INDIVIDUALS' AND DOCTORS' PERSPECTIVES OF LIVING WITH SYSTEMIC LUPUS ERYTHEMATOSUS IN KENYA

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TABLES OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>LIST OF TABLES</td>
<td>9</td>
</tr>
<tr>
<td>LIST OF FIGURES</td>
<td>9</td>
</tr>
<tr>
<td>LIST OF APPENDICES</td>
<td>10</td>
</tr>
<tr>
<td>ABSTRACT</td>
<td>11</td>
</tr>
<tr>
<td>DECLARATION</td>
<td>12</td>
</tr>
<tr>
<td>COPYRIGHT STATEMENT</td>
<td>12</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENT</td>
<td>13</td>
</tr>
<tr>
<td>THE AUTHOR</td>
<td>14</td>
</tr>
<tr>
<td>THESIS STRUCTURE</td>
<td>15</td>
</tr>
<tr>
<td>CHAPTER 1: STUDY BACKGROUND</td>
<td>16</td>
</tr>
<tr>
<td>1.1 INTRODUCTION</td>
<td>16</td>
</tr>
<tr>
<td>1.2 OVERVIEW OF LUPUS</td>
<td>16</td>
</tr>
<tr>
<td>1.2.1 Definition and clinical features of lupus</td>
<td>16</td>
</tr>
<tr>
<td>1.2.2 Epidemiology of lupus</td>
<td>17</td>
</tr>
<tr>
<td>1.2.3 Risk factors for developing lupus</td>
<td>19</td>
</tr>
<tr>
<td>1.2.4 Classification and criteria for diagnosing lupus</td>
<td>19</td>
</tr>
<tr>
<td>1.2.5 Guidelines for managing lupus</td>
<td>20</td>
</tr>
<tr>
<td>1.3. THE EXPERIENCE OF LIVING WITH A CHRONIC ILLNESS</td>
<td>24</td>
</tr>
<tr>
<td>1.3.1. Uncertainty</td>
<td>25</td>
</tr>
<tr>
<td>1.3.2 Changed body image</td>
<td>27</td>
</tr>
<tr>
<td>1.3.3 Facing stigma</td>
<td>28</td>
</tr>
<tr>
<td>1.3.4 Biographical disruption</td>
<td>30</td>
</tr>
<tr>
<td>1.3.5 Experience with treatment and health services</td>
<td>33</td>
</tr>
<tr>
<td>1.3.6 Experience of chronic illness in low to middle-income countries</td>
<td>34</td>
</tr>
<tr>
<td>1.4 CONTEXT OF THE STUDY</td>
<td>36</td>
</tr>
<tr>
<td>1.4.1 Political and administrative system in Kenya</td>
<td>36</td>
</tr>
<tr>
<td>1.4.2 Demography of Kenya and disease profile</td>
<td>36</td>
</tr>
<tr>
<td>1.4.3 Structure of health services in Kenya</td>
<td>38</td>
</tr>
</tbody>
</table>
CHAPTER 3: METHODOLOGY AND METHODS ........................................ 80

3.1 INTRODUCTION ............................................................................ 80

3.2 STUDY AIM AND OBJECTIVES ..................................................... 80

3.3 PHILOSOPHICAL AND THEORETICAL UNDERPINNINGS OF RESEARCH .................................................. 80

3.3.1 Philosophical underpinnings of research ........................................ 80

3.3.2 Theoretical paradigms ................................................................ 81

3.4 THE STUDY PARADIGM ................................................................. 82

3.5 UNDERPINNING ASSUMPTIONS AND THEORETICAL PERSPECTIVES .................................................. 83

3.5.1 Underpinning assumptions ................................................................ 83

3.5.2 Symbolic interactionism ................................................................. 84

3.6 GROUNDED THEORY METHODOLOGY ........................................ 85

3.6.1 Overview of grounded theory ....................................................... 86

3.7 SELECTING CONSTRUCTIVIST GROUNDED THEORY .................................................. 87

3.8 SYMBOLIC INTERACTIONISM WITHIN THIS STUDY ......................... 88

3.9 CONDUCT OF THE STUDY AND APPLICATION OF GROUNDED THEORY STRATEGIES ............ 89

3.9.1 Selecting study centres .................................................................. 89

3.9.2 Ethical considerations .................................................................... 90

3.9.3 Gaining access to study participants and recruitment ....................... 93

3.9.4 Sampling ....................................................................................... 94

3.9.4.1 Purposive sampling .................................................................. 95

3.9.4.2 Theoretical sampling ................................................................. 96

3.9.5 Data generation .............................................................................. 97

3.9.6 Transcribing process ...................................................................... 101

3.9.7 Data analysis ................................................................................ 102

3.9.8 Constant comparative analysis ...................................................... 104

3.9.9 Theoretical sensitivity ................................................................. 106

3.9.10 Memo writing .............................................................................. 107

3.9.11 Data saturation ............................................................................ 107

3.10 Summary ....................................................................................... 108
CHAPTER 4: CHARACTERISTICS OF STUDY PARTICIPANTS AND OVERVIEW OF RESEARCH FINDINGS ................................................... 109

4.1 INTRODUCTION ................................................................................................................................. 109

4.2 CHARACTERISTICS OF THE STUDY SAMPLE .................................................................................. 109

4.2.1 Socio-demographic characteristics of the patients ........................................................................ 109

4.2.1.1 Gender ........................................................................................................................................ 109

4.2.1.2 Age ........................................................................................................................................... 111

4.2.1.3 Cultural groups ........................................................................................................................ 111

4.2.1.4 Highest level of education ........................................................................................................ 111

4.2.1.5 Marital status ............................................................................................................................ 111

4.2.1.6 Symptom duration .................................................................................................................... 112

4.2.1.7 Employment status ................................................................................................................... 112

4.2.2 Clinical characteristics of patients ................................................................................................. 112

4.2.3 Characteristics of the doctors ........................................................................................................ 114

4.3 OVERVIEW OF CATEGORIES AND SUB-CATEGORIES OF RESEARCH FINDINGS ............. 115

4.4 SUMMARY ............................................................................................................................................... 117

CHAPTER 5: NAMING THE ILLNESS ................................................................................................. 118

5.1 INTRODUCTION .................................................................................................................................. 118

5.2 HELP-SEEKING BEHAVIOUR ............................................................................................................ 118

5.3 ILLNESS UNCERTAINTY .................................................................................................................... 122

5.4 SUMMARY ............................................................................................................................................... 125

CHAPTER 6: GOING ROUND THE SYSTEM ....................................................................................... 126

6.1 INTRODUCTION .................................................................................................................................. 126

6.2 HEALTH SERVICE ORGANISATION .................................................................................................. 127

6.2.1. Patient pathways through the health system ............................................................................. 133

6.3 INACCESSIBILITY OF LUPUS SERVICES ....................................................................................... 138

6.3.1 Geographical distance .................................................................................................................. 139

6.3.2 Service availability ......................................................................................................................... 143

6.3.3 Affordability .................................................................................................................................... 148

6.4 SUMMARY ............................................................................................................................................... 150
CHAPTER 7: CULTURAL BELIEFS, PRACTICES AND PREJUDICES ........ 152
7.1 INTRODUCTION ........................................................................................................ 152
7.2 CULTURAL AND RELIGIOUS BELIEFS IN ILLNESS CAUSATION .............................. 152
  7.2.1 Beliefs in witchcraft and evil spirits ................................................................. 153
  7.2.2 Angering the ancestral spirits and curse ......................................................... 155
  7.2.3 Belief in demonic attack ................................................................................... 155
7.3 BELIEFS IN TRADITIONAL AND RELIGIOUS REMEDIES ........................................ 156
  7.3.1 Traditional remedies ......................................................................................... 157
  7.3.2 Religious remedies ............................................................................................ 158
7.4 STIGMA AND DISCRIMINATION .............................................................................. 159
  7.4.1 Stigma experienced in public places ............................................................... 159
  7.4.2 Stigma experienced at the workplace ............................................................... 162
  7.4.3 Stigma experienced from health practitioners ............................................... 162
  7.4.4 Participant responses to stigma ........................................................................ 163
7.5 SUMMARY ............................................................................................................... 164

CHAPTER 8: RESOURCES FOR MANAGING LIFE WITH LUPUS .................... 166
8.1 INTRODUCTION ........................................................................................................ 166
8.2 ECONOMIC RESOURCES ...................................................................................... 166
  8.2.1 Medically insured participants ........................................................................ 167
  8.2.2 Medically un-insured participants .................................................................... 169
8.3 SOCIAL NETWORKS/SUPPORT .............................................................................. 172
8.4 CULTURAL RESOURCES/BARRIERS .................................................................. 175
  8.4.1 Culturally resourced participants .................................................................... 176
  8.4.2 Cultural barriers ................................................................................................ 177
8.5 SUMMARY ............................................................................................................... 178

CHAPTER 9: A SHADOW OF MYSELF: THE IMPACT OF LIVING WITH LUPUS ................................................................. 180
9.1 INTRODUCTION ...................................................................................................... 180
9.2 LOSS OF SELF ....................................................................................................... 180
  9.2.1 Experiencing invisible symptoms .................................................................... 181
List of Tables

Table 1.1: Summary of demographic, socio-economic indicators and disease profile in Kenya................................................................. 38
Table 2.1: Inclusion and exclusion criteria for selected research studies................................. 51
Table 2.2: Search terms ........................................................................................................ 51
Table 2.3: Research methodology utilised by the reviewed studies........................................ 53
Table 2.4: Experiences and perspectives explored in the various studies............................... 63
Table 4.1: Demographic characteristics of participants ............................................................. 110
Table 4.2: Clinical features of lupus as reported by patients ..................................................... 112
Table 4.3: Characteristics of the doctors .................................................................................... 114
Table 6.1: Self-reported differential diagnosis received by patients at different levels of health facilities ........................................................ 128
Table 6.2: Self-reported investigations carried out on patients before receiving a lupus diagnosis .................................................................................................................. 130
Table 6.3: Self-reported patient pathways through the health system ..................................... 134
Table 6.4: Distance travelled by participants to the rheumatology clinic ................................. 140
Table 6.5: Patients’ employment status and financiers of treatment cost ............................... 149

List of Figures

Figure 1.1: Political Map of Kenya ..................................................................................... 36
Figure 1.2: Levels of healthcare facilities .............................................................................. 39
Figure 2.1: Search results ...................................................................................................... 52
Figure 4.1: Summary of categories and sub categories of research findings ......................... 115
Figure 6.1: Going round the system ..................................................................................... 126
Figure 6.2: Distances to Nairobi in relation to the other counties ....................................... 139
**List of Appendices**

Appendix 1: American College of Rheumatology criteria for classification of lupus...... 278
Appendix 2: Summary of pharmacological treatment and monitoring guidelines ........... 279
Appendix 3: Example of search strategy process (Medline search) ......................... 280
Appendix 4: Hawker’s Assessment tool (Hawker et al., 2002) .............................. 282
Appendix 5: Assessment of methodological quality of reviewed studies using Hawker et al. (2002) assessment tool 5a: Qualitative studies ........................................ 284
Appendix 6: Summary of included studies ............................................................ 288
Appendix 7: Methodology and methods utilised in the reviewed studies .................... 327
Appendix 8: Ethical clearance from University of Manchester ............................... 330
Appendix 9: Ethical Clearance from Kenyatta National Hospital ............................ 333
Appendix 10: Ethical Clearance from Mater Misericordiae Hospital ....................... 335
Appendix 11: Participant information sheet ......................................................... 336
Appendix 12: Consent Form .................................................................................. 341
Appendix 13: Distress Policy .................................................................................. 342
Appendix 14: Demographic form .......................................................................... 343
Appendix 15: First Interview topic guide (Final version) ....................................... 344
Appendix 16: Revised Interview Topic Guide ....................................................... 346
Appendix 17: Doctors Interview Topic Guide ....................................................... 349
Appendix 18: Initial line by line coding ................................................................. 351
Appendix 19: Thematic coding framework ............................................................. 352
Appendix 20: Example of coding process .............................................................. 353
Appendix 21: Example of a theoretical memo on diagnostic difficulty..................... 354
Appendix 22: Criteria for judging rigour of the study ............................................ 355

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Abstract

Background:
Lupus is a chronic, multisystem, autoimmune disease of unknown aetiology affecting predominantly young women of reproductive age. The condition affects individuals' physical, psychological and social health with resultant limitations of physical functioning and disrupted social life. Though common in women of black ancestry in Europe and the United States of America, lupus is believed to be rare in black Africans. There is a paucity of data on living with and management of lupus from the African continent.

Aim:
To explore the perspectives of individuals with lupus and their doctors on living with lupus in Kenya.

Methods:
A qualitative study that drew on the principles of constructivist grounded theory approach was conducted between August 2013 and June 2015 in two rheumatology clinics in Nairobi. Purposive and theoretical sampling techniques were employed. Data were collected through in-depth face to face interviews using an interview guide with open-ended questions. Interviews were transcribed verbatim and inductively analysed using the constant comparative method.

Findings:
Twenty-one patients aged between 19 to 56 years with a disease duration ranging between 2 to 7 years, and six doctors were identified. Five interrelated categories explained perspectives of the participants: naming the illness; cultural beliefs, practices and prejudices; going round the system; resources for managing life with lupus and a shadow of myself.

Diagnosing lupus was difficult in Kenya, due to various health system deficiencies and inadequate training and experience of primary and secondary care doctors. Some individuals delayed initial help-seeking. Some also held beliefs regarding supernatural causation of the condition, due to a lack of understanding about the illness, with resultant use of traditional remedies and experience of stigma from those around them. The findings also revealed that lupus care was costly and difficult to access due to: healthcare funding structure in Kenya; inadequate resources; lack of integrated care and some patient related factors, like lack of economic and social resources. Families bore a heavy burden in terms of economic and social resources. The illness disrupted individuals’ lives in various ways. However, they attempted to reconstruct the disruptions with variable success.

Conclusion:
Data from both groups of participants revealed that living with lupus in Kenya is full of challenges. Understanding structural and social processes which influence experiences may assist with informing future strategies. These can be utilised to improve the care that patients with lupus receive and their experience of living with this condition.
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The Author

I am a registered general nurse. I currently work as a lecturer in the School of Nursing Sciences, the University of Nairobi where I am engaged in teaching medical/surgical nursing. I did my Advanced Nursing Studies at the University of Nairobi, and I completed my MSc. in Nursing Studies at The University of Manchester in 2007. I am a trained critical care nurse who has practiced as a critical care nurse both in Kenya and in the UK and taught critical care nursing in Kenya. I am also a trained midwife.

I also worked at the Nairobi Arthritis Clinic where I was introduced to Rheumatology and had first-hand experience of the plight of individuals with lupus. I thus decided to conduct an in-depth study to explore perspectives of living with lupus from these individuals and their doctors.
Thesis Structure

This thesis is organised into ten chapters. Chapter one is the introductory chapter which presents the relevant background to the study and also provides the context of the study setting.

Chapter two provides an overview of the debate about the place of literature review in grounded theory study. The current evidence on perspectives of individuals living with lupus and doctors perspectives on the impact of the condition and service organisation on individuals is also reviewed in this chapter.

Chapter three describes the study design and the methods utilised in the study.

Chapter four provides an overview of the research findings and characteristics of the research participants.

Chapters five to nine present the findings of the study.

Chapter ten is the discussion chapter which discusses the findings in relation to the body of literature with a focus on the contributions of this study. The chapter also discusses the strengths and limitations of the study, the implications of the findings in relation to policy development, education, practice and research and make recommendations. It also presents conclusions of the study.
Chapter 1: Study Background

1.1 Introduction

This thesis focuses on the perspectives of individuals with lupus and their doctors' on living with Systemic Lupus Erythematosus (SLE) in Kenya. SLE is also known as ‘lupus’, and in this thesis, SLE has been referred to as lupus because the study participants commonly used this term.

The introductory chapter provides an overview of lupus by outlining what lupus is and how it affects people. It also describes the epidemiology and risk factors for developing lupus. The classification and criteria for the diagnosis and management of lupus are also discussed. This chapter also provides background literature on the experience of living with chronic illness.

This chapter provides the context for the study by describing the general disease burden on Kenya and the Kenyan healthcare system. It also discusses the management of chronic illness and more specifically, the management of lupus in Kenya.

1.2 Overview of lupus

1.2.1 Definition and clinical features of lupus

Lupus is an autoimmune disease, and its cause is unknown. The disease is capable of affecting many organs of the body simultaneously. The disease follows a relapsing and remitting course (Rus, 2008). Lupus is grouped under chronic diseases which the World Health Organisation (2002, p. 11) defines as a "health problem that require ongoing management over a period of years or decades”.

Lupus is characterised by diverse clinical features which result from widespread inflammation in various organs of the body such as the skin and mucous membranes, joints, kidney, brain, lungs, heart and occasionally the gut (Gladman and Urowitz, 2008). Skin involvement is present in 80% of the patients and includes a skin rash and itchy skin, photosensitivity, painful mucous membranes and hair loss. Musculoskeletal features may include painful or swollen joints and bone necrosis. There can also be renal disease or neuropsychiatric features. Patients may also present with features of cardiopulmonary involvement giving rise to hypertension
and chest pain. Eye problems and gut involvement may also be present. Haematological abnormalities may include anaemia, low platelets and formation of autoantibodies (Wallace, 2007). Although skin disease and painful or swollen joints are the most common symptoms, lupus may present in variable combinations of clinical manifestation as organs may be involved singly or in combination. Therefore, most people with lupus have variable symptoms and an unpredictable course and prognosis of the disease (Rus, 2008). Lupus patients also complain of overwhelming fatigue, persistent fever, malaise and weight loss (Wallace, 2007).

1.2.2 Epidemiology of lupus

Lupus is one of the most common autoimmune disorders affecting women of all ages. The most common age of onset is the childbearing years between 15 to 40 years (Pisetsky et al., 2001; Rus et al., 2001). Prevalence of lupus is also much higher in women compared to men (Naleway et al., 2005; Peschken and Esdaile, 2000) with the female-to-male ratio reported to be between 10:1 and 15:1 (Lahita, 1999). Women also have a 2.5-12 fold increase in the incidence of disease over men (McCarty et al., 1995).

Lupus is reported to be common in individuals of black ancestry around the world, but less common in Africa (Bae et al., 1998; Cooper et al., 2002; Molokhia et al., 2001; Symmons, 1995). This view purported that prevalence increased as individuals moved from Africa to Europe and North America (Symmons, 1995). However, this view has been challenged in recent times. The argument is that the apparently low incidence rate in Africa may be the result of under diagnosis, low disease recognition by primary doctors, limited access to diagnostic services and inadequate numbers of specialist physicians (Adelowo and Bello, 2014; Tiffin et al., 2013). This is assumed to result in misdiagnosis, late diagnosis, increased mortality and subsequently, low rates of reported cases and a paucity of data (Tiffin et al., 2013).

Rus et al. (2001) state that due to the non-specific signs and symptoms of lupus, it is difficult to determine its onset and difficult to obtain national incidence data on lupus. In the United States (US), the average incidence has been estimated to range from 1.6 to 7.6 cases per 100,000 per year, while Europe’s estimated range is 2.1 to 4.8 per 100,000 (Danchenko et al., 2006; Rus et al., 2001). Brazil, which lies in the tropics, reported higher incidence rates of 8.7
per 100,000 (Vilar and Sato, 2002). There are no studies of incidence rates from the Australian and African continents; however, a higher incidence is reported in people of African and Asian origin than in Caucasians (Danchenko et al., 2006).

Prevalence estimates also vary widely, with Asia reporting the highest rate of 30 to 50 per 100,000 persons (Osio-Salido and Manapat-Reyes, 2010), followed by the US with a range between 14.6 to 50.8 per 100,000 persons (Danchenko et al., 2006). Overall prevalence rates in Europe range from 12.5 to 39 per 100,000 persons (Danchenko et al., 2006; Lopez et al., 2003). Only one study from the Australian continent reported a high prevalence of 45.3 per 100,000 persons (Bossingham, 2003), which Mackie et al. (2014) attributed to the large Asian population in Australia. However, a lack of standardised criteria for case detection and passive methods of reviewing records of inpatients may lead to missing patients with mild disease.

Significant differences in prevalence rates have also been found among ethnic subsets in the US, United Kingdom (UK) and Australia. In the UK, Johnson et al. (1995) reported a rate five times higher in Afro-Caribbeans than in Caucasians, while Asians had a two times higher prevalence than Caucasians. This view is supported by studies conducted in the US where prevalence was three times higher in African Americans than Caucasians (Hopkinson et al., 1994; McCarty et al., 1995). Although the two studies, which used similar methodologies, suggest higher prevalence rates among persons of African descent, there is a paucity of population-based studies on lupus prevalence in Africa. Such information from Africa is derived from hospital based studies on clinical features and autoantibody profiles in Tunisia, Nigeria, Kenya and South Africa (Adelowo and Oguntona, 2009; Ekwom, 2013; Houman et al., 2004; Tikly et al., 1996; Tikly et al., 2007), quality of life (Odhiambo et al., 2014) and the outcomes for patients with lupus (Abdou et al., 2003; Adelowo and Oguntona, 2009; Ayodele et al., 2010; Ekwom, 2013; Houman et al., 2004; Kammoun et al., 2011; Okpechi et al., 2012; Tiffin et al., 2013; Wadee et al., 2007). Epidemiology of lupus in Africa remains largely unknown: one seven year study at the national referral hospital in Kenya diagnosed lupus in only 67 patients (Otieno et al., 1990), while Ekuom (2013) identified only 13 patients with lupus over a one year study period in the same hospital.
1.2.3 Risk factors for developing lupus

The underlying cause of lupus is poorly understood, but it has been suggested that it involves genetic and racial predisposition, hormonal and environmental factors (Domsic et al., 2008; Lau et al., 2006; Tutuncu and Kalunian, 2007). Female gender and black ethnicity are associated risk factors. Genetic susceptibility to lupus is strongly supported by genetic components isolated in familial aggregation studies (Alarcón-Segovia et al., 2005; Rahman and Isenberg, 2008) and twin studies (Alarcón-Segovia et al., 2005; Deapen et al., 1992). Sibling risk ratio is suggested to be approximately 30 times higher compared to the general population and is higher in monozygotic twins (Alarcón-Segovia et al., 2005; Deapen et al., 1992; Sestak et al., 1999).

Hormonal factors have also been suggested to contribute to the development of lupus. Lupus mainly affects women of childbearing age with a peak incidence between the ages of 15 to 40 years (Naleway et al., 2005; Peschken and Esdaile, 2000). This is attributed to oestrogen hormone which is known to be a stimulant of lymphocytes and the immune response (Lahita, 1999; Petri and Robinson, 1997). Some studies and expert opinion have also suggested that external exposure to oestrogen, either through oral contraceptives (Petri, 2008; Sanchez-Guerrero et al., 1997) or oestrogen replacement therapy for post-menopausal women (Lahita, 1999; Sanchez-Guerrero et al., 1997), may increase the incidence.

The causes of lupus in relation to environmental exposure are less clear. However, exposure to environmental pathogens have been suggested as potential triggers of lupus (Symmons, 1995). Danchenko et al. (2006) also suggest that low vitamin D levels (which is attributed to lack of exposure to sunlight) also increases autoantibody production in healthy individuals. In the same study, vitamin D deficiency was also linked to B-cell hyperactivity in patients with lupus.

1.2.4 Classification and criteria for diagnosing lupus

Originally there was no precise definition of lupus due to its' diverse clinical and laboratory features, which left assessment of patients in the hands of the treating doctors and their experience. Consequently, clinical practice was open to possible variability in patient care between centres and between doctors (Mosca et al., 2010). This necessitated a standardised
The definition of the disease and criteria for classification and diagnosis (Davis et al., 1973). The American College of Rheumatology (ACR) developed 14 clinical and laboratory criteria for the classification of lupus (Hochberg, 1997), as illustrated in Appendix 1.

In this classification, it was suggested that any combination of four or more of the 11 criteria, if documented either simultaneously or serially during a patient's history, made it likely that the patient had lupus. The classification criteria were widely accepted and used in most parts of the world to aid diagnosis (Cervera and Espinosa, 2012). However, the criteria were developed to allow for uniformity in disease definition for research purposes and not for clinical diagnosis. The classification also did not take into account that developing lupus may take many years from the onset of the first symptom or sign of lupus until the patient eventually meets four classification criteria, making diagnosis not straightforward. However, there is no research evidence which supports or disapproves the applicability of the ACR classification criteria (Hochberg, 1997) in low and middle-income countries like Kenya.

1.2.5 Guidelines for managing lupus
The aims of clinical management for lupus are to achieve remission, prevent flares, prevent damage and improve the quality of life (Van Vollenhoven et al., 2014). However, there has been concern about variability in patient care in different centres (Hahn et al., 2012a; Mosca et al., 2010; Van Vollenhoven et al., 2014). To reduce variability, clinical practice guidelines for lupus have been developed mainly in Europe and the US to support clinical decision making, improve care and optimise health outcomes for patients.

There are at least eight recognised clinical practice guidelines (Bertsias et al., 2010; Bertsias et al., 2007; Bertsias et al., 2012; Calvo-Alen et al., 2013; Hahn et al., 2012a; KDIGO Glomerulonephritis Work Group, 2012; Mosca et al., 2010; Ruiz et al., 2012) and five recognised consensus statements (Aringer et al., 2012; Mina et al., 2012; Mok et al., 2013; Van Tellingen et al., 2012; Van Vollenhoven et al., 2014) which cover diagnosis, treatment and monitoring, in both adults and children. The practice guidelines provide recommendations for both pharmacological and non-pharmacological management measures.
Pharmacological management measures

For pharmacological treatment and monitoring, the European League Against Rheumatism (EULAR) guidelines (Mosca et al., 2010) are the most elaborate, as summarised in Appendix 2. For the treatment of patients with uncomplicated lupus, EULAR (Bertsias et al., 2007) guidelines recommend use of antimalarials, corticosteroids and non-steroidal anti-inflammatory drugs. The benefits of using antimalarials include decreased flare-ups and prolonged life in patients, making it a cornerstone drug (Alarcón et al., 2007). For non-responsive patients or patients with complicated lupus, use of immunosuppressants such as azathioprine and methotrexate are also recommended by both EULAR (Bertsias et al., 2007) and ACR (Hahn et al., 2012b). However, only EULAR (Mosca et al., 2010) recommends that all patients with lupus should be assessed for adequate calcium and vitamin D intake for the prevention of osteoporosis caused by prolonged steroid use. There are no lupus treatment guidelines for Sub-Saharan African patients. Also, there is no research evidence supporting or refuting effectiveness of the recommended drugs by EULAR and ACR in Sub-Saharan Africa.

The long-term monitoring of patients with lupus is recommended due to the variable disease activity, organ damage, drug toxicity and quality of life, with a few variations. To standardise monitoring of lupus activity, use of at least one verified disease activity index for patient assessment, such as the Lupus Activity Index (LAI) (Griffiths et al., 2005) or British Isles Lupus Assessment Group (BILAG) (Gordon et al., 2004), is recommended by EULAR during each visit (Mosca et al., 2010). These assessment tools assess the disease activity, damage and the patient’s assessment of their disease.

The assessment of disease activity is significant in evaluating the total effect of the disease on the patient and in determining prognosis (Tunnicliffe et al., 2015). In mild disease, the international task force (Van Vollenhoven et al., 2014) recommends 3-6 monthly assessments. They also recommend increased frequency for severe and active disease. Petri (2007) recommends 3 monthly assessments for stable patients and weekly assessments for unstable individuals. For patients with inactive lupus and no organ damage or comorbidities, 6-12 monthly assessments are recommended by Mosca et al. (2010), while the other two guidelines make no comment on how to manage this group of patients.
The guidelines (Bertsias et al., 2007; Mosca et al., 2010) specify that monitoring should include specific blood and urine tests, as outlined in Appendix 2. This is because individuals with lupus are at an increased risk of developing severe anaemia, which is associated with kidney involvement. They also have an increased risk of developing a low white cell count which predisposes them to infections, while other tests such as complement tests are useful in determining disease activity. Monitoring for the absence or presence of drug toxicity during each visit is also recommended by EULAR (Mosca et al., 2010), as a patient's clinical picture may sometimes be influenced by side effects of drugs (Tunnicliffe et al., 2015).

Regarding monitoring for presence or absence of co-morbidity, only EULAR (Bertsias et al., 2007; Mosca et al., 2010) has recommendations on checking for cardiovascular risk factors related to smoking, blood cholesterol, glucose, body mass index and blood pressure. Lupus patients have an increased risk of developing osteoporosis, cancers, cardiac events and other treatment related comorbidities (Tunnicliffe et al., 2015). Regarding organ damage, only EULAR (Bertsias et al., 2007; Mosca et al., 2010) recommend an annual assessment. Organ damage assessment has prognostic significance as there is a correlation between early damage accrual, development of additional damage and mortality (Tunnicliffe et al., 2015).

Antimalarials are one of the cornerstone lupus drugs as indicated in all the guidelines, so patients are likely to be on them for a prolonged period. Mosca et al. (2010) also specify that a five year ophthalmic examination should be performed on patients taking antimalarials daily for over a period of five years, as these drugs may produce side effects on the optic nerve, the kidneys, liver and other organs. It is also reported that antimalarials can cause a condition called bull-eyed retinopathy (Costedoat-Chalumeau et al., 2015; Ruiz-Irastorza et al., 2008). In the UK, the recommendation is for an annual optician's eye test and comprehensive ophthalmological screening after 5 years of therapy to rule out ocular toxicity (Gordon et al., 2016). Ophthalmic assessment is also important for patients on corticosteroids as they are at increased risk of developing cataracts or glaucoma (Tunnicliffe et al., 2015).

Regarding quality of life for individuals with lupus, only Mosca et al. (2010) recommends a quality of life assessment by clinical interview and/or use of a visual analogue scale at each visit. However, Tunnicliffe et al. (2015) suggest that there is a poor correlation between disease activity, disease damage and quality of life, each providing information on different
aspects of the patients’ illness status. In addition, all guidelines except Mosca et al. (2010) advocate multidisciplinary monitoring and care of patients involving other specialists and healthcare disciplines.

Prolonged remission and improved survival of patients with lupus has been noted in Europe and North America (Steiman et al., 2014; Zen et al., 2015). This has mainly been attributed to earlier diagnosis and judicious use of medications (Doria et al., 2015; Rus, 2008; Trager and Ward, 2001).

Non-pharmacological management measures
Non-pharmacological management of lupus includes both physical and psychological measures. EULAR (Bertsias et al., 2007) guidelines has some recommendations for physical measures, including physical rest and protection from direct sunlight which may cause a photosensitive rash. A healthy diet, exercise and weight control, smoking cessation, prompt treatment of infections, and avoidance of known allergens and aggravating factors are also recommended. Patients with lupus have a high incidence of premature deaths from accelerated atherosclerotic disease and thus adherence to a cardio-protective lifestyle, such as cessation of smoking, is strongly recommended (Salmon and Roman, 2001).

However, the guidelines do not comment on patient support groups which are seen as another valuable source of information as they provide a forum through which patients may share skills they have acquired to cope with the chronic disease (Mazzoni and Cicognani, 2011). Also, the guidelines do not comment on the use of contraception in women with lupus, and yet this is a disease with peak incidence during women’s childbearing years. Expert opinion recommends avoidance of high dose oestrogen contraceptive pills by these patients, as oestrogen has been linked to immune activity (Ioannou and Isenberg, 2002).

The variable presentation and disease trajectory of lupus in individuals, and its variable management guidelines, may cause variation in an individual's experience with lupus as a chronic illness. The next section discusses the experience of living with a chronic illness using literature from other chronic illnesses; this was useful in distinguishing the extent to which the experience of living with lupus was either similar or different to living with other chronic conditions.
1.3. The experience of living with a chronic illness

This section discusses background literature on perceptions regarding the common experiences of living with chronic illnesses, such as: the effects of the illness, experiences with treatment, and the unique experiences of living with chronic illness in low and middle-income countries. Chronic illnesses are becoming increasingly prevalent across the world due to the changing lifestyles, ageing population, and the improving standards of both treatments and healthcare especially in developed countries (Bonsaksen et al., 2012). In 2012 it was estimated that approximately 117 million Americans were living with at least one chronic disease (Ward et al., 2014). Lindsay et al. (2014) stated that the experience of living with the illness presents both personal and social challenges which may have life-long implications. In addition, the World Health Organisation (WHO) reported that chronic illness is the leading cause of morbidity and 60% of all deaths globally (World Health Organization, 2011a). However, many chronic illnesses like lupus appear at a younger age and not in older age, when one is most productive in terms of educational achievements, paid work and raising families. For example, as already indicated, individuals with lupus are often diagnosed between the ages of 20-40 years (Naleway et al., 2005).

Charmaz (2000) indicates that chronic illness can be episodic or continuous, and the body’s response may be visible or invisible, and may include the experience of intrusive symptoms like pain and fatigue (Herrmann et al., 2000; Kelly and Field, 1996). Pain stands out as a symptom of chronic condition (Herrmann et al., 2000; Osborn and Smith, 2006; Snelgrove et al., 2013). As indicated in section 1.2.1, individuals with lupus experience pain together with persistent fever, malaise and fatigue due to widespread inflammation, depriving them of their previously taken for granted continuity of life as they struggle to make sense of the bewildering symptoms.

Charmaz (2000) also states that chronic illness causes more social, interactional and existential problems because of being long-term. The illness may incapacitate the individual and cause a permanent alteration to their way of life, necessitating re-evaluation of functional abilities in their social world (Jerrett, 1994; Price and Walker, 2015). Chronic illness, therefore, impacts on individuals in profound and various ways, and the lived experience often includes different forms of physical and psychological impact. Background literature has identified some common experiences and shared meanings that emerge across chronic illnesses, as individuals
live and manage their conditions. Although chronic illnesses are not the same, the shared physical, social and psychological issues include uncertainty, changed body image, facing stigma and biographical disruption, as discussed in the following sub-sections.

1.3.1. Uncertainty
Uncertainty in illness has been defined as “the inability to determine the meaning of illness related events” (Mishel and Clayton, 2008 p. 55). Radley (1994) identified three types of uncertainty in chronic illness. When symptoms first appear, especially if they are perceived as mild, people tend to attribute the symptoms to ordinary things in their lives or to personal situations, making them uncertain about seeking medical help; this is the first type of uncertainty in chronic illness. When symptoms become severe, and a conclusive diagnosis cannot be made, a sense of uncertainty is experienced, which is the second type. Doctors’ inability to make a reliable diagnosis is a cause for concern as the patients view themselves as sick, but are not medically defined as sick, putting them in an ambiguous situation.

The third type of uncertainty in chronic illness occurs after diagnosis and relates to the unpredictable disease trajectory (Radley, 1994). Both pre-diagnosis and post-diagnosis uncertainty could affect various activities or the person’s whole existence (Pierret, 2003). Reich et al. (2006) established that illness uncertainty was related to anxiety, depression, impaired coping and negative impacts on significant relationships. Another study determined that illness uncertainty was related to reduced self-efficacy, resourcefulness and life satisfaction (LeFort, 2000).

Mishel (1988) proposed two theories of uncertainty in illness. The first theory addressed uncertainty during diagnostic and treatment phases, especially of acute illness with an established downward trajectory. The theory proposed that uncertainty exist in illness situations where there exists ambiguity, complexity, unpredictability of symptoms and when information is conflicting or lacking.

The second theory of uncertainty in illness is an expanded and re-conceptualised theory (Mishel, 1990) which addresses the experience of living with a chronic illness requiring ongoing management, or an illness with the possibility of recurrence. It refers to the continuous uncertainty one experiences when self-management is the primary focus of
treatment. This type of uncertainty is seen to affect other areas of an individual’s life, disrupting their life patterns. The theory presupposes that individuals undergo a sense of disorganisation and instability with regards to achieving desired goals and maintaining desired relationships, which causes increased uncertainty in the individual. Mishel (1988) argues that characteristics of the illness are the primary source of uncertainty. The uncertainty is influenced by patients’ characteristics, such as their level of education and cognitive capacity on one hand, and health practitioners’ involvement and social support on the other hand. She suggests that these factors interact with patients as they attempt to evaluate and appraise their illness.

LaPushin (2009) argued that the outcome of uncertainty generated by the diagnosis of a chronic illness can be modulated by social support from family and healthcare providers. La Pushin suggested that discussion with other people who are supportive can provide an opportunity to clarify the meaning of illness related events. Also, Mishel and Clayton (2008) suggested that explaining, interpreting and providing information to individuals with chronic illness can help to prevent, reduce or manage uncertainty and promotes positive outcomes in regaining personal control. Similarly, they acknowledged that uncertainty could be reduced by utilising an individual’s level of education to help them understand the condition. They stated that acceptance of uncertainty is a growth process, which evolves gradually over time with the restructuring of a new view of life being a major component of the process. However, Wright et al. (2009) argued that acceptance over time is not always evident for chronic conditions as some patients remain with high levels of uncertainty, especially if one views uncertainty as a danger. To summarise, uncertainty is a major component of chronic illness experience with some patients experiencing higher levels of uncertainty than others due to the unpredictable symptoms, course and outcome of the illness, which could be indirectly influenced by patient’s level of education and availability of support from family and healthcare providers. The next section will discuss changes in body image as an additional experience of chronic illness.
1.3.2 Changed body image

Body image has been defined as "the mental image of one's physical self, including attitudes and perceptions of one's physical appearance, the state of health, skills, and sexuality" (Larsen and Lubkin, 2013 p. 134). Pruzinsky (2004) argues that body image is subjective, dynamic and is influenced by cultural, social, historical and biological factors. Krueger (2002) suggests that body image is brought to the focus of the individual by elements such as physical or psychological illness, pain, age or weight.

With the onset of chronic illness, bodily functioning is altered and the body, which in normal social situations is taken for granted, ceases to be taken for granted (Kelly and Field, 1996). The body image issues which are regarded as important in chronic illness include body appearance, functional limitations and changed sensation (Corbin, 2003; Larsen and Lubkin, 2013).

With lupus, the changes in appearance include swollen joints, alopecia, body rash and weight gain due to extensive use of steroids (Hale et al., 2014; Hale et al., 2006b; Karasz and Ouellette, 1995). Similarly, body appearance can also be changed in conditions such as HIV infection and cancers due to the associated weight loss, scarring and disfigurement (Berneis et al., 2000; Bosaeus et al., 2001; Khal et al., 2005). An individual's appearance may also be changed due to required alterations in bodily functions, such as having a colostomy or a tracheostomy (Gilony et al., 2005; Krouse et al., 2007; Manderson, 2005). These draw out body imperfections and unwanted attention from the public. The more visible the body changes are in adults, the more likely it is perceived as a threat to body image (de Moore et al., 2000).

Regarding functional limitations, the effect of living with chronic illness has been explored by Charmaz (1983) who focused specifically on the notion of loss of self. The endemic loss relates to the restrictions that illness imposes on daily life, the burden the illness can impose on others and the isolation that individuals may experience. Larsen and Lubkin (2013) argue that due to significant others being unprepared for the functional limitations associated with chronic illness, interpersonal relationships may also be strained. Nevertheless, other studies have also established that chronic illnesses can improve interpersonal relationships (Stanton et al., 2007).
Regarding changed sensation, the experience of a changed body is closely related to functional limitations. For example, in lupus the new sensations are mainly linked to the experience of fatigue and pain which also limits functional capabilities, making sufferers unable to participate in work and leisure (Goodman et al., 2005; Mattsson et al., 2012; McElhone et al., 2010; Mendelson, 2006). Other studies also reported that the new sensations could limit or interfere with the individual’s everyday physical, psychological or social functioning as they carry out activities of daily living (Herrmann et al., 2000; Osborn and Smith, 2006). People living with a chronic illness, therefore, feel disrupted. Stoller (2004) concludes that chronic illness sets individuals apart, and even the individual feels changed.

### 1.3.3 Facing stigma
Erving Goffman defined stigma as an “attribute that is deeply discrediting” which reduces the stigmatised person “from a whole and usual person to a tainted, discounted one” (Goffman, 1963, p. 3). Jones et al. (1984) observed that the attribute must be seen in relation to a stereotype that links a person to undesirable characteristics. This suggested that the attribute was defined by the pattern of social control and was, therefore, controlled externally. Goffman (1963) further described three main types of stigma: (1) blemishes in personal character traits, (2) overt or external deformities, and (3) the stigma of group identity. These had a focus on deviance in relation to abominations, blemishes and tribal identities such as race, sex, religion and national origin (Weiss et al., 2006). Additionally, Link and Phelan (2001) felt that the definition of stigma should include discrimination and, like Goffman, they also felt that for stigma to occur, power must be exercised in the stigmatised circumstances. However, Scambler (2009) argued that there should be a distinction between stigma and deviance.

Scambler and Hopkins (1986), and Scambler (2004), further developed two types of stigma which they referred to as 'enacted' and 'felt stigma', in relation to having epilepsy. Scambler was interested in establishing how people internalised stigma. Enacted stigma was seen to be related to overt discrimination against those who had epilepsy, by being seen as socially unacceptable. Felt stigma denoted a sense of shame as well as fear of encountering enacted stigma. This predisposed patients to secrecy and concealment.
Weiss et al. (2006), therefore, suggested that stigma features as a hidden burden in most chronic illnesses. It is a feeling of disapproval that people have about the enduring features of particular illnesses in a person or group and is characterised by exclusion, rejection, blame and devaluation (Scambler, 2009). Other non-health related stigmas which may apparently affect health include one’s race, ethnicity, socio-economic status and sexual preferences, which also results from negative social judgments (Parker and Aggleton, 2003; Weiss et al., 2006).

Stigma is, therefore, a negative value given to a personal characteristic which results in someone being labelled as abnormal and liable to social rejection. Scambler and Hopkins (1986), however, argued that an individual plays a major role in how they perceive and interpret their negative label - either positively or negatively. Therefore, the behaviour of a stigmatised individual may also change as a result of labelling.

The participants in most studies on chronic illness feel stigmatised. Those with visible body changes, like hand deformities in scleroderma and rheumatoid arthritis (Joachim and Acorn, 2003; Lempp et al., 2006), body wasting in HIV and cancer (Fife and Wright, 2000; Steward et al., 2008), and mental illness (Phelan et al., 2000), are stigmatised because they are seen as ‘not normal’ and treated differently. This prevents individuals from telling others about their illness, especially when they are experiencing invisible signs like fatigue (Joachim and Acorn, 2003). Visible body changes are also perceived negatively by affected individuals, who feel that they are less attractive to others.

In Africa, the chronic diseases which are highlighted in the literature as having stigma associated with them include mental illness, epilepsy and HIV infection. HIV is the most significant and the most riddled with stigma (Roura et al., 2009). Maughan-Brown (2010) indicated in her study that despite antiretroviral roll-out in South Africa, stigma is still a recognised problem for the effective management of HIV/AIDS. This is possibly due to HIV being regarded mainly as a sexually transmitted disease which could make the stigma more intense.

As already mentioned in section 1.3.2, lupus is associated with visible body changes like skin lesions, scarring and weight loss (Hale et al., 2006b; McElhone et al., 2010), which are also associated with HIV. Other individuals with lupus also look different due to side effects of medication, for example, weight gain experienced with steroid use (Hale et al., 2006b;
McElhone et al., 2010; Robinson et al., 2010). This can result in increased self-consciousness, shame and withdrawal as they feel like they are the source of attention (Hale et al., 2006b).

The negative emotional impact of stigma in healthcare is seen to contribute to physical, psychological and social burden in terms of delaying seeking appropriate help and termination of treatment for treatable conditions such as leprosy, which has far reaching consequences (Weiss et al., 2006). It is, therefore, useful to identify the social processes which promote stigma and consider interventions for supporting those who feel stigmatised. However, culture may still limit the stigmatised individual's response to the reaction of others and to the coping choices that are available (Stuenkel and Wong, 2013). Other meanings of the consequences of chronic illness on individuals have also been associated with a term referred to as ‘biographical disruption’, as described in the next section.

1.3.4 Biographical disruption

Biographical disruption is also an experience that has been reported to have an adverse impact on individuals with chronic illness. Biographical disruption was first described by Bury (1982) in his study of rheumatoid arthritis amongst newly diagnosed young women. In the study, the onset of chronic illness was described as a biographically disruptive occurrence which undermined the person’s sense of self, leading to loss of self-confidence in the body, and loss of their understanding of the social world. Bury acknowledged that chronic illness disrupts social relationships with others due to the person’s functional limitations with their daily life activities and their growing dependency on others. Biography, in this context, is organised around the illness, the world of the ill person and their significant others, which can become compromised (Price and Walker, 2015).

Bury (1982) argued that disruptions caused by chronic illness can necessitate a rethinking of the individual’s biography, impelling them to make a ‘biographical shift’ from their seemingly perceived unpredictable life trajectory, to a relatively predictable trajectory. Patients often have to adjust their aspirations, lifestyle and employment (Turner and Kelly, 2000). Charmaz (1983), in contrast, suggests that patients may end up leading constrained lives, experience social isolation and feel like they are burdening their families. As they become dependent,
their self-esteem becomes significantly eroded as they appraise their past, present and projected future with the chronic illness.

While Bury’s (1982) work is seen as a critical reference point, critiques of Bury (Faircloth et al., 2004; Pound et al., 1998; Sanders et al., 2002) claim that the onset of chronic illness in older patients is a normal event, making biographical disruption an age dependent experience. However, this may be construed as ageism and stereotyping the elderly by assuming that all older adults develop chronic illnesses as a normal ageing process. Further criticisms suggest that Bury’s work is limited in theoretical and empirical range because it is limited to disruption caused by chronic illnesses that strike during mid and late adulthood, causing maximum disruption to a previously ordered life (Williams, 2000). Williams argued that this view ignores the fact that in some cases, illness can be traced from childhood where normative life already included illness. Williams (2000) asserts that for patients who have had chronic illness since childhood, other frames of theoretical references are needed to explore and explain their experiences and biographies adequately. So, the meanings made of the illness and the context in which the illness occurs is what determines whether the illness is disruptive or simply part and parcel of a life already defined.

Nevertheless, symptoms which interfere with normal activities and routines are a major concern in management of chronic illness (Chong and Wang, 2008; Henoch et al., 2014; Melanson and Downe-Wamboldt, 2003). Many individuals are concerned with degree to which they can maintain control over their illness and also, by extension, themselves. Medications promise personal control over illness and freedom from pain and discomfort which may enable individuals to overcome potentially incapacitating biographical disruption. However, for many patients, the fact that medications are required to achieve such freedom implies their reliance on medicines, while others are concerned about the long-term side effects of medication (Chambers et al., 2007; Goodman et al., 2005). Some individuals, therefore, frequently put up with a significant amount of pain and discomfort or use alternative strategies, such as exercising, resting or taking cod liver oil in arthritis management (Herrmann et al., 2000; Melanson and Downe-Wamboldt, 2003). This is an attempt to remain in control of their health. In essence, biographical disruption in chronic illness results from the effects of symptoms on the individual's body and affects their physical, social and psychological life patterns.
Women with chronic illness also face biographical disruption in their day to day endeavours as they are unable to take care of their everyday responsibilities. In a study of women with fibromyalgia, Crooks (2007) established that a significant number of women had stopped working. They stopped playing the role of being productive paid workers due to their struggle to remain awake and alert as they experienced sleep disturbances. They also lost work related social contacts and experienced reduced engagement with family in regards to social life and social engagements.

In a study of women with gynaecologic cancer, Akyüz et al. (2008) also established that chronic illness disrupted women's ability to carry out society assigned unique gender roles such as housework, cooking, cleaning, ironing and child care during the intensive treatment period. These roles had to be taken over by other family members, predominantly female members, to preserve the balance of household dynamics indicating that they felt tired. Having gynaecological cancer created problems in the flow of the family’s daily life, and the cancer survivors had to take back their roles when their condition improved.

The other role of women in some societies involves pregnancy and childbirth. This role also became disrupted in the lives of younger women with gynaecologic cancer, who became anxious because they felt they had lost the ability to become pregnant and have children (Akyüz et al., 2008). Elderly women in the same study did not see the loss of fertility as a threat to their femininity. However, most of the women in the study did not want to discuss their sexual relations with their physicians or nurses even though there were issues related to their sexual life or femininity.

Some chronic diseases like fibromyalgia, a relatively new disease which mainly affects women, is considered as an illegitimate diagnosis because its pathologic origin is medically unexplained. Thus, doctors rely on the patient’s description of symptoms which mainly consist of constant pain, fatigue and diminished ability to participate in societal activities (Clauw and Crofford, 2003). Its existence has been rejected by some doctors who even refuse to diagnose it, while others feel that it is over diagnosed (Ehrlich, 2003; Hadler, 2003). Fitzcharles and Boulos (2003) argued that the attitudes of doctors towards the unexplained syndrome could be due to the biological sex and social gender issues, which could also be affecting allocation of clinical resources for medical research of such conditions. Åsbring and Närvänen (2002)
suggested that women, therefore, experience stigma associated with living with a disputed illness, making them avoid interactions with those who question the legitimacy of fibromyalgia. This is the type of stigma described by Goffman (1963) as an attribute that is socially controlled externally and in this case, by the medical professionals.

For women with a diagnosed chronic illness, Charmaz (1995) identified three stages of adjustment to life with chronic illness: experiencing the changed body; dealing with the changed body, and accepting that one is inseparable to the changed body. This helps in appreciating that adapting to life with a chronic illness is a process that occurs in due course. Driedger et al. (2004) also indicated that adapting to life with a chronic illness occurs over space and in place. Biographical disruption is, therefore, not only seen as an assault on the physical self, but also on the person’s sense of identity and self-worth (Charmaz, 1983).

1.3.5 Experience with treatment and health services
Patients’ experiences with health services encapsulate a range of interactions which could have both relational and functional aspects, with associated safety and effectiveness outcomes (Doyle et al., 2013). An eight nations (Australia, Canada, France, Germany, Netherlands, New Zealand, UK and US) study, on experiences of patients with chronic illness, with access and healthcare, reported most positive experiences among Netherlands patients, and most negative experiences amongst US patients (Schoen et al., 2009). Patients from countries like Netherlands, New Zealand, Australia and UK reported better experiences with healthcare access. Even though timing varied across countries, patients were able to access care when they needed it within the same or next day. However, patients in countries like New Zealand and UK experienced delays in accessing specialist care. In addition, patients perceived care to be less coordinated when they saw more than one specialist. Conversely, patients in US were more likely to forgo recommended care due to cost-related access and care problems. They also felt that their care was inefficient and poorly coordinated. The main difference between US and the other developed countries was related to different healthcare systems and health insurance which is a country policy in the US. Patients who had health insurance in US had better access to care than those who were uninsured. However, both groups were still likely to forgo care due to high cost of care.
Thorne (1993) suggested that patients experienced chronic illness at three distinct but interrelated levels: the individual, social and structural. She also identified that patients with chronic illness experienced organisational and socio-cultural issues within the healthcare system. At personal level, geographical distance from health services may pose access barriers, while at social level, community support may alleviate some challenges (Brundisini et al., 2013). On organisational issues, Thorne (1993) suggests that patients find themselves in revolving door of specialists and services, with none of the health providers showing commitment to help them make sense of everything. Patients and their families feel alone and frustrated as they discover, by accident, information they are entitled to. This was illustrated in one study of lupus patients in which participants felt they were left to join the dots as health professionals provided minimal information regarding their condition (Hale et al., 2006a). The negative association between patients and health professionals affected the way patients perceived the quality of care they received, and probably their adherence to recommended medical treatment.

According to Thorne (1993), patients with chronic illnesses also have to confront socio-cultural issues as they encounter behaviour and attitudes of both health practitioners delivering health services and the public. Mendelson (2006) indicated that individuals with lupus felt that their life was both medically and socially complex as doctors had a fixed way of managing their condition, such as using treatment guidelines, which they found quite frustrating. Individuals, therefore, gained some support from support groups they attended. This indicated the need to pay attention to patients’ experiences in the healthcare context which are often seen as problematic. It also portrayed self-management as a necessary component in the lives of individuals living with chronic illness.

1.3.6 Experience of chronic illness in low to middle-income countries

The growing chronic illness burden across all regions of the world is also a feature in low to middle-income countries (LMICs), due to better healthcare for acute and chronic conditions (Horton, 2007; Miranda et al., 2008). However, the impact of chronic illness is disproportionately higher on LMICs (World Health Organization, 2014) due to inadequate healthcare systems and high cost of treatment (Reddy, 2015). Patients with chronic conditions
in LMICs present mainly at the primary health facilities and are mostly handled in these facilities. However, most primary healthcare settings are oriented towards a traditional medical model of acute healthcare (Allotey et al., 2011; Remais et al., 2012; Samb et al., 2010). Health practitioners in these facilities often prescribe drugs as part of the overall disease management. The model therefore cannot meet the needs of patients with chronic conditions, because these patients require extended and regular healthcare contact (Allotey et al., 2014).

An assessment of universal coverage for adults with chronic illness in six LMICs (China, Ghana, India, Mexico, The Russian Federation and South Africa) (Goeppel et al., 2016) established that no country provided access to basic chronic care for more than half of the study participants. In addition, poor participants were more likely to face financial hardships and less likely to access care, making access rates unequally distributed. Only one country (South Africa) offered free primary healthcare for all patients however, participants in all the six countries expressed dissatisfaction with quality of health care services. Also, it was observed that long term adherence to treatments was remarkably low in LMICs (World Health Organization, 2002), which is also a reflection of failure of the healthcare system. It is recommended that only healthcare that provides relevant information, support and follow-up can improve adherence, which in turn can enhance patient’s quality of life and reduce the burden of chronic conditions (World Health Organization, 2002). Regarding lupus care in LMICs, only two studies from Jamaica and Ecuador report experience of lupus care in LMICs, and highlight poor adherence to treatment. The two countries utilise the same acute care model (Chambers et al., 2008; Miles, 2011). Moreover, in Ecuador (Miles, 2011), lupus is considered an emerging chronic illness.

In conclusion, there is a growing chronic disease burden LMICs. However, the healthcare system does not support chronic disease management. In addition, care is not free at the point of delivery for most patients, and there is also variable access to healthcare due to varying economic levels. In addition, there is poor adherence to treatment which could also be due to poor patient education and support towards self-care management.
1.4 Context of the study

1.4.1 Political and administrative system in Kenya

Kenya is one of the East African countries as illustrated in figure 1.1 (google.co.uk, 2015). Administratively, it is divided into 47 counties, with one national government and 47 county governments, giving it two levels of government which are distinct in their functions and also interdependent (Ministry of Health, 2014).

![Political Map of Kenya](image)

**Figure 1.1: Political Map of Kenya**

1.4.2 Demography of Kenya and disease profile

According to the 2009 population census, the total population was 38.6 million (38,610,097) with 19,192,458 being males and 19,419,639 being females (Kenya National Bureau of Statistics, 2010). The census results revealed that Kenyan population has a pyramid structure and is youthful with about 63% below 54 years of age. Ninety eight percent of the total population consists of Africans, while non-Africans (Arabs, Europeans and Asians) constitute not more than 1% (Central Intelligence Agency, 2015). Kenya consists of three broad cultural groups: the Bantus, Cushites and Nilotes, with Bantus constituting over 70%. There are 46 ethnic groups within the three cultural groups (Nationsencyclopedia.com, 2015). There are
about 60 spoken languages with English and Kiswahili being the main national languages. Majority of Kenyans are Christians (82%), 11% are Muslims, 5% belong to other religions, and 2% are not affiliated with any religion. About 80% of the population live in rural areas with only about 20% living in urban areas (Kenya National Bureau of Statistics, 2010).

With a gross per capita of US $938.6 in 2012, Kenya is considered a low-income country (United Nations, 2015). However, in the East African region, Kenya is considered as a centre for trade and finance with the fastest growing economy (World Bank, 2015b). The main economic sectors are agriculture, tourism and services (World Bank, 2015a). Seventy-five percent of Kenyan labour-force works in the agricultural sector which explains why majority of the population live in rural areas. However, unemployment rates remain high, at approximately 40%, which is attributed to the economic effects of post-election violence in 2007, drought and global financial crisis (Kenya National Bureau of Statistics, 2015; World Bank, 2015b). Nationally, approximately 46% of the people live below the national poverty line, which makes them vulnerable to poor health (UNICEF, 2015). However, this is better than other sub-Saharan countries like South Sudan (50.6%) and Zimbabwe (68%), but worse than some regional sub-Saharan countries like Tanzania (36%) and Rwanda (44.9%). Table 1.1 illustrates a summary of other key demographic, socio-economic indicators and disease profile.
Table 1.1: Summary of demographic, socio-economic indicators and disease profile in Kenya

<table>
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<tr>
<th>Demographic and Economic Indicators</th>
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<tr>
<td>Life expectancy at birth (2012)</td>
<td>61 years (males)</td>
</tr>
<tr>
<td></td>
<td>63 years (females)</td>
</tr>
<tr>
<td>Fertility rate</td>
<td>3.9</td>
</tr>
<tr>
<td>Crude birth rate</td>
<td>35/1000</td>
</tr>
<tr>
<td>Immunisation coverage (2010)</td>
<td>68%</td>
</tr>
<tr>
<td>Under 5 mortality rate (2014)</td>
<td>52/1000 births</td>
</tr>
<tr>
<td>Leading causes of disease burden (%) (2010)</td>
<td>HIV/AIDS 29.3%, lower respiratory infections 8.1%, tuberculosis 6.3%, diarrhoeal diseases 6.0%, malaria 5.8%</td>
</tr>
<tr>
<td>Leading groups of non-communicable diseases (%) (2010)</td>
<td>Neuropsychiatric conditions 5.8%, cardiovascular 3.0%, sense organ disease 2.9%, respiratory diseases 1.8%</td>
</tr>
<tr>
<td>Leading causes of death among adults (%) (2010)</td>
<td>Communicable diseases 72%, non-communicable diseases 20%, injuries 8%</td>
</tr>
<tr>
<td>Leading causes of death among children aged &lt; 5 years (%) (2010)</td>
<td>Diarrhoea 21%, pneumonia 16%, malaria 11%, prematurity 8%, birth asphyxia 8%, HIV/AIDS 5%</td>
</tr>
</tbody>
</table>


The top five causes of premature death in Kenya are HIV/AIDS, lower respiratory infections, malaria, diarrhoeal diseases and neonatal sepsis, in that order (Institute of Health Metrics and Evaluation, 2010). Non-communicable diseases such as cardiovascular disease, epilepsy, diabetes and injuries from road traffic accidents, are increasingly becoming significant contributors to high disease burden in Kenya (Institute of Health Metrics and Evaluation, 2010).

1.4.3 Structure of health services in Kenya

Structure of health services in Kenya comprises the public (government) and private health sectors. In the public sector, the major organisations providing care are the Ministry of Health (MOH) and parastatal organisations. Parastatal organisations are organisations or companies owned or controlled, wholly or partly, by the Kenya government. Organisations in the private
sector include private for-profit, non-governmental organisations (NGOs), and faith based organisations (FBOs). In total, Kenyan population receives health services through a network of over 4,700 health facilities countrywide, with the public sector operating the largest share of the facilities, accounting for about 51%. The public sector is also the major health service provider in rural areas (Ministry of Health, 2010). In essence, majority of Kenyans access health services through the public sector.

1.4.3.1 The public healthcare structure
The public healthcare system is structured in six levels, as illustrated in figure 1.2, with complicated cases being referred to higher levels of care.

![Figure 1.2: Levels of healthcare facilities](image)

**Figure 1.2: Levels of healthcare facilities**
The community health units promote appropriate health behaviours among community members. Dispensaries and health centres are meant to provide primary care services (Ministry of Medical Services and Ministry of Public Health and Sanitation, 2013). Dispensaries are intended to be the health system’s first points of contact with patients, however in some areas, health centres or even hospitals are the first points of contact. Dispensaries provide preventive health services and treat patients with minor illnesses. They are managed by enrolled and registered nurses who are supervised by appointed nursing
officers. Patients who cannot be managed by nurses are referred to health centres (Ministry of Medical Services and Ministry of Public Health and Sanitation, 2013).

Health centres offer preventive and curative services, mostly adapted to local needs. A typical health centre is staffed by at least one clinical officer, a diploma graduate in clinical medicine, who provides primary care to walk-in patients (Mbindyo et al., 2013). A health centre has a laboratory for simple diagnostic tests, such as blood slides for malaria parasites, sputum for acid fast bacilli, urinalysis, full haemogram, blood sugar, and stool ova and cyst. A health centre also has a pharmacy, minor theatre, maternity unit, maternal and child health services (Ministry of Health, 1994). A lupus patient would be expected to enter the health system at the dispensary or health centre level, where there are at least trained nurses or clinical officers.

The level 4 hospitals are county referral health facilities which provide more services. Also, they have medical officers and graduate nurses. The level 4 hospitals are coordination and referral centres for the smaller units (Ministry of Medical Services and Ministry of Public Health and Sanitation, 2013). They oversee the implementation of health policy at the county level and maintain quality standards (Ministry of Health, 2014). The level 5 and level 6 hospitals act as the national referral hospitals.

Kenya has seven level 5 referral hospitals which used to be the provincial hospitals. There are five national referral hospitals (the highest level of care): the two university hospitals - Kenyatta National Hospital and Moi Referral Hospital, Spinal Injury Hospital, Pumwani Maternity Hospital and Mathari Mental Hospital. The national referral hospitals are regional centres of specialisation which provide general and discipline specialisation (Ministry of Medical Services and Ministry of Public Health and Sanitation, 2013). In the public healthcare structure, rheumatology as a discipline specialisation is only offered at the National Referral Hospital, where there is a rheumatology clinic which operates once a week. There are only four rheumatologists in Kenya who are all based at the Kenyatta National Hospital, with no rheumatologist in any of the county hospitals. This assumes that a patient with lupus who seeks treatment at the other lower health facilities would probably not be managed optimally as a lupus patient, until they can access care at the rheumatology clinic at the tertiary hospital. The nurses who work with the doctors at the rheumatology clinic are general nurses who work in the various specialist clinics run at the same venue on different days. Thus the need to
establish the patients' perspectives of living with lupus and perspectives of doctors on impact of the condition and service organisation on patients.

1.4.3.2 The private healthcare structure

In Kenya, there are private clinics which also fall under level 2 health facilities. They provide mainly curative services and are either operated by nurses/midwives, clinical officers or doctors. They are registered by the appropriate governing bodies, depending on the proprietor’s qualifications (Ministry of Health, 1994). There are also private nursing homes which are the equivalent to level 4 hospitals, and offer similar services but at a fee.

In Nairobi, there are four level 5 equivalent private referral hospitals, two of which also have rheumatology clinics: The Aga Khan University Teaching Hospital and The Mater Misericordiae Hospital. The rheumatologists operate both clinics, and they operate twice a week respectively. Collaboration between the Ministry of Health and the private sector is irregular (Institute of Health Metrics and Evaluation, 2014).

1.4.3.3 Traditional practitioners

In Africa, 80% of the people utilise traditional remedies because of their easy access, sustainability, affordability and cultural status (Ministry of Health, 2011). However, there is no national policy on traditional medicine because they are informal health providers with no legislation, quality assurance or standardisation (World Health Organization, 2005a). Indigenous knowledge of medicinal plants evolves within a community and is passed on orally from one generation to the next (Jacob et al., 2004; Kareru et al., 2007). They are, therefore, not incorporated into the health system. However, there is some evidence regarding efficacy of some traditional remedies. A study performed in eastern Kenya (Kareru et al., 2007), reported that malaria and typhoid were treatable locally with a total of 15 and 12 herbal medicines respectively. Another study conducted in central Kenya (Cyrus et al., 2008) also reported promising results for skin conditions such as scabies, ringworms, burns, warts and boils, which were treated with 51 herbal medicines and soil. These were reported to have antiviral, antimicrobial and anti-inflammatory properties. In Kenya, the extent of the use of traditional medicines in the management of lupus is not known.
1.4.4 Kenyan health systems

WHO suggested a framework with six building blocks necessary for strengthening the health systems to improve health outcomes (World Health Organization, 2007). These comprise leadership and governance, health workforce, health service delivery, health financing, health information system, and access to medical products and technologies. The Kenyan public sector has experienced challenges with all the building blocks.

Leadership and governance

In Kenya, at the national level, health leadership is provided by the Ministry of Health. The ministry offers capacity building and technical assistance to county health facilities, develops quality standards and runs the national referral hospitals. In contrast, the county governments are responsible for providing county health services and promoting primary healthcare (Ministry of Medical Services and Ministry of Public Health and Sanitation, 2013). In this arrangement, the level 5 and level 6 hospitals provide a wide range of services from general specialist to sub-specialist services, while the lower levels provide more limited services (Institute of Health Metrics and Evaluation, 2014). This has an impact on patients who have to travel to access specialist services in level 5 and 6 hospitals. Also, lupus services are only offered in one tertiary hospital and two level 5 private hospitals, making lupus services very limited. The other concern is the inter-regional disparities across service types due to other factors like being remote or rural (Ministry of Health, 2010). There is a definite need to appraise the type of services being offered at the county hospitals which are regional referral hospitals with an aim to build capacities and offer technical assistance to these hospitals.

Health workforce

In Kenya, the health workforce consists of health practitioners and non-health practitioners. Health practitioners constitute those who have undergone a defined and formally recognised training programme (Ministry of Health, 2014). The government of Kenya has put much effort into training to improve numbers of health practitioners. It has been reported that there has been a gradual increase in the number of health practitioners over the years, with an average of 21 doctors and 160 nurses for every 100,000 persons by 2013 (Ministry of Health, 2014). There are also 32 clinical officers per 100,000 persons, who are diploma level graduates (Ministry of Health, 2014). However, these numbers are still below the WHO
recommended averages of 22 doctors and 228 nurses per 100,000 people for optimal delivery of services (World Health Organization, 2006). There are also challenges faced in the deployment of health practitioners to regions which are less favoured socio-economically and are geographically harder to reach. This has created an imbalance in the urban-rural distribution of health practitioners, with urban areas having the highest proportions of staff at the expense of rural and remote areas where about 80% of the population lives (Kenya National Bureau of Statistics, 2010). Also, advanced medical care, essential equipment and supplies are not equitably distributed between the urban and rural areas (Institute of Health Metrics and Evaluation, 2014). There is also a general lack of rheumatology workforce in the country with only four rheumatologists. So there is a great need to train the rheumatology workforce and to review where they are based to practice.

Health service delivery
With the implementation of the new constitution in 2013 (Government of Kenya, 2010), money is allocated from the national government to the county governments. This means that county governments pay staff salaries to persons working in the county health departments. In effect, the counties with high socio-economic ability have the benefit of employing more qualified staff than the poorer counties, which leads to marginalisation of some regions. Marginalisation in Kenya is, therefore, an effect of lack of fair distribution of scarce resources which mainly affects counties and communities situated in the coastal, northern and north eastern regions of Kenya, which are far removed from Nairobi where the central government is situated. The net effect of marginalisation is poor quality health services offered to the population in these areas (Ohenjo et al., 2006; Theobald et al., 2009). Also, most Kenyans reside in the rural areas where health services are not responsive to the needs of patients with chronic conditions like lupus, as illustrated above, due to both geographical distance and socio-economic deprivation.

Health financing
Methods of financing health services in Kenya include taxation, donor funds, health insurance and user fees (Ministry of Health, 1994), with taxation being the main source of government revenue (Kenya National Bureau of Statistics, 2015). The Abuja declaration recommended a 15% health sector allocation from the national budget allocation (World Health Organization, 2001). However, in Kenya, the government's health expenditure as a percentage of the total government expenditure has gradually decreased from 8% in 2001/02 to 4% in 2014/15.
(USAID, 2016). Donor funding has gradually increased from 16.4% in 2001/02 to 27.5% in 2014. Private financing has also gradually decreased from 54% in 2001/02 to 36.7% in 2009/10. (Ministry of Medical Services and Ministry of Public Health and Sanitation, 2010; USAID, 2016; World Bank, 2014a; World Bank, 2014b). This means that in the public sector, health services in Kenya are underfunded by the government and are heavily dependent on donor funding. Also, the public sector is characterised by mismanagement of funds (Ministry of Health, 2010).

Healthcare in public hospitals is also partly financed by funds raised by health facilities through a highly subsidised payment for services by patients, which is popularly referred to as 'cost sharing'. However, majority of Kenyans live on less than the equivalent of a dollar a day and cannot afford any form of healthcare (Kenya National Bureau of Statistics, 2012), which includes lupus care.

In contrast, private health services are financed largely through revenue collected from fees and insurance premiums charged to service users with no cost subsidy. Utilisation is therefore based on the ability to pay. However, only about 10% of the population has some form of insurance cover (Kenya National Bureau of Statistics, 2012), with the National Hospital Insurance Fund (NHIF) being the most affordable. Employers are mandated to contribute towards this fund for employees in formal employment. However, over 82% of the population are in informal (e.g. self-employment) employment making the NHIF inaccessible to most. This leaves most of the population with the option of out-of-pocket payments for health services.

As indicated above, the healthcare in Kenya is unaffordable. However, patients with lupus have to either participate in cost sharing for the public healthcare, or pay for all the services they receive in the private hospitals for the management of their condition. This could be negatively affecting the health outcomes of people with lupus.

**Health information system**

A country’s health information system plays an important role in generating information that can be utilised in monitoring health programmes, and as a point of reference in support of evidence informed decisions (World Health Organization, 2011b). It has the potential of enabling policy makers to recognize service coverage gaps that need improvement for greater
effectiveness. Despite its importance, the health information system in Kenya experiences many challenges regarding its ability to generate valid and reliable information required both nationally and globally (Hahn et al., 2013; Kihuba et al., 2014). The country lacks trained human resources, infrastructure, as well as appropriate data collection and reporting tools. This has resulted in limited quality data (Ministry of Health, 2008). For example, there are no data registries for rheumatologic conditions in Kenya. The lack of required health information has hindered the Ministry of Health in acknowledging the magnitude of these conditions, rendering them to be classified under other conditions. Also, the ministry cannot, therefore, adequately steer resource allocation in line with the needs of patients with rheumatologic conditions like lupus.

**Access to medical products and technologies**

Kenyan Health Policy Framework (Ministry of Health, 2014) allocated the function of medical procurement of pharmaceutical and non-pharmaceutical goods for public health facilities to the national government. The national government provides guidelines for purchase, distribution and management of essential medicines however, some facilities are inadequately equipped with medicine stockouts which limit availability and quality of health services (Ministry of Health, 2010).

In the management of lupus, immunological tests are required to help with making a diagnosis, while for the treatment of lupus the prolonged use of antimalarials and immunosuppressives are required. Availability of pharmaceutical and non-pharmaceutical goods in level 5 and 6 health facilities should be able to support minimum lupus care. However, absence of rheumatologists and essential laboratory equipment and supplies at level 5 institutions impedes specific evaluation which this group of patients require regarding diagnosis and laboratory investigations.

**1.5 Summary**

Lupus is a chronic disease which commonly affects women of childbearing age, due to various risk factors. Presentation of lupus is variable with diagnostic challenges. However, once diagnosed, management, though difficult due to variable disease trajectory, is stipulated in the available guidelines. However, there are no treatment guidelines for Sub-Saharan patients.
Nevertheless, the reality of living with chronic illnesses like lupus creates physical, social and psychological dimensions that need to be acknowledged and addressed. The chapter highlighted that even though chronic illnesses vary, patients tend to share some similar experiences such as illness uncertainty, changed body image, stigma and biographical disruption. They also seem to share similar challenges with treatment and healthcare services, though there are some country specific differences in patients' experiences which are determined by the respective countries' health policies. However, patients with chronic illnesses in LMICs experience greater challenges related to inadequate resources and high cost of treatment.

The chapter has also highlighted the context of the study. It described the political and administrative system in Kenya, the demographic and disease profile, structure and functioning of the health services including lupus services which are located at the tertiary hospitals in Nairobi.
Chapter 2: Literature Review

2.1 Introduction

This chapter presents a literature review about the experiences of living with lupus from the perspectives of the patients and doctors. This review provides a critical examination of the existing primary studies and a comprehensive overview of the existing literature. It also provides a holistic knowledge base for the study. To achieve this, a narrative review was conducted using a systematic approach.

The first section of this chapter visits the debate about the place of the literature review in a grounded theory study. The second section provides the rationale for the type of literature review conducted. This is followed by the narrative review with details of the search strategy, description, synthesis and critique of the included studies. Finally, the strengths and limitations of the studies and the gaps identified in the literature are discussed.

2.2 Debate on the place of literature review in grounded theory study

For the study, principles of grounded theory approach were adopted. Grounded theory approach is a research methodology mainly associated with its founders Glaser and Strauss (1967). The debate within grounded theory concerns when to engage with existing literature relevant to the research topic, how to go about the review and what to cover (Charmaz, 2014). The founders believed that theoretical concepts should emerge naturally from the empirical data collected for analysis, and that this would facilitate ‘the discovery of theory from data’ (Glaser and Strauss, 1967, p.1). They took the stance that a substantive literature review should be conducted after data analysis to minimise the potential contamination of data with extant theoretical concepts (Glaser and Strauss, 1967). Glaser (1998), together with others (Dick, 2007; Dunne, 2011; Locke, 2001), further argue that conducting a substantive literature review before data collection is time wasting because the researcher might not know the relevant literature at the outset, due to the nature of grounded theory research.

Conversely, delaying the relevant literature review is seen as unlikely, indefensible and a possible avenue for promoting deception by researchers to be “theoretical virgins” (Clarke, 2005 p. 13). This is because researchers cannot erase a preceding understanding of their areas of interest. In addition, non-theoretical literature can be valuable in mitigating the study
(McGhee et al., 2007). Other grounded theorists also argue that for practical reasons the researchers have to review the relevant literature in order to include findings in their study proposals for funding and for ethical review purposes (Clarke, 2005; Dunne, 2011; Hallberg, 2010). It was from the basis of ethical review requirements and providing a summary of relevant previous published studies that I proceeded with undertaking a literature review, to identify relevant literature on my research topic to gain an awareness of what research had already been carried out and to inform the study design. Further discussion about the appropriateness of applying grounded theory strategies is provided in chapter three.

2.3 Narrative Approach to the Review

A narrative approach to the literature review was undertaken to make sense of the array of information already published on the perspectives of living with lupus. Although systematic reviews are believed to be superior with their explicit and definite methods of selecting relevant publications, with a rigorous appraisal for the validity and synthesis of specific issues, their use can be restrictive in qualitative research due to their narrow focus (Collins and Fauser, 2005; Green et al., 2006).

Narrative approaches to conducting a literature review offer some unique advantages, such as having the ability to comprehensively address a broad range of issues/questions within a given broad topic, and providing a summary of the most recent and best available evidence for utilisation (Collins and Fauser, 2005). This improves the understanding of phenomena (Dijkers, 2009; Mays et al., 2005). Also, narrative reviews allow the utilisation of both descriptive phrases and metaphors used by the participants, and the contributions of the reviewer's interpretive synthesis which strengthens the evidence and deepens understanding. As narrative reviews have become increasingly systematic, they can also be utilised to integrate both qualitative and quantitative evidence (Dixon-Woods et al., 2005; Pope et al., 2007).

Nevertheless, this approach has been criticised for being subjective and potentially biased. This is due to a lack of clarity on the methods to follow when selecting studies to be included, and the lack of prescribed guidance about how to conduct the review (Dijkers, 2009; Mays et al., 2005). The wide range of evidence may also make decision-making regarding specific issues difficult. This leads to reliance on the skills and experience of the reviewer, especially
in determining and integrating complex interactions (Rumrill Jr and Fitzgerald, 2001). Therefore, it can be difficult to discern whether or not a reviewer has constructed an objective review (Garg et al., 2008; Green et al., 2006).

For this study, a narrative review was considered appropriate for understanding the complex and broad illness experiences and healthcare issues regarding living with lupus, in patients with diverse demographic, socio-economic and illness backgrounds. The review summary was intended to highlight the differences and similarities, and provide a ‘bigger picture’ view of the phenomena of living with lupus. Being a novice researcher, a systematic approach to the narrative review was employed to provide structure and consistency with the review process, and a writing style for the presentation of the research findings (Green et al., 2006). The review process also involved a thematic analysis of the illness experience.

2.4 Aim of the literature review
The aim of the literature review was to identify and critique the studies which have developed concepts to aid the understanding of living with lupus from the perspectives of the patients and doctors.

2.5 Review questions
This review was shaped using five questions developed iteratively from the process of reading the retrieved articles:

1. How do patients experience lupus before diagnosis and what are their help-seeking behaviours?
2. What are the patients’ experiences with the treatment and care of lupus?
3. What are the doctors’ perspectives on service organisation and the delivery of care to lupus patients?
4. How has having lupus affected the patients’ lives?
5. How do the patients manage lupus themselves?
2.6 Review methods

The review of the literature was conducted through the following stages:

- Search strategy
- Search results
- Description of identified studies
- Quality appraisal of identified studies
- Methodological critique of reviewed studies
- Synthesis of reviewed studies

2.6.1 Search strategy

For this review, the following five electronic databases were used: MEDLINE, Embase, PsycINFO, CINAHL and Web of Science. Studies were also identified from reference lists. The search was limited to articles published in peer reviewed journals and written in English between 2000 and December 2016. The decision to only include studies published from the year 2000 onwards was because a lot of progress has occurred in the immunologic knowledge of lupus which led to the revision of the 1971 preliminary criteria for the classification of lupus in 1982 (Tan et al., 1982), in 1997 (Feletar et al., 2003) and also in 2012 (Petri et al., 2012) for the purposes of classifying patients in clinical studies. This, to some extent, has guided the identification of lupus patients and the monitoring of disease activity (Ighe et al., 2015; Yu et al., 2014). It is, therefore, logical to presume that the experiences and views of lupus patients about their diagnosis, treatment and care have also changed over time (between the 1970s and 1990s). For example, the treatment of lupus has improved from the era of only using steroids (Hench, 1952) to the present era of biologic agents (Dooley and Ginzler, 2006). Therefore, the decision to review studies published after 2000 was made to focus on studies which reflect the current views on living with lupus.

The inclusion and exclusion criteria applied to narrow down the search and ensure its relevance to the aims of the review are shown in Table 2.1.
Table 2.1: Inclusion and exclusion criteria for selected research studies

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Empirical studies</td>
<td>Non-primary research articles (letters, commentaries and reviews)</td>
</tr>
<tr>
<td>Involved adult patients (age 18 years and above) with primary diagnosis of lupus</td>
<td>Study addressed patients with lupus complications, such as overt neuropsychiatry and lupus nephritis.</td>
</tr>
<tr>
<td>Addressed some aspect of the physical, psychological and social experiences of lupus</td>
<td>Studies from the explicit perspectives of family members or care givers</td>
</tr>
<tr>
<td>Involved health practitioners in the care and treatment of lupus</td>
<td></td>
</tr>
</tbody>
</table>

The search terms used to identify studies are provided in Table 2.2 below:

**Table 2.2: Search terms**

<table>
<thead>
<tr>
<th>Perspective/view/opinion/perception</th>
<th>Illness perspective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systemic lupus erythematous/Lupus</td>
<td>Living with</td>
</tr>
<tr>
<td>Adult/young adult</td>
<td>Medical practitioners/doctor</td>
</tr>
<tr>
<td>Illness experience, Illness perception</td>
<td>Primary healthcare</td>
</tr>
</tbody>
</table>

The search was refined by using MeSH headings in the database thesaurus and considering alternative key words with similar meanings that could elicit further information, as shown in Table 2.2. Key words were combined by using the Boolean operators ‘AND’ and ‘OR’ to refine the search. An example of the process of the search strategy and the key terms used is illustrated in Appendix 3.

**2.6.2 Search results**

Figure 2.1 shows the process and results of the literature search. The search yielded a total of 1464 citations. After scrutinising the titles and reviewing the abstracts, a total of 1397 articles were excluded because they were not relevant to the study due to being purely quantitative.
studies. These were studies that were either correlation, intervention or survey studies which utilised structured data collection instruments in the form of questionnaires. The study findings were therefore based on the researchers' interpretation of the observed phenomena of living with lupus, rather than on the participants' interpretation of naturally occurring phenomena in the social world. Despite the ability of quantitative research to evaluate and provide a detailed analysis of various dimensions for particular opinions, it is limited by its inability to probe deeper into people's motives and feelings (Macur, 2013). Duplicated articles were also omitted. This left only 67 articles. The 67 articles underwent full textual analysis which further excluded 29 studies, because they were either not relevant to the study area or were non-primary studies. This left 38 studies which met the inclusion criteria by addressing aspects of the physical, psychological and social experiences of lupus, including care and treatment.

Figure 2.1: Search results

2.6.3. Description of identified Studies

Figure 2.1 illustrates that the studies were conducted across 17 countries with the majority in the western developed countries and only 3 in the developing countries i.e. Ecuador, Brazil
and Jamaica. No studies were identified from Africa. Furthermore, no study was identified regarding just doctors’ perspectives. However, one study highlighted both patients’ and health professionals' perspectives on patient education program (Miljeteig and Graue, 2009), whereas one study examined patients’ perspectives of healthcare provision (Hale et al., 2006a). This highlighted the paucity of evidence related to perspectives on living with lupus among doctors and perspectives from Africa including Kenya. Of the thirty-eight studies reviewed, thirty employed qualitative research methodology, while eight were mixed methods studies (table 2.3). Also, the studies were mainly published between 2006-2016.

**Table 2.3: Research methodology utilised by the reviewed studies**

<table>
<thead>
<tr>
<th>Qualitative Studies (n=30)</th>
<th>Mixed methods studies (n=8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beckerman et al., 2011; Gallop et al., 2012; Goodman et al., 2005; Hale et al., 2006a; Hale et al., 2014; Hale et al., 2006b; Howe, 2009; Karlen, 2002; Kumar et al., 2011; Mattje and Turato, 2006; Mattsson et al., 2012; Mazzoni and Cicognani, 2014; McEhlone et al., 2010; Mendelson, 2003; Mendelson, 2006; Miles, 2011; Neville et al., 2014; Nowicka-Sauer, 2007; Ow et al., 2011; Pettersson et al., 2010; Rutter and Kiemle, 2015; Schattner et al., 2008; Spry, 2014; Stamm et al., 2007; Sterling et al., 2013; Stockl, 2007; Taïeb et al., 2010; Waldron et al., 2011; Williams et al., 2015; Brennan and Creaven, 2016</td>
<td>Chambers et al., 2008; Chambers et al., 2009; Hatfield-Timajchy, 2007; Mancuso et al., 2010; Miljeteig and Graue, 2009; Pettersson et al., 2012; Robinson et al., 2010; Wittmann et al., 2009</td>
</tr>
</tbody>
</table>

Richard and Morse (2012) state that the purpose of the research informs the choice of research methodology. In qualitative research, the purpose is to understand complex phenomena where little is known and to make sense of situations by learning from participants (Morse and Field, 2013; Richards and Morse, 2012). The choice of research methodology is also determined by the type of research questions and the phenomena under investigation (Creswell, 2012; Denzin and Lincoln, 2005; Silverman, 2013). Therefore, the best research method is the one that most effectively answers the research question. Researchers need to be clear about the approach
they intend to use from the start to enable them to collect data suited to the method, otherwise, the value of the research is reduced significantly (Annels, 2007; Patton, 2002).

About a quarter of the studies utilised the mixed methods approach to understand the patients’ perspectives of living with lupus. Qualitative and quantitative research methods are increasingly being combined in primary research as complementary, with qualitative evidence offering an explanation for, and interpretation of, the quantitative findings. This enhances the performance of each corresponding method (Murtagh et al., 2007).

2.6.4 Quality appraisal of identified studies

Although there are many validated tools for assessing the quality of studies in systematic reviews, there is a lack of broadly accepted criteria for evaluating the quality of studies with most of the tools developed to evaluate specific study designs (Blank et al., 2012). The retrieved studies were assessed for quality using a generic appraisal tool with a summed scoring system developed by Hawker et al. (2002), (see Appendix 4).

The tool has nine criteria sections, and each section can be rated using a 4-point Likert scale, with a lowest possible aggregate score of 9 and a highest possible score of 36. I classified the lowest score of 9 as very poor, 10 to 18 as poor, 19 to 27 as fair and 28 to 36 as good, as recommended by Hawker et al. (2002). I utilised the assessment tool because:

1. It can be used to assess the quality of studies with differing research methods.

2. The tool can be used to analyse various sections of a study systematically, providing a general impression about specific areas of strengths and weaknesses.

3. The various quality criteria of the tool are almost the same as the Qualitative Research Checklist developed by the Critical Appraisal Skills Programme (CASP, 2013), but with an added advantage of the scoring system which can give a general idea about the strengths of the studies included in the review.

Each of the 38 studies was subjected to the assessment tool and evaluated for each category. The majority of the studies were of good quality (34 out of the 38). Only four studies were of fair quality, as summarised in Appendix 5. All of the 38 studies included in the review
provided a clear statement about their research aims, and the choice of research designs was appropriate for answering the research questions. The areas of weaknesses for the studies with lower scores included: having an abstract with inadequate information (Mattje and Turato, 2006; Mazzoni and Cicognani, 2014; Stockl, 2007), ethical issues which were not clearly addressed (Beckerman, 2011; Hale et al., 2014; Karlen, 2002), and inconsistencies in choice of methodology and methods. The detailed methodological critique of the studies is discussed in the next section.

2.6.5 Methodological critique of identified studies

This section provides an overall critique of the reviewed studies. The reviewed studies varied both in methodology and methods utilised, as summarised in Appendices 6 and 7. A research methodology guides a researcher in planning, executing and monitoring a research study, and a number of different research strategies exist. Selecting a methodology of inquiry for a study provides guiding principles by connecting the researchers to specific approaches and methods for data collection and analysis (Denzin and Lincoln, 2005). The choice of the strategy is determined by the researcher's ontological, epistemological and methodological assumptions (Denzin and Lincoln, 1994). The reviewed studies were undertaken across a variety of urban settings and were both qualitative and mixed methods studies.

2.6.5.1 Qualitative studies

The review included 30 qualitative studies. Fifteen of the studies utilised generic qualitative approaches (see appendix 7a), which Caelli et al. (2003) described as studies that seek to explore phenomena and processes, or the perspectives and views of people, without claiming allegiance to a particular research design; they are classified as interpretive studies. All of the 15 studies had clear aims. However, a significant number did not specify their sampling techniques, while a few did not specify their analysis techniques even though the steps for recruitment were clearly described.

There has been considerable debate concerning the level to which rigour can be preserved outside of the guiding principle of an established methodology (Kahlke, 2014). However,
some of these studies borrowed elements of the traditional approaches, such as purposive sampling which is mainly used in methodologies like phenomenology. Hunt (2009) and Thorne (1991) propose that generic qualitative studies can draw on the strengths of traditional methodologies while retaining the flexibility the approach enjoys.

Besides generic qualitative approaches, the traditional methodologies for qualitative research which were utilised in the identified studies included phenomenology (n=8), grounded theory (n=4) and ethnography (n=3), which are also broadly classified as interpretive. Phenomenology was the most commonly used design. It enabled the researchers to understand the different illness meanings of lupus as a phenomenon, for example, the impact of lupus (McElhone et al., 2010). This is in line with Smith's (2004) idea of phenomenology being the study of consciousness from the first person's point of view. It is about how people experience their lived world without abstracting it.

Grounded theory is used to explore incidents, events, experiences and to understand processes in research areas where little is known about the topic (Richards and Morse, 2012). In the reviewed studies, grounded theory was used to generate an understanding of many different issues including: understanding the perceptions regarding the influence of social support in coping with depression among women diagnosed with lupus (Howe, 2009); the health related quality of life domains of importance to lupus patients (Ow et al., 2011); the informational and resource needs of individuals with lupus (Neville et al., 2014; Waldron et al., 2011). The aim of utilising grounded theory in the reviewed studies was to discover theoretical propositions about the different social phenomena.

Three studies utilised ethnography (Mendelson, 2006; Miles, 2011; Stockl, 2007). Richards and Morse (2012) suggest one understanding of ethnography as exploring cultural groups from the perspective of its members with the assumptions that cultural beliefs, values and behaviours are learned, patterned and influenced by other elements such as social arrangements and systems of power. As an inquiry method, traditional ethnography typically involves immersion in the everyday life of the research setting to enable prolonged direct contact and observation of the interactions and behaviour from an 'emic' or insider's perspective (Pope, 2005).
In one study, the researcher indicated that she utilised focused ethnography (Mendelson, 2006), which is an ethnographic adaption with some unconventional features, such as studying people who do not necessarily know one another. Focused ethnography deals with a specific problem in a specific context within a sub-cultural group, as opposed to exploring a culture-sharing group defined along geographical or ethnic lines (Knoblauch, 2005; Mayan, 2016). Focused ethnography is short term and typified by an interest in a specific research question and involves an intensive method of data collection and recording which may not require extensive field visits (Richards and Morse, 2012). In this case, the researcher focused on the common behaviour and experiences of participants with lupus, with an assumption that they shared a cultural perspective (Mayan, 2016; Richards and Morse, 2012). This method was appropriate for exploring the daily experiences of women living with lupus from a sample of the patient support group (Mendelson, 2006) because, there was intensive data collection during the support group meetings. Attending the support group meetings constituted field visits, which enabled the researcher to discover the activities of the participants.

**Sampling techniques**

In the reviewed qualitative studies, most of the generic qualitative studies did not specify their sampling techniques whereas most of the traditional qualitative studies did. A purposive sampling technique was the most common for included qualitative studies, followed by convenience sampling, while two others studies utilised snowball and random sampling techniques, as illustrated in Appendix 7a.

The primary form of sampling in phenomenology is the purposive sampling of individuals who have experienced the phenomena. The samples tended to be small, though this is expected with phenomenology (O’Halloran et al., 2016; Penner and McClement, 2008), with consideration of data saturation as the marker for sampling adequacy (O'Reilly and Parker, 2012). Ritchie and Lewis (2003) argue that the small sample sizes only work if the researcher has a strong sampling strategy to cover the breadth of the research aim. The other form of purposive sampling that can be carried out in phenomenological studies is theoretical sampling, which was developed from the grounded theory approach (Glaser and Strauss, 1967). Only one grounded theory study specified that they applied theoretical sampling, while the other three grounded theory studies did not specify their sampling techniques.
Convenience sampling, which relies on a sample that is easily accessible, was utilised by five studies. It is seen as an excellent means of providing quick preliminary information about a research topic (Berg and Lune, 2012). However, it has been criticised for some associated risks such as not allowing for the maximum variation of participants (Etikan et al., 2016). In this case, it would not allow the maximum variations of the characteristics of participants with lupus, like sampling younger and older participants or participants with shorter or longer disease duration, which can be easily achieved with purposive sampling. The sample sizes ranged from 10-36 participants, and only three studies had male participants: four men in Goodman et al. (2005), one in Hale et al. (2014) and two in Spry (2014). The snowball and random sampling techniques used in two other studies (Miles, 2011; Williams et al., 2015) do not facilitate the maximum participant variations necessary with small sample sizes. Participant recruitment was mainly from the rheumatology clinics and clearly explained in most of the studies.

Data collection

Data collection was achieved mainly through semi-structured interviews and focus group discussions, as illustrated in Appendix 7a. Data were also collected through observation in ethnographic studies. ‘Bracketing’ the researcher’s experience of the phenomena during data collection and analysis is a main feature of phenomenology which was not addressed in any of the studies. It is aimed at mitigating the potentially adverse effects of preconceptions related to the study (Groenewald, 2004; Tufford and Newman, 2012). However, tension exists on the ‘what’ and ‘how’ of bracketing, which is seen to cause a lack of uniformity in data collection and analysis (Tufford and Newman, 2012).

Conversely, data collection in ethnographic studies may require more than one method, such as participant observation, in-depth interviews, symbols and artefacts to facilitate identification, comparison and contrasting of characteristics (Creswell, 2012). Two ethnographic studies had more than one method of data collection - semi-structured interviews and observations (Mendelson, 2006; Stockl, 2007). Participant observation is a strong element in ethnographic data collection and allows the researchers to gain perspectives about the group norms and values. It facilitates capturing the tacit knowledge which only emerges as the researcher observes the group interactions (Ellis, 2016). One study only relied on semi-structured interviews to reveal the cultural elements of interest (Miles, 2011); however, the
participants in this study were interviewed either two or three times which made data collection both intensive and in-depth.

Mays and Pope (2000) suggest that methodological triangulation is a way of ensuring the comprehensiveness of data collection by capturing different perspectives of the same phenomenon, and is not a test of validity. However, critics of methodological triangulation argue that it assumes that weaknesses in one method are compensated by strengths in the other method, which might not necessarily be the case due to differences in accounts (Mays and Pope, 2000).

Another key feature of data collection in ethnography is reflexivity (Lee et al., 2005), in which the researcher reflects and reports on their background, personal beliefs, interests and in some cases their gender, and how these could influence the study at hand (Lichterman, 2015). None of the researchers in the three studies indicated their reflexive stance, although Lee et al. (2005) argue that in ethnographic studies the researcher can never be assumed to be an objective, disinterested observer. Pope (2005) further claims that the researcher's roles are not static as one can start as an outsider or complete observer and then become an insider as the researcher becomes more integrated.

In contrast, the general elements of grounded theory research design are theoretical sampling, data collection and the constant comparison of data (Strauss and Corbin, 1998). Theoretical sampling is used to gather additional data to corroborate the existing data and continues during the entire interviewing process until theoretical saturation is achieved (Starks and Trinidad, 2007). Data is typically collected in interview form and through observation (Green and Thorogood, 2013). The interview guide may be modified as data collection proceeds to further refine the questions (Strauss and Corbin, 1998).

In the four grounded theory studies, the researchers collected data through focus group interviews. Webb and Kevern (2001) suggest that in grounded theory studies, focus groups can be used as constant comparative procedures are achieved both within and among focus groups. In some of the grounded theory studies, it was not clear whether the principles of grounded theory were applied or not. Especially the amendment of the interview guide (Howe, 2009; Neville et al., 2014; Ow et al., 2011), constant comparative data analysis and theoretical sampling in focus groups (Howe, 2009; Neville et al., 2014; Ow et al., 2011). Only one study
(Waldron et al., 2011) indicated that the interview guide was amended after the first focus group interview in response to emerging data. Only one study (Waldron et al., 2011) reported how theoretical sampling and constant comparative analysis was achieved between the focus groups. Also, only one study (Waldron et al., 2011) described the nature of the group dynamics which might stimulate the generation of data, or otherwise, and influence the outcome of the studies (Parker and Tritter, 2006).

**Data analysis**

In phenomenology, data analysis involves coding, categorising and making sense of the essential meanings of the phenomena (Penner and McClement, 2008). In the reviewed studies, the data analysis for the phenomenological studies was conducted through interpretive phenomenological analysis, except one study (Schattner et al., 2008) that utilised thematic analysis. One study (Taïeb et al., 2010) gave a reflexive account of their research. Reflexivity is perceived as an integral process in qualitative research. Jomeen (2006) suggests that reflexive accounts should show evidence of methodological and theoretical appreciation, and clear awareness of the interaction between the researcher and participants. It helps the researcher, who acts as a research instrument, to develop self-awareness which is necessary for continuously monitoring their thoughts, reactions and emotions. However, critics argue that even though reflexivity is considered to be a common practice, its meaning is not clear and it does not consist of standardised processes, and therefore people exercise it in diverse ways (Caetano, 2015; D’Cruz et al., 2007).

In ethnographic studies, the methods of data analysis were mentioned in all three studies. In one study the data analysis was complex due to the many data sources, but was clearly explained (Mendelson, 2006). While in another study, the researcher indicated that they used grounded theory methods in data collection and analysis, although this was not demonstrated in the study (Stockl, 2007); the same study, however, highlighted the differences between the male and female participants. In one other study (Miles, 2011), the data analysis was inadequately explained.

The principles of ethnography were not clearly explained in two studies (Miles, 2011; Stockl, 2007). However, the researchers were able to understand and interpret the different study cultures as the participants described their experiences and impressions of the medical culture.
For example, one study revealed that the doctors used the lupus guidelines in the context of making a lupus diagnosis even though, in most cases, this caused a delay for the patients in getting a lupus diagnosis (Stockl, 2007). The study also revealed the dynamics of power as only the doctor could give a lupus diagnosis and then start the patients on the appropriate lupus medications.

2.6.5.2 Mixed Methods studies

Of the eight mixed methods studies reviewed, the methodologies of the qualitative arm of four studies also varied and included: ethnography (Hatfield-Timajchy, 2007), phenomenology (Robinson et al., 2010), action research (Miljeteig and Graue, 2009) and case study (Wittmann et al., 2009) (see appendix 7b. Miljeteig and Graue (2009) utilised action research as a strategy for inquiry. Meyer (2001 p:173) states that "action research is concerned with generating knowledge about a social system, while at the same time, attempting to change it". The research method was appropriate for the study which sought to evaluate an educational program for people with lupus by establishing the health practitioners teaching and learning competency needs, and the patients' unmet needs. Thus, the study illustrated the ability to share research problems between researchers and participants, who were able to identify their unmet needs, with the aim of improving their experiences. In the other three mixed methods studies (Chambers et al., 2008; Chambers et al., 2009; Pettersson et al., 2012), the qualitative methodologies were not indicated.

Five of the reviewed studies used semi-structured interviews to collect data. This was appropriate because although the researcher prepares a list of pre-determined questions to help define the areas to be explored, the semi-structured interview allows flexibility of coverage as researchers are free to follow any areas of the participants' interests or concerns (Gill et al., 2008). By probing issues that arise, the process allows for the discovery or elaboration of information and also allows the researcher to enter the social and psychological worlds of the study participants, thus producing richer data (Taïeb et al., 2010). The next popular method of data collection was focus group interviews, followed by the participant observation method. The eight mixed methods studies combined multiple methods of data collection. The triangulation of data collection methods enriches the study and makes it comprehensive, particularly when self-reports which might be less objective are utilised (Sandelowski, 2000).
In one study, the participants illustrated their perceptions in the form of drawings (Nowicka-Sauer, 2007) which enabled the participants to express themselves. This was an informative new way of conducting research.

On the other hand, methodologies of the quantitative arm of the mixed method studies were not clearly specified to facilitate informed decision making on most of the quality issues. The sampling techniques for more than half of the studies were clearly specified (Brennan and Creaven, 2016; Chambers et al., 2008; Chambers et al., 2009; Hatfield-Timajchy, 2007; Mancuso et al., 2010; Wittmann et al., 2009) while others were not (Miljeteig and Graue, 2009; Robinson et al., 2010). Data collection methods utilised were clearly specified in all the eight studies. However, data analysis and presentation of findings were only clearly explained in half of the studies (Mancuso et al., 2010; Miljeteig and Graue, 2009; Pettersson et al., 2012; Wittmann et al., 2009) and scantily in the other half of the studies. In general, the quantitative aspects of the mixed methods studies were not all robust, thus affecting their ability to meet the validity and reliability criteria required for generalisation of the results to the population from which the samples were drawn.
2.6.6 Synthesis of the reviewed studies

The 38 studies explored a range of experiences and perspectives as outlined in table 2.4.

Table 2.4: Experiences and perspectives explored in the various studies

<table>
<thead>
<tr>
<th>Experiences and perspectives explored</th>
<th>Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having lupus in general</td>
<td>Goodman et., 2005; Mattje and Turato, 2006; Mattsson et al., 2012; Mils, 2011; Nowicka-Sauer, 2007; Stockl 2007</td>
</tr>
<tr>
<td>Health related quality of life</td>
<td>Gallop et al., 2012; Ow et al., 2011; Pettersson et al., 2012; Schattner et al. 2008; Mancusco et al., 2011</td>
</tr>
<tr>
<td>Impact of lupus on patients (psychosocial challenges)</td>
<td>Beckerman, 2011; Mancusco et al., 2010; McEhlone et al., 2010; Mendelson, 2006; Pettersson et al., 2010; Robinson et al., 2010; Wittmann et al., 2009; Rutter and Kiemle, 2015</td>
</tr>
<tr>
<td>Patient illness beliefs and reasons for taking medications or not</td>
<td>Chambers et al., 2008; Chambers et al., 2009; Karlen, 2002; Kumar et al., 2011; Taieb et al., 2010</td>
</tr>
<tr>
<td>Concerns about the illness</td>
<td>Hale et al., 2006a; Hale et al., 2014; Stamm et al., 2007</td>
</tr>
<tr>
<td>Information needs of patients</td>
<td>Neville et al., 2014; Waldron et al., 2011</td>
</tr>
<tr>
<td>Support available to patients</td>
<td>Howe, 2009; Brennan and Creaven, 2016; Mendelson, 2003., Miljeteig and Graue, 2009; Mazzoni and Cicognani, 2014</td>
</tr>
<tr>
<td>Healthcare provision</td>
<td>Hale et al., 2006b; Hatfield-Timajchy, 2007</td>
</tr>
</tbody>
</table>

The study findings were analysed in a narrative form and relationships among the study findings were reviewed. The review has been arranged around seven themes which emerged from the literature:

- Uncertainty in illness
- Illness Beliefs
- Changed body
• Stigma
• Biographical disruption
• Social support and emotional distress
• Information needs

2.6.6.1 Uncertainty in illness

In eleven of the reviewed studies, two types of uncertainty were identified: pre-diagnostic uncertainty related to diagnostic delays (Goodman et al., 2005; Hale et al., 2006a; Hatfield-Timajchy, 2007; Mendelson, 2006; Spry, 2014; Stockl, 2007; Waldron et al., 2011) and uncertainty regarding illness trajectory (Beckerman, 2011; Mattsson et al., 2012; McElhone et al., 2010; Schattner et al., 2008; Stamm et al., 2007).

The seven studies which highlighted diagnostic delays were conducted in Australia, the UK and the US, all developed countries. Participants reported the difficulties that medical practitioners encountered in making the initial definitive diagnosis of lupus following the onset of their illness. In the UK and US, the protracted journey of waiting for a diagnosis included being doubted, being misdiagnosed or undiagnosed for a long time, because they did not meet the diagnostic criteria (Goodman et al., 2005; Hale et al., 2006a; Hatfield-Timajchy, 2007; Mendelson, 2006; Stockl, 2007). Some participants felt that they were denied a lupus diagnosis by medical practitioners and felt punished. This led to strained relationships with some doctors as the patients felt patronised (Hatfield-Timajchy, 2007; Stockl, 2007). Some participants were referred to other doctors who gave conflicting diagnoses, while other participants self-referred to other doctors with little success (Mendelson, 2006). Some ended up diagnosing themselves after getting information from family members and the internet, while others went ahead and joined lupus support groups (Mendelson, 2006). However, it is not known whether they had lupus or not.

For some participants, the medical personnel either lacked knowledge about lupus diagnosis or were inconsistent in their practice (Hale et al., 2006a; Stockl, 2007). In one study, the findings indicated that men felt that their diagnosis was delayed because the health professionals did not automatically consider lupus to be a male disease and therefore, they never "thought outside the box" (Spry, 2014 p. 66).
The pre-diagnostic uncertainty occurred when symptoms were not distinguishable from those of other conditions. In one study, the maximum length of time from symptoms to diagnosis took up to 4 years (Mendelson, 2009). This type of uncertainty corroborates with Radley's (1994) second type of uncertainty, which is associated with the lack of a firm diagnosis. It also corroborates with Mishel's (1988) first theory of uncertainty in an acute illness which relates to the ambiguity of information received regarding illness, as described in section 1.3.1.

The difficulty in diagnosing lupus is confirmed by Isenberg and Morrow (1995), and Yu et al. (2014), who state that diagnosing lupus is a complex process which involves the interplay of factors between the professionally agreed diagnostic criteria and the different illness trajectories which vary from person to person (Maddison, 2002). The criteria for diagnosing lupus (Hochberg 1997) require that an individual must have four or more of the indicated diagnostic criteria elements, which patients rarely present with. This causes diagnostic delay.

Regarding the uncertainty related to the post-diagnosis disease trajectory, participants in studies from the US, UK, Sweden, Israel and Australia reported the challenge of living with a disease with uncertain duration, and unpredictable periods of feeling well and feeling very unwell (Beckerman, 2011; Mattsson et al., 2012; McElhone et al., 2010; Schattner et al., 2008; Stamm et al., 2007). Some participants experienced unpredictable and inconsistent periods of disease flares and remissions (Schattner et al., 2008), while others reported uncertainty related to knowledge about consequences, the course and outcome of the disease (Beckerman, 2011; Mattsson et al., 2012; McElhone et al., 2010; Schattner et al., 2008; Stamm et al., 2007). This caused uncertainty in their previously ordered lives. The post-diagnosis uncertainty experienced by some participants with lupus corroborates with the third type of Radley's (1994) uncertainty in chronic illness, in which the impact of the illness is felt and the individual's future seen as unpredictable. It also agrees with Mishel's (1988) second theory of uncertainty, which suggests that chronic illness is viewed to destabilise an individual's life and requires ongoing management.

The experience of uncertainty in chronic illness is shared by patients with other chronic rheumatic diseases like scleroderma (Joachim and Acorn, 2003), fibromyalgia (Johnson et al., 2006) and arthritis (Bury, 1982; Lempp et al., 2006). In these studies, the participants reported having an unpredictable body which experienced uncertain symptoms, which were treated
with uncertain treatments for an uncertain duration. However, in the scleroderma and arthritis studies, the unpredictable body was further compounded by permanent deformities which limit the use of hands for carrying out activities of self-care (Joachim and Acorn, 2003; Lempp et al., 2006). Both are described as worrisome and frustrating as they increase an individual’s dependence on others.

In non-rheumatic conditions, such as HIV illness and cancer, the sources of uncertainty are related to treatment and prognosis, career, fear of the unknown and familial consequences of illness (Brashers et al., 1998; Miller, 2012). These concerns are also expressed by lupus patients (Beckerman, 2011; Goodman et al., 2005; Mendelson, 2006; Miles, 2011; Ow et al., 2011). As with lupus, the main concerns about the unpredictable body relate to worsening of the illness, becoming crippled and losing independence (Gallop et al., 2012; Mattsson et al., 2012). In some instances, the diagnostic delays and the unpredictable body led to participants considering other beliefs about the cause of the illness (Goodman et al., 2005; Taïeb et al., 2010), as discussed in the next section.

**2.6.6.2 Illness beliefs**

Regarding beliefs about the cause of lupus, perceptions of the cause of lupus emerged from the findings of only three studies. One study was from France (Taïeb et al., 2010), another from Israel (Schattner et al., 2008) and another from Australia (Goodman et al., 2005). The most common causal attribution included: autoimmunity, genetic transmission, contagious transmission, psychological distress, familial events such as the loss of a close person or conflict within the family, and lupus being a latent disease. Other causal attributions included: exposure to the sun, prescribed medications, pregnancy, exposure to chemicals, magic and religious causes. The magic and religious causes were mentioned mainly by migrants from North or Sub-Saharan Africa to France (Taïeb et al., 2010). These included evil eye, witchcraft and an ordeal sent from God. On the other hand, in the study from Israel (Schattner et al., 2008), the illness was personified as an evil enemy which was experienced as an internal object. In Goodman et al.’s study (2005), a few participants stated that they did not know what caused their illness.
Some of the causes mentioned in the two studies were congruent with the biomedical model, such as the genetic link, while others were not, such as lupus being a contagious condition. However, the studies did not indicate whether the patients' understanding of heredity was similar or different to the medical understanding. Most participants suggested more than one cause and acknowledged it as a chronic condition. However, some participants did not appear to understand the difference between causes and factors that trigger flares of the disease. All participants, irrespective of the cause of their illness, acknowledged that their body had changed and this is discussed in the next section. Illness beliefs also affected some of the participants' adherence to medications (Chambers et al., 2008; Chambers et al., 2009; Taïeb et al., 2010). However, Chambers et al. (2009) and Taïeb (2010) the studies did not establish whether or not patients sought alternative therapies, such as herbal medicines or other coping strategies, while Chambers (2008) established that they used herbal medicine.

2.6.6.3 Changed body image

The reviewed studies revealed two main types of bodily changes: changes in physical appearance and changes in sensation (Gallop et al., 2012; Hale et al., 2014; Hale et al., 2006b; Karlen, 2002; McElhone et al., 2010; Miles, 2011). These physical changes were similar to those witnessed in patients with HIV and cancers, as described in section 1.3.2. The bodily changes made some of the participants feel less attractive, which resulted in increased self-awareness and social withdrawal. No difference was noticed in the bodily changes reported by the participants from developed countries compared to the participants in a study from a developing country (Miles, 2011).

Regarding changed sensation, pain and fatigue seemed to be the major health concerns reported in more than half of the reviewed studies. All of these studies were conducted in developed countries. For some participants, the two symptoms were described side by side as intrusive pain and fatigue which was incomprehensible (Goodman et al., 2005; Mattje and Turato, 2006; Mattsson et al., 2012; McElhone et al., 2010; Ow et al., 2011; Pettersson et al., 2012; Robinson et al., 2010; Stockl, 2007). These symptoms affected the participants' ability to sleep and to take part in various roles which were physically demanding, such as childcare, working at home, taking up paid employment, joining family and friends in recreational activities. The described roles related well to the functional limitations outlined in section
1.3.2. The functional limitations meant that some individuals were unable to plan (Mattsson et al., 2012; McElhone et al., 2010), while some of them relied more on other people (Hale et al., 2006b; Williams et al., 2015) which they found undesirable (Goodman et al., 2005; Mattsson et al., 2012; McElhone et al., 2010; Mendelson, 2006). Some individuals relied on medication (Mattsson et al., 2012). Other participants also reported that the symptoms occurred in a vicious cycle (McElhone et al., 2010; Rutter and Kiemle, 2015; Sterling et al., 2013); however, the effects were the same whether the symptoms were consistently or intermittently experienced.

Nevertheless, the pain and fatigue experienced in lupus are ambiguous and are invisible body responses, which are not easily acknowledged by others (Brennan and Creaven, 2016; McElhone et al., 2010; Pettersson et al., 2010; Rutter and Kiemle, 2015; Stockl, 2007). This is an experience shared by patients with multiple sclerosis (Pöllmann and Feneberg, 2008) and chronic back pain (Osborn and Smith, 2006). The participants in these studies viewed their illnesses as difficult to understand but causing serious consequences in their lives, such as emotional distress and lack of bodily control. Despite these experiences, it was noteworthy that the invisible nature of these symptoms affected the legitimacy and credibility of their illness (Brennan and Creaven, 2016). Some participants in the reviewed literature reported how the changed body image led to the experience of stigma and discrimination, as discussed in the next section.

2.6.6.4 Stigma and discrimination

As discussed in section 1.3.3, stigma is a negative value given to a personal characteristic rendering one liable to social rejection (Goffman, 1963). There are two types of stigma: enacted and felt stigma. Enacted stigma is the discrimination one experiences due to the negative labelling, while felt stigma is when a person expects to be discriminated against as a result of possessing the stigmatising label (Scambler, 2004).

In five of the reviewed studies, some participants reported experiencing stigmatising attitudes from their friends, family and work colleagues (Hale et al., 2006b; McElhone et al., 2010; Miles, 2011; Schattner et al., 2008; Spry, 2014). All the five studies were conducted in developed countries. The stigma experienced was due to changed body appearance which
included weight gain and skin abnormalities. These were obvious deformities which related the stigma described by Goffman (1963). Similarly, the affected participants were all aware that they looked different. Some reported that they felt like they were less attractive and a source of attention due to their visible undesirable changes (Hale et al., 2006b; Miles, 2011). This was a sign of felt stigma as described by Scambler (2004). Some also felt isolated (Schattner et al., 2008), which is a sign of enacted stigma. This also resulted in some individuals isolating themselves to avoid discrimination (Hale et al., 2006b; McElhone et al., 2010; Schattner et al., 2008). It also resulted in some having depression and low self-esteem (Howe, 2009).

The skin is the most frequently affected system in recent onset lupus, especially in the tropics where skin damage is associated with high levels of ultraviolet rays (Vilar and Sato, 2002). Damage may include excessive scarring and skin lesions, while weight gain arises from the use of steroids (Hale et al., 2006b). Harris and Carr (2001) indicate that physical appearance is a concern of women who are less than sixty years old. Also, in two studies the participants felt stigmatised due to misunderstandings regarding lupus, which was referred to as an autoimmune disease. This made some members of the public associate it with HIV and low morality, as discussed in section 1.3.3, and created a fear of contagion (Miles, 2011; Spry, 2014). Studies have also indicated that the pain experienced may pose a serious personal challenge, particularly if it limits or interferes with the individual’s everyday physical, psychological or social functioning (Herrmann et al., 2000; Osborn and Smith, 2006), as discussed in the next section.

2.6.6.5 Biographical disruption

As discussed in section 1.3.4, biographical disruption is the negative impact of chronic illness on an individual’s life. In almost half of the reviewed studies, some participants reported the negative impact of lupus on their lives. The disruption was a process and not an event, which started with an uncertain diagnosis, as discussed in section 2.6.5.1, and affected most areas of the individuals’ lives.

Most participants reported their inability to fit in the normal routines of work, family and married life due to the lupus symptoms they experienced, especially the pain and fatigue.
(Gallop et al., 2012; Mendelson, 2006; Miles, 2011; Ow et al., 2011), along with an inability to plan for the future (McElhone et al., 2010). This necessitated the need to modify their roles both at home and at work (McElhone et al., 2010; Mendelson, 2006). One study sought the participants' perspectives regarding physical activity (Mancuso et al., 2010) and established that even though the participants believed that exercises were beneficial, some avoided physical activity because they believed that it would exacerbate the condition. However, in the same study, some participants were motivated to exercise to fulfil their family and work responsibilities, and they were also motivated when they had a companion to encourage them (Mancuso et al., 2010).

Having lupus also affected some of the participants' social relationships both at home and at work (Robinson et al., 2010; Stamm et al., 2007). Only one study reported some participants experienced good relationships with friends due to having lupus (McElhone et al., 2010). Some participants experienced financial burdens from the loss of income and high treatment costs (Chambers et al., 2008; Mendelson, 2006; Miles, 2011; Stamm et al., 2007), whereas others had to adjust their values and aspirations (Wittmann et al., 2009). They felt they had lost their health and a sense of normality which affected their self-esteem and self-image (Gallop et al., 2012; McElhone et al., 2010; Williams et al., 2015).

In four of the studies, some participants also reported that lupus had an impact on their sexuality (Hale et al., 2006b; Karlen, 2002; Mattje and Turato, 2006; Schattner et al., 2008). Karlen (2002) and Hale et al. (2006b) established that the changed appearance made some women feel unattractive and they rejected sexual advances by their partners (Karlen, 2002), while others felt that their partners lacked empathy (Karlen, 2002). A few women also reported that coping with lupus had improved their sexual functioning and relationships (Karlen, 2002). Yet, some participants experienced familial discord, broken relationships, divorce and social isolation (Mattje and Turato, 2006; Schattner et al., 2008). Stockl (2007) emphasises that the diagnosis of lupus require individuals, who are mainly women of childbearing age, to re-plan their future in a way that might not meet with society’s expectations about getting married and having children. This was similar to the experiences of women with gynaecologic cancers, as discussed in section 1.3.4.
Tench et al. (2000) and Wysenbeek et al. (1993) state that nearly 80% of lupus patients experience fatigue with associated pains which are self-expressed. The individuals may be ill without necessarily lying in bed. However, their social functioning is usually disrupted. They also experience difficulty in maintaining their social functioning as society seems unwilling to exempt them from their normal social roles and responsibilities. Wittmann (2009) also reported that some individuals with lupus undergo suffering caused by both physical factors and social factors in the environment. The findings of the same study suggested that coping is possible, but is influenced by availability of coping resources, personal characteristics of the individuals and severity of their illness.

2.6.6.6 Emotional distress and social support
The reviewed studies demonstrated that living with lupus involved facing some stressful events and challenges which required both emotional and practical aid. The participants experienced distress and anxiety caused by pain, a sense of isolation and feelings of hopelessness caused by the existential uncertainty (Beckerman, 2011; Hale et al., 2006a; Hale et al., 2006b; Stockl, 2007). They also felt that they were not who they used to be (Beckerman et al., 2011). It is also noteworthy that three studies from the US (Beckerman, 2011; Mendelson, 2006; Williams et al., 2015), and one study from Jamaica which is a developing country (Chambers et al., 2008), reported financial strain and treatment costs as the key challenges and causes of distress. This was mainly because, in the US, healthcare is not free (Fitzpatrick, 2008). While Jamaica, a developing country, has limited financing by the Ministry of Health; funding in Jamaica is mainly through the general taxation system (Class et al., 2014). Some participants also experienced emotional issues of guilt, unresolved anger, shame associated with dependency, and anxiety about death (Schattner et al., 2008; Williams et al., 2015).

Anxiety and depression appeared to occur more frequently. In the studies, anxiety and depression were related to poor interpersonal relationships and lack of understanding from people, lack of employer support which resulted in loss of job and financial difficulties, and lack of psychological support (Gallop et al., 2012; Goodman et al., 2005; Mattsson et al., 2012; Miles, 2011; Rutter and Kiemle, 2015; Spry, 2014). All these led to familial discord and strained or broken relationships with spouses, family, friends and work colleagues.
Findings from the reviewed studies also indicated that some participants with lupus expected to receive social support, but were dissatisfied with the social support provided. Social support has been defined as "the existence or availability of people on whom we can rely on, people who let us know that they care about, value and love us" (Mazzoni and Cicognani, 2011 p. 1118). In the studies, social support was expressed as either minimal or problematic.

About a third of the reviewed studies documented that some participants received minimal support from the significant people in their lives (Brennan and Creaven, 2016; Goodman et al., 2005; Hale et al., 2006b; Mattje and Turato, 2006; Mattsson et al., 2012; McElhone et al., 2010; Mendelson, 2006; Spry, 2014; Stamm et al., 2007; Stockl, 2007). This was because nobody believed how sick they felt. Some participants expressed the challenge they had of explaining their illness to others to receive support. As a result, some participants in these studies reported feeling depressed due to being treated with suspicion about not being so sick; they felt as if they were faking their illness. In one study, participants reported that other people thought they were not coping with the diagnosis (Stockl, 2007). Some participants also lost their jobs due to prolonged absenteeism (Mendelson, 2006). These participants, therefore, did not experience much social support in the social environment; instead, they experienced more social isolation and emotional difficulties.

Poor understanding of lupus by family, friends and work colleagues was reported by participants in five studies conducted in the UK, Brazil, US and Canada (Goodman et al., 2005; Hale et al., 2006b; Mattje and Turato, 2006; Mendelson, 2006; Spry, 2014). In another study, participants felt that their reliance on care givers for travel and meeting financial priorities interfered with their compliance with medical appointments, which distressed them too (Williams et al., 2015).

Some participants from one study acknowledged that they received support from their internet support group in the form of sharing information and receiving emotional support regarding living with the illness and life activities (Mendelson, 2003). It was noteworthy that they also expressed that they provided support by being there for each other through the Internet, a non-physical presence. These participants expressed that they received all sorts of social support from people who were neither family, friends nor employers.
Only one study established that social support plays a major role in the development of coping strategies and the management of depression in individuals with lupus (Howe, 2009). This is a fact acknowledged in other studies, which explored the role of social support in the health status of patients with lupus. Greater social support was associated with higher scores in physical function, social function and mental health (Bae et al., 2001; Sutcliffe et al., 1999). The studies demonstrated that the health status of patients with lupus might be improved by increasing patients' social support.

Nevertheless, one study highlighted that social support could also be problematic (Mazzoni and Cicognani, 2014). In the study, some participants reported that family and friends became too present and were worrying too much, or denying the existence of their illness by not considering them as sick. Furthermore, they withheld useful information from them. The study illustrated that not all types of support are valuable to individuals with lupus. The families must learn the appropriate kind of support and when to give it, to avoid negative feelings.

### 2.6.6.7 Unmet information needs

Lupus is an illness characterised by periods of disease flares and remission, and is experienced differently due to the variety of unpredictable symptoms. This creates a need for sources of information on self-management.

In about a third of the reviewed studies, the participants had little prior knowledge of lupus. Although most participants knew the medical name of their illness along with the signs, symptoms and treatment, a significant number had poor understanding of their disease especially after diagnosis (Chambers et al., 2009; Goodman et al., 2005; Mattje and Turato, 2006; Mattsson et al., 2012; McElhone et al., 2010; Mendelson, 2003; Mendelson, 2006; Neville et al., 2014; Stockl, 2007; Waldron et al., 2011). Despite acknowledging lupus as a chronic disease, participants in Australia (Goodman et al., 2005), Brazil (Mattje and Turato, 2006) and Israel (Schattner et al., 2008) had hopes for a cure. This either meant that the participants doubted that lupus is incurable or doubted the medical practitioners’ information regarding the chronicity of lupus.

Some participants were uncertain about the experience of a flare-up. They were unable to tell if they were in a flare or were suffering from an unrelated illness (Goodman et al., 2005;
Mattsson et al., 2012). They were also in doubt about the course and prognosis of the disease, and were concerned about the effects of treatment such as weight gain with steroid use (Hale et al., 2014; Mattje and Turato, 2006; McElhone et al., 2010; Mendelson, 2006; Stamm et al., 2007). Participants were also concerned about their reliance on medication and healthcare (Kumar et al., 2011; Mattsson et al., 2012; McElhone et al., 2010). Some even indicated that they were not prepared to take medications which caused serious side effects like osteoporosis, heart failure and liver failure (Chambers et al., 2008; Goodman et al., 2005). This highlighted their unmet informational needs and the need to enquire and address lupus patients’ concerns. Caution regarding medication is realistic although it can cause serious concern regarding compliance with medicines and consequently, the progression of illness to advanced stages (Chambers et al., 2007).

In some studies, participants reported receiving information from various sources including their rheumatologists (Brennan and Creaven, 2016; Goodman et al., 2005; Hale et al., 2006b; Kumar et al., 2011; Mendelson, 2006; Waldron et al., 2011), friends, family, support groups (Goodman et al., 2005; Mendelson, 2006; Stockl, 2007) and the internet (Stockl, 2007). However, some participants indicated that the information they received regarding the disease was inadequate (Brennan and Creaven, 2016; Hale et al., 2006b; Mendelson, 2006; Waldron et al., 2011) and sometimes difficult to understand (Waldron et al., 2011). Others experienced language barriers and expressed that the use of translators was not always successful (Kumar et al., 2011). Some participants in one study indicated that apart from patient information leaflets, they received minimal information about the disease from the health professionals (Hale et al., 2006b). This implied that patients needed more information on some issues which were most likely not included in the information leaflets.

Nonetheless, three studies from two different developed countries reported that some participants encountered health professionals whom they felt were not well informed about lupus (Hale et al., 2006a; Pettersson et al., 2010; Stockl, 2007). This caused some participants not to voice their concerns regarding their symptoms, treatment and prognosis (Hale et al., 2006a). In two of these studies, the participants also decried experiencing poorly integrated healthcare when they needed information regarding their illness (Hale et al., 2006a; Stockl, 2007).
The role of healthcare providers in giving information to patients was emphasised in one study in which the participants indicated that they needed better education programs than what was received from outside the hospital, as they felt safe discussing their concerns with health professionals (Miljeteig and Graue, 2009). In the same study, the health professionals felt inadequately prepared and expressed that they needed to improve their competence in teaching and counselling skills. Evidence from other studies indicated a strong correlation between the provision of educational programmes at the diagnosis stage of chronic illnesses, like rheumatoid arthritis, and the positive impact on an individual’s physical and psychological status (Riemsma et al., 2002; Viller et al., 1999). Ward et al. (2003) also established that patients with lupus who had effective ongoing patient-physician communication accrued less organ damage over a period of approximately five years, confirming the significance of patient-physician communication in the successful management of lupus.

Only one unique study reported that some participants felt that the Internet provided information that covered the various aspects of their illness (Mendelson, 2003). Participants in this study indicated that the nature of online information, and the support they received, included information in the form of articles from scientific journals and science reporters, followed by discussions which were beneficial. Some participants also indicated that they shared general advice online with regards to their experiences and what strategies worked for them. It was also notable that some participants reported that there were instances where they also advised each other to consult their healthcare providers. This was a different way of using technology to receive information from an online support group. It can be argued that with technological advancement, the monopoly of knowledge no longer lies with the medical practitioners as individuals can have access to information from various sources. However, in such a study, it was noted that participants were self-selecting. The respondents may only have consisted of those who had internet access, and therefore, non-response bias related to 'non-contact' may not be ruled out (Denscombe, 2014).

2.7 Strengths and limitations of the evidence
This section discusses the strengths and limitations of the available evidence about the perspectives on living with lupus. The evidence was comprehensive and covered a broad range of issues, which improved understanding regarding living with lupus. However, the studies
were mainly from Europe and America, with only three studies from developing countries and none from Africa. It also provided a summary of the most recent and best available evidence.

Regarding the uncertainty of being ill, several studies suggested that receiving a lupus diagnosis was difficult even in the developed countries. Firstly, because lupus presents in various ways and in some cases the condition mimics other diseases; secondly, due to the difficulties in applying lupus guidelines by the bedside because they are meant for identifying patients for research purposes; and thirdly, due to the inconsistent use of the lupus guidelines. Studies also suggested that lupus is considered a women's disease, which makes it harder for men to be suspected of having lupus. There was limited evidence regarding the differential diagnosis and treatment the patients were given before getting a definitive lupus diagnosis. However, the evidence suggested that there is a need to streamline the criteria for lupus diagnosis. The evidence also suggested that similar to patients with other chronic illnesses, uncertainty persisted in patients with established lupus, particularly about the unpredictable body and the future consequences of the disease.

Studies have also suggested that individuals with lupus had mixed understanding about the factors attributed to the causation of lupus, some of which are evidence-based while others are not. One study suggested beliefs in magic and religious causes. This was important because the study involved participants from the African continent who were living in France, and highlighted the differing health/illness beliefs along cultural lines. Also, there was weak evidence suggesting that patients with different/unconventional illness beliefs could be accessing alternative therapies, especially before receiving a lupus diagnosis or when their information needs remain unmet.

Several studies also suggested that individuals with lupus experience both invisible and visible bodily changes which cause biographical disruptions in all areas of their lives, necessitating changes in their way of life. The findings also revealed that there could be issues with symptom control among lupus patients, such as pain and fatigue control. Nonetheless, the visible bodily changes caused alterations in the individuals' perceptions of themselves and how others perceived them. The literature suggested that the visible bodily changes may cause stigma, leading to constrained lives and social isolation. Their self-esteem also becomes significantly dented.
The findings also supported the view that individuals with lupus require support both at work and at home, which is lacking. The evidence was, however, inconclusive regarding the different types of social support that were available to people with lupus and the types of social support that were lacking. Unproven evidence also suggested that some patients received social support from online lupus support groups, while some patients physically attended patient support groups. The evidence was also inconclusive about the perceptions regarding the benefits of support group attendance and the areas which need improvement. Some literature also supported the idea that patients who receive social support have a better quality of life.

The review also found that the patients had legitimate concerns about their unmet educational needs which included: issues of diagnosis, disease causation, medications and disease trajectory. The patient information leaflets seemed inadequate in content and lacked the human face which is necessary for two-way communication. The literature suggested the need to meet the educational needs of the patients, but was not conclusive on the other self-management strategies which patients living with lupus utilised. There was also some literature suggesting the benefit of online information support for lupus patients. However, the accessibility of such information for patients might be limited.

Regarding methodological quality, on the whole, the researchers followed the principles of the selected research designs. However, there were a few studies in which the methods applied were inconsistent with the chosen strategies. The most affected were grounded theory studies in which some researchers did not follow the principles of constant data analysis and theoretical sampling (Howe, 2009; Neville et al., 2014; Ow et al., 2011). They also did not clarify whether the interview guide was amended as expected. This was mainly in studies where multiple focus group interviews were conducted. Also, ethnographic features like participant observation and immersion did not stand out in the ethnographic studies.

The sample sizes were adequate for the qualitative studies, although in 13 studies the researchers did not clarify the sampling techniques used. A few studies did not explain whether ethical issues were addressed or not (Beckerman, 2011; Karlen, 2002; Ow et al., 2011). Additionally, in almost all the studies the researchers did not give a reflective account of their relationships with the participants and how their positions might have affected either
the data collection or analysis processes. Most studies generated data using semi-structured interviews followed by focus group interviews. There were a few studies in which participant observations were also used to triangulate data collection (Mendelson, 2006; Stockl, 2007). Most studies also explained their methods of data analysis, although in a few studies the processes of data analysis were not clearly stated (Howe, 2009; Karlen, 2002; Nowicka-Sauer, 2007). In one study (Miles, 2011), the process was scarcely explained.

The topic of reflexivity was only addressed in one study (Taïeb et al., 2010). On the whole, as illustrated in Appendix 5, most of the reviewed studies were of good methodological quality.

2.8 Identified gaps in the literature

From this literature review, seven themes were identified as key factors influencing the experience of living with lupus. The seven related themes are uncertainty in illness; illness beliefs; changed body image; stigma and discrimination; biographical disruption; emotional distress and social support; and meeting information needs. It can be argued that uncertainty in illness can be addressed by tackling the diagnostic issues surrounding lupus, and increasing awareness about lupus and its trajectory among individuals with lupus and their families. This could help in addressing the issues relating to illness beliefs, stigma and improving the relationship between patients and health professionals. This could, in turn, improve social support and reduce biographical disruption.

Whilst this relationship could be seen in the literature, there was no empirical evidence from Africa and Asia to suggest the socio-cultural specific differences between people of different regions. It was unknown whether the perspectives identified by Western and Asian patients on living with lupus are also important to African patients. This review did not contain the doctors' perspectives on service organisation and the delivery of care to patients with lupus, so the challenges faced by doctors in making a diagnosis are unknown. The differential diagnosis and treatment that lupus patients received before diagnosis was also unknown, and whether patients used alternative/complementary medicines or not, especially when they had non-conventional beliefs about the possible causes of lupus. It was also not known whether the illness attribution factors among Africans are similar to those mentioned by African migrants in France, and whether there are more beliefs or not.
There was also no information about the type of social support available to lupus patients and the types of support that were lacking. Also, the benefits of attending patient support groups were not known, along with what might be missing from the groups. Apart from educational and social support, the perspectives of lupus patients about their other unmet needs were also unknown. The literature review was useful in providing a justification for this study on the views and perspectives of living with lupus in Kenya.

Therefore, this research intended to explore the experience of living with lupus in Kenya from the perspectives of individuals with lupus and their doctors, and understand how different social situations and resources can affect the experience. The study elucidated new perspectives important to African patients and contributed evidence to the existing knowledge base on views on living with lupus.

The literature review was ongoing as the study progressed. This identified additional studies which were not included in this review. However, they were used to discuss the findings of the study.
Chapter 3: Methodology and methods

3.1 Introduction
This chapter provides a description of the study methodology and a detailed account of the methods used. It presents the study aim and objectives, and then examines the general philosophical and theoretical underpinnings which influenced the research, including the selection of grounded theory as a guide to research methods. This chapter provides a detailed account of the consideration of the study's qualitative approach, along with the philosophical underpinnings of interpretivist/constructivist research paradigms; this includes a description of how grounded theory strategies and other methods were applied in data collection and analysis to enhance the rigour of the study.

3.2. Study aim and objectives

Study aim:
The broad aim of this study was to explore the perspectives of individuals with lupus and their doctors' on living with lupus

Study objectives:
• To explore individuals' illness experiences with lupus before diagnosis and their help-seeking behaviours.
• To gain an understanding of individuals' experiences with the treatment and care of lupus.
• To gain an understanding of the doctors’ perspectives on service organisation and delivery of care to lupus patients.
• To determine how having lupus has affected individuals’ lives.
• To identify the self-management strategies of individuals' living with lupus.

3.3 Philosophical and theoretical underpinnings of research

3.3.1 Philosophical underpinnings of research
In the world of research, there are different research paradigms and their corresponding theoretical and philosophical underpinnings, namely epistemology, ontology and methodology (Denzin and Lincoln, 1994).
"Epistemology asks, how do we know the world? What is the relationship between the inquirer and the known? Ontology raises basic questions about the nature of reality. Methodology focuses on how we gain knowledge about the world." (Denzin and Lincoln, 1994, p 99)

Denzin and Lincoln (1994) suggest that the philosophical concepts of ontology, epistemology, and methodology cannot be separated as the consistency between the theoretical and methodological approaches is important in providing the framework for thinking about the social world and giving rigour to the study. The theoretical perspective also informs and predetermines the research design and methods, including the analysis and interpretation of findings (Denzin and Lincoln, 1994).

3.3.2 Theoretical paradigms
Traditionally, there are two broad philosophical paradigms: positivism and interpretivism. They are considered the core approaches to research methods and are depicted as polarised regarding their epistemological and ontological stance (Bowling, 2014; Denzin and Lincoln, 1994).

At one end is positivism, which is often considered as the dominant philosophy underlying quantitative scientific methods (Bowling, 2014). It assumes that phenomena are measurable using the deductive principles of the scientific method, which is objective. The epistemological aspect of positivism suggests that reality is discoverable through the use of rigorous scientific methods, such as statistical and mathematical techniques of the quantitative research process (Avis, 2005). Positivists hold that reality is absolute but only authentic if generated through a rigorous scientific research process which is highly organised, measurable (Jupp, 2006), and amenable to being verified, confirmed or falsified by empirical observation of the reality (Guba and Lincoln, 1994). Positivists also believe that researchers should remain emotionally neutral and detached from the participants by creating a distance between themselves and the research participants (Carson et al., 2001).

Ontologically, positivists believe that the world is external, with single objective reality to any research phenomena. Researchers believe that human action can be explained by factual evidence of the real causes (Carson et al., 2001). However, critics argue that it is naive to
assume that this is achievable in an interactive inquiry of humans (Denzin and Lincoln, 1994) which may be influenced by many interacting variables, making experimentation and prediction impossible or difficult (Denzin and Lincoln, 2000).

At the other end of the scale is interpretivism, which is considered as the humanistic philosophy underlying qualitative research, based on an understanding and interpretation of accounts of social life by research participants (Bowling, 2014). Interpretivism aims to collect qualitative data, interpret and gain an in-depth understanding of social phenomena through an inductive strategy (Weber, 2004; Williams, 2008). From the ontological perspective, interpretivists believe that social reality is multiple, relative, unpredictable and cannot be separated from social actors, and that human experience is a process of interpreting interactions with the external world (Weber, 2004; Williams, 2008).

From the epistemological perspective, interpretivists recognise that knowledge is derived from socially constructed concepts and meanings (Weber, 2004) rather than objectively determined (Weber, 2004; Williams, 2008). Thus, social scientists report the participants' social life through field work based on unstructured interviews and participant observation. These are flexible research structures which are amenable to capturing the meanings in human interaction, and understanding and interpreting what is perceived as reality (Black, 2006; Carson et al., 2001; Weber, 2004). The most important tool in interpretivist research is the role of the researcher and the participants which are mutually interdependent (Avis, 2005). Also, the goal of the researcher is to get as close to the participants as possible and to remain open to new knowledge throughout the research process (Carson et al., 2001; Creswell, 2012). It is important to state the ontological and epistemological positions in a study because they affect the criteria for rigour and claims made regarding knowledge (Vasilachis de Gialdino, 2009).

3.4 The study paradigm
This study used a qualitative paradigm. Qualitative research tries to interpret social phenomena regarding the meanings people make of them, making the research approach interpretive. It is concerned with the nature of human experiences and what the phenomenon mean to the concerned individuals (Holloway and Wheeler, 2013; Polit and Beck, 2004). Qualitative research is also a particularly useful approach when a topic has been little researched or poorly understood, and offers a set of flexible tools that can be selected for their
fit according to the nature of the research question (Creswell, 2012; Richards and Morse, 2012). Qualitative research methods were recognised as useful tools for understanding people's complexities related to experiencing life with lupus because the methods aim to “touch the core of what is going on rather than just skimming the surface” (Greenhalgh and Taylor, 1997 p. 740). The approach fitted the objectives of this study and was therefore considered appropriate for an in-depth understanding of the illness process (Bowling, 2014; Creswell, 2012).

3.5 Underpinning assumptions and theoretical perspectives

3.5.1 Underpinning assumptions

The study aimed to elicit the patients' and doctor's perspectives and convey these in an interpretive manner. The work was therefore grounded in interpretivist tradition because it aimed to focus on how participants’ social worlds were ‘interpreted, understood, experienced, produced or constituted’ (Mason, 2002 p.3). From an ontological perspective, the researcher utilised an ontology based on a social world of meanings. This view assumes that the world has individuals who have their unique thoughts, interpretations and meanings. The researcher believed that these meanings could not be separated from the social actors. The epistemological stance applied in this study was constructionism which is defined by Crotty (2003 p.42) as:

"… the view of all knowledge and therefore all meaningful reality as such is contingent upon human practices, being constructed in and out of interaction between people and their world and developed and transmitted within an essentially social context."

In relation to this study, the researcher believed that the meaning of the experience of living with lupus was constructed from the perspectives of patients and doctors, together with the knowledge and expertise of the researcher. Based on these beliefs, the researcher chose interpretivism as a research paradigm. However, the interpretive approach can be criticised for the objectivity lost due to multiple realities and interpretations (Weaver and Olson, 2005). Interpretivism, therefore, emphasises the importance of reflexivity and the continuous articulation of rigour when studying the dynamic and complex nature of the social interaction...
(Denzin and Lincoln, 2000). Issues of rigour and reflexivity are discussed in sections 10.7 and 10.8. Interpretivism also acknowledges individuals' actions about reactions from other individuals, which is compatible with symbolic interactionism. Symbolic interactionism was thus recognised as the theoretical perspective of the study.

A theoretical perspective is defined as "the theoretical stance informing the methodology and thus providing the context for the process and grounding its logic and criteria" (Crotty, 2003 p.7). Since the ontology of the study was mainly concerned with the world of meanings and interpretations to the individuals, and the epistemological stance was constructivist, symbolic interactionism was logically chosen as the theoretical perspective underpinning the study.

### 3.5.2 Symbolic interactionism

Symbolic interactionism is a theoretical perspective with a focus on interaction and interpretation (Mead, 1934). Mead noted that interaction is the key link between mind, self and society. He considers the three concepts as inseparable whereby people's selves and minds emerged from social interactions (Mead, 1934). His work was further developed by his student, Herbert Blumer, who stated that in symbolic interactionism individuals base their action or behaviour on the meaning they have constructed from external stimuli (Blumer, 1969). This meaning is derived from social interaction and modified through interpretation. Blumer proposed three core tenets of symbolic interactionism (Blumer, 1969):

- **Tenet 1**: Human beings act towards external stimuli on the basis of the meanings that these things have for them. Such meanings arise from the social interactions between people and others in the society. The use of these meanings by people is not permanent and can change due to everyday interactions by the interpretive processes employed by a person.

- **Tenet 2**: The three tenets emphasise the construction of subjective meaning in human interaction with others by use of language and non-verbal symbols (Charmaz, 2005). They suggest that people act intentionally based on the meanings they have constructed (Blumer, 1969). Therefore, to understand the world, the researcher must actively interact with participants to see things from their point of view. For example, patients' and doctors' perspectives on living with lupus may be affected by their interpretation of living with lupus and how they have experienced the 'social world' around them. However, their interpretation is not solely determined by this
external view, but also by how they continue to interact with the social world around them (Cutcliffe, 2000). So, in order to understand the meaning of living with lupus, the researcher must engage actively in the world of the study and identify how participants interpret their individual experiences, and the alternative actions they choose when acting in different situations.

Symbolic interactionism, therefore enables the researcher to explore the inner world which determines human behaviour and the concept of meaning as perceived by participants, in order to understand situations from participants' viewpoint (Jeon, 2004). The arguments of symbolic interactionism also suggest that the relationship between human interpretation and action are dynamic which require a close and detailed study of people's social worlds to understand how meanings influence their behaviour (Charmaz, 2000). This viewpoint informed both the approach and conduct of the study.

In the study of social processes and individual interactions, grounded theory is frequently linked with symbolic interactionism (Gray, 2013). Grounded theory derives its theoretical underpinnings from pragmatist philosophy and symbolic interactionism (Charmaz, 2003; Clarke, 2005; Strauss, 1987). Both philosophies acknowledge that phenomena are not static but change continually in relation to evolving conditions. The two philosophies also recognise that participants have means of controlling their fate by their responses to situations, and can make choices according to their perceptions (Strauss and Corbin, 1990). The interaction between symbolic interactionism and grounded theory in this study is explained in section 3.8.

3.6 Grounded theory methodology

The methodology of this study was guided by the principles of grounded theory. The methodology is "the strategy, plan of action, process or design lying behind the choice and use of particular methods and linking the choice and use of the methods to desired outcomes" (Crotty, 2003 p.3). The main aim of grounded theory is to generate a theoretical understanding of a situation by determining patterns and processes in order to comprehend how individuals define their reality via social interactions (Burns and Grove, 2001). For that matter, grounded theory is widely used to study areas where little prior research has been carried out, or to achieve a new perspective in commonly researched areas (Burns and Grove, 2001). Grounded
theory methodology was appropriate because there is a lack of research on the reality of living with lupus in Kenya.

3.6.1 Overview of grounded theory
Grounded theory was a development from analytic induction and the ground-breaking invention of Glaser and Strauss in the mid-1960s, when they explored the experiences of dying patients in hospital (Glaser and Strauss, 1965). They argued that many existent methods were focused on obtaining facts to verify a particular theory or hypothesis instead of generating theory (Glaser and Strauss, 1967). They criticised the dearth of social theory and emphasised the need to generate theory from social research which would produce a robust hypothesis grounded in research. The theory-research gap motivated them to design a pioneering methodology that fitted the demands of empiricism by using logical deductive reasoning as the method of inquiry to develop theory from qualitative data (Glaser and Strauss, 1967).

The grounded theory proposes several main features to guide researchers throughout the research process. This includes: theoretical sampling and theoretical sensitivity to enable the researcher to generate theory grounded in the research data and not from their own ideas or existing theories; a constant comparative method which is fundamental in assisting conceptualisation and categorisation in the course of data collection and analysis (Glaser and Strauss, 1967); coding and categorising which is the conceptualisation of data in the form of codes and categories, which serve as building blocks of theory (Glaser, 1978); memo writing which is "the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding" (Glaser, 1978 p. 82) and the generation of substantive theory (Glaser and Strauss, 1967).

However, the founders of grounded theory disagreed on the use of the approach, taking it to diverging directions (Charmaz, 2006). The difference in perspectives arose when Glaser, together with a co-author, developed an emphasis on the technical analytic process for data analysis (Strauss and Corbin, 1990; Strauss and Corbin, 1998). Glaser argued that these procedures were a new rigid method which led to the 'forcing' of data into pre-conceived categories and re-emphasised the notion of 'emergence', which stresses the importance of
comparing and connecting categories and emerging theories from the data collected (Glaser, 1992).

Moreover, Glaser and Strauss debated the place of the literature review in grounded theory, as discussed in section 2.2. Heath and Cowley (2004) argue that the authors may not have been disagreeing on the ontology related to their fundamental belief that knowledge might be gained in generating and interpreting data, but rather expressing the same idea in different ways. Furthermore, both Glaser and Strauss recognised that a researcher could not be completely free from the influence of their past experiences (Glaser and Strauss, 1967; Glaser, 1978; Strauss and Corbin, 1998).

A more recent version of grounded theory is 'Constructivist Grounded Theory' which was developed by Kathy Charmaz (Charmaz, 2000; Charmaz, 2006). Charmaz claims that in her version, theory is constructed by the researcher through their interactions with the research participants. Constructivism "assumes the relativism of multiple social realities and recognises the mutual creation of knowledge by the viewer and viewed, and aims towards an interpretative understanding of subjects' meanings" (Charmaz, 2003 p. 250). This approach allows the researcher to bring some of their views, beliefs, and feelings to the data since it believes that theory neither emerges nor is discovered. A constructivist approach also reaffirms studying people in their natural settings (Bryant and Charmaz, 2007).

3.7 Selecting constructivist grounded theory

The research approach that was considered for this study was constructivist grounded theory. The rationale for choosing Charmaz's grounded theory was based on my ontological position that acknowledges that the social world consists of multiple individual realities influenced by cultural and structural contexts. Thus, the main construct was to be the individuals' perspectives, how they engage with their experiences and construct a multiplicity of truths and perspectives together with the researcher, a concept shared by Strauss and Corbin (2008). From the epistemological position of knowledge enquiry, which comes from a subjectivist perspective, I shared the view of looking at how the participants reconstructed their perspective and understanding of lupus through the meanings that they attached to their identity and experience during their interaction with the researcher (Charmaz, 1995). This
position recognised the mutual creation of knowledge by the researcher and the participants, and the interpretive understandings of the participants' meanings (Charmaz, 2000).

Charmaz’s grounded theory was therefore relevant because it denies the existence of a knowable objective reality. It has a flexible approach which allows the analysis of an individual’s interpretation of an experience and acknowledges multiple viewpoints and realities from both the researcher and the participant. Charmaz argues that there are multiple understandings of reality in the world and “generalisations are partial, conditional and situated in time and space” (Charmaz, 2000 p.141). This allows the construction of data with participants and recognises that subjectivity influences their lives. I intended to be responsive to the social context, which is the flexibility that qualitative research and grounded theory approaches offered.

There is little documented evidence which addresses patients’ and doctors' overall perspectives of lupus, and no studies have been conducted in Kenya and Africa. All the published studies identified have come from outside Africa where there are different healthcare systems, which are possibly not transferable to Kenya. The study is useful in evaluating the problems that a defined group of people experience in a situation, whilst simultaneously examining the situation as a discrete entity in its own right. The constructivist approach not only pays attention to processes and actions, but also pays attention to the development of conceptual understandings and perspectives, priorities and interactions of both the researcher and research participant (Bryant and Charmaz, 2007).

3.8 Symbolic interactionism within this study

I used the principles of grounded theory and symbolic interactionism to explore the views of participants about living with lupus. Living with the illness is an important experience for individuals with lupus as they may face a variety of circumstances. Their views on these circumstances and their beliefs may impact on how they interpret meanings, and how they behave with their society. These views could be modified based on the interactions either between the individuals themselves or the interactions with other individuals in their surroundings, such as their families, communities, health practitioners and health facilities.
3.9 Conduct of the study and application of grounded theory strategies

In constructivist grounded theory, Charmaz identified the core characteristics as follows (Charmaz, 2006 p.5-6):

- Simultaneous data collection and analysis.
- Conception of analytic codes and categories from data.
- Constant comparison of data during each stage of analysis.
- Memo writing on identified categories, their properties and relationships, as well as identifying gaps.

In the following sections I describe how the principles of constructivist grounded theory method were applied in this research, along with the application of other methods such as: discussion about the selection of study centres; ethical considerations; gaining access to study participants; sampling and recruitment procedures. I also discuss how the data was collected and analysed.

3.9.1 Selecting study centres

Selecting a study location is one of the decisions required of a researcher during the formulation of the study design (Denzin and Lincoln, 2000). Glaser (1992) points out the importance of collecting evidence from an appropriate setting to generate suitable data for a study. For this study, the aim was to reach individuals who have lupus and the doctors who cared for them. I, therefore, selected two rheumatology clinics in two tertiary hospitals as it was the most appropriate way of gaining access to these two groups. One clinic was attached to a national referral hospital serving the whole country, while the second clinic was attached to a private hospital. Both clinics were located in Nairobi.

The clinics were selected from a total of three clinics, with consideration to practical matters of travel distance, traffic congestion and costs. The referral hospital was also chosen in order to reach individuals who accessed care through the public referral hospital where healthcare was comparatively cheaper, while other individuals went to the private hospital clinic where they paid for all services. This ensured the representation of participants from different ethnic and social groups who had experienced the phenomena.
3.9.2 Ethical considerations

The conduct of research involving human participants may lead to undesirable effects, especially for the research participants as research objects (Sarantakos, 1998). Patton also points out that “interviews are interventions” (Patton, 2002 p. 405). Since this study was mainly conducted by interviewing research participants, I considered certain ethical issues to avoid any physical or psychological harm to the research participants. The study only commenced once ethical approval had been achieved from the Research Ethics Committees of The University of Manchester (see appendix 8), the national referral hospital (see appendix 9) and the private hospital (see appendix 10). Ethical approval was achieved regarding the following considerations:

Informed consent and voluntary participation
Informed consent is the principle of providing potential participants with full information about the research and any risks involved, without any coercion or enticement. Their involvement should be voluntary and based on a complete understanding of their participation in the research (Green and Thorogood, 2013). Informed consent may be given through a verbal agreement, though a written statement is best (Gray, 2013). In this study, the potential participants were first approached by a doctor or a nurse who was currently providing care to them in the respective clinics. The potential participants were given brief verbal information about the study during their clinic appointment, and it was explained that participation in the study was voluntary. If patients expressed an interest in taking part in the study, the health practitioners asked them if they agreed to have their telephone contacts passed to me. I then obtained their telephone number from their files through the records clerk.

I then telephoned the potential participants approximately two weeks after they had initially been introduced to the study, to give them time to consider whether or not they wished to participate. During the call, I explained to them what participation in the study involved and also answered any questions. I was careful to reiterate that their participation was entirely voluntary and that a negative decision regarding their participation would not affect their care in any way. I also sought their permission to meet me during their next clinic appointment.

During the patients' clinic appointment days, I requested to make contact with the potential participants individually and then verbally explained the aims of the study and data collection
methods, and also provided a participant information sheet which they took away (see Appendix 11). I also answered their questions. I then contacted the potential participants after one week to confirm that they were still interested in participating. During this phone call, we also arranged the time and venue of the interview which was either at the participants’ home, office, within the hospital premises or at a neutral meeting place, at the participant’s preferred time during normal working hours.

All of them understood the participant information sheet, and the responses from the potential participants were generally positive. Before the interviews, I asked those who chose to participate in the study to fill and sign the consent form (see Appendix 12) in duplicate, and I kept one copy. I also gave them an opportunity to decline taking part and gave further assurance that they were free to withdraw at any stage, without giving a reason.

**Autonomy**

During the study, I respected the participants’ right of free choice to participate or not. After providing participants with information regarding the nature of the study, I gave them time to think and make a decision about their participation in the study. I also gave them an opportunity to decline to take part or withdraw from the study at any stage, without giving a reason. I also assured them that should they decline to participate; their decision would not affect their care and treatment at all.

The interviews involved discussing the participants' personal illness experiences. Alty and Rodham (1998) suggest that research that focuses on sensitive issues may invoke intense emotions which make participants unable to talk about their feelings, and can also be perceived as irresponsible on the part of the researcher. Therefore, during the interviews, I observed the participants for signs of discomfort, anxiety or distress. One participant became uncomfortable with some issues that arose during the interviews, so I informed her that she did not have to respond to some of the questions. In line with the distress policy (see Appendix 13), I stopped the interview and gave the participant the opportunity to withdraw from the study if she wished, or to postpone the interview and continue on another day, but that did not become necessary. After a break, the participant indicated that she wanted to continue with the interview because it helped her to talk about issues which she had not mentioned before. At the end of the interview, she expressed that she felt much personal relief. She also indicated
that she did not need to see the rheumatologist or a psychologist. None of the participants requested to withdraw from the study or requested to have some of their interview transcripts deleted, even though they had the choice.

Confidentiality and data storage

When conducting research, confidentiality is a key issue (Green and Thorogood, 2013). In this study, privacy and confidentiality were maintained at all times. Information gathered from the participants was anonymised, and all personal details were kept separately. Data in the form of audio recorded materials were also anonymised and stored in a locked cabinet in my office in Nairobi. Audiotaped interviews were transcribed verbatim and anonymised and coded. Once transcribed, the typed data was stored on a password protected personal computer which could only be accessed by me. Any reports sent to the supervisors via email for supervision purposes were anonymised. Also, all participants were informed that quotations from the interviews may be used in presentations of the thesis and any publications, but that they would still be anonymised. Moreover, once the thesis writing and publications are completed, the recordings will be erased. All transcripts will be stored for a maximum of five years according to The University of Manchester's regulations on research data storage.

Lone working

During the research process, a researcher may be susceptible to harm during field work which may involve travelling to locations unknown to the researcher (Tisdale and 1999). It is therefore important for the researcher to consider health and safety issues. To ensure my safety during this study, I adhered to lone worker policy. Before visiting participants in their homes, I would ask colleagues about the area of the visit to assess the safety of the area. Also, the interviews were undertaken at locations selected by the participants and only during the day and within normal working hours. Since I am a long-distance student, my safety contact person was my next of kin who I informed about the location of the interview, expected time of interview and expected finish time. As my method of communication with him, I informed him that I would send two texts: ‘START’ when I started the interview and 'STOP' when I finished the interview. I would also alert my next of kin when I was leaving the area. However, only two interviews were conducted in the participants' homes.
Access to supervision is also suggested in order to deal with any emotional difficulties as a researcher (Dickson-Swift et al., 2008). Throughout this study, I informed my supervisory team at The University of Manchester about my research progress which was without incident.

### 3.9.3 Gaining access to study participants and recruitment

As soon as I obtained ethical clearance from the two hospitals, I met the lead doctors (rheumatologists) and nurse managers of the two rheumatology clinics who requested to see the letters from their respective ethics committees. I also had an opportunity to meet the clinic teams and gain an overview of the two clinics.

The teams in the clinics consisted of the rheumatologists, the clinic managers, nurses and records officers. Though I was not a member of any of the rheumatology clinic teams, I already knew some of the rheumatologists and some of the nurses through my one year stint at a private rheumatology clinic where I worked with one of the rheumatologists, and through meeting some of the nurses at nursing conferences. We discussed the study aims and the research plan which included a discussion about initial sampling ideas. I also requested for them to assist in the identification of potential participants who met the inclusion criteria. The meeting also offered an opportunity for clarification and to answer any questions about the study. At each of the clinics, a nurse was assigned to assist me with gathering information as necessary.

The recruitment of potential participants started in the private rheumatology clinic on 1st August 2013 as ethical clearance process was obtained quicker than expected; while recruitment at the public rheumatology clinic started on 2nd January 2014. A total of 21 patients and 6 doctors were recruited, as illustrated in Table 3.1 below.
Table 3.1 Recruitment of research participants

<table>
<thead>
<tr>
<th>Clinic</th>
<th>Private Rheumatology Clinic</th>
<th>Public Rheumatology Clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>1&lt;sup&gt;st&lt;/sup&gt; recruitment</td>
<td>1&lt;sup&gt;st&lt;/sup&gt; August 2013</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt; January 2014</td>
</tr>
<tr>
<td>Number of patients assessed for eligibility</td>
<td>11</td>
<td>15</td>
</tr>
<tr>
<td>Number excluded</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Number enrolled</td>
<td>8</td>
<td>12</td>
</tr>
<tr>
<td>Number interviewed</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>2&lt;sup&gt;nd&lt;/sup&gt; recruitment</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt; February 2014</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt; May 2014</td>
</tr>
<tr>
<td>Number of patients assessed for eligibility</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Number excluded</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Number enrolled</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Number interviewed</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>3&lt;sup&gt;rd&lt;/sup&gt; recruitment</td>
<td>August 2014</td>
<td></td>
</tr>
<tr>
<td>Number of doctors recruited</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Number interviewed</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>4&lt;sup&gt;th&lt;/sup&gt; recruitment</td>
<td>January 2015</td>
<td></td>
</tr>
<tr>
<td>Number of patients assessed for eligibility</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Number excluded</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Number enrolled</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Number interviewed</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

3.9.4 Sampling

Participants were selected for inclusion based on the following criteria:

- Patients over 18 years age who had lupus for a period not less than 2 years
- Patients who currently had active lupus but were not acutely ill
- Patients who were able/willing to consent
Miles and Huberman (1994) emphasise that a sample in qualitative research must be reflective of the phenomena being studied. If relevant, then ‘thick or rich’ data can be accessed. Grounded theory sampling is based on selecting participants who can provide information which facilitates theory development (Glaser and Strauss, 1967). Glaser (1978) also suggested that the initial sampling technique should seek individuals who meet the study's inclusion criteria to begin the development of concepts, and theoretical sampling to contribute to theory development. Therefore, grounded theory sampling comprises of both purposive and theoretical sampling techniques, both of which were conducted in this study.

3.9.4.1 Purposive sampling

Purposive sampling seeks to recruit participants with features or characteristics of interest to the study (Corbin and Strauss, 2008; Creswell, 2012). For this study, to seek out key informants, an initial purposive sampling strategy was used to guide the study (Bryman, 2012). The strategy was informed by a number of sources including an initial literature review, my prior knowledge on lupus-related issues and from information generated through consultation with the rheumatologists. The aim was to recruit patients with a range of illness severity, different places of residence (for example, those living in Nairobi and outside Nairobi) and differing levels of service utilisation to increase the diversity of the sample. This involved seeking permission to go through the patients' records in the two clinics.

The patient's sample included a balance of younger and older people, those with and without co-morbidities. Also, the decision to select two centres was a methodological one: it was intended to maximise the number of prospective participants and the diversity of cases which had implications for making comparisons between groups, which could be of relevance to the theoretical ideas that developed from data analysis. I considered that such comparisons could not be predetermined from the outset of the study but would probably become necessary during the study, to increase the probability of collecting different data relevant to the core categories (Glaser and Strauss, 1967).
3.9.4.2 Theoretical sampling

Theoretical sampling is an integral part of sampling in grounded theory methodology and is defined as:

"… the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyses his data and decides what data to collect next and from where in order to develop his theory as it emerges." (Glaser and Strauss, 1967 p.45)

It is flexible and provides diversity in choosing different sources of data (Glaser and Strauss, 1967) as it allows the researcher to follow leads in data, and define the properties and relationships between emergent categories (Charmaz, 2000). The process is conducted after the primary data collection and analysis which produces a broad range of descriptive categories. This is followed by simultaneous data collection, coding and analysis to generate theoretical data as the research progresses, in order to seek out participants who can provide further information on issues that arise from subsequent data analysis (Morse, 2007). Data collection is progressively focused and informed by emerging theory.

As this study progressed, I recruited participants with differing illness experiences so as to explore multiple dimensions of the social processes under study. After the first few interviews, it was clear that lupus took a long time to be diagnosed, giving rise to the code of diagnostic delays. It also became clear that patients were seeing doctors in different health facilities which led to the code of going round the system. I also realised that patients had differing illness beliefs which led to the code of illness beliefs. These first codes appeared theoretically relevant, so I applied theoretical sampling which led to further recruitment of participants from different ethnic backgrounds, age groups and socio-economic backgrounds. A decision was also taken, with the approval of the supervisory team, to include doctors in the study to establish what contributed to diagnostic delays and going round the system. I subsequently sampled rheumatologists and postgraduate doctors in the Department of Internal Medicine to ascertain reasons why patients went round the healthcare system.

Theoretical sampling also includes searching for 'negative cases' which do not fit the common emergent patterns in the data (Seale et al., 2004). Such cases are incorporated to illuminate and elaborate the emerging categories (Charmaz, 2006). I also endeavoured to find patients who
had dropped out of services in order to enhance my understanding of, and to elaborate, the emerging themes. However, I only managed to reach two; one was interviewed, while the other refused and stated that she was healed and did not need to attend the clinic anymore. Another important element in the data which influenced theoretical sampling was how the illness had affected the individuals. It was, therefore, necessary to sample the younger and older patients to see if the illness had affected them differently or not.

Theoretical sampling, which is closely connected to constant theoretical analysis, is continued until theoretical saturation is achieved, when no new theoretical categories are formed (Charmaz, 2006). Morse (2000) also suggested that a sample of 20-30 participants is generally sufficient for achieving data saturation in grounded theory. Therefore, I continued to add individuals to the sample until I reached theoretical saturation, when there was nothing new emerging from the data.

### 3.9.5 Data generation

In qualitative research, there are various ways of generating data (Corbin and Strauss, 2008). The main methods of data collection include semi-structured interviews in which the researcher conducts in-depth interviews with the participants. Interviews are useful for eliciting the participants’ views, perceptions and understandings of their situations and experiences in an area where little is known (Kvale and Brinkman, 2009; Thorogood and Green, 2009). Interviews are meant to investigate individuals' views, experiences, beliefs and motivations regarding specific matters (Gill et al., 2008). Interviews also offer the researcher the opportunity to penetrate surface descriptions by probing shifting topics, adjusting pace or returning to earlier points that have been discussed (Charmaz, 2006). The value of interviews as a tool for data collection is linked to the ontological and epistemological assumptions and the ability to generate accounts which are socially situated (Kvale and Brinkman, 2009; Mason, 2002).

The value of interviewing as a tool has also been debated on the basis that it generates accounts which are products of the social setting where data is collected, rather than adequately representing reality (Murphy et al., 1998; Silverman, 2013). However, it is recognised that interviews are real and offer an account of the participant’s world
Interviews must, therefore, be evaluated in relation to the context of the data generated, the cultural perspectives they reveal about the participant’s construct of reality (Mason, 2002; Murphy et al., 1998), and in recognition that they are socially constructed during the interactions between the study participants and the researchers (Thorogood and Green, 2009). Interviews are encounters that are influenced by social dynamics which cannot be separated from the social context (Fontana and Frey, 2005). They offer valuable data regarding their forms and the issues they raise, as well as the content produced (Fontana and Frey, 2000; Silverman, 2013).

Normally, the interviewer has a broad plan of inquiry, with a set of questions which are not necessarily specific and not necessarily asked in a particular order. Rather, the interview flows more like a conversation in which the participants guide the direction of the interview (Green and Thorogood, 2013). Charmaz (2000) and Creswell (2012) suggest using interviews for grounded theory studies about understanding the social world due to their flexibility and ability to progressively narrow the focus of the inquiry along a theoretical direction as themes emerge.

Focus group discussions (FGD) are also common and can be used as a research tool in grounded theory studies (Bryant and Charmaz, 2007; Corbin and Strauss, 2008). FGD enable data collection through a guided group interaction on issues, with the aim of benefiting from the group dynamics. It is meant to encourage participants to talk, respond to each other and compare their experiences (McLafferty, 2004). Interaction is key for successful FGD, and this would have been quite useful in this study. However, it was not utilised because the clinic is a mixed rheumatology clinic and most patients who attend the clinic come as referrals from outside Nairobi which made conducting an FGD unfeasible. Also, critics of FGD indicate that one of its disadvantages is the articulation of group norms which may silence some individual voices (Gill et al., 2008; Kitzinger, 1995).

In this study, semi-structured, in-depth face-to-face interviews were the main method of generating data on the participants' perspectives and experiences of living with lupus. An initial interview topic guide was developed before starting the interviews (see appendix 15). It was used to ensure that all the relevant topics were covered to meet the objectives of the study in a logical manner. The structure of the interview guide was designed following Charmaz’s
(2000) suggestion about using open-ended questions which allowed the conversation to flow where it needed to, in order to address the participants' ideas as they arose (Patton, 2002). This was well suited to the grounded theory principle of discovering participants' complex behaviour without imposing my ideas. The conversations between us enabled me to explore the participants' views about their experience with diagnosis, care and the impact of lupus. After the first few interviews, there was a need to add some topics to the guide. Thus, the interview guide was slightly modified to capture the additional issues that were emerging from the conversations with the participants (see appendix 16). When it became necessary to interview the doctor, I developed another interview guide for the doctors (see appendix 17).

Before starting the interviews, I introduced the interview and explained the process to create a comfortable and informal environment in which participants could discuss their perspectives. Creswell (2012) suggests the need for researchers to create a comfortable environment and develop a rapport with participants, in order to obtain detailed perspectives which ensure quality data. In this study, the setting of the interviews was determined by the participants. Of the twenty-one patient interviews, eleven were conducted within the hospital compounds and not in the consulting rooms; six were held in the consulting rooms; two interviews were conducted in the patients' homes and another two patients requested to have their interviews in a coffee shop where we chose areas which offered some privacy. With the doctors, four interviews were conducted in the consultation rooms and two were performed within the hospital premises in the gardens. The different interview sites had no distractions for the patients and therefore did not affect the quality of the interviews. However, for one doctor who decided to have the interview during the clinic time, we experienced some interruptions from nurses who felt that the interview had gone on for too long. However, he was able to control the situation by informing them that we were almost through with the interview. We were actually at the tail end of the interview. However, I raised the issue of possible interference from the staff before I commenced the interview, but he insisted that it would be challenging to meet him outside office hours.

The structure of the interviews consisted of using initial open-ended, intermediate and ending questions as suggested by Charmaz (2014). I used opening questions such as: 'How did you feel when you first felt unwell?' The intermediate questions were more focused, such as: 'Please explain to me why you thought that you could have been bewitched'. The ending
questions were more targeted and designed to bring the interview to an end, such as: 'Is there anything else you would like to add regarding your experience of living with lupus?' This type of question allowed the participants to talk about anything else they felt was relevant to their experiences.

The initial interviews were conducted with patients. From these interviews, as part of theoretical sampling, it became necessary to interview doctors to clarify why the patients went through some experiences, for example, why getting a lupus diagnosis took so long. The doctors were also individually interviewed. The length of the interviews depended on how much the participants had to say, and at the end of each interview, I thanked each participant.

All interviews were audio recorded using a digital tape recorder which was the size of a mobile phone. The participants were informed beforehand about the need and importance of recording the interviews to ensure the accuracy of their views, and none of them felt uncomfortable about this. Audio recording also enabled me to focus on the interview questions and responses, rather than taking notes. However, I noticed that some participants were more relaxed and talked more freely after the tape recorder had been switched off. Warren (2002) pointed out that such participants either do not want particular issues recorded or prefer discussing their issues without the constraints of the interviewer's questions. In such cases, before leaving the area, I wrote field notes after the conversation regarding the issues that came up and my reflections. For example, the uncertainty of getting married and having children made some participants look sad as they were narrating their concerns. I would reflect on the awareness of society's expectations irrespective of whether one was well or sick, and whether this would change if the same participants were in a different society.

The other main method of data generation is participant observation whereby the researcher studies people in their normal environment by basically observing their interactions and behaviours (Green and Thorogood, 2013). Some researchers prefer using observational methods instead of interviews because they are related to naturally occurring events rather than being deliberately created situations (Dingwall, 1997). Observing research participants allows the researchers to capture and recognise some aspects of social processes and interactions among the participants (Timmermans and Tavory, 2007). Observations also provide a clearer understanding of the participants' verbal reports (Charmaz, 1994b), with the
possibility of inconsistencies between actions and verbal reports being realised (Bryant and Charmaz, 2007; Charmaz, 1994b). However, this method of data collection was not utilised in the research as the purpose of the study did not require participants to be in their natural settings. Also, most participants were from outside Nairobi and therefore far from their families and their natural settings. However, during the interviews, I was able to observe the non-verbal facial expressions or emotional behaviour, such as sighing, while answering some questions which I took note of. I also made notes on my general observation about how I felt the interview went.

Nevertheless, there is still debate about what data is best for grounded theory study since the originators of grounded theory did not define what they meant by 'all is data' (Corbin and Strauss, 2008; Mason, 2002). However, Glaser and Strauss's original work on grounded study utilised interviews and observation as data collection methods.

### 3.9.6 Transcribing process

The process of conducting qualitative studies includes the verbatim transcription of data which provides evidence of how the data was conceptualised (Oliver et al., 2005). Debate exists about the essentiality of the transcription of qualitative and grounded theory research (Glaser, 1978; Stern and Coven, 2001). However, Stern and Coven (2001) advise that novice researchers need to transcribe all data including examining social processes within the social context. This would ground the data in the study. For this study, I transcribed all of the interviews as soon as was practically possible, as advised by Easton (2000), while I could still remember the dynamics of the interviews. This enabled me to insert the non-verbal communications in the right places in the text, minimise misinterpretations and note the preliminary thoughts about possible themes. Each transcription took approximately 8-10 hours. This was followed by reading and re-reading the transcripts, as suggested by Streubert-Speziale and Carpenter (2003), in order to familiarise and immerse myself in the data and have a general sense of each participant's experience.
3.9.7 Data analysis

There is a general data analysis process that researchers use in qualitative research and a number of additional analysis steps for specific qualitative research approaches (Creswell, 2012). The general process includes organising the data, reducing them into themes through the coding process, condensing the codes, and finally, presenting and discussing the findings (Creswell, 2012). The aim is to look for themes or concepts that emerge from the data themselves rather than imposing predefined coding categories.

Glaser and Strauss (1967) suggest that the data analysis process in grounded theory is its greatest strength. It operates differently because it is conducted concurrently rather than sequentially along with data collection and theoretical sampling. The coding processes, constant comparison, memo writing and theoretical sampling enhance the emergence of the theory and formation of theoretical framework (Denzin and Lincoln, 2003). The first step of grounded theory analysis is the intense coding of the early data (Charmaz, 1994a; Glaser, 1978; Strauss, 1987). This entails open coding, an intense line by line analysis of a transcript to ensure that the analysis is truly grounded. The idea is to generate as many codes as possible.

Later stages of analysis integrate a lot of the initial codes into higher level analytic categories which show that they emerged from the data rather than being imposed. Bryant (2008 p. 544) defines a category as "a concept that has been elaborated so that it is regarded as representing real-world phenomena". Various grounded theorists describe coding procedures differently.

Glaser (1978) describes the coding process in two stages: substantive and theoretical. In substantive coding, the emerging codes are constantly compared with other data to form categories; while theoretical codes are the concepts that explain the relationships between substantive codes. On the other hand, Strauss and Corbin (1998) provide a three step structure: open, axial and selective coding. In open coding, data is separated into units. In axial coding, the data is conceptualised into categories and categories integrated in selective coding to produce a theory. Both approaches show that the data has to be analysed and coded to generate categories (Glaser, 1978). Charmaz's analysis (Charmaz, 2006) is similar to Glaser and Strauss's (1967) analysis, which consists of initial and focused coding. However, it
incorporates a more flexible coding process which she considers more appropriate to the interpretive approach (Charmaz, 2000).

In this study, data analysis was based on the grounded theory principles of concurrent data generation and analysis using the constant comparison method and theoretical sensitivity to ensure that the developing codes and concepts were grounded in the data.

**Data management**

At the beginning, I coded the first four interviews in Microsoft Word, which I found very tedious. I then considered incorporating the use of the qualitative data analysis software NVivo version 10 and attended NVivo training for beginners. In the meantime, I continued with manual coding and coded a total of 10 transcripts. After training, I imported all 10 transcripts into NVivo and coded them in the programme, which was a very quick exercise. I found NVivo useful for data organisation and management, particularly in the initial stages of fracturing data into segments for labelling (see appendices 19 and 20). This was probably also made easier by the initial manual coding that I had done earlier. This meant that I tended to rely on what I had done manually without discovering any new codes. I also struggled with identifying the interrelationships between concepts and categories and theoretical integration, probably due to being a novice. From Glaser's standpoint, computer data analysis of a grounded theory study has two major disadvantages which I also experienced: firstly, the computer sorting blocks creativity and the process of theory generation, thus reducing the occurrence and re-occurrence of codes to numbers which weaken meaning (Glaser, 2003). Secondly, as the theoretical codes emerge, incorporating key ideas from memos into the analysis is difficult when the data is already fragmented (Glaser, 2003). Therefore, I reverted to manual analysis which was tedious but enabled me to engage more with the data, and also made constant comparison easier.

**The coding process**

I employed the three stage coding process as suggested by Charmaz (2014): initial coding, focused coding and theoretical coding. This was consistent with constructivist grounded theory approach. The first stage consisted of opening up the data and examining each sentence line by line in each transcript to determine and describe important actions or events with a phrase or code (Fassinger, 2005). This process was facilitated by Glaser's overarching question
for analysis: 'What's happening here?' (Glaser, 1978). Attention was also given to 'in-vivo' codes which used original terms from participants that summed up their experiences and meanings (Charmaz, 2000). For example, 'a shadow of myself' was a phrase used by one of the participants which remained as a provisional code until it was raised to the level of a category. The aim was to stay close to the data by incorporating the participants’ own words and meanings to develop codes that were grounded in the original data (Charmaz, 2014). Also, my supervisors looked at the transcripts and codes. The initial coding generated over 200 codes which needed grouping and structuring.

The second stage consisted of grouping the initial codes into overarching categories by selecting significant codes as markers for organising and synthesising larger sections of data. This process was influenced by the constant comparison of new data for differences and similarities, and the use of memos. Constant comparison raises codes to a more conceptual level where their characteristics are elaborated (Lempert, 2007). The abstract nature of categories gave the codes a more 'analytical weight' which drove the analysis forward to the third and final stage (Charmaz, 2014). Establishing theoretical codes involved interpreting the relationships between categories and moving the analysis towards the development of a theoretical framework by narrowing down the many categories. Glaser (2001) suggested that in order for researchers to be able to identify the main category, they need to focus on the main concern for participants and how they attempt to resolve it. Charmaz (2014), on the other hand, suggests focusing on the complexities of actions, views and experiences, and I adopted this. Thus, the findings chapters refer to main categories and sub-categories. This process was also assisted by the use of memoing and the constant comparison process. Appendix 19 and 20 illustrate some of the coding processes.

3.9.8 Constant comparative analysis

The constant comparison of data is a key tenet of grounded theory methodology which ensures that the coding process maintains its momentum (Glaser and Strauss, 1967). It begins with identifying recurrent events and incidences in the data. The process is iterative whereby new data is compared with existing data for common features that are progressively gathered into overarching categories (Bryant and Charmaz, 2007; Charmaz, 2006). The process also focuses on differences within data in order to identify any emerging sub-categories. In this way, the
full complexity and diversity of the data are recognised. Constant comparative analysis assists the researcher to link and integrate data in such a way that the emerging categories capture all variation of occurrences. The constant comparative analysis is conducted between concepts also to capture variation in the emerging theory. Data collection is therefore alternated with data analysis to avoid 'data overwhelm' (Glaser and Strauss, 1967; Glaser, 1978).

In this study, constant comparison enabled the reduction of initial codes to focused codes. The focused codes were also compared and grouped according to their similarities and diversities within the emerging categories. For example, the category of going round the system was arrived at during my discussion with my supervisors. As the study progressed, it became apparent that participants were experiencing similar signs and symptoms which were grouped as signs and symptoms of lupus. Another similarity was that they were receiving inconclusive diagnoses because despite treatment they were not improving, in fact, some were getting worse. Another similarity was that they were in and out of hospital due to persistent illness, as a result of which they started moving to different health facilities which were termed going round the system, which then became a category.

As the interviews progressed, I also wanted to establish the issues which made them 'go round' the health system. Some were dissatisfied with the treatment they received; others questioned the competencies of the doctor. Some moved from small to bigger facilities which were better equipped; some moved due to decisions made at the family level, while others moved from public to private health facilities which had better laboratories and had all the medication they needed.

I also compared data to establish if there were participants who did not move round for health services and if not, why. Most of those who finally got a lupus diagnosis continued to attend the rheumatology clinic regularly. Those who could afford the cost of their healthcare also tended not to move from the private clinic, especially in cases where diagnosis and geographical distance were not a deterrent. Thus, there was a comparison of concepts like affordability, the availability of lupus services and geographical distance, which became sub-categories. In this way, the full complexity and diversity of what caused the participants to go round the system were recognised. This constant comparative analysis was closely connected to theoretical sampling which it facilitated, as was described in section 3.9.4.2. The
development of categories and sub-categories was jointly achieved with the consensus of my three supervisors.

3.9.9 Theoretical sensitivity

Theoretical sensitivity plays a major role in grounded theory approach (Glaser, 1978). It is the researcher's ability to ask questions of the data, and to understand and give meaning to the data at an analytical level. Glaser (2004) urges researchers to enter the research setting with minimum predetermined ideas or biases and to maintain their analytical stance. This enables them to maintain openness and tolerate the multiple emerging perspectives from research participants. Being sensitive to the data should begin when the researcher immerses himself/herself into the data and is able to select relevant issues, events and happenings. He/she interacts with the data by looking at the similarities and differences within each emerging category, idea or concept (Strauss and Corbin, 1998).

In order to develop the insight, Strauss and Corbin (1998) argue that the researcher draws on a number of resources such as existing literature, professional and personal experience (Strauss and Corbin, 1998). The existing literature makes the researcher aware of the background information and predetermined ideas, such as existing hypotheses, and their ability to give meaning to the data during data analysis. The professional and personal experiences, which are rejected by Glaser, are seen as useful in informing the data analysis, as experience in a particular field enables one to understand how things work (Strauss and Corbin, 1998). Thus, theoretical sensitivity is essential for the process of theoretical sampling, concurrent data collection and analysis (Charmaz, 2014).

In this study, I conducted an early literature review for the study proposal which improved my level of understanding and provided a point of reference for the study (Lempert, 2007). I also conducted a more extensive literature review iteratively as the analysis and writing up of the study findings progressed. Theoretical sensitivity was also addressed during the time of data collection. I became acquainted with the participants’ experiences as I spent extended periods of time listening to their stories. The initial coding process and constant comparison which I used throughout the analytic process also helped me to stay close to the data by continuously reflecting on the codes and looking for relationships between the data. I was, however,
mindful of the possibility of my prior professional knowledge and personal knowledge about Kenyan society influencing the data collection and analysis, which other researchers (Denzin and Lincoln, 1994; Glaser and Holton, 2004) have argued is inevitable.

3.9.10 Memo writing
Memo writing is an important part of grounded theory method. There are two types of memos: operational memos and theoretical memos (Thorogood and Green, 2009). Operational memos prompt the researcher to analyse data and ideas about codes early in the research process. These are operational notes which are more descriptive (Thorogood and Green, 2009). In addition, memos are written throughout the process of data collection and analysis. This assists the researcher in developing ideas about the data and fine-tuning subsequent data collection (Charmaz, 2014). Writing theoretical memos gives the researcher the opportunity to move beyond descriptive codes and construct analytic notes by comparing data, codes, categories and concepts and exploring the emerging relationships between them (see Appendix 21). The memos, therefore, enable the development of categories which are then incorporated to develop a theory (Strauss and Corbin, 1998).

In this study, operational memos were written to document any situations and ideas that arose during the research process. Charmaz (Charmaz, 2014) suggests that memos should be drafted in a free and flowing manner and should be related to the analysis undertaken. For example, early in the research process, I wrote memos related to diagnosing lupus, which seemed to take a long time. As data collection proceeded, I searched for more descriptive codes that indicated that diagnosis was a lengthy process, and codes that explained why this was. These descriptive memos were dated and linked to interviews. They also guided the theoretical sampling and writing of theoretical memos on diagnostic delays. I also explored the emerging relationship between the categories of diagnostic delays and going round the system, since diagnostic delays partly contributed to the participants going round the system.

3.9.11 Data saturation
Glaser and Strauss (1967) define saturation as a state of no new data, when all forms or types of occurrences have been elicited through the detailed description and not through frequencies
of counts. Theoretical sampling is continued until categories, their different dimensions and the relationships between the categories are saturated. Glaser (1978) and Strauss and Corbin (Strauss and Corbin, 1998) suggest that there are two types of data saturation: category saturation and theoretical saturation. Category saturation is a term used when new data does not lead to the development of new categories. On the other hand, theoretical saturation is used when researchers reach a point during data collection and analysis when no more concepts emerge, and the relationship between the categories are clear and have thick descriptions (Morse, 2004).

In this study, saturation was achieved when a concept could be explained across different contexts and by contrasting the participants’ experiences (Charmaz, 2014). For example, the perception of inaccessibility of lupus care was described by the patients and contrasted with the perception of doctors. Saturation was reached when both groups described the inaccessibility of lupus care in terms of the organisation of health facilities and unaffordable cost of healthcare due to various factors. The interviews were stopped when no new concepts were emerging, and no new categories were identified from subsequent interviews. Writing theoretical memos and maintaining discussions with the supervisory team was also useful in deciding that data saturation had been achieved.

3.10 Summary
This chapter has discussed the qualitative approach to the study including the relevant theoretical and philosophical perspectives. It has also described the grounded theory principles that underpinned the study and the choice of utilising a constructivist approach. It also presents a detailed account of how grounded theory methods and procedures were applied in the conduct of the study. The next chapter provides an overview of the study findings.
Chapter 4: Characteristics of study participants and overview of research findings

4.1 Introduction
The purpose of this chapter is to provide information regarding the characteristics of the study participants and to give an overview of the identified categories.

4.2 Characteristics of the study sample
A total of 27 participants were interviewed individually. One group consisted of 21 patients with a confirmed lupus diagnosis from a rheumatologist, currently attending either of the two rheumatology clinics utilised as study centres. Of the 21 patients sampled for the study, 11 were receiving health services from a rheumatology clinic based at a private hospital while the other ten were receiving health services from a rheumatology clinic located in a public hospital. The other group of participants consisted of six doctors who had attended to patients with lupus at the rheumatology clinics.

4.2.1 Socio-demographic characteristics of the patients
A socio-demographic profile of the patients was gathered regarding their cultural background (cultural group, religion and area of residence), gender, level of education (highest level achieved), age at the time of interview, employment status, marital status and the number of children they had, as indicated in Table 4.1 below.

4.2.1.1 Gender
Of the 21 patients, 20 were females with one male. This is a reflection of the disease representation which is assumed to be more common in women than in men with a gender ratio of 9:1 (Adelowo and Oguntona, 2009; Naleway et al., 2005).
Table 4.1: Demographic characteristics of participants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Patients from public hospital</th>
<th>Patients from private hospital</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of participants</td>
<td>10</td>
<td>11</td>
<td>21</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Female</td>
<td>10</td>
<td>10</td>
<td>20</td>
</tr>
<tr>
<td>Age at time of interview (years)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 20</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>21-30</td>
<td>5</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>31-40</td>
<td>3</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>41-50</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>51-60</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Cultural group</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bantus</td>
<td>8</td>
<td>9</td>
<td>17</td>
</tr>
<tr>
<td>Cushites</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Nilotes</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Religious background</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Christians</td>
<td>9</td>
<td>8</td>
<td>17</td>
</tr>
<tr>
<td>Muslims</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>None</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Highest level of education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>High School</td>
<td>6</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Vocational qualification</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Diploma</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>University Degree</td>
<td>2</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>8</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>Living with partner</td>
<td>2</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Having children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Only below 18 years</td>
<td>3</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Only above 18 years</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Both below and above 18 years</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>None</td>
<td>5</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Location of residence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>5</td>
<td>9</td>
<td>14</td>
</tr>
<tr>
<td>Rural</td>
<td>5</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Employment Status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed full time</td>
<td>4</td>
<td>7</td>
<td>11</td>
</tr>
<tr>
<td>Unemployed</td>
<td>5</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Student</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
4.2.1.2 Age
The patients’ ages at the time of data collection ranged from 19-56 years with a mean age of 34 years (SD 9.2). The majority were between 21-40 years with only one patient above 50 years of age. The age range is almost similar to findings of a West African study (Adelowo and Oguntona, 2009) which had an age range of 17-56 years with a mean age of 33 years. This confirms previous statements that the average age of a lupus diagnosis is before 34 years (Pisetsky et al., 2001; Rus et al., 2001), which is the prime career building phase of individual’s life (Agarwal et al., 2015).

4.2.1.3 Cultural groups
The three main cultural groups in Kenya were represented in the sample of 21 participants with 17 Bantus (80%), 3 Nilotes (15%) and 1 Cushite (5%). This is an approximate representation of the population because Bantus constitute over 70% of the total population, while Nilotes and Cushites constitute about 20% and 7% respectively, and others constitute 3% (Central Intelligence Agency, 2015; Nationsencyclopedia.com, 2015).

4.2.1.4 Highest level of education
The majority of the patients in this study (n=19) had achieved high school education and above, with seven of them being degree holders. The lowest level of education was primary school. Five of the degree holders were seeking health services from the private rheumatology clinic. The two patients who had attained primary school education were each receiving health services from the private and public health facilities. However, due to their small number, the relationship between the level of education and socioeconomic status was unclear.

4.2.1.5 Marital status
Among the 21 patients, the majority (n=15) were single with only six living with a partner. Out of those who were single, only one was divorced while two were widowed, and the rest (80%, n=12) had never lived with a partner. The number of those who were single was significant in a country where the mean marital age is 18 years. Some participants suggested that this was because they wanted to avoid being a burden to their partners; some indicated that they were the ones who blocked getting into relationships. This meant that being sick had affected the desire of some participants to get married.
4.2.1.6 Symptom duration

Of the 21 patients interviewed, 70% (n=14) had experienced symptoms for 2-4 years with 30% (n=7) of them having had the disease for a duration of 5-7 years. This means that most of them were relatively newly diagnosed.

4.2.1.7 Employment status

Only about 50% (n=11) of the 21 patients were employed, with almost another half not employed and dependent on their family members or friends for support with treatment and care. None of the participants was employed on a part-time basis. Seventy percent (n=7) of those who were not employed indicated that it was mainly because of their illness.

4.2.2 Clinical characteristics of patients

Since medical records were not available for scrutiny of documented clinical features, self-reported clinical features were utilised as proxy information. This may be potentially inaccurate in some respects due to recall bias.

Table 4.2: Clinical features of lupus as reported by patients

<table>
<thead>
<tr>
<th>Symptom</th>
<th>No. of patients with the symptom</th>
<th>Private Hospital</th>
<th>Public Hospital</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Painful joints</td>
<td>10</td>
<td>7</td>
<td>17</td>
<td>(81%)</td>
</tr>
<tr>
<td>Fatigue</td>
<td>8</td>
<td>4</td>
<td>12</td>
<td>(57%)</td>
</tr>
<tr>
<td>Mood swings</td>
<td>3</td>
<td>0</td>
<td>3</td>
<td>(14%)</td>
</tr>
<tr>
<td>Fever</td>
<td>7</td>
<td>3</td>
<td>10</td>
<td>(48%)</td>
</tr>
<tr>
<td>Chest pain</td>
<td>4</td>
<td>1</td>
<td>5</td>
<td>(24%)</td>
</tr>
<tr>
<td>General malaise</td>
<td>4</td>
<td>4</td>
<td>8</td>
<td>(38%)</td>
</tr>
<tr>
<td>Weight loss</td>
<td>5</td>
<td>0</td>
<td>5</td>
<td>(24%)</td>
</tr>
<tr>
<td>Insomnia</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>(10%)</td>
</tr>
<tr>
<td>Anorexia</td>
<td>5</td>
<td>4</td>
<td>9</td>
<td>(43%)</td>
</tr>
<tr>
<td>Skin rash</td>
<td>6</td>
<td>2</td>
<td>8</td>
<td>(38%)</td>
</tr>
<tr>
<td>Photosensitivity</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>(9.5%)</td>
</tr>
<tr>
<td>Hair loss</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>(24%)</td>
</tr>
<tr>
<td>Oral ulcers</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>(4.8%)</td>
</tr>
<tr>
<td>Kidney problems</td>
<td>5</td>
<td>4</td>
<td>9</td>
<td>(43%)</td>
</tr>
</tbody>
</table>
Table 4.2 illustrates that the most commonly experienced clinical feature mentioned by the patients was joint pains (81%), which is similar to the findings of studies from elsewhere in African populations (Adelowo and Oguntona, 2009; Carey et al., 2008; Houman et al., 2004). Fatigue was also mentioned by more than half of the participants (57%). In this study, fatigue was lower than reported in the developed countries where it is a prominent symptom of lupus reported to be present in up to 90% of patients (Cleanthous et al., 2012; Da Costa et al., 2006; Pons-Estel et al., 2010). However, the experience of fatigue in this study was much higher than in a study among Nigerian participants (Adelowo and Oguntona, 2009) where it was reported to be among the least common symptoms (27.3%).

Fever was also fairly commonly reported by patients (48%), who also mentioned that they had been treated for tropical diseases like malaria and typhoid. Loss of appetite was also fairly common (43%). Skin rash was not as common (38%) when compared to the study from Nigeria which reported 44% (Adelowo and Oguntona, 2009), and a South African study which reported 86.9% (Carey et al., 2008). Mouth sores, sensitivity to the sun, insomnia and mood swings were the least mentioned symptoms.

Most of these clinical features are similar to the ones described in the classification criteria for lupus (Hochberg, 1997), which is commonly used as a diagnostic tool. This means that the tool can be applied to the Kenyan population. Quite a number of patients (43%) indicated that they had kidney disease which, in most cases, is a complication of lupus and probably a sign of the cumulative damage of lupus due to either late presentation of patients or late diagnosis of lupus (Gordon, 2002). It may also confirm the supposition that kidney disease occurs early in the disease among Africans (Adelowo and Oguntona, 2009).

The most commonly mentioned clinical features by the doctor were also joint pains (83%) and skin rash (83%). This corroborated with the literature on lupus as mentioned in section 1.1.1 (Rus, 2008). The least mentioned clinical features by the doctor included sensitivity to the sun (17%), which is reported to be common among Indians (67%) (Malaviya et al., 1993) and Tunisians (53%) (Houman et al., 2004), and weight loss (33%). The dark skin of the Kenyan population might explain the difference in sensitivity to the sun. Recurrent abortions (33%), oral ulcers (33%), chest pain (33%) and surprisingly, fever (33%) and kidney problems (33%) were also least mentioned.
4.2.3 Characteristics of the doctors

A total of six doctors were interviewed; four rheumatologists and two postgraduate students in internal medicine with experience as indicated in Table 4.3. The first rheumatologist qualified 15 years ago and remained as the only rheumatologist for a total of eight years before the training of the second rheumatologist. During the study period, only four rheumatologists were serving the Kenyan population of approximately 39 million people (Kenya National Bureau of Statistics, 2010). Rheumatology is a relatively young discipline in Kenya, being the most recently opened sub-speciality clinic in internal medicine in both the public and private hospitals (opened 5 and 7 years ago respectively). The public hospital trains postgraduate doctors with four or five trainees in internal medicine rotating in the clinic for three months. They work side by side with the rheumatologists. At the private hospital, the patients are seen solely by the same rheumatologists.

Table 4.3: Characteristics of the doctors

<table>
<thead>
<tr>
<th>Doctors</th>
<th>Speciality</th>
<th>Years of experience since qualifying as doctors</th>
<th>Years of experience in rheumatology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor 1 (ID 54)</td>
<td>Postgraduate doctor</td>
<td>5 years</td>
<td>3 months</td>
</tr>
<tr>
<td>Doctor 2 (ID 60)</td>
<td>Postgraduate doctor</td>
<td>4 years</td>
<td>3 months</td>
</tr>
<tr>
<td>Doctor 3 (ID 55)</td>
<td>Rheumatologist</td>
<td>27 years</td>
<td>7 years</td>
</tr>
<tr>
<td>Doctor 4 (ID 56)</td>
<td>Rheumatologist</td>
<td>8 years</td>
<td>2 years</td>
</tr>
<tr>
<td>Doctor 5 (ID 64)</td>
<td>Rheumatologist</td>
<td>25 years</td>
<td>15 years</td>
</tr>
<tr>
<td>Doctor 6 (ID 66)</td>
<td>Rheumatologist</td>
<td>10 years</td>
<td>6 years</td>
</tr>
</tbody>
</table>

Table 4.3 demonstrates that most of the rheumatologists were experienced doctors, while the postgraduate students in clinical medicine were not as experienced.
4.3 Overview of categories and sub-categories of research findings

Data were analysed using the constant comparative method (Glaser and Strauss, 1967). From the analysis, the perspectives and views of living with lupus were categorised into five overarching categories. Figure 4.1 provides an overview of the main categories and sub-categories which were unique to each patient’s situation. The five categories are related to each other and illustrate the social processes as perceived and expressed by the patients and doctors.

Figure 4.1: Summary of categories and sub categories of research findings
In the following five chapters, each category is presented in greater details. Chapter 5 presents the findings related to the first category, ‘naming the illness’. The chapter describes the journey to getting a lupus diagnosis by describing the help-seeking behaviour of patients and the barriers and challenges some of them experienced, such as uncertainty regarding the nature and prognosis of the illness.

Chapter 6 presents the findings related to the second category, ‘going round the system’. This category describes how the organisation of the Kenyan health services influenced the patients’ care process. The participants explained their experience of health service accessibility regarding the geographical distance of the rheumatology clinics, and the cost of care in these facilities versus the patients’ financial abilities. Lupus service availability, coordination of care and treatment, and the challenges experienced due to the unclear care pathway are also described.

Chapter 7 presents the findings related to the third category of ‘cultural beliefs, practices and prejudices’. This chapter describes the cultural and religious beliefs some participants had regarding their illness causation. The chapter also discusses the participants’ beliefs about cultural and religious remedies. In addition, chapter 7 describes how some community members mistakenly associated lupus with HIV infection and how some participants experienced stigma and discrimination from the community.

Chapter 8 explores the fourth category about ‘resources for managing life with lupus’. It describes the precarious economic resources which all participants relied on. It also describes the social support/networks which were available to some participants and the cultural resources which some participants relied on.

Finally, chapter 9 focuses on the fifth category, ‘a shadow of myself’. This chapter describes the patients’ perspectives on how they felt the illness had affected their lives and how they were managing life with lupus. Most patients felt that they had lost their identity due to the visible and invisible changes in their body. They also felt that the illness had caused biographical disruption in their formerly ordered lives and affected their work, career, finances and relationships. Chapter 9 also describes how some participants had attempted to regain some level of biographical reconstruction which helped them manage to live with the illness at an individual level.
In discussing the findings, I used excerpts from patients’ transcripts to illustrate their concerns. Each excerpt is identified with a code number to maintain participants’ anonymity with “PRI” representing patients from the private clinic, “PUB” representing patients from the public clinic and “CL” representing doctors. Any bracketed data represent the information the researcher inserted to complete a statement made by a particular participant which was relevant to the context of the conversation. In accordance with grounded theory rules of integrating literature in findings (Glaser, 2001; Glaser and Strauss, 1967; Glaser, 1992), literature was integrated to the findings to provide supporting evidence and explanations.

4.4 Summary
The section described the socio-demographic and clinical characteristics of patients, followed by characteristics of the doctors. Overview of categories and sub-categories of research findings have also been introduced. The study established that most of the patients were female with the majority having high school education and above. They were mainly in the prime of their life. Most of them were single due to their illness and were relatively newly diagnosed. Half of the patients were employed. Most of the unemployed patients attributed this to their illness. Most of them reported joint pain and fatigue as their main symptoms. The doctor taking care of the patients were adequately experienced in taking care of Lupus. Categories and sub-categories of research findings are presented in further details in subsequent chapters (chapters 5 to 9).
Chapter 5: Naming the illness

5.1 Introduction

This chapter describes the first overarching category of ‘naming the illness’. During the discussions, it emerged that getting a name for the symptoms that participants experienced was a process which was not only hard and confusing, but also took a long time. ‘Naming the illness’ therefore sums up the diagnostic quest which most participants perceived as lengthy and often frustrating. Field (2013) suggests that giving an illness a medical name is significant in legitimising the illness status externally. However, it can get complicated when the symptoms are continuous or invisible. It is suggested that the subjective experience may be influenced by the individuals’ different perceptions of health and the sensory experiences of their symptoms. Variations in perception may be by social class, sex, ethnicity, the level of education and other social factors such as the individual’s environment (Brown, 1995; Salmon, 2000).

This category explores the context of getting a lupus diagnosis by examining the patients’ actions when they decided that their illness needed medical attention. It also describes the uncertainties and challenges that surrounded the naming of the illness. Two overlapping sub-categories emerged from the data: help-seeking behaviour and illness uncertainty. The following sections describe how each of the sub-themes influenced the process of naming the illness.

5.2 Help-seeking behaviour

Help-seeking behaviour was the first sub-category to emerge from the data as a patient’s initiative. During the discussions about how the patients felt when they were first unwell, the patients vividly recalled how their illness started and were able to describe their symptoms. They had various symptoms which included: multiple joint pain, fatigue, fever, headache, loss of appetite, weight loss, hair loss, skin rashes, sensitivity to the sun, mouth sores and mood swings. Some of them experienced miscarriages, frequent infections and kidney problems. These symptoms were similar to symptoms mentioned in the literature (Wallace, 2007). One doctor, however, indicated that malar rash was not as common among the Kenyan patients, as
reported in the literature (Wallace, 2007). Kidney problems, which are a complication of lupus and arthritis, were more common:

The lupus patients here are slightly different from other places because one, the so called butterfly or malar rash is not common here unlike the way it is recorded. Most of them will present with arthritis, ulcers in the mouth, hair loss and there is some photosensitivity although it is not very common... Some also present with serositis or kidney which is also very common. Let's say a third to half of the patients have kidney involvement.' (ID 66, CL)

Some of these symptoms were perceived as mild and taken for granted by the participants. However, during the interviews, it emerged that all of the participants (whether from the public or private health facilities) reached a point where a decision was made either by the patients themselves, or by the family members, that their symptoms needed professional attention. Some of the patients illustrated this:

'Yes, my body suddenly had become very reactive to the sun rays. So, I would feel very uncomfortable in the sun. I developed fever, and I decided to visit a doctor.' (ID 07, PRI)

'It was because of the headache and joint pains. I could not work and walking became a challenge as well.' (ID 12, PUB)

ID 12 indicated that when her symptoms started to incapacitate her, then she decided to go and see a doctor. Most of the symptoms mentioned were those that caused discomfort, especially pain, whether in the form of headache or joint pains, which started affecting their normal social activities. The other factors were persistence and the increasing intensity of the symptoms, as indicated by some of the participants:

'One, I had reached a point where I was like this is enough and God, I need to know what is going through me. When I found out that my finger nails had been deformed, it was a shock. That is because I realised that whatever was happening to me was not just pain. There was something more... The need to know what was wrong with me is what drove me to the hospital.' (ID 03, PUB)

'Since the fatigue was now the main indicator, and given that the nature of my work involves working odd hours, I had already some prior experience of getting tired naturally. Maybe doing a lot of work then you find you are just tired and cannot do anything else. So, we went [together with his family] to several physicians...When the hair loss started, it became another indicator.' (ID 11, PRI - male patient)

It was evident from the data that the participants' experiences with the symptoms made them conclude that all was not well with their health. It was also evident from the data that as the
symptoms worsened or started to impact on the patients' everyday activities, they got concerned and not only sought medical help for symptom relief, but they also sought information about what they were suffering from. This meant that there was a period when the symptoms were regarded as mild and not warranting medical attention. For the male patient, the trigger for his help-seeking was mainly the experience of hair loss and fatigue; he stated that he had no pain.

The study findings also established that all of the participants started formal help-seeking by visiting formal health facilities, where they got some form of treatment. When symptoms persisted, some of the participants sought further help and got further referrals to other formal health facilities:

'I was actually in school, and it was just before my ‘O’ level exams. My fingers used to hurt a lot, like they would just start hurting, then my legs would hurt sometimes and also my joints, my knees, my ankles. So, I would ignore it or I would come to the hospital and they would give me some pain killers. Do you know they would think that you are lying that you are sick, that you just want to get out of school. Ya, so it was just that pain. Then my mum told me that she thinks that it is something serious, because even like when I come home from school on holidays, I would still feel some pain. So, we decided to go to a doctor, like properly, who referred us to the rheumatologist and we did some tests.' (ID 01, PRI)

It also emerged from the data that help-seeking was not a one-off event because of the different or persistent symptoms, as depicted by some participants:

'There was no day I would say I was healthy... I have something in my chest I cannot explain, because it is not asthma, but I cannot sleep without a pullover because I have some pain I am experiencing inside my chest. I had developed some ulcers that also kept me quite unhealthy. So, I was either in the hospital for chest, for stomach, or for head because I had headache and they would say I had malaria.' (ID 02, PRI)

'The first time I felt unwell, I had abscesses all over my cheeks and forehead. They were swollen and black. I was scratching them. That lasted for a long time. We consulted a skin doctor, but the condition worsened. That was 1999. After six months, it affected my head.' (ID 16, PUB)

Some participants also persisted with help-seeking when the investigations were done, and the results revealed no pathology, or when they doubted the diagnosis:

'The first doctor who saw me took x-rays to check my heart and kidneys. He actually checked everywhere, but he did not find anything wrong with me. So, I did not know how he was going to help me.' (ID 03, PRI)
'I could feel a lot of pain, but inside me, I kept feeling and thinking that I had a problem that nobody is identifying because every time I had malaria, I am taking quinine, I am taking every drug that would come along, and nothing is happening.' (ID 02, PRI)

Help-seeking behaviour for most of the participants from the public health facility (ID 12, 16, 17, 18, 20) and from the private health facility (ID 01, 02, 03, 06, 07, 08, 10, 11) was further facilitated by the initiative of doctors and other health professionals as they advised or referred patients for further treatment. For example:

'The physician I had been seeing before I saw my current doctor (the rheumatologist) suggested that maybe I needed to see a specialist to determine whether it was something to do with the autoimmune system.' (ID 06, PRI)

'Now, I decided to change (Hospital), and I went to another Hospital. When they saw my condition, the doctor said there was nothing she could do. She just wrote a letter and referred me to the National Hospital.' (ID 16, PUB)

The narratives indicate that the challenges the patients encountered as they sought help included inconclusive investigations and repeated visits to the doctor due to a lack of improvement in their condition. The lack of a convincing diagnosis also made some patients seek help from various institutions:

'The main reason why we decided to go to Dr K is that the last person who saw me gave me a prescription for blood pressure. My blood pressure was normal though. Still, he gave me the prescription. That was the only medicine he prescribed. So, we were like, "I have no blood pressure concerns, yet he is giving me a prescription for the same". So, we consulted the doctor who had seen me the previous week and explained ourselves to him. In response, he told us, "Let me take a look at the file". He did that. He then called him and told him, "You are not supposed to give them a prescription like this one". That's when my husband decided that there was no need for us to go on but instead seek another opinion.' (ID 15, PUB)

In the doctor-patient encounter, a vital role of the doctor is to give a name to the patient's illness (Salmon, 2007). Studies suggest that some factors such as personal, professional, societal and bureaucratic factors may influence the doctor’s choice of name, with professional factors playing a key role. The professional factors are based on training, research, technical literature and the findings from tests and investigations (Salmon, 2000; Salmon, 2007; Wood, 1990). In this study, some of the professional factors which affected the naming of the illness were level of training of the clinicians and the results of tests or investigations. For example,
some of the rheumatologists indicated that there was a knowledge gap among the primary clinicians due to their low level of training, low index of suspicion for lupus and inexperience:

'Okay, the catch about the country is that we have many clinical officers who treat patients for typhoid, brucellosis and the rest. So, you will have patients who have diabetes, lupus, and even epilepsy who have been treated for those diseases. However, that is just wrong clinical approach to patients by the clinical officers.' (ID 66, CL)

The diagnostic challenges experienced by the patients caused uncertainty, as discussed in the next section. A few of the participants (ID 07, ID 16 and ID 17) also switched to seeking help from traditional healers, as discussed in section 7.3. Salmon (2007) and Wood (1990) suggested that the effect of naming the illness on the individual patient may be determined not only by the doctor's experience and knowledge, but also by social, cultural and economic factors.

5.3 Illness uncertainty

In discussion with patients and doctors about the diagnostic quest, two types of uncertainties emerged; pre-diagnostic uncertainties and uncertainties regarding disease (lupus) trajectory. The nature of the illness became uncertain for some patients as the investigations revealed no pathology, resulting in prolonged periods before the illness could be named. For example:

'...No. I went to, you know the way you go to the private hospital, you go to casualty, they run some tests, and they find nothing. I did that a lot. I think I did it like five times.' (ID 01, PRI)

'By the way, I was in pain for about nine months as I did not know what was wrong with me.' (ID 02, PUB)

When the doctors were interviewed regarding the diagnostic challenges, they also acknowledged that there was a diagnostic delay. For example:

'...many of our patients have gone through the hands of a lot of health providers, passed through many tests, been diagnosed with various conditions. Eventually, when they come with the final diagnosis of lupus they have gone through a lot...' (ID 64, CL)
The patients moved from one facility to another due to frustrations, and this was also mentioned as a contributing factor to the diagnostic delay:

'*...In any case, even when we are talking about public, the public does not have all the diagnostic facilities required for lupus, so the patients move back and forth. However, even those patients who are in the public sector, when they are not getting a diagnosis they run to the private sector... However, the patients are seen and diagnosed when there is a high index of suspicion - especially when they see a doctor who has some idea of lupus...'* (ID 64, CL)

From the response of doctor ID 64, it was evident that some patients moved back and forth between the private and public health facilities, though this came later when patients started to feel desperate about the lack of a convincing diagnosis. Limited laboratory services in the peripheral public hospitals, the cost of laboratory services and the limited number of rheumatologists were also mentioned as factors leading to diagnostic delay:

'But even in our facilities on the periphery, they hardly ever do the tests that are required. May be just here in Nairobi, but there in the periphery, you have to go to the big companies for you to get the tests, but the small hospitals do not offer those tests... Most of the patients are not able to afford the tests... Well, there are very few rheumatologists... Moreover, as far as we are concerned they are all here in Nairobi... Out there in the rest of Kenya, when you suspect it, you have to send them here and sometimes they are not able to come.' (ID 54, CL)

As a consequence of diagnostic delays, some doctors gave patients other diagnoses and treated them for infections such as malaria, pneumonia, tuberculosis and typhoid without improvement, as indicated by some participants. For example:

'...Ok, the first time I went for treatment, my chest was examined, and I was told I had tuberculosis. At another time, I was told I had pneumonia because I was coughing all the time. I did not start taking anti-tuberculosis because I was then told that I had pneumonia... Although if I got a request for a test, all of them would start with HIV.' (ID 03, PRI)

From the data, it was also evident that the pre-diagnostic uncertainty caused some patients to be admitted several times before they received a diagnosis:

'*...I was in and out of hospital, but nobody discovered the disease...'* (ID 02, PRI)
'Okay, at that time I was far gone. Admission, discharge, admission, discharge, 
admission, discharge.' (ID 03, PRI)

From the narratives, it was evident that the lupus diagnosis was not an event but a process, which took a long time for some patients (three years for ID 03 and 15 years for ID 02).

The sub-category of ‘uncertainty’ also highlighted the lack of knowledge about lupus and its trajectory when patients finally got a name for their illness. More than three-quarters of the patients had no idea what lupus was and the possible consequences of having the condition. For example:

'Okay, when the doctor broke to me the news that I had lupus, I was not even shocked 
let me say so. Because I did not even know what lupus was in the first place... So later 
on, my elder sister came, and I told her that they have told me I have lupus. So, she 
was like, “What!” ...that is when I realised that it must be something serious.' (ID 08, 
PRI)

On the other hand, some participants experienced both fear and depression because they thought the condition was terminal:

'Oh, do you know something? Initially, I thought I would die. It was actually something 
that was going to kill me immediately. The immediate thing that comes to your mind 
now is that this is a death sentence. That was my initial feeling, and of course, I felt 
very depressed.' (ID 07, PRI)

Another patient who had some knowledge of medical terms like “autoimmunity” and “chronic” explained that he also experienced fear:

'Okay, before being diagnosed with lupus, to be honest, I had never thought about it...
The first thing that hit me was when the doctor said that it is an autoimmune thing and 
to an extent, it is chronic. Those, I think, were the two key things I heard when he 
explained what lupus is for the very first time... Initially, because I had never heard of 
this, the very first reaction was one of fear because of “chronic”. The idea that it was 
going to be something that I would have to be watching possibly for the rest of my life 
constantly... I think initially I was very frightened. I wondered; what does this mean? 
Does this mean that I would have to start maybe watching certain aspects of my life? And 
does that mean that there are certain things I will not be able to do?' (ID 11, PRI)

Similar sentiment about the unknown disease trajectory was also expressed by another patient who had an understanding of the disease but was concerned about all the systems that the disease could affect in the future:
'There was information that it could attack my kidney, my heart. It can attack my skin, and my hair will fall. Yeah, those facts and the fact that I had to live with medication yet I hated it.' (ID 13, PUB)

Knowing the diagnosis caused more uncertainty because of the unknown and variable disease trajectory. The reaction of the participants highlighted the information gap about lupus and the need for specific information about the disease, its course and management.

5.4 Summary

This chapter indicated that the participants experienced symptoms similar to those found in the existing literature; however, there was a high proportion of participants who presented with renal involvement which is one of the symptoms of a later stage of the disease. The findings highlighted the help-seeking behaviour of the patients, when they became concerned about the impact of their symptoms. The findings also highlighted the role of family members in the whole process.

All participants initially sought help from the formal health facilities. However, diagnosing lupus took a long time for most patients due to knowledge gap and low index of suspicion among the clinicians. This created illness uncertainty. The findings also identified the gaps in knowledge and information among most patients when they finally received the lupus diagnosis, particularly regarding the nature of the disease and its trajectory.
Chapter 6: Going round the system

6.1 Introduction

This chapter discusses the second category of ‘going round the system’. As patients described their efforts to obtain healthcare for their illness from public or private health facilities, it became clear that receiving lupus care was a process which was not straightforward. The process seemed to have been influenced by several factors. The main factors were ‘health service organisation’ and the ‘inaccessibility of lupus services’, which became the main sub-categories. Health service organisation at different levels seemed to determine the types of health personnel deployed to the health facility, the diagnostic support services and the kind of care the patients received. The doctors' perspectives complemented the patients' experiences and perspectives. Figure 6.1 provides an overview of the category ‘going round the system’ in relation to health service organisation and the inaccessibility of lupus services.

Category 2: Going round the system

Figure 6.1: Going round the system
6.2 Health service organisation

The first sub-category to emerge was the organisation of health services. As explained earlier in section 1.4.3.1, the public health services are divided into community, primary (dispensaries and health centres), secondary (county hospitals) and tertiary (national referral hospitals). This section discusses how the structure of the health services influenced the care pathway of patients with lupus.

The dispensaries and health centres provide curative services for minor illnesses, while the county hospitals offer general medicine and surgical services. Patients with chronic illnesses are managed at the county hospitals. However, sub-specialist services such as rheumatology are missing at the county hospitals. They have no sub-specialist physicians due to the formal structure of the health services, which determines the type of staff deployed and the type of services offered.

Since there are no sub-specialist physicians at the county hospitals, there are no advanced laboratory tests provided in these hospitals, which means that the facilities are not able to provide specialist diagnostic and curative services. For example, to diagnose lupus according to the ACR guidelines (Hochberg, 1997), apart from the signs that patients may exhibit, laboratory support is necessary to identify or rule out renal disorder, immunologic disorders and tumour markers, etc., which are not offered at these hospitals. Also, the confirmatory tests would have to be ordered by a doctor suspecting lupus, as mentioned earlier in section 5.2.

More than half of the 21 participants reported not receiving a comprehensive diagnosis at the primary and secondary health facilities, and were treated for other conditions as indicated in Table 6.1. For example, ID 13 had symptoms of lupus which included anaemia and joint pains and was given iron tablets and pain killers at a county hospital. The doctors ordered the available tests at the facility’s laboratory which revealed anaemia, and treated the participant for anaemia and arthritis. The doctors did not suspect lupus:

'I was told I had anaemia. So, I was put on iron tablets. Sometimes, standing was a big problem. At times, I would stand and feel dizzy; like I wanted to fall or faint... I started feeling pain in my right leg and the knee started swelling. I went to the hospital. They told me I had arthritis and put me on some pain killers.' (ID 13, PUB)
Table 6.1: Self-reported differential diagnosis received by patients at different levels of health facilities

<table>
<thead>
<tr>
<th>Patients</th>
<th>Level of health facilities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Level 2 and 3 (Health centres and dispensaries)</td>
</tr>
<tr>
<td></td>
<td>Lupus Diagnosis</td>
</tr>
</tbody>
</table>

**Private Patients**

| ID 1 | Told joint pains due to cold | Level 5 - Private rheumatology clinic |
| ID 2 | Malaria, Typhoid, Pneumonia | Level 5 - Private rheumatology clinic |
| ID 3 | Not specified, TB, Pneumonia | Level 5 - Private rheumatology clinic |
| ID 4 | Skin condition | Level 5 - Private rheumatology clinic |
| ID 5 | Malaria, Rheumatoid arthritis | Level 5 - Private rheumatology clinic |
| ID 6 | Arthritis | Level 5 - Private rheumatology clinic |
| ID 7 | Flu | Level 5 - Private rheumatology clinic |
| ID 8 | Pneumonia | Level 5 - Private rheumatology clinic |
| ID 9 | Malaria, Typhoid | Level 5 - Private rheumatology clinic |
| ID 10 | Malaria, Eczema | Level 5 - Private rheumatology clinic |
| ID 11 | Not specified | Level 5 - Private rheumatology clinic |

**Public Patients**

| ID 12 | Malaria, Typhoid | Level 2 (Private clinic of a rheumatologist) |
| ID 13 | Anaemia, Arthritis | Level 6 |
| ID 14 | Arthritis | Level 6 |
| ID 15 | Urinary tract infection, Typhoid | Level 6 |
| ID 16 | Not specified, Skin condition | Level 6 |
| ID 17 | Not specified, Arthritis | Level 6 |
| ID 18 | Rheumatoid arthritis | Level 6 |
| ID 19 | Malaria, Typhoid | Level 6 |
| ID 20 | Worm infestation, Dysentery | Level 6 |
| ID 21 | TB | Level 6 |
Another participant (ID 15) was diagnosed, also at a county hospital, with typhoid due to symptoms of feeling tired and having a swollen face in the morning, and was given medication which she refused to take:

'I used to wake up in the morning feeling tired. I also noticed that my face was swollen. So, I was a bit concerned. I went to a city council clinic, and they told me that from the symptoms, it was like I had typhoid. They were not sure.' (ID 15, PUB)

Instead, she referred herself to a private clinic because she was dissatisfied with the care she received at the city council clinic. At the private clinic, she was treated for a urinary infection:

'The doctor on duty told me that they could test my urine to see whether they could detect anything... So, from the results, they found that protein was leaking. It was 2+. Also, there was pus in the urine. So, she said, “For now, we can treat it as an infection.” She prescribed some medication for me, which I went and bought. I took them for five days, but there was no change.' (ID 15, PUB)

This participant was showing symptoms of renal disorder which is one of the complications associated with lupus, but again the available laboratory services were limited. While another participant (ID 16) who experienced dermatological problems on her head resulting in hair loss, ended up seeing a dermatologist who did not screen her for lupus and was therefore treated specifically for her skin problem:

'After six months, it affected my head. I had long hair, but now I was just feeling like scratching it. I decided to cut it. I cut it and got some parts without hair around it. ... When we went to the dermatologist, I was just given creams and tablets... I went there for three years but there was no change....' (ID 16, PUB)

All the three participants (ID 13, 15 and 16) experienced the different signs and symptoms of lupus i.e. anaemia, painful joints, renal and skin involvement (Wallace, 2007). They were treated based on the individual signs rather than the doctors putting together the signs from different organ systems and realising that they were dealing with a multisystem disease.

The data also showed that only one participant was diagnosed at a level 2 health facility which was a rheumatologist's private clinic. Almost all the rest of the patients received their lupus diagnosis either at the public or private rheumatology clinics. The patients were mostly investigated for TB and HIV as shown in table 6.1.
The common differential diagnoses of TB and HIV could be due to lupus symptoms mimicking the two conditions, i.e. weight loss, chest pain, fever and cough (Stern et al., 1995; Storla et al., 2008), as discussed in section 10.2.

Some of the interviewed doctors suggested that the limited diagnostic laboratory services could have been a contributing factor to the lack of comprehensive diagnosis or misdiagnosis at lower levels of the health service:

Table 6.2: Self-reported investigations carried out on patients before receiving a lupus diagnosis

<table>
<thead>
<tr>
<th>Patient (Private)</th>
<th>Investigations conducted</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID 01</td>
<td>Blood tests - not specified</td>
</tr>
<tr>
<td>ID 02</td>
<td>Blood tests - not specified, Chest X-ray, HIV</td>
</tr>
<tr>
<td>ID 03</td>
<td>Chest X-ray, HIV, Bone marrow biopsy</td>
</tr>
<tr>
<td>ID 04</td>
<td>Not specified</td>
</tr>
<tr>
<td>ID 05</td>
<td>Blood - not specified</td>
</tr>
<tr>
<td>ID 06</td>
<td>Blood - not specified</td>
</tr>
<tr>
<td>ID 07</td>
<td>Blood tests, HIV</td>
</tr>
<tr>
<td>ID 08</td>
<td>Blood tests, HIV</td>
</tr>
<tr>
<td>ID 09</td>
<td>Blood tests, HIV</td>
</tr>
<tr>
<td>ID 10</td>
<td>HIV</td>
</tr>
<tr>
<td>ID 11</td>
<td>Blood - not specified, HIV</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient (Public)</th>
<th>Investigations conducted</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID 12</td>
<td>TB</td>
</tr>
<tr>
<td>ID 13</td>
<td>Not specified</td>
</tr>
<tr>
<td>ID 14</td>
<td>Not specified</td>
</tr>
<tr>
<td>ID 15</td>
<td>Not specified</td>
</tr>
<tr>
<td>ID 16</td>
<td>TB, HIV</td>
</tr>
<tr>
<td>ID 17</td>
<td>TB, HIV, Thyroid function, ECG</td>
</tr>
<tr>
<td>ID 18</td>
<td>TB, HIV</td>
</tr>
<tr>
<td>ID 20</td>
<td>Not specified</td>
</tr>
<tr>
<td>ID 21</td>
<td>Not specified</td>
</tr>
</tbody>
</table>
'... There is no public hospital which is fully equipped in terms of laboratory diagnosis of lupus or where you can get all the facilities that you need to diagnose...’ (ID 64, CL)

Another doctor added that laboratory investigations were also limited even at the referral hospital:

'In the Hospital[referral hospital] at least we have ESR. We do not have CRP and the specifics like ANA, Anti-dsDNA or anti-SM, anti-Ro and anti-La [immunologic screening]. All these have to be done in the private sector yet these are the mainstay of diagnosis.' (ID 60, CL)

These arguments pointed to the diagnostic limitations caused by the lack of relevant laboratory equipment in the public health facilities. One doctor (CL 56) indicated that the nature of lupus compounded the diagnostic delays as a disease which requires a high index of suspicion on the part of the doctors:

'But the other challenge about lupus is the diagnosis because all the symptoms do not present at the same time. So, you find that maybe somebody had arthritis and it resolved and they present with another symptom now. The challenge is that the clinicians do not have the index for suspicion... I can say it is knowledge gap especially in Kenya where most of the patients are seen by the clinical officers [health personnel trained in clinical medicine at diploma level]. Doctors do not see bulks of patients.' (ID 56, CL)

This observation was supported by all six doctors interviewed, who suggested that the differential diagnosis could have also been due to the clinician’s level of medical preparation and inexperience with lupus which pointed to the cadre of staff in these institutions:

'This is what I meant by education. If you do not know what to look out for, what are you going to look for? Yes, in undergraduate you are taught but, you see, this needs to be emphasised. People who have finished undergraduate as medical officers have no experience behind their back. Experience is another thing that can teach you but clinical officers and new medical officers do not have that experience, and the only way to get it is through repeated education.' (ID 60, CL)

The arguments regarding deficiency in knowledge and inexperience among the doctors in county hospitals could mean that there is a low level of appreciation of lupus at the lower level health facilities. Also, there is a difference in suspected/differential diagnosis in Kenya in comparison to the West, as discussed in section 10.2. The differential diagnoses expressed by some doctors included infections, HIV and TB. For example:
'Yes. That is what I meant by saying that people come in with just joint pains, malaise or fevers. So initially people would look for causes of infection or causes of something else and offer treatment. Now, because we have an outbreak of malaria here and typhoid is not that common but present, every person in the periphery would treat you for malaria and typhoid because of joint pains and fevers... Therefore, when people come early they are misdiagnosed, and it takes a while to finally end up at a specialist.' (ID 60, CL)

'… However, the challenges are number one, lupus-like illness such as HIV which present like it almost in every way. So, people will think that you have HIV and they will test you so many times. Despite being negative, they will keep testing you thinking that it is HIV... You know that infections are the commonest co-morbidities in lupus and infections like TB are the common endemic conditions in our environment. So somebody having lupus will come with coughing, a respiratory infection symptom or something looking like TB and people will go for the TB. They will not think about lupus even in cases of hair change…' (ID 64, CL)

However, the differential diagnoses could have also been due to the lack of continuity of care, because if patients were experiencing different symptoms in different body systems at different times and seeing different doctors, nobody was getting the real picture of the overall disease trajectory, as mentioned in section 5.3.

Also, at the public hospitals, rheumatology services were only offered in one hospital where there was a designated rheumatology clinic which was run by rheumatologists. This meant that there was only one public rheumatology clinic in Kenya, which did not offer some of the specialist laboratory services specific to rheumatology. This necessitated referral to the private laboratories as indicated by some patients and doctors:

'But now testing, there is a big problem. First of all, the public hospitals do not have the facilities so the patient has to be tested in a private hospital and it costs a lot of money.' (ID 55, CL)

There seems to be a need to improve the laboratory services, as suggested by one doctor:

'One, I think the hospital as a public institution should be more engaged in partnering with immunology department to set up a good laboratory.' (ID 66, CL)

Thus, only three patients (ID 14 PUB, 19 PUB, and 20 PUB) were diagnosed with lupus immediately following the consultation with the rheumatologist. The first was a health worker, while the second was seen by a rheumatologist at the private hospital and then referred to the tertiary hospital. The third patient was brought straight to the tertiary hospital by a family member.
In comparison, of the eleven patients who received health services from the private health facilities, table 10 illustrated how the participants reported receiving the differential diagnoses which were similar to those of patients who had attended the public health facilities. However, patients in the private hospital underwent more investigations with unspecified blood tests and HIV tests being the most common, as shown in Table 6.2. This was probably due to the availability of laboratory services in the private hospitals or because they could charge for them. Having more diagnostic tests made no difference to the differential diagnosis, which included malaria, TB, arthritis, skin conditions and arthritis. Malaria was the most common due to the fever they experienced. This also confirmed the low index of suspecting lupus among clinicians. Minor illnesses like flu were also diagnosed.

6.2.1. Patient pathways through the health system

Table 6.3 illustrates the pathways reported by the 21 patients across the different types and levels of health facilities. It also shows the duration that the participants recounted having taken before reaching a rheumatology clinic, from the time they went to the first health facility.
Table 6.3: Self-reported patient pathways through the health system

<table>
<thead>
<tr>
<th>Patients</th>
<th>Types of health facilities visited</th>
<th>Duration from the first consultation to first rheumatology clinic attendance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1&lt;sup&gt;st&lt;/sup&gt; facility</td>
<td>2&lt;sup&gt;nd&lt;/sup&gt; facility</td>
</tr>
<tr>
<td><strong>Private Health facilities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ID 01</td>
<td>Level 4 (private)</td>
<td>Level 2 (private clinic)</td>
</tr>
<tr>
<td>ID 02</td>
<td>Level 4 (public)</td>
<td>Level 5 (public)</td>
</tr>
<tr>
<td>ID 03</td>
<td>Level 2 (private)</td>
<td>Level 5 (private)</td>
</tr>
<tr>
<td>ID 04</td>
<td>Level 2 (private)</td>
<td>Level 2 (private)</td>
</tr>
<tr>
<td>ID 05</td>
<td>Level 2 (private)</td>
<td>Level 4 (private)</td>
</tr>
<tr>
<td>ID 06</td>
<td>Level 2 (private)</td>
<td>Level 5 (private)</td>
</tr>
<tr>
<td>ID 07</td>
<td>Level 5 (private)</td>
<td>Level 2 (private)</td>
</tr>
<tr>
<td>ID 08</td>
<td>Level 4 (public)</td>
<td>Level 4 (public) plus traditional remedies</td>
</tr>
<tr>
<td>ID 09</td>
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<tr>
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<tr>
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<td>ID 14</td>
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<td>ID 15</td>
<td>Level 2 (private)</td>
<td>Level 2 (private)</td>
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<tr>
<td>ID 16</td>
<td>Level 2 (private)</td>
<td>Level 5 (public)</td>
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<tr>
<td>ID 17</td>
<td>Level 4 (public)</td>
<td>Traditional remedies</td>
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<tr>
<td>ID 18</td>
<td>Level 4 (public)</td>
<td>Level 6 (public)</td>
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<tr>
<td>ID 19</td>
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</tr>
<tr>
<td>ID 21</td>
<td>Level 4 (private)</td>
<td>Level 2 (private)</td>
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In general, the data showed an initial back and forth movement of patients across the different levels of care both in the public and private health facilities, in particular for patients attending the public rheumatology clinic. Data showed variability in the duration that patients took to reach the rheumatology clinic with a range of 1 month to 15 years. About a quarter of the participants reached the rheumatology clinic in less than 6 months, while slightly more than half of the participants reached the rheumatology clinic within one year. The data also revealed that most participants attending the public rheumatology clinic had their first contact with doctors at the county hospitals, which was the appropriate level for chronic illness care. Only two of them (ID 15 and 16) started from private clinics which were level 2 equivalent health facilities. One participant was from an urban area while the other was from a rural area.

It was also notable that one participant (ID 14) who was able to access the rheumatology clinic within a month was a health worker; she was familiar with the system and knew how to get access to the senior doctor. The other participant (ID 20) who also had access to the clinic within 2 months was referred by a health worker who worked in the same hospital. The data also revealed that although most of the patients were referred to the referral hospital by health workers, three patients (ID 21, ID 18 and ID 19) moved straight to the referral hospital from the rural areas without going through the referral system, while one participant who was based in Nairobi self-referred. One doctor observed that the healthcare structure was not strictly adhered to:

'The structure of the health facilities is also confused. Health facilities are structured from level 1-6, but you find that the [public rheumatology clinic] which is a level 6 hospital sees everybody while people should be referred upwards. Patients tend to refer themselves to the different level especially when they are not improving.' (ID 56, CL)

It was therefore evident that although there was a structured healthcare system in Kenya with a referral system in place, patients did not necessarily move along the different levels of care as expected. This gave a picture of a porous referral system which could be open to over use by cases that could be handled at lower level health facilities.

Despite the short falls, the system enabled most patients in the public hospital to reach the rheumatology clinic within a year. Nevertheless, two doctors (CL 60 and 64) were of the view
that practicing rheumatology in the Kenyan public health system is a challenge, especially when it comes to the coordination of care at the referral hospital. There is a lack of proper structure for receiving patients which is further complicated by the nature of lupus as a multi-consultative disease:

'Referral from the periphery, on the whole, is not very good... we do get patients referred from the periphery, but they reach us in the clinic after a long journey because when you go to the A & E [accident and emergency], if you are very sick, you will be admitted. If you are not very sick, you will be told to go to the clinic, but it is not very clear how to get to it. So that way, there is also a delay in reaching the patient.' (ID 64, CL)

'We do not have a rheumatology package. I would say that lupus is a multi-consultative disease. So, you need a cardiologist, a rheumatologist, a dermatologist and a renal physician. All these are available, but there is no network to connect everybody...’ (60, CL)

The quotations are illustrative of three levels of patient referral delays: from the peripheral health facilities to the referral hospital; from the A & E of the referral hospital to the rheumatology clinic; and inter-discipline referral delays due to the lack of referral structure within the referral hospital.

The data also revealed that of the ten participants attending the public clinic, half were residing in Nairobi which gave them closer proximity to the clinic. It took them between 2 months and 1 year to reach the rheumatology clinic, while for those who were based in rural areas it took between 8 months and 7 years to reach the clinic. Two patients took an exceptionally long time to reach the clinic (ID 16 took 7 years, and ID 17 took 7 years). It is noteworthy that these two patients, at some point, also started using traditional remedies. One participant indicated that they had to visit her maternal relatives to check if there were any cultural issues which could have contributed to her illness. She only came back to formal healthcare when her condition worsened:

'When I was in school it was on and off... We thought of family issues. That was 2003. We decided to go to my mother’s biological home because we did not know what was happening. We went there, and they said they had no problem. We were going because we thought that maybe my father did not finish paying the bride price or maybe our grandmother was complaining of something... When we went there, the elders were called. We had gone with my father and other elders from home. After seeing how I was, and talking, they said they had no problem. They said they did not even want money because everything had been done. If they had said that the bride price was not
finished, we could have contributed. We could have given it to her to make that thing go off... Seeing that even after they had said there was no problem, there was still no improvement, we thought it was somebody who had cursed us. We looked for fat from a pig because we thought if one applies that the problem disappears. Nothing! At first my head began to develop sores which were soft, pressing like an avocado, and painful... The condition worsened.' (ID 16, PUB)

This participant raised many issues which included the illness possibly being caused by wrong doing to maternal relatives, or illness being caused by disharmony in family relationships or even being caused by a curse from some unknown person. Those issues seemed so important to the patient’s immediate and extended family that they had to remove her from the formal health services to try traditional African medicine, as discussed later in section 7.2.2. The other participant (ID 17) was a student when she first became ill, and she was much younger, so basically, her treatment decisions were made by family members who mixed traditional remedies with conventional therapies as indicated:

'I did my class eight exams, passed and went to... That was a change of environment. Now I was moving to where it was colder. I started experiencing the same thing. I was now sick - the hands started swelling. My relatives said it was better to take me to a herbal doctor... I used to move from one herbal doctor to another... Later my uncle took me to a hospital.' (ID 17, PUB)

In both cases, it is evident that the participants lost some time, because it was only after the cultural issues had been sorted out that they came back to the formal health system. Also, in both cases the participation of family members in treatment decisions was significant. The patients’ pathways to lupus care in the public health facilities were, therefore, not only affected by the weaknesses observed in the health systems controls, but also by the patients’ help-seeking behaviour, their beliefs and decisions made at the family level.

For patients who were attending the private rheumatology clinic, table 6.3 illustrates that the majority started treatment from private health facilities. However, only seven of them managed to reach the rheumatology clinic within one year. Three others (ID 03, 04 and 08) took 2-3 years to reach the rheumatology clinic. However, one participant (ID 02) took an extremely long time to arrive at the rheumatology clinic (15 years). Her illness started in childhood and could probably have been juvenile inflammatory arthritis. She was treated for many other conditions and was not referred to higher levels of care for a long time. It was only after marriage that her family of marriage moved her to private care where she got diagnosed.
and was referred. She also indicated that she was never going back to public care because of her experience with the care she received and the lack of good laboratory diagnostic support in the public hospitals:

'To me, I said no. It is a provincial [county] hospital, it is there by name but the facilities and the services that some people want, they do not have.' (ID 02, PRI)

The use of traditional and religious remedies also featured among patients in the private clinic, though the patients did not necessarily take longer to reach the rheumatology clinic. Only one patient got delayed for 2 years by family who thought that she had allergies, thus gave her herbal remedies:

'… But before I was diagnosed with lupus, my mum used to bring me herbal medicine. Just for bathing. Yeah, because she thought I had some allergies... Yeah. So I used to bathe with it and drink a little. But the pain persisted. It did not help. It didn’t help at all.' (ID 08, PRI)

The lack of diagnosis, despite being investigated, was one of the main causes of concern to patients and their families. Thus, the findings indicated the close link between naming the illness and the organisation of health services. This determined the patients’ movement from one type of health facility to another until they were able to access the rheumatology clinics for appropriate lupus services, which had its own challenges as discussed in the next section.

6.3 Inaccessibility of lupus services

The second sub-category to emerge was the ‘inaccessibility of lupus services’, which was also closely linked to the organisation of health services. ‘Lupus services’ within this context are those healthcare services that are relevant, appropriate and peculiar to a patient with lupus. According to the organisation of the Kenyan health system, there were three health facilities with rheumatology clinics run by consultant rheumatologists: one was at the national (public) referral hospital, and two were at two of the privately run hospitals. All three rheumatology clinics were based in Nairobi.

In this study, the patients identified three main factors which affected their ability to access lupus care: the geographical distance from Nairobi, the availability of rheumatology services and the cost of rheumatology services. The doctors also identified service
readiness/availability and the cost of care. Accessibility has been defined by Peters et al. (2008 p.162) as "the timely use of service according to need". Access to healthcare is suggested to be a multidimensional concept which includes: physical accessibility, service availability, service affordability and service acceptability (O'Donnell, 2007; Shengelia et al., 2005). This section discusses the factors in relation to how they contributed to the inaccessibility of lupus services.

6.3.1 Geographical distance
As mentioned in section 1.4.3.1, all of the rheumatology clinics were based in Nairobi. Nairobi is geographically removed from the other counties with some being further than others depending on the physical distance, as illustrated in figure 6.2.

Figure 6.2: Distances to Nairobi in relation to the other counties
For example, the distance from Nairobi to Mombasa is 300 miles, Nairobi to Kisumu is 212.3 miles, while the distance from Nairobi to Nakuru is 99.8 miles by road. Only seven counties were represented in the sample of patients. Most patients came from the southern counties like Nairobi, Kisumu and Mombasa. These are relatively heavily populated areas that have better transport networks, making the rheumatology clinic in Nairobi relatively accessible to them despite the distance. There were no patient representations from the northern counties such as Lodwar, Marsabit and Wajir, which normally consist of the nomadic communities and make the rheumatology clinics in Nairobi geographically inaccessible. Despite this being a small qualitative study, it does indicate an issue worthy of further investigation. Most of the participants in the study had to travel from outside Nairobi as illustrated in table 6.4.

<table>
<thead>
<tr>
<th>Public patients</th>
<th>County</th>
<th>Distance travelled to the clinic by road transport (in hours)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PUB 01</td>
<td>Kiambu</td>
<td>1.5 hours</td>
</tr>
<tr>
<td>PUB 02</td>
<td>Kirinyaga</td>
<td>2.5 hours</td>
</tr>
<tr>
<td>PUB 03</td>
<td>Nairobi</td>
<td>1 hour</td>
</tr>
<tr>
<td>PUB 04</td>
<td>Nairobi</td>
<td>1 hour</td>
</tr>
<tr>
<td>PUB 05</td>
<td>Nairobi</td>
<td>1 hour</td>
</tr>
<tr>
<td>PUB 06</td>
<td>Nyeri</td>
<td>2.5 hours</td>
</tr>
<tr>
<td>PUB 07</td>
<td>Nairobi</td>
<td>1 hour</td>
</tr>
<tr>
<td>PUB 08</td>
<td>Kiambu</td>
<td>1.5 hours</td>
</tr>
<tr>
<td>PUB 09</td>
<td>Kisumu</td>
<td>7 hours</td>
</tr>
<tr>
<td>PUB 10</td>
<td>Nairobi</td>
<td>1 hour</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Private patients</th>
<th>County</th>
<th>Distance travelled to the clinic by road (in hours)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PRI 01</td>
<td>Nairobi</td>
<td>1 hour</td>
</tr>
<tr>
<td>PRI 02</td>
<td>Nakuru</td>
<td>3 hours</td>
</tr>
<tr>
<td>PRI 03</td>
<td>Mombasa</td>
<td>10 hours</td>
</tr>
<tr>
<td>PRI 04</td>
<td>Nairobi</td>
<td>1 hour</td>
</tr>
<tr>
<td>PRI 05</td>
<td>Nairobi</td>
<td>1 hour</td>
</tr>
<tr>
<td>PRI 06</td>
<td>Nairobi</td>
<td>1 hour</td>
</tr>
<tr>
<td>PRI 07</td>
<td>Nairobi</td>
<td>1 hour</td>
</tr>
<tr>
<td>PRI 08</td>
<td>Nairobi</td>
<td>1 hour</td>
</tr>
<tr>
<td>PUB 09</td>
<td>Kirinyaga</td>
<td>4 hours</td>
</tr>
<tr>
<td>PUB 10</td>
<td>Mombasa</td>
<td>10 hours</td>
</tr>
<tr>
<td>PRI 11</td>
<td>Nairobi</td>
<td>1 hour</td>
</tr>
</tbody>
</table>
The rheumatology clinic was geographically accessible to those who lived in or near Nairobi. This consisted of more than half of the participants who travelled for less than 2 hours to reach Nairobi. A few participants (ID 03, 10, and 17) travelled for 7-10 hours by road transport, making the clinic comparatively inaccessible to them. Nevertheless, those who travelled for more than 2 hours, whether coming to attend the private or public rheumatology clinics, expressed feeling inconvenienced by the geographical distance from their respective counties to Nairobi. One participant expressed that when travelling to Nairobi, she needed to take into account the rest period that she needed as the long distance travelled (10 hours) made her feet swell:

'I travel from [a city outside Nairobi] to this place. My legs become swollen [an overnight journey]. So, I have to rest, that is why I do not leave this place and board the one o’clock bus... that is why I have to get a place and rest for about three hours. When I leave, I head to the station [for another overnight journey].' (ID 03, PRI)

Another participant (ID 16) only had to travel for 2.5 hours to Nairobi but also expressed feeling inconvenienced because she arrived early for the 2 pm clinic and by 3 pm she was still at the clinic, yet there were no vehicles to take her back home in the evenings after attending the clinic. The need to travel back home the same day made her not fully utilise her consultation time with the doctor because she was more concerned about getting transport back to her home area:

'...when I looked at the time, I saw that it was three o’clock and there are no matatus [public vehicles] to my place in the evening. So, I wondered why all that time and you were told to be there at one thirty pm? Then you went in there and found that your file had been misplaced. I decided I was just going to go in and tell the doctor about my condition, he prescribes the medicine, and off I go. Sometimes I don’t have time to discuss.' (ID 16, PUB)

For both participants, coming to the rheumatology clinic was cumbersome. Concern for geographical accessibility was not only regarding the distance travelled to the clinic and transport costs, but also the time spent at the facility before being seen by the doctor. Geographical accessibility is fulfilled when good health services are located close to the people who need them. It is related to the distance the individuals have to travel to reach the place of service delivery (Jacobs et al., 2012).
Service delivery for chronic illness should include preliminary care and follow up care based on evidence and best practice (Schrijvers et al., 2012). Recommendations for lupus care propose 4-6 monthly follow up for stable patients and more frequent follow up for unstable patients (Petri, 2007). In Kenya, the patients are supposed to be followed up every 1-3 months depending on whether or not they are stable, as indicated by one doctor:

'... they will be given a return date depending on the severity of the illness at the time. This can range from one week to maybe a month or so until they are stable. You know, as they get more stable you give them longer return dates.' (ID 54, CL)

This requires regular travelling to Nairobi. One doctor observed that the geographic barrier affected the patients’ ability to honour their appointments and therefore, their access to rheumatology care. For example:

'Another thing I would say is distance. Like if you get somebody who is in Kitale, they cannot come to Kenyatta every so often. So, I did see patients who were seen as long as six months later. That I would not call non-compliance because it is distance but again quality of care is an issue. I mean, if they do get sick in between they would go to the periphery just for some substitute until the next date.' (ID 60, CL)

The data indicated that rheumatology services were geographically inaccessible to patients from outlying counties since all the rheumatology clinics are based in Nairobi. However, some patients who travel from far locations would still prefer to come to Nairobi for illnesses not related to lupus, because they do not feel comfortable about being attended to by the doctors who are not rheumatologists in their respective towns. They feel that doctors in the periphery do not understand lupus:

'... The only challenge that I face right now is proximity to a health professional. I live in [in a city outside Nairobi], and the challenge is that I am not comfortable going to any of the health professionals there. This is because I know they are not familiar with what lupus is. They might not know how to approach it...' (ID 10, PRI)

This participant indicated that she travelled to Nairobi to see her rheumatologist for all health-related problem despite the geographical distance, due to her previous experience with health services and due to lupus services being unavailable in the city where she currently resides.
6.3.2 Service availability

Access to healthcare also includes service readiness which is the availability of resources (buildings, equipment, qualified health personnel, health products and technologies), and the adequate supply of services including service organisation and service provision (Gulliford et al., 2002). In this study, it was established that just like with other specialist services in the hospital, the rheumatology clinic at the referral hospital also received referrals from different sources. This was expressed by the doctors (CL 60 and 66):

’… we have most of our triage done in Casualty. So, if somebody comes in and one of the MOs [medical officers] picks up something, they are usually given a consultation for Rheumatology Clinic. Another way is when people are admitted to a ward with query diagnosis because they do not know what is going on. They can be worked up from any ward and then discharged to the Rheumatology Clinic. So, we have many points...’ (ID 60, CL)

’... Yes. There are those who are referred from [a district public hospital within Nairobi] or from other provincial hospitals or district hospitals (in the periphery), or even from a private doctor’s clinic...’ (ID 66, CL)

Also, one doctor (CL 66) felt that the rheumatology clinic was crowded due to limited space:

'The problem with the system in [the public hospital] is based on space. You have a building which was built in 1971, which is crowded. That is the problem...' (ID 66, CL)

The rheumatology clinic was crowded due to the high number of referred patients who were difficult to control through the booking office. The clinic has only operated once a week since its inception in 2005, yet it has expanded over the years. The subsidised cost of care in the public hospitals also makes the clinic a preferred choice which compounds the problem of overcrowding. The converse was true for the private rheumatology clinic where the cost of treatment was not subsidised. Only a certain group of patients, either with medical insurance or with adequate resources, were able to access private care. Also, the number of patients per clinic each day was controlled by a strict patient booking system, and they ran two rheumatology clinics per week.

The laboratory facilities and services also seemed to be limited in the public hospitals as indicated earlier in section 6.2, with attendant consequences such as late diagnosis and late
initiation of medication. Even at the referral hospital where the laboratory tests were supposed to be present, not all of the tests were available. Two doctors expressed this:

'Sometimes they have problems with reagents. You know it is a bit frustrating to send a patient and tell them that “do these two tests here and the other fifteen tests elsewhere.”' (ID 54, CL)

'In the hospital, at least we have ESR. We do not have CRP and the specifics like Anti-dsDNA or anti-SM, anti-Ro and anti-La. All these have to be done in the private sector yet these are the mainstay of diagnosis.' (ID 60, CL)

The guidelines for lupus care recommend 6-12 monthly blood monitoring and drug monitoring for toxicity (Petri, 2007). However, there seemed to be a problem with the laboratory diagnostic support at the public health facilities due to deficiencies in appropriate resources. The need for laboratory services goes hand in hand with the relevant clinical services, and to support the clinical services, there is a need to upgrade the laboratory services, especially at the county and national referral hospitals.

Service readiness also includes the availability of qualified health personnel. In the study, the competence of health personnel regarding making a lupus diagnosis was a concern expressed by both the patients and doctors, particularly in the primary and secondary health facilities where patients spent a long time before being diagnosed, as already discussed in chapter 5. Both doctors and patients, therefore, recommended the capacity building of staff through the training of more rheumatologists and nurses:

'It would be nice to train other people so that more people would know how to help when there is a need for help, because people are suffering from this disease and they might not even know. That is why doctors were telling me that it was the cold making my joints hurt, because they had not been exposed. So, more exposure to doctors to specialise in Rheumatology. They have not specialised in Rheumatology.' (ID 01, PRI)

'And I think there is a need for a dedicated nurse who is educated in this, to educate patients on a regular basis. Such a nurse should also handle calls should the patients need to speak to someone - a hotline so to speak.' (ID 64, CL)

So, there is need to provide competent rheumatology services and patient support. There is also need to upgrade the clinical skills of the doctors in early diagnosis for appropriate referral of rheumatological conditions, including lupus. For the county and referral hospitals, there is also need to train the rheumatologists and rheumatology nurses.
The findings also suggested a concern regarding the coordination of patient care at the public rheumatology clinic. To a large extent, they expressed some discontent with the services and emphasised the long waiting time, the inability to see the same doctor at every visit, the overcrowding of the clinic by patients, and their unmet information needs:

'I came by a vehicle, got here and sat under a tree to wait, now that is tiring...' (ID 16, PUB)

Some patients explained that they would have preferred to see the same doctors during each appointment, but this did not necessarily happen:

'Yeah. For example, if you would come and be seen by the same doctor for a period of time, it would be helpful. But now every time you come you find a different person. So, I don’t think there is follow-up.' (ID 05, PUB)

'And maybe at the time you want to see the doctor you have been seeing. But you can actually see that there are very many people who want to consult the doctor' (ID 08, PUB)

One rheumatologist explained the organisation of the clinic operations:

'Here, the first time the patient sees you. The second time even if they want to see you, they are forced to see somebody else [a registrar]. And again, the set-up is not such that they can always see us because the new ones are also many.' (ID 55, CL)

Both the patients and doctors alluded to the need for consulting with the same doctors at each clinic visit to provide continuity of care and to foster the patient–doctor relationship. One doctor suggested improvements in the organisation of care at the public rheumatology clinic:

'Clinics in other places are mature, whereby you have a rheumatology clinic which stands on its own and runs every day. Or at least four or three times a week. But it is a rheumatology service. So that is missing. I’ve tried to speak to the head of department and staff at Kenyatta, telling them that they need to actually move from this sort of service that they established in 1970, to more of what those people are offering because that is the type of service that will capture most of the things that the patients require.' (ID 66, CL)

Some patients in the public hospitals also experienced treatment challenges related to the unavailability of drugs, as expressed by one participant (ID 18) and as implied by a rheumatologist (CL 64):

'There are times when we experience problems. You might have a prescription but you fail to find the medicine(s). But you don’t want to buy those from another company. So, you might have to look for the doctor and ask him or her to change it. If
it is not a clinic day, you come hoping to find someone in the ward so they change it for you.’ (ID 18, PUB)

'... medications should be made both available and affordable to the patients.’ (ID 64, CL)

On the other hand, some patients (ID 12, 13, 18, and 19) expressed their unmet information needs especially regarding diagnosis, the cause of illness, treatment and chronicity of lupus. For example:

'I have never read about it [lupus] because I have never got a book... I want to know... whether a time will come when I can stop taking these drugs. I also want to know if going for, say, two months without the medicine will lead to a relapse and me feeling the way I used to feel at the beginning.' (ID 02, PUB)

'I have never been told what lupus is like. Even when I go to the internet I get confused... He [the doctors] says that it is some kind of tissues which is multiplied but I don’t know how... I want this disease to clear completely from my body.’ (ID 08, PUB)

Two doctors (CL 66 and 55), however, argued that they provided patient education during the consultation period, regarding the diagnosis and its management, which seemed inadequate:

'... I normally do a lot of explanations; a lot of talking until we completely understand each other - where we are coming from and where we are going. First of all, once I diagnose it, I have to warn them that lupus is a disease of a thousand manifestations... So, I would prepare them and tell them, “This is you. As long as you keep coming here and we keep interacting, you will be okay. It will be controlled.” You explain whatever the disease affects, like even pregnancy and those kinds of things. We talk about even family planning when you have particular medications, and the medicines which are good when you are pregnant. We discuss all those kinds of things.' (ID 55, CL)

'Majority of the patients do not know what lupus is. So, you inform them that it is an autoimmune disease which affects many organ systems and reassure them that even if it is a multi-system disease that affects many organ systems, it does not mean that all the systems are going to be affected. Of course, you discuss with them the drugs... you inform them that the subsequent management of lupus will depend on the sort of manifestation the patient has and therefore, different drugs will be used in that context - depending on what the problem is.’ (ID 66, CL)

However, one of the doctors (CL 66) also pointed out that time was a constraint due to the busy nature of the clinic:

'… Yeah. Of course, being a busy clinic it does not take half an hour to do that. We just mention to them quickly about it, the treatments that are available and initiate treatment unless there is contraindication.’ (ID 66, CL)
The ‘chronic care model’, which is a widely adopted approach in the West, emphasises a collaborative approach to the care of patients with chronic illness as it promotes a team-based approach (Wagner et al., 1996). However, in the study, only one doctor (CL 66) who was Western trained pointed out that there is no trained rheumatology nurse to provide patients with information on lupus and felt that a rheumatology nurse should be available as the management of chronic illness requires collaborative effort:

'We have not really established ourselves. For example, in Kenyatta we have a rheumatology nurse but all we have done is just name her. In terms of function there is nothing to talk of because ideally a rheumatology nurse should be available all the time so that if a patient has a problem, they can do something. I think those are things that we need to help them in. In Kenyatta, for example, if they have toxicity to a drug whom do they talk to? Where do they get it sorted out?′ (ID 66, CL)

One patient described how she viewed the role of the nurses at the rheumatology clinic:

'We have not really established ourselves. For example, in Kenyatta we have a rheumatology nurse but all we have done is just name her. In terms of function there is nothing to talk of because ideally a rheumatology nurse should be available all the time so that if a patient has a problem, they can do something. I think those are things that we need to help them in. In Kenyatta, for example, if they have toxicity to a drug whom do they talk to? Where do they get it sorted out?′ (ID 66, CL)

Although only one doctor (CL 66) and one patient (ID 15) raised the issue, it suggests that the current role of nurses in the rheumatology clinic is not clearly defined.

Another patient also felt that counselling services were not available but were necessary:

'Is it possible that apart from the way they talk to patients, they also have counselling sessions?... Yeah. I think that would help. I do not know how they can do it because it is always packed in the clinic but can they counsel those patients who are stressed before they can see the doctor?′ (ID 13, PUB)

Signs of psychological distress were expressed by some patients (ID 12 and ID 16). For example:

'Personally, I feel very negative about life. Very negative [with emphasis].′ (ID 12, PUB)

'... That is the time I insisted on knowing what problem I had. He told me it is a lifetime problem and that was why he was telling me that I am not supposed to stop the medication. I told him that if I am supposed to live with it for a lifetime, then I would wish to die earlier than that...I was feeling frustrated because I did not have any penny, whoever I went to disowned me.' (ID 16, PUB)
There was an indication that some patients were experiencing psychological distress and in need of counselling services. It was also an indication of the need to conduct a psychological evaluation of patients during the clinic appointments.

Despite the challenges the participants faced regarding the availability of rheumatology services, the analysis of data relating to the appraisal of lupus services in Kenya revealed that patients receiving care, particularly in the private rheumatology clinic, were content and emphasised that they were satisfied with their encounters with the doctors:

'I would say that the doctors have been very kind. There are times we have come here and I think we make people very uncomfortable because we take quite a long time with the doctor because he is looking at this, I am saying this problem, he looks at this, he looks at another, and he has been very patient. He has given us time, quality time and he has given us good hearing. I did not see him at any time looking offended with anything I asked. Because I asked him so many things about what I am feeling. So, the hearing, the quality time and his acceptance. I think he has accepted us as patient and we have been treated in an excellent way.' (ID 02, PRI)

This highlighted the interpersonal skills some doctors had while attending to their patients. This enabled the doctors to communicate at the level of the patients. It was noteworthy that fewer patients attended the private rheumatology clinic, which enabled the doctors to have more time with them during consultations. Also, these patients had the privilege of seeing the same rheumatologist all the time which provided continuity of care. However, whether attending the private or public rheumatology clinics, all these services came at a cost. The next section discusses the treatment cost in relation to accessing lupus services.

6.3.3 Affordability
The affordability of lupus services included financial affordability and reflected the participants' ability to pay for the costs of healthcare, including the direct cost of frequent travel to Nairobi for consultation or hospitalisation, along with treatment which included lupus tests and medications, some of which had to be accessed in the private health facilities. When services are geographically distant, the cost increases accordingly and therefore; the individuals might not have equal access if the cost is not equal (Lundberg et al., 1998). There was also the indirect cost of the time lost from work. Regarding financial affordability, the study established that quite a number of patients who accessed public healthcare were
unemployed and had to rely on family members to meet their medical bills. Some of them were working before, but stopped working because of illness (ID 12 and ID 15). For example:

'I used to work as a tailor, but I stopped because I cannot even cut something. So, I do nothing.' (ID 12, PUB)

'Now, from 10th April, my condition became worse. I had been working, but I have not worked from November because I developed those things. So, I have only been doing my chores.' (ID 15, PUB)

It was also noteworthy (see table 6.5) that even some patients who were employed (ID 13, 19 and 20) still relied on their family members due to low income. For example, one participant is a teacher and had her financial obligations paid for by her children:

'They finance my treatment, drugs. They are always with me. In every aspect of care...' (ID 09, PUB)

Table 6.5: Patients’ employment status and financiers of treatment cost

<table>
<thead>
<tr>
<th>Private Patients</th>
<th>Employment status</th>
<th>Medical care covered by</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID01</td>
<td>Not employed</td>
<td>Insurance (Mother’s)</td>
</tr>
<tr>
<td>ID 02</td>
<td>Employed</td>
<td>Family</td>
</tr>
<tr>
<td>ID 03</td>
<td>Employed</td>
<td>Employer's insurance</td>
</tr>
<tr>
<td>ID 04</td>
<td>Not employed</td>
<td>Husband’s employer (insured)</td>
</tr>
<tr>
<td>ID 05</td>
<td>Not employed</td>
<td>Family</td>
</tr>
<tr>
<td>ID 06</td>
<td>Employed</td>
<td>Employer's insurance</td>
</tr>
<tr>
<td>ID 07</td>
<td>Employed</td>
<td>Employer's insurance</td>
</tr>
<tr>
<td>ID 08</td>
<td>Not employed</td>
<td>Family</td>
</tr>
<tr>
<td>ID 09</td>
<td>Employed</td>
<td>Family</td>
</tr>
<tr>
<td>ID 10</td>
<td>Employed</td>
<td>Employer's insurance</td>
</tr>
<tr>
<td>ID 11</td>
<td>Employed</td>
<td>Employer's insurance</td>
</tr>
<tr>
<td>Public Patients</td>
<td>Employment Status</td>
<td>Medical care covered by</td>
</tr>
<tr>
<td>ID 12</td>
<td>Not employed</td>
<td>Family</td>
</tr>
<tr>
<td>ID 13</td>
<td>Employed</td>
<td>Self</td>
</tr>
<tr>
<td>ID 14</td>
<td>Employed</td>
<td>Employer's insurance</td>
</tr>
<tr>
<td>ID 15</td>
<td>Not employed</td>
<td>Family</td>
</tr>
<tr>
<td>ID 16</td>
<td>Not employed</td>
<td>Self</td>
</tr>
<tr>
<td>ID 17</td>
<td>Not employed</td>
<td>Family</td>
</tr>
<tr>
<td>ID 18</td>
<td>Not employed</td>
<td>Family</td>
</tr>
<tr>
<td>ID 19</td>
<td>Employed</td>
<td>Family</td>
</tr>
<tr>
<td>ID 20</td>
<td>Employed</td>
<td>Family</td>
</tr>
<tr>
<td>ID 21</td>
<td>Not employed</td>
<td>Family</td>
</tr>
</tbody>
</table>
For the patients attending the private hospital, only four of them had their medical bills paid by family members - they were either students or had stopped working. For example, one participant (ID 08) had not worked for some time and had even to move to her brother’s house:

'From mid-January this year. Eight months [had not worked for eight months].' (ID 08, PRI)

In some cases, the family members also eventually experienced financial constraints. For example, one participant (ID 02) exhausted the family resources, and the family had to go for a bank loan and also organise fundraising:

‘…We had taken some loans and eventually we had to have a fundraising for my treatment…’ (ID 02, PRI)

The rest of the participants had their medical bills paid by their employer's insurance. However, they also expressed financial concerns due to inadequate insurance cover. For example, ID 01 stated:

‘…however, insurance runs out most of the time... My family has to chip in...’ (ID 01, PRI)

Generally, the cost of health services was believed to be unaffordable to some patients in both the private and public clinics. Some patients, especially those who attended the public hospital, reported that they relied on family members who had limited funds, while those who mainly attended the private clinic relied on their employers who offered a specified amount of money per family.

6.4 Summary

From both the patients’ and doctors’ perspectives, the organisation and delivery of health services in Kenya, which was supposed to determine the patient care pathway, was not ‘user-friendly’ to patients with lupus as they ended up going round the different health systems. This had an added negative effect on the ability of the doctors to diagnose lupus.

The main factors which influenced the patients’ experiences were the organisation of health services in terms of inadequate physical structures, the imbalanced staffing structures, the inadequate care structures and the inefficient referral system. The other factors which
influenced the patient care pathway experience were related to the accessibility of lupus services in terms of geographical accessibility, the availability of lupus services and service affordability. The patients, therefore, followed different routes to reach the two rheumatology clinics, and not necessarily through the organised levels of health services due to the lack of comprehensive care at all levels. Surprisingly, there was also a lack of comprehensive care at the higher levels of care, such as the county hospitals and the national referral hospital, due to limited resources. Receiving comprehensive lupus care and treatment, therefore, became a challenge for most patients.
Chapter 7: Cultural beliefs, practices and prejudices

7.1 Introduction
This chapter describes the third overarching category namely the ‘cultural context of living with lupus’ from the perspectives of the participants. During the discussions, it emerged that there was a general lack of understanding about lupus amongst the participants, their families, work colleagues and their contacts. Two main sub-categories emerged from the data: ‘cultural and religious beliefs’ and ‘stigma and rejection’. The first sub-category of ‘cultural and religious beliefs’ explains how some participants, along with the people in their social networks, constructed their understanding of lupus in relation to their cultural and religious beliefs. The chapter also describes how these beliefs influenced people’s treatment decisions and behaviours. The second sub-category of ‘stigma and rejection’ describes the societal lack of understanding of lupus and the labels they attached to some participants due to the visible symptoms they had. Some participants experienced negative social reactions, humiliation and rejection from people. Their response to the discrimination is also discussed. The following sections describe the two sub-categories.

7.2 Cultural and religious beliefs in illness causation
Christianity is the official religion of 82% of Kenyans (Kenya National Bureau of Statistics, 2010) who define their identity largely in terms of their affiliation to a Christian church. However, traditional folk beliefs and superstitions still seemed to play a major role in some of the individuals' social and cultural lives.

Nearly half of the participants (n=8) held cultural or religious beliefs regarding the cause of their illness. This was partly because some participants were not improving on conventional medications, while at the same time most of the participants, together with their families, were not aware of lupus as an illness. Therefore, they attempted to explain the possible causes of their illness with reference to their cultural and religious beliefs. Culture is defined as the sum total of a socially transmitted pattern of thoughts, values, meanings and beliefs (Purnell, 2005) which is inscribed in each individual’s mind (Tan, 2008) and more importantly, shared within a social group (Fischer, 2009). In the study, the traditional folk beliefs which were considered
as possible causes of illness included witchcraft and 'evil eye' (ID 03, 12 and 13), angering the ancestors (ID 12, 16, 18), a curse (ID 16) and demonic attack (ID 07).

The participants who drew on traditional beliefs were from two cultural groups, the Bantus and Nilotes. They included participants who had already been attended to in various formal health facilities, but received an inconclusive diagnosis and failed to improve:

'*If there is a disease but it cannot be diagnosed, and you are told you are okay yet you feel pain, wouldn’t you believe you have been bewitched?’* (ID 12, PUB)

MacLachlan (2006) states that there are cultural beliefs regarding both ‘natural’ and ‘supernatural’ causation of illness; he further states that such beliefs can co-exist in the minds of individuals.

### 7.2.1 Beliefs in witchcraft and evil spirits

A witch is broadly defined as an individual who is capable of causing magical harm to others (Ciekawy, 1998). In the study, two participants believed in witchcraft (ID 03 and ID 12) and one in evil spirits (ID 13). For example:

'*Now in my heart, I did not know what to think. At times, I would think that maybe I had been bewitched. Or I would feel that probably they were evil spirits from my ancestors... I mean, I did not understand what was happening to me.'* (ID 03, PRI)

'*… The first doctor who saw me took x-rays to check my heart and kidneys. He actually checked everywhere, but he found nothing wrong with me. So, I did not now know how he was going to help me...’* (ID 03, PRI)

ID 03 considered being bewitched because she was investigated but no diagnosis was made, as the biomedical investigations were unrevealing. However, in ID 13’s case, it was the relatives who came up with the idea:

'*My relatives started saying that I had been bewitched because of the things I was going through. They would not understand what was happening... so she [Aunt] was like “You were bewitched, and the best thing I should do is take you to my doctor”.”* (ID 13, PUB)

The similarity between the narratives of ID 3 and ID 13 is that both of them were not improving despite receiving treatment. The difference between them was that one participant (ID 03) thought that her illness was either due to witchcraft or evil spirits, while the other
participant (ID 13) was being put under pressure by her relatives to consider the possibility of having been bewitched.

The contradiction in ID 13's narrative is due to the cultural differences between African traditions and Christianity. From her narrative, it was evident that she had rejected the African belief in witches. Therefore, there was a clash between her relative’s cultural beliefs and her Christian beliefs, though she did not state the reasons for her refusal. Gort (2008) argues that from earlier history, Christians who converted to Christianity have maintained a negative attitude towards African and Asian traditions which they perceive as heathen, barbaric and superstitious, a view supported by Adamo (2011). Adamo (2011) suggests that the dialogue between African traditionalists and Christians has improved over the years with more religious independence. However, this was not evident in the study.

From this study, it was also evident that the participants experienced ambivalence about the cause of their illness. ID 03 even asked for spiritual intervention in the form of prayers. This demonstrated the way in which different religious and cultural beliefs co-existed. MacLachlan (2006) suggests that it is important for health practitioners to know about the client’s belief systems, because cultural beliefs may or may not be shared among groups of individuals and families.

Evil eye as a cause of illness was mentioned by one participant who also tended to use it interchangeably with witchcraft:

‘First, I thought of that [witchcraft] but brushed it off my mind. It started with me going to the shamba (Farm), doing a bit of digging and then beginning to feel pain. So, some people started telling me, “Whoever your neighbour is, they might have looked at you with an evil eye. Maybe it is because you work hard and harvest a lot.” At that point, I believed that thought but soon brushed it off my mind, and told the person that I could not see that happening.’ (ID 19, PUB)

In ID 19’s case, it also seemed that her belief in the supernatural causation of illness and biomedical theories of causation of illness co-existed. She was also educated upto diploma level, which indicated that her faith in the existence of witches and evil persons was independent of her level of education.
7.2.2 Angering the ancestral spirits and curse

Punishment resulting from the violation of kinship rules which anger the ancestral spirits was also considered as a possible cause of illness, as indicated by some participants (ID 12, ID 16 and ID 18). Cultural norms have been defined as "the rules a particular group uses for appropriate and inappropriate values, beliefs, attitudes and behaviour" (Grønkjær et al., 2011, p. 1). They are a collective expectation of a wide range of behaviour (Williams, 2011). Two participants (ID 16 and ID 18) indicated that they had to consult with their maternal relatives to check if there were any violated kinship rules which could have contributed to their illness. For example:

'... The thing that crossed our minds was that probably this was something that happened at home. The parents did not do one thing or another, and we should try to find out. We had no idea of lupus. The following day my maternal family came so they could tell that they have nothing to do with this problem. I thought something had happened there but they said they did not know anything like that... moreover, they never have any issues with anyone.' (ID 18, PUB)

ID 18 raised many issues which included illness possibly being caused by wrong doing to maternal relatives, or illness being caused by disharmony in family relationships. This implied that people cause illness to themselves and to others by voluntary anti-social behaviour (MacLachlan, 2006) which enforces corrective behaviour (Adamo, 2011). This narrative also implied that in the patient's culture, good health was seen as a result of good behaviour and living by the traditional values and norms (Iroegbu, 2005). This view is supported by Mbiti (1990), a Kenyan sociologist who suggested that as a community member, one can suffer from a disease due to bad relations with a community member which in turn, can affect the whole family. In this study, considering personal behaviour in past situations seemed very important to the participant’s immediate and extended family. However, she did not get better after consulting her maternal relatives.

7.2.3 Belief in demonic attack

In the study, one participant (ID 07) indicated that she was told that her sickness was due to demonic attack. She also indicated that her illness could have resulted from demonic attack:

'That it is a demonic attack. Actually, there is one lady who told me that, “No this is not sickness, it is a demonic attack”. So, how do you deal with it? Through prayer. It’s
not sickness. It is a demonic attack, probably, yeah; some people believe depending on their beliefs.' (ID 07, PRI)

Webster (2013) states that demonic attack is the religious experience of undergoing spiritual warfare with evil spirits, which is expected as the cost of being a Christian. This implied that ID 07’s causation of illness was also seen as supernatural but was being explained through her Christian belief.

Amzat and Razum (2014) state that sub-Saharan Africans believe that the supernatural diseases can only be handled by clerics or traditional healers who have the spiritual powers to diagnose, treat and advise on the course of action. This was also evident in the study. However, belief in prayers was more common among the participants (ID 02, 07, 10, 13 and ID 19) than consultation with traditional healers (ID 12, 16, 17 and ID 18), as described in the next section.

7.3 Beliefs in traditional and religious remedies

For the purposes of treating the illness, about a quarter of the participants and their families made decisions to take the participants to various traditional healers or to seek prayers for healing. There were also instances where there was overlap in using both traditional and Christian healers.

For another participant, there was tension caused by the different value systems - traditional values versus Christian values - which prevented them from having a shared understanding:

'...Okay, I am a Kamba by tribe, and most Kambas believe in witchcraft. All that juju [evil spirits] stuff. So, she [Aunt] was like, “You were bewitched, and the best thing I should do is take you to my doctor”’… For me, my mother had built a Christian foundation for us and advised that it is not right to consult witch doctors. So, when I refused, she started calling her sisters and brothers.’... she was saying, “You brought this girl who walks like she is about to fall. Come and take her, I do not want her here”. Basically, because I had refused to go to her witch doctor. So, we became enemies, and she deported me to Nairobi.’ (ID 13, PUB)

The narrative of this participant illustrated the possibility of different beliefs existing among people of the same family or ethnic origin. The study also established that some participants also utilised different remedies according to their varying beliefs.
7.3.1 Traditional remedies

It emerged that the use of herbal remedies was the most popular among participants who believed in cultural and religious beliefs in illness causation (for example ID 08, 13, 15 and 17), though there were no cases of symptoms being relieved by herbal remedies. Some participants reported that their conditions deteriorated:

'It got to a time I was so desperate. I wanted to get healed. Then, there is someone who came and told me there are herbal medicines that I could use. So, I withdrew from the normal medications and started using the herbal ones. But they messed me up completely. It is as a result that I got admitted at Kenyatta for three months.' (ID 13, PUB)

'I started experiencing the same thing. I was now sick - the hands started swelling. My relatives said it was better to take me to a herbal doctor. I was taken there. All the time I had a swelling, they would cut my legs. You see these marks?… Then when they saw blood come out, they would say that it was black and that it was the disease. So, they sprinkled some ashes. They cut my arms, my back - all sides of my body. So, most of the time I used to come back bleeding from those marks. I used to move from one herbal doctor to another.' (ID 17, PUB)

Some participants also reported using other types of traditional remedies, for instance, when ID 16’s condition did not improve, her family thought that the illness was probably due to a curse rather than ‘family issues’. They opted for an alternative traditional remedy which also did not work:

'Seeing that even after they had said there was no problem, there was still no improvement, we thought it was somebody who had cursed us. We looked for fat from a pig because we thought if one applies that the problem disappears. Nothing! At first my head began to develop sores which were soft, pressing like an avocado, and painful… The condition worsened.' (ID 16, PUB)

In this culture, the use of pig fat was believed to have the ability to protect someone from evil spirits. Some participants also mentioned the use of prayers for healing, as discussed in the next section.

The study also provided evidence that some patients received incorrect information which removed them from the formal healthcare system, especially when they were either not improving or when they received inadequate information regarding lupus from the health providers. One doctor shared this view:
There is lots of information out there in the media: faith healing, traditional like herbal medication and so on. Some of these patients get bought into some of those messages. Maybe they would attend a crusade and believe they are healed.’ (CL 56, CL)

7.3.2 Religious remedies
A few participants (ID 03, 07 and 08), together with their families, also resorted to prayers for faith healing:

'And then she [her sister] said: “I have a message for you.” She took me to the bedroom, my bedroom, which is very strange. And she sat me down and she started praying... She told me, “God has said you will be well.”' (ID 07, PRI)

'.... I had a few aunts who had a few pointers on that of course... They used to come and pray over me. They used to believe that this was a spiritual illness. In fact, there was a time when one of them urged me to stop taking medicine through faith, and I told her no thanks.' (ID 10, PRI)

There were also participants who were wishing for miraculous cures:

'I keep hoping that one time when God performs a miracle, I get out of it. Nonetheless, even if I do not, I am okay because I know what I am going through.' (ID 02, PRI)

'Yeah. I hope because with God everything is possible. I hope one day I will be completely cured of lupus.' (ID 10, PUB)

One participant explained that she became bitter because she did not understand why God was allowing her to go through the illness:

'I became bitter. Bitter with people, bitter with life and bitter with God because I could not understand why God was letting me go through all this stuff.' (ID 13, PUB)

The narratives from ID 02 and ID 13 illustrated some of the participants' beliefs that their illness had a spiritual significance and that God is a healer who has the power to cure them when prayed to. MacLachlan (2006) explains that there are individuals who believe that the cause of their illness could be a result of ‘God’s will’ and consequently, pray to their God for healing.

However, it was evident that none of the traditional remedies worked for these participants. For example, ID 13 and 17 indicated that they returned to formal healthcare when their condition worsened while on traditional remedies. The failure of traditional remedies was also
closely linked to the negative responses of some individuals towards some patients, as discussed in the next section.

7.4 Stigma and discrimination

In the study, the traditional cultural beliefs and misunderstanding about lupus were among some of the factors that led to some negative experiences, as reported by the study participants in this section. Almost half of the participants described experiencing stigmatising attitudes from both the public and some doctors. Stigma was mainly experienced in public places, at the workplace and among staff in some health facilities, as described below.

7.4.1 Stigma experienced in public places

Some participants reported experiencing stigma from those who knew them from before, due to their visibly changed physical appearance:

'Sometimes you have the butterfly rash, and it is so bad, and you know, you see people looking at you, and of course giving you all sorts of labels. They are not talking about it but you can physically see from their facial expressions - you can really gather a lot... You know, like before I fell sick, before I had the flare up, I had lost so much weight. My clothes are not fitting me.' (ID 07, PRI)

'People were looking at me scarily. Whenever they looked at me, I would feel that they were thinking of something. They would go as far as saying, “Madam has AIDS”. The signs that I had or showed made them feel that I had AIDS.’ (ID 19, PUB)

From the narratives, the visible symptoms of lupus which had caused physical disfigurement for some participants, such as the butterfly rash on the face and weight loss, made them look different from their previous appearance. This new physical appearance was the cause of undesirable differences which made participants feel that people were looking at them in a ‘discrediting’ manner, a phrase suggested by Goffman (1963). The visible changes were interpreted as symptoms of HIV infection (Stern et al., 1995) as indicated in section 6.2.

The community members seemed to be aware of the disfiguring symptoms of HIV infection such as weight loss, skin rash, a sore mouth and hair loss. However, not many people were aware of lupus and its symptoms, even though lupus tends to mimic some symptoms of HIV. This view was also held by some participants who also thought they might have HIV, especially before receiving the lupus diagnosis. For example:
'Mmm. That was the first thing I did. You see, I was looking at the condition and all the symptoms, and I was like, “heh, I had better go for HIV because you can never know.” Right? So, I have. I have been tested for HIV.' (ID 07, PRI)

'I thought maybe I was HIV positive and I did not know. So, we went there twice. Nothing was found.' (ID 08, PRI)

Even children were familiar with the HIV symptoms, as further explained by one participant (ID 12) whose young niece also suspected that she had HIV infection and advised her to go for testing:

'My sister’s daughter, she also thought I had HIV/AIDS. Since the child knows what HIV/AIDS does, she was asking me, “Auntie, grandmother has arthritis, and she only gets swellings on the legs. What happened to your body? Do you have HIV? Why don’t you go for an HIV test?” I told her, “No. I do not have HIV.”… However, I understood where she was coming from… I said, if this child says this, what about other people? What are they saying? (ID 12, PUB)

The comments from ID 07 and ID 12 indicated that the patients were aware of how their body image had changed. They were also conscious of the negative attention that people with HIV attract, which made them feel uncomfortable and also made them experience felt stigma.

In the study, apart from two participants (ID 07 and ID 08) who attended the private clinic and requested the HIV test, most of the participants (e.g. ID 03, ID 17, and ID 18) were tested on doctor’s request. Participants indicated that HIV test was one of the first blood tests they underwent whenever they first encountered a doctor:

'Even if I get admitted, the first blood sample taken from me is for an HIV test, then the other diseases follow. This happened from the time I fell sick, to the time I was diagnosed with this disease… If only I could tell you how much HIV testing I have had since I started seeking treatment for this disease. In fact, you’ll be shocked.’ (ID 03, PRI)

'I have been tested several times. I was last tested in December.' (ID 15, PUB)

It seemed that the similarity between the HIV infection and lupus symptoms made HIV a preferred differential diagnosis among doctors. One doctors also indicated that some patients could have been tested several times for HIV because the patients come with a variety of problems:

'I said that lupus does not take any particular format. It can come with fever, joint pains, anaemia, fatigue, skin conditions, loss of weight or somebody who just becomes sick without any particular issue. You can also get somebody who presents with chest
problems and has been on treatment for TB. The same person could have been tested several times for HIV but found to be negative.' (ID 64, CL)

The above narratives were mainly concerned with pre-diagnosis stigma. HIV was a preferred differential diagnosis not only because of the similarities between its symptoms and lupus as mentioned in section 6.2, but also due to the high prevalence rate of HIV in Kenya which was 5.4%, though comparatively lower than the regional prevalence rate of 7% (UNAIDS, 2017). It is also possibly stigmatised due to the sexual route of transmission which is associated with low morality as mentioned in section 1.3.3.

On the other hand, there were participants who still experienced stigma even after being diagnosed with lupus. This was due to people’s disbelief regarding the existence of a condition known as lupus, as expressed by some participants (ID 02 and 12). This stigma was still associated with blemishes of individual character, a typology of Goffman's (1963) definition of stigma. People had already affixed stigma to these participants due to the earlier assumption that these participants had HIV, which was viewed negatively. For example:

'... many people don’t understand what lupus is. They ask me, “What is lupus?” Now, when I explain it to them, you can hear them saying it is lie, there is no such disease.’ (ID 12, PUB)

'This is how I was told she put it [An acquaintance]. “I am widely read but I have not seen an illness like this one. Sometimes it is the chest, sometimes it is the stomach, sometimes it is the bones. There is no illness like that. Her husband should return her to her home so that they can check what the problem is.”' (ID 02, PRI)

This type of stigma was narrated by patients from both the public and private rheumatology clinics. The lack of understanding about the illness (lupus) by the family also prevailed, and was expressed by other participants:

'I came home and I told my husband that I have a disease called lupus. He said, “what is that?”’ (ID 04, PRI)

'Now at the beginning I did not even know what lupus is. The thing is, even my people were asking me, “What have you been told is the disease?” I would tell them that I don’t know. Even my brother asked me, “Or is it cancer of the blood?” Yet, I was not told it was cancer. My relatives mentioned many names, but I would tell them, “I don’t know, I have been told it is a disease but I don’t understand what disease it is.”’ (ID 03, PRI)

From the narratives, it is evident that in Kenya, public awareness regarding lupus is low.
7.4.2 Stigma experienced at the workplace

It also emerged from the data that stigma was experienced in the workplace. Some participants felt discriminated against by their colleagues:

'... the work place, social places, you know. Either you would see people withdrawing or you hear rumours. In fact, I used to tell my friends, “Please don’t tell me who said what because I know what I have.”... Sometimes we would be able to sit together... and at times I would actually be left alone.' (ID 10, PRI)

'... In the environment I am working, they don’t know what I am suffering from. Actually, they don’t know I have lupus because when I started ailing one of my colleagues went and took the AIDS stickers and then she put it in my class on my cabinet. I felt very frustrated. She even went further to come and ask me, “What are you suffering from? Are you having asthma, TB or is it the big one [HIV]?”' (ID 02, PRI)

Other participants (ID 19 and ID 20) reported being asked to stop working by their managers:

'My boss does not understand the disease. They have really harassed me, by the way. Even the doctor knows about it... At one time the boss even asked me to resign. But I said I will not because I know my rights and this is a condition which is manageable. So, I fought and am still fighting, and they still want the doctor to write to them.' (ID 20, PUB)

'At work, my headteacher just decided to tell me that she wants me to go for a sick leave... However, I have not decided when or where I will go... I have 2 more years then I can go for early retirement if possible, but I do not know if I will make it.' (ID 19, PUB)

The discrimination experienced at the work place was not only about HIV stigma but also related to lack of awareness of lupus and prolonged sickness as indicated by both 19 and ID 20.

7.4.3 Stigma experienced from health practitioners

A small number of patients (ID 10 and ID 19) also experienced stigmatising attitudes in their interactions with health professionals in healthcare settings. As mentioned in section 1.3.5, Thorne (1993) referred to this as socio-cultural issues within the healthcare system. For example:

'In one town it was bad!... Okay, nurses knew me from before. I had been referred from another town to this town, so they knew my case. But a new doctor came in, and his assumption was, “This lady is HIV positive.” So, he proceeded to treat me in that
manner in terms of even his attitude until a blood test was done and he realised, “Oh good Lord!”’ (ID 10, PRI)

From all the above narratives, it was evident that stigma was expressed in a variety of social contexts such as public places, work and health institutions in both overt and subtle ways which the participants had to deal with. The main reasons for stigma were; the public mistakenly associating symptoms of lupus with HIV infection which they were aware off, and lack of awareness of lupus. The next section discusses how the participants managed the stigma they experienced.

7.4.4 Participant responses to stigma

The data revealed how the participants negatively contended with the discrimination in various ways, especially by socially excluding themselves and being fatalistic. Some participants expressed this:

'You see, even socialising, I do not feel like going to public gatherings, I always want to be on my own... I feel like people will not understand me... Everything you are doing, you are thinking about the condition all the time. All the time you are thinking about it no matter how strong you have grown... I must say I look at myself as a very strong person but then still, there is that human aspect of it, that you want to be on your own because you are unique. You are suffering from a unique condition, so you want to close yourself up.’ (ID 07, PRI)

'… For example, my sisters, sometimes they know when I am stressed. At such a time you just find that they have taken me out somewhere and on returning you notice that I am stress-free and jovial once more. It is about being taken out for a walk - they take me with them whenever they go somewhere. However, I usually don’t like it... If it is a place where I am likely to see my friends, I do not like it. However, if it is a place where I am likely to meet my relatives, I usually feel comfortable going.’ (ID 12, PUB)

These were examples of social withdrawal instigated by the participants themselves. One participant (ID 17) also expressed how she reacted as a result of a friend making her feel as if she was going to die:

'I told him, “Okay, finally the doctor has said I have lupus, and he has said he is going to help me.” He then told me that he buried a friend who had lupus. From there, I felt that people were rejecting me since they now knew that I was going to die.’

'... I did not want anybody anymore in my life. I just wanted to be alone. I did not want someone to come close to me because I used to imagine that they would know the good part
of me and when I left them they would cry... My life was now about locking out people out of my way.’ (ID 17, PUB)

ID 17’s friend made her assume a fatalistic attitude. She not only felt rejected with diminished self-worth, but also decided to withdraw socially. In the data, the number of fatalistic statements was also surprisingly high with more than half of the participants expressing their fear of death. This always occurred in conjunction with negative assumptions about the disease being terminal as their condition was initially not improving. For example, one participant expressed how she cried and even made arrangements for the care of her children when she dies:

'I mean, I did not understand what was happening to me. My relatives were telling me that I was asking for their forgiveness. I was crying. I was telling my siblings that when I pass on, I will leave to you, my children. I was leaving my children even with my friends.’ (ID 03, PRI)

This meant that individuals with lupus not only had to deal with the physical body disfigurement caused by the illness and the fear of death caused by the uncertainties of the illness, but also the stigmatising attitudes of the public which included family, work colleagues and health professionals. These participants employed negative coping strategies for the stigma they faced.

7.5 Summary

In the study, it emerged that due to delayed diagnosis, failure to respond to conventional therapy, and the limited understanding of lupus following diagnosis, some participants together with their families resorted to seeking supernatural explanations for the illness. Their supernatural world included both African tradition and Christian elements. The supernatural powers included: witchcraft, evil spirits, ‘evil eye’, and angering the ancestral spirits. The use of herbal medicines, traditional remedies and faith healing emerged as the preferred modes of treatment under the circumstances. Belief in supernatural powers was not universal and was dependent on ethnicity, but independent of the participants’ level of education and residence. It also emerged that the belief in ‘natural’ and ‘supernatural’ explanations of illness causation co-existed among some participants; these participants tried both conventional and traditional treatments. However, there was evidence that cultural factors, such as the indigenous belief
systems about illness causation, were a significant determinant of decision making and help-seeking behaviour amongst some communities.

Also, it emerged that due to the prevailing beliefs and ideas, some participants with lupus felt socially devalued or discredited in a variety of social contexts due to their changed physical appearance. In some instances, there was an assumption that some of the participants had HIV infection which is a stigmatised condition in Kenya. Therefore, they experienced stigma and discrimination from the public, family, work colleagues and health workers. In response to the stigma, some of them became distressed and withdrew from most social activities. However, most of the participants did not give up on seeking means of accessing treatment and managing their condition. They relied on various resources as were available to them, which are discussed in the next chapter.
Chapter 8: Resources for managing life with lupus

8.1 Introduction
The fourth overarching category identified from the data was ‘resources for managing life with lupus’. From the data, it emerged that although lupus services were available at the tertiary hospitals, the participants had a common experience of still struggling to live with the illness. This chapter discusses the participants’ struggles and the different resources they relied on to manage their lives with the illness. 'Economic resources', 'social support/networks' and 'cultural resources' were the three main types of resource mentioned by participants. The resources were unequally distributed among the participants and therefore acted as either facilitating factors or barriers to the process of gaining access to treatment. This caused inequality in treatment experiences and subsequently, varying experiences with the illness. The following sections discuss each of the identified resources as sub-categories.

8.2 Economic resources
The first sub-category to emerge from the data was economic resources. As mentioned in section 6.3.3, most participants struggled with the cost of lupus care. Also, a significant number of participants had inadequate personal finances due to unemployment and poverty. As also discussed in section 1.4.4, Kenyan healthcare in public hospitals is subsidised. For instance, the specialist outpatient consultation fee at the public rheumatology clinic is Ksh 600 (approximately $6 US or £4) excluding charges for the cost of drugs, laboratory and radiological services which are also subsidised. However, the majority of Kenyans live on less than a dollar a day and cannot afford any form of healthcare (Ministry of Health, 2010). In the private sector, health services are not subsidised. The specialist outpatient consultation fee at the private rheumatology clinic is Ksh. 2,500 (approximately $25 US or £17) excluding other services. Whichever clinic the patients attended, they needed economic resources to cover the cost of services. Nevertheless, all patients in this study suggested that lupus treatment was expensive. Thus, patients drew on different types of ‘economic resources’ which determined the place and type of care they received. Most importantly, there were those who had medical insurance cover and those who had none.
8.2.1 Medically insured participants

The study established that only a quarter of the participants had their employers' support in the form of medical insurance cover as previously illustrated in table 6.5, which facilitated their access to treatment. They could afford both inpatient and outpatient treatment for lupus. However, only one participant (ID 03) had her medical bills fully covered by her employer irrespective of the amount. She worked for a private health facility which gave her privileged access to healthcare even though she was a support worker with a minimum wage:

'I did not have any problem... They get me all the medicines because looking at the total cost of these medicines alone, on my own, I cannot manage to buy them. So, I really appreciate my employer. For treatment, I have never run out of medicine. I have the medicines.' (ID 03, PRI)

This narrative showed that the affordability of medication, for this participant, might have facilitated treatment adherence because, at the time of data collection, her condition was stable. She only attended the private rheumatology clinic once every three months for follow up, which is the standard practice for stable patients at this clinic.

The quarter of participants who were insured included a sub-group of two participants whose medical insurance was not always adequate to cover the cost of their treatment. However, these two participants were able to continue accessing treatment at the private clinic as they had alternative sources of funding:

'The fact that I can afford to have medical cover is a good thing, but I know, when you look at the drugs, they are not cheap... it got to a point where I had exhausted my outpatient [insurance cover], but I could afford to buy it [the drug] myself... imagine how many other people can afford that. When you are looking at a dose for a month going for 3400 shillings [approximately £23].’ (ID 06, PRI)

'Ya, I am on insurance... however, insurance runs out most of the time... My family has to chip in [when insurance run out].’ (ID 01, PRI)

Both individuals indicated that when the medical insurance ran out, they or their families could afford to continue buying the medications. For this group of patients it was evident that despite the medical insurance running out, their employment status or the financial situation of their families enabled them to continue accessing treatment from the private clinic. An individual’s or their family’s financial ability was, therefore, a facilitator, as they were able to access lupus care from both the private laboratories and the rheumatology clinics.
The precarious nature of insurance cover provided by the employers only during employment periods (see section 6.3.3) negatively affected some individuals. One participant (ID 09) disengaged from services and treatment when she lost her job at the end of her contract. She discontinued receiving lupus treatments from the private rheumatology clinic because she could no longer afford the cost. Also, she could no longer afford to travel to Nairobi to honour her clinic appointments:

'... Previously, I did not have the problem [of buying drugs], but now when I later lost my job, it became so hard for me. Then, there is travelling. Previously, I used to go to Nairobi twice a month. That means transport and all those expenses. Also, there is a doctor’s consultation fee which is two thousand shillings (£13) per session...When the stock [of her drugs] that I had run out, I stopped taking medication...' (ID 09, PRI)

At the time of data collection, this participant had already been off medication for six months and was still hoping to find an alternative source to finance her treatment. She had no financial support from her family; she had recently lost her mother to cancer and did not want to worry her father with another illness. This led to her inability to afford treatment even at the public rheumatology clinic and this subsequently, led to her treatment non-adherence. This signified that an employer’s economic support, whether adequate or not, provided valuable practical help during the employment period. For some participants, the support gave a sense of gratitude:

'I am fortunate because we have an excellent policy [medical insurance cover] at the University. For both outpatient and inpatient.' (ID 07, PRI)

Another participant (ID 20) had minimal employer support in the form of outpatient cover which was not enough to cover the cost of treatment in the private rheumatology clinic. She decided to access treatment from the public rheumatology clinic, but treatment was still unaffordable to her because she had to access some of the laboratory services from the private laboratories, which were costly for her. The unaffordability of laboratory tests in the private laboratories and the unaffordability of some lupus drugs was a view shared by some of the doctors. For example:
'The public hospital is comparatively cheaper. People can at least afford the services, or NHIF\(^1\) can help. When you go to a private hospital or private labs, these tests are more expensive. So, affordability is a problem.' (ID 60, CL)

However, ID 20 was still able to pay for her treatment because of the positive relationships she had with her family and the financial ability of her family. She expressed how her family members contributed and shared the cost of her treatment:

'\textit{My laboratory tests cost almost 154,000 shillings (£1,026). My medical cover for outpatient is only 50,000 shillings (£333) per year. However, my family came in. Everyone came in and said they are going to pay for a test each... Yes. So, everybody took one [laboratory test].}' (ID 20, PUB)

She had both the employer's economic support, although minimal, and social support from her family in the form of finances. From these narratives, it was evident that financial assistance was precarious even for some insured participants who had to rely on employment, the employer's goodwill and their family's good will, in order to afford lupus treatment and care.

8.2.2 Medically un-insured participants

The study also established that about three-quarters of the participants had no medical insurance, as illustrated in table 6.5. Some of the participants were fully supported by their families and were able to meet the cost of treatment from the private rheumatology clinic. For example:

'\textit{When we began treatment, the prescribed drugs were going to 15 and 16 thousand Kenya shillings (£100 to 107). One time it was 24 thousand (£160 ), and there was a time it went up to 30 thousand (£200). So, we would spend quite a good amount which in our state is not affordable. So that is why I was saying that medication has been quite a challenge because there are drugs that you buy which are quite expensive, you need them yet they are quite expensive. You run out of money, but we thank God we have managed.}' (ID 02, PRI)

This participant's narrative gave a sense of some participants just barely managing. This participant was employed but was not utilising her employer’s medical insurance, because her immediate supervisor had not declared her absence from work to her employer; she was relying on the supervisor's goodwill to stay in employment. The participant’s medical bills

\(^{1}\) National Hospital Insurance Fund (NHIF) paid by employers in order to subsidise the cost of healthcare both in private and public health facilities
were instead being met by her family, who were able to rally financial support from their social networks. Thus, some participants who had adequate economic resources were able to access lupus care from both the private and public clinics with fewer struggles than others.

The study findings also established that a majority (almost three quarters) of the participants were not well resourced economically. Most of these participants were attending the public rheumatology clinic. This included a few participants (less than a quarter) who were employed but with no medical insurance from their employers (e.g. ID 02, 13 and 19). One participant (ID 13) indicated that she was not insured by her employer because she was still on probationary contract, so she was meeting her treatment costs herself. This determined her decision to seek healthcare from the public rheumatology clinic. Public healthcare was supposed to be affordable. However, she still struggled to buy her medications because her funds ran out. Her inability to afford medication had subsequently interfered with her medication adherence and caused her condition to deteriorate on one occasion:

'... You find that the medication you are taking is so expensive. However, you need them despite having no money... I missed medication like for two months, and after that, I got a flare.' (ID 13, PUB)

The disease flare that this participant previously experienced was because she missed her medication for two months. This led her to make a decision to self-medicate with prednisone. This practice was continuing even at the time of data collection without her doctor’s knowledge:

'Most of the time when I know I do not have medication at all and I do not have money to buy these others [showing her prescription], I make sure I have prednisone. Yeah. Even if I do not have any other medication, at least prednisone has to be there... From what I have been seeing the doctor do, when I have an issue they always increase the dose of prednisone. So, when I have some issues, I also increase... I prescribe it for myself. When the lupus is under control, I normally take 5 mg. However, when there is a problem I go up by about 2 mg or 3mg. I remember there is a time I took a packet of prednisone within one week and the doctor told me you start by taking 40 mg. After one week 30 mg and the next week 20 mg. So, I know when I have started a high dose, I go reducing gradually but not at once.' (ID 13, PUB)

Her employment status determined her economic status. Also, her husband walked out of her life after diagnosis. She had also previously disagreed with her extended family over the use of traditional remedies which were against her Christian beliefs. Therefore, ID 13 lacked both economic and social support which influenced where she accessed treatment and her treatment
decisions. There was one other participant (ID 16) who was not in formal employment and had to meet her treatment cost herself. She decided to engage in other income generating activities which were still inadequate to meet her treatment costs:

'It is me [who meets the cost of treatment]... All the time... So, at the point when I stopped drugs, I had seen that I did not have any money and I did not want to bother to ask anybody. So, my condition makes me do this or that. Sometimes I rear and sell chicken. I try the best I can.' (ID 16, PUB)

This participant had been employed before as a casual labourer, but the job required that she stood throughout her shift which she could no longer manage because of the pain she experienced after work. She was poor and had no social support, and thus sought healthcare from the public rheumatology clinic.

There was a further group of participants (more than a quarter) who were not working at all and fully relied on family members for their treatment support (e.g. ID 12, ID 15 and 21). For example:

'Okay, it is my husband who pays for the treatment. But should I say this, because it is a bit personal? He is the one who used to support me although there is one of my brothers who has supported me since 2012. From 2013 my husband started giving me only half the money. So, it is my brother that I would call to add to it. I used to call my brother who would add to the money which I would then use to buy medicine. However, since December, my husband has gotten tired because the last medicine he bought for me was then [in December]... I had so much faith in the medicine that I used to take. But now it has come to a time when to get just a tablet is not easy. I go for weeks and months without getting a tablet ...' (ID 15, PUB)

This participant faced greater treatment challenges due to very precarious finances. Her narrative showed that family support could become inconsistent, inadequate and unreliable during chronic illness. The available evidence suggests that non-adherence to medication can either be intentional or non-intentional. Non-intentional non-adherence to medication can occur due to the financial constraints associated with treatment and the lack of social support (Cohen et al., 2012; DiMatteo, 2004; Fortmann et al., 2011). Family support is suggested to be the strongest and most consistent predictor of medication adherence in other chronic illnesses like diabetes (Glasgow and Toobert, 1988; Miller and DiMatteo, 2013). This was evident in the current study.

The view of economic resource inequality between patients was shared by the doctors:
'Again, some people are very poor. So, financial concerns may contribute to non-compliance.' (ID 60, CL)

The consequences of this were that some patients stopped taking their lupus medication or had periods when they could not keep the doctor’s appointment for lupus care (e.g. ID 9, 15, and 16). One doctor also acknowledged that some patients experienced treatment challenges due to their lack of finances and considered ways of reducing the cost of treatment:

'Patients have varying levels of ability to afford the drugs or the tests. For those who cannot afford, I will do more of clinical assessment and sacrifice the test. I will not make somebody who does not have much money miss the medication.' (ID 66, CL)

The study established that the majority of patients had no access to health insurance which resulted in inequality in healthcare access. The insurance cover was also inadequate for those who had it, and thus most patients relied on their families to fund their healthcare, which was precarious. However, drawing on their social support/networks in an attempt to manage their life with lupus proved useful for some patients, as discussed in the next section.

8.3 Social networks/support

The second sub-category to emerge was social networks/support. The study established that some patients had access to valuable social networks and significant social/emotional support provided by their families, friends and social acquaintances. This enabled some of the patients to overcome some of the barriers they faced, such as securing economic resources as described in the previous section.

Family ties and personal contacts produced benefits for some patients who, for example, received information and moved faster from the periphery health facilities to the rheumatology clinics despite the geographical distance. They were able to secure earlier appointments at the rheumatology clinic:

'It was on a Sunday, and then on Monday, one of my cousins wrote that word for me on a yellow paper... She told me, “Go to the internet and search what lupus is, but if you do not mind come to -- Hospital [a private hospital] and see a doctor [the rheumatologist]”. That is when we knew what disease it was, and she started treatment then [participant’s mother].’ (ID 18, PUB)

'She tried the referral hospital [the provincial hospital]. If only you could see her status and condition at that time and how the health workers were very reluctant to
attend to her - even telling her to go back home and come the following day. She was actually in bad shape. So, the son proposed that she travels to Nairobi immediately... [participant’s daughter-in-law].‘ (ID 19, PUB)

ID 18, who was not employed and had a primary level of education, was referred straight to the private rheumatology clinic while one other participant (ID 19), who was employed and had a college education, was taken by her son to the public rheumatology clinic. Their strong social contacts influenced their access to treatment. In addition, they also benefited from the porous referral system which allowed the free movement of patients from lower levels of care to higher levels of care without necessarily being officially referred with a letter, as discussed in section 1.4.3.1. Some participants managed to reach the rheumatology clinic faster than the others without being referred from the lower levels of care, and therefore did not experience 'going round the system', as discussed in chapter 6.

Similarly, links with family members and close friends who knew specialists led to some participants receiving recommendations to see these experts, as described below. The specialists then referred the participants on to rheumatology. For example:

'Members of the family had said that some of these symptoms could be due to something related to the heart. One of my relatives sent me to a cardiologist... It was now during this testing period that the cardiologist, having failed to find out what was going on, referred me to a rheumatologist.’ (ID 11, PRI)

Also, this participant (ID 11) had other economic and personal privileges like having medical insurance, a college degree, and he was a Nairobi resident which made his access to treatment less challenging. His privileged social connection and social relationships provided beneficial information which eventually facilitated his access to rheumatology care.

It was evident from the study that having access to social networks of friends and family was valuable because there was no representation of participants from some of the far-removed towns from Nairobi, as discussed in chapter 6. It is possible that individuals who have lupus in these towns lack access to privileged networks to link them with the formal health system and lupus treatment.

Some participants also received emotional/social support mainly from family members. Some participants were accompanied by their families when having tests and attending the clinics
for appointments with the doctor. This support was needed as some of them experienced lupus symptoms such as weakness and fatigue:

'We [participant and her mother] come by a matatu [public transport]. When we arrive, we go to Lancet laboratory. That is where we have been going for tests. From there we just slowly come [to the clinic] on foot.' (ID 18, PUB)

'She [her sister] takes me for the clinics whenever she is going for her duties, and I stay with her for the time I am here for treatment, or I can stay with my son and my daughter-in-law.' (ID 19, PUB)

These two participants were based in rural areas, so the practical support helped them to use the health services and also provided them with emotional support. One rheumatologist also pointed out that he encouraged his patients to be accompanied for doctors’ appointments so that the companions could also get some information regarding lupus:

'In fact, what I try to encourage the patients to do is that from the moment they are diagnosed it is better to come with somebody whom it is possible to consistently come with so that they can understand what is happening. This is because the information about lupus is not out there.' (ID 66, CL)

This was an attempt to empower the patient's significant others and enrich the type of social support they provided.

As mentioned in the previous section, some participants also received social support in the form of financial support from family members who could support them. This enabled them to meet their medical bills. For example:

'I even told my brother, “You have spent enough.” You have a family, mum is also there, and you have to take care of her. And now we have reached this far, and there is nothing that is being found. Let it be, but he never gave up... Financially [her brother supported her financially]. Yeah. All through.' (ID 08, PRI)

This participant received direct financial assistance from her sibling who, in addition, was accommodating her in his house even at the time of data collection. Another participant acknowledged that she could have died and said that she appreciated the financial support she received from family and other social networks within the community:

'... And I say that were it not for that support from the family and friends it would have been impossible. I think I would have died in the course of time, but I thank God for the support I have received from friends and family.' (ID 02, PRI)
From the two narratives, it was evident that the social links between the participants and their family members or contacts enabled them to receive financial support to offset their medical bills. In contrast, in some instances the social ties/networks did not lead to the desired social support:

'I have a brother, an elder brother .... I should not mention that ... who takes my sickness lightly. He hears that I am sickly but is not bothered. Maybe he is one of those who has decided that I am suffering from AIDS. I do not know. He has not offered me any significant help.' (ID 19, PUB)

From this narrative, it was evident that the participant expected to receive some form of social support and was unhappy that her brother did not support her. It also meant that the lack of social support might create misunderstanding among family members.

In contrast, some participants reported that they experienced less social support due to their limited abilities in performing their previous roles:

'I have also had the same problem with my in-laws... They expect you to carry out your responsibilities including extended responsibilities with no failure... You know sometimes the comments that you get... Moreover, they give you the same share of work. Not that I cannot work, but I am no longer myself. I am no longer what I used to be... There are those who look at you as a wife with responsibility. As a sister or as a daughter with responsibilities...' (ID 07, PRI)

This was also a cause of strained relationships as discussed in chapter 9.

In Africa, there is cultural expectations about kinship obligations such as staying with members of the extended family and offering material assistance to them especially when one is working while others are not (Siegel, 1996); and carrying out respective gender roles (Sudarkasa, 2005). Sigel suggests that some family members carry out these obligations with a mixed sense of dismay, scepticism and blameworthiness. From the study, it was also evident that some participants relied on cultural resources while others experienced cultural barriers, as discussed in the next section.

8.4 Cultural resources/Barriers

The third sub-category to emerge from the data was cultural resources. In the study, cultural resources referred to the level of education, general knowledge and linguistic skills which enabled some participants to gain access to information about lupus. The information changed
the illness perception for some patients and influenced their choices about how they managed their condition. There were also those who experienced cultural barriers which conversely influenced their illness perceptions.

8.4.1 Culturally resourced participants

It emerged that at the time of diagnosis, most patients lacked knowledge about lupus and the doctors provided some verbal information during consultation time. The lack of knowledge was confirmed by more than half of the patients. They indicated that they gained more knowledge on lupus and its management from various sources. For example:

'I did not think it (the disease) was genetic or anything... Later, I also took interest and went through the internet. Through that, I came to realise that I could have inherited it from someone who had it in our family. Maybe there was someone who had it, but they did not know.' (ID 09, PRI)

'It was the very first time. I did not know anything about it. That is when I started reading and found out that it was in the family of arthritis or rheumatism and it affected my immune system. That is when I started reading to understand this disease.' (ID 10, PRI)

From the narratives, it was evident that despite this group of participants initially having limited knowledge about lupus, due to being educated to college level and having access to other resources such as the internet, they took the initiative to seek information for themselves. This enabled them to understand some aspects of lupus, such as disease causation. It was also evident that this group of participants attended the private rheumatology clinic and were urban based. Access to reading material seemed to be an added advantage to having knowledge about lupus. The data also revealed that the information some participants obtained about lupus influenced their perceptions and conceptions:

'So, when reading about it is when I realised that actually in my family, auto-immune diseases are not rare. Reason being that my aunt, my mother’s elder sister, had a similar problem. But hers was not lupus. It was rheumatoid arthritis... So, despite all this, deep down I always felt that you know, I can lead a normal life. Moreover, I am always a positive person in nature (laughs). So, I can lead a normal life...’ (ID 06, PRI)

'The only thing I was worried about was my organs because when I actually sat down and read everything about lupus. I went to all sites and spoke to my cousin herself and she told me it is a manageable disease. The only reason people die from lupus is
because they do not know it is manageable. But if you find out early and manage it, you prevent more damage to your body.’ *(ID 20, PUB)*

The knowledge that some participants had early on during diagnosis period not only enabled them to understand the nature of the condition, but they also understood the management of the disease. This, in turn, enabled them to develop decision-making skills relating to the self-management of the condition (e.g. ID 08 and 11):

'... What followed was a bit of research on my part to sort of understand what lupus is. What are the symptoms? How would you be certain that you have it? What are the side effects of the medicines I was getting? One of the things I quickly picked up when I was doing that research was that while it is chronic, it is also very treatable and as long as you are constantly monitoring yourself, your life remains the same. You do not have special circumstances or things that you need to look out for.’ *(ID 11, PRI)*

'I am cautious when I go to a health facility that does not have doctors who know me or health officials who do not know me. I have to tell them very well, “This is what I have, and these are the drugs I take.” And this is what I expect.’ *(ID 08, PRI)*

The above narratives demonstrated that some participants had a privileged position due to both their literacy levels and access to online and written information, which enabled them to educate themselves about lupus and gain an understanding of the issues. Their literacy levels also equipped them with linguistic skills; they were able to ask relevant questions regarding their condition and express their expectations. They were also able to interact effectively with their rheumatologists and benefit from the clinic appointments.

**8.4.2. Cultural barriers**

By contrast, some participants faced cultural barriers such as having little informal knowledge due to the inaccessibility of other resources. For example, one participant (ID 12) who attends the public rheumatology clinic had very little knowledge about lupus and also expressed that she had never read about lupus:

'There is a time I was watching TV and a lupus patient - a lady - was brought on. That is when I knew what lupus is. How it eats a person. But let me say that I have not fully understood what it is. Why it eats a person’s body the way it does, why a person becomes so thin that it is as though only the bones remain... Yes, I have never understood at all’ *(ID 12, PUB)*
This participant was rural based even though she indicated that she had watched a patient who had lupus on television. Her use of language such as ‘why it [lupus] eats a person’s body’ demonstrated her limited knowledge about how lupus affects one’s body, even though she had had lupus for more than two years. She also had an O level education, which meant that she could read and write. However, it seemed that the information she got from the television was not adequate and she lacked access to written materials which she could have read to improve her knowledge. It also demonstrated that the information the participant received from the doctor at the rheumatology clinic was inadequate as it did not improve her knowledge. This is an observation echoed by one doctor who treats patients at the tertiary hospital:

'I think it is the challenge of educating them (patients). They need to be educated. However, you do not have adequate time to do so. You do not have time to explain to them what lupus is. That is one of the biggest challenges. The second challenge is unavailability of reading materials especially information leaflets, and that is one of my real challenges.' (ID 64, CL)

As acknowledged by the doctors, written reading materials were missing at the public rheumatology clinics. One participant (ID 13) self-medicating with prednisone, as discussed in section 8.2.2, and exhibited dangerous decision-making skills which may have been detrimental to her health. It was possible that besides experiencing economic challenges, she also had inadequate general knowledge about lupus medication and the side effects.

This study therefore established that the patients had differential access to cultural resources due to their literacy levels and the availability of other resources such as the internet and reading materials about lupus. This determined their understanding of lupus and the personal decisions they made regarding self-management.

8.5 Summary
This chapter discussed the resources that the participants drew on to ameliorate the treatment and care challenges they faced in managing their life with lupus. The resources were mainly in the form of economic, social and cultural. Most of them were externally sourced, and they varied in types, amount and quality. The resources were also unequally distributed among the participants, as later discussed in chapter 10. However, the majority of the patients had meagre resources.
The few participants who were well resourced had the financial ability mainly through the employer's medical insurance cover and family support. They were able to access care through the private rheumatology clinic and had a comparatively better experience of living with lupus. Those who were not well resourced financially, and had inadequate financial support from family to cover treatment costs accessed care from the public rheumatology clinic.

Social support/networks were beneficial to both the rural and urban participants, and to those who attended both public and private health facilities. The social support/networks were in the form of practical and tangible material aid from family and contacts which provided emotional support. Access to privileged networks facilitated access to financial resources in some cases and access to rheumatology services.

Access to cultural resources was an added advantage because it facilitated information seeking and understanding of the nature of the illness, which enabled some participants to make informed choices regarding their self-management. However, it is likely that there are people in Kenya who might not be accessing lupus care due to their constrained social, economic and cultural positions. Also, the socio-economic situation, for example, the cost sharing policies in Kenya, may also be affecting the most vulnerable groups such as those who cannot afford to pay for health services, leading to health inequity.
Chapter 9: A shadow of myself: The impact of living with lupus

9.1 Introduction

While the previous chapter highlighted the inequalities in the resources that individuals with lupus drew on to overcome the challenges of treatment and living with the condition, this chapter discusses how living with lupus affected the individuals’ lives under the heading ‘a shadow of myself’. ‘A shadow of myself’ was the category which emerged from the data and represents the consequences of living with lupus from the perspectives of the patients. During the discussions, it was clear that participants appraised their current lives. They also reflected on their lives before lupus and the hopes and dreams that the illness thwarted. ‘A shadow of myself’ was a phrase used by one participant (ID 07) to summarise her life. She described the disruptions she experienced and said that she saw herself as a different person from the person she used to be:

'There is no joy, you know?... Everything you are doing, you are thinking about the condition all the time. All the time you are thinking about it no matter how strong you have grown... I am no longer myself. I am no longer what I used to be. I am just a shadow of myself... So, even the close-knit immediate family, let me call it your husband and your children. The relationship changes. It does drastically...’ (ID 07, PRI)

This participant articulated the views of most of the other participants when she described being a shadow of herself. ‘A shadow of myself’ comprised of three sub-categories: loss of self, biographical disruption and biographical reconstruction.

9.2 Loss of self

The first sub-category that emerged from the data was loss of self, a phrase which Charmaz (1983) first used in her symbolic interactionist study of individuals with chronic illness. In the symbolic interactionist framework, personal identity is defined as “The person we think we are. It is the self we know” (Christiansen, 1999 p. 548). Identity is conceived as a means of defining what makes one unique from others, taking into consideration people’s preferred aspiration and plans for the future. In the study, all of the participants described experiencing negative physical changes, some of which were invisible while others were visible. The
physical changes affected their personal lives and body image, as described in the following sections.

9.2.1 Experiencing invisible symptoms

The invisible symptoms which some participants experienced included pain, fever, headache and feeling tired all the time, with pain and extreme fatigue being the most frequently mentioned. As highlighted in chapter 5, more than three-quarters of the participants reported experiencing pain in different parts of the body. For example:

FromString 2010 I became literally sick. I had some pains in the body all over. I started feeling pain in my bone... I was experiencing the real pain... I could feel a lot of pain... If it was the head, I would get even muscle pull. It would take me about a week experiencing a lot of pain... and then it would shift.' (ID 02, PRI)

The pain experience seemed to affect her day-to-day activities as she described that she had not been able to do anything. The pain seemed to last for long durations which made her suspend her teaching job.

Some participants also reported that the pain they were experiencing was also interfering with the quality of their sleep:

'I was feeling bad all the time. I was not sleeping well at night... If I turned on one side, I would keep awake because of pain. I would tell my daughter to massage my body. She would boil warm water at night for massaging me, but the massage did not work.' (ID 03, PRI)

While another participant reported that pain was interfering with both the quality of her sleep and her work:

'And at times you wake up with so much pain. You are willing to do something, but your body cannot let you do it. As much as my heart is willing, it is not easy. Because it is field work, I have to keep on moving around. But you see, because I am in pain, even if I meet a client, I will not give my best.' (ID 13, PUB).

The narrative of this participant indicated that the pain had no trigger because she would wake up in pain even before engaging in her daily activities. Also, the pain would limit the quality of her activities.
The body pain was closely associated with the experience of insomnia and feeling tired. About half of the participants spoke of having no strength due to a new sensation of feeling exhausted all the time:

'The first feeling I had was tiredness; extreme fatigue... the one that I really felt was this sort of fatigue that I could not account for... fatigue that came out of nowhere because I had always been a somewhat active person... Even though I had a hectic work schedule that feeling had never been there before.' (ID 11, PRI)

'... Go to work and believe you me... I could not do anything. Fatigue! All tired and my colleague would ask me: “It is early in the morning at ten, what is all this business about being tired?” For me, I thought it was the usual thing... Sometimes I want to do something, but I am unable to do it, I feel tired, I just feel that what I want to do is just rest...' (ID 07, PRI)

From the two narratives, it is evident that the tiredness experienced was new and intense. It seemed uncommon, abnormal, incapacitating and also unrelated to activity as it started in the morning. The participants acknowledged that fatigue frequently compromised their physical functioning and affected their work output. This certainly had an economic impact on the lives of this age group of young women, and increased their risk of work disability. The tiredness, therefore, seemed to concern not only them, but also those around them.

Some participants also felt that the stressful nature of their work also impacted on the severity of their symptoms:

'The changes are that sometimes I had a lot of chest pains. Whenever I did a lot of work, that night I must take painkillers because of the chest... The work I was doing meant standing all the time. If I went there at 5 am, I would stand all the time until 2 pm because it is a kitchen department and there was no chair. I thought that was why there was pain.' (ID 16, PUB)

ID 16’s account also indicated that she became aware that she was dependent on medications for pain relief. This was reflected in other participants' descriptions of the nature of the pain. They described the intensity in various ways like ‘a lot of pain’, ‘so much pain’, ‘pain all over’ and ‘experiencing the real pain’. This participant (ID 16) had stopped working by the time of data collection because she perceived that her job was worsening her symptoms.

There were participants whose lives were also affected generally and socially, by fatigue because they felt tired quickly, could not walk much, got easily irritated by people and were unable to carry out their house chores:
'I think it is harder for someone with lupus to go through the day as opposed to someone who does not have lupus because I get tired so fast, my joints are always having aches and pains, sometimes it is so bad that I cannot walk.' (ID 01, PRI)

'And then, there is lethargy - sometimes I get so tired such that I have to sleep. You are just tired; you have no pain. You are just tired and feel irritable!... You just want to sleep and no one to disturb you. So, it affects my life. Sometimes I cannot cook and have to tell my daughter, “Sort things out on your own today.”' (ID 14, PUB)

The immobilising effects of pain and fatigue are not unique to this study. Tench et al. (2000) also reported poor quality of sleep among 60% of the participants in their study, which was also related to pain. In this study, the experience of pain and fatigue also affected other areas of the participants’ lives – this will be discussed in more detail in section 9.3. The participants became aware of the activities they could no longer perform due to the life changing experience with the illness, which also made them perceive themselves as different from before. Other participants also reported their experience with changes in body appearance as described in the next section.

9.2.2 Changes in body image

The visible negative changes that participants experienced included weight loss or weight gain, hair loss from the head and rashes on the body. About a quarter of participants mentioned that they experienced weight loss. Additionally, about half of the participants reported having loss of appetite, while some participants spoke of having mouth sores. Some participants also reported negative reactions from other people:

'My weight started to reduce. It took about one year before I was diagnosed with lupus. Another thing is being unable to eat. When I eat, I vomit. That is another challenge. In fact, I feel that I cannot go anywhere because when people are enjoying all sorts of food, I get full after just about five spoonfuls... You hear people saying I have HIV... That is because of the way I appear. Again, they know that I looked different before.' (ID 12, PUB)

Most participants who had lost weight were unhappy with their body image and found talking about it very distressing as they emphasised how much the weight loss had changed their outward appearance and threatened their femininity:

'So, why I am telling you this is that sometimes it is so bad; your clothes cannot fit you, now you are changing them, and for ladies, you know how we treasure clothes. That in itself brings you down; it really brings you down.... Clothing, even the way you
look at yourself, like when you are so thin, and your eyes are popping out you know, it is not nice especially when you used to being a vibrant person... moreover, everybody is thinking it could be HIV.' (ID 07, PRI)

These participants seemed to suggest that their social contacts associated their weight loss with having HIV infection. Weight loss is an early sign of HIV infection due to increased metabolism and malabsorption (Mangili et al., 2006; Wanke et al., 2000). In this study, coping with weight loss was often not easy as some participants admitted that the negative body image depressed them and they stopped socialising and preferred not to go out. One participant expressed this:

'It is about being taken out for a walk - they [her sisters] take me with them whenever they go somewhere. However, I usually don’t like it. If it is a place where I am likely to see my friends, I do not like it.’ (ID 12, PUB)

The findings in the study about body image concerns corroborated with findings in other studies of individuals with lupus (Hale et al., 2014; Jolly et al., 2012). However, in contrast, the concern in those studies was weight gain due to steroid use and not weight loss. This was in societies where being slim is associated with femininity. In this study, the few participants who experienced weight gain also felt that they had become more visible in a way that they did not desire, but appreciated the support they received:

'Some people love me regardless of what I am. I have very close friends who have been very supportive. They are here in Nairobi... They do not mind even if am walking with them. There was a time I was 3 times my size, I was wearing free dress, and I was not pregnant. So, they are not uncomfortable that am that way I am and that has helped me to cope.’ (ID 02, PRI)

When living with lupus, it is possible for individuals to experience weight gain or weight loss. However, weight loss is not unique to lupus and HIV. Weight loss is also associated with other chronic conditions like cancers (Bosaeus et al., 2001; Khal et al., 2005).

Besides experiencing weight gain or loss, having skin rashes was also a major contributor to the participants’ negative views of their changed body image. Skin rashes were reported by slightly less than half of the participants, and the affected individuals realised that there was a change in their former self-image:

'I started getting a velvety, dark kind of rash over here [pointing across the face]. The butterfly rash had occurred so when I went to the office, one guy told me “... just go to the hospital. This looks really bad.”' (ID 10, PRI)
About a quarter of the participants reported experiencing hair loss as a visible symptom which also affected their body image:

'... I was fairly weak, had lost a lot of weight and most of the family was concerned... By that time the hair loss had also started.' (ID 11, PRI)

The narratives confirmed that the changed body image due to weight loss, hair loss and skin rashes made the individuals with lupus feel different compared to their previous physical appearance. The narratives also indicated that the comments made by other people in the participants’ lives reinforced their awareness of the changes in their appearance. For example, ID 10’s work colleague plainly told her that her rash looked bad: ‘… just go to the hospital. This looks really bad’.

Berneis et al. (2000), Bosaeus et al. (2001) and Khal et al. (2005) argue that the changed body in chronic illness draws out body imperfections and unwanted attention from the public which can result in loss of body pleasure, as was evident in this study. Corbin (2003) also indicates that in chronic illness, the body can give rise to new sensations or the body can acquire new appearance, as also described in this study. She asserts that what happens to the physical body also affects the individuals emotionally. The findings therefore established that lupus caused physical bodily changes in the individuals, some of which were visible while others were not. The study also established that the participants were emotionally affected, as discussed in the next section.

9.2.3 Emotional distress

Some participants described feeling anxious and depressed by using words like ‘I am emotionally distressed’, ‘feeling very depressed’ and ‘very worried’. These were new feelings which were associated with various factors such as the effects of the illness, stressful life events and a lack of social support.

The effects of illness which caused emotional distress to some participants included: changed physical appearance, loss of health, fear of death and side effects of some lupus medications. Some participants also received both verbal reactions (as illustrated in section 9.2.2) and non-verbal reactions regarding their changed physical appearance from people whenever they came into contact with them:
'... Sometimes you have the butterfly rash, and it is so bad, and you know, you see people looking at you, and of course giving you all sorts of labels. They are not talking about it, but you can physically see from their facial expressions - you can really gather a lot. I had lost so much weight. My clothes are not fitting me, and I am emotionally distressed...' (ID 07, PRI)

This narrative illustrates that the changed physical appearance was stressful to the participant because of the responses her changed appearance elicited. She experienced loss of self-esteem and impaired self-image. Loss of health was also a reality for some participants and was mainly related to the unending sickness and the consequential dependence on other people as a result of activity limitations imposed on them by the illness. For example:

'I started feeling very depressed because I was always sick. I was always unwell, and it brought me down quite a lot.' (ID 10, PRI)

'I was worried because I used to do things for myself. But since I was in pain I did not know who would do them for me. I did not even have parents. At that time I was very worried. In fact, when I remember that time, I start to cry because there are times I would even try to wash the house but fail to.' (ID 12, PUB)

This participant (ID 12) was worried about her inability to do things which she used to do for herself before the illness. While one participant mentioned that she was concerned that people did not understand what she felt because she looked okay:

'Another worry was that people could not understand what I was feeling because at times I would look just okay. But I could not even stretch my hands, and nobody would know. At times, even my family could not believe me. When I told my husband that I was not well, he would say, "you do not look sick". But when it attacks especially the feet joints, it is very painful and uncomfortable. Yet nobody can know unless I express it.' (ID 14, PUB)

On the other hand, some participants were anxious because of fear of death. Fear of losing their life was due to their misunderstanding of the nature of lupus. They initially thought that lupus was a terminal illness which was going to lead to their death. The following vignette of one participant (ID 17) illustrates how after diagnosis she thought she was dying, and how this negatively affected how she related with people who were close to her:

'I knew I was dying. So, I used to only read the last stage of lupus.... I did not want them to get close to me since I would die anyway. It would be bad if they got used to me, and then I left them. I even left the guy. We ended that relationship, and I went and told my sister about the disease... I used to check for nephritis. So, every night, I used to do it by manual palpation. I used to examine my kidneys to see if they are okay. I also used to pray and tell God, “Why did you choose me? Why do you want me to
struggle this much and then die?” ...So, there was that issue of death.... I just wanted to be alone.’ (ID 17, PUB)

However, when her general condition improved while on lupus medication, her attitude also changed positively:

'... I am happy. As much as there was that initial acceptance of the disease and the others, I became strong and even started performing better in school. In fact, in third year, I performed well because I was gaining strength to read for a longer time. Even in fourth year, I did well. Although I have not checked the results, I did well. When I am on medication, even if it is burdensome to take them, I feel strong, like you can find me awake at ten pm. You know, people used to beg me to reach even eight-thirty pm.' (ID 17, PUB)

This participant (ID 17) attributed her improvement and her changed positive attitude towards the condition to the benefits of medication, though she still experienced periods of having to put on a 'brave face' in public and periods of being emotional:

'I discovered that I could present this good Ivy [pseudonym], then when I am alone I talk to myself and cry a lot over my issues.' (ID 17, PUB)

In contrast, other factors such as stressful life occurrences and the lack of social support from significant others also exacerbated some participants' distress about their condition. For example, one participant had the responsibility of taking care of her sisters' children under perceived difficult circumstances when her sisters died:

'But the worst thing is the children were left with me. My father was not working at that time, and all the children were left there. All my sisters went [died]. Although I am the fourth-born in a family of five, I was left alone. I felt the situation was like a big mountain. How would I care for those children? At that time, I went to a counsellor and told her about my condition. I told her that I wanted to go very far and forget about home or if I found an alternative I could die.' (ID 16, PUB)

This was quite an overwhelming experience for her. Another participant (ID 13) described that she was very depressed because of marked life adversity coupled with a lack of social support. She even felt suicidal:

'I was being frustrated because I didn’t have any penny, whoever I went to disowned me... No one was willing to support me emotionally or even financially... I did not have friend; I did not have relatives. They had turned their back on me.' (ID 13, PUB)
'... I remember well that was December 2009. I was just seated in that room feeling stressed up. It is 23rd December, Christmas is about, and I do not even have a penny to buy food. I do not have food, I do not have medication, I am sick, and I am alone. So, I said, “Why don’t I buy some rat and rat [rat poison] and mix it?” I went to the shop and bought it because I was like “If I give it to my son and take it too, and die, at least this suffering will end.”' (ID 13, PUB)

The cause of emotional distress in lupus remains unclear but is linked to social stress, lack of social support, daily stressors or the effects of treatment (Kozora et al., 2005; Nishimura et al., 2015). In this study, the findings established that emotional distress was linked to unpleasant symptoms and similarly, to social stresses and a lack of social support. Charmaz (1983) points out that in chronic illness, individuals develop a consuming consciousness of their illness circumstances as they lose the ability to minimise their physical condition. In this study, the impact of changed physical condition associated with the interference to physical and social activities and the impact of emotional distress caused disruption in various areas of the participants' lives, as discussed in the next section.

9.3 Biographical disruption

The second sub-category that emerged has been termed 'biographical disruption', a concept first described by Bury (1982) as discussed in section 1.3.4. and later in section 10.6. This sub-category fits the data because it summarises the descriptions the participants used to express the extent to which they experienced lupus as biographically disruptive to their formerly organised lives and relationships. This study consisted of a relatively young population with the majority of them being between 21-40 years. Participants described disruptions in their work, career, finances, family and social relationships including their marital lives, making Bury’s concept of biographical disruption relevant.

9.3.1 Disrupted work, career and finances

In the study, some participants described having functional impairment related to their ability to perform daily household or workplace tasks, as already discussed in section 9.2.1. Joint pains together with feeling weak seemed to be the major hindrances to performing tasks:

'... I have become weak. I have become very weak. There are some things I used to do that I cannot do anymore. I would go to the market and buy even four duvets and carry
them myself. But now, sometimes I get to a point where I cannot even open a water bottle or peel off a tangerine. I cannot flush the toilet; I cannot open locks. It has changed my life …' (ID 20, PUB)

Some participants also expressed the belief that their pain would be aggravated by performing some house tasks:

'There is some work I cannot do. Like clothes, I get to wash just a few. Whenever I wash the much I used to, the following day I cannot even stretch these hands because of pain.' (ID 14, PUB)

These participants became aware that their level of doing things was greatly diminished compared to the past. They had to make decisions regarding what activities they could perform which was restricting their lives. It was noteworthy that the tasks the women highlighted as not being able to perform were female gender related chores in the traditional African context, such as going to the market and washing clothes. One participant’s husband pointed out his wife’s inability to cook, which is also a traditional female role:

'Just to remind her to say something. She is a very good wife in terms of going to the kitchen, and she cooks well, but I think it has taken quite a while for her to be able to go to the kitchen and be able to cook something for us. So, we can only now be comfortable with what our house help would do.' (ID 02’s Husband, PRI)

The participant responded with a "Ya" to the husbands remarks, indicating that she acknowledged that she had not been cooking. This meant that making family meals was viewed as a female role, so someone else (another female) stepped in to fill the wife’s cooking role. Having lupus also affected the performance of some participants’ paid employment. For example, one participant indicated:

'Like now, whatever I do is more of fieldwork. At times my legs can be so painful that even walking is hard. I cannot manage to walk because of the pain. Now, do you see that it affects my performance? ' (ID 13, PUB)

This participant became aware that she could no longer perform her work well as an insurance sales person, which also affected her income.

Another participant described how having lupus caused a strained relationship with her employer:

'They feel I’m too weak to work. I’m a person in the public-relations department, I need to move about. But I’m fighting them about it…. I went straight to HR. It was a
very big case because she went ahead and failed to renew my contract which expired last month. And I told them I was not signing any exit form because of being sick... I said, “Let it be because of another cause and if you want me to exit from the bank because I’m unwell, there is a process. Pay me and I’ll go.”' (ID 20, PUB)

Some participants also felt that having lupus had disrupted their career, scholastic dreams and hopes, as illustrated by the vignettes of two women (ID 02 and ID 07) below:

'Am a teacher by profession, but from 2011, I must be very frank but it is quite risk to say it... my headmaster as I began, he said he would help me because he said I had a real problem and from then up to date I have not gone to work. He allowed me to stay away until am well...Writing on the chalk board is a problem. I can do it for one second then my hand refuses. I will not stand for a long time. I cannot sit here for a long time, it is a problem. So even when I am going to work am only seen but I do nothing. So, I must confess that my career is hanging between life and death, but I thank God that that gentleman has been supportive. I had thought that I would go back to school because I wanted to further my studies. Inside me I had a dream that by the time I am 40 I want to have done my masters but that is not feasible. So, there are changes in my life.' (ID 02, PRI)

'... earlier on I was a scholar, you know, with a very bright career and hoping that things will run straight and now that you are at the height of your career, this is the time. But at that point, I was diagnosed with this condition. And that brought my world crumbling... That even thinking about the future has not been part of my thinking. It is something that probably I would have thought about with a healthy mind and everything... So, it has slowed me down. Number two, I used to be a prolific writer. Now, I only do one paper in an academic year, which is very bad... Research work I am no longer interested… I do very little.' (ID 07, PRI)

'... Supervising, my students’ theses are there, I am looking at them and I am feeling very bad... Because physically I am unable to you know, move... When it comes to papers now I sit down and I am so tired. I am feeling tired emotionally all through, and at the same time, there is that feeling that I am failing my students because I am not doing my work... And many times I have contemplated, and I have asked myself, do I have to continue working? But it has also led me to think about my retirement, that I don’t have to wait... I need to think about my exit plan... So, right now what is in my mind is my exit plan.' (ID 07, PRI)

Both women described their shattered dreams of scholastic achievement and career growth due to the physical limitations associated with reduced energy and pain. ID 02 was not working at the time of data collection and also felt that she could not further her education as yet. ID 07 was still in employment but not able to perform her tasks and scholarly work as desired, instead she was considering early retirement. The possibility of transitioning out of employment due to a combination of physical job demands and high psychological job
demands is consistent with the findings in other studies among individuals with lupus (Yelin et al., 2007) and rheumatoid arthritis (Sokka and Pincus, 2001; Verstappen et al., 2004).

Having lupus also seemed to have worsened the financial status of some participants due to expensive healthcare costs and their compromised ability to engage in paid work. Some participants had already used their family finances to meet the huge medical bills, which meant that they had run out of family finances:

'Ya. It had such impact, because we had already spent a lot. We had taken some loans, and eventually we had to have a fundraising. So, part of that helped us to fund my treatment until again this year, we started feeling the pinch because drugs are very expensive... we spend quite a good amount which in our state is not affordable... You run out of money, but we thank God we have managed.' (ID 02, PRI)

This particular participant had been disappointed by the healthcare in the public hospitals and changed to private healthcare. She was not on medical insurance and her family was meeting all her medical bills. This meant that they needed to mobilise more resources to meet her financial obligations. By contrast, ID 07 felt that her financial strains were as a result of her inability to continue with part-time employment to improve her family’s financial status:

'... So, I feel that if I didn’t have this condition, I probably would have made progress... even in terms of my economic status I would probably be better... Okay, initially it would be possible for me to teach. I teach at the university, and I also teach in one of the private universities. Now, I don’t have that kind of energy. Even if I take a class, it is only out of the respect I have for the institution... Otherwise, I wouldn’t bother.' (ID 07, PRI)

The study therefore established that having lupus significantly impacted on household and workplace responsibilities, and scholastic activities. It also negatively affected the participants’ financial situation. Some participants also commented on how having lupus reduced their capacity to participate in family life, as described in the next section.

9.3.2 Disrupted marital life and parenthood

Having lupus also seemed to have led to strained marital relationships among some participants, because either the participants avoided being intimate with their partners or decided to 'put up with it'. For example:
'… Although you haven’t asked me, lupus affects your intimate relationship with your husband seriously because you are always cagey. Today it’s the back, tomorrow it’s another thing. People don’t even understand, they think you are always complaining… So, one, it affects your intimacy with your husband seriously. You no longer have any joy in anything. At the end that strains the relationship… And so, you have to put a lot of effort in everything because sometimes you really don’t want to be intimate. And it is not your wish.’ (ID 07, PRI)

In the narrative, the participant’s use of the words "and so you have to put a lot of effort in everything" brings out the subordinate role of women in marital relationships, and the difficulty they have in making decisions. Pallitto and O’Campo (2005) and Smith (1990) affirm that societies dominated by patriarchal institutions have unequal power relations between the genders with women lacking status and power. In this study, it was also established that about three quarters of the participants were single with only one of them stating that she had been married before and got divorced. She expressed that having lupus was the primary cause of her divorce:

'… I was married to someone at that time. This person did not show any interest or any concern for what I was going through… when I told my husband that I had lupus, he cheated on me with someone else, and he walked out on the relationship, leaving me alone. So, I became single.’ (ID 13, PUB)

Isenberg et al. (2008) established in their study that the divorce rate was high with half of the newly diagnosed female participants with lupus having undergone divorce within five years of the marriage. However, the sample size for this study was too small to make any inferences regarding divorce rate/singleness. Nevertheless, there was evidence suggesting that in Kenya, having lupus was a barrier to marriage and parenthood, as articulated by some participants:

'I am not sure a man would understand a woman popping pills on a daily basis.' (ID 10, PRI)

'Yeah. In fact, when I meet someone, I tell them, “You are just getting yourself into a burden. This is a sick person. If you are willing to take me to the clinic and stay for three hours there” … In fact, I just shut them down from there. I just don’t want to be in that relationship’. (ID 17, PUB)

ID 17 discouraged the start of relationships by pushing away those who showed interest in her. She saw her illness as a barrier, yet this could have been a way of being very realistic about the possible effects of lupus on marital life. There were those who also seemed to have either postponed marriage or having a family:
‘... Let me say... there is a time I wanted to get married, but when I fell sick, I lost interest completely.' (ID 12, PUB)

'The only other thing that I wish I could do but I cannot is, say, to have children. I would like my daughter to have a brother or a sister. However, I cannot have children due to the medication that I take. Most of the medications come with guidelines.' (ID 10, PRI)

From the narratives, it is evident that getting married or having children was an issue that some participants dealt with. They were either doubtful about getting married and having children because of the unknown consequences, or they seemed to have made a decision against getting married due to their condition. Having lupus made them more uncertain about planning for their future.

9.3.3 Disrupted relationships

Disrupted relationships were also mentioned regarding family and other social relationships. More than half of the participants indicated that their illness caused deterioration in their family relationships. For some, the precarious financial situation was the source of the strained relationship:

‘... He [husband] had left in the morning; I was thinking that he was coming back. I waited for him in vain until ten o’clock. So, I knew he had already gone and switched off his phone. I called my brother and borrowed five hundred shilling from him.’ (ID 05, PUB)

Two other participants expressed how they were not playing their parental role as they should have. For example:

‘... Of course, rearing of my children. The whole of last year, I literally did nothing to my children. The way the child comes, you want to hold them and I cannot. My last born is five now; she turned five last April. The way children want to be happy with their mother; I cannot be happy with them... As far as the area of rearing my children, I feel I have been quite inadequate.’ (ID 02, PRI)

The findings also revealed that there were participants who were avoiding getting into relationships due to their fears and due to their past experiences:

‘Yeah. It has affected how I relate to people. I just don’t want people to be close to me. I feel like when they find out they are going to reject me...’ (ID 17, PUB)
'Even socially there are friends I used to see, and yet when I hear they want to be somewhere, I do not want to go... I don’t want to meet them because what am I going to discuss with them? ... There is no news. So, socially, it also affects you. It has affected me and that is my greatest problem... My problem, my greatest challenge has to do with my social relationships... You think the world is beaming you. You think everybody knows what you are going through, right? ... They are not talking about you! ... But on the other hand, some will think you are normal, and you should stop pretending. You know what I mean.' (ID 07, PRI)

This group of participants seemed to acknowledge their role in the strained relationships and the resulting constrained lives and social isolation. The participant (ID 07) feared to get into a relationship because of the experience she had with her friends before.

On the whole, having lupus disrupted various aspects of the participants' day-to-day activities, especially regarding paid work which affected their finances. It also impacted their house work, family life and social relationships. However, despite the disrupted biographies, it was also evident that some participants made decisions regarding regaining aspects of their former lives as discussed in the next section.

9.4 Biographical reconstruction

The previous section outlined the impact of lupus on the individuals. The effects were mainly on the participants’ functioning in daily life due to their bodily changes. This section discusses how some participants attempted to manage their lives with lupus. Williams (1993) describes biographical reconstruction as the pursuit of a positive self-worth in the public domain. On the other hand, Whitehead (2006) states that identity reconstruction is an attempt to return to aspects of the former self. He further states that there are three types of possible identity outcomes: (1) disabled identity as the total self, (2) disabled identity as part of the total self and (3) supernormal identity, all of which are seen to follow a trajectory. The 'disabled identity' represents the acute phase during which individuals experience the initial inability to function. The 'disabled identity representing part of the total self' is the medium term when individuals attempt to regain aspects of their former self. The 'supernormal identity' represents the positive identity in the long run when individuals develop a new self which they perceive as a better self. Whitehead (2006) asserts that if achieved in the long term, then identity reconstruction can lead to positive outcomes for people with chronic illness.
In this study, it was evident that most participants were in the second phase of reconstruction. Participants managed to make changes in various aspects of their lives. Some participants accepted their diagnosis and thus made efforts to learn more about the illness, took their medications, enhanced their changed appearance and paced out their activities. One participant's self-image was affected because she was using a walking stick and could no longer wear high-heeled shoes. She expressed how she once felt that she was treated with contempt by people. However, she decided to make herself feel happy by improving her self-image and ignoring peoples' attitudes:

'I choose to live even when people expected me to die. So, I feel I have been able to manage because I am well. I am happy. You see me wearing bangles because I want to make myself happy. I want to feel good... I want to be happy about the way I look, because at least I have been left with the face and the head that is not a problem... I tell him [husband] I want a perfume; I want to smell good because that is what I have left. So, I want to seize that opportunity that is positive and be happy about it. So even when I am sick, I will call a hair salonist to my house to help me feel beautiful. At least when I look at myself in the mirror, I like what I see and am happy, and that is how I have managed.' (ID 02, PRI)

While another patient, who was a health practitioner, decided to concentrate on improving interpersonal relationships:

'Okay. Positively, when I am clerking patients in the ward, I find myself associating with them so much. I find myself wanting to know more, wanting to help even if it is not lupus. I just want to listen and to be there because I once told people I was in pain. I told people I was tired, but they did not understand me. I am not blaming them, but they are also human beings. It has affected me that way... I want to encourage, hold and tell them it will be okay... lupus has opened my eyes... now I seriously sit down and read so that I can help someone else. Therefore, it has given me so many ways of seeing life.' (ID 17, PUB)

The narratives of these two participants fit with Whitehead's (2006) typology of 'disabled identity as part of the total self'. In contrast, another participant remained bitter throughout her illness period:

'You know, I must cope with life. But if I had another lifetime to struggle, I would ask God, “why cannot you make it shorter?”' (ID 16, PUB)

This participant does not fit in Whitehead's typology of reconstruction because, in spite of not being in the acute stage, she had not quite moved to the medium-term phase. The difference between this participant and the previous two participants were their financial and social
circumstances and the availability of social support. For instance, ID 02 sought treatment at the private clinic, was always accompanied by her husband to the clinic, and had medication even though she had not gone back to paid employment; she also still received her salary. However, ID 16 was struggling for everything because she had a 70-year-old father who was not working, both her mother and two sisters had died and left her with two orphans to support. Additionally, she was a casual labourer which meant that her work was not consistent. She attended the public clinic and sometimes went without medication due to poverty.

On the other hand, two other participants indicated that they manage to cope with the illness by pacing their daily activities at their work place. One received support from work colleagues who understood her condition. As she was a support worker, whenever she was tired, she informed them. However, she indicated that some work colleagues understood her condition while others did not:

'There are those who saw me when I was sick. If they see me seated and resting after I have done my duty at work, they will ask, “Are you unwell?” Because they know where I have come from... But now, those who came after I had started feeling better wouldn’t know how I was feeling. They cannot tell if I am unwell or not. Or even what problem I have, they cannot tell. For them, they are probably thinking, “What has she done since morning? She just came, swept this place only and now she says she is tired.”' (ID 03, PRI)

Another participant indicated that she avoided overworking herself:

'Yeah. I avoid pushing myself so hard because when I do, the next day I become very unproductive. So, I would rather do something today within my energy limits, so that I can finish it up tomorrow. That way, I can be productive every day. I try to make myself productive every day, not that today I am overactive then tomorrow I am down because of pushing myself.' (ID 20, PUB)

Yet another participant (ID 11, PRI) stated that he monitors his body closely:

'Before, I would never have been concerned with such things like listening to my body. That when something is off, you instantly say, “I need to monitor this.” When I was young, whenever I got sick, I would just say, “This will go away.” I would brush it off. Maybe I would go on with my work and say, “Should things get bad then I will go and see the doctor”. But now you find that when something is off, almost immediately I say maybe this needs to be watched, possibly even informing the doctor that, “Okay, I am not sick, I do not need to see you, but there is something we may need just to monitor.” So at least regarding personal healthcare, my attitude has changed.' (ID 11, PRI)
These participants discovered what worked for them and gained a sense of coping with the illness. They focused on what was within their power to control, thus they were able to break down their tasks to limit physical exertion. All three participants managed to stay in full-time paid employment and also acknowledged that they had to pay attention to their health. ID 11 and ID 20 were more educated and had read and gained much information on lupus for themselves. Other participants also focused on becoming more knowledgeable about their condition (ID 03, 04, 06, 08 and 10) and taking their medications (ID 03, 08, 10 and 17) when they realised the benefits of the medication. Others also drew on emotional support from their families and friends (ID 02, 04, 06, 11, and 12). Thus, they were all in the second phase of Whitehead's (2006) typology of identity reconstruction.

In contrast, some participants (for instance, ID 07 and 12) were still not able to project a positive sense of self because of their responsibilities and other social circumstances. For example:

*The amount of work that I do, sometimes I feel like I just want to resign, forget about it and move on... the pressure works on my body, and I feel it instigates a process where you get all those symptoms of aches and what have you... My husband had been actually out of job when I got sick. So, meaning even I was playing two roles, the role of a mother and the role of a father. Moreover, my children have been to private university and private girls' school, and you know how expensive they are....I deal with my issues and bills on your own ’ (ID 07, PRI)

The physical effects of the illness and the experiences of unstable economic and social resources were weighing on ID 07. The decision about whether or not to remain in paid employment was also of concern to her. The significance of economic resources in meeting the cost of lupus care and the importance of social support are described in section 8.2 and 8.3. It was therefore evident that ID 07's circumstances negatively affected her attempts to reconstruction.

Also, a few participants, especially those attending the public clinic, seemed to have held the illness experience as entirely negative and were unable to project a positive self-worth. For example:

*Personally, I feel very negative about life. Very negative [with emphasis]. But now, I don't have an alternative. So, I cannot help but accept it the way it is. But it is negative.’ (ID 12, PUB)
This group of participants remained highly disrupted and appeared unable to reinvent themselves. ID 12 expressed feeling hopeless about her situation. The difference that was observed between these participants and some of the others who had achieved some level of biographical reconstruction was that they had relatively limited economic, social and cultural resources which were established as significant resources in managing life with lupus. For example, as illustrated in Table 6.5, ID 12 who had an 'O' level of education was previously a self-employed tailor who currently relied wholly on her family and was also still looking quite unwell. ID 16 also had 'O' level of education, was not currently employed but supposed to be the main breadwinner in her nuclear family despite her medical and financial circumstances. In addition, both participants had no medical insurance. Thus they both experienced low level of education, had previously worked in manual occupations, and experienced more financial difficulties together with minimal social support.

The findings established that biographical reconstruction is a personal process which meant different things to different participants. The changes in body image were no longer a focus for some participants, while for others being faithful to medication taking and pacing their activities was the focus. The findings also established that there was not much evidence of biographical reconstruction in the areas of disrupted marital life, parenthood and other social relationships.

9.5 Summary
This chapter exemplified participants’ perceptions about the impact of lupus on their lives. The chapter highlighted that lupus was a devastating condition which imposed many losses on the individual’s identity, and exposed the individual to the experience of biographical disruption. This was mainly due to the experience of pain and fatigue which consequently prevented them from performing their daily chores in various ways. Thus, most of them felt that their self-identity was not a representation of what they had always been or what they had aspired to be.

The study also established that individuals with lupus were at risk of experiencing emotional distress due to the effects of illness on their bodies and the uncertainty regarding the outcome of their condition. Emotional distress was also caused by stressful life events and the lack of financial, emotional and physical support. The impact of living with lupus was perceived
negatively by most participants. However, varying levels of biographical reconstruction were indicated by some participants.

Even though none of the participants demonstrated full biographical reconstruction, it was evident that the participants were not passive in their illness experience. They worked at mending the disruptions in their personal lives, although reconstruction of finances and social lives remained a challenge. There is evidence to suggest that their unfavourable life circumstances were the main barrier to biographical reconstruction
Chapter 10: Discussion and conclusions

10.1 Introduction

This study explored the perspectives of individuals with lupus and their doctors' perspectives on living with lupus. A review of previously published studies indicated a gap in evidence from Africa on this topic. Thus, the findings of the study add to the body of knowledge about experiences and perspectives of those living with lupus, providing novel insights from a Kenyan perspective. The findings may also potentially inform strategies for improving experiences of individuals living with lupus in Kenya.

Analysis of the data generated five related categories: 1) naming the illness; 2) going round the system; 3) cultural beliefs, practices and prejudices; 4) resources for managing life with lupus; 5) a shadow of myself, as presented in chapters 5, 6, 7, 8 and 9. The five categories provided an understanding of living with the condition in Kenya. The following sections discuss key issues and concepts that emerged from the study in relation to the categories.

10.2 Navigating healthcare

This section discusses patients' experiences with accessing treatment and care during pre-diagnosis, diagnosis and post-diagnosis phases of their illness (naming the illness and going round the system). The pre-diagnosis phase was mainly characterised by delayed help-seeking and the experience of delayed lupus diagnosis for some patients. The challenge of delayed diagnosis was related to deficiencies in clinicians' skills, deficient resources and the structure of Kenyan health services. In contrast, post-diagnosis phase was characterised by treatment related challenges. Treatment process was largely influenced by Kenyan health service organisation which led to an unclear care pathway for lupus patients and inaccessibility of lupus services.

During the pre-diagnosis phase, most patients reported experiencing painful joints, fatigue, fever, loss of appetite, skin rash and general malaise, as illustrated in Table 4.2 in chapter four. Findings from this study suggested that when symptoms began to negatively impact on patients' everyday activities, they decided to seek formal medical help. So, the main trigger for help-seeking was the functional impact of the illness on activities of daily living (ADLs). This finding implied delays in initial help-seeking which could suggest that at the time of diagnosis,
some participants already had significant damage, possibly including kidney disease which was also reported in this study.

Delayed help-seeking has similarly been reported as a significant finding among lupus patients in South Africa (Wadee et al., 2007) and among patients with arthritis and lupus in some European studies with negative health outcomes (Oglesby et al., 2014; Stack et al., 2012; Townsend et al., 2013; Townsend et al., 2014). Factors that were postulated as likely contributors to delayed help-seeking in South Africa included inadequacies of health services, cost of travel to distant health facilities and health beliefs like presumed cause of illness (Wadee et al., 2007). Similarly, in European studies, delayed help-seeking was attributed to the nature and interpretation of symptoms by patients. In contrast, some patients also consulted with others and used over-the-counter medications before or instead of seeking formal medical care (Stack et al., 2012; Townsend et al., 2013). In this study, both clinicians and patients observed that there was a general lack of awareness of lupus, however, the sample size for this study was too small to establish the factors that could have contributed to delayed help-seeking. Some data in the study vaguely indicated that taking invisible symptoms of lupus for granted like fatigue could have contributed, especially when they were still not impacting on patients' ADLs. Nevertheless, contributing factors to delayed help-seeking in the Kenyan context would need confirming in future work. There is also a need to develop effective interventions that can raise public awareness of lupus, with the hope of encouraging those with lupus-like symptoms to seek medical attention. Public awareness campaigns carried out by formal lupus support organisations have been found to be beneficial in improving awareness of lupus in the general population in countries like UK and Ireland (Brennan and Creaven, 2016; Corcoran and Wall, 2000).

Most patients also reported that when they visited health facilities they experienced diagnostic delays, which was referred to in this study as the challenge of 'naming the illness'. Patients indicated that they underwent several investigations which came back as normal. Some also described how they were treated without improvement for other conditions such as malaria, typhoid and pneumonia, which are common in Kenya (Institute of Health Metrics and Evaluation, 2010). These findings suggested diagnostic challenges.
This study revealed two diagnostic challenges unique to Kenya as narrated by the doctors who were interviewed. The first challenge was related to shortage of skilled doctors both in the primary and secondary health facilities, in both the public and private facilities. According to the doctors interviewed, lupus was often mistakenly diagnosed as a range of conditions common in Kenya, which it mimicked. The doctors suggested that this was especially likely to happen outside Nairobi with resultant frustration of seeing patients who had experienced delayed referral to the tertiary hospital. Interviews with patients corroborated this, as patients also reported having been treated for conditions other than lupus and finding themselves ‘going round the system’ or getting a late lupus diagnosis.

Nevertheless, literature indicates that lupus shares some symptoms with other infections and tropical diseases, such as fever, fatigue, weight loss and chest symptoms (Bhutta and Dewraj, 2006; Hlongwana et al., 2009; Stern et al., 1995; Storla et al., 2008). Fever is the most commonly confusing symptom. The findings suggested that there were deficiencies in how patients with recurring and persistent symptoms suggestive of lupus were assessed, thus illuminating the need to improve knowledge and diagnostic skills of primary and secondary care clinicians.

The second diagnostic challenge was related to lack of resources. The doctors' interviews revealed a lack of resources mainly in the primary and secondary health facilities, in terms of the required laboratory equipment and personnel. This was closely related to the structure of Kenyan health services (Ministry of Health, 1994) which placed rheumatology clinics and specialised laboratories centrally in Nairobi, where tertiary hospitals were located. For example, the four rheumatologists in Kenya were all based at the referral hospital in Nairobi, while 80% of the Kenyan population live in the rural and remote areas (Kenya National Bureau of Statistics, 2010). This is a problem referred to as the inverse care law, which states that “the availability of good medical care tends to vary inversely with the need for it in the population served” (Hart, 1971 p. 405). Thus, those who need medical care are least likely to receive it. Diagnostic challenge was also closely related to the limited health funding for public health facilities in a resource-limited country such as Kenya (Adano, 2008; Ensor and Ronoh, 2005). Findings in this study therefore established that the doctors believed that it was impossible for patients to have appropriate lupus tests and receive a diagnosis in outlying
facilities with limited human and non-human resources. This raises the need to evaluate the necessity for, and distribution of, rheumatology resources and services in Kenya.

Some participants in other studies have also reported diagnostic delays (Goodman et al., 2005; Hale et al., 2006a; Mendelson, 2006; Stockl, 2007), as mentioned in chapter two (see section 2.6.5.1). Literature shows that lupus is a condition which is difficult to diagnose even in developed countries because of its complexity as a multi-system disease with symptoms that can disappear, recur or change (Rus, 2008). This is a view supported by Tiffin et al. (2013), who also suggest that diagnosing lupus is more challenging in resource-limited Africa where there are inadequate diagnostic centres and inadequate skilled manpower, which may result in misdiagnosis and late diagnosis.

In the studies reviewed it was reported that diagnostic difficulties were due to participants symptoms not fulfilling requirements of the international classification criteria for classifying patients as having lupus (Goodman et al., 2005; Hale et al., 2006a; Hatfield-Timajchych, 2007; Mendelson, 2006; Stockl, 2007). The classification criteria recommend the fulfilment of at least four criteria elements (Hochberg, 1997; Petri et al., 2012). Therefore, lupus diagnosis was delayed for some individuals until they met the diagnostic criteria (Mendelson, 2006; Stockl, 2007). Ighe et al. (2015), however, criticised utilisation of the international guidelines for diagnosing lupus because they were intended to identify individuals with lupus for epidemiological purposes and not for diagnostic purposes in a clinical setting.

However, in this study, there was little mention of utilisation of the international lupus guidelines by the rheumatologists. They mentioned that fulfilling the mandatory laboratory criteria might be a challenge in the Kenyan situation due to inadequate laboratory equipment in primary and secondary health facilities. Diagnostic delays were therefore not a unique finding to this study, but factors contributing to the delays were different to those observed in studies in developed countries. Diagnostic difficulties in this study were more to do with lack of skills and resources, rather than with difficulties of patients meeting the international lupus criteria. The findings suggested that the low index of suspicion among clinicians created a gap in the ways that patients were identified at an earlier stage. The findings also pointed to the lack of a simple assessment tool to guide and raise the suspicion index for lupus both in the public and private health facilities, and at all levels of care.
The emerging findings also showed that despite receiving a lupus diagnosis, some patients still experienced challenges related to treatment processes. Factors which were attributed to this experience included inadequate resources, inaccessible services and the high cost of care. From the doctors' perspectives, there were frustrations experienced with the inadequate resources in the public tertiary hospital which necessitated referral of patients to private health facilities for specific laboratory tests and for medications which were missing from the public referral hospital.

In addition, the study established that only patients who had access to economic and social capital were able to move between public and private health facilities, as discussed later in section 10.5. This was a source of frustration, as expressed by the doctors, because not all patients were able to do the specific tests they desired or commence medications as prescribed. This was reflected in the patients' concerns regarding the cost of care, especially in private health facilities. The findings demonstrated that most patients from the public clinic perceived lupus care in the private health facilities as unaffordable, due to their variable financial means. Some patients also indicated that they had to look for additional funds or go without doing tests or taking medications at times. This was a view supported by literature from other developing countries which confirm that income-related disparities can be a barrier to healthcare utilisation (O'Donnell, 2007; Peters et al., 2008). The added cost of private care thus contributed to inequitable treatment of lupus.

Berendes et al. (2011) suggest that drugs may be more available in the private health sector because they are not underfunded like the public sector, and private health providers tend to stock drugs to encourage patients to utilise their facilities. Conversely, the public clinic was underfunded, which was a reflection of the underfunding of the public health sector, leading to medicine stockouts, as discussed in section 1.4. This finding of underfunding was similar to the health sector in Uganda, a neighbouring country which also mainly relies on private sources of funding (Zikusooka et al., 2009).

The inequitable treatment of lupus between the private and the public rheumatology clinics was also apparent in other related services. Care at the private rheumatology clinic was perceived to be quick and easy to access due to better staffing and well-managed appointments. The timeliness of private versus public health facilities is a view shared by
other studies which established that waiting times were consistently shorter in the private health facilities (Basu et al., 2012; Bitran, 2011; Brugha and Pritze-Aliassime, 2003). In addition, patients in this study reported that they were able to see the rheumatologist of their choice for every visit. These findings revealed existence of personalised care in the private clinic. In contrast, the public clinic was perceived as slower and more difficult to access. The doctors reported that due to the large number of patients, there was no guarantee of seeing the same patient for every consultation. The patients also expressed that they had to repeat their histories over and over again, as there was no continuity of care. Chuma and Maina (2012) argued that such challenges could discourage some people from using health services, while Russell (2005) indicated that being able to see a doctor of one’s choice enabled patients to develop relationships of trust with their doctors.

In addition, care at the public rheumatology clinic was also perceived to be less integrated. After diagnosis, some patients were being seen by other specialists such as the renal physicians, cardiologists and dermatologists, who kept separate patient files which often resulted in duplication of laboratory and radiological investigations and fragmented care. This was due to lack of integrated patient records which hampered coordination of patient care across their care continuum, including follow-up. Furthermore, it was established that both clinics had no mechanism for patient follow-up, which is necessary for monitoring patients.

Patients in this study, therefore, moved back and forth between the public and private health facilities when seeking lupus care, and they met various practitioners. Going between the public and private health facilities is similar to findings from Uganda (Zikusooka et al., 2009) and other developing countries like Pakistan (Shaikh, 2015). Shaikh (2015) warns that this could be a challenge in determining the quality of care that patients receive in the various healthcare facilities. Glasgow et al. (2001) also point out that coordination of care is particularly important when various health professionals and other informal caregivers are involved in providing patient’s care. This helps in meeting their complex needs, which can also have a positive impact on their health-related quality of life (Fradelos et al., 2015). However, the lack of continuity of care was not unique to this study. The challenge was also recognised in studies reviewed from the UK and US (Hale et al., 2006a; Stockl, 2007). Similarly, challenges in these developed countries were also perceived to be due to lack of interdisciplinary communication and poorly integrated care.
In addition, most patients in this study expressed that they mainly saw rheumatologists in Nairobi following a diagnosis. This excluded involvement of medical officers in secondary care facilities where most of the patients resided. The difficulty that emerged in the data was the loss of confidence in secondary care doctors. This resulted from their past experiences with a lack of referral from secondary to tertiary care during pre-diagnostic period, due to lack of recognition of lupus in secondary care facilities. The findings, therefore, indicated absence of the critical link between secondary and tertiary health facilities in the care of individuals with lupus. It also highlighted the need to address the strategies which may facilitate backwards referral of patients to secondary health facilities when their conditions became stable. As mentioned earlier, this might require equipping clinicians in these facilities with the necessary knowledge and skills about rheumatology. Other studies have established the desire of primary care physicians for increased integration of healthcare through collaboration with medical specialists, especially in caring for patients with complex conditions (Grant et al., 2011; Loeb et al., 2012).

Western countries practice a concept referred to as the ‘shared care’ model of healthcare. This has been defined as the collaboration between primary care physicians and speciality care physicians, which gives patients the benefits of having both specialist intervention and continuity of care (Hickman et al., 1994; Marshall et al., 2008). For instance, in the UK, there are shared care guidelines for the management of patients with lupus (Amissah-Arthur and Gordon, 2009) and rheumatoid arthritis (Luqmani et al., 2009), due to acknowledgment of the role of general practitioners in the management of these patients in primary care. This model of care enables early referral of patients to specialist units and subsequent shared care pathways for the management of these patients. However, establishment of rheumatology care pathways in Kenya is likely to take time because rheumatology as a sub-speciality is relatively new in Kenya. There must be an initial capacity building of rheumatology personnel which is currently ongoing.

The study therefore established that the diagnostic and treatment challenges experienced by some patients resulted in sub-optimal care leading to a lack of improvement in their condition, as described in sections 5.2 and 6.3.3. Some patients also experienced illness uncertainty as previously described in section 5.3. The illness uncertainty made some patients turn to
traditional beliefs to explain their illness, with subsequent help-seeking from traditional healers as discussed in the next section.

10.3 Traditional illness beliefs and treatment choices

The study established that among the patients in the study, there were some individual differences in illness beliefs, which were either conventional or non-conventional. These beliefs played an important role in how patients made treatment decisions. Unique to this study were the indications that some individuals turned to supernatural illness beliefs following delays in diagnosis, and unsuccessful conventional treatments. Supernatural beliefs were also linked to limited understanding of lupus following diagnosis. These illness beliefs helped them to make sense of their illness.

About half of the participants considered possible supernatural causes for their unexplained illness. This included witchcraft, evil spirits, the 'evil eye', consequences of angering the ancestral spirits, curse and demonic attack. However, only about a quarter of the participants held strong beliefs about supernatural causation of their illness. It was noteworthy that two-thirds of the patients were urban residents, which could have influenced their health beliefs, perceptions and responses. It was also noteworthy that the factors which played a role in the generation of such beliefs included late diagnosis, lack of understanding about lupus, non-compliance to medication and lack of improvement while on conventional medicines. These led to the idea that the illness was supernaturally caused by an outward spiritual power, over which both the individual and doctors had no control. Thus, some participants resorted to traditional remedies. This finding was in contrast to other African studies, which suggested that traditional folk beliefs influenced people's decision to seek healthcare from traditional healers first, before considering conventional healthcare (Austin et al., 2004; Verhagen et al., 2010). This difference could be due to the studies by Austin et al. (2004) and Verhagen et al (2010) being conducted in rural communities, whereas this study only had a small number of patients who lived in rural areas.

Literature suggests many theories of disease causation which include supernatural theories, germ theory, multi-causal model of disease, the theory of general susceptibility and the socio-environmental approach (Locker, 2008; Locker and Scambler, 2008). In supernatural theories of disease causation, there are beliefs about evil spirits, divine retribution for misdoings, or
illness being the result of an imbalance in body humour (Locker and Scambler, 2008). According to Amzat and Razum (2014), beliefs about disease causation in Africa can be divided into natural, supernatural, mystical and hereditary. The supernatural causation of illness deals with divine attribution of any illness which is not understood, and where ordinary treatments have failed (Omonzejele, 2008; Sabuni, 2007). Such illnesses are believed to be the result of punishment for misdoings or an onslaught by other evil forces.

Beliefs about supernatural causation of illness were more or less similar to findings from two of the reviewed lupus studies (Schattner et al., 2008; Taïeb et al., 2010). In the French study (Taïeb et al., 2010), participants who had beliefs about supernatural causation of lupus were immigrants from North Africa, while participants in the other study were from Israel, a country in the Middle East (Schattner et al., 2008). Literature indicates that beliefs in witchcraft and ‘evil eye’ are common in both regions (Gershman, 2015; Spiro, 2005).

In this study, a few participants related their illness to witchcraft and the ‘evil eye’, which were used interchangeably. Witchcraft was associated with envy as a result of the participants' hard work, though in some cases participants did not associate it with anything. However, it was not clear how participants felt witchcraft was carried out on them. The findings indicated that the witch was a speculated person that made the participants feel helpless about their fate. The data also suggested that witchcraft beliefs were held alongside other beliefs as some patients moved from conventional to traditional, and back to conventional treatments.

Foxcroft (2009) suggests that belief in witchcraft is widespread in Africa. Similarly, the 'evil eye' belief is said to be common (Elworthy, 2003) and also deeply ingrained in certain societies in the Middle East, India, North Africa and Sub-Saharan Africa (Gershman, 2015; Spiro, 2005). Similar beliefs are found among the Bantu and Nilotic ethnic communities of Western Kenya where it is also believed to cause harm, which may or may not be associated with envy. The symptoms of illness caused by 'evil eye' are believed to include general malaise, loss of appetite, hiccups, vomiting, headache and fever (Ross, 2010). Only loss of appetite and fever were similar to those mentioned in this study. However, the concept of witchcraft in Africa has been dismissed by some church leaders and health professionals (Kalichman and Simbayi, 2004; Sabuni, 2007). This might have led to some participants in this study being reticent to discuss witchcraft, and to give socially desirable answers regarding
their beliefs about witchcraft during the interviews. As mentioned previously, the study consisted of a more urban, educated sample.

Studies conducted in the Democratic Republic of Congo (Sabuni, 2007) and Malawi (Nyasulu et al., 2016) also established that some participants believed that witchcraft could cause some known diseases like malaria, HIV and TB. These are illnesses which are common in Sub-Saharan Africa (Organization, 2016a; Organization, 2016b). However, this view was not obvious in this study. It was evident that initially, all participants thought their illness was due to natural causes and needed conventional treatment. Nevertheless, when their condition did not improve or when the illness became uncertain, some considered supernatural causes. Again, when their conditions got worse, they all came back to conventional healthcare. This gave a picture of uncertain beliefs and mixed reactions among a study population which mainly consisted of an urban and more educated sample.

Another issue regarding beliefs in supernatural causation of illness was related to angering the ancestral spirits. This was mentioned by a few participants from the Bantu ethnic group from central Kenya. They indicated how, as families, they thought that their illness was due to punishment as a result of past wrong deeds. The commonly mentioned wrong doing was failing to pay bride-price to maternal in-laws. Participants and their families believed that the wrongdoing upset the in-laws, which angered the spirit of ancestors, or God, who either sent illnesses to the afflicted person or withdrew their protection. Nakalawa et al. (2010) suggest that the belief held by people in Africa about the spirit world is an old concept which is also a deeply ingrained belief. Other studies from Africa similarly indicate that illnesses like mental illness are conceptualised as possibly emanating from transgression of taboos or rituals which also anger the ancestral spirits (Quinn and Knifton, 2014; Teuton et al., 2007).

Demonic attack as a cause of illness was also mentioned in this study by a very few participants. Literature indicates that in some African countries, mental illness (Mercer, 2013) and AIDS (Roura et al., 2010) are also associated with the affected individuals being demon possessed. However, existing literature also suggests that the use of the words 'demonic attack' is an attempt to Christianise African witchcraft beliefs (Mercer, 2013; Onyinah, 2002).

Thus, a number of supernatural causations of illness were suggested by participants in this study. Ethnic group, geographical location of origin and level of education seemed to play into
the participants’ beliefs. There were also commonalities between the data in this study and studies from other African countries.

This study also established some factors that could have influenced participants' belief systems about supernatural causation of illness. As mentioned earlier, supernatural beliefs were stronger among participants who were less educated, particularly among those without a college education. The less educated participants also demonstrated a poorer understanding of autoimmunity. One participant expressed that she could not understand how her body was eating itself. This was also reflected in their perceptions regarding how much control participants felt they had over their health. This view was similar to findings in a study conducted in Central Africa (Kalichman and Simbayi, 2004), where supernatural beliefs were common among the less literate populations though not uncommon among educated populations. Omonzejele (2008) also assert that supernatural beliefs about illness causation is true of many Africans, irrespective of whether individuals are educated or not, and whether they are rural or urban. Therefore, this study suggests that patients of African origin may hold differing illness beliefs which may be independent of their age, level of education and area of residence, especially when little is known about the condition and its treatment.

It was also evident that in most instances there was collective decision-making among family members before they consulted traditional healers, making collective decision-making a factor. Kakai et al. (2003) indicate that in collectivist societies, many decisions are made by the individual’s family with the larger good in mind. Some authors suggest that African (Mbiti, 1990), Asian and Mexican (Huff and Kelley, 2003) societies are collectivist in nature, particularly when the community members share the same culture in terms of beliefs, values, lifestyles and religious knowledge.

From the findings, the prescribed traditional remedies reported by participants included: herbs (which was the most common), pig fat, bloodletting and religious prayers. In rural Africa, herbs which are easily accessible and affordable are used as per the herbalist’s instructions (Mahomoodally, 2013; Okello et al., 2010). Bloodletting in this study involved superficial cutting of the affected parts of the body. Few participants who used this remedy mentioned that there was a belief that the dark blood that came out also got rid of the illness. This belief was, however, different from bloodletting reported in various ancient civilisations such as the
Egyptians, Greeks, Arabs, Asians and medieval Europe, where it was believed to cause a balance in excess body humour for the treatment of conditions like migraine, fever, smallpox and plague (Greenstone, 2010; Lone et al., 2011). Regarding the use of animal fat, similar beliefs were identified in other studies from Kenya (Okwaro, 2013) and South Africa (Cocks and Møller, 2002). They also identified beliefs that application of animal fat protected against the effects of evil spirits. According to Asamoah-Gyadu (2014) and Obinna (2012), it is believed that supernatural illnesses can only be cured by both the individual and community members appeasing the spirits, with the assistance of the traditional healers.

In contrast, use of complementary and alternative medicine (CAM) is similarly reported in developed countries like the UK, with herbal medicine being the most prevalent for treatment of various conditions such as gastrointestinal diseases and cancers (Kong et al., 2005; Posadzki et al., 2013). Use of CAM also exists amongst patients with lupus in developed countries. It has been reported that over 50% of patients with lupus have utilised alternative therapies for symptom reduction in the form of food supplements, acupuncture and traditional Chinese medicine, among others (Greco et al., 2013; Jiao and Gao, 2013).

Some participants in this study, together with their families, also resorted to prayers for faith healing. Previous African studies have shown that people believed that supernatural diseases could be cured through repentance and prayers (Omonzejele, 2008; Sabuni, 2007). This was in line with the beliefs that supernatural diseases could come from other supernatural entities such as spirits (demons), deities and witches (Obinna, 2012).

There were also instances where use of traditional and Christian healers was intertwined. This demonstrated that beliefs in traditional African and religious healing could coexist, a view supported by Truter (2007). Some studies in the West have also shown that African immigrants in England, Canada and the US have health beliefs about the effectiveness of herbal medicines in the treatment of conditions like diabetes (Brathwaite and Lemonde, 2015; Brown et al., 2007; Smith, 2012). They also have strong religious beliefs about prayers and faith healing.

The findings of this study therefore suggest that similar to other studies from Africa, beliefs in different traditional remedies also exist among some individuals with lupus in Kenya, especially when the condition is not responding to biomedical approach. This is in line with
the belief that not all diseases have natural causes. However, the unique contributions of this study were that participants recognised biomedical approach as their first preference in their treatment seeking behaviour. Traditional illness beliefs were therefore linked to diagnostic delays, failure to respond to treatment and the experience of stigma, as discussed in sections 10.2 and 10.4. Nevertheless, this implies the importance of understanding patient’s cultural background when they are seeking medical care. The study also brought into focus the role of traditional healers, and the special place that traditional remedies still occupy within the communities.

Mpofu (2011) states that most African governments have recognised the position of traditional remedies which are perceived as accessible and cheap. However, governments also acknowledge that research into the effectiveness of specific remedies for certain conditions is still evolving, which limits their role (Mpofu, 2011; Tshibangu et al., 2004). In this study, it was evident that despite some participants using traditional and religious remedies, none of them were effective in the treatment of lupus. About a third of the participants indicated that they returned to conventional treatment, especially when their conditions became worse than before. The lack of improvement in their conditions, despite using both traditional remedies and conventional treatment, created more illness uncertainty amongst patients and their families. The lack of understanding of lupus as a disease also led to the experience of stigma and discrimination for some participants, as discussed in the next section.

10.4 Facing stigma and discrimination
The experience of stigma and discrimination also emerged from the findings. About three-quarters of the study participants described how they experienced stigma and discrimination in the course of their illness, both before and after diagnosis, but especially before diagnosis. Data suggested that stigma was mainly attributable to their changed body image due to skin rash, weight loss and hair loss. This was due to an assumption that participants had HIV and due to a lack of awareness of lupus.

However, the experience of stigma was therefore not a unique finding in this study, as stigma was also identified in five of the previously reviewed studies (Hale et al., 2006b; McElhone et al., 2010; Miles, 2011; Schattner et al., 2008; Spry, 2014). Similarly, in these studies stigma was associated with altered body image, which also included skin rash. However, unlike this
study, weight gain was mentioned as a stigmatising attribute. Larsen and Lubkin (2013) state that chronic illness and its treatment can cause visible changes in an individual’s appearance, which can significantly affect their perception of their self-image. Jackson (2002) argues that each cultural or social group has its norms governing the ideal acceptable physical appearance which applies to members of the group, including those with chronic illness. This suggests that in the Kenyan culture, imperfect skin, weight loss and hair loss are seen as defects in physical appearance.

In addition, people that the patients in this study came into contact with strongly associated the changed body image with having HIV, a fairly common and stigmatised condition in Africa (Alubo et al., 2002; Ekanem and Gbadegesin, 2004; Rankin et al., 2005). HIV carries a negative connotation about the individual’s character because of the main mode of transmission - the sexual route - which is seen as an individual’s moral failure (Lekas et al., 2011b). Consequently, those who have the condition are blamed for acquiring the condition through immoral sexual behaviour and are seen as undeserving of societal sympathy (Lekas et al., 2011a; Lekas et al., 2011b). This fits Goffman’s (1963) description of one type of stigma which is associated with *blemishes in personal character traits*.

Thus, some participants in this study had to deal with the plight of having predominantly visible physical changes and the assumed moral failure that was associated with having HIV. This also linked well with Goffman's (1963) concept of 'discredited' stigma. Goffman proposed that the discredited stigma occurs when an undesired difference is visible or known. In the social context, some participants reported how others looked at them with disapproval or physically withdrew from them due to the HIV association and the negative stereotype. These were acts of prejudice and discrimination against participants, which made them feel socially devalued because they did not have full social acceptance of 'normal' people. Goffman (1963), therefore, projected stigma as a relationship between a stigmatised attribute and negative stereotype.

In addition, Link and Phelan (2001) suggested that stigma exists when there is a co-occurrence of labelling, stereotyping, separation, status loss and discrimination with an associated power imbalance in the circumstances. Link and Phelan (2001) suggested that discrimination can be experienced by people at two levels: at an individual level through unequal treatment, and at a
structural level through societal conditions that limit an individual's opportunities, resources and well-being. The current study captured all the components. Those who were labelled as having HIV experienced a negative stereotyped connotation that placed them in a distinct and separate category from the non-stigmatised people. Some participants felt segregated by their work colleagues. According to Link and Phelan (2001), participants who were segregated by their colleagues not only experienced discrimination, but also a status loss at an individual level. Also, some participants were being urged to resign. This corroborated with Link and Phelan's (2001) discrimination at the structural level as their work opportunities and well-being were threatened. Unequal power relationships also unfolded as participants were made to feel less worthy and inferior by some work colleagues and bosses. The feelings that resulted can also be referred to as ‘keeping people down’, as suggested by Phelan et al. (2008). It is a form of domination whereby people with more power inflict stigma on people with less power, which maintains inequalities between the groups.

The stigma was expressed either through verbal or non-verbal communication: how people looked at the patients, how people directly asked them if they had HIV, and how people suspected that they were lying about having a condition called lupus instead of saying that they had HIV. The expression of disbelief towards the lupus diagnosis could have either been because people thought the patients were faking the illness, which could also be viewed as character stigma, and could also have been due to people's unfamiliarity with lupus. The social disbelief despite the visible physical symptoms was also an act of 'enacted stigma', as described by Scambler (2004) (see section 1.3.3). These participants were also aware of how their body image had changed and the negative attention they attracted. They internalised how people perceived them. This made them uncomfortable and also made them expect stigma, an experience which Scambler (2004) described as 'felt stigma'. Nevertheless, stigma was experienced in almost all spheres of the participants’ lives and is likely to continue unless public awareness of lupus is improved.

The presumption of HIV, even after diagnosis, was as a result of lupus being a condition which is not publicly known in Kenya. The public was familiar with HIV which mimicked some of the symptoms of lupus. Dumit (2006) and Avellaneda (2006) state that some rare or new illnesses may be socially invisible. They suggest that social invisibility of conditions is intricately linked to politics and argue that the political invisibility of an illness occurs when
the illness is not causing a visible social problem or public health problem. Therefore, the presence of the illness does not become the focus of a political agenda, and subsequently, the illness is not given sufficient political consideration. This means that the illness is inadequately represented in a country’s official statistics and health policies, thus undermining equal access to healthcare. From the study findings it was evident that in Kenya, lupus is a little-known disease with no registry. This makes it invisible both socially and politically, unlike other non-communicable diseases such as diabetes or asthma, which have a higher prevalence. Also, rheumatology services are relatively new in Kenya, as it was reported by one of the rheumatologists that it only started in 2000.

This study also established that some of the patients who experienced stigma and discrimination handled the situation by isolating themselves, especially from people who had been judgemental towards them. Similarly, in previously reviewed studies, the experience of stigma also led to psychological distress and low self-esteem, which also resulted in self-isolation (McElhone et al., 2010; Spry, 2014). This is a form of self-stigma, which Link (1987) referred to as internalised stigma or devaluation. It is described as the degree to which people endorse negative beliefs and feelings associated with their stigmatised attributes. It is also similar to Scambler and Hopkin's (1986) concept of felt stigma. In this study, the associated feelings included guilt, diminished self-worth and embarrassment, which were all similar to the feelings identified in other studies (Kılınç and Campbell, 2009; Person et al., 2009). In addition, participants in this study harboured feelings of bitterness due to a lack of psychological support from employers and work colleagues.

One other finding of this study was that lupus, which was not being recognised, had mainly affected participants who were women. Western literature suggests a disregard for some chronic illnesses which disproportionately affect women like chronic fatigue syndrome, endometriosis and fibromyalgia (Ballweg et al., 2010; Crooks, 2007). These conditions not only affect quality of the women's lives but also cause a significant financial burden, a view which was also established in this study. The conditions are also grossly underfunded by the governments, with resultant lack of evidence-based data (Ballweg et al., 2010; Balogun-Mwangi et al., 2016) and little or no training of health providers who often dismiss their existence (Balogun-Mwangi et al., 2016; Crooks, 2007). In contrast, in this study, it was not possible to tell whether gender was an additional factor for discrimination as the sample size
was small, with only one male patient. The male patient was however treated more quickly and had other advantages such as having a medical insurance and being more educated. In addition, lupus was not being recognised due to the overwhelming difficulties of getting a lupus diagnosis and service delivery challenges which were mainly associated with Kenya being a resource-limited country.

The foregoing discussion indicates that stigma faced by lupus patients is a reality which is mainly fuelled by the visible physical changes, delayed diagnosis and lack of awareness of lupus by most people. There is therefore the need for improved public awareness of lupus and health provider education on lupus to enable health providers to attend to lupus patients effectively. However, due to health system related challenges, which most study participants faced as they attempted to manage living with lupus, it emerged from the study that all participants needed to draw on some specific resources at their disposal, and these were unequally distributed as discussed in the next section.

10.5 Resources for managing life with lupus

The themes that emerged from the data indicated that the resources utilised by participants to manage life with lupus included economic, social network/social support and cultural resources. Pierre Bourdieu’s (1986) theoretical concepts of economic, social and cultural capitals were utilised as the best fit for discussing these resources. They helped to explain the differential resources which were neither distributed equally nor randomly amongst the participants.

All patients in this study perceived lupus care as expensive, irrespective of whether they accessed public or private care. Cost included travelling to attend the rheumatology clinic, which was both a direct and indirect cost. Indirect cost included the cost of time lost from work and time spent on travelling to and from the clinic. Lundberg et al. (1998) state that when services are geographically distant, cost increases accordingly. In the study, some participants travelled long distances compared to others, which increased their cost of travel to the clinic. Direct cost included paying for the consultations, lupus tests and medications.

As patients described the assets that enabled them to afford the expensive lupus treatment and care, it became apparent that patients needed economic capital to access a satisfactory level of
Bourdieu (1986) proposed that economic capital refers to one’s command of economic resources in terms of monetary resources and other tangible and intangible assets. In the study, economic capital referred to the possession of medical insurance and personal or family finances. Economic capital was not only unequally possessed, but was also low among most study participants.

Being in formal employment gave some participants privileged access to medical insurance cover. Also, more than half of the participants who were on medical insurance had diploma qualifications and above. It is therefore possible that family capital gave access to both education and employment as families have to pay for secondary and tertiary education in Kenya. There were also participants who could afford to pay for their treatment through out-of-pocket systems because of their level of income at the individual or family level. Thus, those who had economic capital in the form of good medical insurance or money were able to access care from the private rheumatology clinic, where lupus care was perceived to be better. In contrast, participants who had limited economic capital accessed care from the public rheumatology clinic. These findings are shared with a previous study conducted in Kenya (Ke et al., 2006), which also established that richer individuals and those in employment are more likely to have medical insurance. The study findings therefore demonstrated that there was no universal medical coverage for patients in Kenya. As indicated in section 1.4.4, health insurance provided by the employer is not accessible to most Kenyans because only about 19.8% of Kenyans work in the formal sector (Kenya National Bureau of Statistics, 2015).

Financial strain was also expressed by participants in three of the reviewed studies from the US (Beckerman, 2011; Mendelson, 2006; Williams et al., 2015). Similarly, in the US patients have to pay the doctor's fees and for each service rendered (Fitzpatrick, 2008). They also lack universal medical insurance coverage which creates health access problems and inequity between the insured and uninsured, and low-income populations (Commonwealth Fund, 2014).

Medical coverage for patients in Kenya is in sharp contrast to other developed countries - apart from the US - where there are collective arrangements for funding health services, as in the UK, Germany and France (Altenstetter, 2003; Brown, 2003; Rodwin, 2003). They have a compulsory financial arrangement for health services either through medical insurance
schemes or general taxation (Mills and Ranson, 2012). This mechanism provides protection and universal coverage against the financial risks of ill health. Also, financing health services in these developed countries is a role assigned to the state, which is not always the case in LMICs. In Kenya, there is a shortfall in government budgetary resources for healthcare in relation to the demands for healthcare (Kenya National Bureau of Statistics, 2015). In addition, the existing health insurance schemes in Kenya are mainly intended for salaried public and private sector employees, leaving out unemployed individuals, while Kenya has a high unemployment rate of about 40% (Deolitte, 2011; Kenya National Bureau of Statistics, 2015). So, there is a need to explore strategies for widening the insurance bracket to include those not currently covered by the existing insurance schemes.

The study therefore established that more than half of the participants, together with their families, bore a big burden regarding out-of-pocket health expenditures. This led to chronic financial difficulties for some patients due to their long-term recurring illness and a combination of not being well enough to work and having to look to others for help. The study also established how the long-term downward spiral due to dwindling economic capital eroded some patients’ social relationships, as discussed later in section 10.6, and how their social capital dwindled along with their economic capital. This subsequently led to a lack of treatment compliance as some patients were unable to honour clinic appointments and were therefore not able to access lupus care consistently. Some patients stopped taking their lupus medication or took medications inconsistently due to their precarious financial situations. The doctors' testimonies indicated that patients who disengaged and stopped taking their medication deteriorated. Kelly and Doohan (2012) also suggest that at a fundamental level, being poor is bad for an individual's health.

The precarious financial situations of patients in this study were, therefore, a sign of being impoverished partly because some patients could not hold employment due to their unstable health. This was also a sign of lack of financial risk protection among the poor. It implied that failure to establish mechanisms for more inclusive healthcare for poor people with chronic illness will drive their families into more poverty due to high cost of treatment. A study conducted in Kenya has already shown the general impoverishing effects on families who pay for all their healthcare expenses (Kimani et al., 2016). This calls for a need to fairly distribute the burden of financing healthcare in Kenya to reduce the barriers to health service utilisation.
which were evident in this study. The WHO called for universal health coverage, however, implementation of such declarations is normally left to the discretion of member countries (World Health Organization, 2005b). This study therefore demonstrated the significance of economic capital in facilitating access to lupus care and treatment in a country where there is no universal health coverage. It also highlighted the relationship between economic capital and social capital, which most participants relied on to meet treatment challenges.

The study also established that some participants had valuable social capital in terms of social networks of family, friends and other contacts. Pierre Bourdieu first defined the concept of social capital as “the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalised relationships of mutual acquaintance or recognition” (Bourdieu, 1986, p. 248). He explains that the relationships enable individuals to capture embedded resources which are possessed by their social networks. Access to the resources which are embedded in social relations enable the individuals to gain better outcomes.

The three main social capital settings that have been identified include family, neighbourhood/community and workplace (Ferlander, 2007; Oksanen et al., 2008). In this study, there were varying types of family ties. Some participants had strong family ties with their parents, siblings and extended family members who assisted with payment of medical bills on a continuous basis by virtue of their ties. The findings also highlighted that there were participants whose families raised funds within their communities or took bank loans to pay for their medical bills. These were forms of tangible aid which demonstrated the beneficial link between economic and social capital.

Others patients explained how their networks of friends and family offered information regarding other specialists or traditional herbalists, and accompanied them for consultations when they were too weak. Some patients also described how they were able to reach the rheumatology clinic sooner despite the geographical distance some of them had to travel. These forms of non-tangible aid gave some participants access to better treatment in a porous healthcare system. These aspects of patients’ experiences fitted well with Bourdieu's view of social capital as a network-based resource whereby, by virtue of belonging to social networks/relationships, an individual can mobilise material and non-material resources that are
embedded in the social networks (Bourdieu, 1986). Mohnen et al. (2011) also suggest that the more neighbourhood social capital one can have access to, the more one would be supported, with the result being enhanced health.

Some patients also experienced positive social support at work suggestive of a workplace with high levels of social capital. For instance, individuals reported how their managers and work colleagues supported them once they understood the nature of their illness. This fitted with Bourdieu's (1986) view of social relations which facilitate social interaction within a network of interpersonal relationships. In contrast, in other work settings participants were being put under pressure to resign. Other patients did not have their employer's support regarding access to medical insurance, which was also an evidence of the relationship between economic capital and workplace social capital. Therefore, these participants accessed care from the public clinic due to their limited finances. Oksanen et al. (2008) suggest that the level of social capital in the workplace, whether high or low, is a predictor of an employee's health. Similarly, lack of support from the employer was also identified in one of the reviewed studies whereby some participants lost their jobs (Mendelson, 2006); they expressed a need for their illness to be acknowledged and a need to be supported at the workplace.

The study findings also demonstrated that the inequality in social capital among the participants was mainly due to some patients having a relatively disadvantaged socioeconomic status. In addition, these patients had to rely on families who were not only equally disadvantaged by their low socioeconomic standing in the society, but also had competing financial priorities. According to Bourdieu, social capital possessed by an individual depends on other forms of capital, such as economic and cultural capital in a given space, which increases the possibilities of multiple social hierarchies (Bourdieu, 1990). In the Kenyan society, economic resources earned by members of a family become the economic capital of the whole family. This explains the differences that were observed among participants in this study regarding their ability to afford the cost of healthcare, and their varying abilities to access the rheumatology clinic.

Gender inequality in social capital was also evident in the study, although it was subtle. Differences appeared in the types of social networks and the quality of embedded resources between the only male patient and most of the female patients. The male patient had more
non-kin networks which included friends, work colleagues and acquaintances, some of whom were doctors known to the family. Women who were in employment also had more non-kin networks, like their male counterpart. Lin (2000) suggests that these differences are due to the types of organisations that men are exposed to, which offer many more potential contacts for men than women. In addition, Moody (1983) suggests that men tend to affiliate with other men. They also tend to occupy higher positions in hierarchical structures, making them have larger networks than women. In contrast, the networks of the unemployed women consisted of a larger proportion of different types of kin, like nuclear and extended family members. Moody (1983) argues that women are located in peripheral organisations and are more focused on domestic and community affairs, which makes them less advantaged in relation to mobilisation of social capital and the potential use of resources embedded within their network. Regardless of gender, Lin (2002) adds that an individual's social standing enhances their power and influence. However, due to the fact that there was only one male patient in this study, the inferences that could be drawn from the gender differences were limited.

Therefore, the study established that all participants benefitted from a combination of economic and social capital that were available to them; this facilitated their movement to rheumatology. However, all participants had insufficient resources to assure the best level of care. It was also evident that the quality of their social and economic capital varied, and determined where they accessed lupus care. Bourdieu (1990) suggests that social and economic capital possessed by an individual can also influence their cultural capital, an argument which suggests that individuals need all three types of capitals.

The study also established that some participants had valuable cultural capital in terms of their educational attainments, linguistic skills and accessibility to other resources like the internet and printed literature which improved their general knowledge. Cultural capital, a concept also coined by Pierre Bourdieu (1986), encompasses many dimensions of resources such as the artistic, aesthetic and innate knowledge held by individuals through their life course (Dunt et al., 2010; Khawaja and Mowafi, 2007) and through the process of socialisation (Bourdieu, 1986). Bourdieu (1986) indicated that cultural capital tends to take on three forms: the institutionalised, embodied and objectified states. Institutionalised and embodied states were represented in this study. However, Bourdieu's (1986) objectified cultural capital, which
refers to the material objects or goods that one owns, was not easily identifiable among the study participants.

Bourdieu’s cultural capital in the institutionalised state refers to how society tends to value people based on the measures (Bourdieu, 1986), for example, one's educational attainment. Bourdieu indicates that this type of capital can be exchanged for actual economic capital whereby people with better education expect better paid jobs. The emerging findings of the study illustrated that participants who had more cultural capital in terms of higher educational attainment were equally well bestowed with economic and social capital. They all accessed care at the private rheumatology clinic which was less busy, and they also had more time with the doctors. Having a higher education and a greater level of understanding enabled some patients to have a better comprehension of the meaning of auto-immunity. This was in addition to possessing linguistic skills which enabled them to articulate their questions. The information they gained was useful in their decision making regarding how to live with the condition in culturally accepted ways. They were also handled differently; for example, one participant indicated that he was able to call his rheumatologist at any time to clarify issues. This fitted well with Bourdieu’s (1986) symbolic elements such as status, prestige and credentials, which he suggested were embedded in cultural capital. He thus argued that earning a degree is a significant form of cultural capital.

In contrast, most patients who had less cultural capital in terms of lower than degree level education, also had limited access to economic and social capital. They all attended the public rheumatology clinic which was crowded, had limited exposure to medical staff and a lack of patient educational resources. Among these participants, some did not understand the meaning of lupus in terms of auto-immunity. Healthcare staff, therefore, preferred to use simpler language like 'the body is attacking itself' in an attempt to explain the term auto-immunity. Another patient indicated that even though she had watched a patient who had lupus on TV, she still had very little knowledge about lupus. Apparently, this participant was rural based and had an O level education. It is likely that either she had not received adequate information regarding lupus due to the busy nature of the public clinic, or she did not have linguistic skills to maximise on her appointment time with the doctors.
Bourdieu (1986) argued that it is hard for those who are poor to gain the types of cultural capital that are valued in society, such as having an education. In essence, it means that people in a lower social class tend to have less cultural capital, while people within the upper and middle social classes have more cultural capital. However, if a poor person gains education through a free education system, then their situation can change. In Kenya, only primary education is free while secondary and tertiary education are not, limiting the changes in social situations. In addition, the Kenyan society also tends to give people with more cultural capital more prestige, as was evident in the study. Cultural capital was therefore unequally distributed among participants with some participants possessing more cultural capital than others. Bourdieu (1986), and Grusky and Szelenyi (2006), contended that formal education perpetuates socioeconomic inequality as it forms an apparent hierarchy of gifts and qualities.

In this study, it was also evident that some participants' behaviours were determined by their cultural and religious beliefs, especially when they failed to comprehend the cause of their illness. Those who believed that their illness was related to witchcraft and violation of cultural norms utilised cultural remedies. Conversely, there are those who held Christian beliefs who also refused to use traditional remedies as discussed in section 10.3. This fitted well with Bourdieu's (1986) cultural capital in the embodied state, which refers to the form of knowledge that resides within an individual, which is transmitted in one's life course. It also fitted well with Bourdieu's (1986) 'habitus', which is one of the fundamental components of cultural capital. Habitus refers to the learned set of norms, values and dispositions gained from an individual's cultural history, which enables them to orient themselves to the social world. This, in turn, influences their perceptions, conception and behaviour (Edgerton and Roberts, 2014; Pinxten and Lievens, 2014). Webb et al. (2002) explain that an individual's exposure to a culture in the context of the surrounding social reality predetermines an individual's potential course of action. Therefore, people do not act blindly, but on the basis of what Bourdieu (1986) refers to as practical sense. Webb et al. (2002) add that one's social class, academic achievement, rearing and past choices, all form part of this structure and determine, in part, the behaviour of an individual.

This study therefore established that the types of resources which the participants had access to varied in type, quality, quantity and location in the social network. This linked well with Bourdieu's (1990) explanation regarding the relationship between the different types of
capitals. The economic, social and cultural capitals which individuals relied on were linked together, with individuals with more economic capital tending to have more access to social and cultural capital. The variations in capitals influenced participants' opportunities, constraints, type and place of care received. The variations also influenced their perceptions regarding the effects of the illness on themselves, as discussed in the next section: 'a shadow of myself'.

10.6 A shadow of myself
The other finding that emerged from the study was the perceived sense of loss by the study participants, due to the impact of the disease. This was described under the term 'a shadow of myself'.

On the whole, patients in this study felt that the disease made them experience various forms of loss such as: loss of their previous body image with the associated experience of stigma; loss of productive function both at work and at home; loss of financial stability which affected their economic resource; loss of social and family stability with associated strained relationships and the experience of emotional distress, as described in sections 9.2.1 - 9.2.3.

In this study, the patients' sense of loss fitted with Charmaz's (1983) concept of ‘loss of self’ which she refers to as a combination of the loss of self-identity and self-esteem. According to Charmaz (1983), the self is social in nature and is developed through social relationships. Also, she indicates that “experiencing illness is a social-psychological process in which the inner dialogue between the I and the me changes and definitions of the experience change” (Charmaz, 1983 p. 170). Charmaz argues that loss of self is experienced by people with chronic illness because the illness changes their former activities and lives, and that the loss of self can be continuous, a view which was also evident in this study.

Bury's (1982) theory of ‘biographical disruption’, which refers to functional limitations brought about by chronic illness, was also a good fit for discussing patients’ perceptions regarding impact of the illness. Most participants were no longer able to carry out most of their former daily activities, whether inside or outside the home. This was mainly due to the new body sensations they experienced, like pain and fatigue. As discussed in section 1.3.4,
Bury’s work brought into focus the meaning of illness for the individual. The work acknowledged that disruption arises because the illness disorganises people’s taken for granted lives and the social world in which they live. Both Bury (1982) and Charmaz (1994b) suggest that onset of chronic illness compels people to think about the possibility of dying, a matter which is normally only seen as a distant possibility in one’s life. Charmaz (1994b) also emphasises that the awareness of death disrupts people’s identity, particularly if the individuals had no previous experience of illness, or perceived themselves as healthy or too young to die. This was evident in some of the narratives mentioned in section 9.2.3. Some patients commented on initially thinking that they were suffering from a terminal disease and considered the possibility of dying from the disease.

Lupus also fits well with Bury's biographical disruption theory because it is an illness that strikes in adulthood and disrupts a previously ordered life. This is in line with Williams' (2000) criticism as stated in section 1.2.4. Williams suggested that Bury's biographical disruption was only applicable to people who were previously active and productive, but not to children and the elderly. In this study, patients’ ages ranged between 19-56 years and their previously active lives had been disrupted in one way or another. Some participants stated that they stopped working in paid employment; this made them financially fully dependent on their families, as discussed under economic and social capital.

Job loss was noted to be mainly high among those who were not in skilled employment and those with jobs that required high physical demands. In contrast, those who were in positions of responsibility were considering early retirement. Other studies have also highlighted that lupus can reduce an individual’s ability to work, with an end result of having work disability and/or changes in the nature of an individual's work (Baker and Pope, 2009; Yelin et al., 2007). Similar to this study, Yelin et al.’s (2007) study established that job loss was higher among those who had no high school education. Also, those who had early onset of lupus, or a longer duration of lupus, negatively experienced high physical and high psychological demands of the job (Yelin et al., 2007).

In this study, some patients also described how they felt that their female gender roles - child bearing, rearing and doing housework - were disrupted by lupus, which disproportionately affects women. Some women decided to remain single as highlighted in section 4.2.1.6 or had
no children by choice. Some wondered if they ever will be able to get married and have children, while others suggested that they could no longer have more children despite their desire to have more. This was evident in Table 4.1 (section 4.2) which showed that half of the participants had no children while only two participants had children below 18 years of age. These findings were similar to other studies that involved women with other chronic diseases, as mentioned in sections 1.3.4 and 2.6.6 (Akyüz et al., 2008; Stockl, 2007).

‘Gender role’ is a term which refers to society’s expectations of how men and women should act. This is learnt during the socialisation process from birth through family, education, peer groups and the mass media (Lapinski and Rimal, 2005; West and Zimmerman, 1987). In traditional African society, the acceptable roles and behaviour of both men and women in a family and community are culturally defined along femininity and masculinity lines (Bassey et al., 2012). Males are endorsed as decision makers, which is alleged to be in the best interest of the family (Conry-Murray, 2009). Also, women are expected to act according to decisions made by their husbands or by a male family leader. Participants in other studies from West Africa and India argue that the role division which gives men a higher status than women is not in the best interest of the family, and is therefore a form of gender discrimination (Conry-Murray, 2009; Jayachandran, 2014; Sudarkasa, 1986).

However, available literature indicates that traditional gender roles are breaking down due to the shift from the traditional model of a wife as a housewife and a husband as an employed person. This is attributed to the current equal educational and economic opportunities for men and women (Tong, 2013), and the breakdown of attitudinal and socio-cultural factors which previously acted as barriers created by gender role stereotypes (Askari et al., 2010; Padavic and Reskin, 2002; Steinke, 1997). Participants in a study from West Africa also attributed the breakdown to the fact that gender roles are conventional and can be altered because they are not part of a moral code (Conry-Murray, 2009). However, some studies established that working women perceived themselves as still performing significantly more housework than men (Bartley et al., 2005; Cinamon and Rich, 2002; Kan et al., 2011; Kroska, 2004). On the other hand, some participants in another study insisted that gender segregation in domestic work persists (Kan et al., 2011). This was an observation which was also evident in this study. There were participants who mentioned with concern that they could no longer perform domestic chores like washing clothes and caring for their children and the expectations from
the extended families. However, the study did not establish women's' concerns regarding doing more domestic chores than their male counterparts.

Therefore, this study demonstrated that similar to other chronic conditions, lupus is a condition that is regarded as disruptive, with physical and functional changes characterising the lives of individuals who are in the prime of their lives. The changes, in turn, affect the individuals socially, economically and emotionally. In this study, most individuals attempted to cope with the disruptions in various ways. This fitted with Bury (1982) argument as discussed in section 1.3.4; that individuals undergoing the disruptions caused by chronic illness are capable of attempting to reconstruct order in their lives, with the goal of maintaining control and ‘normality’ of life. The next section discusses some of the individuals' experiences with attempts to reconstruct their lives, which exhibited varying results.

10.6.1 Biographical reconstruction

The study established that having lupus was experienced as a negative turning point for all patients. For most patients, this was a new disease which they knew nothing about, so they decided to seek more information regarding the condition. However, the study established that having an understanding of the condition was still variable among participants. It depended on an individual’s level of education and their other skills, such as information technology skills and linguistic abilities.

Most participants acknowledged that they were not the same as before and some of them realised that they needed to reconstruct their identity in response to the illness. Most of them accepted the diagnosis and decided to take medication, with a positive effect on their general condition. However, it was noteworthy that the effectiveness of medication took time as these patients' conditions improved over time. Other participants also decided to pace their activities, both at home and at work, to help them cope with the experience of extreme fatigue.

For participants who experienced HIV-related stigma, receiving a lupus diagnosis was a positive turning point. They were relieved to know that the illness was not HIV and this transformed them from feeling that their illness was a death sentence, to feeling that it was a chronic disease that could be managed. This became their starting point of reconstruction.
Thus, gaining a lupus diagnosis had more of an individual meaning and significance as it gave a non-stigmatising label to their pain and illness, a view shared by patients in other lupus studies (Hatfield-Timajchy, 2007; Spry, 2014; Stockl, 2007).

For most participants, the illness remained ambiguous with insurmountable challenges, which in turn was a challenge to biographical reconstruction. As described in section 9.4, in this study, it seemed that biographical reconstruction occurred minimally and to varying degrees among the patients. Most participants were in the second phase of Whitehead's (2006) identity reconstruction which constitutes attempts to regain aspects of former self. The wealthier, more educated and more informed participants, who were in the minority, were trying to make a life for themselves and were coping better than the socioeconomically disadvantaged participants. Some participants still experienced challenges such as uncooperative managers and colleagues at work. Others lived in disadvantaged socioeconomic situations which resulted in missed appointments, missed medications and strained relationships. The study also established that positive reconstruction of identity is relatively fragile and can be pendular, moving backwards and forwards depending on other social circumstances. This raises a challenge to the idea of lupus patients in Kenya having a typical illness trajectory, as witnessed in other progressive chronic illnesses like respiratory disorders, cardiovascular diseases and cancers (Lynn and Adamson, 2003). For example, one participant who was striving to be normal was also the one who summarised herself as being ‘a shadow of herself’ due to other factors in her life, which were also affecting her illness.

Bury (1988) argues that some individuals have more control over their lives before onset of their illness than others. The view of having control over ones' life is closely related to social factors such as class, ethnicity and gender (Williams, 2000), and other determinants such as economic and biological factors (Vlassoff, 2007). This study suggests that individuals who possessed positive social factors such as better economic, social and cultural resources had slightly better control of their lives than those who had limited resources. Participants who had financial means to access care from the private rheumatology clinic; social support both at work and at home; and had more access to lupus information and education also described a relatively better control of their lives. However, most participants had not necessarily settled, as many still experienced symptoms of lupus as a negative biological factor. These participants were still unsure whether their condition would be under control despite the
various changes they made. This implied the need to explore strategies which may be used to assist individuals to cope better with the condition, such as symptom control. Thus, lupus was not experienced as a predictable chronic illness as suggested by Bury (1988) who argues that some chronic illnesses are less predictable than others.

Some studies have also suggested that the reconstruction process is not a linear sequence as was evidenced in this study (Madden and Sim, 2016; Yoshida, 1993). None of the study participants had transcended the illness, though all of them recognised that the lupus experience has made them become different people, some stronger than others.

In summary, this chapter has discussed the key findings and demonstrated the implications of living with lupus in Kenya from the perspectives of some individuals living with the illness and from doctors' perspectives. The study established that when participants started to experience lupus symptoms there were delays in the initial help-seeking among some participants. However, when participants showed up for treatment, they experienced diagnostic delays due to various health system challenges. The study also established that some participants attributed their illness to supernatural causes, while some attempted traditional remedies with treatment failures. Others also had to deal with the experience of stigma due to lack of lupus awareness among those around them. Most participants also experienced various treatment challenges due to the varying levels of economic, social and cultural capital that they possessed. Resources for managing life with lupus varied and were inadequate for all participants, and this made the disease affect the individuals differently, and disrupted their lives both physically and psychosocially in various ways. Some patients attempted to restructure their disrupted biographies with variable success as biographical reconstruction had its own challenges and seemed to happen differently for everybody. The study, therefore, established that lupus is a particularly challenging illness to live with as shown by other studies. The study also established that living with lupus in Kenya involved extra challenges.

10.7 Rigour of the study
Ensuring quality and rigour is essential for all qualitative researchers if the study findings are to be considered valuable in influencing decision making, policy and future research (Tong et al., 2007). Quality and rigour are achieved through generation of rich, detailed data and by
defining the stages of the analysis process (Milne and Oberle, 2005; Rose and Webb, 1998). In this study, data were obtained through interviewing some patients who attended the private and the public rheumatology clinics, together with writing field notes. The doctors who took care of the patients in the two clinics were also interviewed to capture different aspects of living with lupus. The constructivist paradigm which was applied in this study recognises the significant roles of both the researcher and the research participants in the co-construction of subjective experience. The paradigm also pays attention to reflexivity and triangulation of the results (Patton, 2002). Therefore, in this study, direct quotations from different accounts were presented in the data to provide sufficient perspectives for the study. To ensure validity and quality during the research process, I considered Charmaz's criteria of credibility, originality, resonance and usefulness (Charmaz, 2014), as outlined in Appendix 22 and as discussed in the following sections.

10.7.1 Credibility
Credibility is defined as the extent to which the researcher's interpretation of the data is endorsed by the research participants (Murphy et al., 1998), and the degree to which the argument and analysis of the researcher reflect the data gathered (Charmaz, 2014). In this study, credibility was enhanced by collecting rich data from both the patients and doctors to seek detailed information and ensure representation of different perspectives. Interviews, field notes and memos were transcribed verbatim. The initial line by line and NVivo coding facilitated staying close to the data and this in turn enabled reflection of the participants' perspectives of living with lupus. The main technique for assessing the credibility of the data is considered to be participant validation, whereby the researcher either returns to the participants to check the accuracy of the individual interview transcripts or confirms the accuracy of particular aspects of the researcher's interpretation of their experiences (Guba and Lincoln, 1994; Seale, 1999). Participant validation is considered as the strongest available check for credibility of qualitative research (Lincoln and Guba, 1985). However, some researchers have suggested that participant validation may lead to confusion rather than verification, as some participants may change their minds about some of the issues because of newer experiences which may have occurred since the time of the initial data collection (Angen, 2000; Carlson, 2010).
In this study, participant validation was not undertaken as participants came from various parts of the country which created a challenge in inviting them to comment on the interview transcripts and the themes identified from the study. Instead, I employed the inbuilt checking process in grounded theory approach of constant comparative analysis and theoretical sampling, including peer debriefing and an audit trail. I also utilised what was similar to peer checking as recommended by Sandelowski (1993). I worked closely with my supervisors who acted as experts and ensured that analysis stayed close to the data.

During the first few interviews with purposively sampled participants, the conversation was mainly guided by the interview guide. Purposive sampling allowed me to include participants from both the rural and urban centres, the younger and relatively older participants, together with participants with different disease duration. During the interviews, I noted the emerging issues and I also conducted constant comparative analysis of the issues that emerged from these first few interviews. I achieved this by comparing the newly collected data with previous data that I collected from earlier interviews for similarities or differences, on an on-going basis. I also carried out theoretical sampling as the study progressed to deliberately collect pertinent data. By using constant comparative method, I included some of the issues and concepts that emerged in the subsequent interview questions. The in-depth interviews allowed me to validate the issues that emerged from the previous interviews by asking direct questions to the next participant. For example, when some participants expressed that at some point in the course of their illness, they felt that the cause of their illness could have been witchcraft. I asked direct questions such as: 'What do you feel was the cause of your illness?' 'Have you ever considered witchcraft as a cause of your illness?' This enabled me to elaborate and refine the emerging concepts. It also enabled me to treat data as a whole rather than as fragments, as is recommended (Anderson, 2010).

I also undertook peer debriefing through regular meetings with my supervisory team to discuss the findings throughout the data collection, analysis and interpretation processes. Themes and relationships in the data were jointly reviewed, which also involved discussions about possible alternative explanations for the data and evolving analysis. This level of debriefing is known to clarify the interpretation process and increase the credibility of the analysis (Denzin and Lincoln, 1994). At the outset, before data collection, the research proposal was subjected to an examination which was also a form of peer review. The proposal was also subjected to a
review by the University’s ethics committee where useful opinions were gained. The initial research findings were also presented to the supervisory team and in internal seminars where useful comments were given. I endeavoured to make the whole research process transparent. I also maintained an audit trail by keeping research recordings, field notes, transcripts and memos. The supervisory team also examined the audit trail which consisted of the various documents from transcripts to analysis and interpretation documents, including the drafts of the different chapters.

10.7.2 Originality
Originality addresses the concern about whether the study has provided new insights regarding the phenomena under study. It is also concerned with whether the findings “challenge, extend or refine current ideas, concepts and practices” (Charmaz, 2014, p.337). The original aspect of this study was the insight provided into the delayed initial help-seeking by some individuals. It also provided insight into the economic, cultural and social context of living with lupus in Kenyan society, which has not been previously documented. In spite of the high poverty levels, patients and their families bore most of the burden of lupus care, both economically and socially, due to the low government health funding and due to the unclear lupus care pathway.

The study identified the lack of awareness about lupus amongst the patients and those around them, and the supernatural explanations for having lupus. The supernatural beliefs were also associated with the utilisation of alternative therapies which were specific to the supernatural beliefs, but very different from those used in the West. The study also identified the strong association of lupus symptoms with HIV, a stigmatised condition in Kenya, which contributed to the experience of stigma among some participants.

The study also brought into focus the perspectives of doctors, with regard to how the organisation and delivery of health services and the doctors’ skills and experiences contributed to diagnostic difficulties and treatment challenges in a resource-limited country. Despite the small sample size, the study identified the need to improve and expand rheumatology services in Kenya beyond the tertiary hospitals and the need to develop the human and material capacity for rheumatology care. In the reviewed literature, there was only one study which
identified health practitioners’ views on the patient education program (Miljeteig and Graue, 2009).

This study, therefore, provides fresh insights and in-depth understanding of living with lupus in Kenya and Africa for the first time with medical, social and theoretical significance. It also extends current documented knowledge about the concepts and practices of living with lupus from regions outside of Africa. By utilising grounded theory method, the study explored the topic from a wide range of perspectives through the views and perceptions of both the patients and doctors. The study revealed the complex social psychological processes which influenced the experience of living with lupus in Kenya.

10.7.3 Resonance
Resonance is concerned with the findings depicting the studied experiences of the participants and whether participants agree with the conclusions (Charmaz, 2014; De Witt and Ploeg, 2006). Resonance was sought by fully saturating the themes. The combination of interviewing both patients and doctors, together with the theoretical sampling and the evolving interview guide, helped to saturate the themes and fully identify variations in the themes. For example, I was able to determine that some participants experienced illness uncertainty and stigma both before and after receiving a lupus diagnosis. The contextual links gave a deeper insight into the lives of the participants.

10.7.4 Usefulness
Usefulness refers to the study's contributions to knowledge (Charmaz, 2014; Fendt and Sachs, 2008) and its transferability to other social contexts for either comparison or application (Speziale et al., 2011). Previous published evidence from Africa on the experiences and perspectives of those living with lupus was limited. Thus, in this study, the analysis of the participants' views contributed knowledge that led to a better understanding of the participants’ concerns and challenges, as discussed in sections 10.7.2 and 10.9.1. The knowledge generated can also be used to inform plans for interventions to improve the experiences of individuals living with lupus. Also, the knowledge generated can be used to inform future research.
10.8 Reflexivity

Reflexivity in research is the process of researcher's conscious awareness of their role and
influence on the research process (Finlay, 2002; Rice and Ezzy, 1999). In qualitative research,
reflexive practice acknowledges that the interaction between the researcher and the research
process, with regard to the researcher's views and beliefs, can affect the whole research
(Denzin and Lincoln, 1994; Silverman, 2013). Reflexivity, therefore, enables researchers to
make personal and theoretical biases explicit, thus potentially enhancing the credibility of the
findings (Murphy et al., 1998). Wilkinson (1988) suggests personal, professional and
disciplinary approaches to reflexivity in qualitative research which interconnect (Gough,
2016). In conducting this study, I was aware of my characteristics as a woman of Kenyan
origin and a nurse.

I was aware of the challenges of living as a woman in a male dominated society, and I knew it
was likely for me to be biased towards the women's experiences. However, I knew that I was
in a more privileged social position than most Kenyan women and therefore, I did not assume
that I understood all the women's experiences which the study needed to elicit. I also knew
that I had experience of taking care of patients with other chronic diseases, thus there was a
need to make a distinction between participants' voices and mine during data collection and
interpretation. As a nurse, I was aware of my privileged position. I had previously experienced
taking care of lupus patients in a private rheumatology clinic, thus I had some understanding
and perception regarding the general management of rheumatology patients and some of their
issues. This influenced my choice of topic. I also had some knowledge regarding the
communication styles between patients and health practitioners.

I was also aware of my responsibility as a researcher, as well as the need to be reflexive, about
the decisions relating to how the research was to be conducted. Regarding the methods and
their application, I was aware that I had previously not conducted any research independently.
I was therefore mindful of the fact that I needed to uphold the defined research practices,
including the perceptions of participants, interpersonal dynamics and communication styles. I
knew that I needed to understand and explain the perspectives on living with lupus in Kenya,
emphasising the concepts based on the social context of the study. Also, I needed to adhere to
the key techniques of grounded theory, such as constant comparison and theoretical
sensitivity, which facilitated the identification of themes from the data. This reduced the potential for bias and promoted rigour. I also adhered to the constructivist orientation of grounded theory as part of an interpretive tradition, which not only seeks to conceptualise the studied phenomenon but also acknowledges subjectivity, the need for dialogue, understanding and meaning (Charmaz, 2014).

Before starting to conduct the study, I realised that I had no experience of working in either of the two rheumatology clinics. In addition, I had not previously worked in a public healthcare institution. Thus, I assumed that the public clinic was a different clinical environment, and viewed myself as an outsider to the research setting with a lack of knowledge of existing policies and guidelines. Initially, I thought that this would probably impact on the recruitment process. I expressed this concern to the nurse managers, who introduced me to their staff, and I was assigned a nurse in each of the clinics to provide any assistance that I required. The clinic nurse was useful in identifying lupus patients and also facilitated my working relationships with the records officers. I also explicitly explained the study aims and objectives to the gatekeepers. The manager at the public hospital also advised me to wear a white coat which both the staff and the patients respected; she cautioned that otherwise, nobody would be willing to talk to me. Wearing the white coat was a challenge for me because I wanted to maintain my identity as a researcher and not as staff. To overcome the challenge, I dressed casually and presented myself as a student of The University of Manchester who was independent of the units, and I also wore my university identification badge throughout the data collection process. Also, in the participant information sheet, a statement was included which explained that the study was part of a PhD degree. My role as a nurse was very instrumental in developing a rapport and building professional relationships with the health professionals.

During data collection, I was aware that I needed to explore the participants’ concerns about the social aspects of the phenomenon. Therefore, I decided to use an interview guide with open-ended questions and use occasional prompts to support the interview and improve the participants’ accounts. I was also aware that I needed to begin the interview with general questions to develop a rapport with the participants (Holstein and Gubrium, 2000). I also used culturally accepted language such as addressing the participants with their titles, as appropriate, and using polite language. For example, we only discussed the participants’
sexual lives if they brought it up first because it is a topic which is not generally discussed in Kenyan culture. I also decided to write field notes and memos. During the interview, I was aware that I needed to identify similarities, contradictions and gaps in and across the data to move analysis from the descriptive to explanation level regarding what was occurring in the data, and to enable patterns to emerge from the data.

During data analysis and interpretation, I was aware of my pre-conceived ideas some derived from explanations which had already been explicated in the initial literature review. I reminded myself that I needed to suspend these ideas and focus on the current study which was being carried out in Kenya, which was a different social context and situation with inherent differences in power, communication and opportunity. I focused on the key features of grounded theory, such as performing the parallel tasks of data collection and coding, to ensure a structured approach and enable emergent themes to be explored in subsequent interviews. I also performed constant comparison and theoretical sensitivity during the whole process of data analysis and interpretation to identify the emerging themes and their explanations which were grounded in the data. This process included identifying what was common and what was rare among the participants' perspectives.

10.9 Strengths and limitations of the study

10.9.1 Strengths of the study

An important strength of this study is that it utilised the perspectives of both the patients and doctors. It explored the patients' experiences with symptoms, diagnostic difficulties, treatment and the impact of the condition on their lives. The doctor's perceptions provided an explanation for some of the patients' experiences, such as why lupus took a long time to be diagnosed, why patients took a long time to reach the rheumatology clinic, and the challenges they faced while providing care to individuals with lupus. This approach allowed the acknowledgement of different constructs of diagnostic difficulties and structural discrimination within the Kenyan healthcare structure. Women's voices were at the centre of the exploration, and the study focused on the black population.
The screening of patients for eligibility and the duration of their condition since diagnosis made it possible to recruit a purposive sample of patients with a range of disease duration and socio-demographic characteristics.

Robust research methods were used throughout the study, which included having regular debriefing sessions with my supervisory team. I also adhered to the principles of my chosen methodology. Also, to ensure the credibility of the study, close independent data checks were conducted by my three supervisors who had no connection with either the rheumatology clinics or the participants.

The study established that there were participants with various cultural identities who conceptualised illness causation differently and thus held different health practices. There was also evidence of dual access to both traditional and conventional medicine. This means that there is a need to provide culturally competent healthcare in the rheumatology clinics.

The study provides a starting point for further research on the experiences of living with lupus in other resource-limited countries. The findings in this study will be useful for informing health practitioners at the rheumatology clinics regarding different aspects of care provided to individuals with lupus, which may culminate in interventions or protocols to enhance the quality of care provided.

10.9.2 Limitations of the study

The findings of this study should be interpreted in the context of some limitations. First, the sample size was modest and cannot, therefore, be assumed to represent all patients with lupus in Kenya. The data presented were from participants who were identified from a manual patient record as there is currently no lupus registry. However, the study design was flexible and allowed for purposive and theoretical sampling; purposive sampling was followed by theoretical sampling which included consulting with the rheumatologists.

The study also did not capture the diversity within and between the Kenyan communities as there were no participants from some regions of Kenya because they were not found in the
patient records. However, I tried to ensure that there was as much variation as possible in the sample by considering factors such as geographical region, age, urban and rural residents.

The study also captured only two participants who had disengaged with treatment and failed to return. I only managed to interview one of them who attributed her disengagement to the cost of lupus care. The other individual declined to participate and claimed that she was healed and no longer suffered from the disease. Therefore, the study did not capture other barriers which could be contributing to patients opting out of treatment, other than financial barriers and cultural beliefs.

The study also relied on self-reports in the form of interviews which leaves a lot of room for social desirability bias (McDonald, 2008). A few participants requested the presence of some of their family members. This may have suppressed honest responses among some participants who depended on the same family members for support.

As all participants had been living with lupus for more than two years at the time of the interview, when I asked them how they felt before diagnosis, some of the information provided by the participants depended on their memory. Therefore, the accuracy of the information could be questionable in some cases due to recall bias, such as the symptoms they had at the beginning of their illness. For example, the doctors reported rash and alopecia more commonly than the patients.

There was also paucity of male patients in the clinics and therefore only one was interviewed. Interviews with more male patients might have brought different perspectives of the lupus experience. However, it is recognised that only 6-10% of men make up the lupus population between the ages of 15 and 50 years (Lahita, 1999).

Despite the limitations identified in this section, this is the first study of its kind in Kenya, and possibly in Africa, that offers some insights into the perspectives of living with lupus in Sub-Saharan Africa.
10.10 Implications and recommendations for policy, practice and education

The study set out to gain an insight into the perspectives of individuals with lupus and their doctors' on living with lupus in Kenya. The findings from the study provided some leads which if further explored and acted on, should improve the experience of individuals living with lupus. Some of the areas identified from the study with implications for policy, practice and education include:

- Delayed help-seeking by most patients which may suggest that in the Kenyan context, there may be some structural or personal factors that act as barriers to early help-seeking. The study established that some symptoms were not considered as being serious enough to warrant seeking medical attention. However, there is need to establish the barriers empirically.

- The diagnostic difficulties experienced by clinicians in primary care settings, and the delayed referral experienced by patients brought into focus the fact that managing patients with lupus required knowledge and skills that extended beyond the traditional training. Thus, there is a need to increase the awareness of rheumatological conditions with an emphasis on lupus among the primary healthcare providers. There is need to look at the current training curricula of doctors and clinical officers, with the aim of enhancing the content of the taught component of rheumatology. There is also a need to improve the clinical competency of the practicing clinicians. This might be possible if funding could be obtained to replicate training like the UWEZO project, which is conducted in collaboration between the Kenyan, UK and Swedish rheumatologists. The training has been successful in equipping health practitioners in Kenya with knowledge and skills relating to musculoskeletal health (Erwin et al., 2016).

- The fact that rheumatology is a sub-specialty and is relatively new in Kenya. It was noted that the care pathway for lupus was unclear due to the structure of the Kenyan health system. The study therefore highlighted the need to make rheumatological conditions visible to the policy makers so that it can be included among other non-communicable diseases during policy decisions. This would help in pushing forward the necessary training for both doctors and nurses, and the needed support for primary and secondary health facilities. This
should be coupled with a community survey on the prevalence of rheumatological conditions in Kenya to open the way for the additional training of rheumatologists, and to establish rheumatology services in the secondary and tertiary care facilities as appropriate.

- The need to develop local guidelines to support primary and secondary care physicians in the early identification and management of lupus patients. The study highlighted the need to develop a simplified version of the existing lupus guidelines which could be used in a low-resource setting. The tool would have to be more clinically inclined with non-immunological blood tests such as full blood count and erythrocyte sedimentation rate. To achieve this, there would be a need for collaboration between the rheumatologists from resource-poor settings like Kenya and the internationally established lupus organisations like the ACR and EULAR. This would provide an assessment tool to support the junior doctors and raise their suspicion index for lupus, and facilitate early referral of individuals suspected of having lupus. The guidelines would have to be disseminated widely through the Ministry of Health channels because the patients who attend the rheumatology clinic come from various geographical regions. This would also ensure quality standards and facilitate the development of backwards referral of stable patients to secondary care facilities in order to reduce the current congestion at the referral clinic.

- The fact that almost half of the participants had to travel from other counties to Nairobi County to seek lupus services. To reduce the physical distance travelled, the study highlighted the need to develop strategies for providing specialist support to secondary healthcare teams in order to improve their knowledge and care provision. Telemedicine, a new approach to patient care in rural Africa, could probably serve as a useful alternative for offering medical support to clinicians who lack some expertise in secondary care. They can conduct remote consultations with rheumatologists in Nairobi. Hjelm (2005) indicated that the use of telemedicine and teleconsulting offers the benefit of improved access to information and provision of care, together with eliminating other costs like travelling and consultation costs. He further states that this would also provide a learning opportunity from more experienced clinicians and the opportunity for personal professional development.
• The realisation that the public rheumatology clinic, which operates once a week, is overcrowded with an inadequate physical structure and inadequately coordinated patient care. This highlighted the need to free the rheumatologists from other general clinician responsibilities to enable them to offer rheumatology services more than once a week. Regarding the fragmented and uncoordinated care, there is a need to develop strategies for achieving a multidisciplinary approach to patient care to address the missing services, such as collaboration with other specialists like the renal team, patient education, counselling and support services. There is also an opportunity to develop the nurses’ role at the rheumatology clinic beyond their current role for the purpose of educating and counselling lupus patients and their families. In addition, there is a need to develop local patient education materials in the form of education pamphlets and websites with the help of other patient organisations like the British Society for Rheumatology and Lupus Foundation UK.

• The need to establish patient support groups which have been successful in other chronic diseases like post-renal transplants and HIV. These have been proven to be useful in counselling support and advocacy for reductions in the cost of treatment, and employer support regarding access to medical insurance and support by work colleagues.

• The burden of financing lupus care. There is a need for the health practitioners to illuminate the plight of poor people with chronic illnesses to policy makers, so that mechanisms for distributing the burden of financing healthcare in Kenya may be established. This may lighten the burden of out-of-pocket health expenditures for the patients and their families. The rheumatologists need to address this with the policy makers and consider ways of making the lupus tests and medications more available in the public hospitals, where the cost of care is subsidised by the government.

• The low public awareness of lupus among Kenyans calls for increased public education through the media and other channels. This will be useful in demystifying lupus and reducing the stigma currently associated with lupus. There is also a need to consider addressing cultural beliefs in the management of patients with complex chronic conditions, in light of possible cultural beliefs which could be interfering with their drug compliance.
10.11 Recommendations for future research

Some of the identified areas in the lives of patients with lupus which could be explored further are highlighted below:

- This study identified delayed help-seeking which was not attributed to any obvious factors. It would be useful to understand individual’s perceptions of health and the factors that contribute to delayed help-seeking in the Kenyan context.

- The apparent knowledge gap among primary and secondary care clinicians regarding the identification and care of lupus patients needs documenting to facilitate the formulation of effective intervention strategies. This would also highlight the inter-regional disparities across health services which could be affecting individuals with lupus from these areas in various ways.

- There is also a need for epidemiological studies to establish the burden of rheumatological diseases, including lupus, to assist in policy formulation regarding lupus.

- The study identified that a number of patients are inconsistent with their compliance to medication. There is a need to establish the factors that determine the treatment decisions among lupus patients in Kenya. Understanding this will illuminate the areas that need attention to improve compliance to medication.

- The study identified the significant role played by families in the provision of the necessary resources required for individuals living with lupus. It would be useful to explore the perceptions of the patients' families regarding their experiences and needs.

10.12 Conclusions

Prior to this study, the perspectives of people living with lupus in Kenya were unknown. In an attempt to contribute to this body of knowledge, the perspectives of individuals living with lupus and the doctors who had taken care of these individuals were explored. The findings showed that limited lupus services are available in Kenya. However, the experience of living
with lupus is riddled with challenges and mainly underpinned by the structure of the health services; the illness beliefs of individuals and communities; the availability of scarce resources and the negative impact of the illness on the individuals. For example, the findings regarding the structure of the health services provided an insight into why diagnosing lupus is more difficult in Kenya. The study highlighted some areas which demonstrated the tensions experienced by both patients and doctors with regard to many aspects of access and the provision of lupus care. A number of recommendations for policy, practice, education and research have been proposed, which could be useful in improving the experience of individuals living with lupus in Kenya.
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Lippincott Williams and Wilkins.


APPENDICES

### Appendix 1: American College of Rheumatology criteria for classification of lupus

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Definition</th>
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<tbody>
<tr>
<td>1. Malar rash:</td>
<td>Fixed erythema, flat or raised, over the malar eminences</td>
</tr>
<tr>
<td>2. Discoid rash</td>
<td>Erythematous circular raised patches with adherent keratotic scaling and follicular plugging; atrophic scarring may occur</td>
</tr>
<tr>
<td>3. Photosensitivity</td>
<td>Exposure to ultraviolet light causes rash</td>
</tr>
<tr>
<td>4. Oral ulcers</td>
<td>Includes oral and nasopharyngeal ulcers, observed by physician</td>
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<tr>
<td>5. Arthritis</td>
<td>Non-erosive arthritis of two or more peripheral joints, with tenderness, swelling, or effusion</td>
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<tr>
<td>6. Serositis:</td>
<td>Pleuritis or pericarditis documented by electrocardiography or rub or evidence of effusion</td>
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<tr>
<td>7. Renal disorder</td>
<td>Persistent proteinuria &gt;0.5 g/d or 3+, or cellular casts</td>
</tr>
<tr>
<td>8. Neurologic disorder</td>
<td>Seizures or psychosis without other causes</td>
</tr>
<tr>
<td>9. Hematologic disorder</td>
<td>Hemolytic anemia or leukopenia (&lt;4000/L) or lymphopenia (&lt;1500/L) or thrombocytopenia (&lt;100,000/L) without drug cause</td>
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<tr>
<td>10. Immunologic disorder</td>
<td>At least one of: Anti- double-stranded DNA (dsDNA), anti-Smith antibody (Anti-Sm), and/or anti-phospholipid</td>
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<tr>
<td>11. Positive Antinuclear antibodies</td>
<td>An abnormal titer of antinuclear antibodies (ANA) by immuno-fluorescence or an equivalent assay at any point in time in the absence of drugs known to induce ANAs.</td>
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<td></td>
<td>Lupus can be diagnosed if any 4 or more of the 11 criteria are present, serially or simultaneously, during any interval of observation</td>
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From Hochberg MG. Updating the American College of Rheumatology revised Criteria for the classification of systemic lupus erythematosus (letter). Arthritis and Rheumatism 1997;40:1725
### Appendix 2: Summary of pharmacological treatment and monitoring guidelines

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<td>For constitutional lupus</td>
<td>- Full blood count, serum creatinine, urinalysis</td>
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<td>(Bertsias et al.</td>
<td>- antimalarials,</td>
<td>Also other tests, including C3/C4, anti–double-stranded DNA (anti-dsDNA), antiphospholipid, anti-</td>
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<td>- corticosteroids,</td>
<td>RO/SSA, C-reactive protein, serum albumin, estimated glomerular filtration rate (GFR), and</td>
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<td>- nonsteroidal anti-inflammatory</td>
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<td></td>
<td>drugs</td>
<td>- Monitoring of comorbidities</td>
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<td>- Vitamin D and calcium supplements</td>
<td>- Multidisciplinary care involving nephrologists, rheumatologists, and other appropriate</td>
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<td>for preventing osteoporosis in</td>
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<td>- antihypertensive drugs and statins</td>
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<td>- Monitoring of drug toxicity</td>
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<td>- Quality of life monitoring by clinical interview</td>
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<td></td>
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<td>and/or visual analogue</td>
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<td>- 6-12 monthly assessment for patients with inactive lupus with no damage or comorbidity</td>
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<td>- Monitoring comorbidities all patients with lupus should be assessed for adequate calcium</td>
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<td>intake, vitamin D intake, regular exercise, smoking status, cardiovascular risk factors,</td>
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<td>blood cholesterol, glucose, body mass index, and blood pressure</td>
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<td></td>
<td>A 5 year Ophthalmologic examination for patients taking antimalarial medication</td>
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<td><strong>T2T International Task Force 2014</strong></td>
<td>For constitutional lupus</td>
<td>- 3-6 monthly assessment for mild disease and increased frequency for severe active disease</td>
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<td>(Van Vollenhoven</td>
<td>- antimalarial drugs</td>
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Appendix 3: Example of search strategy process (Medline search)

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Appendix 4: Hawker’s Assessment tool (Hawker et al., 2002)

Part A

Author and title: _____________________________

Date: _______________________________________

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<td>6. Ethics and bias</td>
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<td>7. Findings/results</td>
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<td>9. Implications and Usefulness</td>
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Part B: Assessment Criteria

1. Abstract and title: Did they provide a clear description of the study?
   Good: Structured abstract with full information and clear title.
   Fair: Abstract with most of the information.
   Poor: Inadequate abstract.
   Very: Poor No abstract.

2. Introduction and aims: Was there a good background and clear statement of the aims of the research?
   Good: Full but concise background to discussion/study containing up-to date literature review and highlighting gaps in knowledge. Clear statement of aim AND objectives including research questions.
   Fair: Some background and literature review. Research questions outlined.
   Poor: Some background but no aim/objectives/questions, OR Aims/objectives but inadequate background.
   Very Poor: No mention of aims/objectives. No background or literature review.

3. Method and data: Is the method appropriate and clearly explained?
   Good: Method is appropriate and described clearly (e.g., questionnaires included). Clear details of the data collection and recording.
   Fair: Method appropriate, description could be better. Data described.
   Poor: Questionable whether method is appropriate. Method described inadequately. Little description of data.
   Very Poor: No mention of method, AND/OR Method inappropriate, AND/OR No details of data.

4. Sampling: Was the sampling strategy appropriate to address the aims?
Good: Details (age/gender/race/context) of who was studied and how they were recruited. Why this group was targeted. The sample size was justified for the study. Response rates shown and explained.
Fair: Sample size justified. Most information given, but some missing.
Poor: Sampling mentioned but few descriptive details.
Very Poor: No details of sample.

5. Data analysis: Was the description of the data analysis sufficiently rigorous?
Good: Clear description of how analysis was done. Qualitative studies: Description of how themes derived/ respondent validation or triangulation. Quantitative studies: Reasons for tests selected hypothesis driven/ numbers add up/statistical significance discussed.
Fair: Qualitative: Descriptive discussion of analysis. Quantitative: The process of data analysis.
Poor: Minimal details about analysis.
Very Poor: No discussion of analysis.

6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?
Good Ethics: Where necessary issues of confidentiality, sensitivity, and consent were addressed. Bias: Researcher was reflexive and/or aware of own bias.
Fair: Lip service was paid to above (i.e., these issues were acknowledged).
Poor: Brief mention of issues.
Very Poor: No mention of issues.

7. Results: Is there a clear statement of the findings?
Good: Findings explicit, easy to understand, and in logical progression. Tables, if present, are explained in text. Results relate directly to aims. Sufficient data are presented to support findings.
Fair: Findings mentioned but more explanation could be given. Data presented relate directly to results.
Poor: Findings presented haphazardly, not explained, and do not progress logically from results.
Very Poor: Findings not mentioned or do not relate to aims.

8. Transferability or generalisability: Are the findings of this study transferable (generalisable) to a wider population?
Good: Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling).
Fair: Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4.
Poor: Minimal description of context/setting.
Very Poor: No description of context/setting.

9. Implications and usefulness: How important are these findings to policy and practice?
Good: Contributes something new and/or different in terms of understanding/insight or perspective. Suggests ideas for further research. Suggests implications for policy and/or practice.
Fair: Two of the above (state what is missing in comments).
Poor: Only one of the above.
Very Poor: None of the above.

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<td>29. Williams et al, 2015</td>
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<td>30. Brennan &amp; Creaven, 2016</td>
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### 5b: Mixed studies

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## Appendix 6: Summary of included studies

### a) Qualitative studies

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<tr>
<th>#</th>
<th>Author, year and country</th>
<th>Study aim</th>
<th>Study design and Methods</th>
<th>Sample</th>
<th>Main findings</th>
<th>Strengths, limitations, and appraisal score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Karlen, 2002, US</td>
<td>To explore the impact of lupus on women’s sexuality</td>
<td>Qualitative - Design not indicated - Purposive sampling - Non directive interviews - Thematic content analysis</td>
<td>Women between 25 to 51 years</td>
<td>Impact of lupus on sexuality - Most women felt their appearance had changed, making them feel detestable - Rejected love from partner and retreated from sex. - Had diminished sexual desire due to fatigue and steroid use - Felt lack of empathy by partner - For some women, coping with lupus brought improved sexual function and improved relationships</td>
<td>Strengths - Sample characteristics described - In-depth flexible approach to data collection well described</td>
</tr>
<tr>
<td>Author, year and country</td>
<td>Study aim</td>
<td>Methods</td>
<td>Sample</td>
<td>Main findings</td>
<td>Strengths, limitations, and appraisal score</td>
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<tr>
<td>Mendelson, 2003, US</td>
<td>To describe the types of support available to individuals with lupus who participate in internet listervs</td>
<td>Qualitative - Observation of 3 Internet support group postings - Inductive analysis</td>
<td>1187 discrete posts to 3 internet listervs made by 90 participants</td>
<td><strong>Available support on the internet</strong> - Participants indicated that they share information with each other - Provide emotional support to each other regarding illness and living with the illness - Give informational content and support for life activities - Internet found flexible and sometimes used to address social issues.</td>
<td><strong>Strengths</strong> - Ethical consideration to ensure participant anonymity well explained - Data collection method well described - Data analysis and audit trail clearly explained <strong>Limitations</strong> - Participants self-selecting, non-contact bias possible - Not easy to establish if all participants were patients or not <strong>Score 32</strong></td>
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<tr>
<td>Goodman et al, 2005, Australia</td>
<td>To explore the content of illness representation (patients’ experience with lupus over time)</td>
<td>Qualitative Phenomenological approach</td>
<td>36 women, 4 men</td>
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<td><strong>Beliefs about cause of illness included:</strong> hereditary, virus and stress most popular. Others beliefs included social and environmental factors, such as sun exposure, prescribed medications, pregnancy and chemicals. <strong>Sources of information on cause of the disease</strong> -Most obtained information from their rheumatologists, friends, family and support groups. -Some were distressed by the information. <strong>Illness representation reported</strong> - physical pain and fatigue - social-inability to work and have leisure, effect on family and friends, relationship breakdown -Psychological-, depression, hopelessness, low self-confidence and self-esteem. The distress reduced over time -Positive attitude towards the illness resulted in less distress over time. -Few participants were positive. This was based on illness coherence <strong>Concerned about:</strong> -Disease taking long to be diagnosed following onset of symptoms -Consequences of the disease, -deterioration of condition in the future. -Many participants had good knowledge about lupus, signs and symptoms, treatment and flares, some not able to tell if they were in flare or not. -Most acknowledge lupus as chronic disease but hoped for a cure.</td>
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<td><strong>Strength</strong> -Appropriate method for understanding phenomena of illness representation -Data collection and analysis clearly explained -Study contributes illness representation over time</td>
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<td><strong>Limitations</strong> -Sample lacking details like age, and duration of illness -Sampling technique not indicated -Reflexivity of accounts not clarified</td>
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<td><strong>Score 32</strong></td>
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<td></td>
<td>Author, year and country</td>
<td>Study aim</td>
<td>Methods</td>
<td>Sample</td>
<td>Main findings</td>
<td>Strengths, limitations and appraisal score</td>
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<td>4</td>
<td>Hale et al, 2006a, UK</td>
<td>To understand the concerns of lupus patients about their appearance and the recognition of this by healthcare professionals</td>
<td>Qualitative -Phenomenology -convenience sampling -Face-to-face semi-structured interview -Interpretative phenomenological analysis (IPA)</td>
<td>10 Women</td>
<td><strong>Concerns about appearance</strong> Observable physical changes caused by the chronic disease made them - become publicly self-conscious - feel less attractive -Cosmetics and clothes used to hide the self which make them appear different. -Negative impact on Self-esteem and altered self-concept -Self-imposed isolation related to depression -Experiencing minimal psychological support. -Poor understanding of lupus by family, friends and work colleagues <strong>Health professionals</strong> -Minimal explanation regarding disease given by health professionals</td>
<td><strong>Strengths</strong> - Detailed information about the sample -Type of interview and data collection procedure clearly explained. -Clear description of data analysis -Study contributes knowledge to subjective concerns about changed physical appearance in lupus <strong>Limitations</strong> - Reflexivity of the account not clarified <strong>Score 33</strong></td>
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<tr>
<td>5</td>
<td>Author, year and country</td>
<td>Study aim</td>
<td>Methods</td>
<td>Sample</td>
<td>Main findings</td>
<td>Strengths and limitations, and Appraisal score</td>
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<tr>
<td>Hale et al. 2006 b, UK</td>
<td>To examine the perceptions of patients with lupus about their healthcare provision in the UK</td>
<td>Qualitative - Phenomenology - Convenience sampling - Face-to-face semi structured interview - Interpretative phenomenological analysis (IPA)</td>
<td>10 women</td>
<td><strong>Perceptions on healthcare provision</strong> - Initial definitive diagnostic delays - Lack of knowledge among Health care professionals on lupus - Unmet information needs caused unvoiced concerns about symptoms, tests, drugs and prognosis - Felt their healthcare was poorly integrated due to lack of interdisciplinary communication - Lack of psychosocial support among lupus specialists - Poor understanding of lupus fluctuation amongst family, friends and employers</td>
<td><strong>Strengths</strong> - Research design appropriate to nature of inquiry - Data collection from two centres made transferability of findings possible - Audit trail clearly explained - Study contributes knowledge regarding patients' perceptions about the inadequate healthcare <strong>Limitations</strong> - Reflexivity of account not clarified</td>
<td><strong>Score 32</strong></td>
</tr>
<tr>
<td>Author, year and country</td>
<td>Study aim</td>
<td>Methods</td>
<td>Sample</td>
<td>Main findings</td>
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<tr>
<td>Mendelson, 2006, US</td>
<td>To explicate the daily experience of women living with lupus</td>
<td>Qualitative -Focused Ethnography -Internet narratives -Ethnographic interviewing -Participant observation -Maintenance of health journal -Immersion and crystallization</td>
<td>Sample One-7 women interviewed Sample Two-52 women recruited through electronic mailing lists</td>
<td><strong>Daily experience</strong> -Challenge of managing a medically and socially complex life -Managing: Initial diagnostic delays, life of uncertainty, health issues like fatigue, unpredictable periods of remission and flares, relying on others -A shifting sense of identity -Need to modify roles at home and at work -Dependence on medications and medical supervision -Poor understanding of disease -Alteration in body image due to illness and medication -Managing financial burden due to loss of income and cost of treatment</td>
<td><strong>Strengths</strong> -Focused ethnographic design well suited for comprehensive data collection -Triangulation of data source and methods of data collection facilitated capturing of different perspectives of the phenomena -Response rate of internet participants indicated <strong>Score 30</strong></td>
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<tr>
<td>7</td>
<td>Author, year and country</td>
<td>Study aim</td>
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<td>Mattje and Turato, 2006, Brazil</td>
<td>To know lupus outpatients' life experiences, in terms of the meanings they attributed to several phenomena associated to the process of becoming ill.</td>
<td><strong>Qualitative</strong> -Case study -Semi-structured interview with open-ended questions -Content analysis</td>
<td>5 Women Purposive sampling</td>
<td><strong>Life experiences</strong> -Poor understanding of lupus by friends and family -Life of uncertainty -Sense of isolation -sexual difficulties -Indented self-concept and self esteem -Coping with symptoms like fatigue -Hope for recovery</td>
<td><strong>Strengths</strong> -Aims of the study clearly stated -Results clearly explained <strong>Limitations</strong> -Abstract scantily described -Small sample size may prohibit transferability of findings -Description of methodology mixed up, needed to be simplified -Data analysis superficially described thus limiting implications and usefulness of the study</td>
<td><strong>Score 26</strong></td>
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<tr>
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<td>Study aim</td>
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<td>Nowicka-Sauer, 2007, Poland</td>
<td>To examine the variety of ways of illness perception and experiences among lupus patients</td>
<td>Qualitative - Drawings - Study design not stated - Method of data analysis not stated</td>
<td>38 Women</td>
<td><strong>Illness perceptions and experiences in drawing</strong> - Lupus drawn as one animal with many heads and faces which sometimes cry, feel pain, feel angry and sad - Sometimes accept the condition. But the many stages come back. - Lupus compared to hydra which attacks many parts of the body and it is sometimes hard to bear it especially during flares. - Lupus also drawn as a monster with a human shape that bites at times</td>
<td><strong>Strengths</strong> - Drawings gave insight regarding patients' non-verbal inner views of themselves. <strong>Limitations</strong> - Ethical issues not addressed - Study design, sampling technique and method of data analysis not indicated - Demographic details of sample not indicated <strong>Score 25</strong></td>
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| Stamm et al, 2007, Austria | To explore concepts important to patients with chronic lupus | Qualitative  
-Design not indicated  
-Focus group discussions  
-Meaning condensation | 21  
-20 females 1 male  
Participants from rheumatology clinic | Concepts important to lupus patients  
- Concepts related to body functions and structures: Course of disease which includes flares, and waxing and waning symptoms, thoughts of hereditary transmission, drugs.  
-Concepts related to activities and participation: Loss of time, loss of income, long time before diagnosis, giving up career plans, own attitudes towards lupus.  
Concepts related to environmental factors: Other people's attitudes, support, friends, colleagues, professionals, employers policies | Strengths  
-Selection of study sample clearly explained  
-Data collection and analysis processes clearly explained  
Limitations  
-Study design not indicated  
-Findings not discussed in much details |
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<th>Author, year and country</th>
<th>Study aim</th>
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<th>Main findings</th>
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</table>
| Stockl, 2007 UK          | Explore lupus as a complex syndrome and the impact of lupus on patients life and their reaction to the situation | Qualitative -Ethnographic observation and grounded theory methods -Convenience sampling -Observed self-help groups -Semi structured interviews -Grounded theory and discourse analysis approach | 30 28 females 2 males | **Lupus as a complex syndrome**  
- Experienced uncertainty in diagnosis by health personnel and misdiagnosis (being told that symptoms are due to stress and viral infection)  
- Did self-referral to doctors, also referred to different doctors by health personnel, still ended with wrong diagnosis, conflicting diagnosis or no diagnosis.  
- Not having a diagnosis for a long time, sense of loss of dignity  
- Reinterpretation of identity and sense of self, felt left alone  
- Received inadequate information  
- Self diagnosed from information obtained from family and internet **Seeking for a Diagnosis**  
- From the medical professionals to determine legitimacy of feeling ill  
- Avoiding being stigmatised as being mentally ill **Strained doctor-patient relationship** as the authority to diagnose and prescribe rested with the doctors due to their expert knowledge.  
- Need to meet ACR criteria before diagnosis.  
- Doctors not consistent in use of lupus criteria guidelines.  
- Patients who didn’t meet the criteria felt punished because they experienced some of the symptoms yet they could not get medication as per the ACR criteria. They felt punished by the rituals of verifying a diagnosis. **Social strains**--nobody believed how sick they felt  
- Patients also didn’t understand why they felt so tired  
- Joining self-help groups gave comfort  
- Male patients felt bad about being feeble. Got more information from internet | Strengths  
- Method of data collection appropriate to study design  
- Study established inconsistent use of lupus guidelines  
- Brought out the gender based differences in patients experiences  
Limitations  
- Application of grounded theory principles not clearly explained in the study  
- Data analysis process not clearly explained | Score 30 |
<table>
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<tr>
<th>Study aim</th>
<th>Methods</th>
<th>Sample</th>
<th>Main findings</th>
<th>Strengths, limitations and appraisal score</th>
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<tr>
<td>To examine the place occupied by chronic illness in the inner lives of women suffering from lupus</td>
<td>Qualitative - Phenomenology - Sampling technique not indicated - Face-to-face interview - Thematic analysis</td>
<td>15 Women</td>
<td><strong>The place occupied by chronic illness</strong> - Illness was seen as something evil, something demonic and personified as an evil enemy - Lupus affected personality Physical and mental suffering, - Broken relationships with spouse - Sexuality problems - Familial discord leading to divorce - Unpredictable nature of the illness - Uncertainty about the future - Anxiety about death - Emotional issues of guilt, unresolved anger and shame, intimacy dependency/autonomy, control, loss, guilt - Sense of isolation being left alone - Self isolation-withdrawing to stay alone due to feeling of inferiority - Hope for healing</td>
<td>Strengths - Data collection process clearly explained - Good description of findings and explanation of data analysis - Study adds knowledge to patients’ meaning of the impact of lupus on their personality which is mainly due to the physical and mental suffering <strong>Limitations</strong> - Sampling technique not clearly explained - Reflexivity account not indicated <strong>Score 30</strong></td>
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<tr>
<td>Author, year and country</td>
<td>Study aim</td>
<td>Methods</td>
<td>Sample</td>
<td>Main findings</td>
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| Howe 2009, US            | To examine perceptions regarding the influence of social support in coping with depression among African-American women living with lupus | Qualitative - Grounded theory - Semi-structured interview and observation - Grounded theory analysis | 10 women | **Influence of social support**  
Social support played a major role in the development of coping strategies, in the management of lupus and depression | **Strengths**  
- Abstract scantily described  
-Good description of study introduction and methods.  

**Limitations**  
- Data collection and analysis processes did not include theoretical sampling and constant comparative analysis  
- Not clear if the interview guide was amended after the first focus-group interview to include emerging data  
Method of data analysis was not specifically described.  
Findings mentioned but more explanations could have been given.  

**Score 29**
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<tr>
<th>Author, year and country</th>
<th>Study aim</th>
<th>Methods</th>
<th>Sample</th>
<th>Main findings</th>
<th>Strengths, limitations and appraisal score</th>
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<tbody>
<tr>
<td>McElhone et al, 2010, UK</td>
<td>Identify the impact of living with lupus directly from patients in relation to Health related quality of life</td>
<td>Qualitative -Phenomenology -Purposive sampling -Semi structured interviews -Interpretative phenomenological analysis</td>
<td>30 women</td>
<td><strong>Impact of illness</strong> Impact of the disease and its treatment ‘on an individual’s ability to function and their perceived well-being in physical, mental and social domains of life. <strong>Concerns</strong> -body image-effects of disease and treatment-e.g. rash, scarring and weight gain with steroids use -emotional difficulties such as anger, frustration, anxiety and poor self esteem -Disease limiting family size - Inability to plan ahead –unpredictability of the disease, leading to self-isolation. -Fatigue and pain preventing them from doing chores -A challenge to explain and receive support prognosis and course of disease <strong>About the future</strong> -Career prospects and loss of income -Memory loss/concentration -Reliance on others to assist with everyday tasks Positive impact-genuine excuse to give up a job they did not enjoy doing. -Good relationships with friends due to lupus</td>
<td><strong>Strengths</strong> -Best approach to explore phenomena of impact of lupus. -Demographic details of participants outlined -Data collection and data analysis processes clearly explained -Study added knowledge regarding subjective experiences of living with lupus <strong>Limitation</strong> Reflexivity of account not indicated <strong>Score 31</strong></td>
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<td>Author and country</td>
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<td>Sample</td>
<td>Main findings</td>
<td>Strengths, limitations and appraisal score</td>
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| Pettersson et al., 2010, Sweden | To describe women’s experience of lupus-related fatigue. | Qualitative, Focus group discussions, Content analysis | 33 women | **Experience of lupus-related fatigue**  
- Nature of Fatigue, overwhelming involved a bodily sensation, occurred constantly and in peaks and had a controlling and unbeatable character.  
- Character of fatigue unpredictable  
- Fatigue dominating and controlling most situations in life  
- Aspects affected by fatigue included emotions like anger and powerlessness, social contacts and interaction at work, family life, leisure activities  
- Striving towards power and control concluded the array of ways used to manage daily life. Categorized into the mental struggle, pacing daily life, establishing boundaries and focusing on rest.  
- Factors influencing perception of fatigue was pain and lack of understanding from surrounding people like family, society and healthcare system | **Strengths**  
- Participants recruitment clearly described  
- Data collection process clearly described  
- Use of focus group facilitated collection of diverse perspectives on fatigue as it stimulated interactions between patients  
**Limitations**  
- Use of observational notes in data analysis not indicated  
- Sampling technique not indicated |
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| Taieb et al, 2010, France | To explore patients’ beliefs about causes of lupus | -Kleinman's explanatory model  
- purposive sampling with random selection  
- Face-to-face semi-structured interview  
- Interpretative phenomenological analysis | 33 Women | **Patients' beliefs about the causes of lupus**  
- The most frequent beliefs autoimmunity,  
- psychological distress and familial events like loss of a close person or conflict with family  
- Heredity transmission,  
- Seen as a contagious infectious disease  
- Magico-religious causes (especially among migrants)  
- A latent disease which, ‘already there’ | **Strengths**  
A clearly presented study with good methodological aspects  
- Sample included a variety of possible cases  
- Various meanings of illness causation established which contributed useful knowledge  
- Reflexivity account given |

Score 31
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<tr>
<td>Beckerman 2011, US</td>
<td>To identify and clarify the unique psychosocial challenges for those living with lupus.</td>
<td>Qualitative Approach - design not specified - Convenience sampling, recruited from rheumatology clinic - Focus group - Thematic analysis</td>
<td>32 women</td>
<td>The psychosocial challenges and needs The four key challenges included: (1) feeling depressed that they are not who they used to be, (2) feelings of depression and anxiety related to coping with the uncertainty of the illness, (3) physical and emotional fatigue of living with a chronic illness, and (4) coping with the financial strain of the illness.</td>
<td>Strengths - Research design not indicated - Method of data collection appropriate and clearly explained - Focus group method facilitated exploration of psychosocial challenges - Sampling variation clearly explained - Observational notes included in data analysis - Development of themes clearly illustrated Limitations - Ethical issues not addressed</td>
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<td>Kumar et al, 2011, UK</td>
<td>To investigate factors that influence beliefs about medicines in patients of South Asian origin with rheumatoid arthritis (RA) and systemic lupus erythematosus (lupus).</td>
<td>Qualitative methodology -Recruitment from Hospital based database and rheumatology clinic -Focus groups with open-ended questions -Method of analysis not specified</td>
<td>14 women</td>
<td>Beliefs about medicines in patients of Southeast Asian origin Three main themes emerged to explain patients beliefs about medicines: (1) Beliefs about the necessity of DMARDs in controlling symptoms. (2) Concerns about DMARDs and other prescribed medicines regarding: (a) long-term side-effects; (b) the apparent lack of efficacy of some therapies; (c) concerns about changing from one drug to another and the large numbers of different medicines being taken due to lack of understanding. (3) Contextual factors which informed the patient’s view on the necessity for particular medicines and concerns about them: (a) Beliefs about the causes of disease which were different from English and non-English speaking patients and the influence of religious beliefs on this. (b) Communication barriers between non English speaking patients and healthcare professionals about the medications and use of translators not always successful. -Different beliefs about cause of illness led to traditional treatments among non-English speaking patients which was also seen as less harmful.</td>
<td>Strengths -Study design and method of analysis not indicated. -Participant selection and recruitment clearly explained -Focus group appropriate for exploring beliefs -Gave descriptive discussion of data analysis Limitations Sampling technique and method of data analysis not specified Score 31</td>
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| 18 Miles, 2011, Ecuador   | To investigate the experiences of urban Ecuadorian women suffering from lupus | Qualitative - Ethnography - Snowball sampling - Face to face semi structured interview twice or thrice - Method of data analysis not clearly explained | 20 women | **Illness experience**  
- Living with ambiguous chronic illness with general lack of biomedical knowledge  
- Difficult aspects of living with lupus was the physical changes in appearance as a consequence of the disease or steroid use, made them feel ugly.  
- Experience of stigma as the word autoimmune was associated with HIV infection, morality and contagion. Experience of feeling that God had brought the disease due to their past moral behaviour  
- Illness impeding their ability to fulfil established social roles like family and family responsibilities in terms of being daughters, mothers and wives. Lupus had disrupted marital relationships.  
**Treatment experience**  
- Structural constraints to accessing reliable healthcare included financial constraints,  
- Acute care model of care offered in primary care,  
- Same day appointment policy and unavailability of required laboratory tests in the public health facilities. | **Strengths**  
- Method appropriate for exploring experiences in the cultural and social context.  
- Characteristics of sample clearly explained.  
- Data collection process clearly explained  
**Limitations**  
- Sampling technique not clearly explained  
- Ethical issues not addressed  
- Data analysis not clearly explained |
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<tr>
<td>Ow et al, 2011, Singapore</td>
<td>To identify health-related quality of life (HRQOL) domains of importance to multi-ethnic Asian lupus patients,</td>
<td>Qualitative -Grounded theory -Focus group, -Semi-structured interview with male participants -Thematic analysis</td>
<td>29 (27 female 2 male)</td>
<td>HRQOL domains of importance to patients -Physical symptoms which included pain, fatigue and sleep disturbance Impact on activities, emotional states and work - Difficulties experienced in performing ADLs, leisure activities, social activities and ability to start a family. Altered emotional state - Anger, Anxiety, and Depression. Male participants added experiencing challenges with coping with the physically demanding outdoor nature of their work. Impact on one's work, income and ability to provide for their families</td>
<td>Strengths -Aims of the study clearly stated -Identification and recruitment of participants well explained -Sample homogenous Limitations -Ethical concerns not addressed -Data collection and analysis processes did not include theoretical sampling and constant comparative analysis -Not clear if the interview guide was amended after the first focus-group interview to include emerging data</td>
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| 20 | Waldron et al, 2011, UK  | To identify the information needs of patients newly diagnosed with lupus | Qualitative - Grounded theory - Focus groups - Thematic inductive analysis | 43 | - At the beginning there was diagnostic uncertainty and misdiagnosis by health professionals. Some experienced trauma of being misdiagnosed - Feeling of relief when finally received a diagnosis, despite its implications. Many felt empowered by receiving recognition of their symptoms. **Information needs at early stage of diagnosis**  
  ‘Impact of early information’ (Theme 1)  
  - Information was scant and, most had little prior knowledge of lupus,  
  - the information was difficult to absorb, leaving them with feelings of fear and confusion.  
  ‘Information received versus information sought’ (theme 2)  
  - Few participants felt they had received clear, consistent information. | **Strengths**  
  Use of focus group allowed participants to validate or challenge one another's their views  
  - Interview guide amended after the first focus group interview in response to emerging data  
  - Multiple data collection centres also brought diversity of participants and information.  
  - Data analysis clearly described  
  **Score 33** |
- For most, information was insufficient, forcing them to seek it elsewhere, which, if unsuitable, resulted in further distress.

‘Early education needs’ (theme 3)
- Patients would rather be informed of potential problems than remain naïve.
- Patients felt that receiving a comprehensive information pack as an adjunct to verbal information from their doctors would be helpful, along with rapid access to knowledgeable professionals when they were ready to ask questions about their lupus.
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</table>
| Gallop et al, 2012, US   | To explore the impact of lupus symptoms on patients' health related quality of life | Qualitative - Cross-sectional, - Purposive sampling - Face-to-face semi structured interview - Thematic analysis | 22 | **Perspectives on symptoms and impact on quality of life**
- Commonly reported symptoms were pain, fatigue/tiredness and skin problems.
- Seven themes relating to the impact of lupus symptoms on patient's Health Related Quality of Life (HRQL) were:
  - Negative impact on appearance,
  - Cognition- having problems with concentration
  - Difficulty in carrying out daily activities
  - Emotions- feeling of anger, helplessness, depression and incompetence
  - Employment activities-experiencing reduced working hours, absenteeism and early retirement
  - Varied loss of independence
  - Modifying social, family and leisure activities. | **Strengths**
Abstract, study aims and methods clearly stated
- Participants inclusion criteria and recruitment clearly explained
- Data collection procedure clearly explained
- Data analysis process clearly described | **Score 32** |
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| 22 | Mattson et al, 2012, Sweden | To describe how patients with established lupus experience their illness in everyday life | Qualitative | 19 | **Illness experience**  
- Multi-faceted uncertainty  
- Unreliable body  
- Difficulty in differentiating between illness and other conditions.  
- Difficulty in determining whether they were in flare or not  
- Experience of obtrusive pain, and incomprehensible fatigue  
- Experience of mood changes and worries  
- Reliance on medication and healthcare  
- Limitations in activities and work  
- Challenge of explaining and receiving support | **Strengths**  
- Abstract clearly written  
- Study methods clearly stated  
- Identification and recruitment of study participants clearly explained  
- Data collection and data analysis processes clearly described  

**Limitations**  
Sampling technique not indicated  

Score 32 |
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<tbody>
<tr>
<td>Mazzoni &amp; Cicognani, 2014</td>
<td>Explore the experiences of problematic support</td>
<td>Qualitative - Purposive sampling - Face to face interviews - Qualitative content analysis</td>
<td>9 women</td>
<td><strong>Problematic support</strong> - Oppressive support: Parents and friends became too present worrying too much and making unwanted remarks - Denying the illness as fictitious, not accepting it or not considering the person as ill - Giving divergent illness and representations: underestimating the disease, not giving useful information, and not allowing patients to carry out activities</td>
<td><strong>Strengths</strong> - Fairly good background and literature review - Method appropriate but needed more description - Analysis clearly described, ethical issues clearly addressed - Gave clear statements of results <strong>Limitation</strong> - Abstract lacking adequate information <strong>Score 32</strong></td>
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<td>Neville et al, 2014, Canada</td>
<td>Identify information and resource needs of persons with lupus and Healthcare providers treating lupus</td>
<td>Qualitative - Focus group - Grounded theory analysis</td>
<td>57 (8 focus groups) - 4 groups for lupus patients - 3 groups of rheumatologists - 1 group of Allied health professionals</td>
<td>Informational and resource needs of persons with lupus, rheumatologists and allied health professionals Four main themes emerged: 1. Persons with lupus need specific information on lupus and support resources to help manage their illness 2. Barriers to engagement in healthcare include lack of awareness in medical and non-medical arenas, language and cultural barriers; and authoritative doctor-patient relationship 3. Facilitators of engagement in healthcare; include tailored information based on individual disease characteristics 4. Tools identified as helpful for the self-management of lupus include lifestyle choices. Information needs change over time</td>
<td>Strengths - Use of multiple centres ensured diversity of participants - Focus group method of data collection useful in facilitating participants to validate or challenge one another's their views - Process of data collection and analysis clearly described Limitations Not indicated if purposive sampling was carried out to achieve a homogenous sample - Use of theoretical sampling not reported - Not indicated if the interview guide was amended after the first focus group interview - No description of the nature of group dynamics Score 31</td>
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<tr>
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<td>Spry, 2014, Canada</td>
<td>To explore the barriers and limitations that are suffered by people with lupus</td>
<td>Qualitative - Semi-structured interviews</td>
<td>15</td>
<td>Various general limitations on participants' life caused by varying disease expression such as pain and fatigue and severity  - Misconceptions about lupus - people associating lupus with HIV/AIDS, others associating it with a form of Cancer  - Lack of positive support systems from family friends and work colleagues and dealing with lack of support  - Negative body image issues in the form of appearance - hair loss, scarring, rapid weight loss and weight gain, and rashes  - Experiencing stigma from family friend and the general public  - Depression as a result of stigma  The gendered experience of lupus where men felt their diagnosis was delayed because health professionals did not &quot;think outside the box&quot;  It was also an impediment to creating awareness and garnering financial support from the public as people thought it was a women's disease  Having fear about the future and frustrated dreams, coping by staying active and socially involved.</td>
<td>Strengths  - Patient identification and recruitment clearly explained  - Study findings clearly stated  Limitations  - Sampling technique not clearly explained  Data analysis process not clearly explained.  Score 31</td>
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<tr>
<td>Sterling, K. L., et al., 2014, USA</td>
<td>To explore the experience of fatigue in patients with lupus and its impact on their lives.</td>
<td>Qualitative - Cross sectional - Purposive sampling - Semi structured interviews and - Thematic analysis</td>
<td>22 women</td>
<td>Patients reported fatigue as fatigue or tiredness - Fatigue is variable in nature and frequency - Has an impact on multiple aspects of an individual's life: emotions, Work, ADLs, leisure, social and family activities</td>
<td>Strengths - Abstract, study aims and methods clearly stated - Data analysis clearly explained - The study generated good knowledge and demonstrated how fatigue had an impact on patients' ability to function</td>
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<tr>
<td>Hale et al., 2014, UK</td>
<td>To explore experiences of body image, self-image and medication use in patients diagnosed with lupus</td>
<td>Qualitative -Phenomenology -Purposive sampling -Semi-structured interviews -Interpretive phenomenological analysis</td>
<td>15</td>
<td><strong>Experience with body image and self-image</strong> -significant dissatisfaction with body image due to weight gain and skin changes, and posture and gait changes, related to steroid use -Felt psychologically stronger due to the illness <strong>Medication use</strong> There was non-compliance to medication use mainly due to effects of medication side effects</td>
<td><strong>Strengths</strong> -Aims of the study and methods clearly explained -The study added subjective knowledge to meaning of the changed appearance caused by medications to patients <strong>Limitations</strong> Ethical issues only briefly mentioned -Differences of image concerns between the male participant and the females not clarified -Reflexivity account not given <strong>Score 30</strong></td>
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<td>Rutter &amp; Kiemle, 2015 UK</td>
<td>To explore how UK South Asian women with lupus make sense of their social and interpersonal experiences within the context of their ethnicity and perceived cultural influences</td>
<td>Qualitative design - Phenomenology - Purposive sampling - Semi structured interviews - Interpretive phenomenological analysis</td>
<td>6 women</td>
<td><strong>Social and interpersonal relationships</strong>  - Lupus complex with ever shifting picture of illness, function and emotional interactions  - The power of lupus of being omnipresent and intrusive results in prohibited functioning  - Sense of personal responsibility and accountability help in taking control, and maintaining independence  - Family support essential but lupus leads to relationship changes and losses  - Struggling in the public view with concealment and social retreat  - Ethnicity and cultural issues do not significantly impact on the experiences</td>
<td><strong>Strengths</strong>  - Aims of the study clearly stated  - Findings explicit and add to knowledge that ethnicity and cultural issues do not significantly impact differently on patients' experiences <strong>Limitations</strong>  - Sample size too small to include the full range of possible cases of lupus.  - Reflexivity of the account not explained</td>
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<td>Williams et al, 2015 US</td>
<td>Explore how lupus patients experience travel issues</td>
<td>Qualitative - Research design not indicated - Semi structured telephone interviews</td>
<td>10 randomly selected</td>
<td>Experience with travel issues - Reliance on caregivers and some travelling for long distances. - Meeting financial priorities - Pain and physical limitations All interfering with medical appointments compliance</td>
<td>Strengths - Data analysis and development of categories clearly described - Study established that travel issues was preventing some patients from participating in some aspects of interventions. Limitations - Random selection for a qualitative study does not ensure diversity of participants Score 34</td>
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<td>Brennan &amp; Creaven, 2016, Ireland</td>
<td>To explore the nature and impact of social support from medical professionals and from support groups for individuals with lupus</td>
<td>Mixed method - Online survey with qualitative data - Thematic analysis</td>
<td>133 participants gave qualitative data</td>
<td><strong>Social support</strong> - invisible nature of lupus affected social support by family, friends and employers and support outlets - Received inadequate care from health professional - Poor advice from support groups - Received emotional support and informational support from some medical professionals and support groups</td>
<td><strong>Strengths</strong> - Response rate indicated - Method is clearly described - Most information regarding sampling given. <strong>Limitations</strong> - Internet may not be accessible to all eligible persons in an online survey limiting sampling frame - Brief mention of ethical issues <strong>Score 31</strong></td>
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b) Mixed methods Studies

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<tr>
<td>Hatfield-Timajchy, 2007, US</td>
<td>To describe the impact of diagnosis delay, treatment options and support group participation</td>
<td>Mixed methods - Ethnography/Case study/quantitative study - Purposive sampling - Multiple Open-ended interviews - Participant observation of support group - Structured questionnaire - Document review - Content analysis</td>
<td>42 women</td>
<td><strong>Impact of diagnostic delay</strong> - Symptoms continued to worsen, caused uncertainty of diagnostic process and heightened anxiety - Symptoms written off as psychosomatic, self-doubt crept in and some women thought they were crazy and consulted with psychiatrists - Some experienced multiple diagnoses, doubt in biomedical practice - Resistance strategies - Conducted independent research and made self-diagnosis - Mixed reaction to diagnosis from being relieved and happy to being shocked and devastated. - Loss of self-loss of health and sense of normalcy. - After diagnosis, experienced both emotional and existential responses <strong>Treatment Options</strong> - Feeling patronised by the doctors. - Preliminary diagnosis marked a significant turning point. <strong>Support group participation</strong> - Shared experiences and created safe environment</td>
<td><strong>Strengths</strong> - Qualitative study methods clearly described with clear statements of analysis and findings. <strong>Limitations</strong> - Abstract scantily described - Quantitative study design not specified</td>
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<td>To examine factors influencing adherence to medication in a group of patients in Jamaica</td>
<td>Mixed methods -Methodology not indicated -Questionnaire -Face-to-face semi-structured interview -Inductive analysis</td>
<td>75 Participants filled questionnaire 20 interviewed</td>
<td>Factors influencing medication adherence -High cost and poor availability of medications were the main reasons for poor adherence -Some patients chose not to take their medications because of side effects, perceived mild severity of disease and/or a preference to take drugs only when symptomatic. -Herbal medicines used to counteract side effects of western medicines, to ‘purge the blood’ and to manage lupus symptoms when they had no medications. -Religious beliefs used as a coping strategy. -Religious beliefs and use of herbal remedies are used when drugs cannot be obtained. -Traditional use of herbal medicines common particularly in patients from rural Jamaica.</td>
<td>Strengths Mixed methods study designs not indicated Data collection process and study findings clearly explained Limitations Data analysis process scantily described Score 31</td>
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| Chambers et al, 2009, UK | To explore the reasons why patients with lupus did or did not take their medications as prescribed. | Mixed methods -Methodology not indicated -Questionnaire -Visual analogue scale -Face to face Semi-structured interview -Framework Analysis | 220 returned questionnaires 33 interviewed -28 females -3 males | **Medication adherence**  
Why patients took their medications regularly included:  
- the fear of worsening disease,  
- Perceived health benefits and respect for physicians,  
- lack of knowledge about lupus to allow confidence in changing medications and feelings of moral obligation or responsibility to others.  
Why patients did not take their medications regularly included:  
- The belief that lupus could and should be controlled using alternative methods,  
- The belief that long-term use of drugs was not necessary,  
- The fear of drug adverse effects,  
- practical difficulties in obtaining medications due to affordability related to low minimum wage of most participants,  
- Poor communication between patients and doctors. | **Strengths**  
Participant recruitment used rigorous inclusion and exclusion criteria clearly explained  
Response rate 70%  
Data collection clearly explained  

**Limitations**  
Mixed methods study design not indicated  
Description of data analysis and how themes were derived not clear  

Score 32
<table>
<thead>
<tr>
<th>Author, year and country</th>
<th>Study aim</th>
<th>Methods</th>
<th>Sample</th>
<th>Main findings</th>
<th>Strengths and limitations, and Appraisal score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Miljetaig and Graue, 2009, Norway</td>
<td>To evaluate an educational program for people with systemic lupus erythematosus</td>
<td>Mixed method - Action research - Questionnaire - Convenience sampling - Focus group interview - Field notes - Ad hoc meaning generation</td>
<td>- 21 health professional - 11 patients 9 females 1 male 1 significant other</td>
<td><strong>Health professional</strong> - The adoption of new roles was a challenge - Need for higher teaching and learning competencies - Professionals recommended training which combine counselling with interactive teaching and learning methods - Need for feedback on their teaching <strong>Patients</strong> - Patients need safe environments which facilitate learning experiences - Need better education programs and communication with professionals is essential. - Need their significant others to join the education programs - Need to be educated on coping strategies, information on latest research and being together as a support group</td>
<td><strong>Strengths</strong> - Appropriate method for practice development - Sample was heterogeneous - The research approach brought out participants potential of being able to identify their unmet needs. - Data collection process clearly described. - Triangulation of data source and data collection methods elicited diverse data Independent analysis of the data by more than one researcher-check for fit. <strong>Limitations</strong> - Description of data analysis process not sufficiently rigorous - The researcher was also the programme developer and facilitator</td>
</tr>
<tr>
<td><strong>Score 32</strong></td>
<td></td>
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<tr>
<td>Author, year and country</td>
<td>Study aim</td>
<td>Methods</td>
<td>Sample</td>
<td>Main findings</td>
<td>Strengths and limitations, and Appraisal score</td>
</tr>
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<tr>
<td>Wittmann et al, 2009, Switzerland</td>
<td>To enhance understanding of suffering and posttraumatic growth in women with lupus</td>
<td>Mixed method - Explorative case study - Semi-structured interview - Self rating instruments - Content analysis</td>
<td>12 women</td>
<td><strong>Suffering and posttraumatic growth</strong> Suffering caused by physical factors, changes in personal values and aspirations and factors in the social environment. Posttraumatic growth determined by availability of coping resources and personal attributes of the person - Findings consistent with the concept of suffering as a psychological process triggered and sustained by an appraised threat to the “Self” or Personhood</td>
<td><strong>Strengths</strong> Inclusion of participants with all disease activity from mild to active - Data collection method clearly explained and complementary in the study - Use of validated self-rated instruments - Data analysis process sufficiently rigorous - Independent analysis of the data by more than one researcher-check for fit. - Study identified need for strengthening one of the self-rated instruments <strong>Limitations</strong> - Sampling technique not clearly specified - Sample size too small to allow for meaningful conclusions to be drawn from quantitative data <strong>Score 29</strong></td>
</tr>
<tr>
<td></td>
<td>Author, year and country</td>
<td>Study aim</td>
<td>Methods</td>
<td>Sample</td>
<td>Main findings</td>
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<tr>
<td>6</td>
<td>Robinson et al, 2010, US</td>
<td>Impact of lupus on health, family and work To investigate these disease-driven health issues.</td>
<td>Mixed method -convenience sample -Focus group interviews -Face to face semi structured interview -Self-administered questionnaire</td>
<td>33</td>
<td>Impacts on health, family, and work The health issues identified were -pain, fatigue, skin manifestation and skin sensitivity most frequent signs and symptoms Functional impairment-in working, recreation and walking. Resulting in-role restrictions, impact on household responsibilities, parenting roles, recreational activities, work or school impairment Mental health -Depressed mood related to persistent pain and sleeping difficulties</td>
</tr>
<tr>
<td>Author, year and country</td>
<td>Study aim</td>
<td>Methods</td>
<td>Sample</td>
<td>Main findings</td>
<td>Strengths, limitations and appraisal score</td>
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</tbody>
</table>
| Mancuso et al, 2011, US  | To ascertain lupus patients' perspectives regarding physical activity | Mixed method - Focus groups with open-ended questions - Physical and exercise index scale - 2 minutes walking test Questionnaire - Grounded theory analysis | 50 | **Perceptions of physical activity**  
- Most patients believed that exercises were beneficial for general health and physical activity in lupus  
- Walking was the preferred physical activity  
- Patients reported they avoided physical activity because they did not want to exacerbate lupus in the short term or fear of getting hurt, lack of time, lack of motivation and comorbidities.  
- Facilitators of exercise included necessity to be active to fulfil family and work responsibilities and having a companion for encouragement.  
**Physical activity measurements**  
- Over 50% met physical activity goals, but lower than the expected  
- Social stress and fatigue contributed to less physical activity | **Strengths**  
- Participant selection and recruitment clearly explained  
- Triangulation of data collection methods enriched exploration of patients' perspectives and activity measurement  
- Methods of data collection and data analysis appropriate and clearly described.  
**Limitations**  
Quantitative study design not indicated  
**Score 30** |
<table>
<thead>
<tr>
<th>Author, year and country</th>
<th>Study aim</th>
<th>Methods</th>
<th>Sample</th>
<th>Main findings</th>
<th>Strengths, limitations and appraisal score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pettersson et al, 2012, Sweden</td>
<td>The aim of this study was to explore the most distressing symptoms of lupus and determine how these relate to health-related quality of life (HRQoL)</td>
<td>Mixed method &lt;br&gt;- Medical outcome measure &lt;br&gt;- Anxiety and depression measure &lt;br&gt;- Lupus activity measure &lt;br&gt;- Disease activity index &lt;br&gt;- Lupus damage index &lt;br&gt;- Written answers to open-ended questions &lt;br&gt;- Inductive analysis</td>
<td>324</td>
<td><strong>Illness experience</strong>&lt;br&gt;- Most frequently reported symptoms included fatigue, pain and musculoskeletal distress. &lt;br&gt;<strong>Health related quality of life</strong>&lt;br&gt;- Only patients reporting fatigue showed a statistically significant impact on both mental and physical components of HRQoL. Patients with no present symptoms &lt;br&gt;-(10%) had higher HRQoL (p &lt; 0.001) and lower levels of depression (p &lt; 0.001), anxiety (p &lt; 0.01), and disease activity (SLAM) (p &lt; 0.001).</td>
<td><strong>Strengths</strong>&lt;br&gt;- Patient identification and recruitment clearly explained &lt;br&gt;- Large sample size ensured diversity e.g. age range of 18-84 years &lt;br&gt;- Triangulation of data collection methods enriched the exploration of the relationship between distressing symptoms and health related quality of life. &lt;br&gt;- Use of validated measures made the findings more objective &lt;br&gt;- Data analysis clearly explained. &lt;br&gt;<strong>Limitations</strong> Qualitative study design not indicated</td>
</tr>
</tbody>
</table>
Appendix 7: Methodology and methods utilised in the reviewed studies

### 7a: Qualitative studies

<table>
<thead>
<tr>
<th>Research methodology</th>
<th>Studies</th>
<th>Sampling Techniques</th>
<th>Data collection methods</th>
<th>Analysis techniques</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generic qualitative approaches</td>
<td>Beckerman et al., 2011; Gallop et al., 2012; Karlen, 2002; Kumar et al., 2011; Mattje and Turato, 2006; Mattsson et al., 2012; Mazzoni and Cicognani, 2014; Mendelson 2003 Nowicka-Sauer, 2007 Pettersson et al., 2010; Spry, 2014; Stamm et al., 2007; Sterling et al., 2013; Williams et al., 2015; Brennan &amp; Creaven, 2016</td>
<td>Convenience, Purposive</td>
<td>Focus group, Semi structured interviews, Unstructured interviews, Focus group</td>
<td>Thematic analysis, Thematic analysis, Thematic analysis, Thematic analysis, Content analysis, Content analysis, Content analysis, Inductive analysis, Content analysis, Content analysis, Not specified, Content analysis, Not specified, Meaning condensation, Thematic analysis, Not specified, Thematic analysis</td>
</tr>
<tr>
<td>Study Source</td>
<td>Sampling Method</td>
<td>Data Collection Method</td>
<td>Analysis Method</td>
<td></td>
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<tr>
<td>Hale et al., 2006a;</td>
<td>Convenience</td>
<td>Semi structured interviews</td>
<td>IPA</td>
<td></td>
</tr>
<tr>
<td>Hale et al., 2014;</td>
<td>Purposive</td>
<td>Semi structured interviews</td>
<td>IPA</td>
<td></td>
</tr>
<tr>
<td>Hale et al., 2006b;</td>
<td>Convenience</td>
<td>Semi structured interviews</td>
<td>IPA</td>
<td></td>
</tr>
<tr>
<td>McElhone et al., 2010;</td>
<td>Purposive</td>
<td>Semi structured interviews</td>
<td>IPA</td>
<td></td>
</tr>
<tr>
<td>Rutter and Kiemle, 2015;</td>
<td>Purposive</td>
<td>Semi structured interviews</td>
<td>IPA</td>
<td></td>
</tr>
<tr>
<td>Schattner et al., 2008;</td>
<td>Not specified</td>
<td>Semi structured interviews</td>
<td>Thematic analysis</td>
<td></td>
</tr>
<tr>
<td>Taïeb et al., 2010</td>
<td>Purposive</td>
<td>Semi structured interviews</td>
<td>IPA</td>
<td></td>
</tr>
</tbody>
</table>

| Grounded Theory                      | Howe, 2009; Neville et al., 2014; Ow et al., 2011; Waldron et al., 2011 | Focus group         | Constant comparative data analysis |
|                                     | -Not specified    | Focus group                   |                     |
|                                     | -Not specified    | Focus group                   |                     |
|                                     | -Theoretical      | Focus group                   |                     |
|                                     | sampling          | Focus group                   |                     |

| Ethnography                          | Mendelson, 2006; Miles, 2011; Stockl, 2007 | Convenience        | Grounded theory methods; Not specified; |
|                                     |                                                | Observation/Semi-structured interviews | Grounded theory and discourse analysis |
|                                     |                                                | Semi-structured interviews |                     |
|                                     |                                                | Observation/Semi-structured interviews |                     |
7b : Methodology of mixed methods studies

<table>
<thead>
<tr>
<th>Article</th>
<th>Quantitative</th>
<th>Qualitative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hatfield-Timajchy, 2007, US</td>
<td>-Structured questionnaire</td>
<td>Ethnography</td>
</tr>
<tr>
<td></td>
<td>-Document review</td>
<td>-Multiple Open-ended interviews</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Participant observation of support group</td>
</tr>
<tr>
<td>Chambers et al, 2008, Jamaica</td>
<td>-Questionnaire</td>
<td>Design not indicated</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Face-to-face semi-structured interview</td>
</tr>
<tr>
<td>Chambers et al, 2009,</td>
<td>-Questionnaires</td>
<td>Methodology not indicated</td>
</tr>
<tr>
<td></td>
<td>-Visual analogue scale</td>
<td>-Face to face semi-structured interview</td>
</tr>
<tr>
<td>Miljetaig and Graue, 2009,</td>
<td>-Questionnaire</td>
<td>-Action research</td>
</tr>
<tr>
<td>Norway</td>
<td></td>
<td>-Focus group interview</td>
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<tr>
<td></td>
<td></td>
<td>-Field notes</td>
</tr>
<tr>
<td>Wittmann et al, 2009,</td>
<td>-Self rating instruments</td>
<td>Case study</td>
</tr>
<tr>
<td>Switzerland</td>
<td></td>
<td>-Semi-structured interview</td>
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<tr>
<td></td>
<td></td>
<td>-Focus group interviews</td>
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<tr>
<td></td>
<td></td>
<td>-Semi structured interview</td>
</tr>
<tr>
<td>Mancuso et al, 2011, US</td>
<td>-Physical and exercise index scale</td>
<td>Grounded theory analysis</td>
</tr>
<tr>
<td></td>
<td>-Questionnaire</td>
<td>-open-ended questions</td>
</tr>
<tr>
<td></td>
<td></td>
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</tr>
<tr>
<td>Pettersson et al, 2012, Sweden</td>
<td>Medical outcome measure</td>
<td>-open-ended questions</td>
</tr>
</tbody>
</table>
Appendix 8: Ethical clearance from University of Manchester

Secretary to Research Ethics Committees

Room 2.004 John Owens Building

Tel: 0161 275 2206/2046
Fax: 0161 275 5697

Email: timothy.stibbs@manchester.ac.uk

ref: ethics/12391

Ms Eunice Omondi,
c/o Professor Ann Caress,
School of Nursing, Midwifery and Social Work.

12th April 2013

Dear Eunice,

Research Ethics Committee 3

Omondi, Caress: Living with a rare chronic condition: Exploring patients’ perspective of living with systematic lupus erythematosus (SLE): a grounded theory study (ref 12391)

I write to confirm that the above project was reviewed by the Committee at its meeting on 27th February and, after the submission of the amendments and additional information in your email of 17th March, the project has been given a favourable ethical opinion.

This approval is effective for a period of five years and if the project continues beyond that period it must be submitted for review. It is the Committee’s practice to warn investigators that they should not depart from the agreed protocol without seeking the approval of the Committee, as any significant deviation could invalidate the insurance arrangements and constitute research misconduct. We also ask that any information sheet should carry a University logo or other indication of where it came from, and that, in accordance with
University policy, any data carrying personal identifiers must be encrypted when not held on a university computer or kept as a hard copy in a location which is accessible only to those involved with the research.

Finally, I would be grateful if you could complete and return the attached form at the end of the project or by March 2014.

Yours sincerely

Dr T P C Stibbs
Secretary to the University Research Ethics Committee

Enclosed: Report form
Progress or Completion Report Form on an Approved Project

The Committee's procedures require those responsible for projects which have been approved by the Committee to report on any of the following:

* Any incident, accident or untoward event associated with the project (Please note that if the incident constitutes an accident or dangerous occurrence, the usual Health and Safety reporting mechanism must still be used)
* Any variation in the methods or procedures in the approved protocol
* A termination or abandonment of the project (with reasons)
* A report on completion of the project or a progress report 12 months after approval has been given.

The report should be sent to the Secretary to the Committee, Dr T P C Stibbs, Room 2.004 John Owens Building, University of Manchester, Oxford Road, Manchester M13 9PL (tel: 0161-275-2046/2206).

Project: Living with a rare chronic condition: Exploring patients’ perspective of living with systematic lupus erythematosus (SLE): a grounded theory study (ref 12391)
Appendix 9: Ethical Clearance from Kenyatta National Hospital

Dear Eunice

RESEARCH PROPOSAL: LIVING WITH A RARE CHRONIC DISEASE: EXPLORING PATIENTS' PERSPECTIVE OF LIVING WITH SYSTEMIC LUPUS RYTHEMATOUSIS (SLE): A GROUNDED THEORY STUDY (P327/06/2013)

This is to inform you that the KNH/UoN-Ethics & Research Committee (KNH/UoN-ERC) has reviewed and approved your above proposal. The approval period is 23rd December 2013 to 22nd December 2014.

This approval is subject to compliance with the following requirements:

a) Only approved documents (informed consents, study instruments, advertising materials etc) will be used.

b) All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH/UoN ERC before implementation.

c) Death and life threatening problems and severe adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH/UoN ERC within 72 hours of notification.

d) Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH/UoN ERC within 72 hours.

e) Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (Attach a comprehensive progress report to support the renewal)

f) Clearance for export of biological specimens must be obtained from KNH/UoN-Ethics & Research Committee for each batch of shipment.

g) Submission of an executive summary report within 90 days upon completion of the study.

This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/or plagiarism.

For more details consult the KNH/UoN ERC website www.uonbi.ac.ke/activities/KNH/UoN.
Yours sincerely

PROF. M. L. CHINDIA
SECRETARY, KNH/UON-ERC

c.c. Prof. A.N. Guaitai, Chairperson, KNH/UoN-ERC
     The Deputy Director CS, KNH
     The Principal, College of Health Sciences, UoN
     AD/Health Information, KNH
     Supervisors: Prof. Ann Caisse, Dr. Greti McHugh, Prof. Erastus Amayo

"Protect to Discover"
Appendix 10: Ethical Clearance from Mater Misericordiae Hospital

30th July 2013

Eunice Omondi,
P. O. Box 19701,
Nairobi, Kenya.

Dear Eunice,

RE: PERMISSION TO CONDUCT A RESEARCH STUDY AT THE MATER HOSPITAL

We acknowledge receipt of your request for permission to conduct a study on ‘Living with a rare chronic disease: Exploring patients’ perspective of living with systemic Lupus Erythematosus: A grounded theory study.’

The Standards & Ethics Sub-Committee of The Mater Hospital, has reviewed your request as entitled above, and found it acceptable.

You are hereby allowed to proceed with your research but must submit a copy of your findings for inclusion in our inventory.

I wish you well.

Thank you.

Yours faithfully,

FOR: THE MATER HOSPITAL

Dr. Andrew Ndonga
CHAIR, STANDARDS AND ETHICS SUB COMMITTEE

CC: Chief Executive Officer
    Director Medical Services
    Director Nursing Services

The Mater Hospital
Trustees: Sisters of Mercy, Kenya
Appendix 11: Participant information sheet

Participant Information Sheet (Version 1: 30 August 2012)

Exploring patients’ perspective of living with systemic lupus erythematosus (SLE) in Kenya: A grounded theory study

Introduction to the study

You are invited to take part in a study that will explore the experiences and opinions of individuals with Systemic Lupus Erythematosus (SLE) in Kenya. We are interested in talking to adults who have been diagnosed with SLE (Lupus) for more than 2 years and are currently being followed up by a rheumatologist. This research is part of a PhD study in the School of Nursing, Midwifery and Social Work, University of Manchester, UK.

Please take your time in deciding whether to take part in the research, if you wish, you can discuss the information provided in this information sheet with your family, friends, your doctor or nurse. You can also contact the researcher using the contact details provided for further information.

Who will conduct the research?

This research will be conducted by:

Eunice Omondi

P.O.Box 19701, 00202

Nairobi, Kenya
What is the purpose of the study?

The purpose of this study is to explore patients’ perspective and understanding of living with SLE (Lupus) in Kenya. It is anticipated that information from the research will inform doctors and other health professionals and may help in improving future care of patients with SLE.

Why have I been chosen?

You have been chosen because you have had lupus for more than 2 years and currently attending the rheumatology clinic. The insight into your individual experiences in living with SLE is important. I would be interested in talking to you to hear about your perspective on living and managing your lupus. We will be interviewing about 20-30 individuals such as yourself drawn from different ages and ethnic background to ensure that we get different experiences and views.

Do I have to take part?

No. It is totally your decision to take part in the study. If you decide to take part, please keep this information sheet, sign the enclosed consent form and return it within a week. After you have signed the consent form you are still free to withdraw at any time, without giving a reason. A decision to withdraw, or a decision not to take part, will not affect the standard of care you receive now or in the future.

What will happen to me if I take part?

Once the researcher receives your form and you agree to participate in the research, the researcher will contact and arrange an interview with you. You will be invited to take part in an interview at a time and location convenient to you, during which, you will discuss with the researcher your experiences since you developed the symptoms of lupus. The interview, with your permission will be recorded to ensure that the researcher has accurate record of what you say. The interview should last between 1-2 hours. Potentially there could be 2 interviews, the second being either by phone or face to face. You will not be personally identified in any data or documents, and the information will only be accessible to the research team.
What do I have to do?

If you agree to participate in the research, you will be requested to complete the consent form enclosed with this letter. If you don’t agree to participate then that will still be okay and this will not jeopardise your care in any way.

What are the possible disadvantages and risks of taking part?

This study does not involve you taking any new medications or changes to your care, and there are no clinical risks to you. It does involve discussing your experiences since you developed symptoms and was subsequently diagnosed with lupus. This may be uncomfortable for some people, although be reassured that the researcher has experience in talking to individuals who have a range of medical problems. If you take part and are uncomfortable with a particular question asked in an interview, you do not have to answer. Similarly, if you take part and wish to stop the interview at any point, simply tell the researcher and they will stop. The researcher will not be upset if you do not answer a question or choose to stop the interview early.

What are the possible benefits of taking part?

There are no particular benefits to you personally from taking part in the study. However, it is hoped that we will be able to have a better idea about the experiences with SLE in Kenya. We hope that the study will help health professionals to develop services for other similar patients in the future. However, we cannot guarantee that health professionals will make use of the information from the study.

What if something goes wrong?

It is not anticipated that taking part in the study will cause any harm to you. It is possible that issues discussed in the interview may raise concerns for you. If this happens, you could ask the researcher to pass these on to the relevant person (the researcher will not tell your doctors or nurses about anything you have said unless you ask them to do so or unless they believe that either you or others are at serious risk of harm).
What if I want to make a complaint?

If you are unhappy with any aspect of the research, please contact the researcher directly using the contact details provided below. Any complaint you make will be taken very seriously and dealt with, with respect. Additionally, if you wish, you may contact the researcher’s PhD supervisor:

Prof. Ann-Louis Caress
Professor
School of Nursing Midwifery & Social Work
Jean McFarlane Building
Oxford Road
Manchester, UK
M13 9PL
Tel +44(0)161 306 7707
Email: ann.caress@manchester.ac.uk

Will my taking part in this study be kept confidential?

All information collected during the research will be kept strictly confidential. Any information about you will be stored in a locked cabinet at the Main researcher’s office or on a password protected computer. We will not name anyone in reports we write as part of the study. We will give people taking part false names and remove any information that could identify them. We will not tell healthcare professionals responsible for your care if you have taken part, unless it is felt that you or others are at serious risk of harm.

What will happen to the results of the research study?

So that others can learn from our study, we will write articles for medical and nursing journals and give presentations at health-related conferences. We will be careful to ensure that it is not possible to identify you individually in any reports, papers or presentations. If you take part, we will send you a summary of the results when we have completed the research.
Who is organising and funding the research?

The research is being conducted by Eunice Omondi, who is doing her PhD in the School of Nursing, Midwifery and Social Work at the University of Manchester. Eunice Omondi, is responsible for the day-to-day conduct of the study. She can be contacted at the address above, or by email eunice.omondi-3@postgrad.manchester.ac.uk or by telephone on 254-(0)722-728-123.

Who has reviewed the study?

This study has been reviewed by the University of Manchester Research Ethics Committee and the Hospital’s Local Research Ethics Committee.

What do I have to do now?

If you would like to take part in this study, please complete the enclosed contact form and consent form and return them to the chief investigator (Eunice Omondi) in the provided envelope. Once this is received, you will be contacted in one week’s time to arrange a time, venue and date that is convenient for you in order to undertake the interview. The interview can take place in your home, at the hospital in a private room, or in a private office room.

Thank you for taking the time to read this information.
Appendix 12: Consent Form

CONSENT FORM FOR INVOLVEMENT IN THE STUDY

VERSION 1 – 30 August 2012

(To be kept in a locked cupboard by the research team)

Patients’ perspective of living with systemic lupus erythematosus (SLE): A grounded theory study

Please put your initials next to the statements below and then sign the bottom of the form where it says ‘name of participant’.

PLEASE RESPOND TO ALL OF THESE QUESTIONS

Please initial box

1. I confirm that I have read and understood the information sheet (version 1) dated August 2012 for the above study. I have had the opportunity to ask the researcher questions about the study and my questions have been answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected.

3. I agree to participate in the study, which potentially could be 2 interviews each lasting between 1-2 hours each time. The first interview will be face to face while the second may be by phone or face to face.

4. I consent to the interview being audio-recorded and understand that no one, apart from the chief investigator and her supervisors, will have access to the tapes, which will be stored in a secure location and destroyed by the researchers once the study has been written up.

5. I consent to the interview being transcribed (typed out) and stored in a secure location, then destroyed by the researcher once the study has been written up.

6. I agree to the use of my direct quotes from my interview in any reports or publications, if they are used in such a way that I will not be identified.

7. I agree to the use of information from the interview about my medical history for the purposes of this research, without referring to my identity.

8. I agree to my Doctors being informed about my participation in this study.

* I agree to take part in the above study. □ □ Y Yes □ No

Name of Participant Signature Date

Eunice Omondi (Chief Investigator) Signature Date

You will have a copy of this form to keep. A further copy will be stored in the researcher’s site file.

Researcher: Eunice Omondi, P. O. Box 19701, 00202, Nairobi Kenya, Tel 254 (0) 722 728 123, eunice.omondi-3@postgrad.manchester.ac.uk
Appendix 13: Distress Policy

Distress Policy for patients participating in the study:

**Exploring patients’ perspective of living with Systemic Lupus Erythematosus (SLE) in Kenya**

If the participant demonstrates that he/she is experiencing any form of distress during the interview, then the chief investigator will respond as follows:

1. The chief investigator will ask the participant if he/she is feeling OK. If they respond and say no, then she will stop the interview and suggest a break. During that time,
   1.1. The chief investigator will ask the participant to talk about the issue that is bothering him/her if it would help.
   1.2. The chief investigator will ask the participant to express his/her feelings about that issue.
   1.3. The chief investigator will reassure the patient and make contact with one of the hospital psychologists (there are psychologists and social workers attached to the various hospital wards and clinics, already there has been discussion with one of the psychologists attached to the medical clinics regarding possible participants’ distress during data interviews) immediately after the interview.
2. The chief investigator will ask the participant if he/she is ready to continue with the interview. If the answer is positive, she will resume with the interview. If the answer is negative, the interview will be terminated.
3. If the patient is still willing to participate in the study, but is not able to continue with the interview that day, the meeting will be rescheduled together with the participant.
4. If the participant prefers to withdraw from the study, he/she will be given the opportunity to do so without explaining the reason.
5. If the participant expresses sentiments which give cause for concern, the investigator will make referral of the patient to the appropriate departments for attention (medical, psychological or social) if he/she wishes to do so, with respect to confidentiality.
6. The chief investigator will follow-up the participant with a phone call (within 48 hours of the interview) to provide further support.
7. If serious risk of harm is suspected during the interview, the chief investigator will report to the lead clinic doctors of the unit, with the patient’s permission and with respect to their privacy and confidentiality.

**Chief Investigator:** Eunice Omondi, P.O. Box 19701, 00202, Nairobi, Kenya, Tel: +254 (0) 722 728 123, eunice.omondi-3i@postgrad.manchester.ac.uk
Appendix 14: Demographic form

Demographic form for study participants (Version 1: August 2012)
Exploring patients’ perspective of living with Systemic Lupus Erythematosus (SLE) in Kenya

Participant’s code number______________ Date________________

**Gender**
Male [ ]  Female [ ]

**Age at interview (years) __________________**

**Disease duration (years) __________________**

**Race**
Black African/African American [ ]
Asian [ ]
Arab [ ]
White/Caucasian [ ]
mixed Race [ ]

**Country of birth**
Africa [ ]
Kenya [ ]
outside Kenya [ ]
Outside Africa [ ]

**Highest level of education completed**
Primary school [ ]
High school [ ]
Vocational qualification [ ]
Diploma qualification [ ]
University degree [ ]

**Employment status**
Employed full time [ ]
Employed part time [ ]
Unemployed/ looking for work [ ]
Registered disabled [ ]
Homemaker [ ]
Student [ ]
Retired [ ]

**Current marital status**
Single, never married [ ]
Living together [ ]
Married [ ]
Separated [ ]
Divorced [ ]
Widowed [ ]

**Attending Doctor**
Rheumatologist yes [ ] No [ ]
Other specialists (Please specify)

Number of children below eighteen years_________

Chief investigator: Eunice Omondi, P.O.Box 19701, 00202 Nairobi, Kenya, Tel: + 254 (0) 722728123, eunice.omondi-3@postgrad.manchester.ac.u
Appendix 15: First Interview topic guide (Final version)

School of Nursing, Midwifery
and Social Work

University of Manchester

Jean McFarlane Building

Oxford Road
Manchester
M13 9PL

Interview topic guide for the study (Final version: 30 September 2012)

Patients’ perspective of living with systemic lupus erythematosus (SLE): A grounded theory study

Participant’s code number______________ Date______________

Introduction
- Thank you for taking your time to meet me today.
- My name is Eunice as I informed you during our earlier meeting.
- We agreed to meet here today in order to talk about your experiences and views about living with lupus. The talk may take between one to two hours but may be stopped at any time.
- I will be taping the session because I do not want to miss any of your comments. However, if you wish to have some recorded information removed, you are free to say so.
- I will also be taking some notes during the session which should not worry you. All your responses will be kept confidential.
- I will ensure that any information included in my reports will not identify you by name.
- Remember, you don’t have to talk about anything you don’t want to, and your participation in this study is voluntary.
- If at any time you need a break please let me know and we can stop and continue later.
- Do you have any questions about what I have explained before we start?
Research questions

1. The research will first discuss about coming to terms with the diagnosis of SLE
2. Then move on to living with SLE after diagnosis
3. Then finally discuss the impact of living with SLE

Questions and prompts

<table>
<thead>
<tr>
<th>Questions</th>
<th>Prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Please tell me how you came to know about your condition</td>
<td>a) What did you experience when you first noticed that something was wrong with you? What did you think then? \n   b) Please tell me how you came to know that you have lupus. How, Where and by whom was the diagnosis made? How long did that take? \n   c) Describe how you viewed lupus immediately after diagnosis? What did you know about lupus then? What were your thoughts and feelings then? \n   d) How did you come to understand the nature of your illness? Who, if anyone, was involved? How were they involved?</td>
</tr>
<tr>
<td>2) Can you describe how you manage to live with lupus</td>
<td>a) What would you say you do to take control of the illness? \n   b) Who has been the most helpful to you with your care and treatment? How has he/she been helpful? \n   c) Has any organization been helpful to you in your care and treatment? How has it been helpful? \n   d) How would you describe the problems you have encountered with your treatment? What are the sources of these problems? What do you do about them?</td>
</tr>
<tr>
<td>3) Please could you explain to me the changes that have occurred in your life because of living with lupus</td>
<td>a) What positive changes have occurred in your life since being diagnosed with lupus? \n   b) What negative changes, if any, have occurred in your life since being diagnosed with lupus? \n   c) How would you describe the person you are now? How have you grown as a person?</td>
</tr>
</tbody>
</table>

Is there anything more you would like to add from your experience of living with SLE which we have not covered in this interview?
Appendix 16: Revised Interview Topic Guide

Interview topic guide for the study (Final version: 15 July 2013)

Patients’ perspective of living with systemic lupus erythematosus (SLE): A grounded theory study

Participant’s code number_____________________________ Date__________________

Introduction

-Thank you for taking your time to meet me today.

-My name is Eunice as I informed you during our earlier meeting.

-We agreed to meet here today in order to talk about your experiences and views about living with lupus. The talk may take between one to two hours but may be stopped at any time.

-I will be taping the session because I do not want to miss any of your comments. However, if you wish to have some recorded information removed, you are free to say so.

-I will also be taking some notes during the session which should not worry you. All your responses will be kept confidential.

-I will ensure that any information included in my reports will not identify you by name.

-Remember, you don’t have to talk about anything you don’t want to, and your participation in this study is voluntary.

-If at any time you need a break please let me know and we can stop and continue later.

-Do you have any questions about what I have explained before we start?

Research questions

1. The research will first discuss about how you came to terms with your illness

2. Then move on to how you are living with the illness

3. Then finally discuss the impact the illness has had on your life and how you cope
<table>
<thead>
<tr>
<th>Questions and prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>QuesQ Topics</strong></td>
</tr>
</tbody>
</table>
| 1. Non-medical help-seeking | • How did you feel when you first felt unwell?  
• For how long had you felt unwell?  
• What did you think then?  
• Who did you speak to? What help or advice did you try before you went to a doctor |
| 2. Explore diagnosis | • Was there a particular incident or trigger that made you go to see a doctor?  
• What did you think you had?  
**What did they tell you about what you had?** Have you been given a name for your condition? How long did it take before you were given a name for your condition?  
• Did you have any worries or concerns at this point? What were they? |
| 3. After Diagnosis | • What did you understand about the nature of your illness?  
• What did you know about lupus? Had you heard of lupus? Did you know of anyone with lupus?  
• Was there anything you were worried about at this point? What was it?  
• Who did you talk to about your worries? |
| 4. living with lupus | • Have any changes occurred in your life since being diagnosed with lupus?  
• How does lupus affect your everyday life?  
• What is a good day like? What is a bad day like?  
• Has it affected your ability to carry out any responsibilities?  
• **How do you feel now about having lupus?** Has it changed your attitude towards life? In what way  
• Do you think your illness has affected people’s attitude towards you? In what way? |
| 4b. Coping | • What would you say you do to cope with your illness? What is most helpful?  
• Who has been the most helpful? Who has been the least helpful?  
• Have you faced any particular problems/challenges as a person with lupus? What are they?  
• How do you cope with them? Do you ever feel you cannot cope?  
• Have you had any problems/Challenges of treatment? How have you
<p>| | |</p>
<table>
<thead>
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<th></th>
<th></th>
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</thead>
</table>
|   | coped with them?  
|   | What do you think is the most important thing a person with lupus needs to know? |
| 5. | Relationship with health professional |
|   | How often do you see the health professionals?  
|   | What happens when you see them?  
|   | What has been most helpful to you in your care and treatment?  
|   | What has been least helpful?  
|   | Is there anything helpful that is missing in your care? |

4. Is there anything more you would like to add from your experience and views of living with lupus which we have not covered in this interview?
Appendix 17: Doctors Interview Topic Guide

Interview topic guide (Final version) August 2013

School of Nursing, Midwifery and Social Work
University of Manchester
Jean McFarlane Building
Oxford Road
Manchester
M13 9PL

Interview topic guide for the study
Hospital Doctors’ perspectives on living with systemic lupus erythematosus (Lupus) in Kenya

Doctor’s code number______________ Date________________

Introduction

-Thank you for taking your time to meet me today.

-We agreed to meet here today in order to talk about your views on patients living with lupus in this country. The talk may take about hour.

-I will be recording the session because I do not want to miss any of your comments. However, if you wish to have some recorded information removed, you are free to say so.

-I will also be taking some notes during the session which should not worry you.

-All your responses will be kept confidential.

-Remember, your participation in this study is voluntary.
<table>
<thead>
<tr>
<th>Topics</th>
<th>Questions and Prompts</th>
</tr>
</thead>
</table>
| **1. Initial consultations** | What journey would a typical patient have gone through before coming to see you in the rheumatology clinic?  
  • How do patients get referred?  
  • How do they present?  
  • At what stage of the illness do they present?  
  • What are the challenges in referral to the rheumatology clinic? |
| **2. Diagnosis**             | What are the main issues in diagnosing lupus in Kenya?  
  • Issues peculiar to lupus?  
  • In the public versus private healthcare system?  
  • In a resource limited country? |
| **3. After Diagnosis**       | After diagnosis what happens to a typical patient with lupus?  
  • How would a typical lupus patient be managed and followed up?  
  • What factors encourage patients to engage with care?  
  • What factors would cause patients to drop out of the service? |
| **4. living with lupus**     | In your view how actively do the patients involve themselves in their care?  
  • What are their challenges?  
  • What are the patients’ information needs?  
  • How does their involvement compare with patients with other long term diseases like diabetes?  
  • What role do patients’ families and careers have in managing the condition  
  • What challenges to face in dealing with patients’ families and careres |
| **5. Treating lupus**        | As a health professional, what do you feel are the major priorities for you when managing a lupus patient?  
  • What support services are available to you as a health professional in treating lupus patients?  
  • What challenges do you face while treating patients with lupus?  
  • What Knowledge/awareness of lupus do your other medical colleagues/health professionals have? |

4. Is there anything more you would like to add from your experience which we have not covered in this interview?
Appendix 18: Initial line by line coding
Appendix 19: Thematic coding framework

<table>
<thead>
<tr>
<th>Name</th>
<th>Sources</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnostic Difficulties</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discovering lupus took a long time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>going round the system</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Going to different health facilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being seen by different specialists</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Undergoing different tests</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of access to a rheumatologist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ignorance and uncertainty of health professionals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Length of time before diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Misdiagnosis</td>
<td></td>
<td></td>
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<tr>
<td>Malaria</td>
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<tr>
<td>HIV</td>
<td></td>
<td></td>
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<tr>
<td>Tuberculosis</td>
<td></td>
<td></td>
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<tr>
<td>Bacterial infection</td>
<td></td>
<td></td>
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<tr>
<td>Typhoid</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Biographical disruption</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relying on social capital</td>
<td></td>
<td></td>
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<tr>
<td>Marital issues</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 20: Example of coding process

<table>
<thead>
<tr>
<th>Category</th>
<th>Focused coding</th>
<th>Initial coding</th>
<th>Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biographical disruption</td>
<td>-Experiencing psychological distress</td>
<td>-Living in fear</td>
<td>ID 0007(Participant) -So I live in a lot fear.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(researcher)- Mm. A lot of fear.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(Participant)- Mm.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(researcher)- Okay. How do you think other people’s attitude have changed towards you?</td>
</tr>
<tr>
<td>Biographical disruption</td>
<td>-Experiencing psychological distress</td>
<td>-She thinks the illness has affected the attitude of her work mates</td>
<td>(Participant)- Mm. I think it has. Even my work mates, I think they have something in mind.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(researcher)- Please explain to me what you mean by something? (Laughs)</td>
</tr>
<tr>
<td>Biographical disruption</td>
<td>-Disrupted paid work</td>
<td>(Participant)</td>
<td>-Works for short periods then fall sick and gets admitted for treatment</td>
</tr>
<tr>
<td></td>
<td>-Strained relationships at work due to frequent absence</td>
<td></td>
<td>-One colleague suggesting early retirement or sick leave.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(Participant)- Whenever I am on duty, I can work for a month or two then fall sick. I am taken back to Kenyatta for treatment and get admitted. So, that period makes them think, “What’s happening to madam?” So it makes them think of so many things. One even went as far as telling me I should go for early retirement or sick leave.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(researcher)- Mm.</td>
</tr>
<tr>
<td>Biographical disruption</td>
<td>-Experiencing psychological distress</td>
<td>-Feeling tortured</td>
<td>(Participant)- All those torture me.</td>
</tr>
</tbody>
</table>
Appendix 21: Example of a theoretical memo on diagnostic difficulty

This was a memo for making comparisons on diagnostic difficulty. The memo also facilitated comparison between data, codes and cases for similarities and differences. It was also useful in sorting other codes and categories.

**Memo/Field notes for interview 0067-12/7/15**

In this case **diagnosing lupus took less than a month**. Why was this? This was because she came straight to the referral hospital and was referred quite early to the rheumatology clinic. Her son who works in Nairobi arranged for her travel to Nairobi, to be seen directly at the public referral hospital. She therefore had **social support** from her family and some support from her work colleagues who shared her responsibilities, though one of them also suggested to her that she should retire. She also had no prior knowledge about lupus before diagnosis which was an **information need**. She is the first patient who was being asked to retire on medical grounds yet she was not ready, this was also a form of **stigma and discrimination**. The distance she has to travel for treatment was also working against her because she only needed to go for therapies on particular days, making her stay away from her work station. This was because lupus services were mainly centralized in Nairobi where all the rheumatologists were based. This made the **cost of treatment unaffordable**.

**Surprises**

1. The patient does not remember whether she was given information on lupus or not so it is questionable whether she understands what condition she has or not but surprisingly remembers that she was told that she would be on long term medication.

2. She wishes the disease could be stopped so I wondered if she has been explained the chronic nature of the disease or whether it was just a wish.

3. It was also surprising that she knew the names of her drugs but not the drugs which were for lupus and the side effects that she may experience yet she is educated.

4. She mentions 3-4 times how the disease has really tortured her like the disease is a person, needed to explore this further
### Appendix 22: Criteria for judging rigour of the study

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Criteria elements</th>
</tr>
</thead>
</table>
| **Credibility** | • Has your research received intimate familiarity with the setting of the topic?  
• Are the data sufficient to merit your claims? Consider the range, number, and depth of observations contained in the data  
• Have you made systematic comparisons between observations and between categories?  
• Do the categories cover a wide range of empirical observations?  
• Are there strong logical links between the gathered data and your argument and analysis?  
• Has your research provided enough evidence for your claims to allow the reader to form an independent assessment and agree with your claims? |
| **Originality** | • Are your categories fresh? Do they offer new insights?  
• Does your analysis provide a new conceptual rendering of the data?  
• What is the social and theoretical significance of this work?  
• How does your grounded theory challenge, extend, or refine current ideas, concepts, and practices? |
| **Resonance** | • Do the categories portray the fullness of the studied experience?  
• Have you revealed both liminal and unstable taken-for-granted meanings?  
• Have you drawn links between larger collectivities or institutions and individual lives, when the data so indicate?  
• Does your grounded theory make sense to your participants or people who share their circumstances? Does your analysis offer them deeper insights about their lives and worlds? |
| **Usefulness** | • Does your analysis offer interpretations that people can use in their everyday worlds?  
• Do your analytic categories suggest any generic processes?  
• If so, have you examined these generic processes for tacit implications?  
• Can the analysis spark further research in other substantive areas?  
• How does your work contribute to knowledge? How does it contribute to making a better world? |

Source: Charmaz (2014): pg 337-338