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Yannick Le Hénaff

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Taking care of oneself and others: the emotion work of women suffering from a rare skin disease

Abstract

In this article, we analyze the emotion work of women suffering from pemphigus, a rare skin disease. We suggest that this approach sheds new light on the upheavals caused by illness and more generally on the experience of illness itself. Our study draws on a series of 27 interviews with pemphigus patients whose average age was 57.

We show that serious and chronic illness does not radically alter the feeling rules in place with close friends and family, despite the uncertainty and emotional upheaval confronting patients. The emotion work they carry out should be understood in light of roles and places established prior to the onset of the disease. Emotion work is embedded in the broader history of relationships with family and friends and prior episodes of illness help create particular configurations and expectations.

Pemphigus is a term referring to a group of autoimmune disorders characterized by the appearance of painful cutaneous blisters and peeling that at first glance resemble burns. These visible physical manifestations disrupt all manner of everyday interactions. Blistering can affect mucous membranes of the mouth and genitals, and less commonly the eyes and anus, so when inflammation acts up, everyday activities such as bathing, dressing, moving around, and eating are often limited and painful. Such outbreaks can be controlled through long-term, or lifelong, medical treatment. These treatments, however, do not exclude the possibility of a relapse, nor are they without potentially serious side effects, especially when they involve corticosteroids. Due to the low prevalence of pemphigus, it is classified as a rare disease. Pemphigus vulgaris (PV), the most common type of pemphigus (75% of all cases), affects around one in 2,630 people in France (Joly, Sin, 2011). As it is a rare disease, the condition frequently leads to various forms of physical and social isolation (Joachim, Acorn, 2003; Anonymous).

Like other chronic illnesses, pemphigus affects a person's relationship both to self and others (Gregory, 2005; Richardson et al., 2007) and involves what can be described as a "relationally traumatizing experience" or even a "relational trauma" (Penn, 2001, 33). In this respect, this chronic skin disease seems to create emotional upheaval that we consider in this article through the prism of the emotion work done by patients suffering from the rare condition in France.

In seminal research, Hochschild (1979; 1983) presents emotion work as an attempt to regulate emotions as part of social behavior defined by "feeling rules". The latter refer to accepted conventions regarding what should be voiced or felt in a given situation and are therefore closely linked both to social and historical ideologies and to the different social roles taken up by individuals. The author draws on the concept of "emotion work" to analyze the activities of professional groups (e.g. flight attendants, bill collectors, nannies) and thus to offer an account of paid emotional labor. We use the term differently here, to examine the experiences

of people suffering from a rare illness in the context of primarily personal relationships (with partners, children, parents, siblings, and friends).

While Hochschild's work follows on from Goffman's, she nevertheless points to his failure to take emotional processes into account. In her view, Goffman concentrates on what she calls "surface acting" and therefore only on visible emotions. Emotion work, on the contrary, also considers the emotions experienced—in this instance, by women living with a rare disease—which are the source of "deep acting". Whereas surface acting aims to modify or control emotions in order to manage their visibility, deep acting is a form of emotion work in which the aim is actually to feel the appropriate emotion in a given situation. Furthermore, by focusing on how the individual influences what others perceive, Goffman places insufficient emphasis on how emotions can affect an individual's behavior and can sometimes overwhelm him or her (Balfe, Brugh, 2010). Emotion work thus both controls and shapes feelings and physical expressions, and is at once self-targeted and other-targeted (Duncombe, Marsden, 1998; Erickson, 2005).

In order to analyze feeling rules, it is necessary to consider the influence of social positions but also of roles within interactions and—following Clark's lead (1990)—the micropolitics of emotion. Clark distinguishes between, on the one hand, the "emotion markers" that allow one to feel and construct perceptions of one's place and role, and, on the other hand, "place markers" (1990, 308) that signal, via "other-targeted emotions", how one wishes to be treated. This approach implies analyzing the negotiations that take place within interactions—made all the more palpable as a result of the new emotional contexts introduced by the onset of illness—while also taking into account the impact of social structures. From this perspective, two dimensions warrant particular attention. First, the "sick role" (Parsons, 1951), the contours of which are blurred in the case of rare diseases and require considerable negotiation (Anonymous). Second, gender relations, which are particularly significant here: in part, because family management of health is largely gendered, with mothers tending to engage in more daily care work—in affective, cognitive, material, and normative terms—particularly where children's health is concerned (Cresson, 1995; James, 1989); in part, because the division of emotion work is also broadly gendered (Erickson; 2005; Hochschild, 1983; Thomeer et al., 2015). From this perspective, our article focuses specifically on women with pemphigus.

Our approach is original insofar as studies addressing emotion work in the field of health have mainly tended to focus on professionals, following the lead proposed by Hochschild's research (Bolton, 2000; Underman, Hirshfield, 2016). We suggest that our perspective can shed new light on the disruption introduced by illness (Wilson, 2000) and more broadly on the experience of illness itself. Some aspects of this approach can be found in research focusing on "care" especially in terms of the sick person's commitment to limiting the impact of his or her illness on others (Karp, Tanarugsachock, 2000; Thomeer et al., 2015). Researchers have shown how patients avoid openly acknowledging certain emotions or even feign a positive attitude for the benefit of their loved ones, sometimes to the detriment of their own needs (Trusson, Pilnick, 2016). In these studies, emotion work is simply one of several dimensions taken into account or is looked at through the prism of the conjugal relationship. We propose, instead, to view this aspect systematically through the prism of the sick individual's experience. In this vein, Franck (2007) suggests a stimulating avenue for analysis with the notion of the "drama" of emotion work, which he argues is produced by the conflicting demands between which patients find themselves caught. He shows that, unlike in the frameworks of traditional interactions where the self is a means through which individuals can avoid discredit, in the context of illness, these performances aim instead to meet the

expectations of others. In order to preserve normal relations, chronic disease sufferers thus limit expressions of distress, fear, or anger. By extending the analytical frame of emotion work to experiences of illness, we analyze how living with a rare disease reconfigures emotion work, paying particular attention to the biographical dimension (Anonymous; Bury, 1982). We give particular emphasis to feeling rules and how they evolve within relationships with close friends and family, putting forward the hypothesis that these performances are complex and vary according to the situations and people encountered (Bolton, 2000).

Methods and data

According to the specialized biomedical literature, the average individual living with pemphigus is between 50 and 60 years of age, and the disease affects males and females indiscriminately (Joly, Sin, 2011). Our study included 27 female pemphigus patients whose average age was 57 (the youngest was 22 and the oldest was 78). The sole criterion for inclusion was that the participant be at least 18 years of age (the age of majority in France). The composition of our sample was heterogeneous in terms of social class, 6 of the participants were single (the majority of whom were widows), and 3 did not have children.

Participant recruitment was carried out by the “Association Pemphigus Pemphigoïde France” (founded in 2005). This patient association meets twice a year in Paris and regularly distributes a newsletter to more than 500 individuals. Recruitment techniques included a presentation given during one of the association meetings, as well as an announcement published in its newsletter.

The interviews all lasted from one to one and a half hours and were fully recorded and transcribed. They were conducted between 2014 and 2020 by the authors of this paper. At that time, the participants had each been diagnosed for an average of five years. The interviews always began with the same request, “Please tell me how it started.” Our follow-up questions were not taken from a pre-established interview schedule; instead, we aimed to explore the widest range of patient experiences possible. Nonetheless, several potentially relevant themes had been identified in advance, such as the doctor–patient relationship, the diverse consequences of the illness and treatment on the patient’s private life, the roles that close family and friends played throughout the illness, and the quest for a diagnosis. In our approach, we regarded the experiences of individuals living with pemphigus as unfamiliar territory to be discovered (Glaser, Strauss, 1967). While our initial questions did not specifically focus on the theoretical frame of emotion, this progressively established itself as a key research issue as our interviews progressed and was taken into consideration in our analysis.

Emotion work was not the main focus of our study, but soon emerged as a key approach to understanding experiences of the illness. During the initial stage of our analysis, each of the authors individually established a preliminary analysis grid using an open coding approach (Strauss, Corbin, 1998). Relying on the data collected, we identified main themes and established coding for concepts that were important to the individuals living with pemphigus. During the second stage, the co-authors met to compare their respective analysis grids. The differences were discussed, leading to a revision of the initial coding. During the third phase, the authors recoded all of the interview transcripts and compared their individual analyses. Once the descriptive categories were identified, we established an axial coding process. Constant comparison (between separate interviews as well as of the concepts found within each interview) revealed underlying conceptual themes.

We turned to the existing literature once our themes and sub-themes were identified. Thus, the main questions that were raised stemmed more from field data than from theoretical frameworks. The literature later allowed us to clarify and further develop our analyses.

Findings

Our analysis shows that the emotion work carried out by pemphigus patients can be divided along two, broadly imbricated lines with, on the one hand, emotion work aimed at avoiding worrying and thus upsetting close family and friends, and, on the other, emotion work aimed at obtaining recognition of their difficulties and especially their sick role. The tension between these two dimensions is part of the broader dilemma of wanting to protect loved ones and trying to preserve relationships by minimizing symptoms, whilst at the same time prompting these same loved ones to recognize a new emotional context.

1. Emotion work to spare family and friends

Given that pemphigus is rare, relatively unknown even among doctors, and highly disruptive, it leaves patients dealing with an array of anxieties. Our study participants living with the condition attempted to lessen the impact of these anxieties upon their family and friends. The work required to achieve this varied according to the timeframes of the illness but also, and above all, the roles that these women took up and the intersecting biographical experiences of those around them. We analyze this in particular detail by distinguishing between, on the one hand, vertical relationships (comprising children and parents) in which the weight of their role as mothers (1.1) is brought to the fore as well as the multifarious, fluctuating configurations these parent-child relationships can take (1.2), and, on the other hand, horizontal relationships (partners, siblings, and friends) (1.3).

1.2. "I didn't want to worry them": the importance of their identity as mothers

Women living with pemphigus frequently present themselves as "emotion experts" (Thomeer et al.; 2013, 153) or even as responsible for regulating the emotional atmosphere in the home, particularly where their children are concerned, but also to a lesser degree with elderly parents. This work is part of a family economy of emotion, as illustrated by the case of Irène (73 years old, married, with 3 children), who, with her husband's help, initially tried to hide her difficulties from her children. Her husband played the role of "team member" (Goffman, 1959) supporting this emotional performance:

"I didn't want to tell my children about it because I didn't want to worry them, I tried to, let's say, to... to deal with my problems on my own and to... to make them wait, as it were".

For most of our participants, reversing the legitimate emotional dynamics of concern (with children worrying about their sick parents) proved inconceivable. They presented the need to maintain their protective parental role as self-evident, including when the children in question were adults. Seeing their children upset or anxious produced guilt, thus encouraging them to pretend to be well or even to try to feel well despite discomfort and feelings of vulnerability. The level of guilt experienced was significant and testified to the prescriptions surrounding the role of mother serving as a place marker. This was the case for Maëva (55 years old, married, 3 children) who found one of her children's failures at school very difficult, linking them to the emotional disturbance generated by her illness:

“Sometimes, I’m the ideal mother, really happy, but I’m lying [...] Sometimes, I hide [things] for the children. I show them that I’m well but when they’re not there, that’s when... I cry [...] I try to forget... I don’t talk about my illness. I always try to talk about something nice, holidays, outings, I try to forget my illness for my children [...]. I don’t want them to always be in darkness, with the anxiety and the fear that... that their mother’s going to die.”

Maëva forced herself to engage in deep acting when she “*tr[ied] to forget*” by “*thinking about positive things*” or tried to take comfort in her children’s happiness—in other words, by trying to maintain her role as an “*ideal mother*”. When she could feel distress looming, she would “*try to nibble on something*” to take her mind off it and above all to avoid “*crying*” in front of her children. This deep acting was therefore part of her daily routine: “*not letting [herself] go*” and maintaining a minimum healthy lifestyle, getting up at a regular time, as well as forcing herself to prepare her children’s lunch at home, despite her exhaustion and the fact the school had a canteen—something that she saw as a real claim marker. For her, being active in front of her children was a way of reassuring them so that they would “*feel that [she wasn’t] ill*” just as much as it was a way of reassuring herself and keeping going. Among our participants, this situation was particularly prevalent among women with children at home and especially young children.

The emotion work carried out by our study participants was also informed by health management routines that had been established in the family before the onset of pemphigus. The women frequently put a lot into these routines, sometimes even taking them over to some extent, as a way of channelling the anxieties of their loved ones more effectively. For example, Charlotte (40 years old, 3 children, married) believed she had enough leeway to manage information and therefore any anxiety, especially while she was struggling to obtain a reliable diagnosis and her health was deteriorating: “*I said: we’re not going to panic, we’re going to wait for the results. I said it like that and no one mentioned it again until the dermatologist’s results came back.*” She therefore drew on the longstanding mode in which health issues were managed in the family (she usually accompanied family members to doctors’ appointments, did Internet research for them, etc.). According to her, the division of roles was accepted: “*that’s just how it is and it suits everyone*”. If necessary, she would firmly call her children back to order when they showed too much compassion, using emotional cues (Clark, 1990): “*I’m the mother here*”.

For the vast majority of our participants, it was important to “*keep it together*” in front of children, as Danielle (53 years old, divorced, 2 children) put it, and to put on a happy countenance. Doing so required our participants to engage in considerable work on both themselves and others in order to convince and dissimulate. In other words, it involved a range of forms of “*face work*”: not complaining, not showing exhaustion, putting on a brave front, seeming happy, etc. In certain instances—forcing themselves to eat, not simply giving in and going to bed, or not expressing pain—it meant fighting a damaged and failing body and could thus require strategic anticipation of interactions. Whenever her condition flared up, Chantal (widow, 61 years old, 2 children) preferred to arrange to meet her children and grandchildren for coffee, after a meal, so they would not witness her difficulties swallowing food. This form of emotion work was therefore largely carried out on the body, taming and masking symptoms—until, that is, the point at which the body betrayed the patient acting as a silence breaker and shattering the effectiveness of this labor. Indeed, for a lot of patients, physical changes (visible blisters or rapid weight loss/gain due to treatment, etc.) undermined the credibility of their emotion work and forced them to reveal the truth about their condition. Gwendoline (43 years old, married, 2 children) hid her illness from her daughters for a long

time but was finally unmasked during a lunch with one of them when she had difficulty swallowing on several occasions. Emotion work was also sometimes put to the test of bodily realities during what might seem to be perfectly ordinary conversations that could nevertheless act as triggers for questions and concerns: for example, when a child asked a sick parent for a favor (e.g. looking after a grandchild, helping with a house move, etc.) that the parent's health made impossible.

For these women, their sense of guilt coalesced in part around their identity as mothers that, at the same time, acted as an emotional resource that was in some respects comforting. In addition to the sense of vulnerability created by the illness, patients also have to contend with a set of emotions triggered by the concerns of their children and even their parents when the latter are elderly and vulnerable—all of which act as place markers. While the verticality of family relationships structure this emotion work to a considerable extent, certain contexts do encourage a re-evaluation.

1.2. Specific configurations: taking into account the family history of illnesses

Emotion work is embedded within the family history of illnesses and their management in the past, which contribute to establishing points of reference and routines. While all our participants were attentive to the need to protect their children emotionally, this attention was not static: around a quarter of them noted changes in this emotion work over time. The work evolved in a dynamic way according to the different ordeals experienced, but also to the various skills ascribed to different family members.

The husband of Martine (69 years old, married, 2 children) had had cancer several years earlier. This challenge brought the couple much closer together and also made them closer to their children, fixing the affective mode of their relationships and fostering what Weber (2005) calls “solidarity between the living”. However, the ordeal also set a precedent when it came to the management of emotion work. Martine and her husband were “*relatively transparent*” about his state of health but this had an impact on one of their daughters who had “*lots of problems linked to stress. She lost her hair, she had panic attacks. She was really scared.*” When Martine was diagnosed with pemphigus shortly after, her daughter's serious prior manifestations of anxiety led the couple to tell her as little as possible in order “*to protect her*”. Just as previous experiences of illness can reinforce the work done to spare others—a relatively rare case in our study—they can also have the opposite effect. Due to an extended period of unemployment, the 30-year-old son of Irène (73 years old, married, 3 children) was forced to live with his parents again for a few months that coincided with the onset of her pemphigus. Alongside his father, he therefore was party to the progressive decline in his mother's health as, to quote her, she “*thought [she] was going to die. It was terrible*”. Irène was so exhausted and so scared that it was hard for her to hide her most negative emotions from her son on a daily basis. Whereas she had always thought of herself as a “*mother hen, always protecting him*”, this episode created a break with the past in this respect. “*He was a huge help to me. Just the fact that he was there took a weight off. I didn't have to hide it from him and he helped me feel better. I'd never have told him, well, not how hard it was, but in this case, he knew*”. The experience gathered in the course of successive illnesses within a family therefore plays a considerable role in shaping current emotion work and can sometimes produce a break with the past.

The division of emotion work within the family context is not set in stone and also depends upon children or parents' presumed ability to handle the situation and to understand it. The patients in our study seemed more inclined to share their difficulties with their children when the child in question had professional resources—whether real or simply presumed—that

could be mobilized to deal with his or her own emotions. Nicole (62 years old, widow, 2 children) acknowledged that she had opened up more to one of her daughters, who was a nurse and whose professional skills were supposed to protect her from any emotional distress. In the case of Gwendoline (43 years old, married, 2 children), it was the fact her daughter was studying psychology that allowed her to speak more freely about her illness with her.

Emotion work within the family thus takes on complex configurations that are embedded within a broader biographical itinerary. While changes and breaks with the past must be taken into account, the context of the illness typically does not entirely disrupt the previously established emotional community within the family. On the contrary, it takes on meaning in light of the different roles taken up within this space (parent, partner, or child) and is part of the moral duties that contribute to “doing family” (Wilson, 2007; Weber, 2005). In the cases of loved ones who are neither children nor elderly parents, however, feeling rules seem to evolve according to contexts of vulnerability.

1.3. “It’s just not possible to give time to anything a bit less serious”: ranking suffering in relation to the suffering of others

In horizontal relationships (i.e. with close friends, partners, and siblings), our participants allowed themselves greater freedom to express emotions such as fear, anger, or despondency, whilst at the same time balancing the extent of that expression with the life events that those around them were experiencing. A hierarchy of suffering, of illness, and more broadly of problems was at work and actively affected relationship dynamics, a process compounded by the fact that pemphigus is a rare condition.

The participants’ disease was sometimes experienced in terms of competition with other illnesses affecting close friends and family. In these situations, the pemphigus was put into perspective in relation to supposedly more serious—but above all better known or recognized—conditions. This was frequently the case with cancer, as illustrated by the situation Lea (64 years old, single, 1 child) experienced with one of her brothers:

“[it takes] over because it was a much more rapid fatal disease than mine. So, already, that kept the family busy for a long time [...]. It just wasn’t possible to give time to anything a bit less serious, well, less serious, let’s say that I wasn’t at death’s door the way my brother was.”

Just under half our participants therefore described a form of competition in suffering, in which one person’s expression of distress counterbalanced or even stifled that of the other person. It is as though there were a hierarchy of disease legitimacy, most often internalized by our patients who did not experience any resentment. However, the boundary was blurred between recognizing the legitimacy of a hierarchy in the right to express distress and experiencing pressure not to complain: “one day there was this slightly hurtful insinuation that my sister [suffering from a ‘serious illness’] talked a lot less about her illness than I did” (Catherine, 67 years old, widow, 2 children). Catherine acknowledged a certain form of emotional censorship, which she came to internalize over time, considering henceforth that her own difficulties had to be put into perspective compared to those of her sister. Pemphigus patients lack not only visible physical signs of their illness—and we will come back to this—but also symbolic signs because their condition is too rare and little known to make sense to others.

While it is necessary to take into account the immediate context of the hierarchy of distress, its longer term effects should also be considered. This is illustrated by the example of Maëva

(55 years old, married, 3 children) who, for a long time, was able to rely on her husband's full emotional support until his brother became ill with cancer and died a few months later. During this period, she largely refrained from expressing her distress as "*it was very hard for [her] husband*". In the face of his suffering during this time, she tried to spare him and to put on a more positive attitude in his presence, which had a lasting impact on their relationship. "*Even now, I'm careful. This relationship is fragile. After his brother's cancer, I was careful to spare him, you know.*" In this perspective, it is therefore important to take into consideration the history of illness within the couple, where dynamics of reciprocity can also appear. Our participants took considerable account of their loved ones' emotional biographies, not simply in terms of illnesses but also, more broadly, in terms of any context involving an excessive emotional burden. Recently given birth, having young children to look after, going through a period of stress, and so forth, were all factors that could produce forms of emotional censorship.

An emotional biography therefore emerges, permeated in complicated ways by the various ordeals endured, but also by the reactions noticed and the difficulties experienced by family and friends. Complicated emotional configurations arise, varying according to the characteristics of those involved: age, assumed vulnerability and skills, prior experiences, etc. While this hierarchy of suffering is rarely experienced as unfair, the emotion work can produce suffering when it results in alienation and injustice as analyzed below.

2. "*With these illnesses, you can't complain*": negotiating the emotional sick role

The majority of our participants also indicated their frustration or even anger about not being able to speak freely about their feelings with their family and friends in certain contexts, especially in horizontal relationships, therefore leading us back to the concept of drama (Franck, 2007). To examine this further, we consider the emotional side to the sick role, through what we refer to as the "emotional sick role". In this section, we analyze, first, the frustration produced by a lack of recognition of emotional difficulties (2.1.) and, second, the negotiation processes that arise as a result (2.2.).

2.1. A little known and relatively invisible illness: coping with an unstable status shield

Although the body sometimes serves as a silence breaker by revealing the illness, conversely, when the pemphigus is less immediately visible, this can also restrict the expression of emotions and thus bear upon the sick role (Parsons, 1951). In its origin meaning, the sick role allows the patient to express his or her difficulties and to receive support, including of an emotional nature, at least when the illness in question is socially accepted. However, many studies have shown that this process involves frequent negotiations according to the situation and the disease in question (Nettleton, 2006).

Certain specificities of pemphigus and the negative side effects of the medication used to treat it (fatigue, irritation, insomnia, osteoporosis, etc.) are, in part at least, relatively invisible to the outside observer. When this is combined with the general lack of knowledge about this rare illness, it can be hard for patients to express emotional difficulties:

"It's not an illness that leaves you bedridden [...] With these illnesses, you can't complain, you can't say what you're feeling, you just can't. I think, whether it's family or friends, they all say: at the end of the day, she's making it up. She's telling us things that aren't true so that we'll feel sorry for her. That aren't true because when we go and see her, she's fine." (Bénédicte, 63 years old, married, 2 children).

The patients in our study, suspected of seeking sympathy, were sometimes accused of manipulating their emotions and those of others, and thus of being specialists in emotion work. The sick role requires social acceptance and pemphigus patients therefore suffer the consequences of the fact that, except during flare ups, their illness lacks visible signs that could prompt empathy and lend legitimacy to their suffering (Richardson et al., 2007). Given that it is also not well known, pemphigus did not allow our participants to benefit from what Hothschild calls a “status shield”, in this instance the sick role, that would protect them from the “displaced feelings of others” (1983, 163).

“It’s also tiring having to repeat it... after about ten seconds, when you see their eyes. You can see it in their eyes, when people aren’t listening to you. So there’s no point. All it does is tire you out. And disappoint you. Especially when it’s family, because you can see... how can I put it? They’re no longer paying attention. It’s the look that says: please make her hurry up.” (Monique, 63 years old, married, 3 children).

Monique found herself in a situation that was relatively rare among our participants: her difficulties were exacerbated by the side effects of her corticosteroid treatment that gave “color” to her cheeks and so, paradoxically, made her “look well” even though the treatment did not give her enough of a “boost” to make her more energetic. There was a radical discrepancy between what she was experiencing and what could be seen on her face, making it even harder to express her difficulties:

“Sometimes, you want to explain a bit, to speak your mind. Afterwards, there are reactions that you often hear: “Really? She’s sick? But she’s always on great form. She’s on her bike, she’s...” (Monique)

The study participants mentioned difficulties in expressing emotions that they considered legitimate given their illness and therefore had to negotiate their emotional sick role. Facing suspicion and a lack of empathy from a loved one produced a mixture of frustration, anger, and even shame—an array of emotions that served as place markers signifying the fact that their sick role had not been accepted. Furthermore, these ordeals compounded feelings of vulnerability. After they had experienced this several times, the patients eventually self-censored their complaints in order to avoid being seen as perpetually dissatisfied and resorted to various tactics to try and bear upon these feeling rules.

The frustrations our participants experienced were not without ambivalence: they sometimes complained about the difficulty of finding a space in which to express their emotions with certain people, while at the same claiming that they were trying to protect those same people.

2.2. Adjusting to feeling rules or negotiating the emotional sick role

Our participants did also react to these emotional difficulties. In particular, they developed two stances that allowed them to bear upon feeling rules—either by anticipating certain interactions or by using “emotion shifters”.

Bénédicte (married, 3 children, 63 years old) noticed those close to her doubting her experiences and on several occasions even felt she was being regarded as an inveterate liar, suspected of complaining without good reason. She acknowledged that, as a result, she had internalized the need to control certain emotions when they did not make sense to others. *“My close friends and family would call me to see how I was, but actually they didn’t really understand what was wrong with me, [so] in the end I just didn’t talk about it anymore”*. In line with what Cheri Register (1999) has shown for individuals with chronic illnesses, our

participants experienced difficulties when family and friends got in touch to see how they were, in a ritualized fashion, especially when asked the question “how are you?” that “does not call for a recitation of horrors, but only for assurance that all is well enough for conversation to proceed” (Register, 1999: 57). In this case, a seemingly banal interaction can in fact lead to feels of uneasiness. By giving reassurance and replying that everything is fine, this “seemingly trivial greeting” becomes “a fearsome moment of decision” (p. 58). This ritualized dialogue is rarely an opportunity to actually describe difficulties and pour one’s heart out because, as Léa explained: “*It’s awful when people ask you that question because it makes both of you feel guilty. One person can’t help, and the other can’t answer the question*”. More often than not, our participants therefore learned to avoid the subject and not to talk about their difficulties or to complain. As a result, their emotional repertoire was considerably restricted. Their misgivings, linked to the fact that their family and friends failed to recognize their situation, had a significant bearing on their place marker and the legitimacy of their complaints.

For many of our participants, when the signs of their illness were not very visible and made little sense to others, it seemed necessary to avoid showing distress. More radically, this sometimes even led some of them to avoid social interactions that might place them in a difficult situation, especially—and this was emphasized many times—invitations to eat with friends. The patients most often followed a strict salt-free diet, hard for the uninitiated to put into practice. Shared meals were therefore experienced as ordeals leading to tension for the women who found themselves caught in a dilemma: they could either force themselves to eat, with all the potential physical consequences (water retention, pain) or risk causing their hosts—who despite their best efforts, often unwittingly cooked with a certain amount of salt—to lose face. The avoidance of shared meals was testament to a desire to avoid tricky situations but also contributed to forms of isolation:

“[Some people] make an effort but they don’t really know what a salt-free diet is, so... They want to oblige. They cook meat with mustard, they also put things in to add salt without realizing it. It’s true that everyone eats salt all the time so...” (Ursula, 44 years old, married, 1 child).

More generally, the patients tended to avoid situations that would produce emotional turmoil and were resigned to not expressing their anger, frustration, and resentment—resulting in a sense of vulnerability. For some of them, avoidance tactics were also about wanting to prevent emotional highs and lows that might potentially trigger a flare up of their condition—at things stand, little is known about the causes of this autoimmune disease.

The weariness, which was as physical as it was mental, prompted them to give up on negotiating their emotional sick role and to turn in on themselves or towards some of the people close to them: “*when you’re exhausted or sick, you tend to try to save your strength... if I have to repeat myself... two hundred and forty times, well...*” (Monique). When strength is lacking and weariness increases individuals tend to focus on themselves and, as Le Breton writes (2017, 47) “the person suffering withdraws into themselves”. This withdrawal from, or selection within, social relations therefore seems to proceed from the difficulty of arousing empathy, given that in this case the sick have internalized the notion that certain emotions are illegitimate in these contexts. Giving up on expressing emotions and withdrawing from certain aspects of social life therefore come to be constructed as requirements over the course of the illness, as a result of repeated disappointment.

Finally, our participants also drew on another approach, albeit less often than they chose to anticipate and avoid emotionally upsetting interactions. In some instances, they worked to

redefine the emotional framework of interactions by drawing in particular on what we refer to as emotion shifters in order to bear upon their emotional sick role. The first of these emotion shifters consisted in openly expressing and owning their difficulties, the seriousness of their condition, and its implications, in the most comprehensible way possible. This stance contrasted with emotional outbursts or uncontrolled displays of emotion, and was instead part of a pedagogical dynamic (Joachim, 2003) allowing our participants to increase understanding of the constraints imposed by their condition through explanation. However, such explanations came at a cost as they required the women to reveal, or worse still negotiate, their vulnerability. For example, when Béatrice (22 years, living with her partner, no children) was told by one of her friends “*there’s worse off than you!*”, instead of answering “*straightaway*” she waited for the right moment:

“When we saw each other again just the two of us, I explained to her that, for me, that just didn’t mean anything, because each patient with the same illness as me won’t experience it the same way as me. It’s always the same symptoms, but we experience them differently.”

For the patients, it was therefore a question of creating a delicate balance between broaching the question and not focusing attention on themselves; in other words, making others aware of the seriousness of the illness and how much support they required but without too much insistence. Such situations bring into play the individual’s “face”, which is revealed and runs the risk of being deemed deceptive. It becomes a matter of making the most of the rare moments that are conducive to intimacy, confiding in others, and letting down one’s guard. Some of the women in our study seemed to have learned how to prompt or make the most of these moments. “*There are also times when you can say more, expose yourself, let go*” noted Gwendoline (43 years old, married, 2 children). “*When it’s a small group, in a quiet place, when you’ve got some time ahead of you, then you can [...] but you can’t do it all the time, that’s for sure.*” The main difficulty—and unknown—is juggling between these moments, others’ expectations, and physical expressions that can be difficult to control.

The second emotion shifter used by our participants consisted in “*casually*” (Laura, 37 years old, living with her partner, no children) leaving clues pointing to the difficulties encountered, without expressing them openly or dwelling on them. This involved drawing the attention of others to certain salient realities such as cortisone treatment, another better-known diagnosis that was a consequence of either the disease or its medication (e.g. osteoporosis, glaucoma, diabetes, etc.), or multiple hospital appointments. These signifiers lent weight to the gravity of the situation, without actually mentioning the illness itself. In these instances, the patients neither dwelled on their problems nor expressed their own emotions; instead, it was about triggering emotions in others and using clues as signals that act as substitutes. Gwendoline felt it was “*difficult to talk about [her condition] because you don’t know how to explain it clearly*” and therefore preferred to mention her cortisone treatment instead: “*as soon as you say you’re on cortisone treatment, people know that, well, it’s a treatment that’s... that’s not to be taken lightly, you know*”. As for Laura, she regularly mentioned her many hospital appointments in conversation, as chronic reminders of her difficulties, especially with friends and family who demonstrated a certain incomprehension. Mentioning appointments triggered questions in return, which allowed her to broach the topic of her problems. This process offers a way of pointing to the seriousness of the illness or its relapses, as well as the attendant emotional consequences, without the individual seeming to be engaging in self-pity. The person’s health status—and potential emotional state—is thus signified not through reference to the disease itself, which is not well-known enough, but instead by using emotional cues to make others aware and to alert them.

Discussion

While analysis of emotion work carried out by patients has rarely been used in the literature as a way of accounting for the experience of illness (Froyum, 2018 ; Thomeer et al., 2015), we have seen here just how salient it proves as an approach. This article's first contribution is thus to show that, despite serious and chronic illness—in this case, pemphigus—plunging patients into uncertainty and emotional upheaval, it does not in fact radically disrupt the feeling rules in place with close friends and family. The emotion work carried out should be understood in light of the roles and places established prior to the illness. In relationships with children, in particular, emotion work is one of the moral duties that contribute to “doing family”, testifying to the fact that there is not a division between, on the one hand, a patient at the center of attention and care, and on the other, the people who provide those things (Chattoo, Ahmad, 2008). The need actively to embody the role of mother, for example, remains strong and the frequent mentions of guilt when deviating from this role can be understood as “rule reminders” (Hochschild, 1979, 563). However, this “key identity” (Wilson, 2007) also constitutes a potential emotional resource in the face of chronic illness and perhaps even contributes to maintaining the patients' ontological security in some respects (Bell et al., 2016). Wilson (2007) has clearly shown that people who are ill tend to focus more on certain aspects of their lives, especially when entire facets of their identity—professional, in particular—are called into question. While the patients' identity as mothers does seem to weigh heavily on these situations, it is also important to take gender dynamics into account more generally. The logic underpinning emotion work can be coercive, in some respects, when it combines a sense of responsibility, indebtedness, and even duty (Cresson, 2006). This giving of oneself, already identified in work on care, produces gender inequalities in the management of emotion work, which can have broader repercussions on well-being or even health (Richardson et al., 2007). From the perspective of gender dynamics, the way in which emotional regulation is carried out, as identified in our study, echoes certain socially-constructed expectations of femininity. These include reducing expressions of anger (Froyum, 2018; Garside, Klimes-Dougan, 2002)—something that corresponds significantly to the work in which our participants engaged in order to normalize day-to-day life. There is also a broad consensus in the literature to suggest that women engage in disproportionate amounts of emotion work, particularly although not exclusively with a view to ensuring the well-being of other family members. (Froyum, 2018; Minnotte et al., 2007), to the extent that they could be considered “emotion experts” (Thomeer et al., 2013, 153) or “emotional gatekeepers” (Denham et al., 2010, 45). Nevertheless, for our study participants, illness seemed to make family emotion work less self-evident, shattering the illusion that such work is necessarily spontaneous, effortless, and a natural expression of motherly love (Hochschild, 1983; Erickson, 2005).

Moreover, thinking about the sick role and emotion work together offers a more fine-grained way of considering both the diversity of experiences of illness and how the latter are negotiated, within a biographical framework (Exley, Letherby, 2001). The two concepts can even be considered heuristically as “sensitizing concept[s]” (Blumer, 1969; 148) and so as ways of exploring and discussing the upheavals that illness entails. This potentially disruptive experience involving the self and others (Bury, 1982; Anonymous) left our study participants torn between the desire to have their difficulties recognized and the desire to downplay them: “on the one hand they want their ‘stranger’ status to be acknowledged, while on the other they do not want their condition to become their ‘master status’” (Exley, Letherby, 2001). Here, in other words, emotion work sheds original light on the experience of illness, particularly when viewed through the prism of emotional biographies. Neither gender dynamics nor the dynamics of the sick role fully account for the variety of experiences endured. It is therefore

necessary to conceive of emotion work in terms of dynamics in order to take into account the ways in which family or friendship configurations change over time. Hoang and Yeoh (2012) have demonstrated that the emotional burden linked to the experience of migration and of separation can be mitigated depending on the family configuration, and this is true more generally for life experience and social characteristics (Williams, 2000). Emotion work is embedded in the broader history of relationships with family and friends and prior episodes of illness help create particular configurations and expectations. As we have shown, considering emotion work in light of these aspects requires taking into consideration the breaks with, or at least the shifts in, feeling rules in place.

It is also important to take into account the failures of emotion work and the dilemmas that patients face (Franck, 2007). Illness introduces new emotional contexts, both for the self and others, that require negotiation. The literature has already pointed to the fact that patients and loved ones do not give meaning to these experiences in the same way (Chatoo, Ahmad, 2008; Rosedale, 2009). Such discrepancies are not disconnected from the shape taken by what we have referred to as the emotional sick role, that is to say the way emotion work is used to negotiate this role with its blurred contours. In the case of an illness that is both relatively invisible, flare ups aside, and relatively unknown, negotiating this emotional sick role is a delicate affair and does not provide a “status shield” (Hochschild, 1983). From this perspective, emotion work should be considered in the long term and analysis should look at how feelings and the limits of what is tolerable evolve for patients. As a result, repeated disappointments and, more broadly, painful experiences, seem to lead to resignation and acceptance of less empathy than would have been considered appropriate at the start of the illness. It is therefore interesting to consider the effect of the illness, in the longer term, on engagement in emotion work. Certain indicators do suggest the existence of profound upheavals in this engagement over time. The illness first appears as a learning process, evidenced by the way patients negotiate their emotional sick role, which in many cases prompts them to internalize restrictions to their emotional repertoire particularly when it comes to expressing distress. Self-control was characteristic among our participants, who found a way of living with their pemphigus in a complex process involving learning about themselves and negotiating relationships with loved ones, peers, and doctors, as Koch et al. (2004, 490) have also shown in the case of asthma patients.

The emotion work carried out is also permeated with contradictory emotions and situations: our participants sometimes sought to spare others, whilst at the same time wishing to spare themselves. They thus illustrate just how difficult it can be to construct an emotional sick role that reflects one’s reality. These apparent contradictions are no doubt sustained by modernity’s chronic reflexivity regarding our emotions and the need to work on them (Williams, 2000). Given that so little is known about the causes of pemphigus, doctors tend to encourage patients to avoid stressful situations and so to rationalize slights rather than to react vehemently against them; in other words, to swallow their anger and to work upon it.

This study set out to reveal the emotion work done by patients, opening up promising research avenues, especially in terms of how feeling rules are embedded in longer timeframes and in the histories of groups and individuals, within which emotional routines are already in place (Karp, Tanarugsachock, 2000; Rolland, 1987). Without going so far as to talk about an emotional “career”, it is clear that the temporal dimension of emotion work cannot be ignored: the patients’ emotions themselves evolve over time (Karp, Tanarugsachock, 2000) and are in part shaped by interactions with others. It should be noted, though, that by focusing on close friends and family, we deliberately excluded other important dimensions of emotion work that could be the topic of future research. It would, for example, be useful to consider

how patient organizations or relationships with healthcare professionals help to co-construct what counts as legitimate expression of emotions and therefore to change the way in which experiences of illness are understood.

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