The man-in-the-moon face: a qualitative study of body image, self-image and medication use in systemic lupus erythematosus

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Abstract

Objective. Little is yet known about the interactions between body image, self-image, medication use and adherence to medication in people with SLE. Using a qualitative mode of enquiry, we sought to understand these experiences within a group of patients diagnosed with SLE.

Methods. Fifteen participants (14 female, 1 male) with SLE took part in semi-structured interviews. Their ages ranged from 22 to 57 years and disease duration ranged from 3 to 20 years. Interviews were audio recorded and transcribed verbatim. Data were analysed using interpretative phenomenological analysis.

Results. Analysis revealed four themes that are presented set within the overarching concept of body and self-image: the road to diagnosis, communication and treatment concordance, living with the medication and self-image—faking it. Narratives revealed significant dissatisfaction with body image, an externally located concept. Worries about appearance and weight were most commonly mentioned and were often related to steroid use. Creative non-compliance with medication was frequently described and greater concordant relationships with physicians desired. Overall, participants sought increased investment in self-image, an internally located concept.

Conclusion. Body and self-image are important issues for individuals with SLE. Yet participants in our study generally felt that their health care providers did not give enough consideration to their concerns over the outward appearance effects of both the disease and its treatment.

Key words: systemic lupus erythematosus, self-image, body image, physician–patient communication, medication side effects, qualitative research.

Introduction

SLE is associated with chronic pain, extreme fatigue, sleep disturbance, cognitive fog, anxiety and depression, which impact negatively on work and social roles [1–3]. Further, the symptoms of SLE are often outwardly apparent. People may have to cope with visible joint swelling, changes in gait and/or posture, rashes, loss of skin pigmentation, scarring and alopecia. Unfortunately the treatments for SLE can also produce visible side effects. Treatment with corticosteroids (CSs) is associated with changes in facial appearance (Cushingoid or rounding of the face), weight gain, bruising and osteoporosis. These visible changes can lead to social isolation as patients opt
out of social contact rather than go through the frustration of repeated explanations [2]. Medication side effects can also be associated with poor adherence to drug therapy. Even when side effects are not overtly apparent, patients worry about the long-term effects of taking potentially toxic treatments [4, 5].

Body image, and especially appearance-related research, is, to quote one author, still a minority sport, particularly as it relates to understanding the psychosocial impact of long-term conditions and their treatment effects [6]. In SLE, some studies have shown that body image is poor compared with non-SLE controls and has less to do with the disease itself and more to do with the negative effects of treatment. Appearance concerns have also been shown to be predictive of depression [7–9].

In other medical populations there is the suggestion that treatment adherence is adversely affected by changes in body and self-image. In various transplant populations, for example, side effects such as weight gain, Cushing’s syndrome, acne and subsequent worsening body image were likely to result in reduced adherence to medication. Non-compliance with medication regimens can produce a host of problems for the patient and physician. There are indications that patients with SLE engage in creative non-compliance, where they may stop, take less or take more of their medication than prescribed [4, 10]. Furthermore, a concordant patient and physician relationship is essential if both parties are to be comfortable with desired outcomes [11–13].

Little is known about the interactions between body image, self-image, medication use and adherence to medication use in SLE. Using a qualitative mode of enquiry, this study sought to explore these experiences by interviewing patients diagnosed with SLE. We asked them what body image and self-image meant to them and we also asked them how they felt about their medications, what they understood about them and if or how they coped with medication side effects. Following our participants’ definitions, we define body image as how one perceives one’s external appearance and self-image as how one views oneself at an internal level, or who you believe you are as a person. This can be influenced by how you believe other people view you (public self-consciousness).

**Patients and methods**

An approach to qualitative inquiry increasingly used within health care research is interpretative phenomenological analysis (IPA). This approach allows the researcher to both explore an important event in the life of a participant (the phenomenon) and understand the event as it acquires meaning for that person in the context of their lives (the interpretation of the event). The research interview set within an IPA approach invites the participant to relate their attempts to make sense of what has happened to them [14]. Furthermore, IPA acknowledges that the researcher plays a role in the construction of the participants’ account by guiding them through a semi-structured set of questions designed to access the detail of an experience from the participants’ perspective; literally an interview [15]. In this way, IPA takes an idiographic approach, trying to understand the experience from an individual account, then building up to commonalities and differences when looking across a series of cases.

A purposive sample of participants was recruited from the rheumatology clinic at a large university teaching hospital on the East Coast of the USA. Demographic information is shown in Table 1. All participants had a confirmed diagnosis of SLE and were between the ages of 22 and 57 years. Disease duration ranged from 3 to 20 years. The sample represents the age, gender and ethnicity typically seen in a population of patients with SLE [16]. This study was approved by the institutional review boards of the Rutgers Robert Wood Johnson Medical School and the University of Michigan.

Participants consented to a semi-structured interview with one of the researchers (D.C.R.), which was audio recorded and lasted for ≤1 h. In order to enhance the reliability and validity of the data, each interview was later transcribed verbatim and made anonymous with any identifying words or phrases removed. All participants were given numbers. Direct quotations from the interviews are presented to illustrate the results.

The transcripts were all analysed by E.D.H. and thematic analysis was agreed upon D.C.R. and A.L.H. Analysis followed an idiographic and repeating or iterative cycle in order to develop a full and deep understanding of what mattered to the participant [17]. Working from case to case and across cases, it is possible to build a picture of the participants’ experiences and the meanings ascribed to them in the context of their lives. While each individual expresses his/herself, it is possible to develop certain themes across cases that can be collected under major and minor thematic headings, which we present here.
Results

The interviews with our 15 participants (14 females, 1 male) invited them to talk about their experiences of SLE in a temporal fashion, from diagnosis to the present day. For some people, diagnosis was a relatively recent event occurring in the last 3 years, for others, it represented the experiences of more than 20 years of living with an unpredictable condition. All participants talked about the major life changes that SLE had brought about and often juxtaposed the new life (with SLE) and the end of the old life. Here we present four themes that emerged from our analysis of this data, set within the major overarching context of body and self-image.

Theme 1: the road to diagnosis

The onset of symptoms that eventually led to a diagnosis of SLE was often recalled as very sudden. ‘The feeling… like you got hit by a truck. You were hit by a truck!’ (Patient 5). Being hit by a truck colloquially captures the suddenness of the onset, the violence with which symptoms were perceived and the feeling that both one’s body and one’s life had dramatically changed. Some of our participants were hospitalized and diagnosis was rapid. Where symptom onset was less extreme, it was often the persistence of visible symptoms that eventually made participants seek a medical opinion: ‘I had a rash that refused to go away’ (Patient 4). Unfortunately, one-third of our participants who had sought help for a variety of symptoms experienced a long period from symptom onset to definitive diagnosis, with doctors attributing symptoms to lifestyle factors such as weight gain.

Theme 2: communication and treatment concordance

Participants valued highly the ability of doctors to give clear and accurate information about the condition itself, treatment options and potential side effects of the treatments. Patient 8 noted, ‘…Well, he was just saying if I didn’t take my medicine I was gonna die’. This is essential to promote concordance in the physician–patient relationship and good patient self-management of the condition. However, concordance in treatment decision making did not always happen. For example, patient 10 recalled the limited opportunity to discuss medications, ‘I was pretty much told what they were gonna give me. I don’t recall them giving me too many options of, on what I could do at the time.’

The perception of poor communication of diagnosis and treatment options led some participants to feel very anxious and fearful for the future. Some explanations were very matter-of-fact and tied to fait accompli medication use: ‘He [the rheumatologist] just said to me, you have an autoimmune disease in your body that attacks your own body, and you have to take prednisone and that’s it’ (Patient 5).

Many of the participants were worried about the side effects of taking their medications in both the short and long term. Some of their worries centred around having more or worse side effects than they currently experienced, particularly when side effects sometimes actually made them feel much worse than they had felt before: ‘No, not really, because I was still, to me, I still felt sick. To me, it made me feel worse’ (Patient 3).

It was not uncommon for participants to have tried a period of non-adherence to medication, often driven by side effects, depression, feeling temporarily better or a desire to exert control. Interestingly, when the doctor involved was unsympathetic, the patient moved on to seek care elsewhere.

Doctors were not always thought to be sympathetic to the psychological effects of being told there might be little or no help for certain aspects of the condition that they deemed cosmetic. The outward cosmetic effects of SLE and its treatments seemed to cause the most distress for participants, quite apart from the internal effects. Patients 4 and 5 both thought that physicians needed more training in how to help patients cope with the psychosocial aspects of their condition, and that greater education and support had been found through patient groups than via the doctor.

Theme 3: living with the medication

The participants were currently taking a wide range of medications. Most commonly, individuals had taken a steroid (usually prednisone) at the onset of their SLE and many were currently on steroids due to an exacerbation of symptoms. Varying degrees of skin involvement were reported. Virtually all participants had experienced side effects to a variety of medications. Patient 5 reported taking prednisone and that ‘The side effects were horrible. I had gained all of this weight.’ The weight gain experienced from taking prednisone was the most commonly cited, disliked and distressing side effect. This was a major contributor to participants’ negative views of their body image.

Almost all participants defined body image as something externally located, i.e. in terms of outward physical appearance. Most were unhappy with their body image due to weight gain, visible skin changes and posture and gait changes. Participants found talking about their body image very distressing, as they emphasized how much they felt their outward appearance had changed: ‘And the baldness of my head is just devastating… It’s just devastating…’ (Patient 15).

Sometimes this was expressed as looking in the mirror and not recognizing the person looking back. Participants suggested the change in outward appearance also threatened their view of how they should look as women. The women in the study said they did not feel feminine when they had gained significant weight due to steroid use, or their hands were swollen and this meant that they were not normal.

Paradoxically, with the associated weight gain due to steroid use they became more visible in society, but not in a way they desired, as described by patient 4:

Uh, the man in the moon face. Umm, I think, yeah, I would say for the most part that was it, the swelling and just your face starts to take on a whole different...
look. Very, very...it really...you know, you don’t realize it yourself, and then I look back at pictures...like from graduations and stuff...and I look like a big white jack-o-lantern. Just...my face was like HUGE! Yeah, very, very stood out in a crowd (laughing).

Inevitably other people did comment on how individual participants looked, which served to reinforce the awareness of how their appearance had changed. Patient 2 recalled the comments from others: ‘And when I’m on the steroids, you know, they were like, “Oooh your face is big”. You know, “you’re shiny, you look like you’re ready to pop”!’

Coping with this was usually dealt with by laughing with people and at oneself, while often feeling sad inside. Patient 2’s co-workers also labelled her hands the claw or the club, and she tried to laugh along with them. Patient 3 admitted that when she was younger she used to be teased about her butterfly rash, ‘Yeah, in middle school...inside, it made me sad...but I dealt with it, like I tried to be strong. To ignore it in front of them. Like, even though, like, it, it hurt, but I learned to ignore it...to keep on going’.

Most of the participants said that as a result of their negative views of their body image, they had experienced periods of time where they would feel so disheartened and depressed that they would stop socializing and preferred not to go out for fear of either seeing other women who looked slim, and therefore better than they did, or being stared at and judged by others.

Sadly, at least two of our participants said that the disease had directly led to the breakdown of their marriages, with patient 6 suggesting that part of the reason was due to the side effects of the medication she took:

As a wife. Umm, I would say because of it, I am in the process of a divorce. Yeah, many things wouldn’t have happened. I believe so. Physical. Intimate, let’s put it that way. Because like with all the medicines, with all the flares that I got, I mean, I couldn’t be the wife maybe that he wanted me to be. So then things happened. He found somebody else. Umm, he said that that was just because I was not there for him when he needed me...Because like, when you take so much medicine in your pores, you can smell the medicine coming out of your pores. So, in that way, I know that there was some rejection because of it.

Theme 4: self-image—faking it

Every participant, when asked to define self-image, said that while body image was externally located (especially with externally related appearance concerns), self-image was largely located internally as a psychological entity in terms of how you feel about yourself or who you believe you are as a person. Interestingly, participants often said they had a positive self-image and that the experience of SLE had actually made them stronger. For patient 15, the value of herself was firmly located within the internal self, as she perceived she had no value in the outside self:

Well, well, I cannot put any stock on the outside of my body, because I was, I think, always so vain and always stayed in shape and this and that and everything was perfect. But what’s the heart of it is in my heart, you know, that I do feel good about myself. I do know that I am a worthy human being and an honest human being, you know, and I have good morals, and...and I don’t feel any negative, you know, about myself.

Participants felt that the two concepts were inextricably linked and further elaboration demonstrated that the concepts overlapped and blurred on occasion. They often returned to the concept of the changed self and how activities and/or dreams were lost as a result of their SLE. Body image clearly affects self-image, as articulated by patient 3: ‘Like, the way that you look at your body—umm, affects the way that your self-image is...like, if you see your body as negative, that’s how your attitude is gonna be, negative, because you don’t want...that’s not what you want.’

There was an indication, in the way that participants talked about their positive attitudes, that these were not necessarily genuinely felt. Developing and maintaining this attitude was actively hard work and was a construction of a new self, and possibly a new mask to hide behind. Patient 14 described this aptly:

Because I always have a smile on my face. So most people just, I mean, they just assume that I have it all together. I have a positive outlook, which I try to. You know, it’s like “faking it till you make it” [laughs]. So I haven’t had anybody—everybody I meet is, you know, she’s strong, she’s dedicated...I know it’s true, but it’s still...it’s still a piece of me that knows that I’m falling apart on the inside.

It is possible that our participants felt they now lived under multiple masks: the psychologically strong mask of a determinedly positive self-image and the mask that medication use may provide. Patient 15 describes the effects of her lupus being frosted over by the medications she takes, hiding the real self within.

Discussion

We invited our participants to talk about their experiences regarding living with SLE from the time of diagnosis to the present day. It was clear from the life stories we heard that the event of diagnosis was remembered as disorienting, whether symptom onset was severe and sudden or milder and intermittent. In both cases, an individual is challenged with respect to previously assumed life paths and expectations held for relationships, work and leisure. With the diagnosis of a chronic illness, the individual has to reinterpret their sense of identity and self, and this may be even harder when the illness and the treatment of it produce changes to the visible self [18]. This has been discussed
as the body changing from a disappeared state (healthy and therefore not requiring attention) to dys-appeared (the body appears because it has become dysfunctional) [19].

One of the difficulties our participants faced was learning to effectively communicate with their health care providers. At the time of symptom onset, diagnosis and treatment options were determined by the physician, with varying degrees of explanation either given or remembered. A diagnosis of SLE is effectively the breaking of bad news, and our participants acknowledged that they were often too overwhelmed or too relieved to take much in. Future discussions with the physician should be more reciprocal, however, and providing information in writing from trusted sources can be useful.

Over time, studies show that ineffective communication between the patient and health care providers can result in serious adverse consequences, and our patients certainly reported instances of non-adherence to medication [4]. There has been increasing emphasis in recent years on creating more concordant relationships between patients and physicians, although the results of our study would suggest that this has some way to go. The term concordance is used to reflect the negotiation of both treatment and desired outcomes between the patient and physician [13]. For this to happen most effectively, the patient has to feel comfortable communicating the issues that are most important to him/her to the physician, and what they would like to achieve in terms of outcome. Yet, one study found that 30% of patients were ambivalent or dissatisfied with their current therapy, suggesting that communication was not as concordant as it could have been [20]. Additionally, patients may go through periods of creative non-adherence to treatments as a coping strategy in itself. While this may seem perverse to the physician, for the patient, it is an attempt to take control of what may appear to be an uncontrollable situation. Support and understanding from the health care team is crucial at this time so that the patient feels that his/her choices are respected.

We would argue that the foundations for the development of a concordant relationship must be laid down during the search for and at the point of diagnosis. Due to a delay in diagnosis, what Stockl calls the typical SLE trajectory [18], p. 4), relationships with health care providers become strained, particularly where symptoms are minimized or attributed to personal factors, such as weight management. In these cases, it appears that future relationships with physicians are affected by these experiences, as patients are less likely to trust physicians’ suggestions.

As other studies have found, our patients certainly had periods where they valued their experiential knowledge of their disease over the knowledge held by their physician, and based their decisions regarding treatment on the former [1, 18, 21]. Our participants also wanted their health care providers to understand the psychosocial difficulties and pressures they faced that impacted on these decision-making processes. They also felt that physicians did not sufficiently consider the outward appearance effects of both the disease and its treatment. This may be due to physicians feeling uncomfortable instigating conversations about appearance concerns, as they may feel ill-equipped to offer any useful solutions. However, as appearance concerns strongly predict depression and anxiety in SLE and other rheumatic diseases, physicians may need to be more aware of the signs that might indicate a serious impact on psychosocial well-being. Discussing appearance changes and concerns, possible attempts to socially isolate oneself and relationship issues should be explored so that patients and physicians can set goals for mutually acceptable outcomes. This may involve a simple acknowledgement of patient distress and/or concerns and a referral to organizations that can help with cosmetic enhancement [7, 21–23].

Other supportive organizations that may be of benefit to the patient, such as marriage and relationship counselling, should also be borne in mind, because the strain that chronic illness may place upon relationships should not be underestimated. In an editorial in 2009, the author noted that half of all newly diagnosed married female patients with SLE divorced within 5 years [24]. Other studies have been more optimistic, suggesting that while patients report problems with self-image and sexual functioning, SLE was not a barrier to marriage or a primary cause of divorce [25]. In any event, the physician and/or wider health care team need to be attuned to these potential difficulties.

Psychosocial interventions designed to help patients cope with appearance changes due to SLE and its treatments might usefully include social skills training so that patients feel more equipped to address comments or looks from others. The women in our study often referred to their view of how they should look as women, and frequently compared themselves with other women who were, in their view, more feminine since they did not have to worry about skin, weight or functional problems. The good intentions of others who suggest treatments and self-help strategies often led to patients trying to appear to be actively doing something, so as not to appear lazy or to be giving up. Our participants felt that once they had become more confident talking to other people socially, they worried less about their outward appearance, putting greater value on their self-image, which, to them, was internally located and more valued.

We acknowledge that this study has a relatively small sample size; however, IPA studies are typically small in terms of the number of participants but generate a large amount of detailed data. The goal of IPA research, as with most qualitative approaches, is not to strive for generalizability of results as would be anticipated from a quantitative study. Rather, IPA studies tell us about this group of people at this time and their experiences. What might be generalizable or transferable are the concepts or themes generated from understanding this group of people, which might inform other studies and practice.

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**References**