

**Exploring Illness and Social Care Management: Comparing Consumer perspectives of Suffering and the Challenges faced by Service Providers**

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This thesis is submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy awarded by the University of Greenwich

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DECLARATION

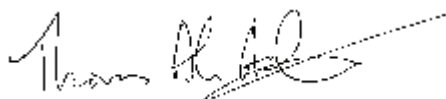
*“I certify that this work has not been accepted in substance for any degree, and is not concurrently being submitted for any degree other than that of Doctor of Philosophy (PhD) being studied at the University of Greenwich. I also declare that this work is the result of my own investigations except where otherwise identified by references and that I have not plagiarised another’s work”*

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I would also like to make special thanks to my family including: my wife April Naomi Moore Robin, my son Joseph Blaine Robin, my newborn daughter Hannah Grace Robin – who I love in equal measure to her brother and, my brother Bonnie, who my mother described as a “willing soul”<sup>1</sup> - a sentiment I acknowledge in equal measure. In addition, I would like to thank all the informants who took part in this study sharing with me valuable insights into their personal and professional lives, in particular those suffering with lupus.

I would like to dedicate this thesis to my late mother, and best friend, born to Adelta Stevens and Joshua “Tanta” Doram and later christened Delia Verdian Doram in the village of Marigot on the Island of Dominica, West Indies. She believed in me even when I stumbled along my journey of life. Without her, I would not be the man I am today. Her pain and suffering with lupus was endured all her life to ensure that I became an educated person and to her way of thinking a better person. In dedication to her life and my own, I would like to give thanks to the teachings of Jesus Christ without whom I would be a very different person.

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<sup>1</sup> His willingness was often recounted in conversations with my mother. The following incident occurred when we lived in Dominica in the 1970s. One evening we were returning from our farm when the Bedford van broke down. In those days there was no breakdown service. The family relied on Bonnie, an 11 year old, to run from the village of Calibishe to Sams Gutter, Marigot as this was where the mechanic was based 10 miles away. Several hours later in utter darkness the mechanic arrived with Bonnie.

## ABSTRACT

This thesis as a case study explored the narratives of a convenience sample of four women with the disease known as lupus. The author used an ethnographic approach to investigate how these women coped and how service providers, including carers, met their needs. The author used participant observation in his role as Occupational Therapist (and son) to gain access to this sample. He asked them to keep written diaries about their day-to-day experiences of living with the illness. These diaries were later given to the author to read, study and analyse. Additionally, the author's personal ethnography as a son was submitted as data for this study. This ethnographic writing centred on the life of one sole informant, his mother, who later died with the disease in hospital.

Qualitative data analysis (QDA) techniques with grounded theory origins (Glaser and Strauss 1965,1967 and Charmaz 2007) was used to analyse the data. The techniques comprised of line-by-line analysis and coding, constant comparison of cases, thematic analysis, theoretical sampling and the development of framework tables. The study revealed a range of findings, which were later conceptualised into an ethnographic ontology of lupus. First, people encounter a daily struggle to cope with illness symptoms. Second, there was evidence of poor communication between the hospital ward staff (and carers) and failure for social workers to be the main advisor/counsellor of end of life care needs including missing referrals to hospice services.

Health and social care professionals sometimes struggle to provide a basic level of service leading to a "know do" gap. This leads to an inconsistent level of end of life care for the individual and limited support for the identified carers. Narratives in diary form have a role to play in helping clinical teams develop meaningful insights into their life of their patients. Clinical teams in turn need to be forthright enough to develop "death covenants" for all patients (and their carers) with palliative care needs. Developing these tools and including them as intervention turn will lead to more cohesive practices within health and social care (Dean 1996, Dean and Melrose 1996, Mol 2008).

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## 1. Chapter one: Setting the scene

### 1.1 Introduction

The purpose of this chapter is to set the scene and introduce the reasons for researching this topic. This doctoral case study is about the experience of living and dying with the disease Systemic Lupus Erythematosus (SLE)<sup>2</sup>. It also aims to highlight the problems caused by the NHS and social care organisations. Specific examples include poor adherence to systems of governance and clinical practice; failing to meet the needs of people unable to articulate and assert their rights for clear and consistent information particularly about how they wish to be cared for in general and how they wish to die when illness is officially known to be terminal (Turner-Stokes 2008). The study will also analyse the dilemma that exists between paid and unpaid health and social care professionals when neglect of patient care emerges. The data derived from narratives will be used as part of an overall case study based on data from people diagnosed with lupus; carers and medical professionals identified by one of the key informants, as well as the viewpoint of the ethnographer himself (as a single carer).

This study will explore the various forms of coping with lupus symptoms and illness management and determine how people with lupus make sense of their life (Baker and Wiginton 1997; Mol 1999; 2002, 2008). Clark and Seymour (1999) found that living with a chronic illness impacts on the individual, social, and societal context. Scambler (1993 p 82) described this experience as a '*profound influenc*' and almost timeless because of the long-term nature of the impact of illness symptoms in the lives of sufferers.

Paid and unpaid carers form part of the social context for people with the diagnosis lupus as it is partly their role to help the person manage the impact of the symptoms within the health and social care system of the UK. An unpaid carer is someone who provides help and support to a spouse, partner, child, relative, friend, or neighbour, who would struggle to cope without their help (DH 2006a). This could be due to age

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<sup>2</sup> The abbreviated term Lupus or SLE will be used throughout the case study.

related infirmity, physical or mental illness, addiction or disability as reported by the Department of Health (DH 2006a).

Doctors and Occupational Therapists are examples of paid health and social care professionals that this study will report on. Their professional narratives are often the only written accounts available in the treatment and intervention. The written narratives of patients or clients are seldom recorded (Good 1994, Hyden 1997). On the occasions when written accounts are available health and social care professionals offer a treatment regime and available support. Horton-Salway's (2002) study of doctors' narratives amongst patients with Chronic Fatigue Syndrome describes the doctors' role as a constructive activity. Professionals record any services that are not available as "unmet needs" (Sheaff 1996, Victor 1997). In addition, arrangements often include prescriptions for medication or the commissioning of services on behalf of the clients from home care agencies to provide home carers (Mattingly 1998).

Physician and anthropologist Paul Farmer studied the underlying reality of suffering in several countries where the health needs of its citizens were impacted on by the effects of war: '*[T]he drama, the tragedy of the destitute sick concerns not only physician's and scholars who work among the poor but all who profess even a passing interest in human rights*' (Farmer 2005 p 18).

Health and social care professionals, involved in the management of long-term chronic conditions, struggle to recognise the expectations of the individual patient and their family (and any other support) to manage their daily experiences (Jung *et al* 1997). They struggle because many in their position as experts look down on people, such as patients, who may have limited knowledge of their practices. In such instances, when the alleged neglect or abuse of power arises, it is often because of a failure to dispense their expert knowledge and practices in an equitable manner thus disempowering consumers (Brechin *et al* 2000, Faubion *et al* 1994, Dean and Melrose 1996).

Much of Michel Foucault's works illustrate how historically health professionals are capable of marginalising people who are ill (Faubion *et al* 1994, Foucault 1973, 2008). He developed the concept known as "Governmentality" for example, which



attempts to describe the body as an object of professional practice (Foucault 2008, Rose 1989). Objectifying patient's disregards, the social plight of living with an illness to the extent that often includes people having to live with the side effects of medication.

Medical science is unable to provide all the answers to treating and managing illness and perhaps should be more honest about its limits (Illich 1995). Examples of the limits to medical intervention appear in the management of health and social care organisations when things go wrong and gaps become identified. In such instances, the consequences for patients and their families can be disappointing especially if they feel that services have been neglectful and inequitable. Armstrong (1995) argues that instead of responding to expressed needs, UK governments and their various health and social care departments continue to provide an approach to peoples needs by surveys. In addition, these government departments study trends in the population and react to these with a "predict-and-provide" approach. The "predict-and-provide" approach tries to fit that population into a service outline based on large scale census data and pre-existing assumptions about what people need and what will work.

It is hoped that the narratives provided by the informants will offer something that can create a new knowledge base about the increased value of shared narratives of suffering and contribute to the good practices of health and social care professionals (cf. Beck 2000, Brechin *et al* 2000). This study will analyse the experiences of lupus sufferers as a group on the margins of discourses around equitable services, particularly during end-of-life care. The persistent failing aspect of an NHS and social care bureaucracy that marginalises lupus sufferers resulting in the need for lupus sufferers and their carers to be taken seriously as consumers in respect of end of life care planning (cf. Higgs 2008, Hughes 1996).

Nettleton and Burrows (2003) and Higgs (2008) also argue that medicine has no real choice but to yield to increasing expectations of members of society. *'[M]edicine is no longer exclusive to the medical school or the medical text. It is no longer contained within institutional frameworks of medicine but has escaped into wider domains where it can be accessed, assessed and reappropriated'* (Higgs 2008 p196). The explanation will provide an insight into the lived experience, and something

about the challenges faced by service providers, including paid professionals and unpaid carers (Bury 2001).

In relation to paid professional carers (e.g. doctors and nurses) plus the author's specific experiences, first as a carer of a relative with lupus and second, as a manager of a team of carers in his daytime job, a pattern of incidents related to work stress and fatigue was revealed amongst a team of members of the caring profession. The daily experiences of health and social care professionals at work can be stressful and unpredictable in respect to positive outcomes for the [lupus] patient. Stressful because of '*[m]anaging time constraints; dealing with conflicting demands; setting difficult priorities; managing tricky relationships; finding short cuts; dealing with stress and frustration (both internal and external); and struggling to hand on to simply doing the job*' (Brechin *et al* 2000 p 25). The narrative below therefore brings together the pressures on sufferers, carers, and service providers.

## **1.2 Research Objective One**

**To explore what life is like for people with lupus, identify processes of survival, and dying within the case study**

The main participants within this study are women diagnosed with lupus. The lives of these individuals will be used to explore how their identities and relationships change because of living with a chronic illness (cf. Kelly 1992). Aspects of their lives will include: their personal space; the ways they listen to their bodies; give voice to their bodies' signs and stories (Lupton 1992); social space and the extent to which they interact with others (e.g. carers, health professionals etc) on a daily basis. Living with a chronic illness often reaches deep into a person's emotional coping reserves. People often find it very challenging to make explicit feelings related to dying and ultimately the meanings of life.

The approach to the subject matter is to describe and analyse some of the life experiences of lupus sufferers. In addition this case study aims to set those life experiences in the context of social system known as the NHS and local government services which controls peoples lives in the way they queue and ask for services (e.g. Hospice services) (Hughes 1996). The core themes that emerge from this study will

provide further explanations of how illness narratives have a particular shape and pattern. At the same time, the case study will take an open approach to the management of illness and social care as there is no possibility of obtaining perfect services. When taken as a case study the experiences of four lupus sufferers and an ethnographer can contribute to the development of a theory about living and dying with lupus, which can classify events and strategies in terms of key conceptual elements that structure perceptions of them. This enables us to make sense of the intentions and perceptions not only of professionals as they manage illness and social care but also of the sufferers of lupus themselves as they manage their lives, and interact with both carers and professionals.

Narratives are essential to this study. The fine-grained details of the narratives are the raw data for this study. The lupus informants recorded and reported what was going on in their lives in first person accounts (cf. McElroy *et al* 2000 on the importance of this). These first person accounts illuminate suffering in a meaningful and valuable way (cf. Kleinman and Seeman 2000). This study will explore how sufferers and service providers dealt with the various tensions that arose in their daily and professional spaces. The narratives often convey a pattern with an outcome message as if reflecting a journey (cf. Frank 1995). For example in this case study, the narratives of lupus sufferers could determine whether there exists a “unique fight for survival” amidst daily pain and discomfort; and at the same time forcing sufferers to think about new ways to cope.

Lupus informants are able to tell a story of suffering using diary entries that describe patterns about living with the disease and receiving treatment for the disease (cf. Charon and Montello 2002). This case study will explore the following: The extent to which the lupus informants experience daily suffering and; assumptions about what suffering means to them when efforts to cope seem to fail. Writers such as Farmer (2005), Frank (1995), Foucault (2008), Kleinman *et al* (1997), and Singer (2006) have added to the social scientific debate on the meaning of suffering in its entire human context - whether through illness, hunger, famine, war, homelessness or other forms such as social deprivation.

In addition, this study explored how these people find ways of managing their lives by requesting help from health professionals. Consent to receiving treatment and care, is led by health and social care professionals (e.g. policy makers; health planners), through various forms of health service provision. The chronically ill and their carers often make decisions about how health directives affect their lives especially if they perceive treatment as “bad for their health”. Doctors would view some of these choices as unacceptable, particularly when non-compliance to prescribed medicine or a “healthy lifestyle regime” occurs (Baker and Wiginton 1997, DH 2005, Harrison 2000 and Lupton 1992). The issues facing people with long-term conditions (LTCs) is important to central government. It is their way of maintaining credibility with professional interest groups such as the General Medical Council and the Royal College of Physicians. In 2005, the government established a National Service Framework (NSF) for long term conditions (DH 2005). The aim of this framework was to transform the way health and social care services enable people with long-term neurological conditions to live as independently as possible. However, there is no mention of lupus in this framework despite its recognition as a chronic condition.

In addition, lupus is a LTC and does not exist on the Department of Health’s list of LTCs. The reason for this is unknown. The NSF for long term conditions listed examples of LTCs including diabetes, heart disease, and chronic obstructive pulmonary disease. In addition the following 17 conditions were listed in the documents appendix to include cerebral palsy, charcot-marie tooth disorder, dystonia, early onset dementia, epilepsy, essential tremor, Huntington’s disease, migraine, motor neurone disease, multiple sclerosis, muscular dystrophy, Parkinson’s disease, post polio syndrome, spinal cord injury, spina bifida, young onset stroke and traumatic brain injury (DH 2005). Yet in terms of number of sufferers, lupus would rank as the eighth highest with approximately 50,000 sufferers diagnosed in the UK (Lupus UK 2009).

People with lupus and their carers can therefore feel isolated from access to specialist services. This phenomenon is not acceptable as it results in most people who are supposed to have limitations taking gambles on what constitutes better decisions and choices about the type of treatment they self-administer each day of their life. It takes popular trends and cultural activities to provide breakthroughs (e.g. use of internet to

learn about personal illness symptoms; using or failing to use an ineffective bureaucratic complaints system). How then will this research make sense of social phenomena in a way that illuminates the issues related to their suffering? One of the ways is by developing concepts based on their narratives and perspectives (which will be discussed later in the study). It will also reveal what efforts they make to overcome their situation.

The second way this study will attempt to make sense of how people cope is by adopting a theoretical perspective that challenges how and why lupus sufferers, and their carers, are unable to participate in the decision making processes by health and social care professionals about end of life care arrangements. In the light of this breach of service provision, the author contends that it occurs because health and social care professionals fail to recognise patients as consumers with a right to receipt of equitable services. To a significant extent, this is an abuse of power by health and social care professionals.

### **1.3 Research Objective Two**

#### **To explore how carers manage and support relatives with lupus within the case study**

People go through a well-known journey when they are ill. This journey is the “care pathway” (Holloway 2006). When people are ill they often recognise that something is wrong with their body for a long while before making social contact with someone else about their problems (Morse and Johnson 1991). Often the first person they make contact with is a carer. The dominant social construct of carers in western societies is that of being warm and supportive individuals, often female (Graham 1983, Twigg and Atkin 1994 and Wilson 1982).

*‘[C]aring means doing things for people that they cannot do for themselves, and personal care tasks such as lifting, toileting and washing provide the clearest examples’ (Twigg and Atkin 1994 p8).*

Our perspectives about the gendered role of caring are shaped by years of socialisation in which women are often performing roles of being an unpaid carer

(Graham 1991, Clarke 2001, Gabe *et al* 2007). Our first experiences of caring are often received from a mother or maternal figure in a kinship environment for example grandmother or other female relation (Finch 1989). During periods of illness mothers and maternal carers, transform into lay social workers and nurses. In these situations, they often provide advice and guidance to others in the community whose needs for dignity and independence remain vital to those who are ill or those who may be dying (Clarke 2001). In western societies, the male “father figure” can be seen as distant and remote with a more functional role as provider of resources for the home commonly referred to as a “bread winner”. *‘[T]he principal role of the husband and father was one of economic provider, for it was the man who engaged in the external world of work in order to provide for his wife and children. In contrast, the role of the wife was conceived more of inward looking, concentrating as it did on maintaining the affective side of family life’* (Clarke 2001 p 200).

The gendered stereotype of caring is contradicted when men fulfil the role of carer (DH 2008, Green 1988,). Lupus sufferers who are women may have to rely on their partners or husbands. In addition, they may also rely on children when the partner or husband is at work.

Carers can reach a point of fatigue as a result of accumulated demands placed upon them to perform their role known as the *‘[d]aily grind of care giving’* (Twigg and Atkin 1994 p4). They endure their role often with near selfless commitment to their duty to give back care after receiving many years of support and affection from their ill relative when they themselves were once healthy and active. In certain cases when carers have reached a point of being unable to provide caring duties, this is described as “caregiver burden” (George and Gwyther 1986, Visser-Meily *et al* 2004, DH 2007e). The caregiver burden covers all the *‘[p]hysical, emotional, social and financial problems that can be experienced by family members caring for someone’* (George and Gwyther 1986, p.253).

The result might mean having to live in isolation if a care giving relationship may have broken down or live in a state of dependency at the prospect of having to ask friends or relatives for constant help. In these instances the care giving role may be shared by other relatives, friends or even paid for and provided by local council social

services home carers. In the last ten years in the UK, there has been an increase in legislation designed to take into account the needs of the carers (DH 2008a). As a result carers are able to request a “needs led” assessment to determine if they are eligible for relief from care, known as respite (Beresford 2008).

There are measures to support the role of carers in our society as reflected in social policy (DH 2008). This study will explore the extent to which personal events, social events and experiences alienate carers from the decision making process by individual sufferers and service providers (cf. Age Concern 2005, DH 2006a, DH 2006b, HSC 2004). Carers are under tremendous strain when the person who they are caring for reaches a point where they are dying and eventually die. Throughout their caring role, carers may reach a point where they rely on the expertise and support of health and social care professionals to provide the right kind of advice and communication in the right way (DH 2007a). The relationship between professional carers and unpaid carers (who are family or friends) tends to be hierarchical and unequal with professional carers often taking the lead on actions and decisions about the family member (Hugman 1994).

Lawton (2000) also argued that unpaid carers, such as family and friends, not excluded from the care arena, have an emotional quality far greater than the paid carer. This is a more altruistic concern known as “caring about” someone (although the same phrase may also be used to describe a paid carer perceived as “really caring” beyond the call of duty – which implicitly recognises the same distinction). Medick and Sabean (1984) argued that the words used to describe the qualities of unpaid carers are not passive reflections of social reality; instead, they argue that those words are symbolic representations of social reality aiming to redress the balance of being left out versus being included in decision-making.

Carers often know that the people they care for would like to die at home. The government recognises this. The government provides high levels of investment for people with illnesses such as terminal cancer to receive support to die either at home or in a hospice where appropriate. The government has stated that ‘*[t]he right to a good death should be fundamental*’ (DH 2004a p 27). There are national standards provided by good practice in health settings around dying such as the Gold Standards

Framework and the Liverpool Care pathway aimed at ensuring services throughout the country can work towards a model of good practice (DH2004b). Carers however should not be 'short changed'. The UK government in principle recognises that it has no right to expect carers to substitute for the role of state funded services in order to save money. *'[R]esource allocation decisions (in the NHS) have highly visible consequences and generate fierce controversy'* (Hughes 1996 p 298).

Carers too often stand by as passive recipients of services affecting their relatives and often only protest when services are negligent resulting in crisis. The words of central government need to be translated into practical meaningful action at the front line of health and social care delivery which should, in principle, be integrated, but in reality remain disjointed as services jostle to avoid responsibility over individuals' in more difficult and complex cases.

#### **1.4 Research objective three**

##### **To explore how lupus symptoms experienced by individuals are managed by health and social care professionals**

A number of doctors and other health and social care professionals are involved in the care of the sufferers. The General Practitioner (GP) is the central point of contact and often the initial point of referral to other expert consultants. All doctors involved in the care of the sufferer are able to prescribe medication to alleviate various symptoms and side effects that the person may be going through.

*'[T]he traditional focus of medicine is on the patient. Medicine defines the problem first in terms of physiological phenomena – the condition or malfunctioning organ or subsystem; the second in terms of the individual patient – his or her body'* (Twigg and Atkin 1994 p 138).

Studies of the patient and doctor relationship have reported on decisions about referring the patient for other types of intervention as bureaucratic and control regime (cf. Freidson 1970). In addition, differences in the language used by doctors towards their patients can be patronising. This leads to a breakdown in the participation of the



treatment regime sometimes leading to issues of patient safety being jeopardized (Freidson 1970).

Other studies report on the positive relationships between doctors and patients. Receiving news of successful surgical operations are examples of the good work for which doctors and nurses receive appreciation. There is also recognition that many doctors are limited in what they are able to do in terms of their limited ability to prescribe medication that is more effective. Sometimes a public outcry forces politicians to prioritise decisions about delivering improved services. The case for the use of the medication Aricept over five years ago in the treatment of early stages of Alzheimer's disease is an example. Aricept has become a popular drug that forced people to make decisions to purchase privately for the care of relatives (BBC News 2004).

The commissioning body for NHS drugs, the National Institute for Health and Clinical Excellence (NICE), makes decisions on behalf of the Department of Health Services and originally did not support appeals for this drug to be made available under the NHS. Sometimes when there is dissatisfaction with services based on perceived poor quality of service delivery from organisation to members of the public complaints to the law courts arise in order to seek redress. The intention of those seeking redress, is for decisions affecting services, to be changed in order to increase access to equitable services for members of the public. An example of this occurred when Pharmaceutical firms Eisai and Pfizer, developers of the Alzheimer's drug Aricept (prescription name is Donepezil), mounted a legal challenge to the "unfair and irrational" decision in May 2007 against the NICE.

Following a hearing in June 2007, the UK High Court ruled that the National Institute of Health and Clinical Excellence was instructed to review the evidence used to determine whether drugs for Alzheimer's disease are cost-effective in early stages of the disease (NICE 2007). The background to the challenge emerged when NICE ruled in March 2005 that, although clinically effective, Aricept, at a cost of £2.50 per patient per day, was not cost-effective and should not be reimbursed on the NHS. The companies claimed that the process leading to the Final Appraisal Determination (FAD) and treatment guidance was unfair, as NICE had repeatedly refused to disclose

a fully working version of the cost effectiveness model used in this decision. This was the first NICE decision to be challenged at this level.

In August 2007 Judge Linda Dobbs ruled that the NICE Appraisal Committee acted unlawfully by not having due regard to anti-discriminatory legislation in the formulation of the guidance, potentially resulting in discrimination against mild patients with learning or language difficulties. The judgment, in effect, upheld the NICE guidance that the majority of newly diagnosed patients with Alzheimer's disease of mild severity should receive drug treatments on the NHS. NICE has been directed to prepare revised guidance to address this issue (PEC 2007). Those lobbying for improved treatment for lupus sufferers will always have the contestability of NICE policies in mind.

Doctors as health professionals offer a range of interventions to those who are ill. They have functional roles and specialisms designed to guarantee an appropriate degree of emphasis and intervention to their patient, who the system expects to behave appropriately, by adopting the “sick role”. Although Parsons’ (1951) classic description of the sick role is the basis of research going as far back as the 1930s, it still provides a useful starting point for understanding the actions of both patients and healing and caring professionals. The sick role is characterised by dependency on the medical team to provide the answers and ultimate cure to the ailments, which have perhaps led to the patient’s admission into the hospital. In the UK, the patient’s first medical contact should be with the general practitioner. The exception should only arise if the person has experienced a traumatic incident, which requires urgent medical attention at a local hospital’s accident and emergency department.

For lupus sufferers their long-standing relationship with the general practitioner will usually have developed because of trust and cooperation between the two individuals. In addition to the prescription of medication or provision of advice, the general practitioner will arrive at (sometimes unpopular) decisions where it may be necessary to alter treatment. In the case of those who suffer with medically unexplained symptoms (MUS), the perception of patients as problematic people leads to a strain in their relationship (Nettleton 2006). Patients may live with the satisfaction of knowing that they have a label for their disease in the form of a diagnosis such as lupus. However, it is possible for new and emerging symptoms to be encountered by lupus

sufferers not attributable to the disease but other ‘*systemic autoimmune syndromes*’ (Reeves 2004 p342).

During times like this, the general practitioner will refer his patient to a specialist at a local or regional hospital. These specialists are often referred to as consultant physicians. They are often perceived as being the lead health professional within the health and social care setting. An example of how the many roles are shared and organised exists in the hospital ward setting where the patient’s care, as an inpatient, is the responsibility of the consultant physician. The physician will then delegate responsibility for care and treatment to the lead nurse or matron. In addition, a range of other professionals will form part of the ward team and decision-making. These other health and social care professionals could include occupational therapists, social workers, speech and language therapists or health care assistants. The ward team interact with one another to ensure that the patient is adequately cared for according to the doctors’ instructions. Doctor’s narratives will be explored using medical records made available after the death of informant one.

However, doctors form only part of the social context for lupus sufferer and the management of their illness. There is a perception that their intervention is not cohesive. For example, this breakdown in cohesive practices occurs when the patient returns to their own home to be care managed by other professionals, such as general practitioners, or by a lay carer. The government has therefore pledged the need for effective communication between professionals and services. ‘*[T]he need for efficient transfer across the interface has become more urgent since changes in health care delivery have led to shorter stays (with less time to communicate information to patients and primary care professionals) and for improved access to day case surgery or open access investigations (raising the requirements for information from primary care to hospitals)*’ (DH 2007a p1).

Within the community, however, the community health and social care teams are responsible for assessing the needs of people with long-term conditions some of whom may have the disease lupus. The services provided by community health and social care professionals are managed by another organisation, which is often the local council’s social services department or the local primary care trust. Confusion

between several organisations responsible for paying for the care services of the individual can arise. In these instances, the public may lose confidence in how large organisations are able to come together and provide a seamless arrangement for the funding of hospice care for people with cancer as opposed to those who have lupus.

Since 2001, the government has recognised that the safety of patients should be an important part of service planning and delivery (DH 2001). Many fatal incidents, involving a range of service led errors, include incidents such as inappropriate prescriptions of medication or inappropriate use of medical devices by patients whilst in the care of hospital ward staff.

Adverse health and social care events cannot be eliminated from complex health care but the aspiration of central government has been to ensure that services are designed to learn that lessons from the past are used to reduce the risk to patients in the future. The cost of adverse events is increasing. The Department of Health has suggested that although changes in clinical governance and increased professional and service regulation have been an attempt to commit to the delivery of high quality services to those members of the public in need of help, there is still a need for more research on reporting and information systems to capture the patient's perspective about service failings in UK (DH 2000a). Specific types of adverse events are seen to repeat themselves at intervals, thus demonstrating that lessons have not been learned (Carruthers and Philip 2006).

## **1. 5 Clinical representations of lupus**

### **1.5.1 What is lupus?**

Lupus is a chronic inflammatory disease of unknown aetiology that occurs in people who have an overactive immune system. This condition is also classified as an autoimmune disease; it affects most major organ systems. People with lupus vacillate between periods of remission (waning) and exacerbation (waxing), with symptoms of fatigue and chronic pain, and experience of disturbances of self-concept (Manson and Rahman 2006, Baker and Wiginton 1997).

One of the main targets for antibodies in lupus is the blood vessels. A frequent complaint is Raynaud's phenomenon, in which the fingers turn shades of white, blue and red due to spasm of the arteries on exposure to the cold. As the antibodies are carried through, the body lupus may strike any organ and so produce almost any symptom. For example, in the case where kidneys are affected, the condition *lupus nephritis* is the diagnosis for this.

Lupus no longer has the high mortality rate of the past due to improved diagnostic tests that allow for earlier detection and treatment. The 5-year survival for lupus patients has risen from 76% in the 1970s to 93–97% in 2000 (Reeves 2004). In 1991 the prevalence rates (i.e. number of people per 100,000 of the population) for lupus was 28 per 100,000. The incidence rates (i.e. number of new cases that develop each year per 100,000 of the population) were 3.8 per 100,000. Therefore about 26,300 developed the disease in 1991 (Lupus UK 2009). The incidence rates for lupus are higher than incidence rates for motor neurone disease (2%) and multiple sclerosis (3%) (DH 2005).

Treatment depends on the severity of the illness and may include non-steroidal anti-inflammatory agents for arthritis, anti-malarial therapy for skin disease and other mild lupus manifestations (Halverson 1992; Illman 1995). Studies have also revealed that lupus patients are susceptible to infections and are likely to have increased mortality rates if they have renal insufficiency (Woon-Leung 2006).

### **1.5.2 Initial symptoms**

Early signs of lupus include fatigue, general weakness, headaches, poor appetite and frequent infections. In addition, the following symptoms are also indicative: sensitivity to sunlight, a red butterfly like rash on the face, a rash below the eyes and around the lips (Baker and Wiginton 1997). The American College of Rheumatology (ACR) have established an internationally accepted list of eleven symptoms the presence of which four are indicative of lupus (Hochberg 1997). The list of symptoms is as follows:

*Malar rash - Malar erythema, flat or raised*

*Discoid rash - Erythematous raised patches with scaling and follicular plugging*

*Photosensitivity - Rash as an unusual reaction to sunlight*

*Oral ulcers - Oral/nasopharyngeal ulcers, usually painless, observed by physician*

*Arthritis - Non-erosive arthritis involving two or less peripheral joints with tenderness, swelling, or effusion*

*Serositis - Pleuritis or pericarditis*

*Renal features - Proteinuria or cellular casts*

*Neurological features - Seizures or psychosis*

*Haematological features - Haemolysis, leucopenia, lymphopenia or low platelets*

*Immunological features - DNA, Smith antibody or antiphospholipid antibodies (based on positive cardiolipin, lupus anticoagulant or false positive syphilis serology).*

*Antinuclear antibody-positive - A positive test result suggests the likelihood of an autoimmune disease but not lupus and the doctor will then carry out further more specific tests (called 'ANA subsets') to assist in making a final diagnosis (Hochberg 1997 p1725).*

Lupus can cause damage to all organs in the body and sensory systems and increase the risk of stroke and heart attacks. It can cause joint pains. It can also cause severe problems in pregnancy, leading to miscarriage (Hughes 1996). Due to the variety of symptoms that comprise the illness it is seldom alike in any two individuals and may take years to diagnose. *'Lupus can be a frustrating illness to manage because many of the symptoms mimic other illnesses and the most debilitating factor, fatigue is dismissed and trivialized'* (Baker and Wiginton 1997 p 129).

Lupus is similar to rheumatoid arthritis to the extent where it produces painful, swollen joints. More than half suffer damage to the central nervous system, resulting in signs and symptoms ranging from mild depression to stroke. The disease can also cause hair loss. Recent advances in the diagnosis and symptom management of lupus have now made the disease compatible with normal life span. However, lupus remains a multisystem disorder with no cure. Consequently, every nursing speciality is challenged in terms of comprehensive care to these patients (Lash 1994).

Several mechanisms probably contribute to central nervous system dysfunction in patients with lupus. Causes may include systemic and brain infection, cardiogenic embolism, and hypercoagulable states. Patients present with a variety of central nervous system disorders of the brain, including seizures, stroke, and psychosis. Events with instantaneous onset probably represent a seizure. In addition, sudden onset is also characteristic of a stroke (Futrell and Millikan 1994).

After diagnosis, living with lupus is a challenge. This study seeks to explore the physical and social repercussions of the illness as far as possible from the perspective of the sufferer as well as the carers and professionals. Patients and their families find ways to incorporate being caregivers and lay health practitioners in their lives and accommodate the effects of chronic disease (Permutt 1994, Bengtsson *et al* 2002). Lupus can be classified into three different main types: Discoid lupus affects the skin only; drug-induced lupus, which manifests lupus type symptoms that fade when the implicated drug is discontinued; and systemic lupus, which causes inflammation in a number of organs. Of the three types of lupus, only systemic lupus can lead to life threatening central nervous system and or renal involvement. Renal involvement is known as lupus nephritis. By the 1960s, lupus nephritis and progressive renal disease emerged as dominant factors in lupus patient morbidity, and kidney failure had become the most common form of death (Schiffenbauer and Seigel 2005, Bijl *et al* 2002).

*‘[R]enal involvement is one of the most serious complications of systemic lupus erythematosus. It has a major impact on morbidity and mortality. The incidence of renal disease in SLE varies with criteria used to define renal involvement and selection of the patients. Using clinical parameters, the incidence varies from 45% to 75% but it is reasonable to assume that on average, two thirds of patients with well documented SLE will develop renal symptoms during their disease course’ (Lewis *et al* 1999 p 79).*

Lupus and its variants have a spectrum of clinical problems, each with its own therapy and outcome. Multiple immunologic abnormalities characterise lupus and include altered control of antibodies and the presence of different antigen antibody complexes. Early recognition of lupus is based on detecting these circulating serum

antibodies that are, in fact, autoantibodies. Treatment with corticosteroids and, in some patients, cytotoxic drugs, also known as chemotherapy, is, associated with prolonged survival. Before making the diagnosis of lupus, it is important to rule out other processes such as infections (Stevens 1993).

### **1.5.3 UK epidemiology**

In 2004, the Department of Health produced the following findings from an investigation into chronic illness (DH 2004c). Their study concluded that the UK with a population of almost 60 million people 8.8m people in England have long-term illness that severely limits their day-to-day ability to cope. Common chronic diseases include:

- a. Diabetes Mellitus current estimates put the number of people with diabetes at approximately 1.3m people with perhaps another million undiagnosed.
- b. Coronary Obstructive Pulmonary Disease affecting 600,000 people.
- c. Asthma affecting 3.7m adults and 1.5m children
- d. Arthritis affecting about 8.5m in UK.
- e. Epilepsy with 400,000 sufferers England & Wales.
- f. Mental Ill Health affecting one in six of the population, including 1 in 10 children. Chronic diseases are diseases which current medical interventions can only control not cure.

There are an estimated 50,000 lupus sufferers in the UK (Lupus UK 2009). Some experts believe that the rate of incidence is increasing, but this may owe more to the improved diagnosis than a rise in incidence amongst people (Manson and Rahman 2006). Lupus no longer has the high mortality rate of the past few years due to improved diagnostic tests that allow for earlier detection and treatment. Lupus is a complex disease that affects the individual and the family. Lupus strikes all ages, but peaks in the mid-twenties. Women are nine times more vulnerable than men are, and it is nearly three times more common among black people than among white people in the UK and USA (Isenberg *et al* 2008, Khamashta *et al* 2003). A disease once thought to be a very rare condition is now believed to affect as many as one in 1,000 young white women. West Indian women may be even more susceptible. The hospital admission rates per 100,000 of the population show that lupus is more



densely distributed in city environments such as Manchester, London, and the West Midlands (Goldacre *et al* 2005).

When compared to national trends of other chronic conditions, lupus is small by comparison for example in 2006 the Department of Health reported that over 15 million people have a long-term condition (DH 2006a). Politicians with a special interest in lupus have pushed for more to be done about the needs of lupus sufferers in parliament and ultimately the NHS and local authority social care.

### **1.5.3.1 The role of politicians in the debating and shaping of lupus policy**

Stimulated by her own personal interest in lupus, Janet Dean former labour MP (Burton on Trent, Staffordshire) has played a role in trying to obtain accurate figures of the number of people with lupus. Her desire as a member of parliament was to enable and encourage people in strategic and planning roles within the health care organisations to take notice, and work hard, to better plan for services on behalf of lupus sufferers and their families. In 2005, she provided an interview for this case study.

Politicians' discourses are vehicles of narrative expression whether in written or oral form (cf. Ager *et al* 2000, Hughes 1996). For this case study contextual explanations about the role of politicians is important because it will demonstrate where their role fits in with the national context in the formulation of legislative health and social care. One politician, Janet Dean, was interviewed and the interview transcript was later thematically analysed. The MP informant in turn referred the author to debate transcripts about lupus that were also used to assess how a group of politicians share their viewpoints and beliefs about what does and should constitute fairer services for people with lupus.

Politicians enter the profession with a belief that they are able to make a positive difference in the lives of the people that they represent as 'vital politics' (Rose 2007). They often come from a background of civic engagement and political activism and become motivated to represent others by a sense of injustice or inequity of services

being provided on a state funded basis. This could be about a particular single issue or a general voice for greater civil rights. This is often in the form of writing into newspapers, attending neighbourhood or community meetings or helping people to articulate their grievances to people in authority such as the local council or their member of parliament.

Once having joined the political process, maybe starting by becoming a representative of a particular community group, many individuals who become politicians take time to understand the role and function of the parliamentary system. There are a range of procedures and meetings that allow politicians under guidance from their senior colleagues, including civil servants, to learn about how to influence change and perhaps raise the issues that they were committed to prior to becoming an elected official. The shape and form of debates takes another turn for the politician elected to represent their community once in parliament. This can include being involved in various sub-committees or working parties or shadow cabinets or even the government front bench.

Elected politicians wishing to argue various issues on behalf of their constituency they have to be skilled at constructing, developing, and delivering speeches (cf. Carter 2004). Speeches have a particular purpose within the organisation of parliament and fit a particular cultural pattern of expressive dialogue including use of metaphor (Musolff 2004, Hughes 1996). Speeches can serve to convey the feeling of injustice about a particular issue. They can act as a reminder about contextual aspects of why a particular situation has arisen. They can act as a springboard for motivating a group of politicians to act in the best interests of the whole community (or national interest) over a particular issue and ultimately create legislation to bring about change and practical improvements in the way in which services are delivered to the electorate

Some changes take a long time to become reality. In times like this, members of the public become cynical of the political process and may describe the actions of politicians as *rhetoric of unimplemented reform* (Hughes 1996). There may be swathes of political narratives, all used to obtain a desired effect of change. These include conversations, speeches, email, telephone conversation, and written proposals. The politician's skills are also to ask questions. Many politicians are trained in the

law and are socialised in their legal training to influence others through carefully constructed arguments. The questioning narrative is common in sub-committees and working parties often chaired by a government (junior or senior) minister. Through this process, amendments to legislation can arise several years later.

The All-Party Parliamentary Group for Lupus is an example of a group aiming to debate the issues at stake for lupus sufferers, and their carers, within the context of resource allocation from state funded health and social services. There are other higher profile parliamentary groups and committees however, and lobby groups such as the charity *Lupus UK* are able to mobilise their networks to play a role in contributing to the debates around the challenges faced by lupus sufferers. The ability to persuade others that a particular viewpoint is morally the right viewpoint is the ultimate skill of politicians. Their ability to create a direct or indirect message through their narrative is part of their major skill in communicating.

Janet Dean MP became the first chair of the All-Party Parliamentary Group for lupus. She helped to organise several actions in parliament. These actions included organising an early day motion about lupus. Early day motions are petitions that politicians are asked to sign up to within the parliamentary setting. They are not mandatory and as such, an MP like Janet Dean would have had to play a role in persuading various members to sign up to this in order to raise awareness of the issues in the house of parliament. Several hundred MPs signed up to the early day motion which led to two main debates in the house of parliament about lupus as well as the formation of the All Party Parliamentary Group for Lupus, chaired by Janet Dean MP. The purpose of this section was not to appraise the speech patterns in detail as many other works had covered this ground in relation to rhetorical strategies (cf. Orwell *et al* 1968, Musolff 2004). The aim of using interview data provided by Janet Dean MP, as well as reading the texts of the All-Party Parliamentary Group meetings, was to contextualise the role and function of politicians in the planning aspects of health and social care policy. This was at one level of politics, the highest level being the formation of a Green Paper and ultimately legislation. This is also another example of a social narrative about lupus, which sits in society alongside, and interacts with those constructed by the medical profession and the sufferers and carers.

#### **1.5.4 Medical and social misconceptions**

Dr. Graham Hughes, leading consultant Rheumatologist at St. Thomas's Hospital, London has reported that many women live with the disease for many years undiagnosed. Women at his clinic frequently tell a story of how their complaints have been diagnosed as growing pains, recurrent glandular fever, or severe migraine (Hughes 1996).

There are many more mild cases, which miss diagnosis. The natural tendency of the disease seems to be to burn out within a couple of years, although some cases are more chronic and the condition may come and go without even being recognised.

Bertino (1993) has argued that rehabilitation professionals (e.g. Occupational Therapists and Physiotherapists) should use a holistic approach to treat altered functional ability and help individuals adjust to lifestyle changes associated with chronic illness and or disability. Health professionals with specialised rehabilitation knowledge and skills can help individuals with lupus realise and reach their optimal level of functioning, and thus improve their quality of life.

Persons affected by lupus and their families need help in understanding their condition and require support as they deal with fear, depression and possible disability. Implications for nursing are varied and include patient/family education about medication, joint protection principles, energy conservation, pain and stress management, and coping techniques (Halverson 1992). In order for views of Halverson (1992) and Bertino (1993) to be tested, we need to understand what people with lupus go through and understand the very varied contexts that constitute their life.

## **2. Chapter Two - Health and social services provider context**

### **2.1 Introduction**

This chapter will explain the National Health Service (NHS) and Local Authority Social Services (LASS) context in the United Kingdom (UK) of which people with the disease lupus and their carers are part. In many ways, it will draw on the influences of Foucault's notion of governmentality as it can be applied to the guiding of behaviour by large health and social care organisations ensuring that individual patients choose the correct way to conform or respond to services (cf. Foucault 2008, Lupton 1997, Petersen *et al* 1997, and Rose 2007). The contextual backdrop of the organisation of the NHS and LASS departments is necessary to analyze how services are planned, resourced, and evaluated (cf. Mandelstam 2005).

This chapter will comprise several sections. The main thrust of the chapter will be historical, arguing that health and social services as separate organisations do not work effectively as a partnership despite encouragement from central government to do so. An example of this is the increasing demand for support for carers. *'[W]elfare reform, must ensure carers experience a system which is on their side rather than enduring a constant struggle so that they are supported to have a life of their own alongside their caring responsibilities'* (DH 2008 p6).

The first section will offer a description of how the role of central government and NHS is funded and report on how responsibility for service delivery to local people is provided by local health organisations. The second section will describe the role of functions devolved to social services departments and local councils and explain their key challenges. Local councils' social services departments operate through various processes and organisational structures. Through guidance and policy initiatives, they are duty bound to work in partnership, where necessary, with health care services. The third section will introduce the importance of health and illness trends, as collected by the Office of National Statistics. In addition, it will examine how trends are utilised by government in the setting of priorities for spending on health and social care in the UK. The fourth section will be an appraisal of how services for lupus patients are provided. The section will detail the role of special interest groups that

have a lobbying function to parliament in helping to raise awareness of the disease. The fifth section will discuss how consumer dialogue is governed in the NHS and Social services and explain how the complaints system operates when things go wrong (Hughes 1996b, Hughes *et al* 1997, Klein 2006). The sixth and final section will discuss health inequalities and contemporary measures taken to alleviate social determinants of suffering within a health and social care setting.

## **2.2 The role of central government (1970 – 2000)**

In response to data regarding unmet need amongst the elderly and the disabled, the Chronically Sick and Disabled Persons Act (CSDPA) 1970 (OPSI 2007) instructed local authorities to make provision for those individuals with “permanent and substantial” disabilities. Section 2 of the act allows local authorities to determine what constitutes “permanent and substantial” without much guidance beyond the DHSS Circular 12/7(2) (1970) which says *‘[T]he duty requires the authority to assess the requirements of individuals determined by them to be substantially and permanently handicapped as to their needs in these matters’*. Mandelstam (2005), Sheaff (1996), and Victor (1997) discuss this at some length. They suggest it is evident, from the intentions of the CSDPA of 1970, that the then central government recognised a gap in service provision at that time.

Mandelstam (2005) suggests that “permanent” is taken as meaning that the person could have any disability that is not curable through medication or surgery and lasting longer than six to twelve months, and “substantial” means that the person was unable to perform more than one essential task in the home. Ultimately, the introduction of this legislation informed the practices of health and social care professionals, including social workers and occupational therapists employed by local authorities.

The formation of unified social service departments under the 1970 Local Authorities and Social Services (LASS) Act (OPSI (2006f) facilitated the operation of the CSDPA 1970. The 1970 LASS Act ended rivalry between Welfare Service Departments, Public Health Departments and Children’s Departments, and brought together the administration of various health and social care professionals, such as occupational therapists and social workers. Various sections of the 1970 CSDPA also

encouraged councils to keep a register of the number of disabled people living in the community.

Occupational therapy departments emerged amidst the increasing demand for people, such as lupus sufferers, to remain physically independent within their own homes as well as to enable speedy hospital discharge and thus reduce the costs of inpatient stays. Their roles would be to assess and provide equipment and recommendations for major home adaptations and rehousing options to more suitable dwellings. In certain circumstances, they would work with social workers to ensure that domiciliary carers received the equipment that they needed to enable them to provide safer care.

Many people with disabilities including lupus sufferers would have difficulty conveying that their condition was substantial, especially with medically unexplained symptoms (Nettleton 2006). Due to the fluctuating nature of the condition it would be difficult to articulate that they had the same barriers to survival around the home as someone for example who may have had more visible physical impairments (Oliver 1990).

All four lupus sufferers within this study met their local social services department for an assessment of need for equipment and or major adaptations to their dwelling. Three met the researcher in his role as community occupational therapist. At the time of research their needs were assessed in the context of a range of local authority legislation such as the NHS and Community Care Act 1990 (OPSI 2006e), the Housing Act 1989 (OPSI 2006g); the Housing Act 1996 (OPSI 2006i); and the National Assistance Act 1948 (OPSI 2006h and Dimmond 1997). Therefore, no matter whether a person is or is not entitled to a specific resource, the safety net mechanism should provide a minimum resource (i.e. information and advice).

Although the CSDPA (1970) laid down the procedure by which local authorities should start the process of counting the numbers of disabled people in their respective communities it was only in 1985 that the government decided to take the lead in commissioning a census of the number of disabled people in the U.K (Martin *et al* 1988, Oliver 1990). Prior to this, data from a smaller scale survey, known as the General Household Survey was extrapolated to assess the needs of the population at

large (Green 1988). No specific mention was made in this survey about people diagnosed with lupus in particular. Lupus is a medical condition on the margins of health and social care policy and planning.

### **2.3 Health and social service roles and responsibilities 2000 - present**

The majority of today's consumers, as taxpayers who become ill, are eligible to receive high quality health and social care services based on clinical need and not on the ability of the consumer to pay (Wanless 2002, Rose 2007). Research undertaken by the Joseph Rowntree Foundation (Turner *et al* 2003) found that respondents viewed access to services, including housing, education, employment and transport, as well as health, social care and benefits as a basic human right. One key factor determining treatment and care, however, will be whether those individuals are eligible to receive certain categories of services (Turner *et al* 2003). The queuing system that is evident in UK welfare services has resulted in criteria being developed so that those people most in need can be prioritised in order for assessments and intervention to be provided. An example of eligibility guidance is the Fair Access to Care Services (FACS) guidance (DH 2002).

The FACS guidance is part of the standardisation of local authority discretionary practices on how to utilise resources for the local population in terms of need (McDonald 2006). The Wanless Review in 2002 warned that health providers (including government) and citizens need to work together to become "fully engaged". The patient is expected to work on improving his or her own lifestyle arrangements (e.g. achieving a balanced diet and smoke cessation).

The NHS, for example, could not be expected to achieve full engagement with staff shortages in key service areas and would have to settle for a performance scenario of either "*slow uptake*" or "*solid progress*". "*Slow uptake*" is a high cost scenario assuming slow improvement in the NHS productivity and no change in patient engagement in the health implications of their own lifestyle arrangements. "*Solid progress*" (clearly the preferred scenario) assumes there is continuous improvement of NHS productivity, and requires greater engagement by patients in the health implications of their own lifestyle.



The present research studies how limited availability of professional staff in key areas across social services and the NHS contributed to limitations in service provision for lupus sufferers. It hopes to show how society, at the central government level, might mitigate the individual experience of frustration caused by the time delays in the functioning of two bureaucratic systems, local councils and NHS providers of care to something more like the “solid progress” scenario.

The 2001 census indicates approximately 2.5 million people as being qualified to work in health and social care in the UK (Dorling and Thomas 2004).

This workforce included clinical and administrative staff: managers, health professionals, researchers, social and care workers, nurses and midwives, therapists, other health professionals and support staff. One million people worked in direct contact with patients. They comprised of the following groups; care assistants and home carers (450,000), nurses (392,000), medical practitioners (115,000) and nursing auxiliaries and assistants (109,000). Other key occupations were dental practitioners (21,000) and midwives (25,000). For every 10,000 people in England and Wales, there were 86 care assistants and home carers, 75 nurses, 22 general practitioners, 5 midwives and 4 dental practitioners. Yet Bajekal *et al* (2006) suggest there is still a shortage of health and social care professionals to meet the demands of the population at large.

Local authorities were given responsibility to take necessary steps to meet the needs of those with a chronic illness. Local authorities accepted that they did not always have the expertise to understand what constituted permanent illness. They established systems whereby social workers would have to liaise with the patient’s doctor to find out more about the sufferer’s symptoms. Even later when local authorities began to employ health professionals in the form of occupational therapists this type of cross boundary rivalry did not diminish between health and social services staff. Often medical fees are invoiced to the local authorities for the doctor to provide his opinion. This often led to feelings of ambivalence between the professionals and perceptions of increased professional bureaucracy (cf. DH 2007).

The author advocates a system of joint working with a broad range of health and social care professionals (Turner- Stokes 2008). This is common in community

mental health teams. In community mental health teams psychiatrists, social workers, occupational therapists and psychologist share information and cooperate with one another in a systematic and responsive way by organising weekly meeting to discuss the needs of patients.

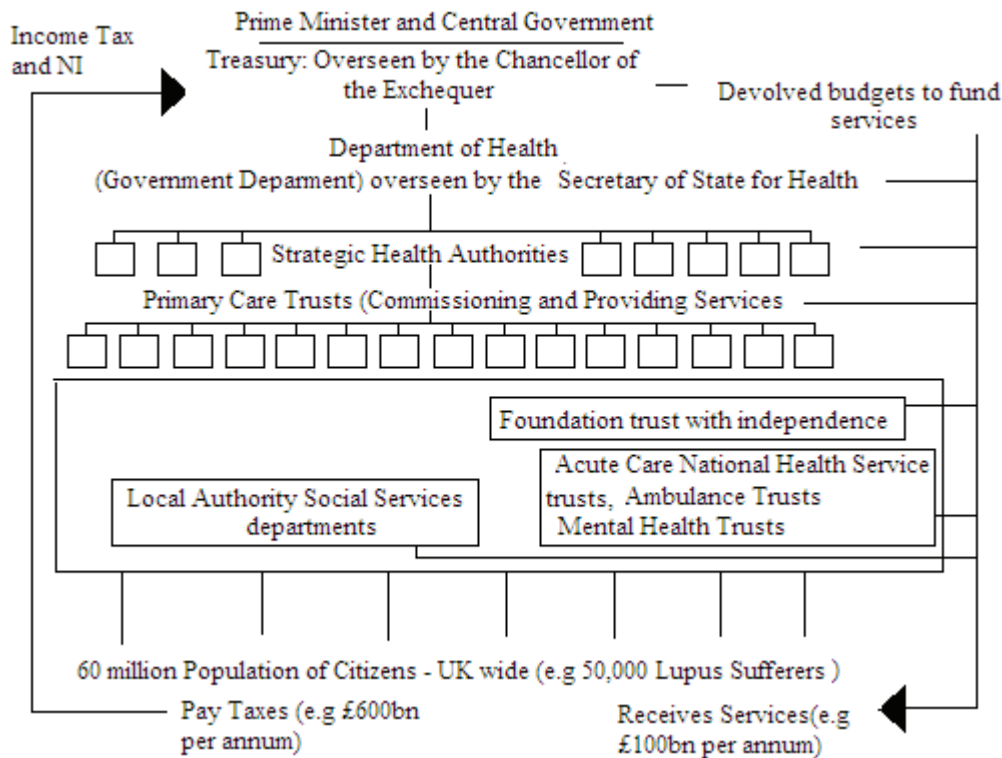
#### **2.4 The role of central government: How are health and social services managed?**

In the UK central government is elected by its citizens to serve a term of office, which may last no longer than five years. Central government manages the public purse. The government comprises a cabinet, another name for a senior management team of leading politicians responsible for different offices (e.g. health, education, transport, local government etc). The named senior politicians in the cabinet are known as ministers. They are responsible and accountable to the Prime Minister. The government works toward its aims and objectives set out in their manifesto and policies. They use information about public health trends to help organise policy and ultimately legislation.

Central government manages the health and social care needs of its population through the state funded organisation known as the Department of Health. This is a separate office made up of non-elected civil servants. They provide a range of expertise in areas such as research, social services, and finance, for example. They support the plans of government as they manage the health and social care priorities of its populations in accordance with government policies.

Regulatory bodies (e.g. the Audit Commission, Care Quality Commission and the Health Commission) are arms - length government organisations that help to monitor the performance of hospitals, councils and social services departments and provide feedback to central government in order that they may plan how services are resourced and managed at a future point in time. Central government is responsible for organising health and social care services on behalf of the population. The diagram below, Figure one, illustrates the relationship between the population and central government who are responsible for the delivery of services provided by the NHS and LASS departments.

Figure 1: Relationship between central government and population

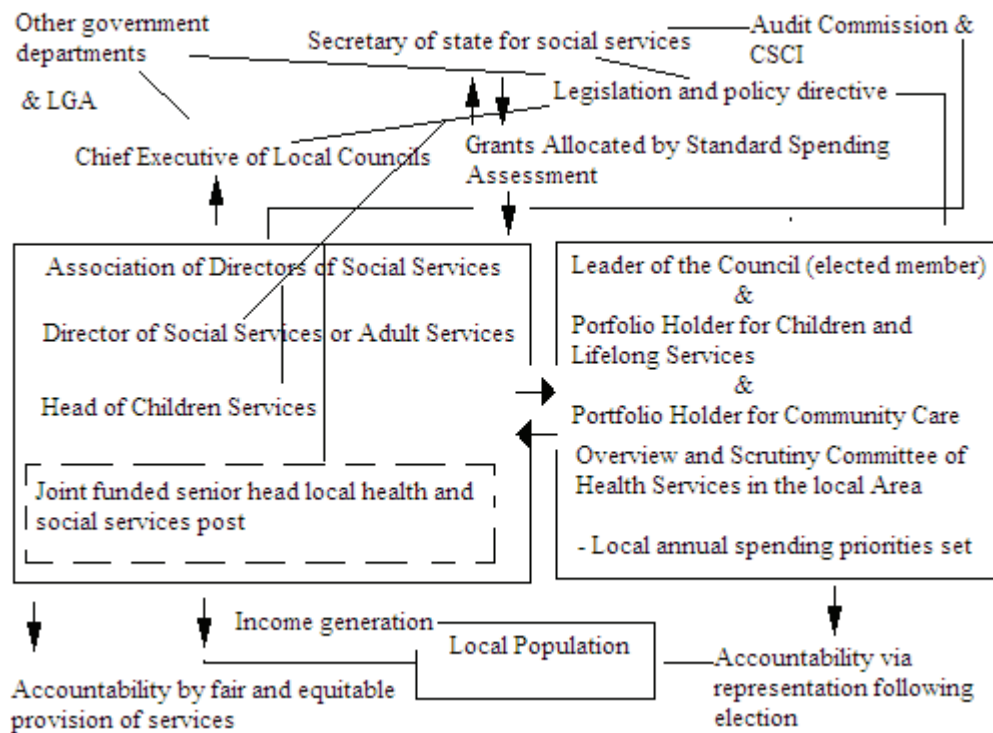


Since the formation of the NHS in 1948, there have been several reorganisations and restructurings of the NHS (Meredith Davies *et al* 1993). The changes in the NHS structure which took place in the mid 1980s set out to introduce commercial management practices into the NHS (Griffiths 1988). The executive function previously held by clinicians was replaced by an administration of professional managers appointed for their management skills rather than their skills in-patient care (Klein 2006).

After the 1980s, reforms the health services would continue to be funded from general taxation and national insurance contributions and the service would remain true to its original goal of being free at the point of delivery. The Secretary of State for Health, a Member of Parliament, had and continues to have complete responsibility for health services and, being a member of the Cabinet, is responsible directly to parliament. The chief executive of the NHS at the Department of Health reports to him/her. The chief executive of the NHS is a paid civil servant who oversees the management of the NHS including strategic health authorities, primary care trusts, ambulance trusts and mental health trusts. The Secretary of State for social services is responsible for services that are undertaken by local authorities. An example of this is the delivery of

services via directives as set down in key legislation such as the Children Act 1989 (Blakemore and Griggs 2007) and the NHS and Community Care Act 1990 (Webster 2002, OPSI 2006e). The following diagram, figure two, illustrates the relationship between central government and local government departments.

Figure 2: Relationship between central and local government



Facing the staff within those organisations is the burgeoning challenge to discriminate among the needs of people, to report using a system couched in the form of eligibility criteria and thus, where possible and necessary, physically to assess those in most need. Today, providing they fulfil criteria of the Fair Access to Care services (FACs) guidance, people with the disease lupus can be eligible for assessments. These include assessment for services such as home care, and meals on wheels, although local authorities may now have to carry out a financial assessment and raise a contribution towards the cost of the services from the recipient. Other services provided for carers have been developed over the past twenty years (Mandelstam 2005). The following legislation provides the rights that carers now have to an assessment for the range of services.

Local Authorities have a duty to assess people, in need of support, under Section 47 of the NHS and Community Care Act 1990 OPSI (2006e) and Section 17 of the Children Act 1989 (OPSI 2005). The Disabled Persons (Services, Consultations and Representations) Act 1986 (OSPI 2004a) states that the needs of family members as carers should be taken into account where they are providing a substantial amount of support for the person with a disability. Carer's needs should be considered when the person being cared for has had their own needs assessed.

The Carers (Recognition and Services) Act, 1995 Section 2 (OPSI 2004b), states the following: a carer providing a "substantial amount of care to someone on a regular basis" has the right to an assessment of their needs, when the needs of the service user are being assessed. The Carers and Disabled Children's Act 2000 (OPSI 2004c) gives carers and parents improved access to services, unavailable in other legislation, in their own right. Carers have the right to have their own assessment, even when the person being cared for has been refused one. Direct Payments are also available to carers under the Act.

The Carers (Equal Opportunities) Act 2004 (OPSI 2008) stipulates that local authorities must inform carers about their right to an assessment. In addition services will consider when assessing carers whether the carer works or wishes to work, or is involved in or would like to be involved in any education, training or leisure activities; have strong powers to enlist the help of health, housing and education authorities to provide support for carers. The personalised care agenda is also a service, which aims to give the person more choice and control in how their services (i.e. home care and domestic services) are planned and organised (cf. Beresford 2008, Carr and Dittrich 2008 DH 2008b, HM Government 2007, Leadbetter 2004, Rose 2007).

The levels of unmet need, however, of those who are defined as not eligible following a screening assessment or interview creates a potential for dissonance between those members of the public and the assessing organisation (DH 2007, Mandelstam 2005, Sheaff 1996, Victor 1997). Hannay (1988) described this phenomenon as the *Illness Iceberg*. The extent to which illness symptoms are not recognised as genuine, or serious enough, by health and social care professionals causes dissonance, which may be felt particularly by those with a chronic illness (whether mental or physical).

For the purpose of this study the diagram illustrates the relationships between service providers and consumers. Service providers are sandwiched between central government (and its various departments) and consumers of the wider health and social care economy. Central government funding from taxes pays for the purchase of medicines from the pharmaceutical industry. In addition, universities and university hospitals receive funding for research into a whole range of topics brokered through government agencies.

The diagram also points to a pattern of outcomes that need to be negotiated between individuals and their representatives. A range of possibilities exists for the sufferer when they encounter health and social care professionals. They will start with a social interaction with a health and social care professional, framed within the context of a clinical assessment at the GP surgery or home visit assessment. The timeframe for exchanging narratives is controlled within a professional process timescale, comprising of start phase (problem identification), middle phase (coping strategies employed) and end phase (conclusion with advice given to the sufferer) (cf. Charmaz 2007, Foucault 2008, Hughes 1996b, Lupton 1992, 1994, Nettleton 1988).

An individual living within the community who has an acute illness episode may have to access the support of unpaid carer(s). This could be a spouse, a friend or a relative. That initial contact may be entirely social, but the ultimate context will be about advising the sufferer to visit a GP or to seek help from a community health worker (cf. Lyons *et al* 1995, Morse and Johnson 1991). Certain services run by the council are financially means tested resulting in people having to make a financial contribution for services (e.g. meals on wheels or home care services sourced from an independent provider of home care services). At the same time in health run organisations similar services are not financially means tested (e.g. intermediate home care services for people discharged from hospital).

The system of distributing equitable health resources is not fair on those who have no idea about how to qualify for health and social care resources (Mandelstam 2005). The advice given by a GP to the lupus patient could include a medicine regime or a

referral to a medical specialist at the local hospital. Sometimes the individuals come away feeling empty, having not had the opportunity to tell their own story (cf. Frank 1995, Rees *et al* 2007).

The methods employed within this case study, by contrast, sought to offer their opportunity to tell their illness story in any way they wish. As Williams indicates, '*[i]t is what is beneath the surface ebb and flow of social life*' (2003) that will be explored for all the informants within this study. The author introduces the discourse around the care of lupus sufferers and the extent to which the social institutions behind the health and social care systems responsible for managing their illness may be represented as effective or ineffective (Foucault 2008, Mol 2008, and Sidell *et al* 2003).

## **2.5 The consumer of health and social care: Holding the system to account**

Earlier in the chapter the role of health services and personal social services in providing treatment and care to people with a chronic illness has been introduced. The objectives of this section are to review how people, such as lupus sufferers, are able to use available complaints processes. Dissatisfaction has been examined in studies, which explore formal complaining in the National Health Service (Owen 1991, Mulcahy & Lloyd-Bostock 1992, Allsop 1994, Coyle 1999, Sidell *et al* 2003). Analysing the complaints process, starting from the historical period of the 1970s, offers a perspective on lay intervention, and the power of the individual lupus sufferer to take action against the health and social care organisation if they are not satisfied with aspects of their care.

The complaints procedures, which are available, derive from legislation (e.g. Local Government Social Services Act 1970 for councils) and the policies of health and social care services. These determine the extent to which people, through appropriate reporting systems, are able to take action when they encounter suffering because of service breakdown as perceived by themselves, and try to provide objective evidence of malpractice (Sidell *et al* 2003). The initial conclusions that will be drawn from this section will provide a backdrop towards an understanding how the client is portrayed

within the NHS and LASS and, explore the extent to which health and social policy shows commitment to reducing suffering.

In the 1970s, the political ideologies of New Right conservatism reframed the patient as a consumer. ‘ *[S]imultaneously, social movements from feminism to disability rights advocates challenged the paternalistic power that doctors exercised over their patients and their lives. And, at the same time, there were attempts to empower the recipients of medical care in ways that varied from country to country but included an increasing emphasis on “active citizenship”, the rise of cultures of litigation and compensation, the transformation of patients into “consumers”* ’ (Rose 2007 p 10).

Minford (1995) describes a minimal concept of the welfare state as a safety net for those less well off. Their advocates suggest that comprehensive approaches are important to avoid accusations of services as paternalistic. There is also a certain degree of paternalism, which sees lay people as needing to be controlled in order to be cared for (Rees *et al* 2007). Paternalism is the philosophical basis of collectivist social responsibility supported and managed by the welfare state. If the term consumer indicates a process offering choice then it is important to note that patients as lay people did not become consumers overnight. The semantics of the label reflects a range of societal values that were being debated that were now available to lay people.

This struggle over the concepts of welfare provision became important in academic research and social policy planning. Previously bipartisan approaches to Health and Welfare (as when the conservative government of Edward Heath implemented Labour Social Service plans in 1971) gave way to increasing political and ideological tensions between the Labour Party, with its philosophy of democratic socialism, and the Conservative Party’s new right philosophy. In the 1980s, the country also began to suffer economically with recession and inflation. Public services became a fertile electoral conflict-ground that could mean the difference between winning and losing an election.

In the last two decades, the notion of market and consumerism still exists in the planning discourse of health and social care managers and policy providers (Nettleton



1998, Gabe *et al* 2007). There is a new bi-partisan consensus that the consumer should have more choice in the planning and delivery of services. It is no longer a political stigma to combine business efficiency within state funded services.

The pragmatic consensus arrangement of the post war period was now changing.

*'[T]he commitment to collectivism and the faith in central planning that marked the Attlee epoch, and shaped the NHS, have both gone'* (Klein 2006 p vii).

Members of the public began to be involved in the NHS. In addition, changes in personal social services were beginning to take into account the need for complaints and service review system. This coincided with a pattern of activities in the 1970s when a climate of veto amongst various groups within the NHS including professional groups (such as doctors) and the ancillary workforce emerged. Klein described the 1970s as being a period, which marked the politics of disillusionment.

*'[B]y the end of the 1970s, the NHS was more than ever a paradigm of British society as a whole: the stalemate society'* (Klein 2006 p 80).

Members of the public who were not satisfied with the care they had received from their local hospital could take their complaints to the local Community Health Council (CHC) who would, in turn, process the complaint in what was seen as an objective manner. Local councils were able to have elected members on the regional health authorities as well as members of the public being able to sit on CHC committees as representatives of special (illness) interest groups (e.g. mental health).

Through the functions of the NHS people were seen to be taking more control of their lives asking questions and demanding higher standards and value for money in the context of a market ideology. The CHC's other role was to support and represent members of the local community and influence policy. *'[W]hen CHC's were set up in 1974 their remit was intentionally very broad, with the role of each being described as to represent the interests of the health service of the public in its district'* (Pickard 1997 p276).

They not only had the right to demand information; they also had the right to be consulted over decisions to close hospitals and other changes. Their power consisted in the ability to slow down the pace of change, rather than stop it entirely. While

CHC's might have been seen as allies of the medical profession they could also be perceived as a threat, an example of lay intervention (Klein 2006).

Under the Conservative government the National Health Service and Community Care Act (NHSACCA)<sup>3</sup> (1990) was one of the first acts of welfare legislation to introduce a market concept within the NHS, albeit gradually (Hughes 2006). There were concessions to professional groups, such as GP and social workers, and possibly to the electorate. The Act set up an "Internal Market" which resulted in professionals in the main acting as brokers of care and treatment for the services that people would receive. For example, General Practitioners as fund holders could determine which health care trust a patient could be referred to for services (e.g. surgery) as the money followed the patient (Mandelstam 2005, Ovretveit 1995, Sidell *et al* 2003). In addition, the NHSACCA 1990 created new health authorities and all residual local authority representation on local NHS bodies was abolished. Not only were consumers and a market place created in Health and Social Care, but democratic representation of lay people and their interests were now being polarized between local councils and NHS trusts as the role of CHC's became less viable.

The effectiveness of CHC's was being monitored especially because of widespread changes that had begun to take place in the configuration of the NHS and social care in terms of purchaser and provider services. On the one hand, purchasers were keen to cultivate legitimacy and to encourage the public to own their decisions, particularly when it comes to difficult and unpalatable decisions such as those around priority setting. However, there was doubt on the part of managers that the laypersons possessed enough knowledge to take more than a token part in decision making, particularly with respect to clinical matters (Pickard 1997, Lupton *et al* 1995).

From 1997 onwards, the New Labour government sought to modernise and reform public services including the NHS. The political nature of the NHS and local government seemed to leave the layperson caught in "no man's land". On the one hand, they were represented by CHCs who were losing credibility within the eyes of central government. On the other hand, lay people who were often also elected local politicians could use their authority as members of CHCs under the NHS

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<sup>3</sup> NHSACCA

Reorganisation Act of 1977, to ensure that complaints by members of the public about poor quality health and social care were taken through a strict process of local jurisprudence.

### **2.5.1 New systems of complaints and lay representation**

Eventually the government decided to abolish CHCs. In its 2003 reforms the Department of Health, under the New Labour administration, sought to increase the presence of lay people in a more public-relations-friendly manner in Patient and Public Involvement (PPI) Forums (Health and Social Care Act 2001 OPSI 2006c).

This gave some scope for local authorities to scrutinise the provision of local health services, thus giving added power to their responsibilities for promoting local community well being under the Local Government Act 2000 (OPSI 2006j). Health Service scrutiny was to be placed in a context of policy, structural and organizational change in both the NHS and local government under a widely dispersed range of legislation as represented for example in various sections of the Health Act 1999 (OPSI 2006b) and the Health and Social Care Act 2001 (OPSI 2006c); it was no longer going to be a playground for “obsessive expert patients” or “disgruntled councillors with an axe to grind”.

Key elements include the restructuring of local authorities and their new responsibilities for promoting the well being of local communities and the creation of the above-mentioned PPI forums and Commission for Patient and Public Involvement in Health (CPPIH) through the NHS Reform and Health Care Professionals Act 2002 (OPSI 2006d). This latter legislation also abolished CHC's from September 2003. CHCs were replaced with several substantive integrated bodies representing consumers within NHS organisations: Patient Advice and Liaison Services (PALS); the Commission for Patient and Public Involvement in Health (CPPIH); Patient and Public Involvement forums and Overview and Scrutiny committees. The introduction of health scrutiny introduces a major new role for elected local councilors within the English health-care system. The legislation describes health scrutiny as reviewing and scrutinizing health service matters and making reports and recommendations to NHS bodies on such matters (Health and Social Care Act 2001 (OPSI 2006c).

The lead responsibility for carrying out health scrutiny lies with local councils that are responsible for social services (County Councils, Metropolitan and UK Boroughs and unitary authorities). In addition the newly formed Health Care commission was formed to monitor performance of NHS trusts and also process high level complaints not resolved at a local level. The NHS ombudsman is able to overturn HCC's decisions and provide direct feedback to central government about a case and is able to exercise power to review complaints not resolved successfully. If a similar complaint emerged in social services the case could be referred for judicial review after the ombudsman's stage, where law court rulings could be passed to determine future arrangements, as to how services should be provided by local councils in future.

## **2.6 Relevance of legislation to lupus informants and social service departments**

*'[L]ocal authorities are agents of law. More than thirty Acts of Parliament confer powers and duties on them to provide personal social services administered by social services departments'* (Looney *et al* 1995 p59).

When service users are not satisfied with the quality of services that they receive their recourse ultimately is the law courts, from alleged medical malpractice to claims against councils and NHS trusts in respect to poor delivery of service. However, the cost implications may inhibit most people from taking their complaint to the law courts. There are a number of case laws, which demonstrate the extent of dissatisfaction resulting in members of the public seeking redress in the law courts via judicial review.

For example, the case of Rogers' v Swindon NHS Primary Care Trust. Mrs. Rogers, the claimant, was a patient with breast cancer who was prescribed by her oncologist a drug Herceptin. The initial funding for this drug was private until she could no longer afford to pay. She paid for two treatments, which were charged £1,950 each. At that point, she and her consultant applied to the local primary care trust for funding. The NHS trust rejected the application. On hearing the claim, Judge Charles ruled that Mrs. Rogers should receive treatment from the date of her next proposed treatment or until the next court hearing. At the next court, hearing Judge Bean ordered that the

interim treatment and funding continue for a further three months. In arriving at his decision, the judge quoted from Mrs. Rogers' witness statement:

*'[I]t is only now with the Herceptin that I feel I have been given a small part of my life back and I have been able to start thinking about the future'* (Weekly Law Reports 2006 p 2650).

The trust was eventually found to have acted unlawfully in its decision not to fund treatment and was instructed to reconsider its policy and to formulate a lawful policy upon which to base decisions in particular cases.

Before cases reach, the law courts there are a number of different steps available to seek resolution both within the NHS and LASS settings. For example, the Health Care commission, the NHS ombudsman, and stages one to three within council procedures adopted from the LASS Act 1970. The Rogers case signifies that even a comprehensive health service such as the NHS still has its own limits in regard to the provision of services (Illich 1995). Mrs. Rogers' own narrative played a vital role in determining to some extent whether she should receive medical treatment. This system of taking a case before a law court can be tiring. However it is, possible to challenge policies and eligibility criteria when things go wrong. *'[M]edical negligence is predominantly a civil matter, but a spate of prosecutions in the early 1990s served to remind doctors that the loss of a patient may sometimes lead to criminal prosecution'* (Mason and Laurie 2006 p 344).

## **2.7 Health Inequalities**

The Black report (Black *et al* 1988) analysed a range of secondary data highlighting inequalities in health in the UK in 1970s. This work reflected variation in mortality and morbidity specifically across occupational social class. There was a direct relationship between those in higher categories of occupational class living longer and suffering from disease morbidity at lower rates.

Inequalities in health can be attributable to individual behavioural factors as well as social and environmental factors. Researchers have continued to focus their attention on structural factors such as housing and employment that combine with lifestyle issues, such as diet. The patterns of inequality have continued to remain broadly the

same in terms of patterns across the social classes (DH 2002b). Where discoveries are made, contentious researchers will adopt a circumspect approach so as not to contradict their sponsors. Findings in the medical sociology community not only serve to uncover inequalities but also serve to inform government policy about particular issues related to risk behaviour and perceptions of risk (Gabe *et al* 2007).

In addition, the cost of care for people with chronic illness is increasing in our society, making it an important topic of research for social scientists and policy makers. This is the main reasons why chronic illness research is important to central government. Long-term chronic illnesses can lead to long-term physical impairments, which in turn provide a cost to the state in terms of finding treatment and providing services. As a result, many individuals diagnosed with a chronic illness have shared experiences with those who society considers as being disabled.

However, since the establishment of the NHS in 1948 UK governments have been cautious about the role of the patients as direct purchasers of their own health and social care arrangements. Unfortunately, the customer (i.e. the patient) is no nearer to brokering services on their own behalf despite the existence of the 'internal' quasi market (Hughes 1996, Hughes *et al* 1997). This quasi market has created a disjointed nexus of frustrating quasi-communication between the actual customer and the provider of services.

The cost of prescriptions can also restrict access to the NHS. Many patients cannot afford to pay for prescriptions. Yet each year the cost of medication increases. In addition when patients experience toxic side effects to a number of prescribed medications, little or no redress, compensation or refund is ever established except in the most serious cases, such as fatalities caused by inappropriately prescribed medication.

The author accepts that no government in the UK can ever deliver perfectly on its mandate to establish comprehensive services on behalf of the population. Nevertheless, this means there is a need to consider how the authorities respond to events that contribute to causing trauma and tragedy, or to unmet need, especially when the health and social care market restricts the ability of carers and families to be

direct brokers of their own services (Sheaff 1996, Victor 1997). Their ability to do so effectively may be compromised, because as McDonald (2006 p 36) warns:

*' [A] resource led definition of need at the assessment stage compromises professionalism; is the occupational therapist constrained never to assess a need for a bathroom adaptation, because all that is available is bath boards and bath seat?'*

Their ability to estimate both community need and community resources is also weakened because: *'[S]upport networks exist for patients but generally families are overlooked within the medical environment'* (Holden and Hughes 2004 p 166).

In recent years, communication processes and procedures have been improved in order to provide support to clients and carers in need. An example of improved communication process has been disseminated through health and local government social services departments (DCSF & CLG 2008). Processes such as this have also arisen because of critical incidents. One such incident was the murder of eight-year-old Victoria Climbié by her aunt in 2000. In response to this incident several social services departments and NHS acute trusts were found wanting in their abilities to work together and communicate effectively about the needs of the patient (Laming 2003). The green paper *Every Child Matters* (DfES 2004) and the Children Act 2004 (OPSI 2009d) called for a commitment to systems to be organised to help agencies (e.g. health, education, police, health trusts) information sharing between agencies working on behalf of children. *'[I]mproving information sharing practice is a cornerstone of the government's strategy to improve outcomes for all people'* (DCSF & CLG 2008 p9).

Another example of services focussed on the needs of good communication between services and patients and their carers is service for patients with a diagnosed mental health problem where their needs can be assessed through the Mental Capacity Act 2005 (OPSI 2009c, DH 2007d). Under this legislation, patients have the right to an assessment to determine whether they have the mental capacity to make decisions about their own well-being and needs at a particular moment in time. If patients are unable to show capacity because of a particular illness (e.g. end stage dementia) then the deprivation of liberty safeguards assessment (DOLS) applies whereby the professionals and relatives of the patient assess what is in the person's best interest to

determine what services are available. Under the Mental Capacity Act 2005 patients are allowed to make declarations known as advanced decisions about health professionals that they do not want to be involved in their care (Turner-Stokes *et al* 2008).

This chapter has outlined the actions of UK government and its departments in responding to illness as a public concern. The Medical Research Council and university research departments, partly at least formulate policies on how the state should manage health and social care as a response to perceived dissatisfaction from members of the public who may wish to seek redress if unhappy about forms of services, and channel their requests through particular institutional pathways. The political process of managing the health and social care needs of the population are bound to produce gaps in the quality of services received by members of the public. Examples of this are evident in services that should be provided in an equitable manner from NHS and LASS departments.

The next chapter will look specifically at debates within medical sociology in order to take into account issues that highlight the perceived experiences, from those who are ill, about living with a chronic illness and explore their actions as they deal with their symptoms and available support.



### 3. Chapter Three: A theoretical methodology and practical literature review

#### 3.1 Introduction

The theoretical orientation of this case study is characterised by philosophical assumptions and elements, which influence how the research process is brought together from start to finish. This chapter explains the overall structure for this case study that the author has chosen. It includes a philosophical standpoint located at the beginning, through to the selection and application of research methods. *‘[At] least, we need to find out what qualitative researchers actually do when they assemble and analyze data from the field’* (Miles and Huberman 1994 p 5).

An analogy will be made at this point with a road map. The road map outlines a distance between two points for the traveller; the theoretical framework is the map of the terrain between two points namely the start and the end. The start of the journey (or theoretical orientation see diagram below) comprises the philosophical principles including the choice and explanation of epistemological and ontological positions. This in turn influences the choice and selection of the research methods and analytical techniques, which explain the phenomena under investigation because *‘... [e]very researcher brings some set of epistemological assumptions into the research process (even if you are unaware of them!), and that these influence how you understand and interpret qualitative data’* (Travers 2001 p9).

Sociology is a pluralistic, multi-level, reflexive discourse about social life articulated in a wide variety of different, and in important respects, discrete traditions (cf. Alexander 1988). It is precisely because sociology uses a wide range of approaches to explore and explain phenomena, however, that Giddens (1987 p 31) states, that *‘[w]e must be sceptical of the ambition to achieve a professionally agreed upon schema of concepts in sociology’*. In addition Miles and Huberman (1994 p 5) state: *‘[N]o study conforms to standard methodology; each one calls for the researcher to bend the methodology to the peculiarities of the setting’*. However, this sceptical stance toward a sociology that strives towards a theoretical consensus does not mean that anything goes: *‘[R]ather it represents a necessary coming to terms with the realities of social enquiry and the inescapable articulation of social knowledge with social life’* (Smart 1993 p71).

The way in which knowledge develops through sociological research is part of a process. The process can be described as empirical or scientific. *‘[S]cience is the use of systematic methods of empirical investigation’* (Giddens 2008 p 78). According to Popper (1972), it is important to keep an open mind when embarking on research. Charmaz (2004) also stated that: *‘[t]o learn participants’ meanings, we need to be reflexive about our own. To understand meanings, we need to bracket our internalised views of reality and rationality. Try to hold them in abeyance and flow with the experience of the world you study’* (Charmaz 2004 p 982). When embarking on an investigation researchers present conjectures. These conjectures as research findings and provisional theories become open to tests by the research community in the form of revisions.

If on completion of this work, the researcher is highly resistant to criticism he can become guilty of being too closed and narrow in his view of the world. Therefore his evidence will only ever be an approximation of the truth. Even if all the other research being conducted on the topic is no nearer to revealing the phenomena we must still be open minded and open to the process of refutation and counter argument by the research community (Hughes 1990). *‘[I]t is essentially their critical and progressive character, the fact that we can argue about their claim to solve our problems better than their competitors, which constitutes the rationality of science’* (Popper 1972 p vii).

It is essential for a researcher to be equipped with the coping skills, such as being open minded, embedded in their research protocol and expressed in his philosophical assumptions (Howe 1988). The study of lupus from a sociological perspective allows us to appreciate that the dominant research activity has come from the field of medicine. Over the century’s medicine as a science has earned its credibility. However, where medicine at one point in history relied significantly on the reported narratives of its patients it is now a profession that struggles with accusations of “not listening enough” to the patient’s perspective (Rose 2007, Foucault 1973). Despite these accusations people expect to be able to trust doctors opinions about treatment as factual and accurate (Brechin *et al* 2000, Good 1994, Parsons 1951). The philosophies discussed in this section are not anti-science nor are they against

biomedical research (Faubion *et al* 1994). Instead, they seek an arrangement of commensurability, which may make possible a philosophy of inductive science (cf. Gouldner 1970, Nettleton 1998, Miles and Huberman 1994). They provide the author with a rationale for recognizing that when medical science does not produce the answers, such as cures and suitable treatments, it is the social approach to illness and social care management that makes a practical contribution to people's lives or the '*[m]edicalisation of social problems*' (Rose 2007 p10).

*'[I]n fact, the dilemma is also between scientific potential and health realization and the true abyss is between what we know and what we do in practice, the so-called 'know-do' gap'* (Haines and Donald 2002 p 26).

Currently there is a wave of research pointing the value of the patient's voice in the planning and delivery of health care (Foucault 1973, Brechin *et al* 2000, Rose 2007). The language of medicine is established in a technical way with biological references to the description of symptoms taking place within an individual's body. This study aims to explore the specific language of experience from the combined perspectives of lupus sufferers and the paid and unpaid carers.

Drawing on the literature reviewed so far the author will examine data that suggests a person's illness narrative does not point out meaning directly, but demonstrates meaning by recreating patterns in literary and metaphoric shape. The author's analytical challenge is to contextualise fully the informants' witnessed accounts that are interpreted within relationships. Symptoms are forms of symbolic communication as they are lived experiences that are spoken and written about. Symptoms are signs to be observed and interpreted in their performance. Within this thesis, the lived experiences the person and the symptoms they encounter are analysed. Stories (and to some extent concepts) give a sense of pattern, a way of speaking, perceiving and existing. The author's task is not to impose a meaning on the story but to allow its meaning to become manifest in relationship to the teller as a part of the theoretical framework. Kleinman (1988) argued that illness is concerned with innate human experience of symptoms and suffering. Being receptive to the innate qualities of the informant is vital in order to set it aside with actions that can be undertaken by carers and managers of health and social care. Illness refers to how the sick person and the

members of the family or wider social network perceive, live with, and responds to symptoms and disability. *'Illness is the lived experience or monitoring bodily processes such as respiratory wheezes, abdominal cramps, stuffed sinuses, or painful joints'* (Kleinman 1988 p4).

### **3.2 Epistemological and ontological position**

Epistemology is a branch of philosophy related to the explanation of theory of the grounds of knowledge (Popper 1972, Bryman 2008, Becker and Bryman 2004).

There is a whole range of epistemologies available to researchers. This section will outline some tenets and arguments that lead to the development and choice of a specific epistemology and ontology for this case study. The quest for knowledge through science and social science has been debated and analysed for hundred of years. *'[I]ndeed the whole history of social science is caught up in the classical enlightenment and a modernist vision of reform and progress'* (Morrow 1994 p305).

At the heart of the epistemological debate is the need to find out what truth is (Charmaz 2004, Faubion *et al* 1994). Popper (1972) discusses the term epistemological optimism to characterise a position that human kind was able to stand away from the need to obtain truth and acquire truth.

*'[A]t the heart of this new optimistic view of the possibility of knowledge lies the doctrine that truth is manifest. Truth may perhaps be veiled. But it may reveal itself. And if it does not reveal itself, we may reveal it. Removing the veil may not be easy. But once the naked truth stands revealed before our eyes, we have the power to see it, to distinguish it from falsehood, and to know that it is truth'* (Popper 1972 p 5).

Popper's affinity for epistemological optimism shapes his articulation of a doctrine of truth as meaning, central to the desire of all social researchers to be brave enough to use reflexivity. This stance perhaps sowed the seeds for social researchers to explore ways of identifying their philosophical roots and how those philosophical roots should be inextricably linked to choice and execution of research methods and analysis and the presentation of truth (Seale 2007; Charmaz 2004, Faubion *et al* 1994). Examining multiple views, whether from a single case or a larger sample of the phenomenon, strengthens the power of the researcher to understand it (Charmaz 2004). The

commitment to deliver work based on sound methodology (theory of the method) is a goal or ideal, reinforced when there is evidence of clearly outlined research methods. Even within this goal a researcher's personal standpoint cannot be discounted because *'[t]he standpoints from which we start shapes what we see and what we view as the truth'* (Charmaz 2004 p983).

In order to counterbalance the need to be value free and yet declare a personal standpoint we must re-examine our standpoint and research tools. It is the goal of the researcher to declare as far as possible to what extent this aspiration may have been compromised. For many years, writers have increasingly detailed their reflexivity as another form of meta-theory using first hand accounts of the researchers' experiences. This degree of transparency will stand the work in good stead for inspection by the research community (Morrow 1994).

This substantive account aims to situate the research in relation to foundational assumptions about the nature of language as a means of expression and representation. Meaning may be subjective, but to convey meaning, our narratives have to be correctly understood by others. In other words, our subjectivities are transcended by the over-riding social need for inter-subjectivity (Faubion *et al* 1994). Although Charmaz (2004 p 983) warns that *'[h]ow we word our interview questions more or less structures what participants will say. How we look, act, and sound affects how they read and receive us'*, the response of the interlocutor can be corrective as well as confirmatory.

The work of Charmaz (2004) and Foucault (1973) is able to articulate an epistemological basis or important layer in the formation of this study known as pragmatism. Pragmatism and particularly the work of Dewey (1896), James (1950), Mead (1934) and Peirce (1934) are part of the interactionist tradition (Denzin 1992). In essence, pragmatism argues that people's selves are the product of their social experiences, deliberated choices and impulsive drives.

Pragmatism emphasises that social life is not fixed, but dynamic and changing. Therefore, if people's social lives are constantly changing, researchers must participate in it, and record their experiences of those transformations, their effects on

people, as well as their interpretations. Tedlock (1991 p 69) described this as '[c]o-participation within the ethnographic encounter'.

In the ethnographic encounter, knowledge comes from experience and undertaking detailed research. It is important to participate in social relations and seek to understand actions within the context of an observed setting, as people behave and make sense of their world by taking meanings from their environment. As such, the author will become part of that environment for only then will he understand the actions of people who occupy and contribute to life within a culture (Tedlock 1991, Rebeiro 2001). Meanings emerge through practical actions to solve problems, and through action people come to know the world. Pragmatists see facts and values as connected rather than separate and truth as relativistic and provisional (Charmaz 2004). This technique is least likely to lead researchers into imposing their own reality on the social world they seek to understand.

Within level one of "the time capsule methodological framework", (see page 61) the author sets out the philosophical and research underpinnings. The research process straddles two periods across a ten-year period, the latter part of the twentieth and early twenty first centuries. This work is set within an era in which lupus sufferers and carers exist and live out their fate with some degree of connected predetermined existence whether that be adopting a sick role (Parsons 1951) or feeling stigmatized (Goffman 1979) because of their problems (Miles and Huberman 1994) or perceived carer burden. More significantly other incidents are taking place outside of these widely held beliefs and explanations of which the persons own language have a key contribution towards (Faubion *et al* 1994, Foucault 2008).

The author therefore notices the potential for antagonism between the lupus sufferer, health, and social care providers. It is the author's intention not to offer a specific moral discourse concerning which of the two categories of protagonists are right or wrong. Instead, these problems interact and co exists. Some of these problems are explored from the narratives of the sufferer and others from narratives of those involved in the care of the chronically ill.

### 3.3 Ontology: Critical Realism

Ontology refers to our basic assumptions as to what exists, a theoretical stance on the nature of (social) entities (Bryman 2008). For each theoretical perspective there is a commitment to understanding “what is” (ontology) and “what it means to know” (epistemology). Ontological issues and epistemological issues complement one another and inform the theoretical perspective (Crotty 1998). Ontology can be contextualised in two forms. First, it is concerned with entities presupposed by a particular substantive empirical stance. Sometimes it is accompanied by a particular hypothesis (e.g. living with lupus as represented in literature review findings based on other research). The second context is that social ontology becomes central to a contemporary post-positivistic social theory (Outhwaite and Bottomore 1993). An example of the context will be provided by a range of sources (informants’ perspectives). These sources provide a perspective on how illness and social care management is influenced by paternalistic ‘top down’ political and health care management guidance.

Post-positivism is explained in terms of the need for “warranted assert ability” (Charmaz 2004) as opposed to truth in absolute terms, traditionally represented by universal law or absolutes. As such, the approach used in this study is *[e]liminating the intractable problem...of forced choice between value – laden/qualitative and value free/quantitative research methods*’ (Howe 1988 p10). Critical realism in this study is committed to the use of multiple methods that will contribute to an empirical account that is inductive, scientific and relativist (cf. Faubion *et al* 1994, Foucault 1973, Cody and Kenney 2006). As a critical realist, the author sees human beings, such as lupus sufferers as constrained by social mechanisms that contribute to their suffering (Foucault 1973, Foucault 2008, Nettleton 1998, Nettleton 2006, Lupton 1997). It is vital for the author therefore to investigate what is happening ‘*[t]o facilitate apprehending reality as closely as possible*’ (Guba and Lincoln 1994 p 110). Reality, seen as “out there” can be objectified for study (Guba and Lincoln 1994, Foucault 1973, 2008, Faubion *et al* 1994, Mol 1999, 2002). How knowledge originates through the research and how elements of that particular knowledge come together (ontology) are an interconnected relationship

The ontological position of this case study is critical realism (Bhaskar 1989). The purpose of critical realism in this study is to observe and conceptualise how lupus sufferers and their carers make sense of their lives while feeling disempowered to complain when their care is going wrong (Brechin *et al* 2000, Lupton *et al* 1995). Within this study, lupus sufferers will express their reality from their standpoint. This is a premise that gives their first hand experiences a degree of expertise to act as their own theorist or writer (Beck 2000).

*' [T]he ethic of individual self-fulfilment and achievement is the most powerful current in modern society. The choosing, deciding, shaping human being who aspires to be author of his or her own life, the creator of individual identity, is the central character of our time ' (Beck 2000 p 165).*

People in the UK health and social care system do suffer regardless of breakthroughs in cures or symptom management of illnesses (Brechin *et al* 2000). They have a support system available through state funded health and social services, but sometimes the relationships between individuals and state funded health and social care professionals become strained due to expectations on both sides, which are often not congruent. Due to western society's increasingly aging population, there is less emphasis in curing conditions and more emphasis on managing illness symptoms (cf. Scambler 1997). Beyond *Sick Role* (Parsons 1951) and, *Stigma* (Goffman 1979), the person and their body find new ways of providing a narrative (Rose 2007). This is especially the case when people take control and conduct their own research about their illnesses especially when symptoms go unrecognized by the qualified professionals (Oliver 1990, Goffman 1979). It is because of this that the author accepts the arguments that our society has moved towards being a somatic society, that is, a social system in which the body constitutes the central field of political and cultural activity (Denzin 1992, Faubion *et al* 1994, Nettleton 1998 , Rose 2007 and Turner 1996). Denzin (1992) wrote of a need for interactionist research to play more of an active role "My story" or "my history" as has been influenced by biography and emergent popular culture and systems of popular discourse (e.g. social networking websites).



In addition, critical realism will allow the author to make sense by developing ideas (based on the reported and observed experiences ) of the treatment and care they receive from paid and unpaid carers. The medical journalist, Payer (1996) studied the belief systems of doctors in the USA, UK, Germany and France. She argued that their range of values and beliefs were culturally biased. In particular where people reached a dying phase, whilst in hospital care, she found that the medical establishments was not inclined to elicit the views of patients when determining whether they made a decision to either stop treatment or increase treatment. Following Payer (1996), the views of those who suffer with an illness should be recorded in advance and taken in account when planning and delivering services right through to the end of life. This research will therefore unmask some the issues behind the arrangement of services, systems and health and social care practices in the life of lupus sufferers.

Using critical realism enables the author to unlock a sequence of social, psychological and environmental mechanisms in order to learn about what is going on in the world of the lupus sufferers. The critical stance reflects an experience of the tense and critical issues that they experience often beneath the text of the narrative or behind the assumptions of a team of medical professionals, for example located on a hospital ward (Brechin *et al* 2000, Foucault 1973, 2008, Faubion *et al* 1994). The symbols that exist within hospital ward life, the language of expressions amongst health professionals, patients and carers and the description of significant life events offer only the beginnings of meanings. The conversion of those descriptive events and experiences can only be transformed into theory once the material has been significantly analysed.

### **3.4 Symbolic Interactionism**

The last element of the overarching aspect of the methodology for this case study is a theoretical perspective known as symbolic interactionism. Its roots lay in a philosophical tradition that requires the researcher to utilise inductive logic and trust their personal judgement. Herbert Blumer (1969) a student of Mead, coined the term "symbolic interactionism" and put forward an influential summary of the perspective: People act toward things based on the meaning those things have for them; and these meanings are derived from social interaction and modified through interpretation

(Blumer 1969). The range of symbolic interactionists' disciplinary tools is broad (Denzin 1992; Crotty 1998). Kelly's (1992) study into the lives of people with Ulcerative Colitis used approaches, which lent themselves to 'Interpretive' and 'Role Identities'. The model of suffering introduced by Morse and Johnson (1991) uses aspects of phenomenological, role construction and contextual approaches. The work of Kleinman *et al* (1997) explored issues from the perspective of the researcher when interacting with the chronically ill.

### **3.4.1 Critique of Goffman's theory of stigma**

Many symbolic interactionists have studied how people live and cope with chronic disease and illnesses. The experience of illness forces the individual to make changes in their life including an acceptance of their changed identity and daily routines. Erving Goffman (1979) published a classic study under the title *Stigma*. Although Goffman never declared himself a symbolic interactionist, he attributed difficulties in personal relationships to social discomfort created by prejudice about people with disability or impairment for example. Goffman (1979) presents a cultural framework contextualising how the phenomenon of stigma comes about. By today's standards (bearing in mind that much of his fieldwork and referencing occurred in the 1940s and 1950s), the language he uses to describe his informants is strong: '[H]is penchant for mentioning troubling truths about individuals is clearly evident when he notes that the blind, the deaf, the ex mental patient, the prostitute...' (Gabe *et al* 2007 p 69). All these forms of expression would be regarded in today's UK society as against the flow of political correctness.

Goffman's first sociological readers lived in a world dominated by a functionalism which Goffman did not so much challenge as just ignore. His assertions defined patterns of human behaviour within society without an initial indication of how and why these issues arose.

Social constructionists, such as Oliver would claim that Goffman's justification for the usage of tragedy-orientated labelling needed to be substantiated, especially as he did not take into account some motivations intrinsic to an individual's own perceived choice about pursuing an activity as an end in itself, which may have given that person a high degree of personal satisfaction.

Much of what comes out in his observations reflect as much Goffman's own values as it does those of his informants and interpretations of what they are experiencing. From this perspective the early chapters are important as Goffman's admirers have read into them (or used them as evidence for) their theory of society within which people experience the stigmatising effects of illness and disability (for example) feel marginalised and not accepted (Brechin *et al* 2000). Denzin (1992 p10) asserts that in reading Goffman we have to be patient to see fully his 'counter – theory to structural functionalism'. An interactionist stance is therefore connected to the data from a personal (researcher's) perspective.

To what extent would Goffman's recorded observations stand up to proponents of the social model of disability (today)? The initial chapter entitled *Stigma and Social Identity* is clearly thought provoking. On the one hand, there are strong descriptions of 'reality', which are uncomfortable to accept. On the other hand, perhaps this is the spirit of his dramaturgical epistemology.

Denzin (1992) states: '*[T]he theatrical aspects of the dramaturgical metaphor have not only crept into everyday life; they have taken it over. Art not only mirrors life; it structures and reproduces it*' (p138).

Goffmann's initial aim was to 'shock, mock, challenge and ridicule' (Denzin 1992 p139) readers out of the aversion of their gaze. His 'preliminary conceptions' (Goffman 1979 p11) categorised stigma in three types; abominations of the body, blemishes of character and, 'tribal' stigma. People without stigma are described as 'normal'. All people have an *actual social identity* and a *virtual social identity* (expectations that others have of an individual that they then have to live up to). When the two forms are at odds with one another, the individual becomes discredited by themselves and others (e.g. the long term unemployed or a sick person with HIV and AIDs): '*[T]he individual is disqualified from full social acceptance*' (Giddens 2008 p 269).

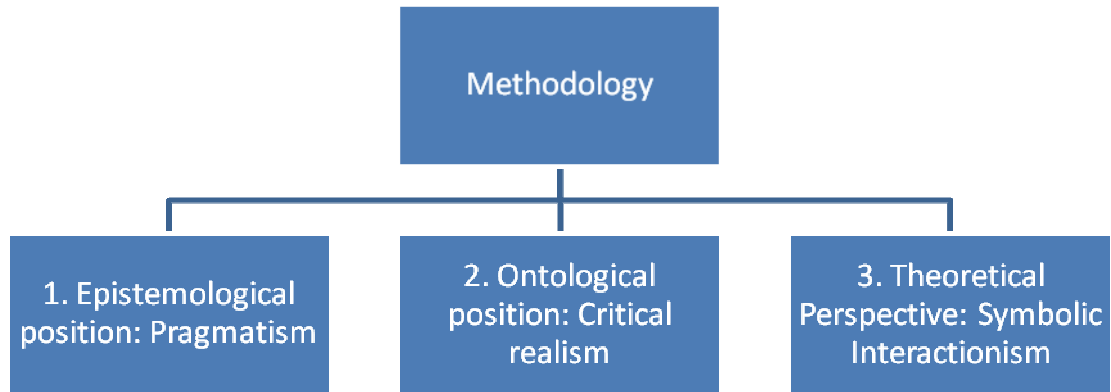
Goffman's ethnographic approach dispenses with the bridge of narrative expressions which are, designed to critique the structural functionalist sociology of that time. The aim of this approach is to let you know (in his own "caring/earnest" way) that the

stigmatized are the persecuted who can take action by telling their story in their own words or using “trusted representatives” (e.g. *‘A man of their own kind, a native who really knows’* Goffman 1979 p36). In addition he outlines a typical journey of life being that of obstacles adding further, that people with a stigma have to go through from a developmental perspective, which he entitles their ‘moral career’. This offers narratives strategies to guide the person who wishes to undertake standpoint research from the perspectives of the sufferer.

Among the strategies derived from his informants and secondary data are the distinction between discreditable stigma (e.g. embarrassment or shame) and discredited stigma (e.g. physical deformity), and the powerful notion of social information as the signs and symbols of communication of stigma are introduced (e.g. medical records, posters, wheelchairs, disfigurements). These lead on to his discussion of the theme of visibility: *‘[V]isibility of a stigma (as well as its obtrusiveness) must be disentangled from certain possibilities of what can be called its ‘perceived focus’* (Goffman 1979 p66).

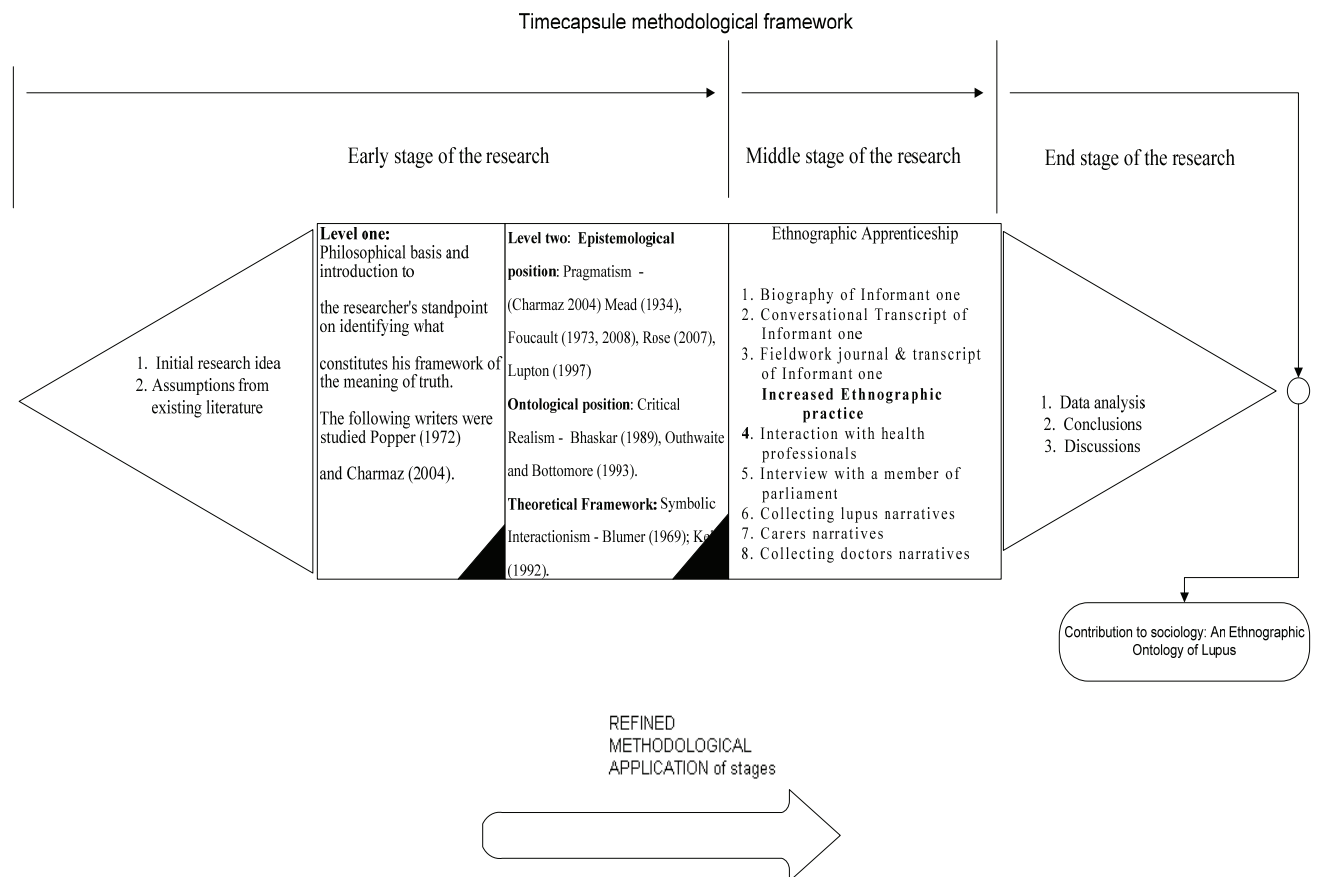
Symbolic interactionism helped the author to realise that the informants in this study (lupus sufferers) should not be the only entities under investigation. In addition, it allowed the researcher to consider what impact this group of individuals can have on society. Using symbolic interactionism as a theoretical perspective in this case study aims to develop a conceptual model of the individual and society, social structures (families, local services, statutory services, professional bodies, chronic illness) and social processes (self expression, needs assessments, eligibility criteria, coping, enduring, suffering). The following diagram, figure 3, shows the contextual methodological framework used in this study.

Figure 3: Contextual Methodological Framework



There are several levels at which the thoughts behind the theoretical framework operate (see diagram below).

Figure 4: Connecting methodology to research methods



This work will develop a system of transparency in order to demonstrate the connections between themes that become available theoretically and as a consequence of the methods utilised throughout this case study. It is an approach that makes a philosophical assumption about suffering with a chronic illness, such as lupus, that not all phenomena can be explained in terms of rational empirical practices (cf. Popper 1972). It aims to use past events of four women's experiences within the NHS and social services to form a case study of that time and thus uncover why people with lupus suffer in the context of government policy and local service delivery mechanisms. This is one of the main means by which suffering with a chronic illness is approached from the theoretical and methodological perspectives within this case study.

Level three is entitled *the time capsule framework* and represents the specific research method of obtaining the data. The details of level three of the framework will be explained in chapter four the methods chapter. The time capsule framework is a schema whereby the author charts the growth of his research competence from apprentice researcher to practitioner researcher. Level four represents the contribution of the whole research enterprise from theoretical conception to conclusion. It is entitled, *contribution made to sociology as ethnographic ontology of lupus* and will be explained in chapter six (cf. Charmaz 2007, Mol 2002).

Kuhn (1962) argued that this radical kind of effort was required for change to take place and bring a new paradigm. Several contemporary thinkers believe a revolutionary cultural change has already taken place. For them consumerism (in health care) is the new "means of production" which in turn is relative to the social context that they are a part of (Faubion *et al* 1994, Nettleton 1998, Mol 1999; 2002, Rose 2007).

This greater readiness to accept change, already gives rise to a greater sense of uncertainty, which is augmented by a whole range of other factors, from global warming to the limited availability of hospice care services for forms of terminal illnesses other than cancer (Turner-Stokes *et al* 2008). These constitute a set of circumstances that is affecting the quality of care and treatment that people, such as lupus sufferers, are able to receive. Nettleton (1998) describes this as an uncertainty

created by the changing nature of medical work. Her presentation also describes this epistemology as a form of “indetermination”.

### **3.5 Medical sociology, politics and theoretical perspectives**

This following section will be divided into two parts. The purpose of this section is to review the history of the relationship between chronic illness research (within medical sociology) and health politics. Throughout the period marking the UK post war era to the present, the direction taken by (medical) sociology and politics has been directly linked, with politics having the upper hand in the direction of travel regarding the priorities set within medical sociology research (Stacey and Homans 1978).

Furthermore, the voice of the sufferers as researched in medical sociology has gained more prominence. This is as a result of members of the public becoming more sceptical about politics. An example of this is evident in decreasing numbers of people participating in voting at local and general elections: *‘[T]he questioning of ethnographic authority by a range of scholars has made it impossible to read or write critically without considering whose voices and interests are being constructed, and those suppressed, within the text’* (Frank 2000 p13). The second part of the chapter will be a critique of theoretical perspectives related to chronic illness issues because they articulate a particular epistemological position. The essence of those theories (and their critique) can be classified as a theoretical context against which this particular research methodology can be juxtaposed (Oakley 1990). The timeline has coincided with medical sociology being less concerned about the consequences of an illness to studies regarding the significance of living with an illness (e.g. Bury 1982).

#### **3.5.1 The influence of Mike Kelly (chronic illness) and Mike Oliver (disability studies)**

The author’s early interest in the disability politics and chronic illness introduced him to the work of Michael Oliver (Oliver 1990, 1996, Campbell and Oliver 1996) and Mike Kelly (1992) both of whom became the author’s early PhD supervisors in the late 1990s. Their work became a starting point for two areas; first, the history of the struggles of people with disabilities and second; an awareness of how and why

government agencies (e.g. Medical Research Council) funded research in order to learn about chronic illness and its effects on peoples' lives. Oliver and Kelly's work showed foundational links with pioneering research and activism from the United States of America (USA). Mike Oliver's work drew influence from the USA 1960s civil rights movements and in its own way reified the view that researching vulnerable groups is fundamental to medical sociology (James and Gabe 1996). Its contemporary equivalent mode of policy activity is social exclusion (Levitas 1996). Mike Kelly's work (with its epistemological roots in symbolic interactionism and pioneers such as Erving Goffman) developed core themes regarding how people constructed identity whilst living with Ulcerative Colitis sufferers. In order to appreciate our understanding of the role played by Mike Kelly and Mike Oliver in medical sociology, it is necessary to explore government policies alongside the shift in public attitude towards how their chronic illness in the past fifty years in UK social research.

### **3.6 Sociology in post war Britain**

In 1948 the National Health Service (NHS) was formed. The development of the NHS coincided with a growing consensus amongst the broad range of political parties from the late 1940s (the post war period) to the 1960s the NHS should be universal (and not a campaign contestable issue). Medical sociology or sociology as applied to medicine was relatively dormant in the UK during this period with the bulk of innovation in the discipline coming from the USA. The main discipline of sociology during this era was focused on studies of poverty and community life. Quantitative surveys were the main methods of research that were used to explore social determinants such as social class. Policy studies were preoccupied with the "distribution of wealth" in society including access to welfare benefits and health services (Bulmer 1989, Dean and Melrose 1996). Post war politics was based on the philosophy of Democratic Socialism. This was considered a justifiable means to an essential end and was a justifiable driving force behind the creation of health and social welfare legislation.

In the absence of medical sociology (as an academic discipline), health policy was influenced by the disciplines of politics and macroeconomics. Health policy was



therefore under the control of those ‘[w]edded to traditional Labour Party loyalties, who saw little to question about the nature of medical knowledge or activity as such’ (Gabe *et al* 1991 p2).

Between the late 1960s to the late 1970s there was a movement away from accepting the total ideas behind grand narratives as explanations (such as Marxism), which coincided with changes in UK society. UK Sociologists were influenced by the work of American sociologists Talcott Parsons (1951), Halsey (1989), Gabe *et al* (1991), Goffman (1979), Glaser and Strauss (1967) and began to question how inequalities in society paying greater attention to issues of conflict and power of government. Parsons’ (1951) seminal work, including sick role theory (which will be critiqued in page 67 of this case study) produced a macro picture of conformist patterns within a social system as well as a theory of human behaviour in the context of the doctor-patient relationship. In this context, health and illness became sociologically defined as a central aspect of post war American (and British) society outlining patterns of welfare dependency and social control.

Gabe *et al* (1991) argued that in the UK medical sociology was struggling to find its intellectual foundation and an ‘*independent approach to both medical and policy issues*’ (Gabe *et al* 1991 p2). Tensions in epistemological approaches are reflected creatively by research conducted by Mechanic (1978) whose work sought to model human behaviour by studying how people coped when subjected to major illness symptoms. The same is true of major government-commissioned survey research conducted by Black on health inequalities (Black *et al* 1988). It would not be until 1981 when the Black Report was produced that we would see sociology, using positivist tradition survey methods to deliver a message (and a “blow to the establishment”) that those inequalities in health and illness had persisted despite thirty years of the National Health Service. The further message from this report was that government could (and should) play a role in tackling this trend in the way it prioritised resources across health and social services needs of the community.

The report had been commissioned in the last days of the Labour Government, and the new Conservative government, elected in 1979 was determined to ignore the credibility of the initial findings of this research. The closure of the Health Education

Council can be described as a reflection of this determination to change the old way of seeing things. One may speculate that the government was not convinced that there was a sound epistemological basis for this research.

Paternalism was characterised by principles such as provision of basics in life for those not able to obtain it for themselves including education, health care and pensions. In this view, people cannot entirely help themselves and are dependent on experts (e.g. social workers, doctors, and nurses) to provide services in the best interest of those they assessed. Many health and social care professionals would not easily admit to the meanings eluded by the term paternalism. However, because it is established in the polemic of medical sociology the next step on from paternalism is marginalisation of those less powerful groups, often the patients, is a damning consequence when other people labelled as professionals take control of people's lives. Welfare should be about shared sincere dialogue and assistance between those in need and those providing the service. Concepts such as oppression, discrimination, and social justice have now become part of the language of health and social care policy and practice (Brechin *et al* 2000).

Minford (1995) was the foremost academic advocate of the concept of the welfare state as a safety net for those less well off, to demonstrate the struggles between the concepts of welfare provision, which had now become important in academic research and social policy planning. Policy researchers were desperate to yield to central government values of "people investing in their own reserves of self sufficiency and be a significant long term burden on taxes". Another social trend occurring at that time was the legacy of unrest amongst ancillary workers. These workers included those within the NHS. The unrest that arose since the 1970s coincided with the break up of the consensus (amongst the main political parties) about the NHS and welfare services as a non political area of policy negotiation. Epistemological social constructivism [and critical realism] research about disability and chronic illness behaviour was developing, some of which was labelled anti - authoritarian (e.g. Oliver 1990): '*[T]he assumption that society was benign, suffering from evils which were reformable, was replaced by anti –authoritarianism which did not lend itself*

[initially]<sup>4</sup> to sociologically informed policy –orientated research’ (Gabe et al 1991 p3).

### 3.7 Critique of Parsons’ Sick Role theory

Parsons’ (1951) study of patients in a hospital setting was one of the first theories of “doctor to patient relationships” and is known as *the* sick role theory. The theoretical perspective, which guided his work, was “functionalism” (Giddens 2008).

Parsons used this framework to explain how (American) society functioned in the way it did. His theoretical framework was dedicated to looking at how people performed their predetermined roles (e.g. doctors and patients). Parsons described the doctor-patient relationship as an “ideal type”. An ideal type he saw as a kind of blue-print concept that explains what are considered as fundamental conjunctures of roles that are a key features of any social organisation (e.g. employer to employee; master to servant). Describing, or identifying, ideal types constitutes an important method of analysing social phenomena under observation. He depicted the role of sick people as involving four general expectations: First, when people become unwell or sick they are forced to give up their previous roles (e.g. member of a club); secondly, they take on a new role as a patient within a hospital setting, as being in need of care. Parsons classified these two areas as expectations and privileges. They are contingent on the sick person being motivated to recover and cooperate with the doctor in order to get better.

Parsons viewed the sick role as being temporary so that the person could return to their former role in life. The doctor is considered an equal partner in this relationship whose actions are also committed to the desire for recovery and the well-being of the patient. He is expected to apply his specialist knowledge to the needs of the reducing acuteness of the patient’s symptoms.

Parsons’ analysis is important in recognising the importance of social expectations between both parties, which guides their behaviour towards one another. However,

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<sup>4</sup> This qualification is not in the original. Mike Oliver’s work for example influenced the development of the 1986 Disabled Persons Act and the Disabled Discrimination Act (1990). His work contributed to the widespread advocacy of the social model of disability in many council departments throughout the country in the 1990s and early millennium decades.

his model overlooks the conflict and tensions that can arise between doctor and patient, as well as the extent to which the relationship between the two might be one of incongruence. An example of this is the ethical assessment of “best interest” in which doctors are considered to be the leaders in determining whether or not an act of surgical intervention may or may not be beneficial to someone who does not lead a healthy lifestyle. Parsons recognised that doctors are the official gatekeepers involved in determining who is “healthy” and who is “sick”; while people who adopt a “sick role” are entitled to benefits such as paid time “off” work or state benefits (e.g. incapacity benefits). Being a gatekeeper assumes a moral responsibility for the doctor to trust the patient’s narratives when they report their illness symptoms.

Freidson (1970) described three versions of the sick role not accounted for in Parsons model. The illegitimate sick role describes patients who perhaps contributed to their own symptoms. In such cases, the individual is considered as being responsible for causing their own illness through for example drug and alcohol dependency. In cases such as this, the proclivity toward rights and privileges may not be sanctioned. Conflict can arise if the patient is expecting a “sick note” and yet the doctor is unwilling to support their request. Health and illness for many researchers are social constructs. The second category is the conditional sick role. This refers to individuals who are suffering temporary symptoms from which they can recover. They conform to the sick role principles and receive rights privileges due to the extent of their condition. An example of this is people with acute asthma. People with the same label of illness may display less intense symptoms may not be considered as sick. The third category is described as the unconditional legitimate sick role. This category is characterised by individuals with incurable diseases (but not medically unexplained symptoms). They automatically qualify for sick role rights and privileges. However, for many in this category they may never be able to return to their normal or original duties. Examples of conditions may include terminal forms of cancer or motor neurone disease.

### 3.8 Social Construction of health and illness

Social constructionism is the view that reality is socially constructed and individuals and society can understand it to be so, and thus reach '*[t]he view that scientific knowledge and biological discourses about the body, health and illness are produced through subjective, historically determined human interests, and are subject to change and reinterpretation*' (Gabe *et al* 2007 p130). Berger and Luckmann (1966) examined the cultural formation of common sense as the way to create understanding of social processes and phenomena. Researchers of health and illness who advocated an epistemology of social constructionism include David Mechanic (1962, 1978). Mechanic explored lay systems of referrals to health professionals. He wanted to understand why people behave in the way they did in reaching out for help and support when they became unwell. Understanding how people with an illness construct their view of the world allowed the development of a theory of ill behaviour. In social constructionist research into illness there is a deeper philosophical connection between the internal desires of individuals who want to restore (a balance) and a renewed self in order to live a pain free existence (cf. Burr 2007).

Mechanic (1978) recognised that health and social care professionals involved in the lives of people with long-term chronic conditions were often the last resource that the sufferer considered visiting. For example, people would have identified the extent to which treatment resources were available including the distance of the health and social care facility and weigh up the psychological consequences (and costs) of taking action, before consulting a professional. Mechanic's work provided an explanation about the lived experience, and also something about the challenges faced by health and social care professionals to meet the sufferer's perspective. It would be possible for people to endure their symptoms for a long period of time before making decision to access services.

Freidson (1988) undertook a study of the medical profession to explore the extent to which practices were socially constructed. His work suggested that the way in which medicine was practiced served to promote and maintain the political and social interests of the medical establishment. The ability to practice autonomously and draw

on personal space for clinical reasoning and decision making, including diagnosis and treatment or labelling the person and classifying their status (as with Sick Role theory) was indeed powerful and not quite appreciative of the viewpoint of the lay person. *'Illness therefore becomes a social state, constructed through the power of doctors to create labels and meanings for lay experiences'* (Gabe *et al* 2007 p 131).

Studies such as this were able to reveal details of people's resources and networks of support not readily available or credible in earlier research such as that of Parsons (1951). Sufferers were shown as constantly attempting to discover new ways of moving out of the "shadow of silent suffering" and observing and interviewing them enabled researchers to describe powerful and insightful patterns about living with diseases and receiving treatment for those diseases (Charon and Montello 2002). The narratives were about their experiences of daily drudgery that were punctuated with evidence of perceived support from, and dependency on, friends and relatives.

Mechanic's (1978) work presented coping strategies amongst people living with active symptoms brought on by an illness. His research was focused on uncovering the issues reported by the sufferers and presented a model of interaction between *self-defined illness* and *other - defined* disease. There had been very little previous research into how the problems of the health service may have played a role in the negotiation of illness identity. The study attempted to explain people's behaviours in terms of variables and independent variables reflective of an attempt to integrate a positivist framework into the research effort. Although a brave effort to theorise illness behaviour, this work clearly suffered the limitations of British empirical social policy climate of the 1970s. The researchers needed to elaborate a model (in almost statistical terms) of how someone's behaviour may be influenced by personalised (often psychological) variables. People were not presented as "statistical beings" *per se* but were still seen as being able to be accounted for in social and perhaps economic modelling terms. Nonetheless, the strongest element of the illness behaviour theory, applying the notion that the self and others socially construct people's identity, continues to be of use.

### 3.9 Medicalisation critique

Since the 1970s, the term medicalisation has been critiqued in sociology. The original arguments were characterised by the emphasis in individual freedom, human rights and social action (Foucault 1973, 2008). In particular challenging the role played by members of high status occupational groups such as the medical and legal professions.

Good (1994) asserts that western medical practice including health and social care approaches in hospitals and community setting is based on the biomedical perspective with the view that illness and disease can be explained in factual terms. It is the view that the origin and treatment of disease are best understood through the application of concepts from physiology, anatomy and biochemistry (cf. Radley 1994, Good 1994). Despite western medicines alleged lack of effectiveness in treating a wide range of medical conditions and its iatrogenic side effects it has amassed power and influence in society (Petersen *et al* 1997).

Supporters of the medicalisation critique contend that social life and social problems had become more and more medicalised, or viewed through the perspective of scientific medicine as ‘diseases’. Critics, such as Zola (1972) and Eliot Friedson (1970) argued that medicine provided a form of social regulation for social problems formally the domain of religion and law. One of the strongest supporters of the medicalisation critique was Ivan Illich (1995), who argued that medicine did not essentially serve to improve people’s lives. Instead, the medical profession for him undermined people’s health and well being both through side effects of medical treatment and by diminishing lay people’s capacity for autonomy in dealing with their own health and social care (Illich 1995 and Lupton 1997).

Several academics who were part of the disability movement in the 1970s and 1980s (e.g. Oliver and Campbell 1996, Barnes and Mercer 1996) argued that individual explanation (with a predominantly biomedicine message) was pervasive in its definition as to what constituted meanings of illness and disability. In contrast, their work was able to develop socially constructed models of disability (Oliver and Campbell 1996, Barnes and Mercer 1996). They undertook to show limitations in the

original World Health Organisations (WHO) classification of illness and disability. Disability was defined as *'[t]he loss or reduction of functional ability and activity consequent upon impairment. It is characterised by excesses and deficiencies in behaviour and other functions customarily expected of the body or its parts, and represents objectification of impairments in everyday life and activity'* (Goodwill *et al* 1990 p 7). This model was part of the International Classification of Impairments, Disabilities and Handicaps (WHO 1980).

The World Health Organisation is an inter-governmental organisation that provides support and directives about health policy, health and illness trends (including the outbreak of epidemics and its management of them throughout the world). Their remit includes communication to countries in the world the extent of the global burden of disability in the world. This involves recognition that *'[G]iven the populations of western societies are ageing the proportion of consultations in medical practice devoted to the psychosocial and other problems of daily living associated with chronic illness will increase. As a result, there will be a fundamental shift in medical practice from 'cure' to 'care'* (Scambler 2008 p 84).

The original classification was thought to be too entrenched in the biomedical framework. In its simplest form the ICIDH expressed disease or physiological disorder leading to the cause of impairment; the impairment in turn leading to the person being disabled; disability leading to the last stage of handicap (Goodwill and Chamberlain 1990)

One of the key arguments against the one-dimensional outline of the original ICIDH is that impairment and disability give rise to handicap by the interaction of other socially constructed influences. One of those factors is the physically (planned) and built environment. Once a community occupational therapist provides (for a wheelchair user) a recommendation for a ramp, stair lifts, level access showers and wheelchair adapted kitchen heights the "disability" reduces. If society, through its welfare provisions and mixed economy of building planning, provided accessible buildings at the start of all planning processes then the need to refer to people as being disabled would take another meaning. There would be no need to refer to them as "disabled". This gave rise to the social model of disability (Oliver 1990, Barnes



1991) which is the academic reflection of the work of the disability movement. Key assumptions of the social model were that illness and disability should not be considered as a personal tragedy. That people with disabilities should have equal access to opportunities for living and working; that the barriers of oppression were constituted by society, therefore disability was society's problem not that of the individual with their impairment.

Challenging the values of organisations, responsible for international messages about global health and illness, the rise of the disability movement coincided with wide ranging debates about the extent to which biomedicine was socially and culturally constructed. This has now largely resulted in a consensus expressed by Burr (2007 p 38) that '*[h]ealth, illness and disability are not only socially created; they are sustained by social practices that often serve the interests of dominant groups in society*'. The healer, whether a surgeon or a GP, a chiropractor or the latest breed of psychotherapist – interprets a health problem '*[w]ithin a particular nomenclature and taxonomy, a disease nosology, that creates a new diagnostic entity, an "it"- the disease*' (Kleinman 1988 p5).

In western society, governments and health and social care providers have now followed the WHO and the disability movement, to adopt a holistic approach to health, which goes beyond the bio-medical approach in their responses to changing disease patterns. Examples of these changes are increased incidence of cancers and the management of HIV and Acquired Immune Deficiency Syndrome (AIDS). People are increasingly utilising positive coping strategies and preventative behaviours to manage their health needs (Janz and Becker 1984). This is demonstrating that people are more aware that they can play an active role in helping themselves remain healthy, through diet and exercise for example.

Despite these available measures, as a result of increased awareness through health promotion, illness for many people is inevitable. Lay people may become frustrated if the medical profession takes a long time to find a diagnosis to a problem and work toward alleviating the symptoms.

*'[T]he crisis in medicine could allow the layman effectively to reclaim his own control over medical perception, classification, and decision making' (Illich 1995p4).*

The next section will describe one sociological framework whose proponents have looked closely at illness experience.

### **3.10 The role of narratives within the sociology of health**

Narratives give a sense of communicating about illness that gives an image of the experience from the patient's perspective. The challenge for the researcher is to present a degree of realism in their analysis that does not overtly distort the message of the person whose narratives are being studied. The researcher reports on someone else's suffering in a valid way. The earlier sections explored the key theoretical frameworks that have made a significant contribution to medical sociology. Those key areas provided frameworks and theories about the following; first, the extent to which people were stigmatized by their situation (e.g. Goffman 1979). Second, the type of relationships people have with their health and social care professionals (e.g. Parsons 1951). Third, the extent to which society measures the impact of the needs of a population where illness and socioeconomic positions conflict (e.g. the Black Report, 1981, cited in Black *et al.* 1988); and fourth, how people cope with a whole range of health and illness symptoms (e.g. Mechanic 1978). These theories were derived from the work of authors with a clear perspective about their chosen epistemology (Anfara and Mertz 2006).

The following quotation, although old, conveys the essence of the author's theoretical stance. It also indicates the sense of the main arguments presented in a cross section of contemporary social science literature on chronic illness to promote a standpoint on the voice of the sufferer and explores some of the raised expectations of health and social care professionals and the employers. Where possible the work will attempt to match the author's chosen perspective of symbolic interactionism and closely related areas (e.g. medical anthropology because a significant degree of material and cross cutting themes have been reported about illness experience from this field).

*‘[S]tory telling is a creative art, and therefore knowledge of underlying principles is as indispensable to the narrator as to the sculptor or painter. The beginning of the oral story should never be an introduction, because from the first word the listener expects something to happen, and if nothing does happen attention may wander and interest is lost. Therefore, the narrator must bring his actors on the stages and get them to work at once. There is no set phrases or clauses with which one must begin a story, and it would be a mistake to say that dialogue can never be used safely in opening the oral story, for the professional uses it with fine effect; but it is easier and safer for the amateur to use the narrative beginning, and introduce dialogue as the plot develops’ (Cather 1926 p79).*

The challenge for this author, almost one hundred years later, should be to plunge directly to the thread of the story (although not naively). The consistent *leitmotif* running throughout this chapter has been the author’s expressed desire to link theory of method (methodology) to the eventual selection of research methods and the eventual explanation of the phenomenon. In terms of the literature review, it is fair to state that medical sociology has reported on what it means to cope with a chronic illness. Coping is therefore one of the main themes drawn out from the literature.

This is a study about two things: First, the experience of illness of four women with lupus and second, an ethnographer’s account about health and social care practices regarding one lupus sufferer who died whilst in hospital care, without any family present. The literature will illuminate some of this. Some of the aims (and accompanying references) of the research highlighted in chapter one will be expanded.

The purpose of this section is to focus down on the experience of living (and dying) with a chronic illness in general and lupus in particular within the general literature of sociological studies on chronic illness. The conclusions emerging from these pieces of research will provide a stronger indication of the kind of themes, in addition to coping, that are likely to emerge from a study such as this one.

The literature review revealed very few sociological accounts solely dedicated to the experiences of lupus informants (e.g. Baker and Wigninton 1997; Engle *et al* 1990). The few that were obtained included small extracts or vignettes from a wider body of work. An example of this is Charmaz's report of a single lupus informant named 'Bonnie Presley' (Charmaz 2007 p43). The literature review also revealed studies on how people with illness in general made sense of their life (Mol 1999; 2002).

The "experience of illness" in medical sociology explores what people go through in their personal lives whilst diagnosed with an illness. This area can be regarded as a contribution to the Health Belief Models (HBM) and the Common Sense Model (CSM) (Baker and Wigninton 1997) which looks at the problem of experience from the perspective of the informant (although it has been stated that it is not possible for a study to be value free from the researchers own perspective) (Janz and Becker 1984). The HBM and the CSM relies on individual perceptions of suffering and how they go about trying to maintain their health in the midst of illness events, often as symptoms, that affect the lives of individual lupus sufferers.

In particular, the notion of experience is concerned with the context around how people deal with their bodily symptoms and situations around them. Bury (1991) argued that how illness is conceptualised depends on two specific directions. The first direction concerns whether we are interested in the consequences of illness. Consequences refer to how illness affects people's personal roles and relationships. The second direction is the study of significance, which refers to how our meanings are packaged culturally. For example, how people interact and deal with symbols and signs associated with their life as they come to terms with their coping.

Scarry's (1985) work on illness experience focuses on how pain and suffering is regarded in society. For her pain as *consequence* can be the result of political and governmental action (and symbols) with their combined impact on the person's life having disastrous consequences. She believed that people develop "language agency" or verbal strategies for developing a particular language of pain as a consequence of their particular turmoil of living with an illness. For her, bodily pain is comprised of three characteristics: first, pain as communication inhibitor; second, pain as the consequence of various forms of political and perceptual contexts (e.g. civilian

populations killed or permanently injured during the Vietnam War or warfare in general) and three: the social context of pain and its impact on those in our social and support space. *‘[P]hysical pain has no voice, but when it at last finds a voice, it begins to tell a story, and the story that it tells is about the inseparability of these three subjects, their embeddedness in one another’* (Scarry 1985 p3).

Mol and Law (1999) used social constructionist epistemology and ontological actor network theory to explain how health and social care professionals report stories about people’s bodies. They argue that patients’ lives can be socially constituted by health and social care professionals in terms of the body as an object (i.e. the use of a regulatory mechanism within the medical profession ) and body as a subject (i.e. the reported personal experience of living with a condition). The (ill) body is used as an object within the health and social care professions, reductionism is a philosophical stance used to describe this. Reductionism is regarded as a negative concept by many who comment on the limitations of medicalisation. They claim that it offers limited account for social determinants of the body (cf. Good 1994, Illich 1995).

The regulatory power of health and social care professions means that illness is often witnessed through the eyes of people with “expertise” framed within their professionalism. Practice tools, which are represented in this form of regulation/assessment, include the use of microscopes, X rays, sphygmomanometers and other forms of visualising machinery. They perform the function of measuring a range of aspects of the body including blood pressure, heart rate, blood sugar levels etc. Social constructionists view medical power as necessary to the medical encounter between patients and doctors, and not inherently repressive (Foucault 1973, 2008, Lupton 1994, Rose 2007). Rather it is productive of medical knowledge and of the social world in which it participates (Lupton 1994).

*‘[P]rofessional power is the result of a professional delegation of autonomous authority to health occupations which was enacted during our century by other sectors of the university trained bourgeoisie’* (Illich 1995 p6).

In the personal experience of the author as a carer, suffering emerges as a phenomenon beyond the concepts of coping, which can best be reported when gaps

exist in services aimed to support the private (subject body) experience. Although the patient's perspective of illness and that of their carers have long been ignored in medicine despite documented problems in gaining patient compliance to recommended medical regimens, there have been efforts in the social research of lupus to highlight the voice of the sufferer and to try to understand their context (Baker and Wiginton 1997, Rosenfield 2006).

Given that treatment within a health and social care regulatory context is coordinated within the public realm as contextualised in chapter two, research findings provided by Mol and Law (1999) inspired the author to write about living (and dying) bodies from the perspective of the sufferer. Perhaps this can fit well with Williams' (1996) quotation when he talks of '[w]hat is beneath the ebb and flow of social life'. Not all the work of health and social care professional (as observers) is invalid because of their assumed philosophical links to forms of population control such as eugenics which emphasise today a bioethical conscience within health and social care professionals about the powers they use to decide how services should be provided (Rose 2007). Mol and Law (1999) demonstrates that the role of these professionals can be studied to determine characteristics of the health professionals as they participate in coordinating coherent systems of intervention.

Mol (2002) conducted ethnographic research into the lives of people with atherosclerosis in a Dutch university hospital. Her particular theoretical framework drew upon an eclectic mix of work from medical anthropology and sociology. Her work was able to reframe such issues as the disease-illness distinction, subject-object duality, boundaries, difference, situatedness, and ontology. Her eventual theory itemised the importance of changing contexts such as, place, the use of medical apparatus, the variability of the doctors' specialty as they interact with patients. Examples of her work included the emergence of different forms of "atherosclerosis" being discussed, measured, observed, or stripped away. Mol demonstrated that this multiplicity does not imply fragmentation. Instead, the disease is made to cohere through a range of health professional tactics including transporting forms and files, making images, holding case conferences, and conducting doctor-patient conversations.

Some interactionist authors lived with their own personal experience of the illness and have brought their personal and real perspective into their work (e.g. Kelly 1992; Barnes and Mercer 1996). Kelly conducted a study of fifty people with ulcerative colitis. He stated that his study was influenced to some extent by his own life experiences with the disease and this experience along with other pioneering studies helped him to develop pre-coded themes that he wanted to look for in the research data. He acknowledged this combined approach when he stated '*[t]hese attuned me to issues beyond my own experience*' (Kelly 1992 p14).

His study identified that people took a while to come to terms with the fact that something was wrong with them. '*[T]he sufferer has an impaired bodily function. That impairment is eventually recognised as something which prevents fulfilment of some desired social, psychological or biological function*' (Kelly 1992 p21). He identified one central theme in his study '*[c]oping with illness and surgery*' (Kelly 1992 p15). Kelly used the theory of coping outlined by Lazarus and Folkman (1984) as a theoretical framework to explain what coping was necessary for people with ulcerative colitis and the transforming effects of living with a colostomy bag. As mentioned earlier, he also concluded that people's identities were affected and their concerns about how others perceived them heightened.

Kelly, used descriptions of erosion of self and selfhood to describe the impact of the disease upon the individuals identity: '*[F]acets of self...the ileostomy is required to be bracketed out of feelings of and about self and therefore be bracketed out of interaction more generally*' (Kelly 1992 p86). According to Browner (1998), identity is performed in various social arenas with a variety of purposive actors that lend meaning to what is performed. Culture is an ecological activity binding the meanings of individuals in relationships together. What we do as individuals is understood in the setting of our social activities and those settings are informed by the individuals that comprise them (Browner 1998). Therefore, if someone is experiencing a problem such as a series of medical symptoms it will place demands on them in a way, which is dependent on what they are doing at that particular time. For Kelly, Browner and others then coping as a response is dependent on ones identity as viewed from ones own perspective and from the perspective of others.

Lazarus and Folkman's (1984) model of coping is what Bury (1982) would see as one that looked focussed on the "consequence of an illness". Sometimes "consequence" studies helped on the journey to find out more about "significance" studies. Just as Goffman's theory of stigma was influential in helping Kelly understand the role of social actors in reporting their story (as significance). Lazarus's model of coping is also influential in the literature to understand some of the intrinsic motivations of lupus sufferers in this case study. The principle of Lazarus and Folkman's model is as follows: All human life encounters problems along its journey. For example individuals who are not ill will one day become ill and enter a different situation.

Some stresses outweigh the individual's capacity and ability to deal with them fully. At this moment, the individual is forced to confront the demand on their physical being. This is known as a stressful situation identified by the processes of primary and secondary appraisal. When the individual confronts the demand (stimulus), the process of primary appraisal helps to make clear whether that person views the stimulus as irrelevant resulting in no action needed to be taken. On the other hand, if the stimulus is stressful it will be deemed the result of harm and unhappiness caused by the stressful situation. Secondary appraisal follows from primary appraisal and is known as the coping process. Secondary appraisal is about mastering the situation that causes harm, threat or confrontation when a routine or instinctive reaction is unavailable. Coping can involve help seeking behaviour such as obtaining information, taking direct action, not doing anything or internalising (Lazarus and Folkman 1984).

Baker and Wiginton (1997) conducted a qualitative research study of thirty women with lupus in the USA. Their study aimed to identify the common sense representations of lupus made by women and to evaluate the impact this had on how they managed their illness. The main assumption made by the authors was that patients with chronic diseases created their own *common sense* models about illness that influenced the self-management of their disease. An example of a common sense approach involved the way in which patients made decisions concerning the extent to which they would comply with medication regimes, which were often based on their own personal belief system. The common sense approach was able to show a tendency toward compliance with medically prescribed drugs and other interventions



once the patient sought and gained the support of a carer. When asked how they coped with their illness women in Baker and Wiginton's study stated they had to take personal responsibility for the management of the disease. Very few stated that they placed the management of the disease in the control of other health and social care professionals. This included adopting a positive attitude to get through the tribulations each day as well as making efforts to become as knowledgeable as possible about the disease. When the sample were asked about how they coped '*[t]he strategies most frequently reported*' (Baker and Wiginton 1997 p134) included; taking active rest, stress avoidance, praying, asking for help; living a health lifestyle, using a support group, become informed and using vitamins.

The common sense framework adopted by Baker and Wiginton in their study is consistent with findings that have emerged from general studies on other chronic illnesses. In particular, that people once diagnosed with an illness develop coping strategies to get through life. In addition, aspects of their life and personal identity are disrupted often to the point where they feel that other people do not believe that they are ill. The study however did not report in any detail about how people reported and coped with the negative aspects of the disease. Instead the emphasis of the study was to develop recommendations about how to promote educational resources about how people cope.

Baker and Wiginton's study only expresses positive consequences of illness behaviour for lupus sufferers. In the same way, it would be also naïve to emphasise the negative aspects only. Along the way in peoples' lives illness presents a whole range of negative obstacles. An example of a theoretical framework that deals with negative processes of living with an illness is the work of medical sociologists such as Bury (1982). He coined the phrase 'biographical disruption' to explain how illnesses disrupt people's lives. For Bury, there was a sense that people with illnesses, such as rheumatoid arthritis, reached a point in their lives when what they knew as a normal way of life changed in inconceivable proportions. At that point, they accepted that their body had changed and made mental adjustments to live with the discomfort of joint pains, physical deformity, and the limitation to activities of daily living.

“Biographical disruption” as a theoretical framework points to a series of endless challenges that impact not only on the person’s life and body but also on relationships with their carers. In his later work, Bury (1991) distinguished between three dimensions of the process of biographical disruption. In the first dimension, Bury argued that “coping” is characterised by the person utilising cognitive processes to balance a coherent sense of self alongside the changes brought about by adjusting to life with the initial illness symptoms. The second dimension is the mobilisation of “strategies” designed to enable the person to take necessary action and calculated decisions aimed at managing the illness and the impact that it has on a person’s life. The third dimension is the “active adjustment” that the individual makes in living a particular lifestyle. In the face of the daily challenges people make choices that determine the best options or actions. These actions perhaps reflect a range of classic medical sociology (e.g. sick role; stigmatized body; social model antecedents – impairment as enlightening). Biographical disruption may not be the only outcome. Depending on the person’s outlook and circumstances, biographical reinforcement may also be possible (Faircloth *et al* 2004; Pound *et al* 1998; Carricaburu and Pierret 1998).

Biographical disruption assumes that the illness presents the person with an intense crisis, which is static (i.e. an event that happens forcing the person into a life of perpetual darkness or suffering). In a study of over one hundred stroke survivors who were interviewed one month, six months and twelve months after being discharged from hospital Faircloth *et al* (2004) argued that people find ways of coping that enhance their biographies. They challenged the notion of Bury’s (1982) concept of biographical disruption. Narrative excerpts are presented to describe specific discursive resources these people use that contradict the disrupting connotations of stroke. Findings suggest a conceptual framework known as biographical flow more than a biographical disruption to specific chronic illnesses. In other words, people are able to move on with their lives after the diagnosis of a particular illness or disease.

Nochi’s (2000) grounded theory study of ten informants with traumatic brain injury (TBI) revealed findings similar to work on identity conducted by Kelly (1992) and work on biographical flow carried out by Faircloth *et al* (2004). Nochi’s grounded theory research produced a conceptual framework of reconstructing self-narratives to

account for how people adjusted and coped with their new life after experiencing a traumatic brain injury. They adjusted to change of self-images, daily life using rehabilitation, and the support of health and social care professionals. Five main themes emerged from the study indicating how people behaved and reacted to real situations that presented themselves. The first theme was “self better than others were”. Under this theme, respondents would speculate that their life was relative to the lives of other people: *‘[T]hings could be worse’* (Nochi 2000 p 1798). The second theme was entitled, “The grown self”. Under the second theme, the respondents disclosed what type of changes they would be making in their life in order to show themselves as more mature, compared to their pre-trauma lifestyle. The third theme was entitled, “the recovering self”. Here the respondents would talk about strongly held beliefs concerning how they would restore some degree of functioning. This was also characterised by some personal past reflection of former skills, abilities and motivation with future aspirations. The fourth theme was entitled, “living here and now”. This is characterised by informants talking about psychological strategies for getting on with their lives. This included beliefs about acceptance of their body image and level of impairment.

*‘[S]ome other informants employed similar strategies to focus on the selves that existed here and now. Sam, for example, did not like to use a word like “recovery” because it was strongly associated with the pre-injury conditions. From this frame of constructs, he maintained that thinking of himself before the injury often made him depressed. Instead of that word, he concentrated on words like “progress” or “improvement” so that he could attach more significance to small, positive changes of his day-to-day performances’* (Nochi 2000 p1799).

The main themes derived from a cross section of the literature about chronic illness are that it is debilitating in the way it affects the lives of sufferers (and carers). All the authors cited in the literature review indicated that people’s personal identity and sense of self are challenged. As Williams stated: *‘[T]he exploration of the experience of illness becomes a vehicle for exploring basic questions about the nature of the self in the world, the fundamental meaning structures in a person’s life’* (1996 p 201).

People develop cognitive processes for dealing with the challenges that arise as a consequence of illness known as coping strategies. Not all experiences have to be negative. Isolating illness as a phenomenon for research is also not always useful as it can be part of a multiple perspective where interaction of the person with the environment, people, and medical equipment can play a part in explaining how illness is constituted. Illness therefore does not have to challenge the person's life permanently. Some experiences can reconstruct the lives of those affected with illness. There is a world for people with chronic illness where acquiring coping status is strained (Lazarus and Folkman 1984, Scarry 1985, Bury 1982, 1991, Morse and Johnson 1991). This represents much of what this study will investigate. The strain brought on by chronic illness as people strive towards coping not only affects the life of the person diagnosed with the illness. It has an impact on the carers - paid and unpaid. The next section will review literature on caring.

### **3.11 Carers in chronic illness**

Sociological research into the role of carers in chronic illness is relatively new. The meaning of caring varies and is a relative concept. In its practical form, caring is viewed as supportive in character where specific tasks are viewed as beyond the call of duty. The 2001 Census has established that there are 5.2 million full time carers in England and Wales, including over one million people providing more than 50 hours of care per week (National Statistics, 2003a, 2003b). Caring has connotations of doing things for people, who are unable to perform the required tasks in an independent manner, to enable the care recipient to feel that their dignity needs can be managed, enabled, restored, and maintained. There are three strands that have led the way in which the role of carers have been studied (Twigg and Atkin 1994). The first are studies into kinship obligations and the role of family relations (Young and Wilmot 1957, Finch 1989). The second influential strand has been the feminist critique of caring in our society (e.g. Twigg and Atkin 1994; Finch and Groves 1983; Graham 1991) exploring the gendered division of labour of caring. The third and final area covered in this literature review is from the social constructionist framework (e.g. Oliver 1990).

In the late 1980s, Twigg and Atkin (1994) reported on work looking at the role of carers. They argued that carers occupy an often overlooked and ambiguous position within the health and social care system. This is because services are predominantly planned and provided for the person with the chronic illness. Friends and family members who act as unpaid (or informal) carers are an integral part of the well-being of people who suffer with a chronic illness. The informal care required, can be substantial. Many aspects of the ill person's daily activities of living skills will have been reduced and the level of dependency increased as the carer not only has to manage their own life but that of the relative who has become chronically ill.

Examples of the activities of daily living needs that will arise includes arranging for social services home care, doing housework, as well as feeding, washing, assisting with toileting, and providing emotional reassurance. While caring can often put people under strain, it can also be an important source of happiness in people's lives (Brouwer *et al* 2005). It is not surprising that loved ones, who were once in receipt of care, perhaps as children, would derive great pleasure and satisfaction in giving back caring to their relatives as unconditional display of affection. Government policies as represented in carer specific legislation are a sign of the need to encourage health and social care professionals, as paid carers, to listen more to the needs of carers. This has arisen as a result of the increasing numbers of people who suffer with a chronic illness relying on informal (and unpaid care); as well as a large number of carers being excluded from decision making made by health professionals towards their loved ones: '*[W]e envisage a much greater role for informal carers and people who use services in training staff – with 'expert carers' running courses for nurses, doctors, allied health professionals, social workers and other care staff*' (DH 2006a p196). In order to evaluate the wider effects of health and social care interventions on carers, careful consideration needs to be given to issues provided by informal carer when they come into contact with health and social care professionals (DH 2009).

Morse and Johnson (1991) used a grounded theory methodology to investigate the processes involved in caring. They identified a process comprising of several main themes. One of the significant aspects of their conceptual framework - '*[t]he illness constellation model*' (Morse and Johnson 1991 p 321) was that two parallel journeys take place between the person who is ill and the carer. The model aims to present an

alternative explanation offered by medical discourse and symptom explanations of illness. This model views illness as an experience that affects the individual and those close to him/her (e. g carers, friends, family). As a result of events triggered off by the emergence of unknown or known symptoms (diagnosis) the individual and those, significant others are subject to a range of life impacting changes. The table below represents the stages within the model together with the emergent themes describing the experiences of the carers.

**Figure 5: The Illness Constellation Model**

Individual	Carers
Stage 1: The Stage of Uncertainty <ul style="list-style-type: none"> <li>• Suspecting</li> <li>• Observing</li> <li>• Being Overwhelmed</li> </ul>	<ul style="list-style-type: none"> <li>• Suspecting</li> <li>• Observing</li> <li>• Being Overwhelmed</li> </ul>
Stage 2: The Stage of Disruption <ul style="list-style-type: none"> <li>• Loss of control yielding to the help of others</li> <li>• Distancing Oneself</li> </ul>	<ul style="list-style-type: none"> <li>• Accepting responsibility</li> <li>• Being vigilant</li> </ul>
Stage 3: Striving to Regain oneself <ul style="list-style-type: none"> <li>• Making sense</li> <li>• Preserving self</li> <li>• Renegotiating roles</li> <li>• Setting goals</li> <li>• Seeking reassurance</li> </ul>	<ul style="list-style-type: none"> <li>• Committing to the struggle</li> <li>• Buffering</li> <li>• Renegotiating roles</li> <li>• Monitoring activities</li> <li>• Supporting</li> </ul>
Stage 4: Regaining wellness <ul style="list-style-type: none"> <li>• Taking charge</li> <li>• Attaining mastery</li> <li>• Seeking closure</li> </ul>	<ul style="list-style-type: none"> <li>• Relinquishing control</li> <li>• Making it through</li> <li>• Seeking closure</li> </ul>

(Adapted from Morse and Johnson 1991)

When people are ill they spend time alone trying to understand what their body is telling them. The carer can often be unaware of what is going on. The next stage is disruption and involves seeking help from someone else usually a close friend or relative and possibly a health and social care professional. The parallel experience for the carer is trying to be assertive and take responsibility for the person who is ill.

Morse and Johnson's work detailed the challenges faced by carers and the person who is ill on a similar timeline. Their work also supports similar patterns mentioned on identity in interactionist studies on chronic illness research. Carers in western societies are often constructed as warm and supportive individuals, who are often female (Wilson 1982, Graham 1983, Twigg and Atkin 1994). Early sociology studies such as Young and Wilmot's (1957) study of family kinship networks in East London studied caring relationships amongst families. Their studies demonstrated the role and function of care and support provided between families across several generations. Society at that time was made up of more geographically static communities; Families lived and worked locally. The role of women involved in domestic routines was evident and their giving and supportive roles were regarded as *'enclaves of survival rather than a reality that could be considered to be widely current'* (Twigg and Atkin 1994 p 2).

We are conditioned to believe that women perform the role of being an unpaid carer (Graham 1991, Gabe *et al* 2007). Our first experiences of caring are often received from a female relative such as a mother (Finch 1989). During periods of illness, our mothers support and tend to us as children and men. Maternal carers are transformed into lay social workers and nurses providing guidance to others in the community in times of critical illness and even dying. In the sexual division of labour of caring there are anomalies. Men fulfil the role of carer (Green 1988, DH 2008) for lupus sufferers also. In those with chronic illness such as lupus rely on children, some of whom are boys, when the partner or husband is at work (Charmaz 2004).

Social structuralists and feminist writers (Davies *et al* 2000; Thompson 2003) have argued that the role of caring is gendered. Gendered forms of inequity are organised and sustained by static (albeit flexible) rules and power arrangements. According to such theories, power is something one-group exercises over another; it is a kind of possession or property legitimated by laws, standards, hegemonic practices, and institutional relations. Davies *et al* presents a theoretical framework that links the role and identities of the paid and unpaid care within a gender framework known as *'cultural codes of gender'* (Davies *et al* 2000 p346), where the process of the gendered role is defined as a culturally built resource as opposed to a fixed biological entity. Caring then is socially constructed and conditioned into our behaviour through

the years of socialisation. In their arguments they explain the gendered division of labour within health and social care professions, between doctors and nurses for example, and use this organisational perspective to argue that professionalisation constructs another pattern of how caring is manifested. In their example nurses participate in a world of trade off between themselves and imitate the behaviour of their male counterparts and senior colleagues (e.g. doctors as role models). The gap identified between the two worlds of health and social care professionals and lay carers is evident when service providers and lay carers disagree with the pattern of intervention provided.

According to Davies *et al* (2000): *'[C]aring is firmly expunged from the masculine gendered ideals of bureaucracy and profession. The ideal profession is not uncaring, but detached, treating each patient or client with a correct professional concern, but not being visibly moved, not getting bound up in their crises or their pain. There is a parallel here with the impersonality of the bureaucrat. The bureaucrat always adheres to rules of the organisation, processes the work in a calm and distant manner, is entirely reliable, shows no favouritism, is interchangeable with any other role'* (Davies *et al* 2000 p348).

Carers however do become tired (Department of Health, 2000) and stressed as a result of the *'[d]aily grind of care giving'* (Twigg and Atkin 1994 p4). The social constructionists from the social model of disability have argued that the system which forces people with impairments to become disabled also forces family members to become informal carers. The solution they believe is that society should own the full costs of care and underwrite that. There are measures to support the role of carers in our society as reflected in social policy (DH 2008, DH 2006a).

*'[T]he NHS and social care sectors spend more than £5 billion annually on training and developing staff. Only a small fraction is targeted at staff working in support roles – the least qualified don't get the opportunity to participate in learning and development. None is spent in supporting informal carers'* (DH 2006a p 196).

The gaps in services that exist for people with chronic illnesses and their carers have been explored in the literature review and have been evident since the first social



studies recognised the need for health and social services to work in a more joined up manner (Clare 1976, Roberts 1992). Service providers from the government level down to the front line health and social care providers have been found wanting in their ability to operate in a consistently high level of joined up services. As a result, the government have expressed commitment to narrowing the gap in service to carers by utilising their skills and knowledge to assist front line services. Recently affirmations from central government have been made to let members of the public know more about how the gaps in service provision will be bridged.

*‘[W]e envisage a much greater role for informal carers and people who use services in training staff – with ‘expert carers’ running courses for nurses, doctors, allied health professionals, social workers and other care staff’ (DH 2006a p196). The service pathway where the chronically ill enter (e.g. acute care) and leave the service either as a result of surgery, rehabilitation (e.g. intermediate care) or end of life (DH 2004a) all have flaws which predispose the sufferer and their carer to levels of dissatisfaction as a result of poor understanding between service provider and those in receipt of their services (Turner-Stokes *et al* 2008).*

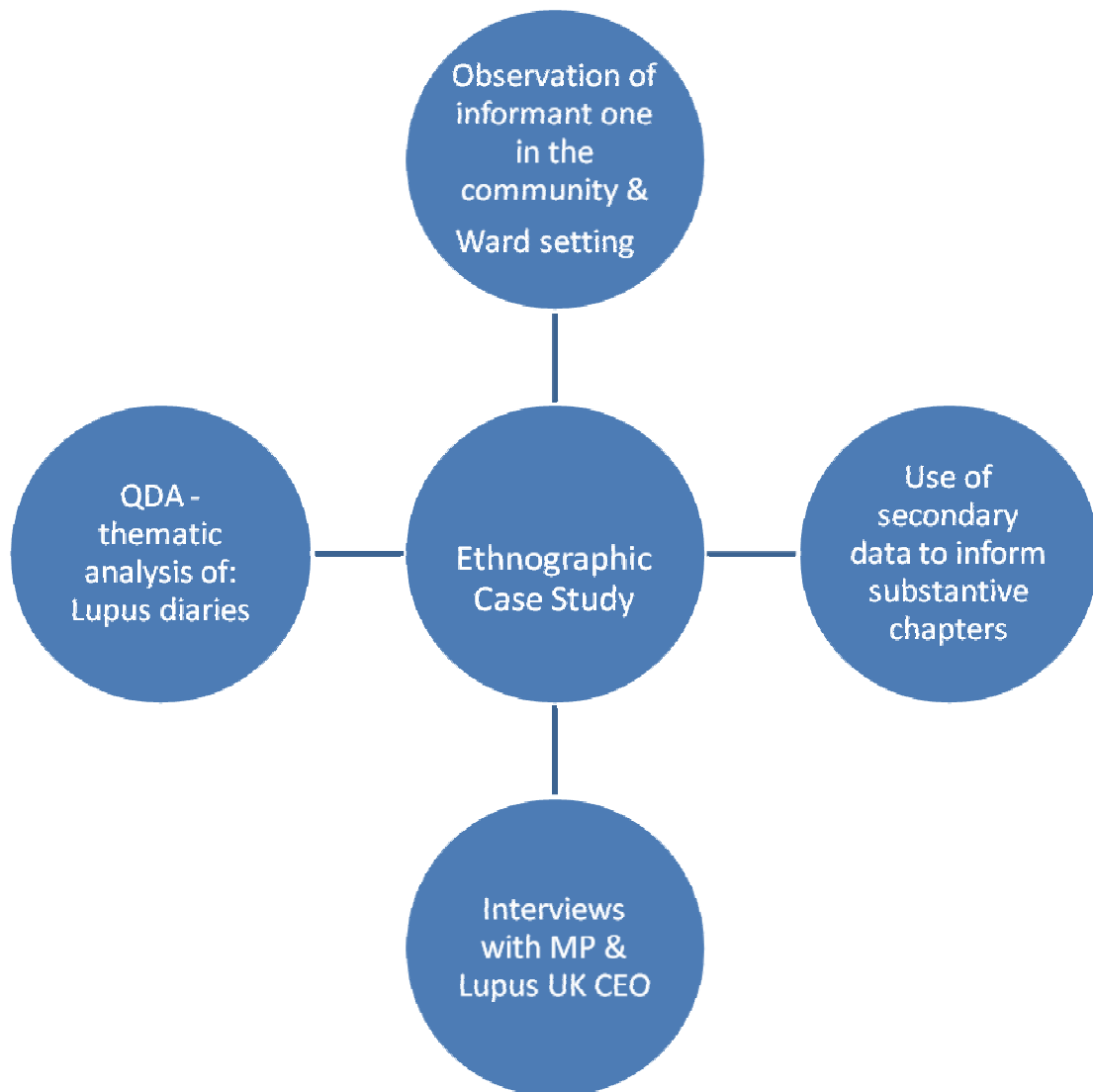
## **4. Chapter four: Research Methods**

### **4.1 Introduction**

Several modes of enquiry were utilised within this case study under the main banner of the ethnographic method. The first mode was participant observation (cf. Good 1994, Ellis and Bochner 2002). Participant observation was used in various interactions between the author, the informants, and the subject matter as a whole. The second mode of enquiry used by the author included self-analysis when reflecting on his role as a son observing his own grief and his experiences of caring for his mother in the final stages of her illness. The third mode of enquiry involved the literature search and analysis of data taken from publications such as books and journal articles. They were analysed for specific themes and trends. The fourth and final mode of enquiry used by the author was qualitative data analysis (QDA). They were used to analyse the narratives provided by the lupus informants. QDA included line- by- line coding, thematic analysis, constant comparison and framework tables (cf. Miles and Huberman 1994, Braun and Clarke 2006, Glaser 1978, Miles and Huberman 1994).

Glaser and Strauss (1965), pioneers of ‘Grounded Theory’ methods also conducted research into death and dying, and their substantive discussion and reporting included professional reflection from the perspective of the author. This author has used a reflective style in substantive chapters, in his many roles as son, carer and health professional. The diagram below, figure seven, illustrates the different types of tools used within the research methods.

Figure 6: Tools of investigation



#### **4.2 Ethnographic case study**

This ethnographic case study followed the lives of four lupus informants. Three of the informants were in receipt of social services from local authorities for whom the researcher worked. The key informant was the author's mother, who was in receipt of services from another geographic area. The characteristics of the informants will be discussed later in the chapter. It is important to define what a case study is as these informants were situated in a particular time and place and it is their shared experiences that form the backdrop for their unique daily accounts about living with

lupus. As detailed in chapter two, the author examined documents and publications, about how health and social care services were contextualised in respect to the needs of people with a chronic illness or permanent disability at a particular time in the UK. A case study, by definition entails a detailed analysis of a single case (Bryman 2008), and has the key characteristic of being focused on a particular topic, of which the case is an example, perhaps located in a particular place in a specific time frame. The author analysed the written diary narratives of four informants suffering lupus. In addition a convenience sample of people who have a connection to services for lupus sufferers was undertaken (e.g. interviewing one Member of Parliament, reading doctor's letters about one of the informants and reading transcripts of political debates about lupus). Although not directly part of the case study their contributions have helped the author to develop an understanding of how lupus sufferers manage their lives. Additionally, another main feature of a case study is often the use of a small sample of informants. The author chose a small sample because he wanted to explore and reflect the detail of their lives in a way not possible in a large sample size that is characteristic of sample survey research design (cf. Gomm *et al* 2008).

The author has made comparisons including the study of a single diabetes sufferer by Anderson (1991); three diabetic women by Anderson *et al* (1997) and eight women with angina by Miklaucich (1998). Each of these studies generated core themes based on explanations about the experiences of the informants whether they included maintaining control, living through the pain or restructuring their lives.

When the analysis of the data from this case study has been completed, the author will present a conceptual or explanatory framework about lupus based on the experiences of the four lupus informants. In addition, the analysis of data will include the author's ethnographic accounts, thematic analysis narrative texts and transcripts of an interview with a politician. In addition discussion transcripts of the All Party Parliamentary Group on Lupus, and ethnographic reflections of being a carer (someone with over thirty years experience as a carer immersed in the field of living with lupus (chapters eight, nine and ten).

Ethnography is a process, which in part uses introspection on the part of observers and those being observed (Seale 2007). The author will analyse the words of women with lupus, and their carers, which honour their own subjectivity, while making it commensurable with his own subjectivity, and that of the readers of this case study (cf. Buckingham *et al* 1976, Good 1994, Ellis and Bochner 2002). As mentioned earlier, the decision to use ethnography resulted from identifying the philosophical basis for this study (i.e. pragmatism, critical realism and symbolic interactionism). The author is guided by these three philosophical elements. In addition, the author was influenced by life shaping experiences as a child carer qualifying him to recognise the language and symbols inherent with living with people who have the condition lupus.

Ethnography as a method was chosen because of the combined qualities of the author's perspectives on truth seeking philosophy and his personal qualities as a lifelong observer and carer. The ethnographic case study involves reflexivity that allowed the author to challenge himself when analysing the contributions provided by other lupus informants. Reflexivity in general refers to “*[t]hat which turns back upon, or takes account of a person's self*” (Holland 1999 p 464). Social sciences require this type of transparency in order to move from the: ‘*[i]ndividual cogito of epistemology and the rational 'agent' of social theory to the embodied socially situated person-in relation*’ (Sandywell 1996 p 377).

The author as ethnographer became the instrument of data collection. Ethnographers gather data by their active participation in the social world; they enter a social setting in which people are already busy interpreting and understanding their environments. Ethnography usually supports a physical observational focus of ongoing involvement with people in their everyday settings. ‘*[T]he self must not only be offered, it must be accepted*’ (Goffman 1979 p 41). This type of research action is akin to immersion in a culture attained by anthropologists who live in the society they study over a period of one or more years (Gomm *et al* 2008). This substantive account aims to situate the research in relation to foundational assumptions about the nature of language as a means of expression and representation. The words of women with lupus, their carers and the ethnographer, will aim to make credible assumptions about their own subjectivity (Good 1994, Ellis and Bochner 2002): ‘*[L]anguage (and the verbal*

*reports it permits) has been taken as the window into the inner life of the person'*  
(Denzin 1992 p2).

For many years, the role of the ethnographer (and anthropologist) has been criticized for having an effect or bias on fieldwork setting and results. Their presence has in some way influenced their informants to behave in ways that they would otherwise not have, had they not been in those settings in the first place. For the author it is taken as a given that there will be a researcher interaction effect. To counterbalance this effect as much as is practically possible the author will deploy a system of scrutinizing as many of the other influences that bear down on the individual's life. '*[T]he ethnographer needs to be sensitive to the nature of a condition governing their own participation as a part of the developing understanding of the people they study*' (Davies *et al* 2000 p73). It is an acceptance that other phenomenon could be at work, beyond our immediate recognition that indirectly interacts with us and influences various components of life and experiences such as suffering (Scarry 1985).

The tradition of drawing generalisations from a small sample is a valid method of scientific research and that this research is a further demonstration that people's lives are intricate whether the sample size is five or five hundred. The key assumption of morphology requires the research to focus on conceptualising new entities within a single case and contributes to the notion of studying people as a universe of phenomena in themselves. One method involved getting close to the people, sometimes by living with them. This was the case with informant one (the author was very close to informant one, Mrs. Robin, his mother, who died in January 2006) and to a lesser extent with the other informants in his capacity as an occupational therapist providing support and care to them.

As a consequence of these close relationships, the author wanted to develop three aspirations: first, to draw concepts from an analysis of diaries that could be used to develop explanations about lupus sufferers' experiences. The second aspiration was to present an ethnographic account of caring and observing suffering and finally to present perspectives gained from interactions with health providers, government officials, and relevant publications that could contribute to concepts of service

provision. As Wright Mills (1970) suggested personal trouble is a mirror of public issues; the personal issues of lupus sufferers can have a public service impact.

In order to explore the relationships in this case study between service providers (in public service) and lupus sufferers (with personal troubles) the analysis of the data involved constant comparison, and cross tabulation in the form of framework tables. Use of multiple methods of investigation (sometimes described as triangulation) has been described as a mixture of two or more theories, data sources, methods of investigation in the study of a single phenomenon (e.g. living with chronic illness) (Kimchi *et al.*, 1991). The goal of multiple methods such as the two main ones used in this study is to cancel the bias of investigators and to overcome the deficiencies intrinsic to a personal investigator, single theory or single method study to promote greater confidence in the data and proposed theoretical formulation (cf. Denzin 1970).

The use of multiple analyses is a way for research such as this case study to extract raw data from field observations and set a foreground of issues taking place against a particular backdrop. In this case, the relevant health and social policies of the time (including the published accounts of substantive debates) form the backdrop. Therefore, for the lupus sufferers in this study their portrayed personal troubles are accounted for in their narratives. The relevant public issues include those areas that influence them via a range of devices such as access difficulties gaining access to public services, as evidenced by political informants or the patterns and actions of workers in a health and social care department such as a ward.

In the process of ethnography, the author explicitly drew upon his own biography. This is an example of reflexivity (cf. Holland 1999; Gouldner 1970; Hertz 1997; Chriss 2002), which will be discussed again in the findings chapter. What this represents is a rejection of the idea that social research is, or can be, carried out in some autonomous realm that is insulated from the wider society, and from the particular biography of the author. There were several aspects of field research that assisted in the process of recording memos and analysing field notes:

The author took the opportunity to use his experience of working as a manager in the National Health Service. He employed this role in order to engage fully in the activities of the group or organisation under investigation (i.e. a staff group of twenty

occupational therapists and their support staff). An example of similar work using critical realist ontology was that of investigation into racist language of a particular group (Potter and Wetherell 1987).

### **4.3 The author's reflective use of self**

In the findings section the author will include an analysis of his interpretation of ward life and occasionally draw parallels from his own experiences as health manager to assist in the analysis. This method of self-reflection will allow the author to explore what challenges exist in managing and delivering a service on behalf of and for people who are chronically ill and disabled and their carers (cf. Zola 1982; Frank 2000; Murphy 2001). The author aimed to make transferable assumptions about health care teams working from the team, which he managed, to that of the hospital ward team where he witnessed the actions of staff in the setting of providing care for lupus patients (Brechin *et al* 2000). Writing from the perspective of a health professional was study necessary in order to conceptualise what patterns existed when people who are chronically ill came into contact with health professionals. Insights were then compared with specific experiences presented by lupus sufferers in their narratives especially when exploring how and why inconsistencies arose in the receipt of services that are supposed to be equitable.

Ethnography enabled author transparency to take place and prompted the author to convey various aspects, which are often hidden from the view of others. This allowed the author to reflect on, and report, the issues challenging this research. The chapter on observing and participating in grief provided personal opportunity for immersion into the field and provided invaluable life experiences about people with lupus.



#### **4.4 Case study setting**

Observational data and narrative data were used within this ethnographic case study. Observation and analysis emerged as the principal approach to ethnographic research. This principal approach relied on the cultivation of personal relationships with informants as a way of learning about their lives at a moment in time within the specific cultural setting of UK society. For the author there were several social groups and research entities that are the subject of this study. In this study, the cultural settings were the participants' homes and community settings that they interacted with (e.g. hospitals). The study was conducted over a ten-year study period between 1997 and 2007. The ethnographic fieldwork took place in one social services department in Essex in 2001 and a hospital trust ward in North West London in 2005.

The data were collected from the lupus informants in two different council locations namely the London Borough of Brent and Nottingham City Council. The 2001 census data (National Statistics, 2003a) reveals the population of the London Borough of Brent as 263,000 people and Nottingham City Council as 266,000. Both locations are similar in terms of ethnic profile and are examples of cities within the UK, which were affected by the increases in the population because of New Commonwealth migrants from the West Indies and South Asians in the 1950s.

The cities compare closely to the national average across a range of indicators including those with long term limiting illness and ethnic profile. At the time of research, both borough locations had access to NHS and Local Authority social services department infrastructure for the receipt of treatment for lupus. The management journal recorded in the author's time as manager of a team of occupational therapists in the Southend Borough Council (SBC) was used as additional data. SBC has a population of 165,000. The population profile of SBC is not as ethnically diverse as Nottingham City or the London Borough of Brent. Ethical issues about preserving the identity of the lupus informants will be discussed in section 4.6.1.

#### **4.5 Informants**

The real names for the authors family are used within this case study (cf. Kiesinger 2002). In order to protect the anonymity of other key informant pseudonyms are used for everyone else.

Informant one was named Delia Robin. She is now deceased and was the mother of the author. At the time of the research commencing, she was 52 years old, married, and had just been made redundant from her place of work after twenty years of service on the grounds of ill health. She had been diagnosed with the illness lupus in 1976 after many years of suffering a range of rheumatic type symptoms including joint pains as well as being diagnosed in 1976 with having an enlarged heart. She came to live in England from the Caribbean as a 16-year-old girl in 1959. At the age of eighteen, she married. Her husband was also from the Caribbean Island of Dominica. At the age of twenty, she had her first child named Bernard and at the age of twenty-five, she had her second child Blaine. Her childbirth experiences for the second child were particularly difficult and she suffered her first experiences of high blood pressure whilst giving birth. The second child was born four weeks prematurely.

Informant two, Debs, was 40 years old when invited to participate in this study. She was of white UK origin. Her main diagnosis at the start of the study was lupus. She was married to Del and they had a 17 year-old son named Liam. They lived in an end terraced three bedroom property which was council owned. Del stopped work as a builder to become a full time carer for his wife at home. Debs had been newly diagnosed with lupus however; there was much uncertainty from the medical profession about how best to help Debs manage her illness symptoms. She met the author in his capacity as Community Occupational Therapist for the local authority. She made a referral to the social services team for an assessment to determine what type of equipment, minor adaptation or major adaptations would be possible to help make her life more bearable in terms of moving around the home safely and independently.

Informant three, Shelly lived with her 90 year-old mother in a two-bedroom bungalow. She was in her mid 40s of white UK origin and was unable to work as her illness had taken a full grip of her life to the point that it made moving about within the home and out in the community problematic. She was increasingly dependent on receiving care support from her mother and other members of the family whenever they would visit. Her main diagnosis was sarcoidosis and lupus. She was particularly photosensitive to light. She became acquainted with the author in his role as Occupational Therapist with the local authority social services department. Her main challenges were related to difficulty transferring into and out of the bath due to illness associated mobility needs.

Informant four, Primrose, was a 55 year old lady of African Caribbean ethnicity. She lived with her estranged husband. She had two adult children with families of their own. They would provide support by telephone and visited her whenever they were able to. Primrose came to this country from the West Indies in the 1960s and trained to be a nurse. This was an achievement of which she was extremely proud. When she became diagnosed with the illness in the 1990s it came as a surprise because it cut short her career yet at the same time a relief because her illness was finally discovered. She lived a particularly stressful life in the same home as her estranged husband who wanted her to leave home in acrimonious plans for a divorce. According to her, he had a history of mental illness and she found it increasingly unbearable to share the same living space as him. Her contribution to the study was relatively short but on reflection she recalled having to hide her letters and private documents within the home for fear of her invasion of privacy by her estranged husband. This is probably why her contribution to the study was short lived.

#### **4.6 Method of making contact and data collection**

The tools within ethnography were essential in developing relationships with all the informants. The four women with lupus were asked by the author to become involved in a study related to the experience of people living with lupus. In addition, in the hospital ward environment detailed observations were used in order to elicit trust of some of the hospital ward staff. The author observed how hospital ward staff cared for his dying mother.

The author decided to use ethnography in his role as a carer to reflect on the experiences of observing his mother live and die with lupus. Apart from those accounts provided by the lupus sufferers it is the only first person account reported in this study. Scheff (1997) introduced a methodology known as part /whole morphology which has helped the author to consider the value in using single case exploration as part of his ethnography as a carer and analysis. This is an example of part /whole morphology from the perspective of the carer, but entirely determined by the life accounts of informant one.

The ethnography thus provides context from the perspective of a carer. The accounts provided by the author illuminate the range of challenges faced by his family when confronted with the reality of death. The author was very close to informant one, Mrs. Robin, his mother, who died in January 2006. The author considers this position as being *privileged* and *local*, within what Atkinson (2001) identified as ‘[I]ndigenous ethnography’ (Atkinson 2001 p3) or cultural immersion.

The author managed the challenges dealing with ethnographic credibility by constantly reflecting on his practice - as a researcher (Van Maanen 1988, Jenks 2002) and identity –as a son or blood relative (Kiesinger 2002) and applying what Seale (2007) describes a ‘[c] onfessional tales’ ( Seale 2007 p160). One role has informed the other role through acquired insights based on decades of observation and interaction as a carer in the capacity as son. The other role challenged the author to be disciplined enough to objectively analyse and reflect on the experience in order to present an analysis of the data including his ethnographic data.

‘ [C] onfessional tales ...often consist of a ‘natural history’ of the project, with a major emphasis on describing fieldwork experiences. The fieldworker is portrayed, quite commonly, as infiltrating a group in spite of a series of blunders, leading to more sophisticated performance and honorary ‘insider’ after a period of (sometimes painful) learning of the group. These have, eventually, the quality of persuading the reader that the researcher has indeed ‘been there’, seeing and understanding the way of life thus penetrated in a manner that can give unique authority to report it truthfully, so that the reader can rely on the writer’s hard won objectivity’ (Seale 2007 p161).

The author adopted an overt (open) role, and made his presence and intentions known to the lupus informants. They were all on the city council's waiting list for a professional assessment for either equipment or a major adaptation solution to help them live more independently within their own home. On each occasion after completing his professional assessment he informed each of them that he was undertaking a study into what life was like for lupus sufferers. He notified them that he wanted them to keep a diary of what they were going through and would visit periodically to collect the diary and learn how they were coping. They all agreed to participate. Informant four however provided limited participation but this was still valued and included in the case study.

The author did manage to gain the trust and co-operation of several informants. He had a shared common experience of "life with lupus" and they all agreed to support him on this basis. He conveyed to them that he was fully aware of what it meant to live with the disease, having played a supportive role with his mother. In addition they learned that he was a qualified health and social care professional; a child carer; the son of a lupus sufferer and a passionate and committed academic using what he perceived was an innovative diary method for lupus sufferers. The informants all wanted to help make a contribution to research especially if it could provide some answers.

He was able to further utilise the ethnographic method by reflecting on his own demanding career within the caring profession in a bid to bring together a challenging team of occupational therapists whose own role it was to care for other people. This gave him insights into the dynamics of team working as a means of further understanding the challenges faced by his mother particularly when she was an inpatient on a hospital ward. His experiences as a manager will be utilised to draw parallels with the happenings on the NHS ward environment.

#### 4.6.1 Access and Ethics

The author's main desire was to conduct a study into the lives of those who have been diagnosed with lupus and asking the informants to provide a record of, what it was, as if living with this chronic illness enabled this. Indirectly he was conscious of the intrusiveness of asking them to provide a contribution of their private life, which would come under the scrutiny of social research, and ultimately asking them to gain access into their lives. This was very much a "researcher's gaze" (Petersen and Bunton 1997). The four women gave consent to participate in this study, and therefore permitted the author to gain access into their lives. All consents to participate were verbal. In order to preserve the anonymity of three of the informants fictional names have been used. The author made a decision to reveal that his mother was informant one because she wanted to help the author in his studies. She stated that her life was an "*open book*" to the medical profession meaning that the consultants and GP knew many things about her life that were no longer private. She gave the author permission to make open records about her life through this case study. In addition, the author accepted that if at any time informants would like to change their mind and withdraw from the study, then he would abide by their wishes.

Informants two, three and four became acquainted with the author in his role as an occupational therapist working for two East Midlands local authorities. They made a self-referral, to the council, in order to have a 'needs led assessment'. They were placed on a waiting list awaiting an assessment. This poses another ethical dilemma. They made a choice to request help, based on their day-to-day struggles and did not expect a researcher to approach them in the guise of an occupational therapist. The author was aware that the informants could construe this as deception. He therefore undertook several steps in advance of this problem. First, he informed his line managers of his interest and the nature of the study requesting permission to include these informants in the study. They both gave their agreement, which was verbal, at a supervision meeting. Second, when he made contact with each person he explained his two roles and asked if they would be interested in participating in this study. As an occupational therapist, the author's professional code of conduct also makes representations about the extent to which practitioners should bring no harm to those we decide to treat (Ethics Committee, College of Occupational Therapists 2005).

It should be noted, however, that because he was able to obtain informed consent from the informants, this did not mean he was able to afford them extra privileges concerning their occupational therapy intervention. They were concerned at having to wait a long time for their assessed needs to be met. It could have been a factor in encouraging them to participate and maybe was perceived as a trade off for no longer having to wait for an assessment. Nevertheless, he was able to work through their original issues quite methodically, weaving in visits about the builder's progress, with diary monitoring. Over the course of the author's involvement with them their needs were assessed and either resolved with the recommendations of specialist equipment or major bathroom adaptations.

The greatest concern to the author as a researcher, not an occupational therapist, was to listen to informants' observations as they to 'opened up' in a way that they would not have previously done. This included committing themselves to writing into a blank diary anything related to their daily struggle living with lupus. The author was prepared for deeply private narratives to be presented. In the case of informant one the author witnessed very private social and physical parts of her life because she was his mother.

However, the author made assumptions about the informants' level of literacy that could have been a limiting factor in the research methods. To demonstrate this point further it is important to recognise that dexterity also is compromised with many lupus sufferers, yet the assumptions about holding a pen, for committed day-to-day periods, were not explored in detail at research planning stage. People with lupus also have limited energy reserves, which could have been challenged by committing themselves to the study. One of the informants provided material written on two sides of A4 paper. Her contributions revealed powerful issues about domestic abuse that the author failed to request her permission to report to the social services authorities. The authors did provide a verbal handover to his line manager about this level of perceived abuse. His own lack of specific training in adult abuse at that time prevented him from escalating an adult abuse report. He assumed that his line manager would have this matter in hand by liaising with the relevant social work department.

The author never asked that person why they were not prepared to write more information because her comparatively few notes revealed an array of themes that proved invaluable to the study. He was grateful that any of them were prepared to participate in the study. There was a concern from the author and a former academic supervisor at one point that the variability of all the data from the informants could invalidate this study. However, the informants' own consistent contributions derived through constant comparison could be seen as providing a reconciling effect (cf. Glaser and Strauss 1967).

These informants knew that there was no inducement for participating in the study. They all hoped that something could be done to help the lives of others affected by the disease. There was however, a personal perception from the author, that the participants believed there would be greater awareness in the world at large about their illness as a result of this study. Somehow, the world was going to listen and hear their story. As a result, members of the public, including health professionals could perhaps develop a deeper level of understanding of the issues faced by lupus sufferers and therefore become better health and social care professionals.

#### **4.6.1.1 Fieldwork setting: The council organisations social services department**

It is important to explain in detail how the author worked with informants two, three and four in his professional capacity. The author through his various places of employment knew the informants initially in their capacity as patient or service user and in his capacity as an occupational therapist. In formal health and social care settings the informants are described as cases or patients (Gomm *et al* 2008). Cases are practically documented in case files. Files are records about the individual and the history of past interventions made on behalf of the individual. New files are created if an individual is not known to the service and signify that individuals are being assessed or waiting to be assessed by the social services department. The description of individuals as “cases” can be seen as a metaphor describing the relationship between the professional social worker and occupational therapist (Reeves *et al* 2007).



Professional occupational therapists or social workers tend to be allocated a “case” following a referral to a social services department. If the patient or service user made a referral, an assessment by the social services department at the screening point would be the main outcome if they were deemed to be eligible. A priority grade will be assigned to that referral depending on the level of complexity. In a time-pledged commitment, the individuals will be contacted and an appointment would be made to undertake the initial assessment/interview. The needs of the individual (suffering) will then be assessed often in the community within the client’s own home. Not everyone who makes a self-referral qualifies for an assessment. The relationships tend to have a lifecycle (professional process) comprising; initial interview, problem identification, care plan formulation, resource mobilisation (commissioning), review, and case closure.

Permission was requested from the author’s respective service manager to approach these individuals for the research investigation. The response schedule given to the informants was a blank diary given to each of the lupus informants. Each informant was invited to complete a diary over varying timescales. In the case of three informants diaries were completed. After her death in 2006 informant one had several annual diaries starting in 1976, the year of her initial diagnosis. Although this was discovered very late in the research the contents of those diaries mark poignancy as her initial research vignettes were less, in terms of quantity, when compared with the other lupus informants. This and other artefacts allowed the author to uncover a range of issues she lived with.

#### **4.6.2 Anonymity and subjective adequacy**

In respect to lupus informants with the exception of informant one, the identities have been protected and fictitious names used. At first, the author attempted to disguise the identity of informant one. However, over the years of this research there has been a greater belief and comfort for the author, to disclose that this person is not only a relative, but also his mother.

The dilemma for the author was about revealing that private part of both of their lives. Ethnography allows the author the space to deliver this revelation and work with it.

The author's professional code of ethics as an occupational therapist would have required him to collaborate with another practitioner and probably "pass the case file on". Some of the code of ethics between the two professions has similar values.

However, he learned about ethnography as he went along, reading around the subject more after the event than before his fieldwork. Therefore, his primary point of reference in establishing ethical points of stability has been to depend on his vocational training as an occupational therapist. That vocational reserve of values had trained him to listen, empathise, observe body language, and make inferences about certain psychological states and not to cause pain or harm in the course of his intervention.

Informant one opened up a world of opportunities in relation to increasing the author's skills as a researcher. This made it easier for the author to engage with other lupus sufferers and listen to their stories (cf. Nelson 1998). Initially, the author practiced undertaking conversational narratives, biographical notes and later participant observation. Informant one's availability afforded the author the opportunity to improve this craft, from "methodological apprenticeship", through to refining methods of research techniques. The author moved to the east of England in 1999. It would have been a greater challenge to continue to be involved in practical ethnography with those case participants who lived in Nottingham. Over the years, the author's contact with those individuals became less and less. He did however make attempts to debrief them on each visit made to their homes when collecting the diaries for word processing.

The author's most recent contact with informant three, for example, was in the form of a telephone contact in 2003. He reintroduced himself and let her know what progress he was making. He gleaned from the conversation that her involvement with health professionals was not a good one. She was also dependent on support from her elderly mother.

Informant two made significantly large quantities of narrative contributions to the study. She was also very ill. The author shared the same birthday and they would

exchange birthday cards every year. One year she wrote an update letting the author know what her progress was. This was invaluable. Several years after the diary was completed she had an operation to remove a ruptured spleen. He remembered writing to her and not receiving a reply. He also called by her home on one occasion visited and there was no answer at the door. He feared the worst. However, following the death of his mother the author received some valuable advice from her.

The greater the shared understanding between the observer and those being researched, the better the levels of data analysis resulting. Two informants, one of whom was Mrs. Robin, frequently interacted with the author to validate aspects of the data that they provided.

#### **4.6.3 Going (or staying?) native**

The emotions of compassion and caring did at times commit the author to providing advice and sharing feelings of sadness with each person interviewed. The term native does not refer to the inferior position of those being observed as perhaps common in the original use of the term by anthropologists in the late nineteenth century. During that era, they would have explored the African continent alongside Christian missionaries to study the lifestyle of the “natives” or “savages”. The author’s use of the term is ironic because lupus sufferers are not “savages” but human beings on the margins of inconsistent care practices. This degree of empathy shown by the author to the lupus sufferers was at times painful, in particular with his mother. Yet, the irony was that it was during contacts with her that the author, as her son, drew immense strength to continue his research and to use this study to highlight the issues facing lupus sufferers when services fail to meet their needs. There were times when Mrs. Robin may have been snappy or quick for asking perhaps “silly questions”. Those moments of acute irritation made him realise “*something is going on with her. She is experiencing something, which is disturbing and is totally alone with these experiences disturbing her body*”. This is something that the author came to term as a core theme “statements of suffering”. Never was this more poignant than when he witnessed his mother dying in hospital. It was on the ward where he observed, at first hand, the challenges faced by health and social care professionals trying to alleviate her suffering (Further details of these themes will be explained in chapter nine).

Despite his personal involvement, the author tried to be detached and record behaviour at a distance. In particular this was important when the author as a son witnessed his mother die whilst an inpatient. He observed the ward setting and the actions undertaken by a range of health professionals. He describes in the extract below what the ward setting looked like and how he began to interact with that setting as an observer.

Witnessing at first hand the immediate consequences, the death of a loved one is a painful experience. The author never expected his mother to die. The author's views were that she had the resilience to fight another "flare up". She had fought so many before. The author made the following observations<sup>5</sup>:

*Perhaps I was missing the point and am somewhat naïve to this area of the life process. I had never experienced any form of death or dying before. Even though I was trained as a health professional I cannot ever recall participating in any form of intense training, in module format, related to death and dying. As a result after qualifying as a health and social care professional I veered away from death related specialisms (e.g. Cancer Services; Palliative Care) and more toward disability awareness in community settings. When I did work in hospitals it was part of a regime of assisting people to be discharged home after a period of treatment.*

The author's last enduring memories of his mother being alive were when he saw her on the 13<sup>th</sup> January 2006. As he entered the side room of the ward, his mother's eyes caught his own and there was a split second of intense joy in her eyes. They widened and she smiled. Shortly after that, her smile disappeared and she closed her eyes as if to sleep. She was too tired and unable to speak. He introduced her to an independent adviser whom he brought to attend a meeting with the doctors on the evening of the 13<sup>th</sup> January 2006. A church friend, Dora, was sat in a chair in the corner of the room. The author's mother lay on her back. He fixed some of the bed coverings and left the room to attend the meeting with the doctor.

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<sup>5</sup> This is an extract from the author's substantive account of this death made soon afterwards.

#### **4.6.3.1 Other field sites**

The author operated in several roles during the ethnography including observer of people and carrying out an ad hoc one to one interviews to meet a particular informant guided by “theoretical sampling” (cf. Glaser and Strauss 1967, Charmaz 2007, Bryman 2008). “Theoretical sampling” within the terminology of Grounded Theory is a method of seeking data from cases exemplifying particular theoretical possibilities revealed by ongoing investigations. It challenges the researcher to follow other lines of investigation perhaps seek new informants or analyse other forms of secondary data to elucidate the phenomena ever more. This section describes how the author was able to gain access to his political informant. Almost by coincidence the author was introduced to the politician by word of mouth recommendation by Mr. Brian Hanner, former chief executive of Lupus UK who himself agreed to an initial interview from a cold enquiry made in writing.

Mr. Hanner introduced the author to Mrs. Janet Dean, former Labour Party Member of Parliament for the Burton on Trent constituency, who in turn later directed the author to a full set of narratives of which she and her colleagues, who were other Members of Parliament, contributed to developing in the form of parliamentary debates. This interview relied on relatively more formal interview methods than either informal observation or participation. Here, there was a possibility of misunderstanding as it was more of an encounter between strangers that did not utilise the strengths of time in the field, so unable to understand the rules, roles and relationships. In order to counter the disadvantages outlined the author conducted narrative analysis of the transcripts of the parliamentary sub group on lupus.

Extracts from the interview extract with Janet Dean MP reveal some personal motives and professional aspirations that emerged from her own life experiences. This and interviews with other key informants provided a platform to explore various topics that emerged from a House of Commons debate on lupus by politicians, who were members of the all party parliamentary group on lupus.

Brian Hanner, former chief executive of the Charity Lupus UK explained how influential Janet Dean MP had been in raising the profile of the disease on a national and international level. Lupus UK provides support and advice to lupus sufferers

throughout the UK. As a charity, they fundraise through events led by sufferers and carers. In addition, they provide lupus awareness promotion through a web site and a monthly newsletter of events. The newsletter features interviews with health professionals who report on a range of medical developments. The charity also provides sponsorship for specialist lupus nurses in partnership with NHS trusts as well as a lobby role in to parliament.

## **4.7 Thematic analysis**

### **4.7.1 Introduction**

This study employed thematic analysis of documents and narratives. Thematic analysis is a general tool in qualitative analysis. It requires the researcher to read the text (repeatedly), create codes and later identifying core themes within the data. This helps the researcher to build an explanation of the phenomenon under study. As mentioned in the previous chapter symbolic interactionism (SI) is the guiding theoretical framework for this research. The key assumption of SI provided by Blumer (1969) that people act toward events and experiences and the meanings those experiences have for them can only be understood fully through (living with them) and reading their texts and searching for themes. SI is the foundation for the flexible analysis of data provided in this study. The lack of clear and concise guidelines (e.g. present in classical grounded theory) within thematic analysis means that the “anything goes” critique of qualitative research may stand. However, data cannot be coded in an epistemological or ontological vacuum. The position taken by the author allows thematic analysis to reveal the personal and institutional events are taking place to the detriment of the lives of the sufferers and to question (and explain), through analysis, why they are occurring (and sometime made worse) against a background of health policy as revealed in a ward setting.

### **4.7.2 Thematic Analysis of published texts**

Thematic analysis also proved a useful way of examining the assumptions and outcomes of a range of studies that focus on topics such as lupus. In thematic analysis, the data from a series of publications and findings was analysed. This case

study employed thematic analysis of published data as well as ethnographic data to produce the substantive chapter eight on *Death and Dying*.

A range of themes were obtained from the textual documents to be linked together in the thread of the arguments. Salient extracts in the form of quotations emphasise the main thread of the argument. A range of books and reports were selected by the author that related to health and social care. They were read and conclusions were drawn from the documents that related to global topics outlined above which served as findings or summary arguments in substantive chapters.

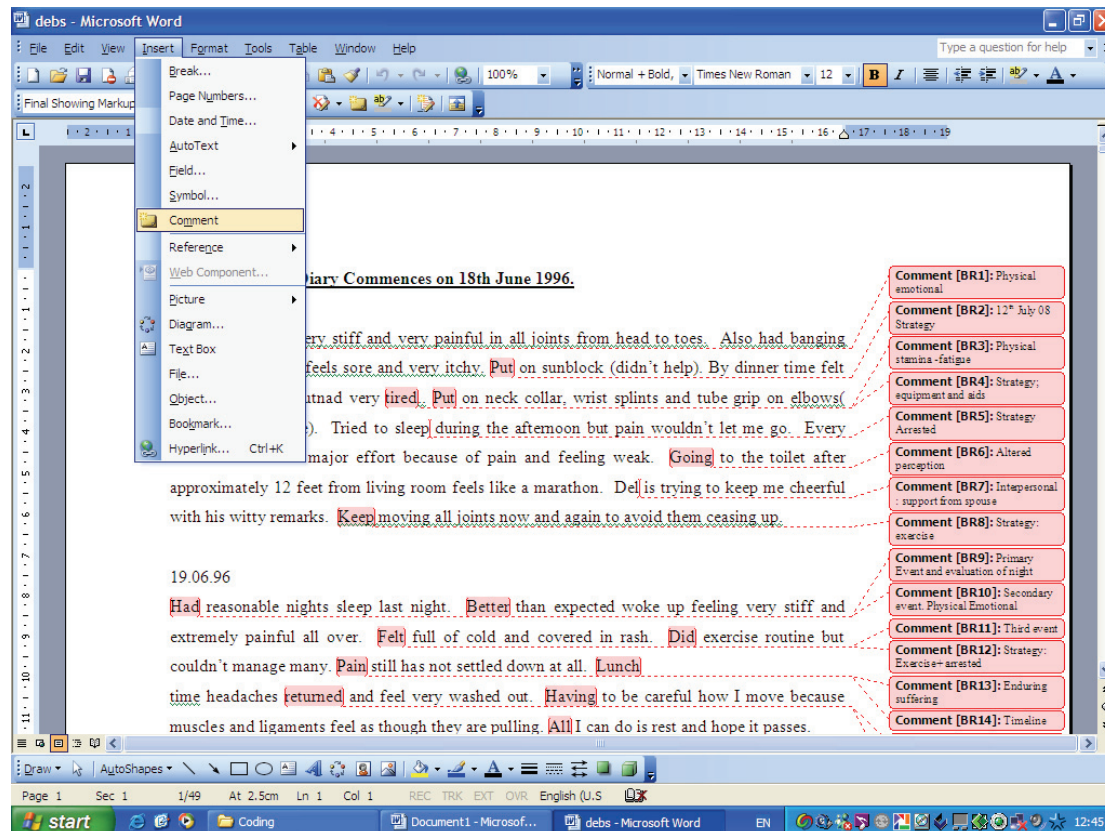
Thematic analysis of these sources was selected as a method of investigation because it allowed the author to compile background research on a variety of data and work backward and forward in time. It allowed the data to be conceptualised and located in this case study for which data from past studies were able to have relevance in terms of service user experience in present time. This application of this method brought together the lupus sufferer's diaries and the contribution provided by authors of published works. There was, however, a danger that qualitative analysis re-visiting secondary data that was already rigorously debated and analysed by others, could lead to an infinite regress of reflection upon reflection. A more defined content analysis was therefore employed by the author to place limits upon this analysis. Where similar findings emerged from different sources this was an indication of the reliability of the evidence. Using content analysis to demonstrate the unconscious assumptions in the narratives of those involved helped the author to demonstrate neglected gaps in service provision for lupus sufferers that may not be immediately obvious to providers.

#### **4.7.3 Thematic analysis of the lupus narratives**

The diaries completed by the lupus informants, the carer's narrative were analysed using visual inspection and later line-by-line coding (Charmaz 2004). Coding is a significant part of qualitative data analysis (Miles and Huberman 1994). During the process of coding, the author often asked many questions of the phenomena being identified in relation to the research questions and the overall research enterprise (Bryman 2008). This allowed the author to see what events and relations were typical and widespread with the data.

In order to undertake coding the transcripts were typed into the word processing software *Microsoft Word* and were then inspected and coded manually on a line by line basis. The coding took the form of the author assigning a conceptual label beside the lines that matched a particular phenomenon. In the data set provided by all informants the author used the Microsoft Word function known as *comment* to create the coding categories manually in the text. Bogdan and Biklen (1992) developed a ten point coding system to help researchers understand the coding structure of narrative data (e.g. such as illness narratives) of which events and strategies are mentioned as being part of a wider more generalised characteristic of data. Their work reports on the use of two coding labels, events and strategies. It is by coincidence that this study intends to use those two coding labels in the analysis of illness narratives. The following diagram, figure 7, provides an illustration of how Microsoft Word was used.

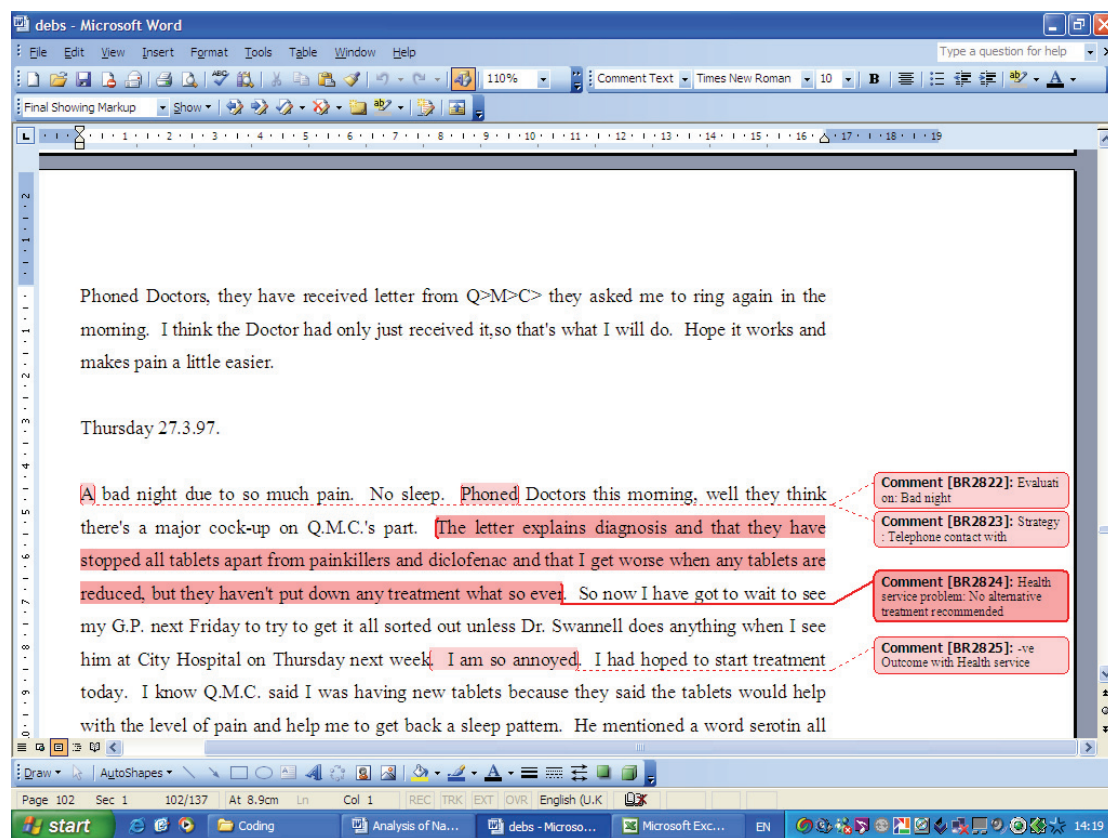
Figure 7: Use of Microsoft in line-by-line coding





In the second diagram below, figure nine, the following analytical explanation details how the core theme of “event” was represented in the initial coding and later developed into a core theme. The bubbles in the right hand side of the diagram have the emblazoned title “*Comment (BR2822 to BR 2825)*” depicting that a coding category has been formed. Comment BR2824 – Health Service Problem is an example of a “memo” (Glaser 1978, Miles and Huberman 1994). The author is telling himself that the doctor, in the case of informant two, has not recommended alternative treatment. As a phenomenon related to doctor patient relationships, the author can use this memo as a more detailed inference of the minimum expectations that patients have of their doctors.

Figure 8: Coding for events



In addition coding took the form of statements provided by the author particularly if there was something of interest that did not fit a conceptual category. In combination with one another memos and codes helped to generate higher categories of coding essential for analysis and later what will be classified as the building of a conceptual (as opposed to the theoretical) model. It is a higher level of coding which will be used in

the presentation of the conceptual model of lupus. The conceptual themes emerged from the author reaching an intellectual saturation point where the description or the label “felt intuitively right”.

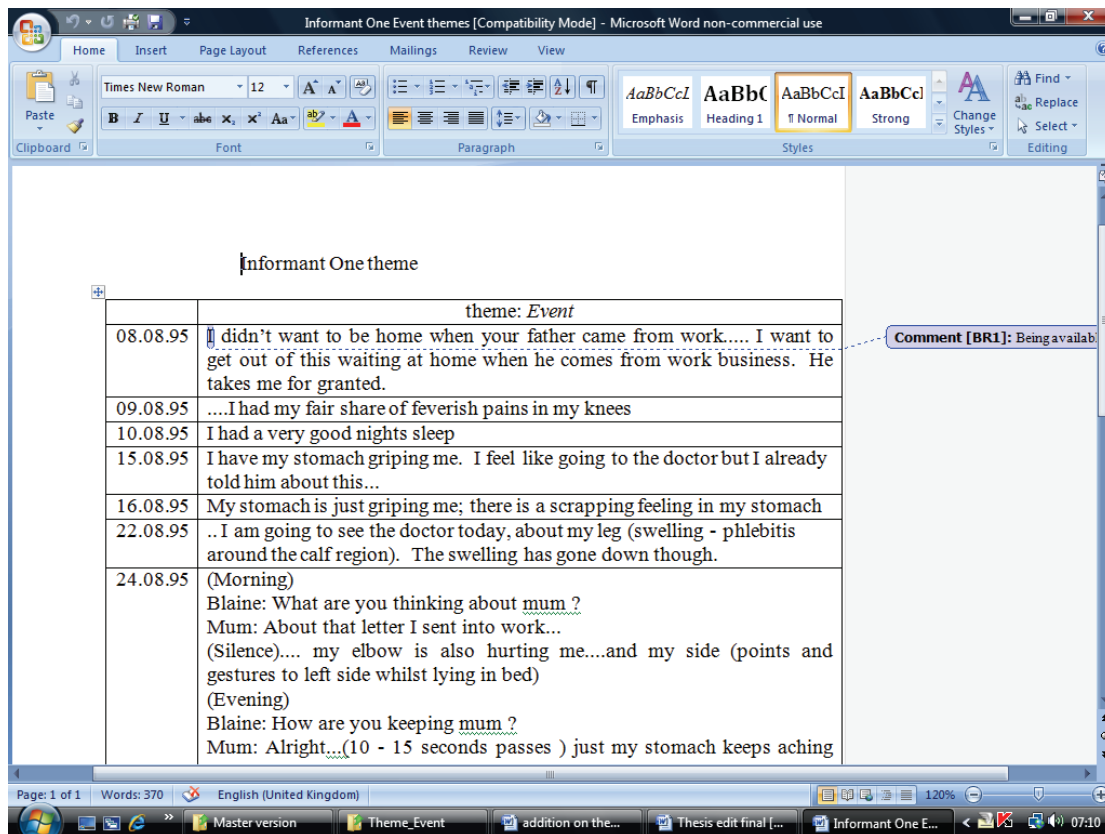
Concept or theme identification was further influenced by the author conducting a basic statistical procedure (more commonly associated with content analysis) by counting the frequency of body symptoms within the text of all the informants. They provided descriptive statistics, which are represented in the form of the shaded area under the bar graphs. Several mapping diagrams were sketched concerning each informants’ view of the world. From these perspectives concepts were drawn out after the author read the texts. The differences and similarities were noted between each of the informants until a point of conceptual saturation was once again arrived at and one overall conceptual map seemed to represent the first stage of the ethnographic ontology of lupus sufferers (Charmaz 2007, Mol 2002).

The author looked for the meanings that word or chunks of words generated. Codes then took the form of tags or labels for assigning particular meanings to the descriptive or inferential data. Where patterns arose in the style of writing a note was made of this. Some patterns were then monitored and represented with descriptive statistics, in the case of body symptoms.

Some statements made by the lupus informants tended to reflect events that they may have experienced or were about to experience (e.g. hospital appointments, tasks to complete around the home). Once the problems and concepts were established, observed phenomena will then be placed within a conceptual framework suffering with lupus for explanation

Framework tables (Bryman 2008) were then developed. *‘Framework is described as a matrix based method for ordering and synchase studying data’* (Bryman 2008 p554). Framework tables represented samples of the total word census of the data set and were made up of the salient themes as depicted from the narratives of the informants. Each theme was exemplified by using quotations and extracts from their texts as a measure of that particular theme. The following screen shots provide examples of how the tables have been constructed.

Figure 9: Screenshot of a framework table



#### 4.7.3.1 Introduction to core themes and sub themes

The themes generated by the lupus narratives (and from the third person carer's narratives) will be discussed fully in the findings chapter's five to nine. Miles and Huberman (1994) explained that it is possible for researchers to present pre-coded themes that can be later supported or refuted by the main study. The author undertook a similar role by undertaking a review of specific issues that were to be tested against a backdrop of research enquiry. The author does acknowledge that the experiences of people with chronic illness are not new. What has emerged from this study however is specific evidence about the experience of service users being part of inconsistent and fragmented arrangements in the services provided by the NHS and local government social services departments. The introduction chapters explained some of the issues that he expected to be studied. Therefore, this study builds on the themes generated by previous accounts of coping with chronic illness. The specific themes that were developed from this study are presented in this section in order to clarify to

the reader what was explored and analysed. The process of analysis will be discussed in further detail in the following chapters.

The following table list the core themes identified in this study and a breakdown of examples of sub themes. They comprise key entities of what the author aimed to define as the “ethnographic ontology of lupus” (Charmaz 2007, Mol 2002). To this aim, the first three chapters of the findings and analysis section focussed on three of the core themes: events, strategy and statements of suffering and the final two chapters of the finding section concentrated on the author’s ethnographic accounts. Events and strategies are the main themes that dominate the lives of lupus sufferers. People’s lives are filled with strategies which are essentially a vital part of how people mobilise their personal ambitions to do things. Events are not often in the control or the will of lupus sufferers but place is vital to the effectiveness of the strategies that are put in place. They are mutually dependent aspects. Fuller discussion of the general concept will be made in chapters ten and eleven.

Figure 10: Table of core themes and sub themes

	Core Themes	Sub Themes				
1.	Event	1a. Evaluation of activity e.g. previous nights sleep				
		1b. Positive and negative outcome				
		1c. Negative personal experience e.g. unusual symptoms				
		1d. Multiple Events and Overload Event				
2.	Strategy	2a. Idea				
		2b. Psychological planning				
		2c. Support from spouse e.g. maintaining sense of Humour				
		2d. Carer struggling to cope				
		2e. Positive interaction with others				
		2f. Use of Equipment				
		2g. Exercise				
		2h. Being passive				
		2i. Yielding to the symptoms				
3.	Arrested Strategy	Arrested Strategy - Failed attempts at regaining wellness				
		3b. No relief following exercise				
		3c. Poor concentration to watch television				
		3d. No relief using alternative therapy e.g. use of hot Water bottle				
4.	Strategy Overload	4a. Use of alternative medicine				
		4b. Changing posture				
		4c. Call for help				
		4d. Visit health professional				
		4e. Take medication				
5.	Statements of Suffering	5a. Lamentations/exclamations of uncertainty				
		i. Religious	ii. Street	iii. Popular		
		5b. Cry for help				
		5c. Self doubt				
		5d. Possibility of hope				
6.	Self Analysis	6a. Impact of medication				
		6b. Impact on illness on day to day life				
		6c. Linking events to an aspect the illness				
7.	Limitations to function	7a. Struggling with physical mobility skills				
		i. Washing	ii. Dressing	iii. Sitting comfortably	iv. Standing	vi. Poor sleep
8.	Carer contributions and observations	8a. Enabling “cared for” person pre hospital admission				
		8b. Observing medical treatment in a ward				
		8c. Social context of dying				

### Core theme: Event

The first theme that was developed was derived from the line-by-line coding was “event” (Futrell and Millikan 1994, Sheaff 1996, Victor 1997). As explained in earlier chapter’s events are physical activities that have a direct impact on the lupus sufferer’s life. ‘*[Q]ualitative researchers are always interested in events: what they are, when they happened, and what their connections to other events are (or were) – in order to preserve the chronology and illuminate the processes occurring*’ (Miles and Huberman 1994 p111). The specific labelled events within this study are symptoms of the illness that the lupus sufferer experiences. They can include a seizure or cramps, a trauma or tragedy affecting the person’s psychological and social state.

### Core theme: Strategy

All the lupus informants within this case study shared in a common desire to do something about what was happening to themselves. If the specific “event”, mentioned in the earlier section, are the cause of the problem then adopting a “strategy” represents the person’s plans and physical attempts to resolve the cause of the problem. All events are then followed by a series of strategies regarding what actions and plans will be undertaken by the informant to counteract the adverse effects of the event. The act of “doing something, to take control”, is what the author terms as “strategy”. They can be singular (strategy) or plural (strategies). They can be *action based* encompassing four main aspects of life: Personal well being; activities of daily living; social circles and transparency to medical profession. They can occupy a certain intensity of low to high level of personal strategies – where high level of personal strategies coincide with the need either to suffer in isolation or reach out for help from others (see figure 7). All informants, throughout their daily routines of dealing with the symptoms, take action. Some actions are private and only known to themselves or other actions they share socially with relatives or friends and can include making another decision: to ask for help and assistance from a health professional or someone else within their social circle. Strategies are a reaction to the scale and proportion of the events that the sufferer is experiencing. The series of

strategies can be frequent during a single day. Their frequency will be described by the author as “strategy overload” (SO).

The “strategy overload” (SO) are characterised by a series of strategies that the informant puts in place to reduce the adverse effects of the symptom. Overload assumes that there is a disproportionate amount of reaction to a single event (or vice versa). In addition, the descriptions are vivid enough to indicate expressions of desperation. Therefore, the more potent the symptoms became, then the greater the propensity for the informant to adopt a strategy overload. Sometimes strategies would lead to the person developing a new learned response to a repeat of a symptom. This could include self-management of medication. Some informants knew when to alter the dosage of a drug depending on when an incident arose. This took place without the advice from doctors.

Core theme: Arrested strategy

When plans fail to have an immediate positive result for the lupus sufferer this has been coded as an “arrested strategy”. Chapter six will provide a more detailed explanation and examples.

Core theme: Statements of Suffering

Statements of suffering are verbal exclamations of sorrow or sadness. They represent a point of utter desperation. However there is an irony to their existence as, they have a function and act as an emotional or spiritual release allowing the individual to find one last element of renewed hope to “go on” or “start again”. These often arise when the lupus sufferer is alone and quite often socially isolated with no one to express their concerns to.

Core theme: Self Analysis

Self-analysis is the lupus sufferers capacity to self appraise in a logical non-emotional (almost clinical) way what they are going through. This is most used when the person takes time to reflect on their experiences. It is a time for the lupus sufferer to make connections with previous experiences and to sometimes discover patterns in their

illness that helps them to draw conclusions as to why they are experiencing the things that they are going through.

Core theme: Limitations to function

Limitations to function refers to the persons struggle to be successful in maintaining their own dignity and ability to remain independent in personal activities of daily living. Limitations to function are the total opposite outcome to the aspirations presented in the person's *action based* strategies. They can represent significant disappointment and frustration for the lupus sufferer as they often emerge as a non-abating experience to the sufferer, who is determined to regain mastery of skills, that were once in their total control. They present a realisation that dependency on help from other people is necessary in order to "move on" with other aspects of their life.

Core theme: Carer contributions and observations

The role of the carer emerged in both the lupus narratives and in the author's ethnographic accounts, specifically when observing his mother enter the dying phase of lupus whilst in hospital. They are linked in as core themes because of the importance of their relationship in the lives of lupus sufferers. There was a mutually dependent relationship between the lupus sufferer and the carer (e.g. husband, friend or children). In respect to lupus sufferers' experiences in the community (e.g. pre-hospital admission) carers formed part of the vital strategy for the lupus sufferer ranging from social interaction to utility roles such as helping with washing and dressing, fetching and carry items from one part of the home to another. During hospital admission, the core role of the carer has been transferred to a group of health and social care professionals. The author witnessed a range of interventions provided by health and social care professionals, which required dependency on advanced medical equipment and often limited social dialogue between the health professional and the carer. Specific observations related to the dying process were also observed by the author for the very first time in his life and therefore became a vital part of witnessing how services are provided for a lupus sufferer throughout their life to death.



## **Findings & Data Analysis**

### **Chapters 5 - 9**

## **5. Chapter five**

### **An analysis of the themes from the lupus informant's narratives focusing on the core theme known as "Events"**

#### **5.1 Theme – Events**

Events relate to a particular "happening" in someone's life. They are characterised by something taking place in the informant's life that has an immediate impact on their management of the illness. This perceived experience is usually associated with health seeking behaviours of the kind that have been categorised within Health Belief Model (Janz and Becker 1984), the Common Sense Model (Baker and Wiginton 1997) and the Social Model of Disability (Campbell and Oliver 1996) which all model how perceived barriers to health, preventative strategies and sick role behaviours have relevance and meaning to sufferers. The author decided to initially code these incidents as "events". There can be more than one event taking place at any one time. During the line-by-line coding these were described as the sub-theme "multiple events". If some of the events are brought on by levels of interaction with health and social care professionals then these are forms of perceived barriers to health and social care as a consequence of non-integration of patterns of personal self-governance, professional governance and organisational governance (cf. Faubion et al 1994, Foucault 1973, 2008).

##### **5.1.1 Informant One**

Informant one's early contributions were recorded by the author using a notepad and pen, writing conversational transcripts, that were later word-processed. The structure of those texts were characterised in the fieldwork notes as entry by "Blaine" and/or "Mum". This initial third person representations by the author shows the marks of the researcher's early "novice role" as an ethnographer recording notes after spending some time in the "field".

Below is a conversational record of informant one's narrative interaction with the researcher (as caregiver, son, health resource worker). It has been presented here to

demonstrate examples of the tensions that exist as both try to negotiate order in their lives in the context of events. It also aims to demonstrate the type of *enabling* language offered by the author to his mother as he tried to find out how she was coping with day-to-day challenges. This technique eventually contributed to the author developing the approach discussed in chapter four. Informant one also contributed another piece of work in the form of a diary. She was indeed a valuable pilot in trialling different qualitative techniques used in this study.

The author used his short-term memory to make entries on the word processor following each conversation between himself and his mother. The author's interactions would be a combination of small sentences and detailed exchanges about relational incidents. The small sentences would be questions about her welfare. They were never too probing. "Are you alright?" was a frequent question that was often asked.

Examples of the questions are as follows:

*How are you mummy?*

*Did you sleep ok last night?*

*You ok mummy?*

*Are you alright mummy?*

*How are you feeling mum?*

*How was your hospital appointment?*

Each question has been used as a trigger for an initial reaction, followed by an open conversation about a related topic or another topic. A key requirement however, was not to probe to a point that does not deliberately trigger breakdown. The reason for this ethical stance was based on valuing and appreciating the role of the informant. The position of the interviewer or participant observer is not to offer a level of specialist interaction common to specific counselling methods where tearful expression is valued as a positive breakthrough.

Some of the conversations happened either over the telephone or in a face-to-face context. Often the telephone conversations were punctuated with silences from Mrs. Robin. During some conversations she would occasionally be quick.

*“What is it?” or “What do you want?” she would ask. The author’s response would often be “Sorry...just to find out how you were keeping”.*

*“Oh...just the same, no change. I just have to get used to living with my illness”.*

Other telephone conversations would revolve around the relationship with her husband. She would state time and again that *“he has not changed”*. She was never really satisfied with her perception of his *“macho”* behaviour as always present after nearly thirty to forty years of marriage. His behaviour she felt would impact on the way in which housework tasks were to be carried out. This could include clothing being left places like the dining room, and dishes being piled up in the sink overnight.

On many occasions when the author visited his mother (when she was not hospitalized) she would state that she was fed up. In particular she was fed up with her husband and her marriage to him. The author occasionally commented on her exploring separation or divorce, she would just state each time that her situation was in *“God’s hands”*. The topic would always end there. The author’s mother would then attempt to continue to be busy undertaking various tasks such as washing dishes or preparing a small snack. She would occasionally retort in her West Indian dialect *‘I’m leaving his socks and beer cans right there! where you see he left them. I am tired of cleaning up after him!’*. What would follow would relate to her feelings of devaluing her position as a sick spouse. *‘I don’t think your father ever, believed I am sick’*.

After a few months informant one began to keep notes herself and provided diary entries. The author encouraged this because he felt it offered more realism about the phenomenon if the informant were to record information in his or her own words and from their own perspectives. The third person representations were helpful in a number of ways. In particular they were able to help generate more information about an issue with the use of *“subtle”* probing questions in ways not possible when informants complete diaries independently of an ethnographer. An example is presented as follows:

*Date of entry: 24.08.95 (Morning)*

*Blaine: What are you thinking about mum?*

*Mum: About that letter I sent into work...*

*(Silence)... my elbow is also hurting me.... and my side (points and gestures to left side whilst lying in bed).*

The “event” that is recorded as taking place in the morning is bracketed to identify a specific timeline context (e.g. am or pm). The specific coded event is “*my elbow is hurting me*”. This symptom has more increased meaning for the informant when it is expressed as part of a particular context. For example the silences and pauses allow the sufferer to regain a comfortable position in her bed before detailing what is taking place. It is not surprising that Informant one uses long deliberate silences as a precursor to describing what is happening because the experiences of bodily symptoms are intolerable. Furthermore, the location of the events for example the conversation taking place in the informant’s bedroom represents the level of trust and intimacy between mother and son. Additional contexts are represented in informant ones thoughts and concerns about how her employers would react to receiving her letter regarding sick leave. There was always a yearning by informant one for her illness to be taken seriously by her employers and this statement also captures this tension.

Informant one provided evidence that some events are also social and have a positive or negative impact on her life. Informant one provides an example of some tension and strain with her spouse in the following extract.

*Date of entry: 08.09.95*

*I didn’t want to be home when your father came from work... I want to get out of this waiting at home when he comes from work business. He takes me for granted.*

The event was about her perceived expectations about being available for her husband. She felt safe and comfortable to express this opinion in the confines of her diary indicating that the diary acted as a safe space for personal, confidential expression of perceived personal stresses. Mrs. Robin was 52 years old in 1995. She had been together with her husband for thirty six years from the age of 16. There was a sense that the relationship has weakened over the years with tensions arising as a result of relationship breakdown, overt infidelity, and hostile communication between

the married couple. In addition she prided herself on paying her way financially in the household and not being dependent on her husband for financial support. Examples of the marital strain are further exemplified with Mrs. Robin ignoring her husband's suggestions to seeking assistance. Although in response to the bodily event there is a reaction from the Mrs. Robin to seek help.

*Date of entry: 25.08.95 (Morning)*

*Mum: Have you got everything you need for work?*

*Blaine: Yes mum (I continue to stand in mums bedroom for about 10 - 15 seconds then mum sits up in bed)*

*Mum: I got a fair amount of sun this summer (pointing to arms and legs) as if I had gone home on holiday. It's probably that that helped to cause my (r) leg to swell it's going down now.*

*(Evening) Mum has reported increasing discomfort with her leg. It is early evening. Dad feels that mum may need to go to hospital. Mum phoned a friend (who is a nurse). The friend advised mum to call the GP surgery. After doing that we obtained an emergency telephone number. Three hours later the emergency doctor arrived and prescribed antibiotics. Reason: inflammation is in the legs, Blood pressure is alright.*

The main event coded by the author is “(r) leg to swell”. However, there are multiple contexts all working together in the life of people with lupus, albeit at mixed purposes, that somehow defines the impact of lupus on the person's body as well as the social life of the sufferer and those who care for her. For example in the morning of the 25<sup>th</sup> August informant one slowly and deliberately builds up her actions before expressing her narrative. The slow pause tells us about the detail of the impact that the illness is having on her body. Finally she is able to express what the “event” is and how she thinks it affects her life: “[i]t's probably that [the sun] that helped to cause my right leg to swell”.

By the evening the situation has become worse, as the leg symptoms have resulted in informant one taking the lead after some consultation with friends and relatives, to contact an out of hours doctor. It did not matter how positive her health and situation may seemed in the morning (e.g. providing her nurturing and support role to her son

or commenting in almost positive ways about her sun tan) it seemed as though there was always a threat that something could go wrong to disturb the balance.

Events then do not “stand alone”. They come with a whole package of possibilities or multiple contexts some of which are physical, psychological, social and environmental (Blumer 1969) . Whether events combine (as “multiple events”) or act in isolation they all challenge informant one to make choices about which decisions to make. An example is the occurrence of a “psychological event” presented (and identified) by informant one as represented in the following data extract:

*Date of entry: 29.08.96*

*Pain and mental concerns... I don't know how things will be for me in my later years... (Mum walks out of room).*

The psychological concern's is a reflection of the future doubt. There are little symbols of “hope” for informant one in this extract.

The events had an immediate impact on informant one's life. The author read the text of bodily symptoms on repeated occasions and analysed how the informants would contextualise them in terms of the adverse effects on their life. The most striking feature is the presence of “*stomach*” related events in the top twelve of most frequent events initially occurring twice as much as the second highest event “*head or hair*”. “*Stomach abdominal*” events were the most frequently occurring event in informant ones diary. In addition “*belly*” and “*stomach*”, as separate individual events, occurred in the top ten most frequently occurring events. As a result the author decided to analyse the occurrence of different words used by informant one to describe the same event. On closer inspection it may be possible to allude that other referents to the kidney organ are the events located in the text as “*side*” as in “*pains in my side*” which occurred in the top eleven body parts where events took place. It is striking and significant because several years later informant one died of kidney disease. Therefore, events in this part of her life (body) are significantly consistent with the deterioration of her kidney organ because of lupus. These narratives became a predictor of informant one's pathography. There is perhaps no more profound expression of the power of narratives when Denzin wrote that ‘*[I]language, and the*

*verbal reports it permits, has been taken as a window into the inner life of the person'* (Denzin 1992 p2).

Further examples of informant one using different words to describe the same event also occurs in the top twelve of the most frequently occurring events and later served as a predictor of drastic deformity or change in body image. The specific reference to this is the second highest event in the chart "*hair and head*". Informant one suffered with total hair loss with significant eruptions of scabs and skin discolouration to the scalp. It is not certain whether this was iatrogenic (cf. Illich 1995) or symptomatic of the lupus disease. However, some medication used in the treatment of cancer was prescribed to Mrs. Robin for which there are known side effects of hair loss. Therefore other references to hair or head events occurring in the top ten of most frequently occurring themes for informant one is "Itch", "Headache" and "Scalp".

Seven specific body part events relate to two parts of the body where the disease was most aggressive the stomach (kidney) and the head (total hair loss).

### **5.1.2 Informant two**

The following is an extract from a framework table about "events" for informant two.

*Date of entry: 19.06.96*

*Woke up feeling very stiff and extremely painful all over.*

In the entry recorded on the 19<sup>th</sup> June 1996 "event" is captured by the adjectives "stiff" and "painful". Informant two conducted an evaluation of what has taken place by describing how she felt when she woke up. The event is a generalized expression of being "painful all over" but represents intense discomfort at the same time. She goes on to talk about other events that have taken place.

*Have not been able to talk much, because face hurts like hell.*



The power of her description is exemplified by the phrase “*hurts like hell*”, leaving the reader in no doubt about the scale of discomfort. Events about the body symptoms therefore are graded according to severity. Sometimes the use of metaphors gives a vivid sense of degree. . For example:

*Date of entry: 21.06.96*

*Legs feel like jelly*

*(Code: Seventh event)*

*Date of entry: 26.06.96*

*Face hurts like hell fells like severe tooth ache right through face; its also slightly swollen got banging headache feels like bad hangover.*

*(Code: Event 3, 4, 5)*

The intensity of informant two’s experiences as represented by events is conceptualized as multiple events. Informant two expressing an array of events almost as if her body is being bombarded with events and painful experiences characterizes these. An example is given in the following extract:

*Date of entry: 25.06.96*

*Woke up with really painful back, hips and legs again*

*(Code: event1)*

*Had stomach ache and felt sick*

*(Code: event 2)*

*Itchy skin again (Code: event 3)*

*Still got sharp shooting pains*

*(Code: event 4)*

*Had runny nose for about two hours this morning*

*(Code: event 5)*

Multiple events such as those outlined above are a common feature of informant two’s narrative. They are present because her symptoms are challenged by lupus mixed with the diagnosis fibromyalgia rheumatica. An illness with a strong feature

of pain and sleep deprivation. Just as in the case of informant one there was a consistent link between events and physiological link (i.e. stomach pains and the later diagnosis of kidney disease) and so here we also see two's is this represented in informant two's use of the word pain and sleep as being consistent with the manifestation of the disease fibromyalgia. Once again on close inspection of the narratives written by the informants there is a major use of the word "pain/painful" occurring over 1500 times throughout the text sleep is the second most occurring event sleep over 300 times. These experiences of bodily symptoms are intolerable.

Informant two expressed a high frequency of events in her diary. She kept her diary for 12 months and provided over 40,000 words worth of data all of which were coded line by line. The framework table above provides an example of "events" that have been coded by the author. Every part of her body was reported on in her narrative (Good.1994). For example she was able to report on her face, mouth, shoulders, eyes, head,, bottom, feet, and hands. Events represented core activity of lupus symptoms for informant two.

There are similarities in the diary for informant two compared with informant ones diary. The first similarity is the occurrence of twenty to thirty body parts referred to in the diary. The comparison is conceptual not purporting statistical significance as informant two recorded her diary for twelve months compared to informant one recording her diary over a six-month period. The similarities of event patterns are similar but not identical.

### **5.1.3 Informant three**

The core theme of events represented qualities about informant three's personality, in particular a form of literary expression not dissimilar to the expression of metaphors and similes provided by informant two (e.g. face hurts like hell). The entry on the 20<sup>th</sup> March 1997, for example, the event is accompanied by a core theme labelled self-analysis. Many of the coded items of text have more than one property – essentially a description *and* an implication. This gives a deeper context around which ailments and body symptoms exist:

*Date of entry: 20.03.97*

*My eyes are always blood-shot; it's rather like having a mixture of sand and syrup thrown into your eyes.*(Code: Self-analysis and event)

The power of the simile provides an imagery of suffering at that moment in time. Later in the analysis the author introduces the concept of “SOS – Statement of suffering” to depict the use of narratives to represent punctuating and defining moments in their daily journey of living with lupus. There is another entry a few days later, which provides another example of what these events are doing to informant two.

*Date of entry: 24.03.97*

*My bones are sore and aching rather like a massive toothache all over the body.*  
(Code: Multiple event and SOS)

The detail of informant three’s “events” really brings home the sufferer’s experience to the reader. With the use of phrases such as: *elbow cracking; toes are hot and tingling; I feel as though I have been labouring on the building site for six months.* The words become alive for the reader. Reading these narratives provides a sense of realism to the drama of personhood and the impact these events have on their personal identity.

When analysing the “events” in the diary there are similarities with the previous informants diary entries in terms of the frequency of occurrences. Informant three’s most frequently reported “event” is related to pain. This is similar to informant two. Although ‘pain’ represented the highest frequency, the author observes that ‘eyes’ (108), ‘blurred vision’ (42) and ‘bloodshot’ (134) once combined represent the highest number of (284) for the most frequently occurring “event” in informant three’s three months entry into the diary. Aggregating the items was undertaken because of the issue occurring around a similar body part, in this case the eyes. Once again this is consistent with the ailments that informant three suffered on home visits. She always wore dark glasses because she suffered with sensitivity on exposure to daylight.

On inspection of the diary clustering frequencies of incidents related to the face: including ‘nose’ (80), ‘cheek’, (79), ‘pink’ (45), face (35), ‘ears’ (12), generates an

aggregate occurrence of (251). It becomes clear that facial events and abrasions are highly contextualized for informant three, as this is one part of her body where lupus is highly manifested. These events would affect the concentration levels of most healthy people. However, informant three seems to have a highly developed sense of concentration, analysis and will power. Examples of will power and determination will become more evident later in the chapter when the core theme of strategies will be analysed.

#### **5.1.4 Informant four**

Informant four's account is more of an autobiographical account of her life with the symptoms and ultimately the disease lupus. On observation informant four's narratives are set in the 1960s the author notes that thematic analysis lends itself to data set in past timeframe without limitation. Her account reports on a whole range of events that have taken place in her life, extracts of which are reported in the framework table. When compared with the other lupus informants there are similarities in terms of dual diagnosis with other chronic illness. For example informant two suffered with poly arthritis, and was later to be diagnosed with lupus; informant three was diagnosed with the respiratory disease sarcoidosis; and informant one was diagnosed with rheumatoid arthritis and lupus nephritis. Informant four introduced more details than any other informant about the negative impact of relationship breakdown on her illness. Although similar issues were raised in the narrative of informant one, informant four specifically connected the problems with her estranged husband and the effects of his unreasonable behaviour on her life.

## **6. Chapter six**

### **An analysis of the themes from the Lupus Informants narratives focusing on the core theme known as “Strategies”**

#### **6.1 Introduction – Strategies**

All lupus informants in the case study were determined not to let their illness or symptoms “get the better of them”. They acknowledged the immense power of this almost alien process within their bodies, which seemed beyond their control. The outcome of being victim to these events resulted in feelings of pain, misery and sorrow. Often they felt an incredible sense of torture, isolation and personal suffering. The suffering would bring them to high levels of distress, often leading to an expression of metaphoric representation of that experience or an outpouring of emotional release such as becoming tearful. In the earlier section the author talked about the process of experiencing these alien and identity-changing aspects whereby the person challenges their need to be dependent on other for fear of becoming a burden on loved ones. The causes of this level of distress are complex often in the form of uncontrollable and unpredictable events. The nature of living with the events meant that the informant could often be “taken by surprise”; there often was not a trigger or warning. The person’s life “becomes consumed” by the activity of the illness. Their time or daily routines are in a large part dedicated to dealing with the illness. This could include thinking about ways of accommodating the symptoms, relieving the symptoms or yielding to the symptoms.

As mentioned earlier, events have fuller meaning when we know about their context. Strategies are part of the context around which events exist. In relation to illness symptoms, events and strategies are interacting aspects. Events and strategies can also have an impact on social relationships, which in turn can affect how the sufferer manages their illness. For the onlooker the sufferer is acting out their illness as if on a stage. The full glare of intimate behaviour that has been overtaken by illness does not always result in support from the carer but is a source of competing expression and need for attention. Examples of this have been evident in the case of three informants who were married or living within an estranged partnership. Some strategies are therefore socially orientated to counter negative experiences of some of their social

relationships. This can include an outward expression of wanting to be alone or isolated from the person perceived as causing the negative social experiences.

### **6.1.2 The act of “doing something” is a Strategy**

For every event that has taken place the informants carried out a plan to combat the problem caused by the event. The following example is taken from informant one’s framework table as follows:

*Date of entry: 22.08.95*

*Mum has reported increasing discomfort with leg. It is early evening. Dad feels that mum may need to go to hospital. Mum phoned a friend (who is a nurse). The friend advised mum to call the GPs surgery. After doing that we obtained an emergency telephone number.*

In the data extract above the strategy of telephoning a friend has arisen as a result of experiencing discomfort of the leg. Before contacting a friend Informant one did not directly receive or accept the advice of her husband. His suggestion was to some extent ignored possibly because of the need for Informant one to make her own mind up. It was only after receiving advice from a friend who was a qualified nurse that the action of obtaining an emergency number took place. Sometimes however, the informant was overwhelmed by the sheer number of events that they were experiencing and were unable to do anything about it to alleviate the levels of distress. Ultimately, yielding to the intense levels of pain became the coping strategy in itself and is another example of the core theme of strategy. Informant three provided an example of this in the following data extract:

*Date of entry: 27<sup>th</sup> March 1997*

*I cannot do anything about this because it's something that overtakes the whole of my body, no matter how hard I try and fight the tiredness it still wipes me out physically and I can't carry out some simple things like holding objects in my hand, sometimes I will get forgetful.(Code: Strategy: Yielding)*

The author coined the phrase “overload” event to account for the person being overwhelmed by the symptoms. Very few informants were able to produce strategies

to combat the presence of effects of those events. Only rarely was this ever achieved. Informant two expressed (and performed) a range of strategies to counter high volumes of events in the following extract.

*Date of entry: 27.07.96 \* STRATEGY OVERLOAD \**

*Pain took quite a while to eventually settle down but managed to go to sleep sometime after 3.00am.*

*(Code: Evaluation: Sleep deprivation).*

*Pain kept waking me up but on a whole I didn't sleep too badly.*

*(Code: Event: Sleep interruption)*

*Today however, from the moment I got up I have been in agony.*

*(Code: Evaluation; Multiple Event; Suffering)*

*I have had a sharp, pulsating, throbbing, aching pain right through every joint. All at the same time. It's affecting everything from head to toes. I also have cramp like pain in all my muscles (Code: event 2)*

*I have tried the hot water bottle (Code: strategy 1)*

*Cold compresses, (Code: strategy 2)*

*Massage, (Code: strategy 3)*

*Ralgex spray, (Code: strategy 4)*

*splints and tuba grips but nothing has helped. I don't know what to do with myself the pain is awful. But there is not a lot I can do but just hope it settles down. The pain has not eased at all. (Code: statement of suffering)*

A range of themes from the data extract above have been identified and analysed by the author these will now be explained. Informant two's first sentence for the day has been coded as an "evaluation" of what has taken place throughout the night. She described the aspects of her functioning that have been affected as a result of being unable to sleep. Although her sleep pattern has been interrupted she reports a positive aspect of the experience. In the next sentence she gives specific examples of how her body feels on first gaining a conscious state in the next sentence as follows: *Today however, from the moment I got up I have been in agony. I have had a sharp, pulsating, throbbing, aching pain right through every joint. All at the same time. It's affecting everything from head to toes. I also have cramp like pain in all my muscles.*

This sequence of activities is described by the author as "multiple events" characterized with more than one event either taking place sequentially or happening

at the same time in informant two's own words: *All at the same time*. At this point the reader realises that this experience is intolerable and requires action. However, more events are described in the next line, which includes specific details of physiological functioning of the person's body. She is trying to convey to the reader what her world is about. She continues: *It's affecting everything from head to toes. I also have cramp like pain in all my muscles*.

We can see in essence the importance of events as a pre cursor to strategies. In the space of one sentence informant two, takes action and adopts five strategies expressed in the following extract: *I have tried the hot water bottle, cold compresses, massage, ralgex spray, splints and tuba grips*. Yet these are to no avail. In informant two's own words: *... but nothing has helped*. The author contextualises another core theme labelled "arrested strategy". Arrested strategies denotes the persons efforts to "put things right" through careful planning. The term "arrested," conveys some degree of submission against ones will, choice or desire to choose a more successful option. There is no hope for informant one at this moment in time. This marks an occasion where planned strategies fail to fulfil what they were hoped to achieve. Once again yielding is the next stage but it does not present itself as mere verbal acknowledgement of acceptance of the "end as hopeless" but what the author describes as "Statements of Suffering (SOS)". There is an expression of words denoting a form of lamentation of almost cathartic proportions. For example informant two says: *I don't know what to do with myself the pain is awful. But there is not a lot I can do but just hope it settles down. The pain has not eased at all*.

Within SOS there is a possibility of "hope" for the sufferer. It allows the sufferer to begin to cope again and attempt to fight for a normal life: Informant two says: *But there is not a lot I can do but just hope it settles down*. "Hope" becomes the new strategy reborn from what seemed to be failure and hopelessness. In her last diary entry that day she wrote: *I just hope for a better day tomorrow*. The author entitles this theme as "future strategy".

## **6.2 Strategies**

Strategies can mean many things to sufferers and can be expressed in many forms. All strategies are part of a wider context of events and outcomes or measures of the



effectiveness of those strategies by the individual once they have tried to use them. In healthy individuals strategies of daily living are part of daily routines, which have taken several years to master from childhood, through the developmental phases of adolescence to adulthood. The skills are strategies applied to daily living and become instinctive and routine. Amongst these lupus sufferers every recorded strategy is designed to have a direct impact on the illness itself or on people who may be having a negative impact on them.

#### **6.2.1.1 Personal**

Strategies can be private. They are often not known about by anyone else except the sufferer. They are used or expressed in the narratives in range of contextualised situations such as those related to the way in which one's dignity is managed.

Personal care is an example of a contextualised space where strategies take place. The informants share a unified experience of having difficulty meeting their personal care needs. They struggle to manage in this area. Where there is a need to rely on help from someone else there is a concern as to whether they are having a negative effect on their loved ones. So once the personal takes a social form the consciousness of delegated strategies to other people has an inner deeper psychological consequence for the sufferer and could include stigma, embarrassment, shame or guilt.

Only one informant mentioned specific examples of alternative options to medicines as a way of relieving the symptoms. These included the use of hot water bottles, massage from a relative, neck brace, bandages, use of ointments and drinking water. For informant two alternative medicines are frequently utilised to alleviate the symptoms because she has a belief that they can play a role in combating the demands being made on her body. The beliefs when manifested as actions become routine in the battle to combat the onslaught of "events" or happenings to the body. Routines are therefore a mode of action when the symptoms are regarded as intolerable to live with.

#### **6.2.1.2 Spiritual**

Informant one, three and four expressed forms of acknowledgment to a higher being or metaphysical outlet coded by the author as "spiritual aspect". When involved in a

situation of helplessness expressions of lament or satisfaction can provide the will to live and continue the fight. Informant four stated:

*I really just wanted to die, just to be out of pains and misery,*

*(Coded: SOS)*

*Yet I wanted to live because of my three small children.*

*(Coded: future hope)*

*I used to pray, "Please God, help me to see my children through the rough".*

*(Coded: strategy and self-analysis).*

### **6.2.2 Social strategies**

Social strategies involve help provided by other people. The help could take the form of assistance with personal care or a supportive conversation. When body symptoms persisted the women would rely on the support of other people in their social network to help them fulfil the specific task or activity. A spouse, partner, friend, parent or child would provide support. Informant two made the following entry where she initially described the context for a series of painful events affecting her. Her narrative then explains the role of her husband and the connection to the help he provides and the benefits of the help.

*Date of entry: 20.07.96*

*Didn't get to sleep until some time after 5am. It was so hot and sticky. The heat was causing cramp like pain in all my muscles and I had a niggly gnawing pain in all my joints. I was so uncomfortable when I got up this morning I was still full of cramp in muscles and the same gnawing pain in joints also feeling quite stiff. Del washed me down and massaged my legs and arms to try and relieve some of the pain. Been using cold compress on leg and arm and back muscles, it helps for a little while but the cramp is soon back again.*

Strategies therefore can take the form of physical assistance or emotional support. Informant ones diary entry provides an example of support offered by her friend in the midst of illness symptoms:

*Date of entry: 29.01.96*

*The shingles are still with me and lumps and joint pains. Woke up with a splitting headache, itchy flaking scalp hot to the touch, washed hair in cold water. Went out, returned to find note. It was a doctor's appointment at hospital for 12.30pm.*

*Because 12.05pm I made a quick dash to the hospital. Carmen took me. When I arrived I learned that the appointment was for the following Wednesday. Returned home, tired and worn out. Went direct to bed, within minutes I was shivering, and then roasting with fever. At exactly 6.30pm I began feeling a little better.*

Some friends would provide para-medical help such as assistance with bandaging or strapping or massage. Mrs. Robin for example comments on this with a discussion

*Date of entry: 29.08.95*

*Blaine: What did the doctor say about your foot mum?*

*Mum: He told me to continue with the antibiotics for the rest of the week and see what happens. I didn't get home until 12 o'clock this morning. Later on I went to Merle (Nurse- family friend) who strapped up the foot. But I decided to remove the strap, after the doctor didn't mention anything about a strap.*

Others would provide assistance with preparing getting into and out of bed using a wheelchair. Informant three's entry below describes such an issue.

*Date of entry: 21.03.97*

*At present my sister is having to wheel me out of the bedroom into the living room because I cannot walk. My sister and her husband help the same at bedtime because it is impossible for me to walk. I feel frustrated because I can't manage the things I could do this time last year.*

On some occasions there were moments of tension between the informant and their social support. This is exemplified in the data in the relationship between the informant and their spouses.

Strategies therefore involving other people can be implicit or explicit. Implicit support may be assistance to undertake the most demeaning task that requires critical

help with an aspect of the person's dignity needs. Very little cues or commands may be involved as agreements to undertake the specific task may have been established over a long period of time. Another example of implicit social support could include making a snack for a sufferer or helping them to stand up from a chair. Explicit social support is characterised by a firm request for assistance. It could also involve the lupus informant requesting to abruptly end a telephone conversation to a friend who they cannot tolerate any longer due to levels of irritation caused by a poor exchange of words. Informant two makes the following entry in her diary:

*Date of entry: 22.03.97*

*I don't like to be around people who moan and complain a lot, I feel better in a stress free environment,*

*(Code: strategy –mental outlook)*

Therefore what might have started as a positive strategy has resulted in an effort by the lupus sufferer to initiate their “arrested strategy”.

### **6.2.2.1 Health and Social Care Professionals**

For the lupus informants who become ill, health professionals are a central focus around which activities are planned. The phrase: “I am going to see the doctor” is frequently used to denote a specific activity required by the lupus informant to visit a GP or a consultant. This strategy would often be deployed when all other strategies had been exhausted. It was therefore often a “last resort”. There is seldom a consideration given as to whether a GP wanted to see the patient. However, when consideration did arise it would be in the context of the patients being afraid of wasting the doctor's time for fear of being “struck off” the register. The sheer intensity of the need to see the doctor created a climate of expectation from the lupus informant.

Informant four wrote the following: *I complained to my General Practitioner (G.P) about the pains in my ankle and sole of my feet, he told me to get a good pair of shoes.*

Informant one wrote the following:

*Date of entry: 16.10.95*

*Dr. S said that all I was experiencing was a temporary flare. Not even telling me about any examination that I could have. My stomach...nothing. My finger that I can't do nothing with ...nothing. You see how doctors can be conflicting?*

Consultants tend to schedule appointments with the patient. Strategies adopted by informants of this nature tend to be more balanced in terms of expectations. There is determined effort by both the informant and the consultant to learn more about what is the underlying process taking place in the person's life and within their physical body causing them to feel unwell. Sometimes the reaction from the lupus sufferer is not always positive. They did not always agree with the sentiments of both sets of doctors. This often left the lupus informants having limited faith in the ability of the doctors to help relieve their suffering. In some instances there were significant expressions of anger from lupus informants as a result of poor verbal exchanges between themselves and the doctors. There is an underlying expectation from the lupus informants that doctors should be more understanding of their day-to-day struggles with the disease. Despite being the expert in the illness it was the lupus informant that would occasionally have to "correct" the doctor on matters relating to their disease.

### **6.2.2.2 Social Services**

The social services departments were contacted by each informant requesting an assessment by an Occupational Therapist. Under the Housing Act (1996) and the NHS and Community Care Act 1990 (OPSI 2006e) people are entitled to an assessment of their needs for services such as housing adaptations and the provision of equipment such as commodes and grab rails. All of the informants were eligible for an assessment. To arrive at the point in their life when they made contact with social services would have required a process of waiting for and ultimately receiving a diagnosis about their illness. Having a diagnosis for lupus sufferers was a passport to eligibility of services managed by the council. During the course of their narratives they reported on visits by occupational therapists to determine how their home would be adapted to make their life easier. In the case of informant two she was relieved that the stairlift and ground floor shower room conversion would meet her needs. The strategy of relying on a carer to assist either implicitly or explicitly would be reduced

and she became more independent in keeping hygienically clean or accessing her stairway.

Three informants commented on aspects of major adaptations from their local councils. The entries about adaptations are associated with alleviation of symptoms or challenges faced by the illness. Informant two commented on the expectations of having a level access shower facility provided in her home and a threshold between her doorway and the path at the main entrance. This was to be filled with cement so that she could negotiate it more safely:

*Date of entry: 4.11.96*

*Showers been started today. I am looking forward to having one. Step that's been filled in has made a big difference, especially at the moment with my legs pulling badly up the back.*

Informant two also reported on the benefit of having a small step built between her doorway and the path at the main entrance completed. In addition informant two commented on the benefit of having a stairlift. The stairlift allowed her to take control of her life and access another opportunity to manage her illness by utilising the strategy of "lying on the settee". This was an act of desperation because she felt helpless to do anything else. Some strategies therefore are often perceived as a final act of survival. Social services occupational therapy is therefore an opportunity to access other forms of survival through the creation of other strategies.

*Date of entry: 20.11.96*

*Been feeling nasty tempered although I don't know why. It's been a really bad day today. I wouldn't have got down stairs today if I hadn't got the stairlift because of pain and weakness. Been lying on the settee all day. Just couldn't do anything else. [She recorded her body weight as 7st 2lb].*

Informant three commented on the role of therapeutic benefits of having a shower installed. The role of the social services:

*Date of entry: 07.05.97*

*Due to my disease spreading into the central nervous system I can no longer get in and out of the bath, so I am having a shower installed by the O.T. department, social services that have been very helpful to me.*

These items of equipment and adaptations to the home helped to provide more appropriate access into places such as the bathroom and to alleviate some dependency on carers. There is a connection being made by the informant between the scale of the problem (event) affecting her central nervous system and the potential gain from having a shower facility (strategy). Informant three realises that her paralysis is a limitation to her functional independence. The shower room is an opportunity to “fight back”. It can allow her to “keep going” with life in an independent and dignified manner. In order to receive funding from the council, the application process lasted between twelve and twenty four months. Grant funding allowed the council surveyor to commission builders to carry out the work. This waiting period resulted in dependency on carers.

### **6.3 Healthy interludes – welcome non-events?**

There were periods of pain free existence for the lupus informants in this case study. In times like this people with chronic illness (in a healthy phase) draw of low intensity personal strategies and can pursue “normal” aspirations, those occasions were rare. Whenever they did arise those moments were celebrated, often alone, as intimate moments of thoughtful privacy. If those incidents arose first thing in the morning, for example, the informant might mention having had a “good night’s sleep”. They may also comment on “not being too bad”. In moments such as this, the need to adopt a specific personal strategy or social action strategy to combat the symptoms would be marginal.

Acknowledging good days was, therefore, rare but whenever the “good days” did arise it allowed respite from dealing with the battle against “events”. Temporary normality or healthy interludes best describes the situation of respite from the onslaught of events. In the majority of days there is a repeat performance of

events bombarding the body of the informant. The intimate space for celebrating normality is limited.



## **7. Chapter Seven**

### **An analysis of the themes from the lupus informants narratives focusing on the core theme known as “Statements of Suffering”**

#### **7.1 Introduction – statements of suffering**

In the context of this study the theme “statements of suffering” (SOS) arose at periods when strategies seemed to fail to provide a long-term resolution. All lupus informants in the case study were determined not to let their illness or symptoms beat their determination to overwhelm them. Instead they strove to regain a normal pain free existence and hold onto the hope that one day they would no longer be ill. They acknowledged that most of their efforts to take control were countered and met with an “arrested strategy”. When this happened their survival skills ebbed away to a point where they felt that their own life seemed beyond their control. Losing their aspiration for a good quality of life resulted in expressions of feelings of pain, misery and sorrow. Nonetheless, none of the lupus informants were going to yield without a fight. They may not have been born with the illness but their life and identity were transformed by their experiences of torture, inner isolation and personal suffering.

The theme “statements of suffering” was developed by the author. In SOS all the lupus informants reached a point of heightened emotional expression. Just as there could be more than one event as in the situation coded as ‘Overload Principle’ (Event, countered by “Strategy Overload”), so too there could be multiple statements of suffering expressed in a single data extract. SOS’s are characterised by the use of a language expressing misery and sorrow. The points were often not laboured. The reason for this is another indicator of their will to live and survive against all odds and a testimony to their enduring spirit of hope and courage in the face of adversity.

These informants did not want to be the “other person” whose identity was bathed in a cloak of physical blemishes that they had become. They had become this spoiled identity with limited or no control over their life. They very seldom returned to their previously fit and healthy self. Informant one for example talked of having the body of a 90 year old, although she was 52. The following data extract captures this:

*Date of entry: 23.06.95*

*Laying on my side and back is very problematic. This is what I know which happens to the 90 years old plus person. Abdomen gripes; gripe as if as if something itchy is crawling inside, the left side has a continuous growing occasionally a couple of quick needle like jabs. I have no appetite or taste for any food at all I only force myself for the medication purpose. (Code: statement of suffering)*

There is anger expressed in the narratives about how they are expected to live with the chronic illness. The following data extract from informant two reveals this:

*Date of entry 19.06.96*

*Feel very nasty and agitated with myself because I cannot settle pain anywhere. (Code: enduring suffering/effects on self)*

The uncontrollable and unpredictable nature of the causes of the events led to informants revealing a potential to adapt using another strategy sub theme entitled “self analysis”. Self-analysis was often characterised by a personal reflection of their life or an instant in their life, which reaffirmed a strategy of coping. Informant three for example, was able to determine how ill she would be depending on the conditions of the weather.

When events did take the informants by surprise, it was an emergency situation. It could be the result of acute pain and distress, warranting immediate support and attention from a friend, relative or health professional. If this particular strategy were a success the particular intervention would result in temporary respite to the issues. On other occasions when the sheer multitude of events outnumbered the strategies that were available to the informant the result would be an inner cry for help in the form of a statement of suffering.

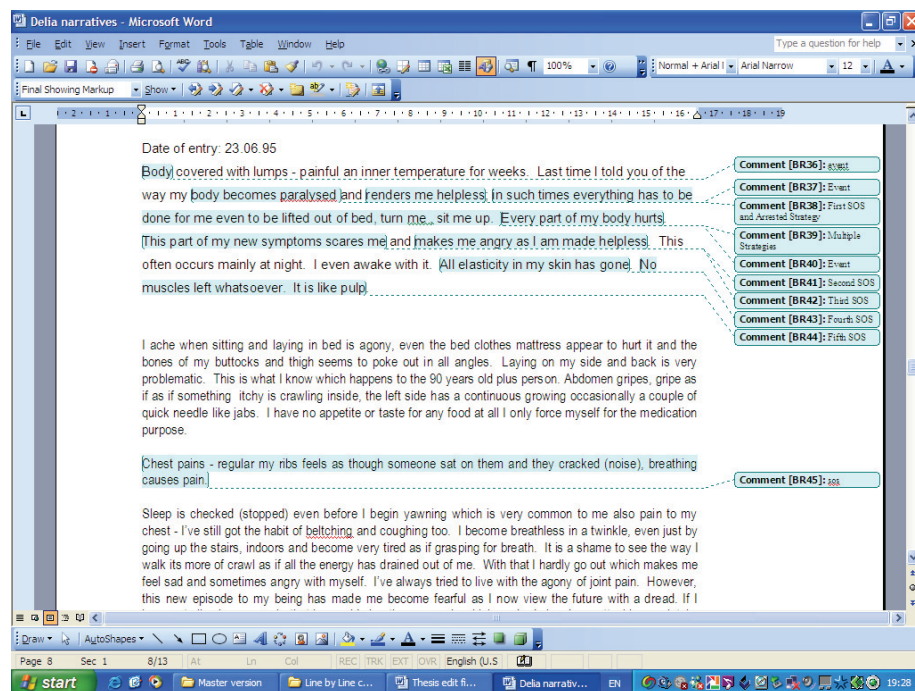
Statements of suffering take on an added meaning when they are expressed in a certain way. The author has conceptualised these as religious lament; street and popular lament. Religious lament occurs when the individual makes expressions of exclamation with reference to a higher being (e.g. *Oh God!* or *Oh God help me!*). Street lament refers to a behaviour, which can be expressed loudly in the street

included use of abusive language, such as swear words. Popular lamentation refers to the individual using expressions common with cultural verbal expressions pertinent to what is commonly expressed in popular culture through music, art and or entertainment (e.g. this is absolutely *minging man!*). Within popular lament there is can also be poetic lament which uses words to create a visual process of suffering at a particular moment in time.

The analysis of the theme “statements of suffering” has arisen out of close inspection of the narratives of all four lupus informants. In the following section data extracts have been compared for similarities and difference as ways of assessing how far genuine maturity of the concept has been achieved.

Informant one’s data extract reveals SOS (see figure 11) and arrested strategy can be the same expression. Informant one describes herself as reaching a state of being helpless. For informant one there is no indication that there is positive hope about recovery although the expression “in such times” denotes some lingering hope that the worst pain may not last forever:

Figure 11: Screenshot of statement of suffering



Informant three uses similar language to informant one in order to express lamentation but her approach has a more optimistic strategy. Informant two’s data

extract reveals SOS as generalised expressions of multiple events all condensed into a form of personal harm. This is followed up by an expressed strategy that informant two believes will relieve the problems.

Informant one reluctantly lost her desire and hope for lasting relief or a cure. At the time of completing the diary she was 16 years older than informant two and had lived longer with the disease than informant two. There are times however when informant two expressed SOS in a similar way to informant one.

The strategies of receiving help from others are relief and respite from falling into a permanent state of “doing nothing” or “giving up”. There is a trade off between feeling alone and a permanent state of sorrow or receiving help. Events can punctuate the process of recovery as reflected in the example: *‘this part of my new symptoms scares me’*, followed by another SOS: *‘makes me angry as I am made helpless’*. These statements reveal an expression of lament falling short of asking or even praying for help. Especially if we understand that moment of lament often comes with a request to a God like presence. Informant one was a devout Christian who worshipped and prayed regularly. It would not be uncommon therefore to expect patterns of narrative expression to take the form of prayer like narratives. In the following data extract she described what must seem to be a permanent state of identity change to body image.

*Date of entry: 24.06.95*

*All elasticity in my skin has gone. No muscles left whatsoever. It is like pulp.*

In the following data extract informant one reveals more about her personality and admits trying to live with the pain. This very aspect of accommodation or yielding is a strategy consistent with her Christian principles and has helped her to accept some degree of suffering.

Informant two seldom uses SOS as religious-style lament but more what the author defines as ‘popular’ or ‘street’ lament. Informant two frequently utilises strategies to counter her ailments. This reveals a characteristic of unyielding, “gritted” teeth, perseverance used between contrasting terms.

*Date of entry: 16.11.96*

*Body all over hurts like hell from head to toe.*

*Or*

*Date of entry: 08.08.96*

*Whole of body is aching like mad with a very heavy feeling as well.*

*(Code: SOS)*

The following data extract taken on the same day reveals how Informant one's skills such as walking have been affected by a new episode of lupus. This leads to another core theme that will be discussed later known as "limitations to function". The second limitation to function expressed is Informant one building up to the emotion of losing her independence revealed in a coded SOS which is not lamentation however, it is a revelation of "fear" and future prospect where there is no hope.

Outside of the diary perhaps Informant one knew that help from others including health professionals was a sop. The following data extract is an SOS reflecting on her plight with the health services:

*Date of entry: 19.08.95*

*Yes some people get proper examinations when there are problems. As far as they are concerned I must be a long gone sufferer and nothing can be done.*

*(Code: Ignorance from health providers)*

Informant one's negative emotions are expressed as anger toward herself as if losing the battle to present counter strategies for dealing with challenging events brought on by the illness. The prospect of receiving help from others is not regarded as a positive strategy but a form of burden or loss of personhood.

*Date of entry: 22nd June 1995*

*It is a shame to see the way I walk, it's more of a crawl as if all the energy has drained out of me. (Code: limitations to function)*

*With that I hardly go out (Code: limitations to function)*

*which makes me feel sad and sometimes angry with myself. (Code: statement of suffering)*

*I've always tried to live with the agony of joint pain.*

*(Code: strategy –yielding)*

*However, this new episode to my being has made me become fearful as I now view the future with a dread, (Code: statement of suffering)*

SOSs occurs as a result of the body being bombarded with illness symptoms and failing attempts by the person to manage them. Words in the narratives can be contextualised and represent a range of competing codes, themes and concepts as well as predictors of damage or pathology. Informant one describing experiencing in her stomach “two needle like jabs” has been coded as a query for kidney dysfunction. These are also representative of events analysed in previous sections.

*Date of entry: 26.06.95*

*Belly griped and gnawing feeling on the left side gave out two needle-like jabs. (Code: query kidneys affected?)*

In addition an SOS can express disruptions to personal dignity or biography. Informant one has provided an example in the data extract above with the expression of “Shame” in her loss of abilities. The following data extracts provides further examples of loss of dignity and make it possible to explain why informant one had a fear of dependence of others:

*Date of entry: 26.06.95*

*Just tiredness with a session of sneezing, which caused me to wet myself uncontrollably.*

*Date of entry: 29.08.95*

*Pain and mental concerns... I don't know how things will be for me in my later years... (Mum walks out of room).*

All the lupus informants were able to use language sometimes in a literary form, to make lamentation into a kind of poetry to depict their circumstances. Informant three however regularly provided a vivid description of the breakdown of her body using words in a literary style. This added vividness to the insight into the enduring hardship of living with lupus. These expressions were consistently applied by the informants as if to find new ways of letting others know about this aspect of their lives through reading their narratives. The narratives therefore provided a vehicle for communicating their message in ways not available in their consultations with their

health professionals or with the social space of friends and family for fear of embarrassment. In the following extract informant three presents a statement of suffering with a build up of “events”. The statement is small but immensely revealing about the trauma of body part disintegrating.

20.03.97

*My toenails are breaking away, like when I cut them they go into a powder form and start splintering. (Code: statement of suffering)*

She continues to use vivid description, including metaphor, in the process of expression later in the same extract:

*Still feel that horrible fatigue, I drop to sleep so easily it's like being drugged with drugs, I feel as though someone else is in control of my own body, i.e. a bit like a puppet on a string. (Code: statement of suffering and self-analysis)*

This revelation clearly depicts the extent to which informant three believes her identity is being transformed when she refers to herself as ‘*like a puppet on string*’. Her retort to this challenge is however, optimistic. Her optimism is a consistent strategy throughout her narrative. Compared with the other informants her optimistic spirit is her main strategy as represented in her statement: *My physical side today is ugh!. But my sense of humour is just great.*

Informant three repeats her lament again with photographic vividness and the spirit of humour, as strategy, in the silences that exist between the words. Informant two therefore seems to present a paradox that statements of suffering do not always have to depict sorrow.

*Date of entry: 22.03.97*

*I feel like a rusty old machine that's in need of a bit of oil.*

Instead, like an artist, informant two is deliberately allowing the reader to come into her life with the words. She is challenging the reader to almost ask the impossible from his/her analytical standpoint: Can suffering be consuming to the point where it erodes one’s spirit until the person feels like nothing? Informant three is not suffering any less than other informants simply because she is playing with the words of her expression. What she is doing is using every tool at her disposal including the pen,

the diary and her mind to weave her words into a network of support for herself and any other who might be willing to read her narrative.



## 8. Chapter Eight: Death and dying

### 8.1 Introduction

In chapter one the works of Lawton (2000), Clark and Seymour (1999) and Marris (1986) were discussed to introduce issues related to death and dying. The aim of this chapter is a substantive discussion of death and dying and a fuller context about the process of dying as related to lupus sufferers and others with chronic illnesses, and their carers.

*‘If there is a single dimension of illness that can teach us something valuable for our own life, then it must be how to confront and respond to the fact that we will all die, each of us...’* (Kleinman 1988 p157).

Whenever profound statements are mentioned the mythical and philosophical connotations about why we are born, live and die emerge. In this era many people tip toe their way around the topic of death. We only deal with it fully as a topic when someone close to us passes away.

*‘In the modern Western world many of us, at least until we undergo our own demise, will only ever have limited experience of death’* (Clark and Seymour 1999 p8).

For the author being in a position to consciously think less about his mother and rather what he witnessed in terms of her suffering has been difficult. Relatives will find it difficult to accept that their relative is dying. The thought of never seeing that person again is another emotional challenge. A whole range of psychological processes and issues have to be dealt with as part of the grieving process.

*‘Be careful, then, and be gentle about death.  
For it is hard to die, it is difficult to go through  
The door, even when it opens’.*  
- D.H. Lawrence, ‘All Souls’ Day’  
(Cited in Enright 1983 p 49)

For the author D.H Lawrence’s poem All Souls’ Day is as much about the grieving process for those left behind as well as for those who have face near death

experiences. It reflects the fear and struggles that relatives hold within themselves regarding imminent loss of a loved one.

Many people weigh up the conflict of wanting their relative to live on at all costs versus the taboo like acceptance that death of a loved one is the best option for the dying person. Sometimes these feelings correspond to either the selfishness of wanting a relative not to die or selflessness, and notions that the relative is better off dead than alive enduring suffering.

The author will present arguments throughout the case study emphasising how much is required from institutions of health and social care to help families deal with death and dying either within institutions such as a hospital or within their own home. One hospital that has gained a reputation for treating lupus sufferers and helping their families to cope is St. Thomas's Hospital in London. More efforts could be made by central government to continue to evaluate what makes this service successful and replicate its service design in many more regions in the UK. The leading specialist in the treatment and care of lupus is Dr. Graham Hughes. The service he has helped to develop not only treats people living in the local catchment area but treats people that are referred there by other specialists from different parts of the country should they choose to do so. Dr. Hughes has published several books on the disease and travelled to various countries giving lectures and assistance in overseas clinics.

The St. Thomas Hospital serves a locality with a high proportion of residents in South West London who originated from the Caribbean and this is one possible factor that has contributed to services being responsive to the needs of the local community over time. The philosophy of engagement of that service to members of the local community is warm and inviting. Many lupus sufferers who perhaps live a long way from the facility or who may be physically limited to travel in the event of crisis at home can speak to someone directly connected to the service in order to obtain help. This approach enables sufferers and their carers to believe that they can have a personal and responsive dialogue with the service across a range of perceived needs. The following quotation from Dr. Hughes and a colleague expresses the practical support available:

*'Although the system is geared towards patients, as a family member of a person who has lupus you shouldn't be afraid to ask for help. At St. Thomas' lupus clinic, for instance, there is a special phone line for patients and their families to call for advice'* (Holden and Hughes 2004 p 160).

In the event of death and dying for lupus sufferers associated with such a support as St. Thomas's hospital there is a sense that preparation can be better placed to facilitate high standards of care in end of life. The main reason is that coming to terms with the issue is a difficult process for the majority of people who expect health and social care professionals to help carers and the dying deal with these matters. Often the grieving process creates a series of conflicting feeling for families about whether it is satisfactory to either give up on their loved ones or let go of the belief that they should be kept alive at all costs by health and social care professionals.

The attitude of people in the UK society can be better understood when one looks at the social and economic conditions of society today. There is greater life expectancy and mortality is increasing. Most people expect to live into their 70s and 80s. This coupled with the relative security and availability of public services combine to produce what Elias (1985) termed the *postponement of death*.

*'More people now die as a result of chronic illnesses such as heart disease, cerebrovascular disease (including stroke), respiratory disease and cancer. Older people may suffer from several conditions at the same time which may make it difficult to determine the main cause of death'* (Age Concern 2005).

The next section will open up a number of themes that will contribute to aspects of suffering which lupus sufferers and their families and carers have to confront or deal with. The extent to which existing support structures run effectively will also be discussed. *'One of the best ways of dealing with all the family issues that lupus raises is to open lines of communication –to bring the strong emotions out of the shadows and learn to express them'* (Holden and Hughes 2004 p 166).

## 8.2 Social impact of death on families

In the course of receiving treatment or receiving health and social care the choice of where to die is increasingly becoming more of a public necessity (HSC 2004, DH 2006a, and DH 2006b). In the author's ethnographic accounts he cites his own personal degree of unhappiness as a son in relation to the way in which health and social services did not prepare his family to have positive and worthwhile end of life services for his mother: '*...[c]ontact with the people to whom he or she is attached, and whose presence can be of utmost comfort to a person taking leave of life, are frequently thought to inconvenience the rational treatment of the patient and the routine of the personnel. Accordingly, these contacts are reduced or prevented wherever, possible*' (Elias 1985 p 86).

This rationalising model is pervasive in the service-planning environment of most central government planned services. In discussing how end of life care should be planned for those coming to the end of their life whilst in the care of the NHS the government have however explained that it is not possible to provide a universal standard for all its citizens. The following quotation captures this: '*The option to die at home will only be realisable if there is a guarantee of 24- hour care and support, with back-up from appropriate specialists. In the absence of such backup, relatives and other carers will, understandably, be reluctant to take care of a patient at home*' (HSC 2004 p4).

This reactive approach contrasts strongly with the proactive approach of the hospice movement, which advocates that: '*[E]nd of life care requires an active compassionate approach that treats, comforts and supports older individuals who are living with, or dying from, progressive or chronic life threatening conditions. Such care is sensitive to personal, cultural and spiritual values, beliefs and practices, and encompasses support for families and friends up to and including the period of bereavement*' (Clarke et al 2006 p15).

## 8.3 Health Economics and Inequalities in End of Life Services

The Audit Commission (1999) estimated that the UK's annual expenditure for intensive care is £675 - £725 million, and is increasing at 5 per cent per year. Bion

and Strunin (1996) argue that costs of this nature arise when people experience multiple organ failure. This coupled with the availability of new technologies make options available for enhanced survival rates which may be ethically confusing that would have otherwise not been available;

*'...[i]t costs twice as much to die in an intensive care unit as it does to survive... (and) resources to generate a survivor are considerable. For those patients destined to die, prognostic uncertainty encourages protracted organ system support, with the result that death is merely deferred at greater expense'* (Bion and Strunin 1996 p1).

However, the inescapable corollary is that many people are unhappy with the way in which their relatives are being treated within the NHS during dying and eventual death (O'Gorman 1998, Elias 1985). Help the Aged (2007) comment; *'[O]lder people who die in hospital can endure dirty and noisy wards, where busy medical and nursing staff may not be able to devote the necessary time and attention to them. Older people who are dying have fewer support networks, and more financial hardships compared to younger people. Taboos surrounding death and dying can lead to older people feeling unable to say how or where they would like to die. It is a perverse system that allows the people who have been paying for the NHS for the longest to receive the poorest quality care as they are dying'*.

The prevalence of the various forms of people diagnosed with the “killer disease” cancer in our society is far higher than lupus (DH 2004b). It is therefore no surprise that investment into those services should be greater than that which is currently invested into lupus. The government and the NHS have made commitments to tackle the causes of the disease through research and investment into preventative measures and treatment of the disease. The following quotation from the NHS cancer plan poignantly reports on the trends of the disease:

*'More than one in three people will be diagnosed with a cancer in their lifetime and one in four will die from cancer. In 2001 around 225,000 new cases of Cancer was diagnosed of whom 141,000 were aged less than 75 years. The total number of new cases is increasing by 1.4% per annum. This is mainly due to the ageing population, screening and better diagnosis. Around 130,000 people die from cancer each year of whom 65,000 are aged less than 75 years'* (DH 2004b p9).

Due to the high incidence of cancer compared to other forms of chronic illness such as lupus the author asserts that people with cancer receive far more specific attention, such as end of life specialist care, than those who are diagnosed with lupus. This level of inequity can push many relatives to challenge service providers to make the system of end of life services fairer across the board for people who have a chronic illness other than terminal cancer.

Le Fanu (1999) expressed the view that medical intervention for those requiring intensive care was part of the transforming power of the technological innovation of artificial ventilation and oxygenation that heralded the development of intensive care. *'Over 50 years later those systems of care and intervention have become a means of prolonging the 'pain and misery of terminal illness for many'* (Le Fanu 1999 p259).

In these instances doctors may feel inclined to exercise their judgment to withdraw services, as long ago as 1965 Glaser and Strauss (1965 p 201) suggested *'[a]lthough the medical ideal of prolonging life at all costs and with all possible facilities conflict with the awareness that prolonging life is useless and unduly painful, the ideal often wins out. As one doctor said, "There are too many instances, in my opinion, in which patients in such a situation are kept alive indefinitely by means of tubes inserted into their stomachs, or into their veins, or into their bladders, or into their rectums –and the whole sad scene thus created is encompassed within a cocoon of oxygen which is the next thing to a shroud"'* .

According to Clark and Seymour (1999) hospice and palliative care has gathered a reputation of avoiding overly interventionist treatments and of offering a range of 'low tech' options to people dying with advanced disease which enable relatives and carers to be part of the last moments of dying (cf. Hasman et al 2006).

Mulkay (1993), Lawton (2000) and O' Gorman (1998) all describe the progressive exclusion of relatives and friends from the bedchamber of the terminally sick as a process of social death; *'[P]rofessionalization of the rituals of death and dying an individual can be socially dead before being biologically dead'* (O'Gorman 1998 p1130). This exclusion fails to accommodate the grieving process and its associated rituals tend no longer to be observed.

Timmermans (1998) suggests the tendency to privatise death and dying in the Western world began in the nineteenth century. The *privatisation of death* is closely linked to the rise of medicine as science and as a profession. In the Middle Ages, dying involved the entire community. When death was imminent, friends and neighbours gathered at the deathbed and engaged in rituals to prepare for the transition between life and death.

These events changed because doctors complained about the presence of neighbours and friends, which was unmanageable. Consequently, the last moments of dying became reserved for close friends and relatives: *'[A]s technology advanced last-resort medical procedures required the dying body to be transferred to hospital, this was the start of the gradual mediatisation, commercialisation, and technologisation of dying. The final result is a lonely, isolated, private, anonymous dying in a hospital room'* (Timmermans 1998 p147).

#### **8.4 The role of health and social care professionals**

Many families are not aware that their relative is dying. There is an expectation that the experts have a responsibility to inform the family as to whether or not their relative will die. Social workers receive training for offering counselling and breaking news to families about end of life scenarios (McIlpatrick 1997).

Nonetheless this case study will argue that a lack of clarity pervades practice in hospital ward settings. This creates a shroud of secrecy and confusion for families trying to understand the various roles of professionals on the ward. As the Commission for Healthcare Audit and Inspection (2006 p 10) remarks *"... [t]he provision of services for people at the end of their life was inconsistent, with integrated systems that were developed well in some areas but with room for improvement in others. The provision of out-of-hours support was patchy and a lack of practical support may mean some people have to be admitted to a hospital or a hospice at the end of their life when they may have preferred to die at home'*.

Kubler-Ross (1977) reminds us that doctors are the main people responsible for breaking news about death to patients and their families. If the doctor feels it appropriate they can delegate the task to a priest, nurse or social worker. She asserts that the relative's next of kin may only rarely be the one to break the news to the dying relative. The experience reported in this case study emphasises the importance of the role of professionals when relatives do not know that their relative is going to die. Kubler-Ross's (1977) recommendations on the division of labour and best practice are still not commonly implemented over thirty years later in the UK.

*'[A] patient has the right to be told how seriously ill he is and I believe that the family also has to be notified of the seriousness of the illness. It is the physician who has to relay this news to them. If the physician is unable to do so, the patient or the family should then approach other members of the helping profession and ask them. This is usually the chaplain, the priest, the rabbi, or the nurse. If another member of the helping profession is asked directly by the family or the patient, it is his duty to inform the physician of these needs, and if necessary, ask that the job be delegated'* (Kubler Ross 1977 p 4).

O' Gorman's (1998) typology argues for a holistic development and set of practices to be part of the end of life treatment of the chronically ill. The author will also argue that the holistic turn needs to take into full account the cultural background that people belong to, as there are often significant expectations from people in those communities that pertain to end of life. These expectations are often part of the ritual of signifying belief systems (e.g. religious practices).

For example in most non-western societies death is seen as a valuable cultural process in which religion plays an equal part with medicine (Kleinman 1988). It is characterised in terms of the deceased slowly being transferred from the land of the living to that of the dead (Helman 1987).

*'[M]any contemporary authors agree that western affluent societies are unable to look upon death and its rituals as a rite of passage to be compared with birth, coming of age, marriage, and retirement'*(O' Gorman 1998 p1132).



Like Timmermans (1998), O’Gorman (1998) also states that relatives often feel unwelcome by health professionals and uncomfortable especially when visiting relatives in intensive care units. The situation is potentially more strained when the sufferer and their family are from the black and minority ethnic communities. Field et al (1997 p 16) suggests; *‘[L]anguage difficulties, religious differences and family customs may generate or exacerbate misunderstandings between minority group members and health workers. Ethnocentrism and insensitivity to cultural difference may mean that service delivery and provision may unthinkingly take the white middle class pattern as normal. For example, taking the isolated nuclear family as the norm may lead to ignoring and excluding extended kin from participation in birth, death and chronic illness especially in hospital’.*

Despite a high degree of criticism of medical involvement in managing the dignity, death and dying of the chronically ill, however, health professionals maintain the authority to negotiate culturally appropriate deaths. The author will examine how they do this, and suggest that there are culturally specific answers contemporary medical experts can offer to the ambiguity of finite living.

The author will argue that in clinical settings such as hospital wards, health and social care professionals contribute to a variety of cultural scripts of how we should make sense of apparently senseless deaths. Rather than questioning the authority of medical professionals to manage and explain suspicious death, deaths that fail to follow cultural scripts underscore the need for full communication between health and social care professionals, family members and the individual that is dying. Timmermans (2005) refers to this type of negotiation as death brokering; *‘[D]eath brokering refers to the activities of medical authorities to render individual deaths culturally meaningful’* (Timmermans 2005 p993).

Kleinman calls for health and social care professionals, the institutes that they work for and families to work together to meet general social expectation to help the dying to be part of a “good death” scenario; *‘[T]he doctor’s work is to assist his patient to die a good death. This is a traditional task of medicine in the West, although it has been usurped by medical technology’s mandate to keep the patient alive at any cost.*

*Under a “good death” the care of the dying makes the personality of the practitioner and the quality of the patient to doctor relationship the major mode of therapy’* (Kleinman 1988 p153).

When death occurs, medical experts help negotiate a culturally acceptable form of passing, and after death they rationalise the inevitability of its occurrence with a classification of its causes and document this including medical records and the patient’s death certificate.

In the UK, 71 per cent of people die in hospitals, hospices or nursing homes (Field and James 1993). Over 75 per cent of adults are hospitalised at some point during the year before they die, and almost 60 per cent visit a general practitioner at least five times during the last year of their life (Seeman 1992).

*‘[T]he care providers by default broker an ideal death; in this case a death without dying. The disadvantages of hospice care include the impossibility for relatives to prepare for impending death’* (Timmermans 2005 p996).

Anspach (1993) believes that a consensus among healthcare providers is only necessary to withdraw or withhold care in the test of best interest; as long as at least one key member of the medical team wants to continue with therapy, the treatment paradigm will prevail. Timmermans (2005) argues that medical teams believe that giving a bad prognosis might make the patient and care-givers lose all hope and withdraw from treatment, and that their words might make things happen *‘[t]o predict death is almost the same as to withdraw life support’* (Christakis 1999 p144).

It is no surprise that families and carers feel confused and often overwhelmed as these ritual dramas are played out in reality especially when; *‘[t]hose who enter hospital at a moment of acute illness risk receiving protracted multiple organ support in the hours and days immediately before death’* (Seymour 2001 p1).

Kubler-Ross (1990) indicated that, she herself, as a doctor never volunteered information to a patient that they were going to die. Her belief was that the family

and the dying patient needed as much hope as possible that they were going to fight the situation of dying as best as possible. Whilst this is commendable it still presents for the family the vivid reality that information is often concealed by health and social care professionals around death and dying. *'[I] think I have never told a patient that he is dying. The people who have done the poorest are the ones to whom information is given in a kind of black and white fashion without any hope. It is very important that we allow for hope'* (Kubler-Ross 1990 p167).

The medical team aims to broker one of the three most common ideals of death depending on where the patient dies, perceived patient characteristics, interactions with relatives and the disease trajectory; *[t]he natural death, the good death and the dignified death*. These three typologies of deaths react against the default death to be avoided, technocratic dying or a lonely death in hospitals among strangers surrounded by advanced technologies that stretch the dying process without offering information to the patient or their carers that end-of-life is pending (Moller 2000).

During the natural death staff invite relatives to be present at the moment of active dying, quietly say their goodbyes, and keep physical contact (Harvey 1997). In addition, the health and social care professions decisions to withdraw care are measured in such a way that they reduce the perception that the staff 'killed' the patient but that the death was preordained by the terminal disease, reducing the possibility of litigation (Zussman 1992). *'[W]hile hospice care was originally developed as an autonomy-centred alternative to hospital dying, it is now institutionalised around the highly specific 'ideology of a good death''* (Timmermans 2005 p 998). The good death involves aggressive symptom management, and attention to the religious, social and psychological needs of the dying and their loved ones to achieve the normative goal of accepting impending death.

Legal physician-assisted suicide is likely to be the most orchestrated and scripted death involving doctors and patients. Here, death is viewed as a relief from suffering and maintaining personal autonomy in end-of-life decision making. In Oregon in the USA, physician-assisted suicide is permitted but closely regulated; an adult Oregonian diagnosed with a terminal condition can voluntarily make a written request

in the presence of two witnesses for medication to end their life. *'[N]o studies have evaluated the actual process of managing assisted deaths. The anonymous accounts of active euthanasia show physicians and nurses acting from a motive to reduce suffering'* (Timmermans 2005 p999).

In UK hospices sudden death generates feelings of unfinished work (Field and James 1993) and in intensive care these deaths harbour suspicions that something important was missed (Seymour 2001) and might thus prevent the aim of a natural or a good death.

Contemporary institutional death brokering involves an active management of the dying body, social and psychological aspects of dying with medical technologies in order to preserve life, to allow dying to occur uninterruptedly, or to hasten death but without being held accountable for the actual death. Most studies have reiterated that medical personnel do not simply take their clues from relatives but manage the expectations of relatives and patients in an attempt to align them with a medically acceptable notion of dying, even if this involves not informing relatives to avoid giving up 'hope' (Timmermans 2005).

There are studies that show the staff often fail to obtain an ideal death. Barriers include opposing opinions among clinicians (Anspach 1993), diagnostic and prognostic uncertainty and ambivalence (Christakis 1999), patients refusing to die, wanting to die, or dying too quickly, relatives abandoning the dying or refusing to let go, divided families or relatives intending to speed up dying (Seymour 2001), staff shortages, staff apathy, diverse staff cultures (Zussman 1992) budget cuts, failing technologies (Timmermans 1999), medical errors (Bosk 1979), apparent divine interventions (Christakis 1999), lack of resources (Field and James 1993), and other unforeseen situations. The deaths that clearly deviate from the ideals might provoke anger, embarrassment, expense, suspicions of medical error, and the possibility of litigation if the relatives feel wronged. If relatives disengage, the staff might get away with an approximation of acceptable death (Lawton 2000).

Sudden deaths whilst under the management of health and social care professionals are sometimes suspicious, not witnessed, unexpected (making resuscitative efforts

moot) or even violent. About 20 per cent of people die in ‘suspicious’ circumstances, meaning out of place and time (Bonnie 2003). Post mortems consists of classifying deaths into morally wrought manner of death categories including suicide, homicide, accident and natural death, although this is not a universal requirement (Timmermans 2005).

Health professionals offer collective trust and stability by rendering the end-of-life *socially* meaningful while inevitably accentuating the existential ambiguity that death invokes. Healthcare workers should provide relatives with a cultural script of how to behave and what to expect in the dying process. They socialise with patients and relatives to enable patients to die well: with dignity, naturally, quickly without realisation or slowly with time to say good-byes, or while everything medically has been done to keep patients viable but not so much that suffering takes place.

The conditions that determine a person’s end of life differ significantly from one person to another and also in respect of medico legal and ethical perspectives. An adult may well be able to express their wishes regarding end of life. However, those who are not in a position to do so divest that responsibility to relatives and health and social care professionals. In the majority of cases the medical team will have background on the patient’s previous abilities and aspirations from which to reach a conclusion.

The prohibition on taking human life in our society is based on fundamental and deeply held values. These values underlie our reactions both when we are contemplating the uncomfortable conflict in Shakespeare’s tragic hero Hamlet as he contemplated taking the life of his uncle to avenge the death of his father and when we are shocked by the death of the many drug addicts in Singer’s (2006) research into social suffering caused by illicit drug taking. In his research Singer laments his frustration that large multinational corporations continuously manufacture many such abused drugs legally. Whatever the origins of these different influences, the most abiding premise of civility is about the sanctity of life, which forms a major part of our moral lives. Respect for life is embedded in religious texts such as the Bible. The right to life in contemporary society is still accorded serious weight and consideration

in the European Convention on Human Rights. Under the charter in article two for example “everyone’s right to life shall be protected by law” (Herring 2006).

The convention however does recognise that there are some exceptions to this including the principle of self-defence or in the cause of a just war. In medicine also many who accept abortion of a foetus as legitimate may be staunch opponents of euthanasia.

Amongst health and social care professionals information management about death and dying is shaped by norms created within the professional, cultural environment that they are part of. The right to life is contextualised within a social framework about the right to information about death and dying. “Closed awareness” for example is characterised by the dying person not having any awareness that death is imminent. Health professionals may have some idea but do not tell the patient that death is probably inevitable.

*‘ [T]he physician states from “clinical experience” that when we announce terminality to a patient, he is likely “to go to pieces”, one must clearly judge whether or not to tell after sizing up the individual patient’* (Glaser and Strauss 1965 p 29).

“Suspicion awareness” is characterised by the patient suspecting that the doctors and nurses know that he is going to die. “Mutual pretence” awareness is characterised when both health professionals and the patients know that the patient is going to die but both agree to act as though he were going to live.

The final context is “open awareness”: *‘ [W]henver both staff and patient know that he is dying and acknowledge it in their actions, the context is one of open awareness’* (Glaser and Strauss 1965 p79).

Glaser and Strauss’s (1965) grounded theory study on death and dying presented valuable insight into the nuances that exist within hospital settings between doctors, nurses, those suffering and their relatives, which are relevant as much today as they were over 40 years ago.

## 8.5 Reflective Heroism of loved ones

In the past 10 years the government through the Department of Health has recognised that the safety of patients should be an important part of service planning and delivery. Many fatal incidents involving a range of service led errors have been recorded for such incidents as inappropriate prescriptions of medication or inappropriate use of medical devices by patients whilst in the care of hospital staff. Adverse health and social care events cannot be eliminated from complex health care but the aspiration of central government has been to ensure that services are designed to learn that lessons from the past are used to reduce the risk to patients in the future. The cost of adverse events is increasing. Clinical governance and increased professional and service regulation has been an attempt to commit to delivery high quality services to members of the public in need of care or treatment. There is a need for more research on reporting and information systems to capture the patient's perspective about service failings in the UK (DH 2000). In 2001 the Department of Health in the report entitled *Building a Safer NHS for Patients: Implementing an organisation with a memory* stated that:

*'[T]here has been no systematic focus on patient safety in the NHS so far. In this country we are uniquely placed to build this important strand into a programme of quality assurance and quality improvement which has come into being over the last three years'* (DH 2001 p7).

Seale and Cartwright (1994) describe a process of *reflective heroism* to describe the role of relatives who hold their relative, who are dying, in high esteem to the point where they may be closed to the idea of death being imminent. *'[I]n my experience, fear of dying...is common among the chronically ill and their families'* (Kleinman 1988 p 156).

Reflective heroism is characterised by an intricate process of carers and the dying struggling to reconcile remnants of social roles and status in the face of courage. *'[T]he problem, however, is not simply technical since there is an essential difference between medical death and social death. Dying is a social process, involving changes in behaviour and a process of assessment, which do not necessarily correspond to the*

*physical process of bodily death. Death, like birth, has to be socially organised and, in the modern hospital, is an outcome of team activities*' (Turner 1996 p 198).

According to Elias people in society have limited experience of death and dying. As a result of greater affluence and life expectancy people expect to live longer. They are not prepared for death nor do they have much experience about relating or identifying signs of death and dying. Elias's argument then is that the knowledge of death is more of a problem for human beings. '*[T]he sight of dying and dead people is no longer common place. It is easier in the normal course of life to forget death. Death is sometimes said to be repressed*' (Elias 1985 p 8).

## **8.6 Medical Ethics and Managing the end of Life**

Recognition of the issues facing doctors, families, their carers and the dying has focused the debate about medical ethics in relation to intensive care (Bion and Strunin 1996; Mason and Laurie 2006). This provides a framework for discourse around the situation of managing the care of those dying with chronic illnesses such as lupus.

The logical starting point of the debate is the presumption, grounded in the Hippocratic Oath that health care professionals will seek to prolong life so long as it is possible to do so (Sokol 2008). There should however be more communication between health professionals and relatives especially when their patient is unable to speak for themselves. Doctors take too much of the responsibility for deciding whether or not to stop providing treatment when they conclude that their patient is dying. Technological advances of the last half-century have increased our capabilities to sustain survival, but at the same time have sharpened the dilemma of choice between merely prolonging life and sustaining its quality. Slater (1973 p 285) summarised the challenge to previous policy thus: '*[T]he whole resources of an advanced medical service are currently deployed in the pursuit of the preservation of life. It is becoming obvious that costs of this policy are becoming insupportable...we must face an inescapable duty to let some patients die*'.

Sometimes the sufferer themselves may be unable to endure medical regimes designed to keep them alive. At other times the health and social care professional is the one who worries as to whether or not sustaining life and enduring suffering is a



worthy cause, and whether they are just '*[k]eeping people alive who are functioning purely as organ systems due to some equipment that is hooked up to them*' (Kubler-Ross 1977 p76).

In the UK health care it is now recognised that *where death is inevitable*, life prolonging interventions such as resuscitation, artificial ventilation, dialysis or artificial feeding may be withdrawn or withheld. In such cases the goal of medicine becomes the relief of symptoms (Clarke et al 2006).

Perhaps it is because of this that society has become more and more aware of the role that health and social care professionals play in managing chronic illness when "end of life" emerges. The dilemmas that they face are ably expressed by Kubler -Ross (1977 p78); '*I ] think any patient who has a chance of getting better should get all the technical assistance that we have available. Patients who are beyond medical help and whose organs are kept functioning only with machines are not benefiting from this kind of management, and we should have the courage to learn when to call it quits*'.

The problem is that calling it quits is very similar to a decision to allow euthanasia. We can counter this superficially and simply, like the Select Committee of the House of Lords chaired by Lord Walton, by adopting a restrictive definition, limiting use of the term euthanasia to; '*[a] deliberate intervention undertaken with the express intention of ending a life to relieve intractable suffering*' (Walton 1994). The medical ethics debate prefers to consider rather just the strength of the intervention to preserve life, taking into account the age and quality of life of the person when determining whether levels of intervention, and the decision on whether to withdraw futile treatment, constitutes a category of passive euthanasia as well as that of active, or deliberate euthanasia (Seymour 2001).

Mason and Laurie (2006 p.599) suggest that everyone in our society needs to realise that euthanasia does take place in our NHS and Community Nursing Home services, but that there are several different categories of euthanasia; they detail this as '*[t]he classification of assisted suicide*'. The ones which receive the most controversy are

involuntary euthanasia and assisted suicide. These two types of practices of euthanasia are clearly illegal in the UK, but the others, they argue, are not. .

The ethical problems arise with these latter decisions, which have to be taken by doctors and sometimes nurses. In end of life scenarios when they believe that treatment is futile they exercise an ethical test of best interest. They make brave estimates of the length of time someone will live with their particular critical illness and make decisions about what treatment should stop (e.g. turning off a life support machine; switching off a naso-gastric pump).

The author will argue that in the best interest of families that doctors and nurses should make clear statement about their plans to withdraw treatment so that the family can adjust to the thought that their relative is going to die. The government has now introduced plans for hospitals to perform appropriately in end of life scenarios (DH 2004b). Hopefully this may enable health professionals and families to feel more comfortable talking about death and dying, in the same way as we talk about birth and recovery from surgery.

There are two areas of policy which are being addressed here, that of information and that of environment. Society needs straight answers from health and social care professionals (e.g. social workers) in sensitive situations regarding the care of those who are dying, and investment is required both for this, and to ensure hospitals look like places fit to live and die in. How can people, near the end of their life (needing intensive care) be expected to die in a ward with 30 other people? The information technology at the service of organising treatment, and administering the health service has undergone an enormous electronic revolution over the past 40 years, but the smoothing of the information pathway between professionals and administrators has led to security policy, and sheer complexity which have excluded patients and carers, who cannot even e-mail their hospital doctors and nurses for information. The next chapter will explore these issues within a case study of the death of informant one.

## 9. Chapter Nine: A grief observed<sup>6</sup>

### 9.1 Introduction

The first informant was related to the author, as his mother. He sought assurances from his academic supervisor at the time as to whether this was ethically satisfactory. Reporting on informant one as kin by the author was not considered to be a problem. For a long time he was able to adopt a '*ghost writer*' stance with this informant because he had lived with her for most of his life.

The contributions made by this first informant included conversations, recorded in the author's field notes and entries in her own diaries kept at the request of the author. They provided snapshots of day-to-day life around her illness symptoms on a daily basis (Baker and Wiginton 1997 and Mol 1999; 2002, 2008). The author's life-long experience of living with this person has provided him with the skills, tact and sensitivity to develop relationships with other lupus sufferers involved in this study. As a result of what the author regards as his privileged position he was able to utilize biographical research methods to help build a broad picture of the life of informant one. In addition data from his own autobiography has been included to provide an equally vivid depiction of his role as carer.

The following account of the life of informant one, Mrs. Delia Robin, places the concepts developed in this thesis in the context of a narrative of the author's time as an observer living in a caring situation with a woman diagnosed with Systemic Lupus Erythematosus.

Mrs. Robin was born in 1943 in the Commonwealth of Dominica, in the then British West Indies . She was the daughter of a 50-year-old subsistence farmer, Joshua Doram, and possibly the grandson of a slave. He and his father purchased over 40 acres of land, which was passed onto his three sons on his death. Her mother Adelta Stevens, 26 years old at the time of giving birth to Delia, was a seamstress and craftsperson. Mrs. Robin, christened Delia Verdun Doram, was one of ten children. She came from a line of people who used their hands to make a living. Her mother

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<sup>6</sup> This is the title of a book by C.S.Lewis (originally writing under the pseudonym N.W.Clerk).

plaited straw and made hats, baskets and bags. She died at the age of 36, giving birth to her tenth child.

At the time the research started, informant one was 52 years old. She arrived in Great Britain in 1959 as a 16 year old. She was one of ten siblings from a family who undertook subsistence farming for a living. Her family structure was matriarchal-led. Following the death of her mother at the age of 10 she recalled suffering a severe fever – typhus. The main symptom recalled by her included being in a “coma like” state for several months. When she recovered from that illness, she was ‘outsourced’, by her older sister (who on the death of their mother became head of household), into a house far away from her rural village to board as a house girl (maid).

In 1959 she immigrated to the UK at age of 16. Her main livelihood in the UK was derived from working as a factory worker and later she became a skilled wire person and engineering technician in the growing electronic engineering industry. Somewhere between 1959 and 1961 she recalls her first critical health incident, resulting in symptoms of pains and paralysis in her hands and upper limbs. Her fiancé, a rail worker, on that occasion, was at work. Their home was a rented bed-sit in East London, Stafford Road, London E3. She called out to her landlord – Mr. Low who came to her aid with a fresh orange. She recalls being unable swallow the zest of juice being offered. He promptly called for the doctor. The doctor arrived and then called the ambulance. Later in hospital her fiancé visited after work. She recalled feeling extremely sad. She felt sad being in a country far from her place of birth. She was lonely and missed her relatives. Her initial diagnosis was described as inflammation of the blood.

The author’s early encounters were based on face-to-face encounters that took place in social and domestic activities around the house. These activities included sharing the bathroom or making sure there was enough food in the home to nourish them, listening to one another’s stories and interpretations of messages from those stories. In effect they interacted in roles as family members. Mrs. Robin, now deceased, was married and lived with her husband who was 5 years older than herself. Her son, the author and her elder son, *Bonnie*, both now live in homes of their own with careers

and responsibilities of their own. She stood at 5 foot 3 inches. In bare feet she has a slight paunch leaning forward at her hips.

Mrs. Robin experienced significant hair loss. Whatever hair remained at the end was located at her temples and greying. The areas of baldness were white, although her complexion was light brown, with mixed pigmentation. Her face had many blotchy scars particularly around the lips and under the eyes, at the cheek area. The lining of her nose had also shown discolouration and self reported tenderness. These were the remains of previous flare-ups or relapses.

The author's first recollection of a flare up for Mrs. Robin happened in 1974, when as a 31 year old she lived in the West Indies with her husband and two children, who had all returned there to live from the UK. At that time she had a lot of exposure to sunlight. She carried out some very active outdoor work including clearing land with a machete or cutlass, and organizing farmland fires in order to build or establish a small holding of farm land. There were times when Mrs. Robin regretted not being more of a housewife, but she felt, in a way, she had no choice. Her husband had high expectations of what partnership meant. The flare up happened at a time, when Mrs. Robin did not have a diagnosis of lupus. Nevertheless, the vivid image of exposed weeping flesh around her lips and underneath her eyes was the first time the author had ever witnessed disfigurement to Mrs. Robin.

She never cried. Perhaps she could not. The perspiration was not enough to relieve the pain of her open wounds and exposed flesh in the searing tropical heat. As a result she remained housebound, only seldom coming out of the house, and mainly at night, when the temperature was cool. People in the community did mock her. Many often asked whether Mrs. Robin had dabbled with 'obiah' a form of mythical witchcraft beliefs brought to the West Indies from Africa. Others blatantly described her as having a face, which was 'rottening' (pronounced rockenning). There was not only biographical disruption (cf. Bury 1982) for herself, but open primitive social stigma (cf Goffman 1979) in the face of others in the then primitive village of Wesley, in Dominica, West Indies. This was hurtful for Mrs. Robin, especially because this was the village of her husband's birth. Most of its locals were related to him. She was born in the neighbouring village of Marigot, three miles away, and knew that in

her husband's village people never really accepted her but she sacrificed her needs to live amongst them for the sake of love and marriage. Had she been the type of person to insist she could have lived in her own village of birth, as there was no shortage of land.

At the time of commencing this study she weighed approximately eleven stones. The outsides of her thighs had stretch marks, as did the underside of her abdomen. Her flesh was raised at her hips, with noticeable muscular bulk and is noticeable in her posture when attempting to stand or walk.

Deformities were noticeable at her finger joints. Her thumbs, index and middle finger had been assessed for surgical correction or straightening. Mrs. Robin welcomed this intervention. The middle finger of the left hand has been repeatedly knocked against objects, such as cupboards, plates, doorframes and at time have been infected at the distal interphalangeal joint as well as leaking discharge of pus from the cuticle where the fingernails are located.

She did recall one day having an altercation with her husband in 1991. On that occasion he stepped on her hand on the communal stairway of the block of flat where they lived in South Kilburn. She describes having her index finger crushed under his feet. Later she warned him that if he ever did anything like that again, she would kill him. The author believed it was an accident rather than a fight, but the problem was for Mrs. Robin that her husband never apologised convincingly. There were also marital problems as Mrs. Robin's husband was openly having an affair, which was deeply distressing for the whole family. This type of dialogue therefore exemplifies the impact of other social forces on illness experience and the person and the body.

This may seem an undue revelation, something not required to chart the course and treatment of a physical disease, but the experience cannot be captured without such frankness, as Charon and Montello (2002 p10) warn, in their work on narratives in medical ethics: *'[A]t the center of each case described in these chapters lies the recognition that serious illness raises the veil in the lives of those involved. Old family secrets, long time troubling issues, deeply felt but unexpressed emotions – all muted*

*or somehow removed from the surface of daily lives over the years - often become visible and expressed in ways that they are at no other time during our lives'.*

Mrs. Robin recalled early childhood experiences of illness. She had a bout of fever as an 11 year old that left her in a coma for several weeks. She recalls pining for the loss of her mother when she was 10. She stated that she could not eat much food through sheer sadness at the loss of her mother. This period of non-nutrition intake quite possibly left her vulnerable to fever. Forty years later she was able to talk comfortably about the loss of her mother without breaking down tearfully.

Mrs. Robin and the author recalled one incident in the 1990s where the soles of her feet had stripped and peeled. On a return trip from the South of France the author was horrified to see Mrs. Robin come through the concourse at Heathrow airport. The airport porter wheeled her through in a wheelchair. She wore large dark glasses to cover her cheeks and a large hat. The author escorted Mrs. Robin to the car park. Walking was a problem, she could barely stand.

On the way home Mrs. Robin recalled her stay in France. *'It was a bad one'* she said. She had had several flare ups of this kind at approximately three to five year intervals. She seemed battered physically but not beaten mentally. The drive back from Heathrow to Wembley seemed empty. The silences did not want to labour her suffering experiences. The skin had cracked and curled up on the soles of her feet, and the left foot had swollen to the point where the skin had a shiny texture. Mrs. Robin found out that this was called 'phlebitis'.

Her home was a three bed roomed terraced property in Wembley in the London Borough of Brent. All the bedrooms were located on the first floor and were accessed via the stairway. The local authority's Occupational Therapy department provided additional stair rails to enable Mrs. Robin to negotiate them effectively. The home space was a place for thinking, reflecting and praying. Sometimes, she looked motionless in her bed. She often groaned in response to courtesy questions.

The home was where Mrs. Robin spent most of her later years. She was made redundant from her place of employment following sick leave in 1994. This affected

Mrs. Robin greatly because she had worked with that firm for 19 years and felt they did not have to make her redundant. The redundancy event took place whilst Mrs. Robin was having surgery to her hands. Her hands were very important to her role as a wire-person. She had trained as a wire-person when she came to the UK as a 16 year old in 1959.

By 1994 Mrs. Robin's stamina was affected to the point where she took to her bed for frequent and prolonged resting. In the winter months she would not always turn the gas central heating on during the daytime. She told the author on many occasions that she wanted to keep within the household budget. She also explained the importance to her of being able to live within her means at this stage of her life, in the knowledge that instead of burning gas she would wrap up using a thick quilt. She could not really sleep. Instead she would turn and turn and turn throughout the day when home alone.

She would also pray. Mrs. Robin used prayers almost endlessly. Her home was adorned with images of Jesus Christ and a wooden cross ornament, measuring approximately two feet, on the mantle piece above her bed. Another model, on her chest of drawers, is a Creole French woman that stands approximately 3ft in height. The Creole model is wearing the colonial costume worn by Dominican slaves in the 16<sup>th</sup> and 17<sup>th</sup> Century at rituals and celebrations. This is now the national costume of Dominicans. Around the body of this model is a rosary placed by Mrs. Robin. Periodically she would be seen holding the rosary in her hands when having bed rest.

## **9.2 Observing hope versus suffering: The researcher's background as a child carer**

In 2004 the author decided to write about the dynamics that existed in caring for his mother. He felt that the best way to experience this would be to live the experience and report on it from a first hand perspective.

This section will describe the first hand experiences from the carer's observation about the hope of life for the sufferer when they are surrounded and comforted by family. The second part will describe in detail what life is like when support is absent and delegated to those health and social care professionals in end of life



circumstances. The role of carer is studied in terms of the challenges faced by a carer when their loved one has been hospitalised. Throughout the account there are references (almost like flashbacks) to key timeline events in the life of Mrs. Robin that have been provided in order to detail the moving events of temporal nature of mortality in general.

Living through these events and witnessing them first hand as a child almost desensitised the author to the potential goriness of coping. In other words the author became used to the harshness of the day-to-day reality of what his mother was experiencing. She would often say: “Come and help me” (the task might include providing assistance with toileting). In that instant observing a slight pause or hesitation in his actions she would continue: “Don’t be ashamed of mummy, there may be a time when my situation is much worse and who will I then be able to call on for help?” As an eight or nine year old this was persuasive charm at its best. The author was sold the vision of being a carer. That very situation of being much worse would come to pass thirty years later in a hospital ward when his mother would suffer and end her last days in isolation, with nobody to help her pass away peacefully.

The author’s earliest memories of helping his mother would be as a nine-year-old child carer, having to go to the chemist to collect her prescriptions. As he became older, the quantities of these drugs became heavier and heavier to carry in a single carrier bag provide by the Pharmacist - as she required more treatment. He later learned that many of these drugs carried with them side toxic effects that contributed to additional illness symptoms in their own right. Because his mother, like many other patients, saw themselves as passive recipients of expert care, they internalised a trade off between the short-term relief and the hope of a future promise of long-term symptom alleviation against the anxious thoughts or prospects that treatment without any alternative will leave them in a far worse position (cf. Frank 1995).

The author regarded his mother as a very caring person in her own lay community role. This was particularly reflected in the way she would always organise gifts for her friends and relatives, particularly at Christmas and whenever she would travel to see them. The gifts would include clothing, food and money. Sometimes at the end of each year she would secure the services of a courier delivery firm and post a large

barrel filled with food and clothing. The build up to completing the packing of these items would entail weeks and weeks of preparation by visiting charity shops in the UK as well as grocery shops where she would buy tinned foods in particular. These tasks she would undertake with her husband as he drove a car.

This ritual of caring and providing gifts was not only carried out to friends and relatives abroad. Equally, the act of giving at home here in this country was also very important. Since she first came to England in 1959 and made many friends, who became surrogate relatives. Many were from Jamaica including; Annice in Hackney, Carmen in Kensal Rise and later Perivale and Melva from Willesden Green, all friends from the 1950s. More recently, in her network, friends who she got to know in the 1990s included the Dattani family from Uganda now resident in Alperton, Maxine and Robert who also lived in Wembley.

Some of those friends died whilst the author's mother was alive such as Aunt Rose and Aunt Mary from Maldon in Essex. They befriended the author's mother when they all worked at a factory in East London in the early 1960s. She would have been in her late teens when they would have been nearing retirement. On their retirement they moved from Romford to Maldon, Essex. This was a familiar pattern undertaken by East Londoners on their retirement.

Every year a family pilgrimage-like journey would be made to Maldon via Liverpool Street station to visit Aunts Rose and Mary. Whenever the author's mother arrived they would be overjoyed to see: "Delia and the little boys!" The sisters had a special affection for the author's brother who was born in Bow, East London in 1963. They would have been around at the time of his birth. Unconditional sharing of gifts for nothing in return was an active part of their support to one another. She would also do a discrete clean up of some parts of the bathroom especially as they became more frail and unable to probably notice the occasional signs of "mess" in their bathroom. When the day trip ended aunts Rose and Mary would always give the two little boys a Tupperware box filled with fairy cakes and five pounds each pocket money. Every year at Christmas times until they died they always gave a card with a five-pound gift.

The author provided support to his mother by driving her to the funeral of aunt Mary who lived to 92 years of age in 2001. It was an honour and privilege to undertake this duty. The funeral was small. Most of Aunt Mary's friends were dead and her sister Rose died several years before, prompting Mary to move to a warden-aided complex for the elderly. At the funeral the author recalls his mother crying and fighting to wipe away the tears from her eyes with her handkerchief. This would be the last ever trip they would make to Maldon together. This is a place where she brought the author every year from childhood until he became a fully-grown man. At that time he did not recall experiencing feelings of grief or loss. For him the event was quite "matter of fact" but observing his mother's sadness and witnessing her distress left a mark in his mind of how hurt she was to lose someone so close.

Rose and Mary were like surrogate parents or indeed grandparents to the author's mother. To lose them both was a mark of grief and a point in her life perhaps indicating once again of the temporary nature of life. She often recalled with nostalgia the salient advice they would give her in the factory as she recalled being a fast worker.

*"Don't do all the work today D! Leave enough for tomorrow (pronounced tommora)!"*

The author's mother admired the spirit of the East Enders and would almost be filled with pride recalling their unique traits, mannerisms and drive. Whether tangible or not, gifts were an important part of the life of Mrs. Robin and the friends she made along the way.

In the 1990s, the author's mother made a visit to Israel and the "holy land" of Jerusalem. She visited the Holy Land with a church party from Quex Road Catholic Church in Kilburn, North London. In the build up to the event she somehow managed to persuade several surrogate Aunts to join in this tour. They made a special effort to be part of this special event. As surrogate "sisters" in arms they made the trip and enjoyed it immensely. Whilst in Israel she got to know Stan and Tsipsi Kimmel. They lived on a Kibbutz. Stan was a retired US Naval Officer who made a conscious decision to return to live in retirement in Israel. The author's mother and Stan struck up a wonderful and special friendship that lasted until he died in 2003. To this day

the author cannot recall what bonded them. Over the years up until his death in the year 2003 they would share letters and every year a gift of oranges would arrive from Israel. The author's mother would really appreciate this gesture.

Many of the friends in particular would see her often when they were in difficult circumstances and often the most precious gift from her perspective was gentle advice and a special prayer of support. All her friends knew about her illness. She would willingly share information about the disease and for this reason the author is inclined to believe that his friends were all part of her very special "Lupus Support group" although it was never really framed in that way.

The author always acknowledged that he first learned to be the social worker he is today from the skills passed on by his mother. She was the most skilful social worker that he ever knew. As a young child he would often accompany his mother to visit friends and relatives all over London. There was "*My Rose*" who up until her death lived in Willesden. She too was from the "old country" (i.e. Dominica). She was one of the first from the community to die in England. But those visits required the author to sit quietly in the corner of the lounge with a glass of orange and slice of cake or biscuits and let the "big people" get on with their "big people" conversations. Somehow he cannot help believing that he was fulfilling an essential requirement in his role as "social worker apprentice" although he did not know this at the time.

There was Uncle Daniel. The author's mother would often describe him as her stepbrother. The author later learned from the family tree that Daniel was in fact a stepbrother to his mother. The author's mother fondly referred to "times gone by", when the young Daniel would go hunting with her father in the old country. In Dominica the men would go hunting with "young apprentices". In the dark of night with specially made torches known as "booz eyez". They were accompanied with specially trained dogs they would hunt the "Manicou", a large rodent like animal similar to a ferret, or wild pigs. Uncle Daniel died of cancer in 2000 in a council-funded care home. The family would often visit him when he was poorly. In recluse-like manner he shied from attention and often wanted to be left alone in his lodgings in Harlesden. In spite of this trait he was always welcoming.

The author, then, was brought up in an atmosphere of providing gifts whether tangible or otherwise, and this enabled him to appreciate the importance of giving (cf. Mauss 2000). In return for all the support provided to the author by his mother it was never difficult to return the gesture later in a caring role. He would willingly provide support and assistance often, but not always, without question. The act of giving something back to his mother seemed a selfless equivalent act. He did not call what he did caring. The label of caring almost devalued his contribution.

### **9.2.1 An Intensive episode of caring**

In 2004 the author kept a reflective diary of events that took place in a week in his life as full time carer for his mother. The author spent one week as a full time carer for his mother when he travelled with her to the land of her birth, Dominica. It had been several years since the author had left the family home. Returning to hands on caring situation required adjustments to be made by the author's own immediate family circumstance (e.g. securing support from his own wife to perform this function away from the family home).

This full time caring situation now allowed a renewed aspect of life with lupus to be observed closely. For one week the author left his academic and professional world to assume the role of carer. The account informed the author about matters, which would otherwise not have occurred, and therefore the voice of suffering with lupus would have been diminished. There were now two witnesses of living with lupus, the sufferer and the carer.

On day two of their time together he made the following comment in order to emphasise the point:

*I am not really contributing much in terms of direct caring. If I have to summarise what my role has been at the moment, it has been a physical and social one. I have had to carry luggage. Three quarters of the contents have been gifts for my mother's relatives. Clothing, biscuits, sweets, other condiments, tinned food. I am someone to talk to. I am someone different from her husband. She is still quite critical of my dad's role in terms of what he didn't achieve, in terms of putting home furnishings in*

*place while he lived here for six months, where he attempted to bring it to a liveable fashion. It is really difficult to say whether my role is a caring role. Any moment now I am expecting something bad to happen. The bodily reaction from my mum could be cramp, fatigue or even collapse. She does however take her medication, which will help her to cope.*

In the week long direct caring role the author was always vigilant however, just in case something did go wrong. The environment of Dominican rural life can be harsh in terms of limited infrastructure such as running water, no air conditioning systems. He felt therefore compelled to be vigilant and being on the look out for signs of bodily symptoms and being prepared to travel back to the UK in an emergency should things go wrong.

On their first few evenings together the author's mother was dressed very lightly, as the temperature was hot. Their bedrooms were linked via a corridor. They did not have many items to unpack. The majority of the items in all cases were gifts for friends and relatives. The flat began to look untidy, as the gifts were strewn out on the back of armchairs or on dressing tables. The author was surprised at his mother's high energy levels. At one point he did mention to her how surprised he was at how she was able to sustain this level of energy continuously to unpack items from the suitcases in one evening. The authors concern was for her health and in particular her blood pressure. He did not want it to go up. This was one of the key indicators of her illness and he knew his mother was susceptible to her blood pressure rising.

She did respond by stating that whilst she felt fine for that particular moment, she was in fact hoping that she would not pay dearly for this effort, later that night or a few days later, with pain and discomfort. In order to avoid this type of strain the author would have preferred for both his mother and himself to be in a hotel, where facilities like running water would be laid on. However, he accepted that the purpose of being at the family home in Wesley was to be close to family relations and that the majority of the items brought with them from the UK were gifts for friends and relatives. The gifts comprised of items such as clothing (shirts, blouses, underwear, night dresses); tinned food (baked beans, sardines).

They unpacked cases with gifts for about two hours. At one point they had a small quarrel. They could not find the keys to one of the main suitcases. They paced up and down the apartment looking for a bunch of keys. The author saw this as a form of unnecessary hassle. At one point she said something to the effect of ‘You don’t help much’. The author retorted, ‘those words are not going to affect me mum...if they are supposed to make me feel guilty they won’t!’ Things seemed positive after that. The author was mindful that this level of stress was not needed on a holiday like this.

At the end of the first day he performed a range of tasks. This included carrying luggage at the airport environment, being a companion on the aircraft (including close supervision on the stairway of the small LIAT jet between Antigua and Dominica). In the apartment the author shuttled back and forth between rooms at her request to place items into piles or categories.

Later in the evening mummy was seated on her bed folding an item of clothing, pointing with her index finger and gesticulating at the curtain. She asked the author to carry out the task of pulling the curtains to be closed, as they were difficult for her to pull to a close. The runners were made of string and so therefore provided friction when pulled to close in small tugging movements. In asking the author to perform this task his mother stated how unhappy she was that her husband, when he travelled to Dominica last November 2003 he had not provided and fixed better curtain tracks. The author completed this task and walked back down the corridor to his bedroom. At approximately 10 pm he went to bed.

After that first day, right up until the author’s last day with his mother, things did not go wrong. In his mother the author saw a person in full bloom of life. It was amazing. This was a real contrast to the person he witnessed in the United Kingdom being bed-bound and often heavily contemplative in thought and prayer. The author’s mother had just turned 61 years old. She was happy. They travelled together to her primary school where she reminisced about her childhood. She showed her son where she played as a child and described the kind of games they played including pole-vault with bamboo sticks. They walked past the Marigot Village graveyard where she looked for her father’s grave. There was some disappointment, as the local relations had not tended it. Further into the village they visited and greeted several friends who

respectfully greeted the daughter of Joshua Doram. The author perceived that his mother had a regal quality about her that shone through her frail body and gentle gait as she walked slowly through the village. The author felt that people could not help but give her honour and respect whenever they saw her.

One of the most meaningful events however was time spent with all her three full brothers named Joshua, Davidson and George. She took great pride in sharing her recollections of memories of their mother that she felt it was important for these men to know. There had never been a previous opportunity in their lives for them to meet and socialise. They were all very young when their mother died. The author's mother felt fulfilled telling them about the type of person their mother was.

A year later the author and his mother would all visit France in July 2005 to see her other son Bonnie. The author's mother was by then very poorly. In the previous twelve months she had lost two stones in weight. This would be the last time they would be together as an extended family with Joseph her grandson playing in the meadow of the Toulouse countryside with his grandmother looking on and listening. The author had to return to England. He did pledge to collect his mother from the Gatwick airport, which would happen to be on the same day as a family wedding in Mitcham, Croydon.

They attended the wedding ceremony and part way through the event the author left for Gatwick airport. April, the author's wife gave encouragement. The author collected mum who came through the concourse via the airport disability services. They drove back from Gatwick and the author's mother was in contemplative mood and seemed quite sad. It seemed that things were going on with her body internally. She was experiencing weight loss. They did not say much. Although his mother was committed to getting home to Wembley, the author did ask if it would be alright to call into the wedding event in Mitcham, South London, as it was on the way to Wembley. She agreed. If his mother had insisted they would have gone straight to Wembley, without doubt!

She made what seemed a majestic entrance in the reception hall the venue for which was a tennis club in Earlsfield. From every crevice of the club and orifice of recessed



sitting and standing areas people paid her “live and direct” greetings. She gave a majestic nod and gentle wave. What had the author’s mother done to deserve this level of stature? The family relations were all from her husband’s side. They originated from Wesley village in Dominica known for being a “harder race” of people compared to “Marigot village folk”. But they simply yielded with respect. When the author’s mother finished her walk and he was now reunited with his son and wife, the author’s mother took a seat with some dear friends and for the rest of the evening everyone enjoyed themselves and the wedding reception of Cousin Shane and his wife. This would be the last major social event that the author’s mother would ever attend.

### **9.3 Social context of dying**

#### **9.3.1 The death of a lupus sufferer - resilient mentality as resistance**

On reflection the process of dying had commenced weeks before the author’s mother finally died. For the author it comprised increasing moments of dependency on other people to perform routine dignity tasks of feeding, washing and toileting. She was unable to self-toilet to pass faeces or urine. She lay on her back with large pressure sores on her buttock, which often came into contact with urine and faeces. She relied on a “male” catheter to pass her urine and her body had to be turned in order for her pads to be removed and changed without damaging the injured skin surrounding the site of the pressure sores. In addition she became unable to press the call alarm for help and assistance.

The encroaching social death in Mrs. Robin’s situation was a precursor to actual physical/biological death (cf. Mulkey 1993). This process of social death began to appear to the author as a series of power plays between others and his mother. This began as others began to take control of his mother’s body.

### 9.3.2 Others taking control of Mrs. Robin's body

#### 9.3.2.1 Heroism in dying

For the author his mother, Mrs. Robin, never lost the respect of her children. She never became less of a mother because she was in an advanced state of illness. If anything they counterbalanced for her gradual loss of function, by ensuring that they remained committed to her state of personhood in the presence of themselves and others thus displaying how they would expect others to behave in her presence at this time. The author's mother *was* a heroine to her children (cf. Seale and Cartwright 1994). When required they cared for her and tended to her as if they were nurses, without shame, embarrassment or any other reservations. She deserved this status.

#### 9.3.2.2 Voyeurism, vigil and social gaze

The author felt that others came to see his mother for a number of different reasons. Some did not share the same kind of reflective heroism traits that he and his brother aspired to; some would often come to pray (the author could not be certain whether this was for healing or *willing her over* to die and therefore go to a place without suffering); some would come to gaze; some would not come to visit because they did not like to see their relative in such a state.

Some relatives, friends and well wishers therefore took control of Mrs. Robin's body. This was sometimes in the form of feeding her, when she could no longer self-feed, and sometimes in laying of hands through prayer. The author once witnessed the reverend laying his hands on his mother's head to carry out a prayer. After the reverend left the room the author told his mother, Mrs. Robin, that he did not like the reverend touching his mother's head, but his mother said that she thought it was satisfactory for him to do so. In her weakest state, she was barely able to muster the strength to shun away her sister's arm. If actions had words, it would be as if the author's mother was saying; "*Stop it. Stop holding my arm. Stop making a fuss of me!*". Elias (1995) refers to people expressing a need to be left alone during last moments of dying. It is as though the dying often still want an opportunity to retain their former roles including caring for others. '[*T*oo much expression of sympathy may be just as unbearable for them as too little' (Elias 1995 p59).

Many elders from the community came to visit Mrs. Robin. Following their mothers death, Bonnie, her eldest son, confided in the author that he believed the *elders* who had experienced death in some form, should have raised the alarm with nurses and doctors and family members about their perception and perhaps openly ask; “*Is she dying?* ”. The author believes that not saying anything was their way of keeping their concerns private. It is possible that this also signified that the tradition of passing on information by word of mouth had now become an almost lost tradition in late modern African-Caribbean culture (cf.Harrison 2000).

A new repertoire of the gaze, the ‘clinical gaze’ as Foucault, (1973) has it, had emerged as a more fitting arrangement by those more able, towards those less able. The author saw this as a social gaze, a social version for lay-people of the ‘clinical gaze’. This process involves looking on from a privileged position of health and wellness without being able to pass on any valuable advice or perform much action. Traditional and socially acceptable norms of group behaviour informed those who visited to pay tribute or contribute their form of vigil. Many visitors, as strangers, came to pray for his mother. Some said that they knew her husband from his church and were part of a daily rota to help feed Mrs. Robin at lunch times.

### **9.3.3 Infection control**

#### **9.3.3.1 Fragmentation of social networks**

Several weeks after Mrs. Robin’s admission on the hospital ward, she contracted a resistant strain of bacteria on her skin and in her wounds. The ward instituted a procedure known as barrier nursing, for all people who entered the side room. This involved all visitors to Mrs. Robin’s side room “*gowning up*” using personal protective equipment such as plastic aprons and gloves, which were available in the porch entrance to the ward. On leaving the ward these items that had to be disposed of, “*gowning down*”. When the doctor did reveal that Mrs. Robin had contracted a bacterium the author sons made an announcement to reduce the number of visitors to his mother in order to reduce the possibility of people “*bringing in bugs*”. It was announced that this would be for two weeks until the new antibiotic treatment had ended.

Several weeks later friends of Mrs. Robin took personal offence at this. Some felt that their presence could have made the key difference in Mrs. Robin's recuperation. Others felt that the sons were not allowing them time to adjust to the loss of their relative. Others felt that the barrier nursing was the ultimate answer to this process. It became important to the author that everyone should give Mrs. Robin the best possible chance of fighting the latest flare and infection. In situations such as this the author took control of his mother's interests and made a decision that was not popular by all of her social network. He did ask as many people as possible to spread the word and let others know what was being done and why. He stated that after two weeks they could resume a full visit schedule if they wished.

#### **9.3.4 Exercise as taking control**

Following advice from a doctor the author started a process of passive exercise for his mother for several weeks. The family mobilised her limbs with the aim of reducing the possibility of contractures forming at the knee joints. Mrs. Robin's shoulders and elbows were passively mobilised. The hope was that it would promote voluntary mobility and Mrs. Robin lay passive most occasions. An approach of always asking the medical teams permission to start the exercise and carry out the task was always undertaken. The regime here was to minimise the risk of increased immobility. The family wanted Mrs. Robin to have every possibility of being part of a recovery regime. Those moments of leading those passive leg exercises (e.g. three sets of ten, sometimes twenty repetitions of leg flexing and extending at the knee; the same type of exercises at the ankle) were all at that moment a way of controlling Mrs. Robin's healing regime.

#### **9.3.5 Creaming her skin as taking control**

Three members of the family visited frequently: the author, Mrs. Robin's husband and her younger sister. At about the same time as they began the exercises they also introduced a regime of creaming Mrs. Robin's arms and feet. There were several areas of dry skin beneath Mrs. Robin's feet at her heel. These were potential pressure areas due to limited mobility. We always asked Mrs. Robin whether we could begin to apply the cream. Whenever she was able to, she did provide her consent and

acknowledgement. The cream was a liquid paraffin base, which dissolved into the skin after continuous massage. This process could take forty-five minutes. The general view held by us was that the nurses were too busy to do this type of work.

## **9.4 Organising medical treatment and the use of devices**

### **9.4.1 Medical assessment of the body**

Doctors on the ward led the treatment of Mrs. Robin. The lead doctor was a consultant rheumatologist. She is the equivalent of a director of a business unit and is one of the highest grades of staff in a tightly structured chain of command. In this respect she is seldom involved in *hands on* role and more in an administrative role. She was the named professional lead for Mrs. Robin's care and another twenty to thirty patients on that ward, as well as perhaps another one hundred or so active outpatients who attended various clinics. A person of her professional grade would take many years after first qualifying as a doctor working her way up the professional hierarchy, and sitting many examinations. She would have the assistance of a team of doctors, including the next grade below, registrars and then grade below them, senior house officers and newly qualified house officers.

She made recommendations for the course of treatment that Mrs. Robin received and made decisions as to when such interventions would be reviewed. These decisions would be made with, and in the presence of, other professionals such as her registrars or house officers, who at this stage of the professional grade, are still in an active process of learning and would look to her as a mentor and role model. In terms of Mrs. Robin's care there was not always a doctor present on the ward. Nurses are the professionals with delegated responsibility for issuing drugs and monitoring bodily processes and reported these findings to the doctors at ward rounds, via charts, medical records and *verbal handovers*.

#### 9.4.2 Symbols of health and illness management

It was noticed that during the time the family visited Mrs. Robin on the ward, doctors and nurse managers did not approach the family to greet them and provide updates. Instead the family attempted to do this on several occasions. It was common for the family to walk onto the ward, spend several hours with Mrs. Robin, then walk out of the ward without much interaction or update from the health and social care professionals. To approach a health professional, with status, on this particular ward required an approach to the nurse's *station*, where key staff were gathered quite busily writing information. If one could get the attention of someone it might happen after a period of waiting, and usually the family had to greet that staff member first (e.g. *"Excuse me, can I ask you about my Mrs. Robin's progress please?"*). On most occasions it seemed as though the family were an inconvenience, because the health professionals seemed so busy.

The body language of those professionals was always one of being preoccupied. It was not uncommon to notice a scowling facial expression on the lead nurses' face. Indeed the regime of the ward was one of a control regime. Visiting times commenced as 11am to 1pm and 3pm to 7.30pm. The security doors to the ward would become unlocked at opening times and a queue of visitors would enter the ward. Just past the entrance was a container of liquid disinfectant that all visitors had to use to cleanse their hands on entry and leaving the ward. The author would walk past the nurse's station and see the nurses and doctors always writing information, their heads looking down into a file.

The family would then enter Mrs. Robin's side room and greet her. They would look about the room to ensure that there was sufficient water in her jug or that her bed covers were intact. There were often other problems related to the morning visiting times. On most occasions nurses would be tending to Mrs. Robin whenever the family arrived. They were providing Mrs. Robin with washing, wound dressing and toileting between 11am and 12 am. In effect Mrs. Robin was one of the last patients to be tended to on the ward. Towards the latter stages when Mrs. Robin had difficulty feeding herself, the family was concerned that Mrs. Robin's last meal at 7pm the

previous night, would have to last until 1pm when relatives arrived to feed her at lunch time.

The family observed how meals and tea drinks were provided to Mrs. Robin. At main meal times the nurses would distribute the meal of choice (often made by the patient completing an order form the previous evening). They would place this on the over bed trolley, perhaps after briefly greeting the patient and leave to continue to distribute the rest of the meals to other patients. The *domestic worker* would also visit every patient with a tea trolley and pour a beaker of tea, leave on the over bed trolley and also continue to visit other patients. For someone like Mrs. Robin where self-feeding capacity was waning as she became weaker and weaker, the propensity for malnutrition and dehydration was increasing. Eventually, the nurse and the tea lady would return to collect the utensils. Some of the messages we would often receive would be, “*She is not eating!*” This made the family distressed. They would often ask each other: “*Haven’t they realised that Mrs. Robin needs assistance to feed?*” Their body language and attitude was such that we did not feel that many were approachable to pass on our observation and concerns.

Even getting a general greeting from a nurse seemed to be an ordeal. On one occasion two nurses entered the room, went straight to Mrs. Robin and asked us to leave the room. We did not even receive a greeting. Mrs. Robin was part of a system, which deliberately tended to her as one of the last patients on the ward. In addition the family’s social contact with Mrs. Robin was reduced by one hour. There was never any real apology from the nurse manager for this inconvenience.

### **9.4.3 Monitoring Blood Pressure**

The device for measuring blood pressure on the ward where Mrs. Robin received treatment was a sphygmomanometer, which was an electronic machine on a portable stand with wheels. The blood pressure was monitored several times throughout the day. Nurses and sometimes their assistants known as health care assistants (HCAs) would undertake this task. The procedure would require the nurse to hold Mrs. Robin’s arm, attach the cuff around the biceps region of the arm, which was secured by the nursing attaching Velcro material fastening to Mrs. Robin’s arm. A small screen on the stand with a control panel allowed the nurse to commence the procedure

and automatically the machine would inflate the cuff. After about two minutes the machine would be deflated. The nurse would detach the device from Mrs. Robin's arms, park it to one side of the bed and then leave the room. The nurse on the main communal corridor of the ward would then complete charts.

#### **9.4.4 Blood Monitoring (BMs)**

This procedure took place several times throughout the day. It required the nurse to find a suitable finger on Mrs. Robin's hand to execute a small pinprick using a small machine. Once blood became visible the nurse would pass a strip of specially graded paper over the blood and then enter this into a machine. The targeting finger would then be cleaned up with a swab. The machine would then give out a reading. Several times it was observed by the author that the nurse had to squeeze Mrs. Robin's fingers to try to obtain blood. The readings would denote her level of insulin. When Mrs. Robin entered hospital she was tablet controlled diabetic (type II); by the time Mrs. Robin neared death she had become an insulin-dependent diabetic (type I).

Mrs. Robin's insulin levels increased to the highest score she ever experienced in her life, a measure of 21. This resulted in Mrs. Robin receiving insulin via a drip. Often steroid use induces insulin dependency as the pancreas also become inflamed. The prospect of Mrs. Robin having to use a syringe crossed the author's mind, when this first occurred.

#### **9.4.5 Urinary catheter**

This device replaces the person's capacity to self-toilet. We were not given an explanation why this device was in place because Mrs. Robin had always self-toileted. A long plastic tube was inserted into Mrs. Robin's bladder, via her vagina and a bag attached to the end of the tube. The bag would hold the urine passed by Mrs. Robin. Sometimes the colour of the urine was dark brown, other times it was clear green. Only at the meeting on the 13<sup>th</sup> January 2006 did we learn that Mrs. Robin was given a male catheter to wear because it was longer. What we did notice on many occasions was that the urine would leak between Mrs. Robin's legs. This concerned the family immensely as they knew that urine against skin for long periods of time can contribute to skin burns.



#### 9.4.6 Medication

Mrs. Robin was on prescribed doses of Prednisolone for over thirty years. Prednisolone belongs to a family of drugs known as steroids (George et al 1992). In the context of lupus sufferers they are immunity-suppressant drugs. For Mrs. Robin's treatment on the ward these drugs played a crucial role. Mrs. Robin's abscess and pressure sores, in combination with the bacteria she contracted on the ward, combined to produce an inflammation, known as a flare up. This flare up was Mrs. Robin's most enduring and significant battle to date. Mrs. Robin's flare up lasted for several weeks up until the time of her death. In the case of this flare up episode the role of the steroid was to suppress the over active immune system, which is a key characteristic of lupus. In addition this was supposed to allow the site of the wounds to heal. For this Mrs. Robin's body temperature would be raised as inflammation at the site of the injury often accompanies the healing process.

Mrs. Robin was introduced in this last period of hospitalisation to the morphine derivative, Oramorph (cf. George et al 1992) for the first time ever. This was prescribed in liquid form. We were not told, but we speculated that this was part of the pain management regime. Whenever, the nurses entered the side room to administer Oramorph, they came in pairs. One looked to be in a senior position, as she wore a darker uniform, and looked more refined and carefully presented. She was always based at the nurse's station and did not ever seem to get her hands *dirty*. The family observed that there must be great importance attached to this drug, which is why it required staff to work in pairs when providing it. Mrs. Robin was on a small dose, 3 milligrams.

On one occasion the author observed the nurses walk into side room, without even greeting anyone. They approached Mrs. Robin, held her hand up like an object and proceeded to read from Mrs. Robin's wrist band: "*Name: Mrs. Robin, Date of Birth: 07.03.43, today's date. /.../... Time, Name of drug.*" After this procedure they lifted a plastic syringe with the medication and directly injected the drug onto Mrs. Robin's tongue. They then left the room. The family were totally ignored.

When Mrs. Robin could no longer feed herself the medical team, including the dietician, made a decision to introduce a naso-gastric tube. This comprised of a long transparent plastic tube which passed through the nose of Mrs. Robin down to her stomach via the back of her throat. The feeding mechanism involved bags of liquid food, placed on a metal stand at a fixed height to determine downward feeding via gravity. This was placed beside Mrs. Robin's bed. The family did not recall being notified as to when this would take place; instead they arrived to visit one day and observed the implement in place.

On another occasion the family visited to find that Mrs. Robin had a mask over her face. The family did not recall ever being informed that she would be provided with oxygen.

### **9.5 The Social Work Referral that never took place: The Arrival of physical Death**

A referral form was faxed to the social work department regarding a proposed community care assessment. The social work team never did visit the family to complete a carer's assessment. After Mrs. Robin's death the family learned that the social services department only provided assessments to people who were nominated for going home. They never did comment on the procedure for referrals for continuing care (a joint funded arrangement between health and social services for hospice; nursing home care or residential home care referrals). A social worker based on the ward did not make contact with the family to discuss this aspect of service nor did they provide their expertise on counselling in relation to death and dying.

#### **9.5.1 Withdrawing treatment – the doctor's announcement**

A meeting organised at very short notice to discuss Mrs. Robin's care and progress. This took place on the 13<sup>th</sup> January 2006. At the meeting the doctor stated that due to difficulties of extracting blood from Mrs. Robin, the doctors had arrived at a decision not to resuscitate Mrs. Robin should her heart stop. The family said that they did not agree with this decision, because there were basic functions on the ward, which were not being fulfilled, namely the poor response to a ward alarm system from Mrs. Robin's side room, which could be up to one hour. The family stated that they

wanted time to think about the doctor's decision and would liaise with them in due course.

### **9.5.2 The last moments**

What emerged in the last stages of Mrs. Robin's life from a biomedical point of view were a combination of processes acting against one another: first, the lupus flare up with the characteristic over active immune system; second, steroids increased to lower the activity of the immune system; third, the lowered immune system having to combat *bacterium* and eventual septicaemia; fourth, Mrs. Robin's increasingly malnourished state impacting on the healing process of the pressure sores; fifth, morphine based painkillers having a sedating effect and contributing to slowing down the body's circulatory system; sixth, toxic material seeping into the open wounds and thus impacting on the healing process.

The announcement of the death of Mrs. Robin was by telephone. The hospital nurse telephoned Mrs. Robin's husband on the morning of the 15<sup>th</sup> January 2006 to notify him that his wife had died. The time was approximately 7.30am. When the author, as son, later spoke to Mr. Robin, his father, he stated that he was just getting ready to leave for the hospital, for the breakfast feeding session, when the telephone rang.

Ironically, the ward's form within Mrs. Robin's medical records entitled When a Patient Dies notes the time of death as being 09.47am. What does this discrepancy indicate about the overall process of announcing a death to certain relatives? The author believes it demonstrates the haphazard processes of a busy ward with people who are often too exhausted to work effectively. Case forms are legal documents and with it comes responsibility for health professionals to effect due care and attention. The team, for example, were aware that the family would be visiting between 7am and 9am to assist with breakfast feeding. Someone discovered Mrs. Robin dead on the ward and a decision was made to contact the family.

The ward advised Mrs. Robin's husband that his wife's belongings could be collected from the patient's office. Close observation of the medical records revealed that on the last night of Mrs. Robin's life no professional documented in the case diary sheet whether or not they had checked on Mrs. Robin throughout the night. This

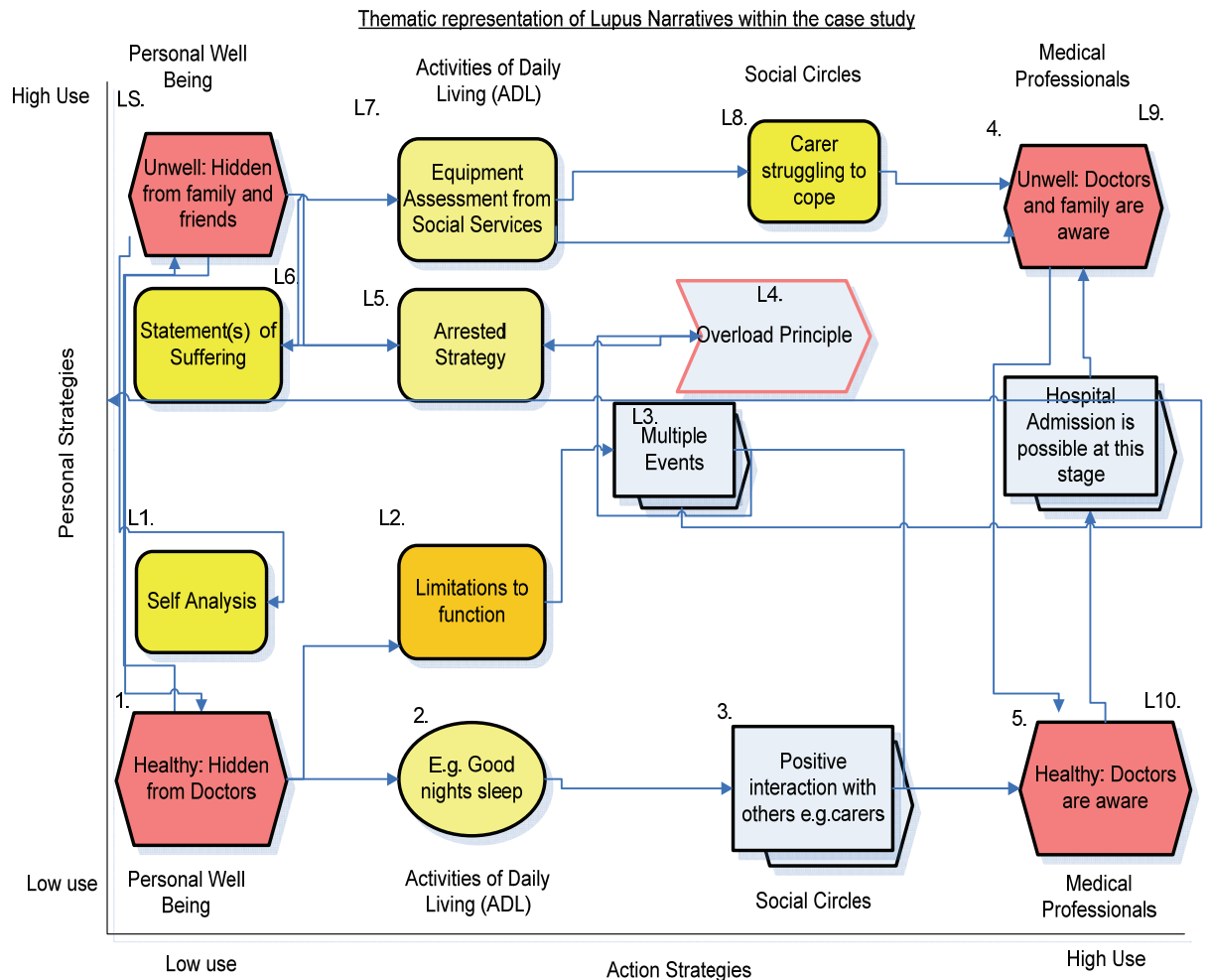
demonstrated that either Mrs. Robin was left alone or that nurses could not be bothered to write in the medical records the outcome of their actions.

The body was not laid out for the husband or children to come and say goodbye to Mrs. Robin, and they were not able to see the site of death. The practice of laying out the body is known as Last Offices (Quested and Rudgett 2003). The nursing team on the ward would have been responsible for preparing the body to be taken to the morgue. The family were not invited to be part of this process nor were they informed about this procedure.

## **10. Chapter Ten: The ethnographic ontology of lupus**

This chapter will draw out from the case study an ethnographic ontology of suffering from lupus (Charmaz 2007, Mol 2002). It will chart the pattern of sufferers' experience of living with lupus within the community and as an inpatient in an acute hospital setting where the end of life scenario is experienced. Four diagrams are presented as part of the process of conceptualisation. All the diagrams are associated with fulfilling the objectives one – how lupus sufferers live with their illness; objective two – explaining the role of carers in supporting lupus sufferers and objective three – exploring the role played by health and social care professionals. The author presents below conceptual diagrams. They represent the outcome of an analytical process developed by the author. The first conceptual diagram, in figure sixteen will be used to represent the fulfilment of objective one in the context of the specific lupus narratives. In combination all the concept diagrams represent the lupus sufferer's experiences in the community and acute hospital setting, where end of life is the prevalent issue. The first diagram that has been drawn from the findings and relates specifically to how lupus sufferers and their carers perceive the hospital encounter. The author believes that this represents how carers feel about the encounter with health and social care professionals. It is a generic depiction of how lupus sufferers and perhaps other patients with a chronic illness may have to adjust when coming into contact with health and social care professionals.

Figure 12: Conceptual diagram 1



“Events” and “strategies” are the two core categories of ontological entity that were used to constitute the thematic analysis of the four sets of lupus narratives. The events and strategies coded from the data have been displayed in the diagram above represented in various coloured cells. There are two sets of numbering systems assigned to the cells to represent patterns in the likely experience of people who are healthy and lupus sufferers specific care pathway.

For the purpose of discussion a non-numerical graphical display has been used with the x-axis contextualising action strategies across four domains. Action strategies are the moment-by-moment actions that individuals utilise in order to get through the day. The domains which are part of the action-strategies include the person’s self-defined well-being, the activities of daily living that they set out to achieve each day, their reliance and association with people in their social circle and finally the levels of

interaction that they are inclined to have with members of the medical profession (as an example of health and social care professionals).

The y-axis depicts usage of personal action strategies by the lupus sufferers. Personal strategies involve specific entities of linking cognitive processes to physical actions. The greater the progression up the y axis the greater the level of intense effort that has to be made on the part of the lupus sufferer to combat the illness and a range of symptoms that threaten their ability to achieve comfort or wellness in the day or night. All the cells within the matrix with the exception of the four hexagonal shaped cells and the central multiple events cells - represent personal strategies utilised at some point in their life (whilst living in the community).

The hexagonal shaped cells each signify in an arbitrary manner the lupus sufferer's health status as perceived by other people (including health professionals, relatives and friends). The average person, without lupus, experiences health and illness not dissimilar to that identified on the pathway as identified in cells one to five. At cell number one, the person regards himself or herself as healthy. At this stage the doctor is unaware of their patient's health status. The person utilises low levels of personal and high levels of action strategies. As they progress along their action strategies they regard their life as healthy and successful along all aspects of their personal domains. If they do become unwell with an acute illness they visit their doctors (at cell number four) and after a period of intervention progress to a state of being healthy (cell number five) and eventually returning to cell number one. Most people in our society live between cells one to three until they become unwell. At some point in their biography lupus sufferers do experience this level of wellness possibly before they have become ill. However, although they experience good days and bad days any experience of consistent respite of this nature is short lived for the lupus sufferer.

The starting point for lupus sufferers within this case study has been identified as cell labelled LS (Lupus sufferer). The rest of the cells all coded with the pre fix L followed by a number representing in chronological form a typical journey made by lupus sufferers. The cell LS is therefore represents a state where the lupus sufferer is living with their illness symptoms and enduring them in a private manner. The lupus sufferer in the personal and well being domain oscillates between high and low levels

of personal strategies often as a result of yielding to the symptoms, reflected in theme conceptualised and labelled as statements of *suffering*. The cell LS marks a point where illness symptoms are still being hidden from family and relatives. It is an intense space for the lupus sufferer who is utilising a high degree of personal and intense strategies to get through each daily cycle. L1 is the next cell in the journey. It is the theme conceptualised as *self-analysis*. This is a stage where the person is in a position to take “time out” from the struggle to reflect on how they are getting on. It may be a time of reminiscence about periods in their life, which bring them fond memories of their former skills and abilities. It may be an opportunity for the person to make an inner calculation of hope and aspiration about what actions they will take to overcome the trauma of living with the symptoms.

The cell labelled L2 is entitled *limitations to function*. At this stage the lupus sufferer acknowledges the tasks and activities that they are struggling to achieve. These may include essential activities of daily living such as getting on and off the bed, having difficulty climbing into and out of the bath and going up and down the stairway.

The next stage L3 is known as the experience of *Multiple Events*. It is characterised by a process of personal implosion of positive coping skills for the sufferer as they acknowledge that a whole barrage of surprise symptoms and ailments is overwhelming them. This experience affects the person’s sense of self and personal identity. They use this stage to question their existence and either become more stoic in their reactions or relate to surreal (often mythical or spiritual) aspirations of themselves. Compared to all the other cells in the diagram this is the *renegade cell* as it aims to destroy all forms of hope for the sufferer as they become overwhelmed by the extent of the trauma that they are falling victim to. All of the informants in the study experienced a high level of events having an impact on their body before making substantial contact with another person for advice, consultation and ultimately seeking help and assistance.

The next process, which arises in cell L4, is the *overload principle*. Not only is the lupus sufferer burdened by the magnitude of events that are happening to them, they make a conscious mental and physical effort to fight back. For every symptom experienced the lupus sufferer counters with strategies in direct correspondence to the



negative events that they are encountering. Initially this seems to be an effective strategy. However, most personal strategies are stopped by the persistent occurrence of more events. They fail to be long lasting and sustaining. This is described in cell numbered L5 as the *arrested strategy*. The lupus sufferer has to recover from the demoralising effects of failed attempts to alleviate their suffering. The cell L6 entitled statement of suffering represents the expression of their *suffering*. These are swathes of expressions described as lamentations, which exist throughout the narratives where the person talks in mournful sorrow about what they are going through and the frustrations around being no longer competent to carry out the activities that they once mastered in an earlier stage of their life. They are expressing hopelessness and total sadness about their situation. Without realising it this becomes a powerful strategy in itself for lupus sufferers who from this mournful perspective discover meanings about themselves and their resolve to fight another day or tackle another situation. An example of this is represented in cell labelled L7, entitled equipment assessment from social services.

For lupus sufferers it is the realisation that councils as well as health trusts provide help for people who are struggling to live independently within their home due to permanent and substantial disabilities. All of the case study informants reached a point of realisation that their home environment was a constraining factor limiting their mobility and independent living needs. They made contact with their local council social services department enquiring about an Occupational Therapist's assessment. The aim of the service is to provide a statutory assessment under the Chronically Sick and Disabled Persons Act (1970) and NHS and Community Care Act 1990 (OPSI 2006e) guidance in order to qualify for stated funding to purchase equipment and adaptations to their property. These items of equipment and adaptations eventually helped them to cope and achieve mastery of activities that they were once able to do in a pain free existence and with less dependence on carers.

Carers provide support for their loved ones, but due to lack of training and preparation are faced with a lot of strain regarding the uncertainty of managing to support their relative in an effective way. The next cell is L8, which represents the point at which carers become uncertain about how effective they are in their role. The informants provide an array of information about their perception of the care that they receive.

There are examples of tensions that exist between the carers of lupus sufferers and the lupus sufferers themselves. In situations of uncertainty about the illness symptoms, the carers and the lupus sufferer become aware of the need to request further help and advice from a GP. The cell L9 corresponds to the point at which the lupus sufferer makes contact with a member of the medical profession (including a consultant's appointment) about their illness symptoms, which may be new or non-abating. Normally if medical consultants are involved, via their outpatient consultations, they confine their specific skills to the management of conditions within their area of expertise (e.g. Rheumatology or Nephrology). Once it is perceived that the scope for further treatment within one's field is limited, the consultant will refer the patient to a colleague who could offer more insight into the problem for the patient. This liaison work is usually carried out by way of a formal written referral to a colleague.

People with lupus suffer from a variety of other conditions. They experience a plethora of symptoms and complications throughout their life. The effects of these new or recurring symptoms coincide, interact and present a challenge to the doctors and the sufferer alike. Examples of these conditions include skin lesions, joint and muscle pains, and fatigue. Informant one for example frequently experienced many of them simultaneously, such as fatigue, arthritic pains, high blood pressure, skin bruises and shingles. The intervention made by the doctor can result in prescription of medication or even result in the recommendation for admission to a hospital ward for further examination.

Thus the journey highlighted in the diagram above is common to chronic lupus sufferers. They often experience a flare up and ultimately require hospital admission. The whole journey constitutes the concept of suffering. It is characterised by the experience of being on the receiving end of rapid and uncontrollable negative experiences, within the context of provision of services by health and social services that do not have standardised approaches for communicating the essential points to carers and relatives about what they can and cannot do. The lupus sufferers are on the receiving end of rapid and unrelenting episodes of change and features bodily disturbances, multiple and unpredictable. The sufferer reacts by utilising a range of personal action coping strategies. These strategies operate at many levels. The levels can be individual, physical (e.g. change of posture or exercise), psychological (e.g.

prayer, mental focus of positive tasks, hope), social (e.g. relying on help and support from a relative or friend). Not all strategies are positive. Some can have unintentional negative consequences (e.g. a carer misunderstanding what is expected of them). The coping cycle has a flow and a direction.

Visiting the doctors occurs after many hours and days of the person getting to grips with their symptoms as well as talking to other people that they are related to. The purpose of the visit to the GP in essence is to seek help and support. As a coping strategy the perceived outcome can be positive or negative depending on the nature of the discussion that has taken place between the lupus sufferers and doctor. At least three of the four informants reported occasions where they were dissatisfied with the level support provided by the GP. The GP's role, in addition to being attentive listeners, is to provide advice, medication prescription or referral to a specialist within a hospital setting.

Additional data was gained from correspondence between the GP and the main consultant of informant one, made available after her death. Studying a series of letters in informant one's medical records, the nature of the exchanges between the doctors reveal how cordial the professional relationships can be between colleagues. This reflected a genuine commitment to proceeding with certain tests to rule in or rule out a particular diagnosis. Sometimes the GP was influential in recommending hospital admission if the illness was severe enough.

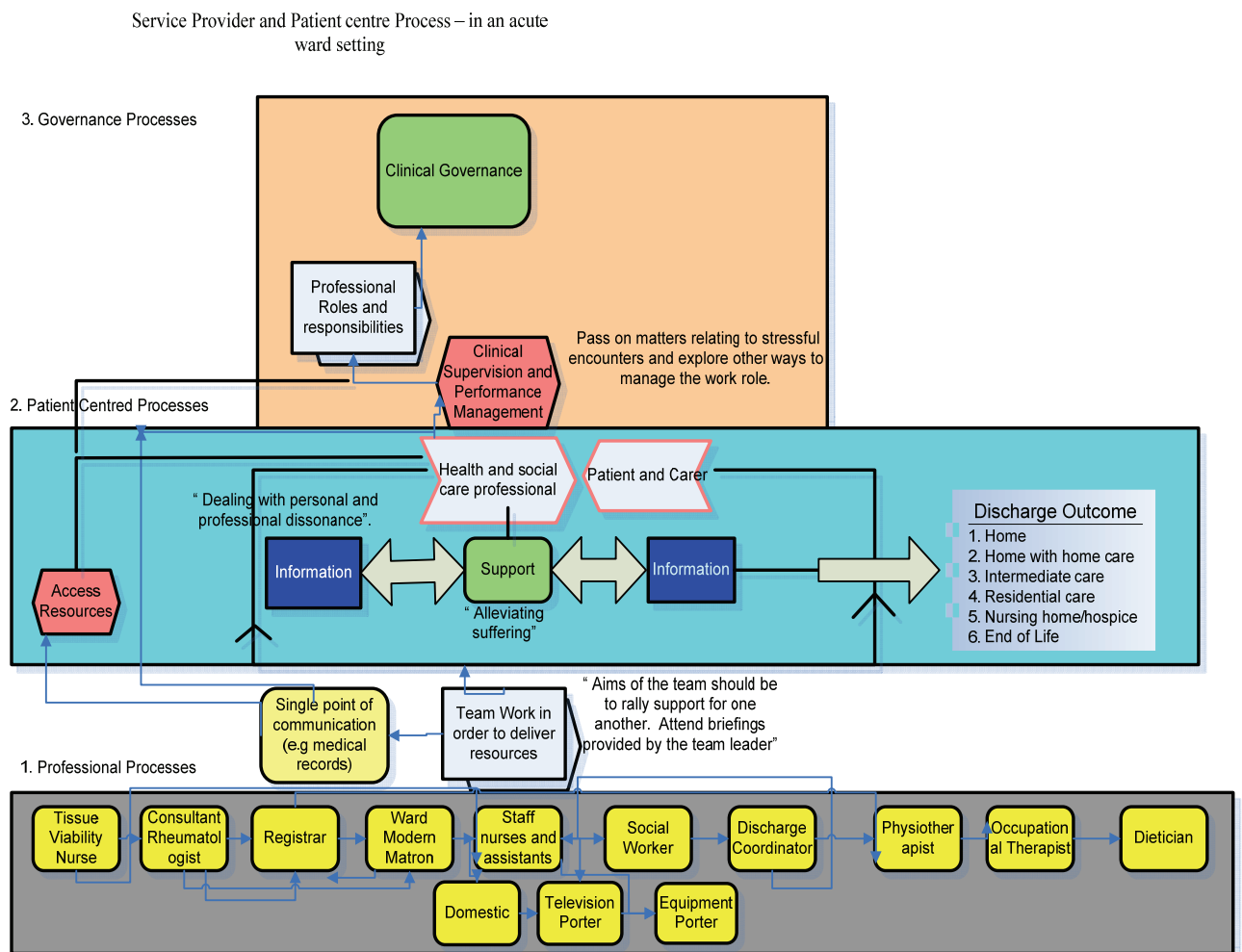
This was not the only route for hospital admission. If the bodily symptoms were severe enough, the family could request an emergency admission. For the lupus sufferer hospital admission would correspond with a whole series of strategies (to combat the events being "arrested"). The term arrest is used here to denote a stoppage in a plan that was designed to ease the experience of suffering. The person at this stage is officially unhealthy and unwell. There is also likelihood at this stage that a range of the lupus sufferer's social contacts are aware that their relative is unwell.

Whether or not lupus sufferers are discharged home, the aspiration of health and social care professional is always that they become healthier than when they were admitted to the hospital ward. The journey for the lupus suffers from the stage LS,

being unwell to stage L10, healthy, is not a linear relationship. It is chaotic, hesitant and marked with uncertainty on the part of the lupus sufferer about their readiness to access professional help and support from health and social care professionals.

The life space of the lupus sufferer changes when they are admitted into hospital. The following diagrams are based on the findings to emerge from the ethnographic observation of informant one. The conceptual diagram has been entitled *service provider and patient centred process in an acute ward setting*.

Figure 13: Conceptual diagram 2



At the centre of the diagram is the meeting point of health and social care professionals with the patient (and their carer, although this is not considered mandatory). This area has been entitled *patient centred processes*. At this stage in the relationship the lupus sufferer (if they are conscious) will provide information about what they are experiencing. At the same time they will receive information and support about what stage in the intervention process they are in. This section of the relationship provides an opportunity for the lupus sufferer to be reassured as best as possible about various aspects of their care.

The intervention aims to ameliorate any aspect of unbearable suffering and to explore possible answers to challenging and overwhelming symptoms that are experienced. Sometimes it is not possible for health and social care professionals to produce or discover answers due to the complexity of the illness. Sometimes this is the stage where personal and professional dissonance between patients and the health and social care professionals occur, especially if the patient (or their carer) believes information is being hidden from them.

The main aim of both parties is to progress towards an outcome that can enable a safe and successful discharge into the community. In terms of discharge outcome there are several options or permutations of possibilities depending on the recovery of the acute episode known to lupus sufferers as a flare up. The ideal scenario or expectation from all parties (e.g. carer, patient, and health professionals) is for a safe and successful discharge into care in the community. This can be with or without the intervention any formal home care service assessment organised by the hospital-based social worker. In some cases the patient may require a period of rehabilitation in a specialist residential facility. The primary care trusts and local authority social services departments often jointly resource these, known as intermediate care settings. After a standard period of care (e.g. of six to twelve weeks) that patient is discharged to return to their own home perhaps with the support of home carers and social services funded equipment and minor adaptations.

In certain circumstances where the patient is dependent on paid carers to manage their dignity needs on a permanent and substantial basis (e.g. meal preparation, medication issuing, washing, dressing and toileting) returning to their own home may not be an

option and transfer of care to a care home will be the appropriate stage following an application for funding by a social worker after an assessment, of the person and their carer, has been completed. The final option in the discharge process is end of life care. This will be contextualised in a later section, as this was the basis by which the carer's ethnography became involved in the study.

The activities of the health and social care professionals have been identified in layer one as professional processes. Layer one is characterised by a whole range of professionals comprising the multidisciplinary team aiming to work together to achieve the common aim of helping the patient have more controlled symptoms and ultimately becoming medically fit for discharge and a return home to a functionally able lifestyle. The roles and responsibilities of each of these individuals have been established through years of professional training (like a kind of apprenticeships known as clinical placements amongst medical, nursing and allied health professionals) in order to become reasonably versed in how to contribute their particular skills and intervention to assist the life of the patient whilst in their care.

The main leading professionals involved in the management of the care for the lupus patient is the consultant physician and the ward matron. The other members of the multidisciplinary team contribute their expertise as advisors on a referral basis from the ward matron. The patient's information is documented in the patient's medical records and observation charts often located on a clipboard at the foot of the patient's bed. The medical and nursing team can quickly update and access this information when assessing all the patients on the ward. The medical records, which include the care plan, are the single point of information management for the duration of the patient's admission episode. The medical and nursing care workforce work in split seven and a half hour shifts throughout a twenty-four hour rotation basis. In the absence of the most senior professionals a deputy is delegated to take responsibility of the management of the ward and the care of the patient.

Hand-over meetings regarding the progress or deterioration of the patients are held when each new shift commences. The outgoing team finishing their shift provide information to the incoming staff. All patient issues that have been observed by the ward team are discussed and main goals are established and reviewed. Whilst this

meeting takes place a decision is made to pause direct patient care, and provide a cautionary observation and listening role should a patient need any help.

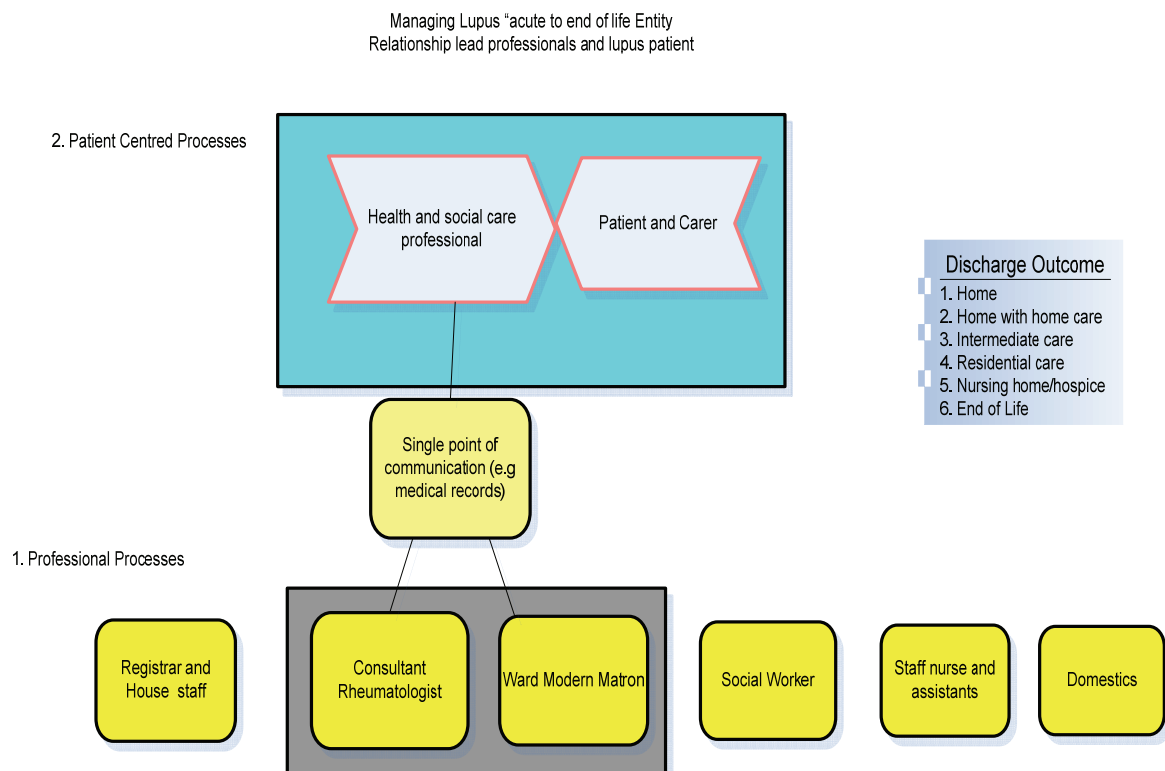
If the ward team requires resources to enable more appropriate intervention for the lupus sufferers, they are agreed at the handover and later requested from the appropriate department, usually by the lead nurse making a telephone call to a particular department (e.g. x ray photography). Several ancillary grade staff that have no particular professional grade or direct responsibility in patient care interact with patients and carers in an informal way, including the ward domestic, the television porter or the equipment porter. Each of these ancillary grade staff has a particular utility function and is expected to provide this role without direct involvement in patient care. They do however, witness examples of patient suffering, patient care, and family stress and occasionally provide indirect support to the professional grade staff and the lupus sufferers and their relatives. Sometimes they are able to reveal information to the carers about what they may have observed although this form of information is not documented as clinical practice. The list of ancillary staff reported in this study is not exhaustive but the ones included here are those that were involved in the life space of informant one.

The third layer of this c diagram depicts the governance processes. All health and social care professional's work within a governance framework. Some aspects of the framework are managed by the organisation that they work for. These may include the requirement for all staff to have an annual appraisal of their development as well as agreed supervision meetings and an opportunity to document their clinical professional development within the context of the national database on Knowledge Skills Framework (KSF). For staff employed by social services these elements are similar with the exception of the KSF. The supervision meetings are a valuable opportunity for frontline staff to share their concerns about work stresses, and reveal incidents that may impede practice and development. The named supervisor should help the practitioner to explore various ways of coping as well as provide re assurance and confidence building strategies to enable the practitioner to return to the ward environment with greater clarity about their role and performance. The details of staff governance are not considered to be essential for patients and their carers to know about. They are therefore not party to what levels of support that a particular

practitioner may be receiving to enable them to improve their interaction and intervention with the patient (and their carer).

The next section will drill down closer into the lupus sufferer’s experience toward the end of life. The diagram below, figure 14, is entitled Managing Lupus “acute phase” to end of life entity relationship lead professionals and lupus patient.

Figure 14: Conceptual Diagram 3



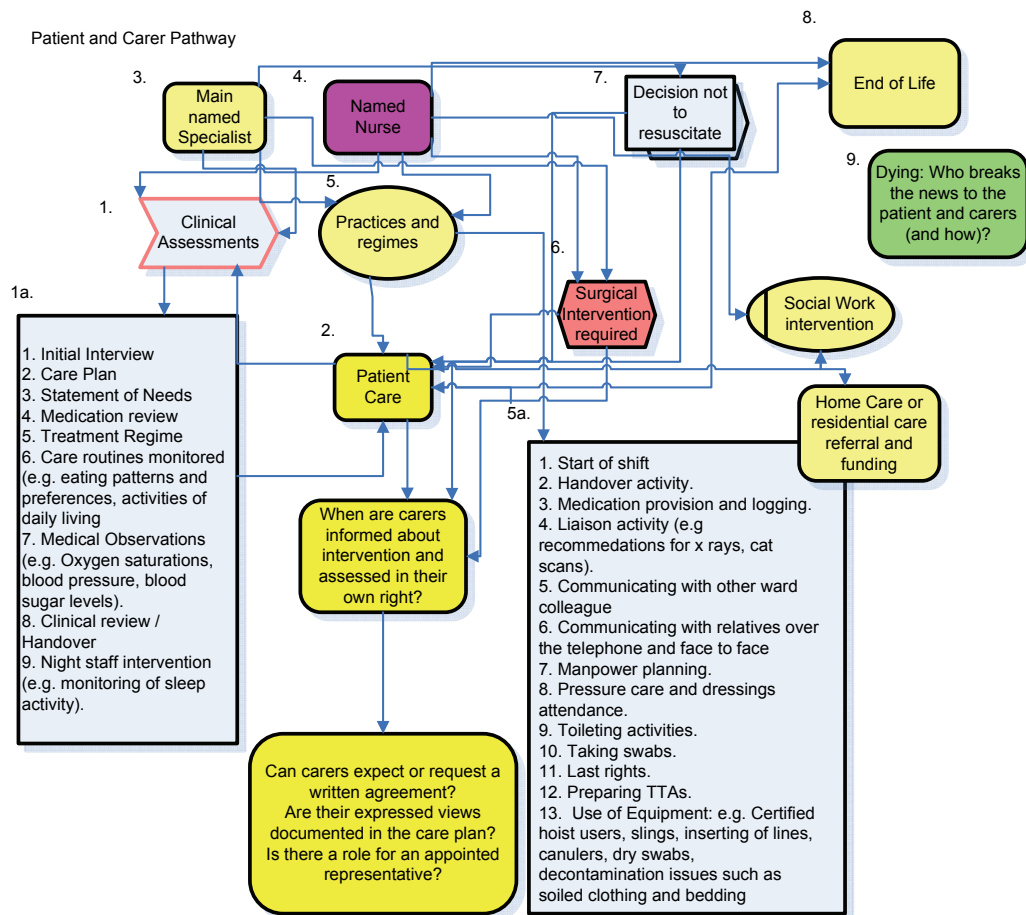
As the period of discharge draws nearer the process of managing care presents certain challenges for the multidisciplinary team. Professional processes are more cohesive than the generic approach offered in the figure 14. There is a strong relationship between three parties: the consultant, the ward matron and the patient and to a lesser extent the patient’s carer. The disjointed boxes either side of the consultant represent the direct relationships with subordinates involved in the care of the patient. They follow the instructions of their line manager/professional and provide appropriate feedback to the medical handover. The discharge outcome is also a remote target that



becomes a pressure point for health and social care professionals challenged to account for delays in discharge outcomes for all patients on the ward.

Drilling down further another diagram, figure 15, represents the patient and carer pathway in respect to the end of life journey for the lupus sufferer.

Figure 15: Conceptual diagram 4



The conceptual diagram above indicates a whole raft of activities that take place on behalf of the patient by the lead health professionals known as clinical assessment and practice regimes. Cell numbers 1, 1a and 5 indicate examples of these activities and intervention that are done to and for the lupus sufferer. An example of a specific and invasive intervention is the decision to perform surgery. The consent of the patient is sought and they are invited to sign a document presented to them by the medical team to perform surgery after the clinician has assessed the risks and procedure explained. The carer is not invited to be part of this decision making process where the adult lupus patient requires surgery. As the lupus sufferer progresses in their care, if they are not responding to treatment and deteriorating in their health, the medical team led

by the consultant and supported by the lead nurse will discuss to what extent their intervention will be considered as useful.

When intervention is no longer considered useful, one clear indicator is the decision not to provide resuscitation, should it be discovered that the lupus sufferer's heart has stopped functioning. This is colloquially referred to as "not for the twos" or "not for resuscitation". A label is often placed above the patient's beds indicating this. The family are not required to agree or disagree with this as the medical team are deemed to be the lead in what is in the *best interests* of the lupus sufferer whilst in their care. The family have no recourse to appeal this clinical decision. They have to accept it and live with the uncertainty of how they will cope when their relative's heart stops.

The role of the social worker is not clear at this stage. They are trained professionals with expertise in counselling about death and dying and are not requested by the medical team to be part of the breaking of the news about dying support processes, or to support vigil practices. In the diagram there is no connection or link between the social worker's role and that of the cell entitled death and dying. The carers at this stage are left on their own to make a cognitive connection between the doctor's decision not to resuscitate and introduce the idea in their mind that their relative with lupus is dying. Not all relatives want to ask the question: "How long has she got to live doctor?" especially if they are in a process of denial or not satisfied about the level of care that their relative has received to date. There is no suggestion made by the medical team that the lupus sufferer is entering an end of life stage of care and there are no options offered for transfer of care to a hospice environment; families of lupus sufferers are not invited to sleep in the ward to provide vigil care. The carers are required to self-navigate their way through the process of the "assumption" that their relative may or may not be dying without guidance or support from a qualified social worker.

## **11. Chapter Eleven: Discussion**

### **11.1 Introduction to discussion**

The case study comprised of the narratives of four women with lupus and the detailed observation by the carer of one of the informants towards the end of life and final death. The social phenomena of the challenges faced by service providers (paid and unpaid carers and policy makers) become alive for this study when explored alongside consumers (lupus sufferers') perspectives on suffering (Sidell et al 2003). All participants in this case study experienced changes in their access to services affecting their perceived ability to cope (cf. Bertino 1993, Halverston 1992, Mechanic 1978, Sheaf 1996, Victor 1997,). The whole study adds up to an ethnographic ontology of lupus (Charmaz 2007, Mol 2002). Ethnography because this was the means by which the phenomena was investigated and ontology because a whole series of interacting entities were uncovered, explaining for the first time in medical sociology the life journey made by women with lupus in the context of health and social care provision in the UK. In other words a study of how things that happen to people who are ill and actions taken to resolve them by not only on an individual basis but by carers and policy makers (Baker and Winginton 1997, Bury 1982, Mol 2008, Williams 2003 and Carr et al 2008).

Constructing a specific knowledge base from the perspective of lupus sufferers experience and reporting on their dying experiences is new to medical sociology and this is mainly what this case study has added to the sum of human knowledge in medical sociology. It reinforces our understanding of the role played by professional knowledge embedded in health and social care professional process and practices and largely influenced by the national political context (Good 1994, Kubler Ross 1990, Williams 2003, Mol 1999, 2002, 2008, Mol and Law 1999). This knowledge embedded in practice in turn structures the world of health and social care for lupus sufferers and their carers and is based predominantly on the intellectual grounding that health professionals received as a result of their training (cf. Mol 2002, Hugman 1994, Lupton 1994).

The coherence and consistency of the knowledge-world of the professionals and the knowledge-world of the sufferers may be disrupted, when treatment assessed solely

through the rule of medicalised processes may confound the sufferers (and their family's) assessments of care in the face of an unexpressed narratives of illness.

This case study has not created an ethnographic ontology of lupus sufferers using a conflict based approach, just for the sake of doing so, or because of any hostility toward the biomedical model, which remains the framework of medical discovery (cf. Rose 1989, 2007). Rather it seeks to explore the needs and possibilities for increasing interactive capacity of the knowledge-worlds of health professionals and their clients, within the context of health and social care policies, professional practices and the social impact of these on lupus sufferers and their carers (cf. Mol 1999, 2002).

The discussion of the main narratives of the lupus sufferers, using a health belief model enables preventative actions to be analysed as strategies. Strategies are essential parts of the behavior of someone playing out a 'sick role' and leads to the conclusion that understanding, and working with such strategies is essential if health and social care assessments of sufferers are to inform effective care provision for them (cf. Baker and Wiginton 1997, Friedson 1970, Janz and Becker 1984).

Current debates in medicine and latterly medical sociology, for example, in the area of genome research, are being forced to recognize that biomedicine has merits. Perhaps social-constructionist critical discussion undervalued the merits of biomedicine. It is important to acknowledge that it may also still have unrealized benefits to deliver to lupus sufferers, such as possible answers to the problems of autoimmunity, which impact on a person's ability to fight off viruses effectively (cf. Mol 2008, Tauber 1996, Rose 2007). Continuing bio-medical research at the molecular level is also a valid part of the socially construction– and re-construction, or social re-ordering – of the social processes of sickness, suffering and dying as policy affecting the interactions between patients, carers and NHS staff, but the former cannot just substitute for the latter.

Rose provides a poignant message when he states the following: *[T]oday, however, biomedicine visualizes life at another level –the molecular level. The clinical gaze has been supplemented, if not supplanted, by the molecular gaze, which itself is enmeshed in a “molecular” style of thought about life itself* (Rose 2007 p 12).

The challenge remains for society to determine if it wishes to increasingly medicalise social problems that emerge in places such as hospital wards when patients present. negative coping strategies, failure to talk throughout treatment. Medicalisation is prevalent when it takes over the terrain previously led by social workers, volunteers and lay people to offer support and consolation during times of pain and suffering when medical intervention failed. As Mol argues: ‘... *[it] would be wiser to try to improve care on its own terms*’ (Mol 2008 p2).

For all the critiques put forward of relevant theories of medical sociology that biggest threat to eroding human rights and fairness is corrupt practices of human beings not prepared to offer a fair service for whatever reason. Health and social care professional practices have high levels of status in society and for this reason members of the paying public deserve a consistent minimum guarantee of high standards of care and communication.

*‘[M]edical jurisdiction extended beyond accidents, illness and disease to the management of chronic illness and death, the administration of reproduction, the assessment and government of risk, and the maintenance of a healthy body’*(Rose 2007 p 11).

Whether we dress the problems of social and health inequality in populist and sometimes divisive language such as ‘medicalisation’ or ‘the social model’ we cannot get away from the fact that those in terminal care with lupus require their dignity around how and where they die not to be exploited on a daily basis. What is required are new laws to promote living wills so that people wishes can be carried out to the letter if they lose the ability to communicate for themselves.

What remains is the tiring process of identifying how and why health professionals are unable to communicate effectively with members of the public about "end of life" care resources and process. Why does the rhetoric of planning and policy development never translate into truly fair levels of services for all? Is there a genome factor for human behaviour among lazy politicians, lazy health and social care professionals? This ethnographic ontology of lupus is an attempt to

systematically identify the relationship between patients, carers, health and social care professionals, legislation, members of parliament, government departments and policy papers.

Earlier chapters of this case study have provided a way of appraising the health and social care needs affecting people with a chronic illness. The key theoretical framework that has influenced the body of the research has been symbolic interactionism (including data analysis and literature reviews of secondary published sources). The central tenets of this research have been that individuals are social actors with a story to tell. When these stories are expressed through narratives it brings to the fore how their identity within a wider cultural setting of health and social care is shaped and affected (Good 1994, Mechanic 1978). The findings of this study in particular show that the narratives of lupus sufferers can influence how decisions are made to plan and deliver services to lupus sufferers. In addition their carers views need to be recorded formally in a carers assessment and reviewed at all points of the care pathway including the hospital ward setting in order to ensure that their needs are taken into account.

Understanding how and what provision welfare authorities have made towards meeting people's needs have been derived from letters written by doctors, literature reviews of secondary data sources as well as through the author ethnographic experiences. These additional accounts have helped to highlight the service effectiveness as well as specific service shortfall to lupus sufferers. It is a given that health and social care organisations cannot be omnipresent and perfect in every aspect of their service delivery. During end of life care for lupus sufferers there is an absence of perfect intervention, the next best solution should be clear, well timed, accurate and honest communication towards the lupus sufferer and their carer (DH 2007a). In this study it has been highlighted that pledges from central government to ensure effective communication during end of life care did fail to live up to its promises in the case of informant one. Members of the public including carers and loved ones would like to know that full consideration has been given to where their relative should spend their last days (HSC 2004, DH 2006a, DH 2006b, and Age Concern 2005). People are unhappy about not having a real choice and insist that universal services be regarded as a basic human right (Turner et al 2003). The

government has made repeated attempts to convey a wish to take the needs of their citizens into account when planning services including end of life care. In this study, the author discovered that this was not the case.

The patient and their family are encouraged in our society to take responsibility for their actions and read between the lines of what the health and social care professionals are trying to communicate. This is not good enough as health and social care professionals should be more supported to offer skilled services at communicating the news about whether a relative is dying. When it comes to chronic illness management towards end of life a lot more care has to be taken to ensure that effective communication protocols are in place for all services led and managed by the NHS and local authority.

*‘[P]rofessionals should provide good information, and properly implement the interventions for which they opt. They should be knowledgeable, accurate and skilful (Mol 2008 p 63).*

In exploring the activities of welfare authorities, value systems that drive central government and local government have been analysed and contextualised in chapter two and further explored in the literature review of chapter three. Examples of those values have been represented by extensive government guidance and legislation (e.g. The Carers (Recognition and Services) Act 1995 Section 2 (OPSI 2004b). The majority of health and social care legislation of the past 10 years take the view that the taxpayer as service user and their carers have a greater say in the development of health and social care arrangements.

*‘...[b] ut it is patients who determine the direction to be taken. Patients manage, doctors implement (Mol 2008 p64).*

Currently not only are there established expert patients as advisers to Primary Care Trusts but determined efforts to introduce expert carers’ programmes (DH 2009). This is an example of the push by government to value the role of the sufferer and their carers in aspects of service planning and service delivery. However, when those values are compared with the experiences of the informants and the carers as in this study, it is clear that real needs are not being met in certain circumstances. An

example of this is carers not receiving with an assessment of their needs in hospital ward settings where lupus sufferers receive end of life care. The know-do gap prevails. The author would describe these phenomena as rhetoric of unimplemented reform. This is where policy and requests from central government are being constantly repeated over a period of years and re-expressed by central government with only limited follow through at the front line to make the policy changes become a reality) thus leading to gaps continuing to exist in services provision and unmet needs to certain groups such as lupus sufferers.

Findings from this study indicate that the patient or sufferer as consumer has a story to tell about their experience, which is often not, heard or recorded in depth. This voice is personal to them even when they are suffering within the confines of their own space, outside of an organisational social structure of that of a doctor's surgery or social workers initial interview (cf Frank 2000).

An example of the outward manifestation of the rhetoric of unimplemented reform is the degree of policy iteration in the legislative and practice intervention level. It takes place when the links made between the individual's experiences (identified within the narrative) and the links between those individuals and other individuals within and outside their network. The constant message emerging from the findings is that services to lupus sufferers are not consistent with the promises from the Department of Health and central government in general.

Daily arrangements and interactions force the sufferer to repeat often-futile approaches, as they live a life in a dark place beyond coping. These measures often include relationships they have with manufactured devices that are used to sustain dependency (e.g. medicines and medical equipment) connectedness with service providers through eligibility criteria, policy and legislation. Therefore people with lupus suffer before they enter hospital; during their stay as an inpatient and in certain cases when their dying fails to be managed effectively. In other words, their experiences are challenging from a biomedical and social conformist point of view. The management of their chronic illness is inconsistently provided for by health and social care professionals.



The act of completing diaries and writing an ethnographic account from the perspective of carer was a way for informants to make sense of their lives through constructing narratives. Narratives emerged from the inner being of the person. The person's capacity to think through their life and reflect on what was going on around them in real terms provides the advantage of the experience of writing down information about their lives. The specific entities and interactive details of the person, the people, the environment, the equipment and regulations contribute to a system always trying to reach coherence. Narratives and their analysis are a way of moving forward to redress some of the imbalances in UK society. A specific example of an imbalance includes the provision of services and the weight of expectations about what lupus sufferers and the carers need in terms of basic communicative rights.

An historical approach and appraisal of health policy and NHS social care practice is used to illustrate that people suffering is universal despite their unique biographies. The focus on individual experience is used to show that their illness narratives are the signifiers of meanings about experiences in terms of relationships, feelings, emotions and suffering narratives in symbolic forms.

Lupus sufferers have no choice but to accept narrowly defined services and live (and die) with the consequence of poorly interpreted guidance from the Department of Health (e.g. legislation on carers or referral criteria for hospice care). There has been no consideration the need for greater parity with cancer sufferers, to determine whether their needs are comparable to that of an end stage cancer sufferer.

## **11.2 To what extent was objective one sufficiently explored?**

The following section aims to examine the extent to which objective one been has been answered. Objective one, introduced in chapter one, was as follows: To explore what life is like for people with lupus and identify processes of survival and dying within the case study.

This study looked at effectiveness of language as a tool for exploring different realities of living with an illness and being a recipient of voluntary and statutory services. The themes are strong indicators of the challenges faced by people with the illness lupus. As a study the results challenged the conclusions offered about living

with lupus by Baker and Wiginton (1997). They alluded to a range of positive coping strategies offered by people with lupus. This study talked more openly about living beyond failure when coping strategies are seen to fail.

Lupus sufferers in this study were able draw from their own personal experiences to talk about how they manage by writing down their stories and explanations. Narratives are forms of relating experiences as stories verbally or in writing. To narrate is to tell a story based on one's experiences or viewpoint of an event and hope that the listener or reader can make an empathetic connection with that experience. In this study narratives allowed the women to describe in a reflective manner their feelings and opinions on a given set of happenings, in particular the extent to which experiences and situations impacted on their lives and that of their significant others.

The findings showed how narrative has structure to it (cf Kelly, 1992). Indeed informant four's entry was the shortest contribution made by the four women, comprising only a few pages, yet there is enormous power in the prose that she presents. An example from her narratives of her expressions is as follows:

*'I really just wanted to die, just to be out of pains and misery...'*

These challenges about life link with a person's spiritual experiences; daily drudgery and toil with illness experiences often lead people to identify meanings of suffering within themselves from inspirations, which could be autobiographies of others or religious activities – such as prayer and worship. Religiously guided funerals are still very common and a reflection of cultural mores and an expression of community and unity from generation to generation. Two of the informants within this case study had a strong sense of connectedness to Christian worship.

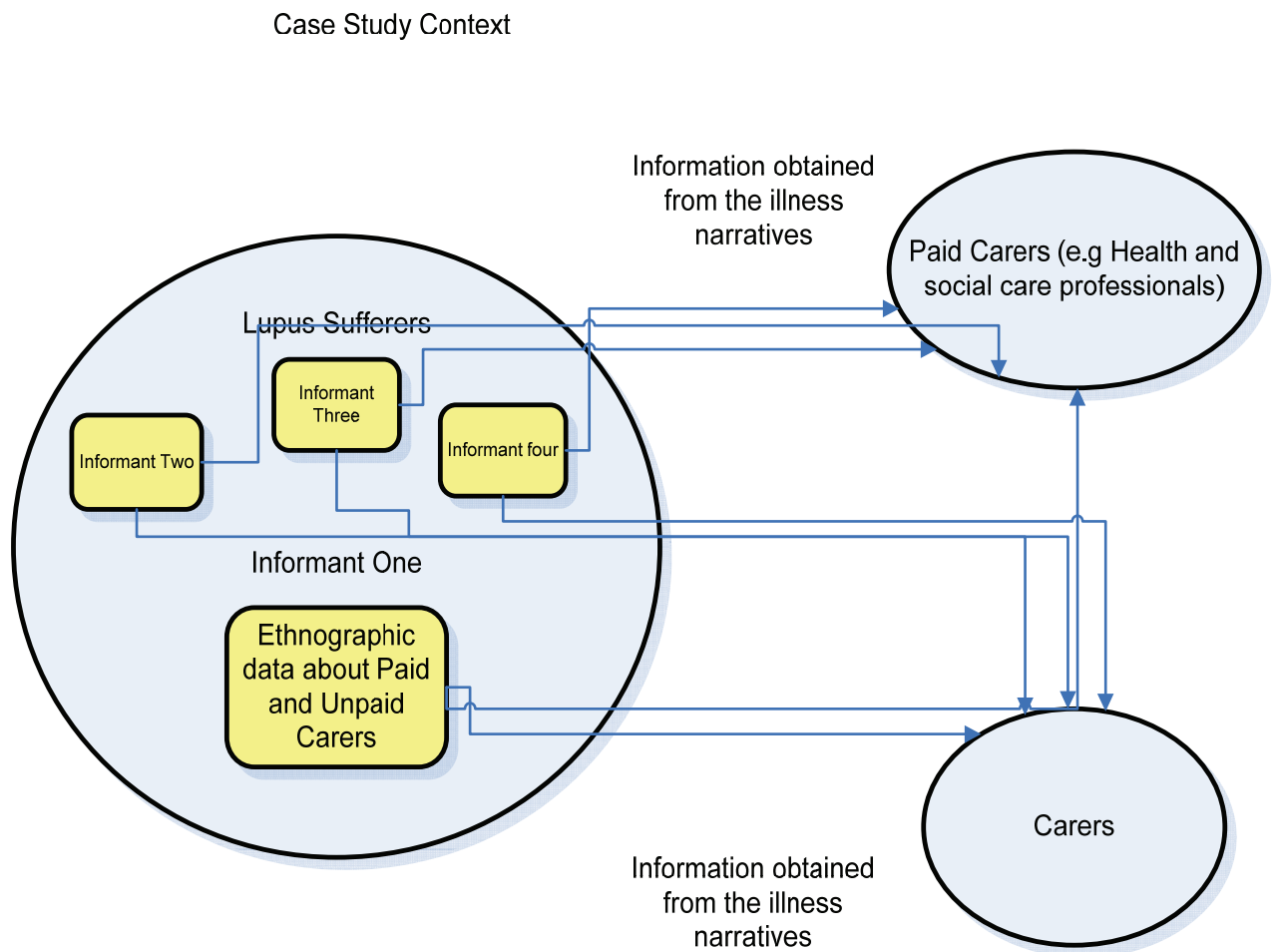
Informant four's narrative of suffering is high in poetic literary form and is revealing evidence in this study that lupus sufferer's expressions are shaped by one's cultural surroundings over the timeline of the person. The few lines she uses appear to have rhythm and make use of metaphor and oxymoron to display her pain and emotions. This is the subtle use of oxymoron; the conflicting desire to live and die. These suffering narratives use contradictions that exist side by side to reflect the desperate

desire to regain balance in one's life. Informant four may not have realised this but her diary is a powerful cultural artefact of suffering narrative or lupus narrative.

### 11.3 To what extent was objective two sufficiently explored?

Objective two wanted to explore how carers manage and support their relatives with lupus and to identify processes of enduring for carers within the case study. In order to develop the investigation about carers involved in the care of the lupus sufferer, the role of the carer, was reported on based on data obtained from two sources within this case study. The first source being the third person accounts about carers written by the lupus sufferers themselves and the second source being that provided by the author's ethnographic accounts in chapter eight (which also utilised secondary data) and nine, which presented end of life observations within a hospital ward setting. The way in which this worked is presented in the following figure 16, below

Figure 16:



The sample of this research is too small to make wider generalisations. The findings do however existentially inform debate about the issues that are at stake for future quantitative research with larger samples, which may seek to address some of the issues highlighted in this study such as end of life care for lupus sufferers and the dynamics of carer relationships in relation to lupus sufferers.

In relation to carer dynamics, this study also revealed that many official carers (e.g. spouses) might no longer be in a supportive relationship with one another. They could be “locked into a loveless marriage” for example. The adult child may be the “real” carer locked out of formal arrangements, between the health and social care establishment, due to the assigned role of his/ her parent who in law is the named next of kin (e.g. husband or wife) and thus the official appropriate person for health and social care professionals to be in liaison with. Yet the assumption that a spouse is the most appropriately identified carer to communicate with may not be appropriate. This study also showed that the importance of the wider social groups and networks of the patient was not acknowledged sufficiently. Sometimes these social networks provide valuable insight and support into the chain of command in the family during times of crisis. Their behaviour may however also cloud the picture for health and social care professionals when providing care to lupus sufferers within the hospital ward setting.

The author’s role as a carer within this study gave his ethnographic research effective access to the goings on (and problems) that existed on the hospital ward where his mother, Mrs. Robin died. He linked his personal values from childhood to adulthood and professional training into his ethnographic viewpoint. As a result, he was able critically to evaluate what he felt was going right or going wrong in the context of the ward setting particularly in relation to end of life care. The main discovery to emerge from the ethnographic approach was that health and social care practice was deficient in communication about end of life to the carers. In principle, this should not have happened (DH 2007a). The decision of health and social care professionals to leave a lupus sufferer, hospitalised for 12 weeks, to die alone, without the support of her family, around her was not good practice. Measures in good practice should match other standards embraced by health and social care professionals for people with illnesses such as cancer where gold standards in practice have been established in the UK for the last eight years.

The author's experience and observation may or may not be representative of what happens to the majority of lupus sufferers as they approach end of life care, but it is not merely anecdotal. The evidence based on the analysis within this study and ethnographic observations show what has happened needs to be accounted for in a conceptual explanation of the social contexts and processes surrounding lupus. The challenge for future research is to measure more effectively than this case study how health and social care professionals can bring about effective communication to carers of lupus sufferers about end of life care. There are varieties of processes of enduring for carers identified in this study. They include a mixture of living in a state of interdependence, with a lupus sufferer in an estranged relationship, poor family dynamics, provision of dedicated care by a spouse who often makes mistakes, and being helpless in the presence of qualified health and social care professionals before the spectre of the death of a loved one.

This study has also demonstrated that carers also learn about how the system works once thrust into the situation of taking charge of the responsibilities of the person with lupus. They study the meetings that their relatives attend with health professionals, they observe the impact of the intervention from statutory services (e.g. home improvements); they themselves interact with health and social care professionals to find out what recorded levels of progress are with their relatives within a hospitalised context.

A range of legal procedures and processes can allow the carer to negotiate on a stronger footing with health professionals, such as lasting and enduring powers of attorney (DH 2007, DCA 2006). Legal procedures within frameworks such as these can allow the named person to be responsible for carrying out their wishes in the event of critical care and even death. Without such a document in place health and social care professionals are not obliged to provide the main carer with information about the proposed actions that they wish to carry out (e.g. minor surgery or use of controlled drugs) in the patients best interest. Physical medicine, often the main field involved in the care of lupus patients could, with help from the government, utilise the good practice mechanisms developed in the field of mental health care. Good practice from the field of Mental Health (e.g. the application of the Mental Capacity Act 2005)

could allow patients to make advanced decisions about whether or not named health (and social care) professionals can be permitted or restricted from providing them with care toward end of life.

In addition the patient can assign a relevant personal representative, under deprivation of liberty safeguards, to take responsibility for negotiating aspects of their care if there are not able to do so independently. This is an area where services for people in physical medicine can learn. The findings from this case study prove that services and good practice regimes, whether examples taken from the Children Act 2004 OPSI (2009b) or Mental Capacity Act 2005 (OPSI 2009c, DH 2007d), are disjointed. It is uncertain why standards of excellence to promote timely information sharing are available in other services within health and social care industry and not available in physical medicine setting or health and social care services to lupus sufferers where those in the majority of adult age category receive treatment.

### **11.3 To what extent was objective three sufficiently explored**

This section aims to discuss how this study fulfilled objective three; to explore how lupus symptoms experienced by the individual are managed by health and social care professionals. Lupus sufferers by the very act of committing pen to paper and recording key aspects of their lives begin to take control of their lives and convey through their story their expertise and knowledge (cf. Beck 2000). This approach increases the health and social care professionals capacity to understand their suffering and intervene in a more client centred way. This study discovered that gaps in services for lupus sufferers are partly due to limited understanding of (or even attention to) their narratives and their struggles. Consequently health and social care professionals often fail to communicate properly to carers about what will happen to their relative in an end of life scenario, and fail to communicate why end of life lupus patients do not qualify for hospice care assessments. There is a failure to identify suitable professionals to play a role in offering counselling to families who may encounter death and dying for the first time; or possibly failure to invest in mental health services for people with lupus living in the community who could benefit for psychological therapy

Managers and health and social care professionals within health and social care settings promote a business ethos in organisational culture, which aims to ration/control resources to those in need. This type of practice is exemplified in the weekly reporting on the “delayed discharge” patients who have been identified as “medically fit” to return to their own home but for one reason or the other have not returned to their own home. This drive for economy reflects the political values held by civil servants (including health managers) and politicians (local and national). They dominate and shape delivery of health and social care policy through the political decision making process which is limited in its capacity to integrate the views and lifestyles of people such as lupus sufferers.

The health and social care “organisational” world helps to perpetuate a constraining structure, which slows down the pace of change described earlier as rhetoric of unimplemented reform. The term constraining structure because bureaucracies within those settings do not typify real change, but a predicted perpetuation of social processes by social actors (e.g. politicians, civil servants, directors of social services and health professionals) reacting to crisis as highlighted in earlier discussion such as the Climbié murder (Laming 2003) or the Aricept case (PEC 2007). On the other hand when the health and social care “organisational” world is expressed as social network it signifies a whole set of predictable and unpredictable routines, which affect individuals with lupus and their carers. The main part of the research this case study was therefore committed to highlighting the tensions that exist between individual patients/consumers of health and social care and service providers (paid and unpaid carers).

The organisational world contains many tensions and power struggles between workers at all levels within organisations. The impact on the role as service providers is important to study because of their duty of care enshrined in law. The narrative of health and social care service providers from the perspective of the ethnographer is used within this study to shed a spotlight on the happenings of health and social care organisations. This has been undertaken to determine whether expressions of work roles and equipment contexts signify processes amongst health professionals within organisations that aim to meet the service needs of its consumers. In particular the

extent to which advocates who identify with experiences of their service users are somehow able to influence local service policy.

Despite user involvement in present day health and social care management, there are still examples of how this is perceived by critical theorists as being not adequate or sufficient to reflect genuine partnership between individual consumers on the one hand and large monolithic health and social care system on the other hand.

Current “modernization” policies in the UK involve the need for lay people to have increased information towards judging the quality of medical work, and medical ethics. For example, chapter ten of the NHS Plan (DH 2000b) includes major increases in the citizen and lay membership of all professional and regulatory bodies, including the general medical council and looks at its expert patients and carers programme as a way of empowering patients. However, it is not certain that all NHS professionals actually want lay views expressed on these bodies. Lay representatives go through a process of training so that they know “what to look for” and the legitimate ways in which they can contribute.

In-depth illness narratives have strengths, which tokenistic systems of patient representation do not. They provide a platform for greater collaborative working between the health and social care professionals and the lupus sufferer and their carer. The tensions that exist between health and social care professionals on the one hand and lupus sufferers and their carers on the other hand are the result of poor communication between them. One proposed solution is to continue to seek to understand the struggles and find ways of communicating more clearly across the bridge of expectations between the lupus sufferer and their paid professional carers (cf. Walter 2002).

The aim of this type of new knowledge is to allow the sufferer to present their narratives to be part of the health and social care professional decision-making process. The person, through their ownership, and their body will truly become the subject of the study through the words of the person living with the illness (cf. Mol and Law 1999). The lupus informants within this study made very little mention of the role of service providers. As part of the overall context however an account of the



processes at the government level were debated and contextualised. This is because governments and government departments are the custodians of the expenditure taxes that ultimately fund the National Health Service and Local Government social service departments, who in turn manage health, illness and social care. In addition the goings on within those organisations including their practices are guided through a set of rules and mores. In the case of local authority employees these rules are based on acts of parliament and include guidance. The rules as interpreted as policies and procedures in turn are applied by employees of those organisations to effect service provision to those people in need. In this case study the health and social care professional's actions were analysed in the narratives and ethnographic notes to explore aspects of their service provider responsibilities. The contribution highlighted that the "goings on" within those teams does influence practice (including how people with need are included and excluded from services).

The secondary sources of data helped to present other aspects of the "goings on" within political organisations. These include publications and reports on health and local authority policy, guidance and news media publications. Working through these two sources of data helped to present evidence about the controlling nature of some health and local authority service providers. Through this type of control some people with chronic illness feel their own locus of control and self and social identity being stripped away and possibly contribute to a form of social suffering.

In organisations such as the NHS and social care institutions, service provision does have its shortfalls and is therefore not totally universal (in the way that Zola 1982 talks of universalism). Many sick people become dependent on health and social care organisations. People adopt a sick role. This study however has discovered that other coping behaviours exist. These behaviours include those, which are about forming different ways of using the system and internalising patient/consumer status. Some of these processes are established such as accessing health services, using self help groups or making complaints if not satisfied about the quality of care that they may not be receiving. When organised tax funded health and social care services fail to meet the expectations of its customers it is because there is a gap in service provision. The gaps in expectations from patients such as lupus sufferers can exist

because of the changes in their identities caused by the long-term side effects of medication for example.

The gaps can be expressed in terms of the altered personal identities, which are borne by narratives of suffering, brought to the fore in diaries kept by the women with lupus. If more time was given to understand the social and emotional changes that take place in the lives of patients with lupus perhaps practices can be “borrowed” from the Mental Capacity Act 2005 (e.g. advanced decisions) or the Children Act 2004 (e.g. information sharing) to help improve their quality of care that they receive.

## **12. Chapter Twelve: Conclusion**

### **12.1 Introduction**

When the ideas for this research began in the late 1990s the author wanted to explore how women coped with living with a chronic illness, such as lupus, in the context of welfare services in the UK. The main methods focused on at that time were sample survey methods. By the time the study was completed the author understood that research methods in social sciences should not be a random “pick and mix” approach but must be based on a sound appreciation of the theory behind the chosen methods. That theoretical justification of the choice of methods is known as methodology. The decision to use qualitative data analysis methods emerged from shared values from the author’s own professional background as a health professional and the philosophical basis offered by the symbolic interactionism (covered in chapter four)

The resultant work is a case study about lupus from the methodological perspective of symbolic interactionism, combined with influences of social constructionism pragmatism and critical realism. The case study includes the use of ethnography and qualitative data analysis techniques such as thematic analysis. These have helped to bring together a range of findings that can be presented as a conceptual explanation of how people live with lupus and how people manage the illness. This section aims to bring together the case study’s conclusions and discuss how they relate to the main aims of the study introduced in chapter one. The limitations of the study will also be discussed.

#### **12.1.1 The specific conclusions from this case study**

Narratives exist amongst people diagnosed with lupus and can be called lupus narratives. They are structured in a way that reveals a specific ontology of lupus with entities that enable the reporting of personal and social events, strategies and transformational statements of suffering. The structure reveals that lupus sufferers experience multiple events on a daily basis, which are often private to them but very distressing. Lupus sufferers counter these events, often in private, by employing multiple strategies and personal resources with a limited degree of success. The doctor is approached for help and assistance often as a last resort.

The events that take place reveal that every part of the body of the lupus sufferer is ravaged with change on a moment-by-moment and daily basis. Each lupus sufferer's bodily experiences provide a unique personal lupus "blueprint" of life beyond coping. Life beyond coping is characterised by the reality that there is an imbalance of positive and negative coping strategies skewed more in favour of negative coping outcomes.

The study, despite limited coverage, observed that lupus narratives are expert accounts in themselves and rival academic enterprise as data-sources in the information age, and are of significant cultural worth as literary documents in their own rights.

These narratives of lupus sufferers are structured and have value that is often not available in or outside of medical and social care settings. The main implication of illness narratives is that if utilised by willing clinicians and medical sociologists, they can help to develop more cohesive practices between the health and social care professionals, lupus sufferers and their carers.

In adopting these strategies those sufferers adopt an overload strategy and draw enormous power often from limited reserves of psychological, spiritual and physical strength, often with little effect on alleviating the bombardment. In turn they become overloaded with the sheer scale and volume of events.

Medical experts and their surrogates (e.g. nurses; junior doctors) have difficulties to consistently practice collaboration with the lupus sufferer and their carers despite the presence of legal duties to undertake carer assessments within a clinical setting such as a hospital ward. Expert intervention from health and social care professionals result in consequences for the lupus sufferer's body, which in turn affects social relationships with those in the sufferer's social life. This is an example of medicalisation of social problems discussed in the previous chapter (Rose 2007). From observations of the encounters between doctors and lupus sufferers in the ward setting there may be very little discussion between the medical experts and the lupus sufferers or their carers (e.g. lack of completed carer's assessments) about how to deal with social challenges.

There is a “know–do gap” contributing to a rhetorical re-iteration of unimplemented reform from government down to the health and social care organisation. Therefore the immediate carers feature very little in the NHS approach to patient care on the basis of “patient confidentiality” as a preventative caution for limiting dialogue in written form to the carers of lupus sufferers. Carers have a role to play in the lives of lupus sufferers, but they are used selectively as lupus sufferers struggle to manage their dignity. If they push themselves forward in a health and social care clinical context this can confuse the practitioners especially in times of end of life care when their own skills are being challenged to provide the best care possible.

Health and social care professionals participate in social processes and practices that can determine how much or how little resources lupus sufferers and their carers can receive (e.g. access to referral for hospice care during the end of life phase). The health and social care practices as social processes result in sporadic and random practices, and can have a negative impact on effective joint working between health and social care professionals. The author is inclined to agree with Brechin et al (2000) who vividly acknowledge the strain placed upon health and social care practitioners expected to work together sometimes across partner organisations:

*‘[S]ometimes these experiences have left people feeling bruised and battered’* (Brechin et al 2000 p3).

Inconsistent service delivery such as those accounted for in this study is not satisfactory to patients (and their carers) who are supposed to be consumers or customers of equitable care that they should receive. Although lupus sufferers (as UK patients) do not pay by cash directly for health and social care services in a hospital setting they do so through National Insurance contributions and taxation. It is not good enough that patients and their carers have to be on the receiving end of professionals “delaying tactics” simply because they have their own vested interest in deciding how and when specific services should be delivered (Gabe et al 2007). This “know–do gap”, is a failure of services to meet its promise of being ‘fully engaged’ as they cause delays in the receipts of services. The resultant is what has been described as ‘slow uptake’ of delivery and service receipt (Wanless 2002). The care pathway identified in the case study warns of service failure for lupus sufferers particularly as end of life approaches in a critical care setting of a hospital ward.

## 12.2 What has been learned from this investigation?

The contextual assumptions of planning and carrying out a personal or action strategy by lupus sufferers is as follows: people who are ill have difficulty coping in their daily lives and use a high level of energy just to achieve normality for them. During certain phases of their illness they have a real need to minimise harm to themselves, but in order to survive, they often operate at high level of energy just to carry out the simple things healthier people take for granted. The main need of lupus sufferers is to achieve and sustain small moments of wellness, physically and psychologically. In the absence of any cure of their illness people want to cope with their day-to-day tasks including the ability to participate in relationships.

*'[F]or someone to be 'happy' and to be seriously ill is usually a contradiction in terms. Illness is feared not just for its physical consequences but also because of the distress - the pain, fear, anxiety and depression - it can engender'* (Doyal 1995 p8)

An action strategy is a way individuals try to connect to their society. They do this by trying to maintain daily routines including attempting to master personal activities of daily living (e.g. washing and dressing), managing and maintaining relationships from people within their social circles. For the lupus sufferer things that happen to them (and their bodies) are "events". Events are couched in terms of the strategies that people utilise to get on with their lives. Events initially are outside the lupus sufferer's locus of control. The initial plan for the lupus sufferer is to determine what the best ways to manage them are. In the lupus narratives events are the body's illness symptoms and the resultant impact that they have on their personal identity and the narrative components that allow them to give voice to the socially unknown traits of suffering.

Introducing a user-focused evaluation of health and illness management, within this case study is in part to create a concept about what it means to suffer with an illness. Many writers have witnessed the long and inhibiting processes that have overpowered citizens or patients within health and social care settings (Bury 1982, Charmaz 2007, Faubion et al 1994, Foucault 1973, 2008, Glaser and Strauss 1967, Goffman 1979, Illich 1995, Levitas 1996, Oliver 1990, Mol 1999, 2002, 2008, Parsons 1951, Scarry

1985). The structure of the narratives as presented in diary form within this study creates meaning as derived from the analysis of the structures and patterns of the text using words. There is also written forms describing intent to do something and aspirations, to represent feelings of hope. There are also written forms used to describe pain and lamentations and what eventually are lupus narratives. The individual makes use of narratives to affirm the self by giving voice to what would have been silent and hence would have been part of the non-expressed self (cf. Charon and Montello 2002).

The essence of these personalised accounts have now informed central governments drive to introduce new practices amongst health and social care professional known as personalisation (Leadbetter 2004, HM Government 2007, Beresford 2008). UK society will see a shift in services for people with illnesses run by people with illnesses. They will have a greater stake in statutory organisations as a reflection of greater civic engagement and citizenship.

The key to theoretical clarity within this case study is has been to accept that a certain reality of health and social care practices exists which is regulated by government agencies. Being critical of these agencies is one way to debate to what extent resources for lupus sufferers and their carers are taken into account. Organisational values of health and social care providers including the will of individuals to communicate their experiences as representatives of those organisations (e.g. Health Professionals) and third the capacity for people with a chronic illness to report their perceptions of living with an illness.

Illness narratives examined in this case study reveal an overwhelming set of goings-on and almost denote feelings of being trapped as represented in the core theme “statement of suffering” expressed by all informants. The narratives within this study reveal iteration of hopelessness that reinforces the view at the theoretical level of lupus sufferers being trapped in the health and social care system. Politicians provided examples of such narratives in their third person’s representations. The difference arises from the nature of the interaction between individual experience (identified within the narrative) and other individuals within and outside their network: the relationship with devices that are used to sustain dependency and

connectedness with service providers through their various rules (such as eligibility criteria, policy and legislation). Without first hand experiences the ontology of certain practices by health and social care professionals would be biased. Uncovering the experience can allow us as observers to see firsthand how inequalities in the health and social care of lupus sufferers exist.

This case study revealed that for lupus sufferers a silent and often painful journey living with the illness symptoms through to death exists. When people with lupus record their experiences in the form of diaries, those writings can act as a useful outlet of expression in literary form. Giving voice to their suffering by reading and acting on their narratives can show how society can change its approach to actively listening to the voice of those most in need, often marginalised minority groups, when planning health and social care services (Brechtin et al 2000, Faubion et al 1994, Foucault 1973, 2008, Glaser and Strauss 1967). Often the first people to comfort and support the lupus sufferers are their closest friends and relatives. There is a need for more detailed investigations of how the carers of people with lupus feel about their involvement as carers. These same networks can however be the last to understand that lupus is an incurable disease whose symptoms come and go throughout the person's life and for the lupus sufferer this can be a strain to deal with.

The medical profession has a wide range of resources available for supporting people with lupus. However there is lack of joined-up working between the various health and social services departments especially when referrals should be made for joint funding between those organisations for hospice care for lupus sufferers.

The lupus narratives revealed that sufferers are resourceful in their day-to-day struggle to survive. They adopt a whole array of strategies in order to overcome the negative impact of symptoms not only brought on by the disease but also quite possibly by the toxic side effects of medication designed to alleviate the symptoms. The author coined the phrase "overload" in chapter ten to describe the characteristics of those coping strategies used by the lupus sufferers to combat symptoms that affected their day-to-day lives.



### **12.3 What are the limitations to this case study?**

This case study was initially too ambitious in its attempt to cover this topic using limited sample size of informants across a range of backgrounds. It would have been more beneficial for the author, in terms of economy of time and effort, had he concentrated his efforts solely on a larger sample of lupus sufferers and worked on analysing their narratives in detail. This is common practice amongst medical sociologists and anthropologists (e.g. Kelly 1992, Nochi 2000, Bury 1982, Anderson 1991). The case study approach has helped to triangulate the perspectives brought to bear on the life of lupus sufferers. This was the only serious way that this research could obtain any particular semblance of credibility at PhD level. The author believes that this was achieved because of one, the analysis of lupus narratives; two, the inclusion ethnographic material and; three, the use of content analysis of published material such as health and social policy and medical sociology texts. The latter two areas, highlighted above, being high in researcher orientation selection of data analysis material by the author.

The study fell short in present due to a shortage of space (e.g. sample size) the study did not allow comprehensive analysis of all the themes, so the author selected the most significant core themes, identified in chapter four, in an identical format using the framework table qualitative data analysis method. Instead in the first of two steps, first, the author described all the core themes as presented at the end of chapter four but; second, chose to present only a cross section of those themes in the framework table analysis. This decision was taken because the objectives of identifying the core themes were already achieved using line-by-line analysis of the lupus narratives. Despite this technical shortfall the collective QDA (qualitative data analysis) provided a comprehensive analytical enterprise using the following QDA methods: initial line by line coding, framework tables display, conceptual diagrams plus intuitive knowledge through years of ethnography would be sufficient to represent a balanced presentation of the overall concept.

The other limitations to this case study at the level of research design are the sample size. In defence of the sample size used many published case studies have used small sample sizes the rationale for which was presented in chapter four (Anderson 1991;

Anderson et al 1997, Miklaucich 1998, Nochi 2000, Charmaz 2007). However, as a high level academic exercise the credibility of this study in respect to the contribution it can make to knowledge will always be questioned based on sample size. Future studies may wish to consider working with a larger sample size in order to increase the external validity of the study. Other limiting factors not covered in any detail in this study affecting external validity include lack of perspectives on gender, socioeconomic profile, carer profile, ethnicity and age. There are just a few examples of areas that this case study failed to significantly represent. A larger sample size study would have been better placed to explore how these factors were determined in the context of the lupus experience.

The role of carers was considered an important part of this study yet the majority of the reports about carers were taken from the perspective of the lupus sufferer themselves. It may have been helpful for the author to have also asked the carers to keep diaries in order to provide a view of how they coped written and reported in their own words. This would have helped to increase the richness of the data. Future research may wish to study the effects of caring by investigating a sample of people who care for lupus sufferers in particular the impact on spouse (and partners) and perhaps children (as adult) or even child carers.

There were several non-conventional academic steps taken in this study, which pose real opportunities for academic work of this nature. All informants provided verbal agreements to participate in the study. The author chose to study his own mother and his own role as ethnographer and identified both himself and his mother throughout the case study. He argued that by using himself as a subject of his own study and naming himself he wanted to promote a degree of reflexivity not common in medical sociology. In the study the author took professional pride and courage to go into areas not often explored in medical sociology such as working with his mother. The steps explained in the methodology chapter to detail ethical dimensions helped to increase the consideration given to research ethics in relation to working with and researching blood relatives. He gained his mother's verbal permission to use her details, including disclosing her real identity. Furthermore, when she died he was willed her possessions, which further prompted him to obtain the release of her medical records and thus enriched the study further. He then looked closely at the doctor's letters to

observe patterns of communication between doctors and found a whole range of courtesies and formalities existed between. In terms of research design he felt that future studies could look specifically at patient medical records to explore these aspects further. This is something that was derived as a benefit from this study.

Driven by the pain of his mother's death the author took further risks by reporting his experiences of hospital ward life. He did not seek permission from the health trust for permission because this setting now became the critically realist focus of his exploratory journey. In his mind injustice had taken place, it was his place to seek the truth, and meaning behind why certain patients and their families were treated in the way he perceived himself and his relatives to be treated. The author consulted the university about the change of direction his research design was taking as a way of acknowledging the informing protocol of student and supervisor. However, the author could have taken more ownership of the situation by informing the hospital and doctors that he was going to use the experience to be part of an academic study.

When he did make contact with the health services for information it was solely in the guise of being a grieving son and they duly obliged to provide information pertaining to his mother in return for an administrative fee. He provided pseudonyms for the other lupus sufferers because he wanted to protect the anonymity of lupus informants. In addition the author deleted the names of doctors in the letters that came from his mothers medical records to respect the clinical anonymity of members of the medical profession who met his mother. The author also chose to reveal the identity of the Member of Parliament who took part in an interview and Chief executive of the charity Lupus UK because they were willing to do so. Disclosure of their identity was in keeping with their public service role to advocate for lupus sufferers and they were keen to take advantage of an opportunity to raise the profile of the illness.

The case study would have been able to be consistent with the approach of informed consent if backed up by written permission from all informants. Whilst the basis for this has been represented in earlier chapters, it was highly unusual for an academic piece of work to report on the use of relatives as part of the sample of informants. The author was able to locate similar pieces of work looking at the challenges of ethnographers experience (Jenks 2002) and challenges of observing a blood relative

(Kiesinger 2002). The dearth of UK based work of this nature confirmed that this ethical aspect is uncharted territory in medical sociology. The views of health and social care professionals were also limited in this study.

#### **12.4 Summary**

There are gripping and poignant messages that have emerged from this study with a compelling argument for changes to be made in the law around end of life care specifically for people with lupus and generally for those with a range of other illnesses that become terminal and to therefore be on parity with services provided for people with cancer. Living with lupus is the same universal experience of suffering as those people who suffer with other chronic illnesses (cf Friedson 1970). There is no pleasure in suffering. The forms of shared commonality reaches into the lives of people with other higher profile and higher incidence illnesses such as rheumatoid arthritis, HIV and AIDs, multiple sclerosis and cancer to name a few. The challenges for sufferers to overcome the day to day barriers are not only personal but also socially determined and social constructed as a result of interaction. The challenges are personal yet are compounded further in society's bid to distribute resources fairly in terms of the NHS and local government priorities. Governments need to take responsibility for committing to social action when medical science is not able to provide solutions and challenge it to give up some of its status and prestige in order to strive for better social care in hospital ward settings. At the very minimum a genuine communication covenant about death and dying should be signed up to by ward doctors, social workers, the patient and their relatives and a family solicitor about what has been agreed between all parties and under what circumstances. Legislatures need to be called on to organize better conditions about how end of life care is improved in order to surpass the rhetorical expectations of the Gold standards framework (DH2004b).

The challenges of good health and social care practice which lay at the feet of service providers operate in bureaucratic organizations which slow down the process of actual services that lupus sufferers are supposed to receive particularly at end of life. Members of the public are increasingly cynical about the quantity of policies which promise to provide service improvements but deliver very little in terms of consistent services across the country often described as the postcode lottery (i.e. where the

quality and consistency of services vary depending on where you live in the UK). This study has described this as rhetoric of unimplemented reform (p213). Any gaps in services affecting people's lives will naturally lead to either blame or apathy towards a "system" that can take years to communicate how complaints are best managed. When incidence such as this arise people can lose faith in a system which is supposed to be fair. In terms of this study the problem of fairness was found wanting in the absence of proper referral to Hospice care when the doctors identified terminal care for Mrs. Robin - informant one. The team of experts and social care professionals failed to organise a case conference to decide on the best course of action to support the end of life care needs of Mrs. Robin. This is an example of an abuse of power where medicalisation and strong armed bureaucratization combine to sap the will of individuals (such as surviving carers or relatives) seeking social justice from a system that may have contributed to negligent practices such as excluding a lupus sufferer from receiving hospice care at their end of life.

A study such as this has served to illuminate the problems of poor communication between the hospital ward, the failure of the social workers, employed by the council, located in the hospital ward to be the main advisor/counsellor of end of life care needs.

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