Individuals’ perspectives on the impact of living with lupus in Kenya

Omondi EA[1], Caress A[2], Cooke H[3], McHugh G[4]

[1]*Department of Nursing Sciences, Faculty of Health Sciences, University of Nairobi, Kenya*
[2]*University of Huddersfield, UK*
[3]*University of Manchester, UK*
[4]*University of Leeds, UK*

Corresponding author
Dr. Eunice A. Omondi,
Department of Nursing Sciences,
Faculty of Health Sciences,
University of Nairobi, Kenya.
Email: eaomondi@uonbi.ac.ke

Abstract

Background: Lupus is a chronic, autonomic, multisystem disease that predominantly affects women of child bearing age. Lupus has both physical and psychosocial impact on affected individuals. There is paucity of data on the impact of living with lupus in Kenya.
Objective: To explore how living with lupus has affected the individuals’ lives.
Design: A generic qualitative approach with principles of constructivist grounded theory.
Setting: Two rheumatology clinics in Nairobi, one private and one public health facility. Ethical approval was obtained from the relevant institutional ethical committees.
Methods: Participants were identified using purposive and theoretical sampling techniques. Face-to-face interviews were conducted. Interviews were transcribed verbatim and analyzed inductively using the constant comparative method.
Results: The study identified a key category of “a shadow of myself” and two sub-categories; i.e. loss of self and biographical disruption. The findings revealed that the illness disrupted individuals’ lives in various ways. However, they attempted to reconstruct their disruptions with variable success.
Conclusion: The study revealed that living with lupus was disruptive to individuals who previously had ordered lives and the need for support.

Key words: Lupus, Individual perspective, Impact

Introduction

Lupus is a chronic autoimmune disorder affecting more than one organ. It is characterized by various clinical manifestations which are consequences of widespread inflammation in numerous organs of the body such as the skin and mucous membranes, joints, kidney, lungs, heart and occasionally the gut[1]. Skin involvement is present in 80% of the patients and comprises of skin rash, photosensitivity, hair loss and painful mucous membranes. Patients may also present with musculoskeletal features giving rise to painful or swollen joints and bone necrosis. Haematological effects may include anaemia, low platelets and formation of auto-antibodies. Patients may also present with cardiopulmonary features which may include hypertension and chest pain. Renal disease, neuropsychiatric features, eye problems and gut involvement may also be present[2]. Although skin and musculoskeletal manifestations are the most common symptoms, lupus may present in variable combinations of clinical features as organs may be involved separately or in combination. Most people with lupus have variable symptoms and an unpredictable course and prognosis[3,4] indicates that chronic illness can be episodic or continuous, and the body’s response may be visible or invisible, and may include the experience of intrusive symptoms like pain and fatigue[5]. Pain stands out as a symptom of chronic condition[6]. Lupus appear at a younger age when one is most active in terms of educational achievements, paid work and raising families. Individuals with lupus not only complain of pain but also bewildering fatigue, persistent fever, malaise and weight loss[2], depriving them of their previously taken for granted continuity of life[7].

The experience of living with chronic illness presents both personal and social challenges which may have life-long implications. In addition, Heydari *et al*[8] reported that non-communicable diseases are the leading cause of morbidity and 86% of all deaths globally. Charmaz[4] also states that chronic illness causes more social, interactional and existential problems because of being long-term. The illness may incapacitate the individual and cause a permanent alteration to their way of life, necessitating re-evaluation of functional abilities in their social world[9]. Chronic illness, therefore, impacts on individuals in profound and various ways, and the lived experience often includes different forms of physical and psychological impact. The purpose of this study was to explore how living with lupus has affected the individuals' lives and identify their self-management strategies.

Materials and methods

This was a qualitative research which utilized a generic qualitative approach and principles of costructivist grounded theory. The research sites were at Kenyatta National Hospital and Mater Hospital where there are rheumatology clinics. Ethical approval was sought from the University of Nairobi/Kenyatta National Hospital and The Mater Misericordiae ethics and research committees respectively. Study participants were purposively and theoretically sampled. Data collection was conducted following informed consent, through face to face in-depth interviews, using an interview guide. The data was coded and analyzed by constant comparative method and thematically.

Results

Twenty-one individuals with confirmed lupus diagnosis were recruited. Eleven were from Mater Hospital which is a private hospital while the other ten were from Kenyatta National Hospital rheumatology clinic which is a public hospital. The participants' ages ranged from 19-56 years with a mean age of 34 years (SD 9.2). Majority were between 21-40 years with only one patient above 50 years of age. Majority (n=19) had achieved high school education and above but only 5 of them were in employment. In addition, about 75% of the participants were above 30 years of age and not married (Table 1).While exploring how living with lupus had impacted individuals' lives,'A shadow of myself', a phrase used by one of the participants emerged as a theme from the data. The phrase summarized her life as she described herself as a different person from the person she used to be:

'There is no joy, you know?... All the time you are thinking about the condition no matter how strong you have grown…I am no longer what I used to be. I am just a shadow of myself… ' (ID 07, PRI)

'A shadow of myself' fitted other participants descriptions of themselves too and comprised of two sub-themes: loss of self and biographical disruption.

Loss of self

Loss of self is a phrase[4] which first used in her study of individuals with chronic illness. In this study, all participants described experiencing negative physical changes, some of which were invisible while others were

Table 1: Demographics

Characteristic	Participants (public hospital)	Participants (private hospital)	Total
No.of participants	10	11	21
Gender			
Male	0	1	1
Female	10	10	20
Age (years)			
Under 20	0	1	1
21-30	5	2	7
31-40	3	6	9
41-50	1	2	3
51-60	1	0	1
Highest level of education			
Primary	1	1	2
High School	6	0	6
Vocational	1	2	3
Qualification			
Diploma	0	3	3
University degree	2	5	7
Marital status			
Single	8	7	14
Living with partner	2	4	6
Employment status			
Employed full time	4	7	11
Unemployed	5	3	8
Student	1	1	2

visible. The invisible symptoms included pain, fever and fatigue, with pain and extreme fatigue being the most frequently mentioned. For example:

'Am a teacher by profession, but from 2011… up to date, I have not gone to work… I could feel a lot of pain... It would take me about a week experiencing a lot of pain… and then it would shift... I have not been able to do anything. Writing on the chalk board is a problem. I can do it for one second then my hand refuses.' (ID 02, PRI)

The pain seemed to last for long durations which made her suspend her teaching job. Some participants also reported that the pain they were experiencing was also interfering with the quality of sleep and work:

'And at times you wake up with so much pain. You are willing to do something, but your body cannot let you do it. As much as my heart is willing, it is not easy..'(ID 13, PUB).

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

'The first feeling I had was tiredness; extreme fatigue... the one that I really felt was this sort of fatigue that I could not account for… fatigue that came out of nowhere because I had always been a somewhat active person.' (ID11, PRI)

It is evident that the tiredness experienced was new and intense, incapacitating and also unrelated to activity as it started in the morning. The participants acknowledged that fatigue frequently compromised their physical functioning and affected their work output.

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

'My weight started to reduce. It took about one year before I was diagnosed with lupus. When I eat,I vomit. That is another challenge…You hear people saying I have HIV...That is because of the way I appear. '(ID12, PUB)

Most participants who had lost weight were unhappy with their body image and found talking about it very distressing as they emphasized how much the weight loss had changed their outward appearance and threatened their femininity. Some participants seemed to suggest that their social contacts associated their weight loss with having HIV infection. Coping with weight loss was often not easy as some participants admitted that the negative body image depressed them and they stopped socializing and preferred not to go out. Besides experiencing weight gain or loss, hair loss and having skin rashes were also major contributors to some participants' negative views of their changed body image. The affected individuals understood that there was a change in their former self-image:

'I started getting a velvety, dark kind of rash over here [pointing across the face]. The butterfly rash had occurred so when I went to the office, one guy told me "… just go to the hospital. This looks really bad."' (ID10, PRI)

The changed body image due to skin rashes made the individuals with lupus feel different compared to their previous physical appearance.

Feelings of emotional distress was also attributed to loss of self. Some participants described feeling anxious and depressed by using words like 'I am emotionally distressed', 'feeling very depressed' and 'very worried'. The effects of illness which caused emotional distress to some participants included: changed physical appearance, loss of health, side effects of some lupus medications, fear of death and lack of social support:

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

This narrative illustrates that the changed physical appearance was stressful to the participant because of the responses her changed appearance elicited. She experienced loss of self-esteem and impaired self-image. The impact of changed physical condition associated with the interference to physical and social activities and the impact of emotional distress caused disruption in various areas of the participants' lives.

Biographical disruption

The second sub-category that emerged has been termed 'biographical disruption', a concept first described by Bury. This sub-category fitted the data because it summarized the descriptions the participants used to express the extent to which they experienced lupus as biographically disruptive to their formerly organized lives and relationships. Participants described disruptions in their work, career, finances, family and social relationships including their marital lives, making Bury's concept of biographical disruption relevant.

Some participants described having functional impairment related to their ability to perform daily household or workplace tasks due to joint pains and feeling weak. For example:

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

Participants became aware that their level of doing things was greatly diminished compared to the past. They had to make decisions regarding what activities they could perform which was restricting their lives. It was noteworthy that the tasks the women highlighted as not being able to perform were female gender related chores in the traditional African context, such as going to the market and washing clothes. Having lupus also affected the performance of some participants' paid employment. For example, one participant indicated:

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

This participant became aware that she could no longer use her hands to work as a tailor, which is a technical job, and she had to give up her source of income altogether. Having lupus took away her financial independence. Another participant described how having lupus caused a strained relationship with her employer:

'They feel I'm too weak to work. I'm a person in the public-relations department, I need to move about. But I'm fighting them about it…. It was a very big case because she went ahead and failed to renew my contract which expired last month. And I told them I was not signing any exit form because of being sick… "(ID 20, PUB)

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

'*Ya. It had such impact, because we had already spent a lot. We had taken some loans, and eventually we had to have a fundraising. So, part of that helped us to fund my treatment until again this year, we started feeling the pinch because drugs are very expensive... You run out of money, but we thank God we have managed.' (ID02, PRI)*

The study therefore established that having lupus significantly impacted on household and workplace responsibilities. It also negatively affected the participants' financial situation. Some participants also commented on how having lupus reduced their capacity to participate in family life thus disrupting their married life and parenthood:

'... Although you haven't asked me, lupus affects your intimate relationship with your husband seriously because you are always cagey. Today it's the back, tomorrow it's another thing. People don't even understand, they think you are always complaining… So, one, it affects your intimacy with your husband seriously. You no longer have any joy in anything. At the end that strains the relationship… And so, you have to put a lot of effort in everything because sometimes you really don't want to be intimate. '(ID 07, PRI)

In the narrative, the participant's use of the words "and so you have to put a lot of effort in everything" brings out the subordinate role of women in marital relationships, and the difficulty they have in making decisions. In this study, it was also established that about three quarters of the participants were single with only one of them stating that she had been married before and got divorced. She expressed that having lupus was the primary cause of her divorce:

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

While another participant stated that she discouraged the start of relationships by pushing away those who showed interest in her. She saw her illness as a barrier, yet this could have been a way of being very realistic about the possible effects of lupus on marital life. There were those who also seemed to have either postponed marriage or having a family:

'... Let me say… there is a time I wanted to get married, but when I fell sick, I lost interest completely.'(ID 12, PUB)

'Yeah. In fact, when I meet someone, I tell them, "You are just getting yourself into a burden. This is a sick person". ... In fact, I just shut them down from there. I just don't want to be in that relationship'. (ID 17, PUB)

'The only other thing that I wish I could do but I cannot is, say, to have children. I would like my daughter to have a brother or a sister. However, I cannot have children due to the medication that I take..'(ID 10, PRI)

From the narratives, it is evident that getting married or having children was an issue that some participants dealt with. They were either doubtful about getting married and having children because of the unknown consequences, or they seemed to have made a decision against getting married due to their condition.

Disrupted relationships were also mentioned regarding family and other social relationships. More than half of the participants indicated that their illness caused deterioration in their family relationships. For some, the precarious financial situation was the source of the strained relationship:

'... He [husband] had left in the morning; I was thinking that he was coming back. I waited for him in vain until ten o'clock. So, I knew he had already gone and switched off his phone. I called my brother and borrowed five hundred shilling from him.' (ID 05, PUB)

Two other participants expressed how they were not playing their parental role as they should have. For example:

'... Of course, rearing of my children. The whole of last year, I literally did nothing to my children. The way the child comes, you want to hold them and I cannot… The way children want to be happy with their mother; I cannot be happy with them… As far as the area of rearing my children, I feel I have been quite inadequate.' (ID 02, PRI)

The findings also revealed that there were participants who were avoiding getting into relationships due to their fears and due to their past experiences:

'Yeah. It has affected how I relate to people. I just don't want people to be close to me. I feel like when they find out they are going to reject me...'(ID 17, PUB)

'Even socially there are friends I used to see, and yet when I hear they want to be somewhere, I do not want to go... I don't want to meet them because what am I going to discuss with them? ... There is no news. So, socially, it also affects you. It has affected me and that is my greatest problem... You think the world is beaming you, right?' (ID 07, PRI)

This group of participants seemed to acknowledge their role in the strained relationships and the resulting constrained lives and social isolation. The participant (ID 07) feared to get into a relationship because of the experience she had with her friends before.

On the whole, having lupus disrupted various aspects of the participants' day-to-day activities, especially regarding paid work which affected their finances. It also impacted their house work, family life and social relationships.

Discussion

On the whole, patients in this study felt that the disease made them experience numerous forms of loss such as: loss of their previous body image with the associated experience of humiliation; loss of productive function both at work and at home; loss of financial stability which affected their economic resource; loss of social and family stability with associated strained relationships and the experience of emotional distress. The individuals' sense of loss fitted with Charmaz's[10] concept of 'loss of self' which she refers to as a combination of the loss of self-identity and self-esteem. According to Charmaz[10], the self is social in nature and is developed through social relationships. Also, she indicates that "experiencing illness is a social-psychological process in which the inner dialogue between the I and the me changes and definitions of the experience change"[10]. Charmaz[10] argues that loss of self is experienced by people with chronic illness because the illness changes their former activities and lives, and that the loss of self can be continuous, a view which was also evident in this study.

On the other hand, Bury's[11] theory of 'biographical disruption', which refers to functional restrictions brought about by chronic illness, was also a good fit for discussing patients' perceptions regarding impact of the illness. Most participants were no longer able to carry out most of their former activities of daily living, whether inside or outside the home. This was mainly due to the new body sensations they experienced, like pain and fatigue. Bury's[11] work brought into focus the meaning of illness for the individual. The study acknowledged that disruption arises because the illness disorganizes people who had taken for granted live and the social world in which they live.

Lupus also fits well with Bury's[11] biographical disruption theory because it is an illness that starts in adulthood and disorders a previously ordered life. This is in line with Williams'[12] criticism. Williams suggested that Bury's biographical disruption was only applicable to people who were previously active and productive, but not to children and the elderly. In this study, patients' ages ranged between 19-56 years and their previously active lives had been disrupted in one way or another. Job loss was noted to be mainly high among those who were not in skilled employment and those with jobs that required high physical demands. In contrast, those who were in positions of responsibility were considering early retirement. Other studies have also emphasized that lupus can diminish an individual's capability to work, with an end result of having work disability and/or changes in the nature of an individual's work. Similar to this study, Yelin *et al.*'s[13] study established that job loss was higher among those who had no high school education. Also, those who had early onset of lupus, or a longer duration of lupus, negatively experienced high physical and high psychological demands of the job.

In this study, some patients also described how they felt that their female gender roles - child bearing, rearing and doing housework - were disrupted by lupus, which disproportionately affects women. Some women decided to remain single or had no children by choice. Some wondered if they ever will be able to get married and have children, while others implied that they could no longer have more children despite their desire to have more. These findings were similar to other studies that involved women with other chronic diseases[14,15]. 'Gender role' is a term which denotes a society's expectations of how men and women should behave. This is learnt during the socialisation process from birth through family, education, peer groups and the mass media[16]. In traditional African society, the acceptable roles and behaviour of both men and women in a family and community are culturally defined along femininity and masculinity lines[17]. Males are endorsed as decision makers, which is alleged to be in the best interest of the family[18]. Also, women are expected to act according to decisions made by their husbands or by a male family leader. Participants in other studies from West Africa and India argue that the role division which gives men a higher status than women is not in the best interest of the family, and is therefore a form of gender discrimination[19]. However, literature indicates that traditional gender roles are breaking down due to the shift from the traditional model of a wife as a housewife and a husband as an employed person. This is attributed to the current equal educational and economic opportunities for men and women[20], and the collapse of attitudinal and socio-cultural factors which previously acted as obstacles created by gender role stereotypes[21]. Participants in a study from Africa also attributed the breakdown to the fact that gender roles are conventional and can be altered because they are not part of a moral code[19,22]. However, some studies established that working women perceived themselves as still performing significantly more housework than men[23,24]. On the other hand, some participants in another study insisted that gender segregation in domestic work persists[24]. This was an observation which was also evident in this study. There were participants who mentioned with concern that they could no longer perform domestic chores like washing clothes and caring for their children and the expectations from the extended families. However, the study did not establish women's' concerns regarding doing more domestic chores than their male counterparts.

Therefore, this study demonstrated that similar to other chronic conditions, lupus is a condition that is regarded as disruptive, with physical and functional changes in the lives of individuals who are in the prime of their lives. The changes, in turn, affect the individuals socially, economically and emotionally. Bury[25] argues that some individuals have more control over their lives before onset of their illness than others. The view of having control over ones' life is closely related to social factors such as class, ethnicity and gender, and other determinants such as economic and biological factors.

Conclusion

The study established that having lupus was experienced as a negative turning point for all participants as most participants acknowledged that they were not the same as before the illness.

The illness remained ambiguous with insurmountable challenges. This study suggests that individuals who possessed positive social factors such as better economic, social and cultural resources had slightly better control of their lives than those who had limited resources. The study established that lupus is a particularly challenging illness to live with and that living with lupus in Kenya involved extra challenges. This implied the need to explore strategies which may be used to assist individuals to cope better with the condition.

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