from their experience. They need to offer reassurance and explain the roles the patient and the professional will play throughout this journey. Good communication involves health care professionals working with the patient to regain control and empower them to develop their expertise by offering individual care plans, guidance and management strategies.

The study has identified numerous aspects which negatively impacts on the participant's everyday world and if those with lupus are to be helped to gain a more home-like being-in-the-world then these constraints need to be diminished. This would open possible ways for

assisting those with lupus to be able to move forward and progress and has real implications for the development of health care delivery which is person centred, designed around real needs and enables an improved quality of life.

Over time, most participants with determination and courage pioneered their personal means of coping. It was a lonely struggle, where specific healthcare would have eased their way. The participants increased their knowledge and understanding and slowly learnt to interpret what their body was telling them.

The development of the participants' embodied knowledge was vital for assisting them to feel more in control and better equipped to adapt and regulate their activities, medication and lifestyle. This is not surprising considering the unpredictability of lupus and the limitations the lupus body can impose upon the lives of the participants. Embodied knowledge is therefore an extremely important resource within lupus which should be embraced and used. Patients should be encouraged to learn, listen, become sensitive to, and trust their bodily experience.

The NHS has commendable aspirations for person-centred care, but for lupus, this individual care planning provision seems to be lacking. This study has revealed the many barriers, towards a better life faced by those with lupus. If some or all were removed, their condition and quality of life could be much improved. Understanding by others, increased public knowledge, more healthcare interaction and political support are aims for the future. The concern is whether lupus will become more invisible with health services striving for more efficiency, achieving targets and the reducing NHS economy.

10.1 Introduction to recommendations

One of the aims of this study was to discover findings which may assist in making evidence-based recommendations to improve services and change health care delivery. From this study the understandings about the lived experience of lupus can assist in devising person-centred approaches with interventions tailored around real needs rather than assumed needs, to improve quality of life. Numerous recommendations were identified from the findings and this section will be discussing some of the recommendations for practice.

10.2 Recommendations for practice

Listening to the person: One of the most important things identified throughout the findings is that health care professionals need to give people time to talk about their experience. Health services must be attentive to the patient's narrative of their lupus experience and the person's life. Services need to be attuned to the person's narrative of the illness experience. Health professionals need to give space to the voice of the everyday life world (Barry et al 2001). Services need to understand what lupus means to the individual person, what is important to them, and what makes a significant difference to their lives.

Given the impressive challenges presented by lupus, health care providers must listen and learn from their patients and have a greater understand of their individual needs to help them facilitate coping skills necessitated by this debilitating disease. They must engage with patients and communicate.

Pre-diagnosis experiences: The pre-diagnosis experiences of those with lupus can have a huge impact on how they understand, accept

and manage their condition. It is vital that health professionals have a greater understanding of the patients experience during this pre-diagnosis time and listen to their narratives. In the absence of a diagnosis, patients need to be managed sympathetically and should be supported by health services.

General practitioners need to have more understanding and awareness of lupus and its possible indications. They need to learn from the patient and use this experiential knowledge in clinical practice rather than relying purely on the medical objective measures and should refer on to specialists sooner. This is important because SLE can be a real challenge to diagnose. The medical profession need to consider the reclassification of lupus and make it less restrictive, perhaps following Hughes's (1997) example of creativity and scope for lateral thinking.

Diagnosis experiences: Diagnosis is a pivotal moment that offers possibilities for building a long term relationship of trust, and respect. Relationship building should be a high priority in the healthcare delivery system through all interactions.

During the diagnosis consultation patients need to be given the information they need. Health professionals should explain the diagnosis clearly, and give people enough time to be able to explore and address existential concerns.

Health professionals need to work with the patient and assist them to develop their own expertise, offering individual person centred plans, guidance and management strategies. Professionals need to help show the patient the way back home, from an uncanny experience.

There is a need for more information so that patients can understand clearly what lupus and autoimmunity is. This needs to be in a variety of formats to assist people's own individual learning styles. Patients need detailed information and the person needs to be able to obtain the information at the right time for them and for their own individual needs. Patients also need to be supported by professionals at whatever point in time they are needed so concerns and questions can be answered.

Healthcare communication: Time constraints severely restrict the establishment of health interactions. As such it is important to challenge the normal care models and build on the elements that hold potential to set patients on a suitable course of action. Patients need a consistent approach, with patients being actively involved, and health professionals should listen, offer encouragement, and work with the person to enable control over their situation. They need to provide care which is person centred and help signpost patients to other services. Health professionals should help develop the patient's expertise and offer individual care plans, guidance and management strategies. Health care professionals need to acknowledge the patient's expertise with regard to their own situation. Lupus challenges health professionals to empower patients by acknowledging their embodied experiences. There needs to be more understanding that patients may have to travel a long distance to attend their appointments and may experience increased uncertainty. This needs to be acknowledged during the interactions. Patients need more flexibility with the times of their appointment. Clinics should have telephone contact, so patients can speak to a nurse and have immediate concerns addressed. It is important patients learn about infections and have things in place to reduce anxieties, rather than isolate themselves in fear of getting ill.

<u>Interactions with general practitioners</u>: There needs to be better access to services when needed such as quicker appointment times when there is a change in the person's condition, or they have an infection. More contact through phone or e-mail reducing unnecessary journeys and appointments. There needs to be a better system for managing prescriptions and day to day things, such as results from blood tests. This would reduce the amount of stress on the person who feels they have to cope, monitor and organise everything, which places extra burdens on them. The GP needs to talk to patients and identify simple solutions to these issues, and this would have a huge beneficial effect on their everyday life, and reduce ongoing stress.

There needs to be better communication between consultants and GP's so that changes in medication, treatment or the need to refer to other services is communicated. Health professionals need to acknowledge and understand the ongoing uncertainty those with lupus experience about illness and flares.

<u>Support to learn and develop coping strategies</u>: During appointments daily life and coping strategies should be discussed regularly. Communication that facilitates problem solving and the development of self care management competencies is vital. There needs to be better information and sign posting to others services, such as occupational therapists, physiotherapist, psychologists, orthotics who can provide support and help patients develop their own strategies and management, such developing coping strategies Mothers need support to build up coping strategies so they can manage their children.

Health professionals must engage with patients in finding solutions to their challenges. They must offer support and guidance along the way so that patients can develop their own expertise by discovering their

responses to symptom patterns, learning to detect, monitoring, interpreting bodily cues, and creating effective internalised problem solving strategies. They need individual plans, which work for them not just general advice they cannot use.

Developing self management strategies and learning ways of coping can open up new possibilities. For example access to equipment could make a real positive difference to a person's quality of life. It can open up new opportunities, offer the person increased privacy, dignity, independence, and freedom. This helps to re-gain independence and increase quality of life.

It would be valuable to ask those with lupus who have lots of experience to be involved in developing information about all the things they have learnt to assist them to cope with lupus for those newly diagnosed. This could be designed offering multiple solutions and possibilities as 'one hat does not fit all'. This may also let those newly diagnosed see that there is a way forward, giving them hope and a picture of what could be.

Patients need advice and information on meaningful activities that can give them purpose and the opportunity to have control, be creative, make choices, judgements, and to make friendships, which are all important in giving a sense of meaning in life. Having things to do which are meaningful can fill life with purpose and this gives a sense of movement in life.

Lupus patients have no social model of the disease to refer to when describing their experience to others. They need support in ways of communicating their condition to others so that others can understand. Organisations such as the benefit agencies, and social services need to have a better understanding of lupus. It is important

for those with lupus that they are supported to continue to work if they want to. They require flexibility and employers need to understand the condition. Family and friends need to be provided with more information and be actively involved throughout (if the patient wants them to be) so that they have a better understanding of lupus and can support the person in positive ways.

10.3 Dissemination:

There are a number of things I have to consider when thinking about a plan for dissemination. I need to think about what my goals are for dissemination? What am I trying to communicate? What impact do I want it to have? Who will be my audience? Who is affected by this research? Who would be interested in learning? And who needs to hear this message?

I need to be able to transmit usable knowledge to appropriate audiences including health practitioners, the public, policy makers, organisations, family and friends and those with the experience themselves in such a way that encourages them to use that knowledge and information. Dissemination can be through any means including power point presentations using pictures, videos, photographs, words, pictures and music. I also need to think who can assist me, networking the right people, and who has the expertise to help me to develop presentations such as DVD's, power-points and films.

10.4 Initial proposed dissemination thoughts and plan

I need to disseminate the research findings to the participants. The participants are aware that when this study has been completed they would receive a shortened version of the results. The process of

writing this report will help me summarise the work clearly and provide an accessible document that can be circulated more widely.

The study's findings need to be disseminated and discussed with Lupus UK who gave me assistance in gaining access to the participants. This can be done in various ways.

Meeting the chair person and discussing a way forward for dissemination. Involving Lupus UK would be advantageous because they have contacts and connections which would aid the dissemination of the findings in wider circles. I will also be able to get feedback from those with the experience, and it would be interesting to find out what they think about the study, and in what ways they feel the findings should be disseminated.

Articles can be written for the lupus UK magazine which has an audience made of those with the experience, family and friends, health practitioners, and the public. I need to carefully consider this audience and what the main message will be. I need to access training on how to present information, and build my presentations skills.

Presentations at Lupus UK support groups and conferences where the information will be targeted to those with the experience, family and friends and health professionals.

For targeting health professionals the lupus conferences would be good and there are professional based conferences. Information can be disseminated through presentations, stands or small group discussions. Emphasis can be placed on specific messages such as interactions with patients and discussions on the meaning and application of finding can be facilitated in small groups.

There are also the usual routes of journal publications and academic conferences. I am hoping that I can make contact with other researchers who will have experience in writing publications and may want to jointly write a paper so I can learn from them.

An area which I am interested in is developing multi-media presentations. I feel these can be very powerful, especially if someone with the experience can be present as well to talk about aspects.

Staff development, education and training can be facilitated through using power points and DVD's with pictures, music and describing the experiences. These are powerful ways to help health professionals gain a deeper understanding of the experience aiding reflection and discussion.

Multi-media presentations can be used in numerous ways to different audiences, such as ways of conveying the experience to family and friends to increase their understanding of the experience and the importance of offering the right support.

GP surgeries can be targeted with findings relevant to their setting through information, power points and videos. Health facilitators can aid me in this project as they have good connections and access to GP surgeries and know the right people to be introduced to.

I think the media aspects of this study have great potential in helping with the dissemination of the findings. Building up contacts with colleges may assist as they may help with film making, or putting presentations together as they will have the technology.

I also need to consider how to evaluate the dissemination process, and what has changed if anything and is it making a difference.

Finally, the aim of this study has not been a quest for a 'true' answer, or to solve a problem. It was purely attempting to make visible something that was not previously seen, by offering a deeper insight and an alternative viewpoint. To achieve this required vividness, emotional connection, and empathy through illumination, imagination and recognition and, an 'untiring effort and sensitive grasp of being itself' (van Manen 1990:132).

I am offering to the reader a tentative elucidation of aspects of the everyday world of lupus, and opening up a field of possible interpretations. These interpretations allow a further deeper understanding of the lived experience of SLE from the insider perspective.

The descriptions are powerful and have the potential to move others, encouraging the connection to evolve between the reader and the insider's story both emotionally and empathically within the journey. These descriptions of the holistic perspective allows us as human beings to intuitively share in the phenomenon described, drawing us in to their world. This can have implications for person centred health care, changing people's views and ways of working, improving and changing health care delivery. It can provide evidence based recommendations.

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Appendices

Appendix 1.

Lupus Criteria

To assist distinguishing lupus from other diseases, physicians of the American College of Rheumatology have established a list of 11 criteria which when combined, point to lupus. To make a diagnosis of lupus the patient must have at least four of these 11 criteria at any time since the onset of the disease.

Specific Symptoms

1) **MALAR RASH** – Fixed red rash over the cheeks
2) **DISCOID RASH** – Red patches of skin associated with scaling and plugging of the hair follicles
3) **PHOTOSENSITIVITY** – Rash after exposure to sunlight
4) **ORAL ULCERS** – Small sores that occur in mucosal lining of mouth and nose
5) **SEROSITIS** – Inflammation of the delicate tissues covering internal organs, and abdominal pain
6) **ARTHRITIS** – Very common in lupus, usually pain in the joints and tendons
7) **RENAL DISORDERS** – Usually detected by routine blood and urine analysis
8) **NEUROLOGICAL DISORDERS** – Seizures or psychosis, balance problems
9) **HAEMOTOLOGICAL DISORDER** – Haemolytic Anaemia, Leukopenia, Thrombocytopenia, Lymphopenia
10) **IMMUNOLOGIC DISORDER** – Tests anti-DNA, anti-SM antibodies, antiphospholipid antibodies
11) **ANTI-NUCLEAR ANTIBODY** (ANA TEST) – When found in the blood and the patient is not taking drugs, it is known to

cause a positive test for lupus in most cases, but it is not necessarily conclusive

The above criteria were laid down by the ACR in 1982. Dr Graham Hughes (St. Thomas' Hospital, London) has since come up with an alternative list of criteria, the St Thomas' 14 Criteria for the Diagnosis of Lupus.

THE ST THOMAS' 14 CRITERIA FOR THE DIAGNOSIS OF LUPUS

The American Rheumatism Association criteria have provided the benchmark for the classification of lupus for the last 20 years. Many thousands of lupus patients passing through St Thomas' Hospital, London, have led Dr Graham Hughes to offer the following 14 criteria aimed more toward <u>diagnostic</u> help and not to classification (as ACR criteria).

1. Teenage "growing pains"
Growing pains in the UK is a label widely used for joint pains in teenagers and seems to cover a spectrum of rheumatology from arthritis through to lupus.

2. Teenage migraine
Headache, cluster headache and migraine can be encountered and a strong history of teenage migraine may be of lupus significance, either at the time or subsequently.

3. Teenage "glandular fever"
Prolonged teenage glandular fever is a label which crops up time and time again in lupus patients and prolonged periods off school in many SLE patients is a recurrent theme.

4. Severe reaction to insect bites

This is a feature of so many lupus patients. Not only are they susceptible to insect bites but often reactions are severe and prolonged - the skin is a major organ affected by lupus.

5. Recurrent miscarriages

Lupus itself seems not to be a cause of recurrent miscarriage but where the antiphospholipid syndrome (APS) is present, recurrent spontaneous foetal loss can be significant.

6. Premenstrual tension

Although difficult to quantify, it is believed that significant pre-menstrual disease flare is sufficiently prominent in lupus to be included in this list. All rheumatic diseases are clinically influenced by the menstrual cycle.

7. Septrin (and sulphonamide allergy)

Adverse reactions to these drugs are quite common in lupus and the clinical onset of the disease may have coincided with the use of e.g. Septrin.

8. Agoraphobia

Agoraphobia/claustrophobia are often present at a time when lupus disease is active. A history of these conditions (including panic attacks), can be protracted, lasting for months or even years. In many cases the history is not volunteered or the episodes are in the interim considered unrelated to lupus.

9. Finger Flexor Tendonitis

Arthralgia and tenosynovitis are common features in lupus and although not specific, the finding of mild to moderate ten-finger flexor synovitis is a useful pointer in the presence of other lupus features. It

is subtly yet significantly different in pattern from other arthritic diseases.

10. Family history of autoimmune disease

As the genetics and statistics of the various autoimmune diseases become better defined, the strength of a particular family history will become more precise. The family history is important, as lupus is genetically determined (although not 100% concordant as with, for example, genetic diseases which are always passed on e.g. haemophilia).

11. Dry Shirmer's Test

A "bone dry" Shirmer's Test (levels of eye moisture) points towards one of the autoimmune diseases and in the patient with vague or nonspecific symptoms is worth its weight in gold.

12. Borderline C4

Genetic complement deficiencies have been known to be associated with lupus for over three decades and in the diagnostically difficult patient, especially where a family history is present, borderline C4 levels can be significant indicators.

13. Normal CRP with raised ESR

An important diagnostic aid is a very low CRP in an otherwise inflammatory situation. It is strongly supportive of lupus or primary Sjögren's Syndrome.

14. Lymphopenia

In the patient with non-specific complaints and unremarkable blood tests, a borderline or low lymph count can be overlooked. It can be common in lupus and is certainly worth inclusion among minor criteria.

Dr. Graham R.V. Hughes MD FRCP (Source: Lupus UK News & Views, summer 1998, Number 55. This paper was presented at the XVIII ILAR Meeting, Singapore, June, 1997 printed in Clinical and Experimental Rheumatology 1998).

Diagnosis of Lupus

LUPUS is a complex disease in which almost every system of the body can be affected, and DIAGNOSIS is bases on a combination of symptoms, signs and test results. Diagnosis of LUPUS may be established using the 5 step programme.

1) Review patient symptoms

2) Detailed physical examination

3) Battery of tests

4) Rule out other diseases

5) Time is sometimes necessary to observe the course of the disease

The individual has clinical evidence of a multisystem disease and several manifestations these could include:
1) Skin - Rashes, mouth ulcers, hair loss
2) Joints – Pain, redness and swelling
3) Kidney – Abnormal Urinanalysis
4) Lining membrane –Pleurisy, Peritonitis, Pericarditis
5) Blood – Leukopenia, Haemolytic Anaemia
6) Lungs –Cough, Shortness of breath
7) Nervous System – Psychosis, Convulsions

Symptoms of lupus can fall into two categories, Non- specific and specific. The specific criteria have already been discussed under

Lupus Criteria.

Non- specific Symptoms include:

1) Fatigue
2) Weight loss
3) Weight gain – as a result of organ involvement
4) Fever
5) Swollen Glands

Additional problems could include high blood pressure, vasculitis, and increase in hair loss, Raynaud's phenomenon, headaches and miscarriage.

Examination of the immune system and the patients' clinical history

What blood tests are done to help diagnose Lupus?

Full Blood Count (FBC) - Detects anaemia, low platelets, low white blood cells

Creatinine and electrolytes - Measures the salts in the blood and gives an idea of kidney function

Liver function tests - Includes measurement of liver enzymes (indicator of liver cell damage). Measures albumin (marker of kidney problem with leakage of the proteins)

ESR (Erythrocyte Sedimentation Rate) - A marker of non-specific inflammation, tends to be raised in lupus

CRP (C-reactive protein) - Another inflammatory marker, but this does NOT usually go up in Lupus

Urine - Measure protein and blood cells in urine (should be none). Identify 'casts' (blobs of protein escaped from the bloodstream because the kidneys are leaky)

<u>Blood clotting tests</u> - Tell how 'sticky' the blood is. Includes 'lupus anti-coagulant'

<u>Immunological tests</u>

Appendix 2 Characteristic of the included studies

Author/ year/	Archenholtz et al (1999)
Country	Sweden
Focus/ Participants experience explored	Domains of importance and dissatisfaction. The study aim was to determine what aspects of life Swedish females with SLE and RA found to be, most important to their quality of life, what they were most dissatisfied with and whether they perceived a change in the quality of life in the last year.
Research design	Qualitative
Sample	Fifty participants (females) with SLE and fifty participants (females) with RA were chosen from a register of a large university hospital in Gothenburg Sweden. The study was after a diverse sample, with a wide range of disease severity, age range (20-70 years), disease duration (1year- plus), social status and treatment status.
Method	One open-ended telephone interview using five open-ended questions including: what does quality of life mean to you? What things are most important to your quality of life?
Analysis	Content analysis

Author/ year/	Auerbach and Beckerman (2011)
Country	USA
Focus/ Participants experience explored	To identify and clarify the unique psychosocial challenges for those living with lupus.
Research design	Cross sectional study
Sample	Three hundred and seventy-eight respondents (96.5% were females and 3.5% were males). Age range from 20-60 plus, diagnosed with lupus from 0-5 years plus. The sample included various ethnical backgrounds including Hispanic (37.7%) African American (40.2%) and Asian (4.7%).
Method	Survey consisting of four parts: Part 1 sought demographic information such as gender, age. Part 2: consisted of the Systemic Lupus Erythematosus Needs Questionnaire (SLENQ) which uses a 5 point scale for 12 different psychosocial factors. Part 3: The Multidimensional Health Locus of Control Scale which measured the participant's beliefs about how much control they have over their SLE, and Part 4 open-ended questions about participants range of medication regimes. Once completed the survey was posted back to the researcher.
Analysis	Quantitative analysis for frequencies and correlations.

Author/ year/	Baker and Wiginton (1997)
Country	USA
Focus/ Participants experience explored	Illness experiences. To determine if the participants develop common-sense representations of lupus and evaluate the impact of these on their self-reported coping with lupus.
Research design	Qualitative
Sample	A convenience sample of thirty-eight participants (females) was recruited from formal and informal lupus-support group networks in Oklahoma and North Texas. Age range from 18-75 years; years since diagnosis from 0-29. The sample included varied ethnic backgrounds including (5.3%) African-American, (5.5%) Hispanic, (2.6%) Native American and (2.6%) Multiracial.
Method	A structured interview for 30 to 40 minute with open-ended questions followed by probes to explore participant's perceptions of causes, mechanisms and consequences of lupus. Questions included: what are the physical feelings you have that let you know you are in a flare? Would you describe your lupus as acute, episodic or chronic? How do you think having lupus has affected your life? A written questionnaire with open-ended questions exploring length of time since initial diagnosis, symptom status and demographic information.
Analysis	Systematic coding of interview transcripts

Author/ year/	Beckerman (2011)
Country	USA
Focus/ Participants experience explored	Psychosocial experiences, challenges and needs.
Research design	Qualitative study
Sample	The study employed a convenience sample of thirty-two participants, (29 females and 3 males) from several rheumatology clinics in the United States. The sample included participants from varied ethnic backgrounds including, Hispanic and African American Length of time since diagnosis ranged from less than 2 years to 5 years plus.
Method	Focus groups with an interview guide. Each participant was in one focus group session.

In each group participants were asked to respond to a series of general open ended questions such as: what are the biggest challenges to living with lupus? How has lupus affected your mood? |
| Analysis | Thematic analysis |

Author/ year/	Bray (1998)
Country	Canada
Focus/ Participants experience explored	The fatigue experience.
Research design	A descriptive design
Sample	A convenience sample of twenty-five participants (24 females and 1 male) with an age range 16-71 years, were recruited from a hospital in Ontario and from the Ontario lupus group association.
Method	Interviews and questionnaires. Questionnaire included: demographic information, and assessment scales including: the Perceived Quality of Life Index; The sensory subscale of the Piper Fatigue Scale (1989) and the mental subscale of Wessley and Powell's (1989) 14-items Fatigue Scale; Emotional fatigue was measured using a 24-item questionnaire; The Centre for Epidemiological Studies Depression Scale; A modified version of the Mishel Uncertainty in Illness Scale (Mishel 1981, 1989); The Self-Administered Systemic Lupus Activity Measure (SA-SLAM). General fatigue was assessed using a 10-point rating scale that asked participants to describe the severity of their fatigue when it was at its worst and when it was at its best.
Analysis	Statistical Package for the social sciences

Author/ year/	Chambers et al (2009)
Country	UK
Focus/ Participants experience explored	The study explored the reasons why patients with lupus did or did not take their medication as prescribed.
Research design	Qualitative
Sample	Three hundred and fifteen patients were invited to participate in the study by completing a screening questionnaire. Participants were asked if they would be willing to participate in a semi-structured interview to discuss their medications. A purposive sample of thirty-one participants (3 males and 28 females), with an age range of 19-70, years, from varied ethnic backgrounds including Indo-Asian.
Method	Thirty-three participants had a face to face interview following an interview protocol: Each interview lasted 60 minutes. Questions covered: demographics, lupus background, medications and beliefs and practices.
Analysis	Framework analysis, using familiarisation, thematic analysis, indexing, charting and mapping interpretations.

Author/ year/	Danoff-Burg and Freidberg (2009)
Country	USA
Focus/ Participants experience explored	To assess unmet needs of patients with SLE.
Research design	A descriptive, cross-sectional, survey
Sample	One hundred and twelve participants of whom (95%) were females with an average age of 50.1 years. The participants had varied ethnic backgrounds including African American (11.6%), Hispanic (5.4%), Native American (1.8%), and Multi-Racial (2.7%).
Method	Participants (n=112) were recruited through the lupus mailing list of America and a lupus support group meeting. Participants were invited to complete a survey designed to ascertain service needs of people with SLE. The 75-item questionnaire was a modified version of the SLE needs questionnaire (SLENQ). This uses a 5-point scale (1=not applicable, 2= already satisfied, 3= low need, 4=moderate need, 5=high need) participants indicated their level of need for help during the past 6 months with various issues within the following domains, physical symptoms, activities of daily living, psychological/existential, social support, health services, health information and employment/ financial.
Analysis	Stepwise logistic regression analysis

Author/ year/	de Barros et al (2012)
Country	Brazil
Focus/ Participants experience explored	How SLE has affected patients and their lives
Research design	Qualitative, phenomenological existential approach
Sample	A convenience sample of twelve participants (females) between the ages of 15- 40 years.
Method	Semi-structured interview asking the question 'How is it for you to have lupus?' Interviews lasted between 11 to 30 minutes and were carried out by the same psychologist.
Analysis	Phenomenological existential approach.

Author/ year/	Druley et al (1997)
Country	USA
Focus/ Participants experience explored	Emotional and physical intimacy in coping with lupus
Research design	Not stated
Sample	Seventy-four participants (females) recruited through the lupus foundation of America. Participants mean age 42.8 years, (8%) were African American, (4%) Hispanic or American Indian.
Method	Participants were sent a questionnaire asking for information about age, symptoms, and episodes as well as: emotional intimacy behaviour; emotional-intimacy disruptive behaviour; physical intimacy behaviour; psychological well-being; relationship satisfaction; episode severity; the internal health locus control and questions about general levels of disclosure.
Analysis	Hierarchical multiple regression analysis

Author/ year/	Goodman et al (2005)
Country	Australia
Focus/ Participants experience explored	Illness representations.
Research design	Phenomenology
Sample	Thirty-six participants (4 male and 32 females)
Method	Face to face semi-structured interview. Interview questions covered five domains of the illness representations stage of the self-regulatory model, including, identity, cause, consequences, time line and cure or control. Questions included: identity: what do you call your problem? Causes: I'd like to hear your ideas about what you believe caused your problem. Consequences: How do you think having SLE has affected your life? Time line: Would you describe your SLE as acute, episodic or chronic? Control/ cure: What things do you do to handle your SLE? Additional questions were added to obtain information about how those representations had changed over time. Face to face interview lasted between 45 minutes to 2 hours.
Analysis	Interpretive phenomenological analysis

Author/ year/	Hale et al (2006)
Country	UK
Focus/ Participants experience explored	To examine the perceptions of patients health care provision in the UK.
Research design	Phenomenology
Sample	Ten participants (females) were recruited from two sources within the Dudley Group of Hospitals NHS Trust. Five were recruited from the Lupus UK Drop-in Clinic, and five were recruited from outpatients' appointments. Age range from 26-68 years, and diagnosed with lupus from 1 -12 years.
Method	Semi-structured interview undertaken by one researcher, lasting from one to two hours. A semi-structured interview schedule was employed to allow flexibility and probing of issues that arose.
Analysis	Interpretive phenomenological analysis

Author/ year/	Hale et al (2006)
Country	UK
Focus/ Participants experience explored	Concerns about appearance
Research design	Phenomenology
Sample	Ten participants (females) age range from 26-68 years and time since diagnosis 1-12 years.
Method	Face to face semi-structured interview
Analysis	Interpretive phenomenological analysis

Author/ year/	Hatfield-Timajchy (2007)
Country	USA
Focus/ Participants experience explored	The factors that contribute to the delay in diagnosis
Research design	Anthropological cross-sectional study from 2000-2004 using quantitative and qualitative methods.
Sample	Forty-two participants (females), 20 with an African-American background, with an age range from 29-63 years.
Method	Open ended interview lasting from 45 minutes to 1 hour; observations at support group meeting; document review; disease activity measures; demographic details and medical details; psychological measures of coping style; social support; pain, and trust in physicians. The structured questionnaire included questions about education, age, disability, depression, anxiety, current medications, illness severity, and length of time leading up to diagnosis and a checklist of symptoms. Two case studies drawn from overall sample were interviewed multiple times over a 6 month to 1 year.
Analysis	Content analysis

Author/ year/	Jolly (2005)
Country	USA
Focus/ Participants experience explored	A comparison of health related quality of life (HRQOL) of patients with SLE with other common chronic illnesses.
Research design	Not stated
Sample	Ninety patients from a rheumatology clinic, (82 female and 8 males), (71%) had African American background and (10%) were of varied ethnic backgrounds, mean age 40, mean disease duration 10 years.
Method	Researchers used the lupus database at the University of Chicago, (which contains self-administered Medical Outcomes Study Short Form-36 questionnaire data), to analyse responses from 90 SLE patients followed in a rheumatology outpatient clinic. The self-administered Medical Outcomes Study Short Form-36 questionnaires were analysed. Comparative norms and domain scores for patients with other chronic diseases (hypertension, congestive heart failure (CHF), adult onset diabetes mellitus, myocardial infarction and depression) were used and are based on the general US population.
Analysis	T tests were used to make comparisons.

Author/ year/	Jones (2003)
Country	USA
Focus/ Participants experience explored	The experience of depression and anxiety
Research design	Phenomenological interpretive design.
Sample	Eight participants (females) aged 45-68 years, diagnosed with SLE for 2-13 years. Participants were recruited from the lupus foundation of Alaska. The inclusion criteria included a diagnosis of SLE, and a history of depressive or anxious symptoms.
Method	Face to face interview. Questions included: How long ago did a health care provider tell you that you had SLE? Would you like to describe your experience with depression or anxiety since you were diagnosed with SLE? During the second part of the interview demographic information about the participants was collected including, age, years of education and household income.
Analysis	Interpretive descriptive process

Author/ year/	Karasz and Ouellette (1995)
Country	USA
Focus/ Participants experience explored	Role strain and psychological well being
Research design	Cross-sectional
Sample	Sixty-four participants (females) all assessed as having SLE, average age 36, age of symptom onset ranged from 8-59 years, various ethnic backgrounds including (17.2%) African American, (14.1%) Hispanic and (7.8%) Asian. All recruited from a large hospital specialising in rheumatic diseases.
Method	Date collection was by three ways: a formal diagnostic assessment of disease severity completed by the patient's doctor; the disease severity SLE-Activity measure (SLAM); the demoralization scale to measure levels of general psychological distress; the Centre for Epidemiological Studies Depression Scale (CES-D); role strain using role dysfunction scales: a structured interview and a self administered questionnaire completed after the interview.
Analysis	Cross-sectional analysis

Author/ year/	Kumar et al (2011)
Country	UK
Focus/ Participants experience explored	To investigate factors that influence beliefs about medicines in patients of South Asian origin with SLE and RA.
Research design	Qualitative methodology
Sample	Hospital clinical databases were used to identify potential patients who fulfilled ACR criteria and had been taking Disease Modifying Anti-Rheumatic Drugs (DMARD) for more than three months prior to the study and had been diagnosed for 6 or more months. The sample included thirty-two participants (31 females and 1 male), 14 SLE and 18 RA participants with an age range of 44-55 years.
Method	Participants participated in focus groups (4 SLE focus groups= 2 in Punjabi or Urdu, and 2 in English) all focus groups took part at a hospital site lasting one or two hours. Open ended questions were used to encourage patients to talk and generate discussion regarding their perceptions about their medicines.
Analysis	Not identified: the data was searched for similar words, patterns and themes.

Author/ year/	Mattje and Turato (2006)
Country	Brazil
Focus/ Participants experience explored	To identify and interpret the meanings of becoming ill, and adaptation mechanisms in lupus.
Research design	Qualitative
Sample	Five participants (4 females and 1 male)
Method	Semi-structured interview with open-ended questions at a lupus outpatient department.
Analysis	Content analysis

Author/ year/	Mattsson et al (2012)
Country	Sweden
Focus/ Participants experience explored	How patients experience SLE in their everyday lives including both negative and positive aspects.
Research design	Qualitative
Sample	Nineteen participants (3 male, 16 female), age range from 27-80 and 7-34 years since diagnosis.
Method	Focus groups interviews, each participant participated in one focus group, interviews lasted from 1-1½ hours. The interview started with a general question 'how has your experience of the SLE influenced you?' Then included opened ended questions such as, how has the disease influenced your body? Has there been anything in the environment or concerning yourself that has hindered / facilitated your everyday life?
Analysis	Interviews were analysed using content analysis (Elo and Kyngas 2008).

Author/ year/	McElhone et al (2010)
Country	UK
Focus/ Participants experience explored	To understand the patient's perspective about having SLE and how the disease has impacted upon their life, both positively and / or negatively.
Research design	Interpretive phenomenological approach
Sample	Thirty participants (female) were recruited from the rheumatology service at Blackburn Royal Infirmary, age range (21-75 years), SLE duration (1-28 years), and ethnic backgrounds (south Asians).
Method	Each participant had one semi-structured interview at home or at the hospital. Questions included: how has having SLE impacted on your life, are there any positive aspects that make your life more enjoyable? Other areas included: Prognosis, course of the disease, pregnancy, effects of treatment, effects on family life, body image, difficulty concentrating/ memory, socialising/ worry about infections, physical and emotional aspects.
Analysis	Interpretive phenomenological analysis

Author/ year/	Mendelson (2006)
Country	USA
Focus/ Participants experience explored	Daily experiences of living and managing lupus
Research design	Ethnographic and informed by a feminist perspective.
Sample	Sample 1: Seven participants (females), with an age range from 23-59 years, recruited from the local Mexican community with the aid of the American Lupus Foundation, (50%) had African American, Hispanic, and Asian American backgrounds. Sample 2: Twenty-three participants (females) recruited from online lupus listservs and bulletin boards from USA, Australia, UK, and Ireland.
Method	Sample 1: participated in 3 audio-taped, in-depth interviews, over 2 months and kept a daily symptom journal. A demographic questionnaire, medication inventory and a 1 year retrospective symptoms inventory were completed. Sample 2: participated in narratives via e-mail and completed a demographic questionnaire, medical inventory and a 12-month retrospective inventory of medical and treatment options.
Analysis	Immersions and crystallisation

Author/ year/	Mendelson (2009)
Country	USA
Focus/ Participants experience explored	Diagnosis experiences
Research design	Ethnography, a narrative approach and informed by a feminist perspective.
Sample	Twenty-three participants (all females) were recruited from online lupus listservs and bulletin boards from USA, Australia, UK and Ireland. The participant's age, ranged from 18-57 years, years since diagnosis ranged from 2-22 years and the number of years to get diagnosed was from 1-47 years.
Method	Participant's narratives via e-mail. Participants were asked to provide in writing the story of their experiences with lupus from the time they knew they were sick through the diagnosis process to the present. A demographic questionnaire, medical inventory and a 12-month retrospective inventory of medical and treatment options.
Analysis	Immersion and crystallization

Author/ year/	Moses et al (2008)
Country	Australia
Focus/ Participants experience explored	Unmet needs over time of patients with SLE
Research design	A descriptive, prospective, longitudinal study
Sample	Three hundred and eighty-six participants (28 males and 357 females) with a mean age of 52.9 years and time since diagnosis 11.4 years.
Method	An information letter and survey was sent to 594 members of the lupus association of New South Wales Australia. Each person was asked to complete the survey and if they would be willing to complete a survey again in 6 months. Measures: The SLE Needs Questionnaire (SLENQ) involves the completion of 97 items, each of which requires the participant to indicate the extent and magnitude of support needed in the previous 6 months using a 5-point scale. The SLENQ addresses 7 domains of care needs: psychological/ spiritual/ existential; health services; health information; physical; social support; daily living issues, and employment / financial. Symptoms: The survey sought participants self reported experiences (yes/no) of seven commonly experienced symptoms (joint ache, skin rash, fatigue, mouth ulcers, muscle pain, hair loss and weight loss) in the previous 6 months. Symptoms were selected based on consultation with local SLE specialist and review of the literature. Demographical information was sought.
Analysis	Statistical calculations

Author/ year/	Nowicka-Sauer (2007)
Country	Poland
Focus/ Participants experience explored	Illness perceptions and experiences
Research design	Qualitative
Sample	Thirty-eight participants (females)
Method	Drawings. Thirty-eight participants with SLE attending psychological sessions of 'my life' courses were asked to draw their disease with no time limits. Every person had the same colours to choose. The participants were ensured that their drawing abilities had no meaning. Participants were also asked to comment on their pictures.
Analysis	Analysis of the disease was from the participants as well as psychologists.

Author/ year/	Pettersson et al (2010)
Country	Sweden
Focus/ Participants experience explored	Experience of SLE-related fatigue, the impact on daily life and strategies developed to manage fatigue in daily living.
Research design	Descriptive qualitative methodology
Sample	Thirty-three participants (all female) age range 25-70 years, diagnosed for at least 2 years
Method	Data to assess fatigue and health related quality of life (HRQOL) was collected from each person at inclusion into the study. These two self assessment questionnaires, the Short Form-36 (SF-36) and Multidimensional Assessment of Fatigue (MAF) were completed again following the focus group discussion. Focus group discussions with a researcher-generated interview guide containing open ended questions including: Can you describe the feeling of fatigue? How does it affect daily living?
Analysis	Content analysis

Author/ year/	Pettersson et al (2012)
Country	Sweden
Focus/ Participants experience explored	To explore the most distressing symptoms of SLE and determine how these relate to health-related quality of life (HRQOL), anxiety/ depression, demographics and disease characteristics.
Research design	Mixed approach
Sample	Three hundred and twenty-four participants (30 males and 294 females) with an age range of 18-84, and disease duration from 0-58 years.
Method	Written answers to open ended questions. Participants completed self assessment measures of Health Related Quality of Life (HRQoL), including Medical Outcomes Study Short-Form 36, the Hospital Anxiety and depression scale.

These self assessments were followed by a physical examination, assessment of disease manifestations, activity and organ damage, all of which was performed by a rheumatologist. |
| Analysis | Inductive analysis |

Author/ year/	Porter (2000)
Country	USA
Focus/ Participants experience explored	The effects of lupus on daily experiences, to determine how debilitating and disabling lupus could be during its most active stages.
Research design	Grounded theory approach.
Sample	Twelve participants (females). Participants were recruited from Illinois, Tennessee, Missouri and Mississippi with the help of the lupus foundation of America.
Method	In-depth, standardized, open-ended interviews were conducted with twelve participants. Each participant had two interviews in their home. An interview guide was used focusing on: physical leisure activity, employment experience, family/ doctor and effect on previous family tasks.
Analysis	Thematic coding

Author/ year/	Rennegarbe (2002)
Country	USA
Focus/ Participants experience explored	To understand the methods used by rural women with SLE to explain and define their chronic disease process.
Research design	A qualitative study using a combination of phenomenological, narrative and life history approaches
Sample	Twenty participants (females), with an age range of 20-57 years, and a disease duration from 1-32 years.
Method	In-depth telephone interview using a semi-structured format. Questions included, What is the first thing that comes to your mind when you think about SLE? What things do you do specifically to control your lupus?
Analysis	A combination of phenomenological, narrative and life history approach was employed for analysis and thematic coding.

Author/ year/	Robinson et al (2010)
Country	USA
Focus/ Participants experience explored	The life experiences of SLE patients and its impact on health, family and work.
Research design	Phenomenology, mixed approach
Sample	A convenience sample of thirty-three patients (6 men and 27 females) was recruited from a private rheumatology practice, California. <u>Focus groups</u>: 23 participants mean age of 43 years and mean disease duration of 8 years, (83%) were female, with three had Hispanic backgrounds. <u>Face-to-face interviews</u> with 10 SLE patients, with a mean age of 42 years and mean disease duration of 7 years, (80%) were females.
Method	Focus group, patient endorsement questionnaire and face to face interview. <u>Step 1</u>: A narrative literature search which supported the creation of a patient questionnaire for use in step 2 of this study. <u>Step 2: Focus groups</u>: one or two 90 minute focus group with open-ended questions including: what are the disease-based signs and symptoms? How do they impact on daily life? The endorsement questionnaire was administered at the conclusion of the focus group. <u>Step 3: Face-to-face interviews</u> explored: 1) health issues that had been identified by the focus groups, 2) additional disease-driven health issues that may exist 3) perceptions of an accurate recall period.
Analysis	Key words in context and word count analysis documented the frequency of disease issues.

Author/ year/	Sansom (2010)
Country	UK
Focus/ Participants experience explored	To explore the experiences of care, doctor/patient relationship and the management of those with lupus.
Research design	Discourse analytic approach
Sample	Fifteen participants (females), two had ethnic backgrounds, age range 20-80 years. Participants were recruited from the Lupus UK national magazine.
Method	Narrative task. The study requested a story to explore how participants told their lupus stories. The narrative task was to, 'tell me your lupus story. You might like to talk about your care, your identity before and after the illness, your relationship with doctors, how lupus might be better managed in your opinion'. Thirteen e-mailed and two hand written stories.
Analysis	Iterative process for categorising and coding data

Author/ year/	Schattner et al (2008)
Country	Israel
Focus/ Participants experience explored	The impact of SLE on personality and the ways in which SLE affects the inner lives of sufferers.
Research design	Phenomenological
Sample	Fifteen participants (females) with a mean age of 45.67 years. Average duration of SLE 16.4 years. First and second generation immigrants from North Africa and Asia
Method	Open ended face to face interview lasting between 40-70 minutes. Illness narratives were elicited through five questions presented to participants. The main questions included: Can you describe in detail what it means for you to have lupus? What are the main changes the illness caused in your life?
Analysis	Thematic analysis following Giorgi (1975) method

Author/ year/	Schattner et al (2010)
Country	Israel
Focus/ Participants experience explored	Illness-related and personality-related aspects of SLE depression.
Research design	Longitudinal study
Sample	Thirty participants (females). Participants mean age was 40.8 and the average duration of SLE was 15.5 years. Participants came from diverse socioeconomic backgrounds.
Method	Questionnaires were administered within the participant's home, and this was repeated after several months. Questionnaires included: The SLE Disease Activity Index (SLEDAI); the Depressive Experiences Questionnaire (DEQ); the Centre for Epidemiological Studies-Depression Scale (CES-D); the illness Intrusiveness Rating Scale (IIRS) (measures the extent to which chronic illness and/ or treatment interferes with routines, activities and interests); and the Patient Reactions Assessment (PRA). The Illness-Related Interpersonal Relationships was assessed by the researcher asking participants about the extent to which illness-related information was shared or concealed from significant others.
Analysis	Descriptive regression analysis

Author/ year/	Seawell and Danoff-Burg (2005)
Country	USA
Focus/ Participants experience explored	Body image and sexuality in lupus
Research design	Not stated, Questionnaires
Sample	Fifty-four participants with SLE (females), age range from 22-75 years, (91%) were European Americans, (6%) were African American, and (3%) were Asian Americans. A comparison sample was obtained by asking SLE participants to invite a similarly aged friend to participate anonymously in the study. Twenty-nine healthy participants (females).
Method	Questionnaires regarding the study were sent to one hundred twenty-six females listed in the database of the New York lupus foundation of America. Fifty-four participants returned the questionnaires. The questionnaire sought demographic and illness related information. The measures included: a Visual Analogue Scale to measure pain; a Fatigue Severity Scale (FSS); The Centre for Epidemiological Studies Depression Scale (CES-D); a Health Assessment Questionnaire; a Sexual Dissatisfaction Scale, and the Multidimensional Body Self-Relations Questionnaire-Appearance Subscales (MBSRQ-AS).
Analysis	Means and Standard deviation analysed

Author/ year/	Shortall et al (1995)
Country	UK
Focus/ Participants experience explored	The importance of psychosocial factors in understanding mood and psychological distress in individuals with SLE.
Research design	Cross-sectional study
Sample	Eighty participants (76 females and 4 males), age range 18-72 years, with a disease duration of 1-37 years.
Method	Questionnaires and assessment. The questionnaire was designed with 28 of the most frequently cited problems for SLE. Open questions included: what was the most difficult aspect of having SLE? Questions also asked about stress, restrictions in life, daily life activities and roles. Participants had a scale rating from 'very much, quite a lot, somewhat, a little, and not at all'. The assessments included, the Hospital Anxiety and Depression Questionnaire, the Functional Limitations Profile (FLP), The Self Esteem Inventory, Neuropsychological Assessments, The British Isles lupus Assessment Groups Index (BILAG) which measures disease activity, blood tests.
Analysis	Hierarchical multiple regression analyses

Author/ year/	Stamm et al (2007)
Country	Austria
Focus/ Participants experience explored	To explore concepts important to SLE patients
Research design	Qualitative
Sample	Twenty-one participants (1 male and 20 female), an age range from 20-66 and 2-30 years since diagnosis. The sampling strategy sought maximum variation based on disease duration, organ involvement, and age group.
Method	Focus groups. On average 4-5 individuals participated in each the focus group. Questions included: 1) which limitations/ restrictions of activities were significant, 2) which environmental factors and 4) personal factors were barriers or facilitators. The focus group sessions lasted between 11-78 minutes.
Analysis	Meaning condensation. The concepts in the meaning units were extracted and linked to the International Classification of Functioning, Disability and Health (ICF).

Author/ year/	Stockl (2007)
Country	UK
Focus/ Participants experience explored	The impact of diagnostic delays on those with SLE.
Research design	Ethnographic observations in combination with grounded theory methods
Sample	Thirty participants (28 female and 2 males) referred by a rheumatologist.
Method	Semi-structured interview. Questions included: how did you decide there was something wrong? Which strategy of help seeking did you employ? Observations of lupus self-help group meetings and debates on the internet with SLE mailing lists.
Analysis	Eclectic approach combining grounded theory with discourse analysis

Author/ year/	Taieb et al (2010)
Country	France
Focus/ Participants experience explored	Patients beliefs about the causes of SLE
Research design	Interpretive phenomenology
Sample	Thirty three participants (female), from varying ethnical backgrounds including Caribbean; Algeria; Sub-Saharan Africa; Morocco. Age range from 15-65 years, and time since diagnosis 0-26 years.
Method	Face to face semi-structured interview, conducted by a psychiatrist lasting 2-3 hours at Avicenne hospital. The explanatory model framework developed by Kleinman (1980) helped to construct the schedule which contained the questions: what do you call your problem? Could you give me a brief history of your illness? What do you think caused your illness?
Analysis	Interpretive phenomenological analysis

Author/ year/	Waldron and Brown (2007)
Country	UK
Focus/ Participants experience explored	The impact of uncertainty for lupus patients between onset of symptoms and diagnosis.
Research design	Qualitative study
Sample	Ten participants. Purposive sampling was used to include both recently diagnosed patients and those who had been diagnosed for many years.
Method	Participants took part in a face to face interview to explore the experience of onset of symptoms and diagnosis.
Analysis	Content analysis

Author/ year/	Waldron et al (2011)
Country	UK
Focus/ Participants experience explored	Information needs of patients newly diagnosed, so an education package can be designed
Research design	Grounded theory
Sample	Purposive sampling identified forty-three participants (40 females, 3 males), some newly diagnosed, and others were diagnosed for some time, with an age range from 20-70 years.
Method	Eight focus groups in seven rheumatology centres in the UK, each participant attended one focus group for an hour. A semi-structured interview schedule was used that was compiled following a literature review. Disease severity was assessed by visual analogue scores and clinicians completed a disease activity index assessment.
Analysis	Thematic inductive analysis

Author/ year/	Waldron et al (2012)
Country	UK
Focus/ Participants experience explored	The experience between onset of symptoms and receiving a diagnosis and the perceptions of receiving a diagnosis
Research design	Grounded theory
Sample	Forty-three participants (40 females and 3 men). Same as Waldron et al (2011).
Method	Focus groups. Same as Waldron et al (2011).
Analysis	Thematic inductive analysis.

Author/ year/	Whitehead and Williams (2001)
Country	UK
Focus/ Participants experience explored	Exploring the experience of medical treatment for patients.
Research design	Qualitative and quantitative
Sample	Participants were recruited through advertisements in specialist clinics, and publications. Forty-five participants (females), 7 participants had ethnic backgrounds, age range 26-55 years.
Method	Postal questionnaire which explored participant's experiences of treatment and the significance of patient consultation. The questionnaire collected both quantitative and qualitative data. Participants were asked to describe particular aspects of their experiences of medical treatment, including 'best' and 'worst' experience of being treated.
Analysis	Content analysis

Author/ year/	Wiginton (1999)
Country	USA
Focus/ Participants experience explored	Perspectives on SLE. The study explored: 1) What personal concepts and relationships do participants use to explain living with lupus? 2) Would there be significant differences in concepts and overall cognitive maps when categorized by disease duration, age and disease status?
Research design	Self-Q techniques
Sample	A convenience sample of twenty participants (females), two had an African American background; age range 27-60 years, 10 participants had been diagnosed with lupus for at least 5 years, and 10 had been diagnosed with lupus for no more than 2 years.
Method	Interview and concept maps. A modified version of the Self-Q technique was used to derive cognitive maps of participants with the investigator interviewing each participant. The interview lasted approximately 30-60 minutes.
Analysis	Each map was individually analysed for qualitative information. Quantitative analysis was performed on certain data groups, demographic characteristics, including disease duration, and self-reported indication of active disease was analysed using descriptive statistics.

Author/ year/	Wittmann et al (2009)
Country	Switzerland
Focus/ Participants experience explored	To enhance understanding of suffering in SLE
Research design	Qualitative and quantitative
Sample	Twelve participants (females), age range 30-69, disease duration from onset of symptoms 2-35 years
Method	Semi-structured interview (average 94 minutes) focusing on the subjective experience of suffering and self-perceived changes due to illness. Participants were asked open questions, followed up by specific questions. The first part of the interview focused on illness. The questions specified domains of health, social, professional, emotional life and self-perceptions and goals. Subjects were asked what they understood by the term suffering. How do you behave when you are suffering? Then asked which aspects of the illness cause you to suffer? The assessments of suffering included: 1) PRISM (pictorial representation of illness and self measure) (Buchi et al 2002, 1998), 2) the Sense of Coherence Scale (SOC) (Antonovsky 1993); 3) The Posttraumatic Growth Inventory (PTGI) (Tedeschi and Calhoun 1996); 4) Health Related Quality of Life (HRQOL), the Short-Form (SF-36); 5) Clinical and laboratory investigations including SLICC/ACR (Systemic Lupus International Collaborating Clinic/American College of Rheumatology) Damage Score and the BILAG (British isles Lupus Assessment Groups Disease Activity Index) and laboratory Investigations.
Analysis	Content analysis

Appendix 3 Ethics Approval

University Research Ethics Committee

Headington Campus, Gipsy Lane, Headington, Oxford OX3 0BP UK
t. +44 (0)1865 483484
ethics@brookes.ac.uk
www.brookes.ac.uk/res/ethics

Mr Lindsay Coombes (Director of Studies)
Dr. Helen Aveyard (Second Supervisor)
School of the Health and Social Care
Marston Road Site
Oxford Brookes University

7th July 2009

Dear Mr Lindsay Coombes and Dr. Helen Aveyard

UREC Registration No: 090416:
"An interpretative phenomenological exploration of the lived experience of systemic lupus erythematosus"
PhD study Ms. Fran LLoyd

Thank you for your letter of the 26th June 2009 outlining your response to the points raised in my previous letter for the above study and attaching the revised documents.

I am pleased to inform you that, on this basis, I have given Chair's Approval for the study to begin.

The UREC approval period for this study is two years from the date of this letter, so the 7th July 2011. If you need the approval to be extended please do contact me nearer the time of expiry.

In order to monitor studies approved by the University Research Ethics Committee, we will ask you to provide a (very brief) report on the conduct and conclusions of the study in a year's time. If the study is completed in less than a year, could you please contact me and I will send you the appropriate guidelines for the report.

Thank you for your kind comments about how positive you have found the UREC feedback in respect of your PhD ethical approval. I will pass those on to committee members who always find it so useful to know that you have found the process constructive and facilitating.

It just remains for me to wish you all the best with the research,

Yours sincerely

Dr Elizabeth T Hurren

Chair of the University Research Ethics Committee

cc Fran Lloyd
   Hazel Abbott
   Jill Organ, Graduate Office
   Louise Wood

Appendix 4 Invitation letter for Group members

<div align="right">

Oxford Brookes University
School of Health and Social Care
Jack Straws Lane
Marston
Oxford
OX3 0FL
7 September 2009

</div>

Dear Lupus Group member,

      I am writing to you to ask if you would be able to assist me with a research study. I am a part-time research student at Oxford Brookes University School of Health and Social Care and an occupational therapist.

My research study will seek to explore what it is like to live with lupus. I am asking for your participation as you are a member of Lupus UK and live with lupus.

Your input would involve one or more, interviews with me, 'Fran', at your convenience. The interview would last about one to two hours. All information would be strictly confidential, and you could withdraw at any time and without giving a reason. Your present medical treatment would not be affected.

The enclosed participation information sheets, explains the research study in more detail. You are under no obligation to take part. If after reading the information sheets, you are interested in participating in this study, or you would like more information about the study before deciding, please do contact me.
My details are: Fran Lloyd, phone: 07920700237
Address: c/o Fran Lloyd, Bridge Centre, New Road, Basingstoke, Hants RG21 7PJ.
E-mail: 07132799@brookes.ac.uk
Alternatively you can post the reply slip to me, I have enclosed a stamp and self addressed envelope for this purpose.

I would be delighted to talk to you about this study or answer any questions you may have relating to it.

Thank you very much for taking the time to read the invitation letter and information sheet, I hope that you may be interested in participating and I look forward to hearing from you.

Yours sincerely

Fran Lloyd, Research Student   Lindsey Coombes Research Supervisor

Appendix. 5 Participation Information Sheet

Participant information sheet

Oxford Brookes University
School of Health and Social Care
Jack Straws Lane
Marston
Oxford
OX3 0FL

Miss Fran Lloyd Research Student: Contact detail: 07920700237
Mr Lindsey Coombes BA, MA PGCEA RMN RGN Research
Supervisor

Title: 'An interpretive phenomenological exploration of the lived
experience of systemic lupus erythematosus'.

Researcher: Fran Lloyd.
**This study will explore the lived experience of lupus and will be
asking 'what is it like to live with lupus?'**

You are being invited to take part in a research study. Before you
decide whether or not to take part, it is important for you to understand
why the research is being done and what it would involve. Please take
time to read the following information carefully and discuss it with
friends, relatives and your GP if you wish. Please contact me if there
is anything that is not clear or if you would like some more information.
Take time to decide whether or not you wish to take part. Whatever
you decide, the care and treatment you are currently receiving will not
be affected. My full contact details are at the end of this sheet. Thank
you for reading this.

What is the Purpose of this study?
To increase insight into 'what is it like to live with lupus?' from the
perspective of 'you', the person who has lupus. This research study is
about gaining a deeper insight and understanding of an area which
has received limited attention and little is understood. Your
involvement would be over a few months. The overall study should
take around four years to complete.

Why have I been asked to take part?
The Chair of your support group, has kindly agreed to disseminate this
information on my behalf via Lupus UK. I am approaching you
because you have the experience of living with lupus. Around sixteen
people would be involved.

Do I have to take part?
It is up to you to decide whether or not to take part. Your involvement is voluntary. If you decide to take part you would be given this information sheet and would be asked to sign a consent form. If you decide to take part, you are free to withdraw consent at any time, without giving a reason and to withdraw any data previously supplied prior to analysis. This study would not affect any care that you may be receiving at this time or in the future. It is possible that I might not be able to interview everyone that volunteers to be involved because participants would be selected according to their lupus profile and to enable me to recruit a varied sample of people.

What would happen to me if I take part?
You would be asked to talk to me, Fran, in an interview for about one to two hours. The interview would be at your home or an alternative venue of your choice. You would be interviewed at least once. Further interviews may be needed for me to hear more about your experiences but this is unlikely to be more than two further interviews. Although, I would have some questions I would like to ask you, I am interested in what you have to say and would be led by what you tell me.

The interview would be audio-taped so that I can record accurately what you tell me and later listen to what you have said. You would also be asked to keep a weekly journal of one important experience that you may have had during the week, related to your living with lupus. This could be about a visit, or how your day was, something that is important to you that you would like to share with me. I would ask you to do this over a few months. I would also ask you to draw or photograph what lupus means to you. This could be anything that you feel describes your experience, such as photos of your life, important things to you, or a picture of how you see lupus. I would provide you with the necessary equipment to do this. Talking about these photos/ pictures help me gain a deeper understanding of your experiences.

What are the possible benefits of taking part?
This study would not provide any extra benefits in relation to treatment you are currently receiving although it would be an opportunity for you to express your feelings about life with lupus. However, it may provide a deeper understanding and insight into an area that has received limited attention and it may help health professionals, family, friends and the general public to gain a deeper understanding of lupus.

Would my taking part in this study be kept confidential?
All information collected about you during the course of the research would be kept confidential and will be kept securely. Your name and those of any others you talk about will be removed, so that you cannot be recognised. On completion of the research study all data and

paperwork generated will be stored securely for a period up to five years at Oxford Brookes University after which it will be destroyed.

What would happen to the results of the research study?
You would not be identified in any of the research results. I will give you a copy of the interview transcript, either typed or in tape form. I will also supply you with an outline of the results of this research study when I have finished. I will tell you if the research is published and how to get hold of any articles. I will return the diaries, photographs or drawings to you on completion of the study.

Who has reviewed this study?
This research has been reviewed by the Research Ethics Committee at Oxford Brookes University. If you have any concerns regarding the conduct of the research please contact:-
The Chair of the University Research Ethics Committee, Oxford Brookes University, Headington Campus, Gipsy Lane, Oxford, OX30BP or e-mail: ethics@brookes.ac.uk

Thank you very much for reading this information. Please contact me if you are interested or would like to talk to me further about this study. You can contact me, 'Fran Lloyd' by sending the Reply slip to me (self addressed envelope and stamp are included). Or you can phone me 07920700237.

Fran Lloyd.

....

A self addressed envelope and stamp are included.

Reply slip

To: Fran Lloyd.
c/o Bridge Centre
New Road
Basingstoke
Hants
RG21 7PJ

It would be very helpful if you could give me some basic information:

I am interested in talking to you further about this study:

Name:

Contact number/ address:

The best time to contact me is ....

How long have you been diagnosed with Lupus?........................Years

Did a rheumatologist diagnose your lupus?   YES

NO   **please tick one**

Please could you tick your age group?

23 to 35   36 to 45   46 to 55   56

to 65.   Years of age

Please could you tick which sex you are?   Male   /   Female

Please could you state your ethnic background?

....

Thank you for your help and I hope to speak to you soon.

Fran Lloyd.

Appendix. 6 Participant layout 2012

Outline of the thirty two participants including age range; length of time since diagnosis, gender; ethnic background, any additional lupus associated conditions; and any additional information.

Key for age range=: Green 23-35 years; Red 36-45 years; Blue 46-55 years; Black 56-65 years; Purple 66-85 years

Participant	Age Range	Length of time since diagnosis	Gender	Ethnic background	Lupus associated conditions	Additional information, employment
P1 Peter	46-55 years	5 years	Male	Caucasian		
P2 Joanne	23-35 years (30)	8 years	Female	Caucasian		
P3 Amy	36-45 years (43)	4 years	Female	Caucasian	Yes	
P4 Daphne	66-85 years (66)	15 years	Female	Caucasian		
P5 Michael	66- 85 years (71)	23 years	Male	Caucasian		
P6 James	46-55 years (54)	6 years	Male	Caucasian		Yes
P7 Jane	46-55 years (48)	2 years	Female	West African		Yes
P8 Meg	36-45 years	15	Female	Caucasian		Yes
P9 Lisa	56-65 years (58)	17 years	Female	Caucasian		

Outline of the thirty two participants including age range; length of time since diagnosis, gender; ethnic background; any additional lupus associated conditions; and any additional information.

Participant	Age Range	Length of time since diagnosis	Gender	Ethnic background	Lupus associated conditions	Additional information; employed
P10 Barbara	56-65 years (65)	19 years	Female	Caucasian		
P11 Lora	23-35 years (28)	3 years	Female	Caucasian		
P12 Phoebe	46-55 years (52)	26 years	Female	Caucasian		
P13 Jenny	46-55 years (55)	9 years	Female	Caucasian		
P14 Liz	66-85 years (68)	14 years	Female	Chinese	Yes	
P15 Christine	56-65 years (62)	15 months	Female	Caucasian		
P16 Vivian	46-55 years (47)	15 years	Female	Caucasian		

Outline of the thirty two participants including age range; length of time since diagnosis, gender, ethnic background any additional lupus associated conditions; and any additional information.

Participant	Age	Length of time since diagnosis	Gender	Ethnic background	Lupus associated conditions	Additional information; employed
P17 Rachel	46-55 years (46)	18 years	Female	Caucasian		Yes
P18 Peggy	56-65 years (63)	25 years	Female	Caucasian		
P19 Karen	56-65 years (56)	32 years	Female	West African		Yes
P20 Rebecca	66-85 years (73)	21 years	Female	Caucasian		
P21 Angie	36-45 years	31 years	Female	Caucasian	Yes	
P22 Penny	36-45 years (45)	17 years	Female	Caucasian		Yes
P23 Angela	36-45 years (39)	10 years	Female	Caucasian	Yes	Yes

Outline of the thirty two participants including age range; length of time since diagnosis, gender; ethnic background; any additional lupus associated conditions; and any additional information.

Participant	Age	Length of time since diagnosis	Gender	Ethnic background	Lupus associated conditions	Additional information employed
P24 Nadine	23-35 years (35)	4 years	Female	Caucasian		
P25 Dawn	46-55 years (49)	5 years	Female	Caucasian		Yes
P26 Margret	56-65 years (64)	13 months	Female	Caucasian		
P27 David	36-45 years (37)	5 years	Male	Caucasian		Yes
P28 Abigail	56-65 years (60)	11 years	Female	Caucasian		
P29 Lorraine	66-85 years (68)	23 years	Female	Caucasian	Yes	
P30 Ann	23-35 years(24)	2 years	Female	Asian		
P31 May	66-85 years (81)	54 years	Female	West African		
P32 Abby	23-35 years (26)	5 years	Female	Caucasian		

The sample size consisted of thirty-two participants. Four were males, and twenty-eight females, five of whom had varied ethnic backgrounds (Dalhberg 2008, Sandelowski 1995). This varied sample was selected because they could provide further insights into the phenomenon of SLE (Dalhberg 2008, Sandelowski 1995, van Manen 1997, Sadala et al 2002, Wertz 2005).

Outline of the thirty two participants involved within the research study (multiple in-depth unstructured interviews and a variety of other data collection methods, including drawings, photography, journal, and other media).

Participant	In-depth unstructured interviews			Variety of other data collection methods					In-depth unstructured interview discussing media		
	Interview 1	Interview 2	Interview 3	Journal	Artistic medium	Photograph	Music	Drawing	Interview 1	Interview 2	Interview 3
P1 Peter	Yes					Yes			Yes		
P2 Joanne	Yes	Yes						Yes	Yes		
P3 Amy	Yes	Yes	Yes	Yes			Yes	Yes	Yes	Yes	Yes
P4 Daphne	Yes	Yes				Yes		Yes	Yes	Yes	
P5 Michael	Yes	Yes							0		
P6 James	Yes	Yes							0		
P7 Jane	Yes	Yes		Yes				Yes	Yes		
P8 Meg	Yes	Yes	Yes					Yes	Yes		
P9 Lisa	Yes	Yes		Yes	Yes	Yes		Yes	Yes	Yes	

Outline of the thirty two participants involved within the research study (multiple in-depth unstructured interviews and a variety of other data collection methods, including drawings, photography, journal, and other media).

Participant	In-depth unstructured interviews			Variety of other data collection methods					In-depth unstructured interview discussing media		
	Interview 1	Interview 2	Interview 3	Journal	Artistic medium	Photograph	Music	Drawing	Interview 1	Interview 2	Interview 3
P10 Barbara	Yes	Yes		Yes		Yes			Yes		
P11 Lora	Yes	Yes	Yes					Yes	Yes		Yes
P12 Phoebe	Yes	Yes	Yes	Yes	Yes	Yes		Yes	Yes	Yes	
P13 Jenny	Yes	Yes			Yes	Yes		Yes	Yes	Yes	
P14 Liz	Yes	Yes		Yes					Yes		
P15 Christine	Yes	Yes		Yes				Yes	Yes		
P16 Vivian	Yes	Yes		Yes				Yes	Yes		
P17 Rachel	Yes	Yes						Yes	Yes		
P18 Peggy	Yes	Yes		Yes	Yes			Yes	Yes	Yes	

Outline of the thirty two participants involved within the research study (multiple in-depth unstructured interviews and a variety of other data collection methods, including drawings, photography, journal, and other media).

Participant	In-depth unstructured interviews			Variety of other data collection methods					In-depth unstructured interview discussing media		
	Interview 1	Interview 2	Interview 3	Journal	Artistic medium	Photograph	Music	Drawing	Interview 1	Interview 2	Interview 3
P19 Karen	Yes	Yes						Yes	Yes		
P20 Rebecca	Yes							Yes	Yes		
P21 Angie	Yes	Yes		Yes					Yes		
P22 Penny	Yes	Yes						Yes	Yes		
P23 Angela	Yes	Yes						Yes	Yes		
P24 Nadine	Yes	Yes						Yes	Yes		
P25 Dawn	Yes	Yes		Yes				Yes	Yes		
P26 Margret	Yes	Yes	Yes				Yes	Yes	Yes	Yes	
P27 David	Yes	Yes		Yes	Yes	Yes		Yes	Yes	Yes	

Outline of the thirty two participants involved within the research study (multiple in-depth unstructured interviews and a variety of other data collection methods, including drawings, photography, journal, and other media).

| Participant | In-depth unstructured interviews | | | Variety of other data collection methods | | | | | In-depth unstructured interview discussing media | | |
	Interview 1	Interview 2	Interview 3	Journal	Artistic medium	Photograph	Music	Drawing	Interview 1	Interview 2	Interview 3
P28 Abigail	Yes	Yes	Yes	Yes		Yes	Yes		Yes	Yes	
P29 Lorraine	Yes	Yes	Yes				Yes	Yes	Yes	Yes	
P30 Ann	Yes	Yes	Yes	Yes				Yes	Yes	Yes	
P31 May	Yes	Yes				Yes		Yes	Yes	Yes	
P32 Abby	Yes	Yes	Yes		Yes		Yes	Yes	Yes	Yes	

Appendix7. Media Data Collection Methods

"................Can you describe in as much detail as possible your experiences of what it is like for you to live with lupus?"

"Can you draw or photograph what lupus means to you"

You can use anything you would like to, pencils, paints, pastels; collage, anything you feel happy using. If you would prefer you could photograph things, or do both, it is entirely up to you. I will ask you to talk to me about it, so that I can understand your experience.

Would you be able to keep a weekly journal? You do not need to do it daily, once a week would be fine, but this is up to you.

Appendix 8 Consent Form

Consent form

Oxford Brookes University
School of Health and Social Care
Jack Straws Lane
Marston
Oxford
OX3 0FL

Title of Project: An interpretive phenomenological exploration of the lived experience of systemic lupus erythematosus (SLE).
Name of Researcher: Fran Lloyd
Contact details: Fran Lloyd, Bridge Centre, New Road
Basingstoke, Hants RG21 7PJ. Telephone: 07920700237   Please initial box

	Yes	No
1. I confirm that I have read and understand the information sheet dated …………… (version…………) for the above study and have had the opportunity to ask questions	☐	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without my medical care or legal rights being affected	☐	☐
3. I agree to the interview being audio taped	☐	☐
4. I agree that any words I say during the interview may be used, anonymously, in the presentation of the research	☐	☐
5. I agree that any words I write or tape in the weekly journal may be used anonymously, in the presentation of the research	☐	☐
6. I agree that any drawings/ photographs may be used anonymously in the presentation of the research. All identifiable features of other people would be removed	☐	☐
7. I agree to take part in the above study	☐	☐

_____   _____   _____

Name of participant   Date   Signature

_____   _____   _____

Name of Researcher   Date   Signature

When completed, 1 copy for participant; 1 copy for researcher

563

Appendix 9 Letter of decline for participant

Oxford Brookes University

School of Health and Social Care
Jack Straws Lane
Marston
Oxford
OX3 0FL
Date:

Title: 'An interpretive phenomenological exploration of the lived experience of systemic lupus erythematosus'.

Researcher: Fran Lloyd.
This study will explore the lived experience of lupus and will be asking 'what is it like to live with lupus?'

Dear ....

I am writing to thank you for your interest in this study. I have been very fortunate and have now managed to recruit a sufficient number of participants. Unfortunately, I will not therefore be able to interview you for this study.

Thank you again for showing your interest and I wish you well in the future.

Yours sincerely

Fran Lloyd, Research Student