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**Gender and Care in the Context of Rare Diseases: Exploring Nuances of Emotional Support and the Division of Household Labor**

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## Abstract

This article explores the ways in which having a rare skin disease (pemphigus) can reveal and redefine individuals' interpersonal relationships and how they experience and use the support of loved ones. It examines two aspects of "care": emotional support and practical support (through the division of household labor). It takes a relational ontological approach that is especially attentive to the biographical repercussions of care, and its gendered dimensions in particular.

Our analysis is mainly based on interviews with 25 individuals in France (13 women and 12 men) with pemphigus, a rare disease that affects the skin and mucus membranes that can be controlled through long-term medical treatment. Its burn-like lesions often take the form of blisters, making pemphigus a bullous disease.

Use of the concepts of "caring for" and "caring about" prove heuristic in studying care relations, especially when taking a gendered perspective and probing underlying tensions. The distinction between caring "for" and "about" is also relevant to comprehending biographical disruption, which mainly results from a lack of emotional support when the negotiation of practical support has made it possible to normalize everyday life.

Key Words: Gender, Care, Rare Disease, Emotional Support, Household Labor

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Pemphigus is an autoimmune disease whose flare-ups include visible lesions on the skin and mucous membranes (otorhinolaryngologic region, eyes, genitals) resembling burns. These lesions are often in the form of blisters, putting pemphigus in the larger category of bullous diseases. Outbreaks can be controlled through long-term or lifelong medical treatment, but the possibility of a relapse remains and treatment may have potentially serious side effects, especially if it includes corticosteroids. The needs of people living with pemphigus may vary from day to day according to the severity of their case, ranging from applying a skin cream to the (frequent) need for dietary changes to occasional challenges in performing housework due to fatigue (Le Hénaff et al., 2022).

Pemphigus is classified as a rare disease. Each year there are between one and 16 new cases per million inhabitants (Joly, Sin, 2011). Pemphigus vulgaris (PV), the most common type, affects around one in 2,630 people in France, where we conducted research. Typically, healed pemphigus blisters leave no scars, so many of pemphigus' consequences and the side effects of treatment are unapparent to the outside observer. This factor has a singular impact on the self-perceptions of people with pemphigus and how they relate to their bodies, as well as their relationships with others. As it is a rare, and partially invisible, disease, it frequently leads to various forms of isolation. Having a rare illness can undermine a person's credibility or recognition (Plage et al., 2018). They may feel even more isolated due to difficulties in sharing their experiences with loved ones and caregivers, who may not understand what they are going through (Joachim, Acorn 2003; Le Hénaff et al., 2022). This article studies the care experience of people living with pemphigus in France, particularly exploring gender dynamics.

The onset of an illness, especially when it is chronic, has a relatively permanent impact on the affected person, but also on their interpersonal relationships (Anderson, Bury, 1988; Gregory,

2005; Richardson et al., 2007). Consequently, care dynamics cannot be analyzed in only one direction (from caregiver to care-receiver): these dynamics are intricate social relationships and distributed activities (Hudson et al., 2020). Care is part of everyday interpersonal relations. This makes the notion of reciprocity – a sense of mutual obligation – central, especially in the relationships of couples (Gibson et al., 2018; Hudson et al., 2020). This sense of reciprocity is especially undermined with the appearance of a severe chronic illness (Aasbø et al., 2016). Sulik (2007) finds such expectations of reciprocity particularly salient in women with cancer, forced to find a balance between self-care and the care of others, which reveals how deeply gender norms saturate the dynamics of care. More generally, Casey and Stone (2010) find that men in heterosexual couples enjoy more informal support than women. Indeed, women generally assume responsibility for caregiving, ultimately with repercussions on their health and well-being (Anderson, Bury, 1988; Richardson et al., 2007).

Several kinds of support have been distinguished in the literature, and they seem to be touched by gender dynamics. Richardson et al. (2007) propose distinguishing between “caring for” and “caring about.” “Caring for” refers to various forms of practical support such as help with dressing, washing, cooking, and shopping, but also giving information or advice, whereas “caring about” relates to emotional work and emotional support such as listening to an ill person’s problems, trying to understand their difficulties, and improving their psychological wellbeing (Strazdins & Broom, 2004). This emotional support is usually understood as a foundation of the family, associated with expectations of reciprocity (Baldassar, 2007).

Furthermore, although one form of support (caring for) can occur without the other (caring about) (Richardson et al., 2007), they are not necessarily mutual exclusive (Baldassar, 2007).

Gender dynamics run through this distinction, for both the person who gives the care and the person who receives it. For example, Thomeer et al. (2015) find that many husbands whose wives are ill take on tasks of practical support, but that they are less invested in emotional support (Gibson et al., 2018). Women seem to take on much more emotional support work in the family setting in general (Strazdins, Broom, 2004), and, more specifically, several studies have demonstrated that some women with a long illness may resist offers of domestic help, especially from their children (Wilson, 2007). Illness does not necessarily mean that housekeeping duties, which still largely fall to women in France (Ferrand, 2004), will be redistributed (Gregory, 2005). Wilson (2007) has shown that motherhood is a “key source identity” for HIV-positive mothers, because it contributes to normalization work. Among people with cancer, men seem to be more concerned by the practical aspects of the illness, privileging the exchange of information, while women appear to be more sensitive to emotional aspects and mutual support (Seale, 2006). The relevance of a distinction between caring for and caring about is debated, however. It is difficult to discern such a division in some writings, where both aspects seem inextricably connected, as is the case in Emslie et al.’s work on colorectal cancer (2009).

Less binary approaches have gained prominence in research on gender and health in recent years, notably the performativity of gender and the variability and influence of local contexts (Seale, 2008). This research emphasizes the many similarities between the behaviors of men and women under depression (Emslie et al., 2007), multiple chronic conditions (Hurd Clarke & Bennett, 2013), and Alzheimer’s disease (Cahill, 2000), to such an extent that France et al. (2013) found men’s and women’s experiences in confronting serious illness to be more similar than dissimilar. For cancer, Emslie et al. (2009) demonstrate that men and women alike engage in a variety of forms of support (both emotional and practical) to help their ill partners. They also show that

both try to control their emotions in front of their sick partners and keep a normal everyday life for the family.

Care relations and the negotiations and adjustments implied by an illness in a couple contribute to the biographical experience, and even the variations the biographical disruption of the illness might take (Sulik, 2007). The illness unsettles family relations in what Gibson et al. (2018) term *relational disruption*. The impact of chronic illness on daily life, identity, relationships, and other aspects of existence is well documented. For Bury (1982), such illnesses involve reorganising everyday life, redefining the self and how one relates to others. More recent work has further defined this concept, singling out the work that the ill and their loved ones do to normalize everyday life with the disease (Williams, 2000), work that occurs within the couple's relationship and care relations (Aasbø et al., 2016; Sulik, 2007).

The literature largely demonstrates that gender dynamics structure care work, with women in the predominant role (Anderson & Bury, 1988; Richardson et al., 2007; Sulik, 2007). These tendencies are not set in stone, however, and analysis of care relations must also consider biographical processes and past family configurations (Hudson et al., 2020) and take account of gender scripts (Chattoo & Ahmad, 2008; Gibson et al., 2018). Gender is understood here as a dynamic set of socially constructed relationships (West & Zimmerman, 1987). Taking a relational ontological approach in sociology (Chattoo & Ahmad, 2008; Gibson et al., 2018), this article concerns the biographical repercussions of two forms of care (of/about) for people with pemphigus, taking gender dimensions into account.

## ***Methods***

Our analyses are primarily based on interviews with people living with pemphigus. According to the specialized biomedical literature, the average individual living with pemphigus (ILP) is between 50 and 60 years of age, and it affects males and females indiscriminately (Joly, Sin, 2011). Our study included 13 female and 12 male ILPs whose average age was 55 (the youngest was 22 and the oldest was 78). Our sample was highly socially heterogeneous because of the diversity of our recruiters (including a nurse, businessmen, teachers). At the time of the study, 14 participants were retired, and 10 had no offspring. The first part of the findings section addresses all participants, while the other two parts focus on relations in the couple and thus only concern the 19 participants who were in a couple at the time of the study or who had been in a couple when the illness declared itself.

As a sociologist of health (lead researcher) and sociologist of the body (secondary researcher), we were approached by dermatologists specialized in pemphigus to conduct a joint study with them and representatives of the pemphigus association. We had the most regular contact with the latter. We were thus in a position of initial distancing (relative to the experience of the illness) and implication with these organizations (Le Hénaff, Héas, 2019).

Participants (N=25) were recruited by the *Association Pemphigus Pemphigoïde France*, the only association for people living with pemphigus in France, which has hundreds of members.

Recruitment techniques included a presentation at an association meeting as well as an announcement 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 2016 by the authors of this paper. At that time, each participant had been diagnosed for an average of five years. Our life-story approach interviews (Berthaux, Kohli, 1984) always began with the same request, “Please tell me how it started.” Our follow-up questions were not taken from a pre-established theoretical framework; instead, we aimed to explore the widest possible range of experiences of living with pemphigus. The main themes that emerged included the doctor-patient relationship, the diverse consequences of the illness and treatment on the ILP’s private life, and the roles that close family and friends played throughout the illness. We regarded the ILP experience as unfamiliar territory to be discovered (Glaser, Strauss, 1967).

By using a primarily inductive approach paired with a constant comparative method (Glaser, Strauss, 1967), we identified “the lack of support from the partners”, especially expressed by women, as an important theme in our research. During the initial stage of our study, each of the authors individually established a preliminary analytical grid using an open coding approach (Strauss, Corbin, 1998). We used the collected data to identify the main themes and establish coding for points that were important to the ILPs. During the second stage, the co-authors met to compare their respective analytical 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 (particularly the “partner’s denial of the disease”, the desire to “remain a mother”, the woman caregiver), 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 (key resource persons, rearrangement of daily schedules, differing expectations).

We only turned to the existing literature once our themes and sub-themes were identified, so the main issues emerged from field data rather than theoretical frameworks. The literature subsequently allowed us to clarify and further develop our analyses.

### ***Findings***

The first section of the article concerns the expectations that people with a chronic illness have of their friends and family, demonstrating that these expectations vary heavily according to gender. In the second section, we show that expectations are particularly high for spouses, and most particularly ill women's expectations concerning emotional work ("caring about"), which can be a vector of tension and disappointment. The article then turns to "caring for"; focusing on the question of housework, it shows that this aspect of care is a secondary expectation.

### **Justifications of Gendered Care**

In this first section of the paper, we will demonstrate that ILPs are invested in expectations of support from their loved ones in a variety of ways, and that these expectations are partially gendered.

From the outset, the personal investment of ILPs' close friends and family appears lopsided, with women seemingly more involved in caregiving. Mothers, girlfriends, sisters or daughters are designated as key resources. This gender imbalance goes largely unquestioned by ILPs and their families. This observation exposes the socially accepted, even naturalized, figure of the "woman caregiver", reflecting the traditional division of domestic labor. When explaining the lower level of male commitment and support, some female ILPs point to supposedly "natural" masculine traits.

For example, Eloïse noted several positive consequences of having the illness, including the development of closer relationships with her children, aged 19 and 25 at the time of her diagnosis. She stressed that her relationship with her daughter had strengthened even more than that with her son, explaining: “Since men are a lot less communicative, they speak a lot less” (Eloïse, 61 years old, diagnosed for 17 years).

This female support is sometimes associated with caregivers’ profession or training in fields where women are overrepresented. The particular skillset of nurses and nurse’s aides or having studied some psychology (both socially constructed as feminine) only serve to strengthen expectations – and probably dispositions – regarding gender and care. Thus, Pierre’s wife, who is a nurse’s aide, takes care of family health matters in accordance with an explicit division of household labor:

*“She is the one who...since they were little – the children are big now – we established ways of doing and watching over things. So, all of that...I don’t have...I don’t worry any more than usual about that [...]. She is the doctor in the family. So... me, I’m the technical person...to each his own.”* (Pierre, 57 years old, diagnosed for three months).

Pierre systematically consults his wife before making any decisions concerning his health. She suggests and makes all the medical appointments for her ailing husband. She also encourages her spouse to stick to his medical treatment, and keeps a close eye on him to ensure that he does. It was obvious to Pierre that his wife take on this role, associating her personal investment with her profession because “she is in the healthcare field!” Individuals living with pemphigus also often connect their children’s professional skills to the amount of assistance they provide their ailing parents. Christine’s family is an enlightening example of the association of gender and supposed professional dispositions: her husband and daughter are both medical professionals, the former a

doctor and the latter a nurse. But it is the daughter who keeps close track of her mother's treatments and medical appointments, even though she sees her mother less frequently than her father does.

*“[My daughter] is a nurse too, so...she knows, she knows about my appointments, my IVs, my treatment. I don't have to tell her twice. She knows what day I have my consultation, which day I have my drip, how much cortisone I was on. She keeps close tabs on all that.”* (53 years old, diagnosed for 3 years)

There is also an assumption that a person who had the disposition and knowledge to care for a sick loved one in the past would be predisposed to caregiving thereafter. The experience of having accompanied a sick loved one in the past, sometimes at their deathbed, seems to be a sentinel event. Such past caregiving experience is seen as providing them with skills that can be drawn upon when long-term illness strikes the family. These mechanisms maintain a gendered division of labor that is partially self-justifying; when specific family members take on certain tasks, expectations develop that they will do so in the future. When there is a new illness, returning to a previously used system seems justifiable, to the point that some (more often than not women) come to be thought of as the family experts. This was the case for Charles and his sister, who helps him with his relations with the medical world, which is new for him:

*“My parents were seriously ill as well. They died from their illnesses, so... she [my sister] knows a bit. She knows a little about how things work in the medical world, all that, so...she alerted me to some things [...]: the information you can get, or can't get, things that you can miss, that you can't understand...she tells me, 'Be careful. It's important. You need to ask the right questions.' Yeah, she advised me.”* (53 years old, diagnosed for six months)

His sister's knowledge of the medical world, whether it is real or simply supposed by Charles, reflects a gendered allocation of tasks between the siblings. He "naturally" identifies his sister as the person best suited to help him.

Thus, whether or not they consider the activity a burden, there are many, often compounded, factors that push women into caregiving, such as professions or professional training in which women are predominant, naturalized predispositions, or sentinel events. Although it can be rewarding, the role of caregiver is nevertheless restricting when it is seen as a moral obligation, as it may be when a loved one is ill (Grégory, 2005). As it is frequently associated with compassion, the logic underlying caregiving may be all the more coercive, mixing feelings of responsibility, personal indebtedness, and even duty (Macleod, Mcpherson, 2007). It may prove difficult to distinguish between a person's will and duty to become involved in the health problems of a loved one and the legitimacy of their involvement. Such grey areas may be negotiable, but usually only through tacit agreements made by those concerned.

Although our respondents did not question this gendered division of labor, many expectations were placed on ILPs' partners, who were designated as the main source of support. As a result, the partner may become the biggest cause for disappointment if the care they provide does not meet an ILP's expectations.

#### "The Partner's Denial of the Disease": A Question of Differing Expectations

Among friends and family, male and female ILPs both invest heavily in their life partners, but women are the only interviewees to complain of their partners' behavior. In this section we will analyze the mechanisms behind these complaints, showing that their recriminations concern a lack of emotional, not practical, support, and that they stem from unmet expectations of reciprocity.

Indeed, chronic illness has an impact on couples' relationships. During flare-ups, pemphigus can make living together a challenge. Intimacy is generally impeded by the pain, because an ILP's sense of touch is significantly altered and physical contact can become altogether unbearable in extreme cases.

*“It was a very, very, very clear break because I had to sleep in a separate room, because the slightest movement during the night hurt me. I had sores everywhere and, then, most of all, I slept so poorly that...I kept him from sleeping [...] when you are on cortisone [for more than 13 years], it creates another life, another kind of relationship. You are extremely irritable. There are times when you are hyperactive; you do 40,000 things. And then, there are others when you are dog-tired. You don't do anything. You are very irritable even. You're on edge.”* (Bérangère, 64 years old, diagnosed for 15 years)

The individuals living with pemphigus who we interviewed widely lamented the side effects attributed to the substantial daily intake of steroids, such as changes in behavior or personality. These side effects have a variety of consequences on the couple's relationship. A third of our female research participants bemoaned the deterioration of their married life, whereas the men at most alluded to complications in their relationship. The former lamented their partners' indifference to their plight, whereas nearly all of the latter acknowledged having benefited from their spouse's support (of those in a relationship, which included the majority of the male participants).

Some female ILPs did not signal profound transformations in their relationships, but they did complain of a lack of emotional support. In such cases, they criticized their partners' posture when faced with the new restrictive reality of the disease. Such reactions were presented as a form of mental protection or sign of psychological weakness, as female ILPs thought that their

male partners were psychologically unable to accept the reality of their new life. Having to face their partner's lack of understanding, in addition to feeling as though they could not rely on their support, was a disturbing experience for some, and devastating for others. This was Danielle's case:

*“After 25 years of marriage, I found myself with a husband who could not deal with the illness. And who made my life a living hell for...one year. Until I asked him to leave when he brought his mistresses to our house. All those kinds of things had never happened before, and it was a way of... well, it revealed that he had very, very serious psychological problems.”* (53 years old, diagnosed for seven years)

This situation ended in divorce. Although the tensions the illness raised in the couple make Danielle's case exceptional, it is nonetheless relevant. Often the partner is subject to specific care expectations that are not anticipated from the ILP's other loved ones. When these expectations are not met, they can become major factors in a process of biographical disruption.

Without going as far as doubting their relationships, a minority of female ILPs in our study nonetheless intimated that it took their partners a long time to realize the seriousness of their symptoms. This temporary neglect seems to correspond to the time that it takes to adapt to life changes caused by pemphigus. During the time it takes a husband to appreciate the severity of his wife's symptoms, he may demonstrate less empathy toward her or even dismiss her pain. In such instances, the real or seeming lack of empathetic listening, whether it is temporary or enduring, is sometimes naturalized and thus excused. One example is Chloé (60 years old, diagnosed for several months), who contrasted her husband's behavior with that of the women in her family. She explained away her husband's dearth of support and empathy (at first, he “did not realize the extent of the damage”), affirming “[It's] just not his thing.” The relationship between

gender and listening skills was stated, without necessarily being denounced. As a consequence, certain women sought psychological help (some expressing regret at not being able to find it), whereas none of the men in our study declared having taken a similar initiative.

This problematic transformation in marital life and mutual comprehension is exacerbated when it is left unaddressed. Life with an ILP requires the establishment of new modes of communication; negotiation between the partners is key. Clémentine has attempted just that, with limited success. She felt like she was facing the disease on her own: her family was living abroad and even though her friends checked in on her from time to time, she did not consider such interaction tangible emotional support. As for her partner, she was “under the impression that he was in denial about the disease. He didn’t want to hear about it.” This situation created tension that she attempted to resolve. Her account of a medical visit provides a demonstrative example:

*“He didn’t want to come to the hospital. So, that hurt me even more [...]. Afterward, I understood that he was in denial about the disease, that maybe it hurt him to know that I was sick and he couldn’t do anything about it. But he doesn’t talk [...]. He came to the hospital for the last IV, but it didn’t go well because he stayed in the waiting room [...]. They [the nurses] didn’t want him to be there. So, he got angry [...]. But I wanted him to be with me, to accompany me. But, when he did it, it was actually worse.”* (Clémentine, 37 years old, diagnosed three years)

Sometimes the partner is given an assignment; he is expected to regularly accompany his spouse and lend her an unfailing empathetic ear. Clémentine tried to fully express her physical and psychological struggles and to ensure a source of emotional support during periods of doubt. Clémentine’s interview clearly describes an adjustment process.

Many of the women declaring a lack of emotional support from their partner implied that it is a breach in the principle of reciprocity. Irène’s story is rather enlightening in this regard. She



demonstrated a strong inclination to care for her loved ones and for others more generally, not just before but even during her own illness. She was there for her son (“*once again, I had to get him out of a situation, too*”) and her husband (“*if he hadn’t had me, he wouldn’t even be alive anymore*”), who both went through significant health problems. She was actively engaged at their sides, coordinating care and taking care of administrative tasks. As far as her family’s health was concerned, she had the impression that she “[*held*] *everything together.*” Yet, when she in turn was diagnosed with pemphigus, she saw a gap between her own engagement in health-related tasks for her loved ones and what they gave her in return since she needed help:

*“No-one comes to save me [...] I’m starting to have had enough of it, to always be there for others, and then no-one sees that sometimes I’m also in a bad way.”*

She evoked the broken reciprocity, whose tacit terms are suddenly in the spotlight. She had a particularly painful experience of her relationship with her husband while suffering from the disease. Feeling that her husband does not want to hear about it, she ended up not talking about it with him at all and living alone with her complaint:

*“My husband didn’t want to hear a thing about it. To the contrary, it was even worse, because he saw me - I was sleeping all the time, I wasn’t doing well. And then I hid it from him as much as possible, because it invariably created conflict. I preferred to not talk to him about it. So, I can say I was suffering in silence.”*

Expectations for emotional support were high for female research participants who indicated their husbands’ failure to reciprocate. When these expectations were not met, they could become major factors in a process of biographical disruption. Loved ones are thus an essential component of this disruption of life as it was before the illness, and can lead ILMs to feel like they are in crisis and losing a secure identity (Bury, 1982). Additionally, it is difficult for others

to make sense of this rare and little-known illness for its absence of visible physical and symbolic signs (Plage et al., 2008). Our hypothesis is that women are particularly impacted by such difficulty in getting their challenges acknowledged, especially women who have internalized them (Le Hénaff et al., 2022).

### The Delegation of Household Chores: An Overlooked Source of Support

In this third section, we set out to understand one dimension of practical support - domestic chores - by analyzing some of the impediments to more equitable distribution of housework. This will help us to examine how ILPs experience emotional versus practical support and elucidate the relationship between expectations and support.

Generally speaking, the redistribution of domestic labor is a marginal issue at the onset of the illness. The disease does not excuse female ILPs from their previous household responsibilities, especially if they had handled the majority of the housework before falling ill. Despite the severe fatigue caused by the medical treatment, individuals living with pemphigus rearrange their daily schedules in order to complete household chores. Female ILPs commonly reduce the time they spend at work or on leisure activities so that they can meet their domestic responsibilities, and their limited energy is redirected to ensure that the household continues to run smoothly.

Several aspects of these adaptations demand attention. The first is the woman's desire to maintain her pre-pemphigus life and identity. The second is the element of constraint and the possibility of negotiation that exist within the household. For example, when Julie (diagnosed six months earlier) was asked about the prospect of delegating certain tasks, she rejected the idea outright:

*“No, I don’t know how to do that. So, I don’t work on Wednesday afternoons. I have the weekends. Well, where I used to have more leisure time on the weekends, I have less now, because on the weekends I do the things I couldn’t physically accomplish after work during the week. I plan. Let’s just say I organize my life differently.”*

Although she does less, the greatest change in her daily life came from the fact that she had sacrificed part of her leisure time in order to preserve her identity as a mother and good housekeeper. This entailed finding a balance between needed down time and fulfilling what she felt were her household responsibilities. The tension between the need to accomplish tasks and the desire to rest is apparent:

*“When there are times when I am tired, my husband says, ‘Go rest. I will take care of things.’ Because the children too... I, myself, wanted to continue but I can see that there are things...I have reduced. Well, I have slowed down and don’t work as much. And when, I don’t know, the living room is a mess or dusty, I say, ‘Psh, it’s good enough.’ I don’t let myself get worked up about it. I have also learned to tell myself, ‘Listen, the earth isn’t going to stop turning...’.”* (Christine, diagnosed for two years)

She has “learned” to put things into perspective, though not without effort. Her trouble delegating responsibilities has surfaced numerous times. Occasionally, she even struggled to relinquish tasks that are commonly given to partners or children. Reorganization can augment feelings of uselessness and may shift an ILP’s attention to their lack of autonomy and physical weakness. When physical deterioration is too severe, some female ILPs change their goal to retaining a small number of largely symbolic responsibilities.

*“As for the housecleaning, my husband takes care of it, because I don’t do the housework anymore because, in the past, I have injured myself doing it. So he has taken over that sort of*

*thing, while me, I do more of the cooking. Cooking is less dangerous for me, well...it's little arrangements like that that help me live normally [...]. Him, he deals with the harder things, the bigger things, and me, I do everyday things, the laundry, the cooking... the dishes, the meals, etc. Things that are... almost normal, I mean, there isn't much difference with someone who isn't sick." (Ursula, diagnosed for 10 years)*

Once again, negotiation is paramount to maintaining one's identity and it proves necessary for the normalization of the ILP's daily life. Even though she was obliged to reduce the extent of her activity, she still "does things".

Thus, when the woman falls ill, the spouse's roles are rarely completely reversed. On the contrary, many women attempt to keep certain household responsibilities, even if they need help along the way; they may reorganize their schedules or modify how they do things. They try to meet the demands of each day, rather than having a regular routine (Richardson et al., 2007).

This pattern is particularly evident in households where a traditional division of labor existed before the onset of the illness, but women in this situation do not see this distribution of labor as a constraint. At most, they see it as a constrained choice, but not one that leads them to criticize their partner's behavior, let alone the traditional distribution of household chores. Not all women we interviewed were reticent to delegate domestic chores, however. Several, especially younger ones, have limited their domestic investment and were happy to see their partners take over for them.

The desire to "remain a mother" surfaced during several interviews with female participants. This concern reflects their efforts to preserve this central aspect of their identity, regardless of the consequences of the illness or whether their daily lives have been modified by its onset. They have abandoned some tasks, while deeply investing in others that they felt were central to their

role as mothers. Thus, Géraldine (diagnosed for five years) reshuffled her daily schedule in order to focus on what she determined to be essential: normalizing her two daughters' daily lives.

*“I am the mom. They aren't the ones who are supposed to look after me [...]. It's as it should be. So, in any case, I will always fight [...]. I would say that they can't help me because I don't give them the chance to [...]. Sometimes I tell myself that maybe it's not a good thing because, well, when I'm really tired, I ...but, it's me. No, I don't know how to delegate.”*

Her behavior was shaped by personal desire as well as feelings of obligation. She had to put up a front for her children's sake. Taking care of her children, and her household in general, provided some continuity, both for herself and others. For some female ILPs, caring for others becomes a way to normalize their own lives.

*“I have two sons that I protected by telling them the least possible. So, they didn't realize that I was going through hell because I tried to hold on, especially when I was on sick leave, to at least make sure that they had something to eat in the evening [...]. So, I had to hang in there anyway.”* (Brigitte, diagnosed for three years)

Though Brigitte allows that she has not always been the perfect mother, she clung to certain symbolic aspects of motherhood, such as making meals and being present for her children at important times. As Wilson notes (2007), individuals whose lives have been touched by illness are impelled to focus on activities that help them preserve direction and meaning in their lives. This is especially true when various facets of their identity (particularly their professional identity) are in danger or no longer exist. Male ILPs of working age seem to use their work as a means of normalizing their situation. This is also true for female ILPs, but to a lesser extent. The tendency to normalize their life through work is made easier by the security net that many of these men enjoy. Indeed, their partners frequently take over tasks that allow the men to continue

their lives “as before”. One excellent example of this is Xavier (diagnosed seven years before the interview), who did his utmost to avoid using his sick leave in order to pursue his professional activity. As the corticosteroid therapy obliged him to follow a strict diet low in salt and sugar, his wife packed his lunches and changed her diet to follow suit. When he was too physically weak, she drove him around and assisted him in his daily activities. By tweaking her daily routine, she afforded him the opportunity to continue his particularly intense professional life.

### *Discussion*

In this article, we set out to document the experiences of two forms of care in people with a rare skin disease.

We found that gender dynamics saturate experience of the illness, and especially care relations. Both male and female individuals living with pemphigus expressed greater expectations of the women close to them. This trend is part of gender relations going back into their family history, which reminds us of the importance of taking account of family configurations prior to the onset of pemphigus (Hudson et al., 2020). The gendered division of care work is partially self-justified based on this history. Pre-pemphigus experience with the illness or death of a loved one has an impact on this distribution of labor, and previous care experience seems to be an indicator of possible subsequent care roles. Once again, women seem to shoulder these roles more readily than men (Gibson et al., 2018; Thomeer et al., 2015). These gender dynamics can also be seen in the expression of suffering, especially in relation to unmet needs, which women do much more than men. Men often receive care, especially from their partners, without directly asking for help. There is a generational dimension that must be taken into account in this situation, and it could be posited that the salience of traditional gender roles might be connected to the higher age of our participants (whose mean age is 55) (Gibson et al., 2018).

Despite the debate in the literature over the utility of distinguishing between caring for and caring about (Emslie et al., 2009), these conceptual tools seem especially relevant to our study by helping us understand care relations, particularly from a gendered perspective. They allow us to account for research participants' experiences, chief among them their frustrations. Throughout this study, ILPs' most difficult experience in terms of their relationships with loved ones was feeling as though they lacked emotional support, much more than a lack of practical support. This was especially true for women, who tended to value the expression of emotional support and to experience self-silencing as a repression of feelings. Women overall reported having more unmet needs. Compared to men, women also seemed to receive less attention than they expected; male caregivers appear to have been less attentive to the signs of pemphigus displayed by their partners (Hayes et al., 2010). The experience of disease should be interpreted as a series of negotiations within the couple, ultimately mediated by that couple (Wilson, 2007). Beyond disease, emotional support is part of dynamic interpersonal processes involving forms of reciprocity (Casey & Stone, 2010; Emslie et al., 2009). But as our analysis illustrates, emotional work may sometimes be experienced in terms of a breakdown of reciprocity, especially in situations where the person with an illness had supported her partner in the past (Cahill, 2000; Gibson et al., 2018; Hudson et al., 2020; Sulik, 2007). This feeling is at the heart of their tensions (Aasbø et al., 2016). This lack of support is sometimes associated with a lack of understanding of their situation as an ill person, leading to a feeling of loneliness (Joachim, Acorn 2003; Plage et al., 2018), especially as the physical and symbolic invisibility of the rare disease makes it hard for others to understand it (Plage et al., 2008). Our hypothesis is that women are particularly impacted by such difficulty in getting their challenges acknowledged, especially women who have internalized them (Le Hénaff et al., 2022).

Although the distribution of housework appeared uneven from an outside perspective, sharing or reshuffling domestic responsibilities was not a major concern for the interviewees. In spite of fatigue, a significant number of female ILPs had reorganized their schedules by reducing work or leisure time in order to continue performing their household chores. People with pemphigus employ their limited energy to ensure that their households run smoothly (Wilson, 2007), but also to normalize the daily lives of family members. Generally, when research participants mentioned problems with care, they linked such difficulties to their conjugal relationships and to a dearth of emotional support from their partners.

This distinction between caring for and caring about is also relevant to understanding the biographical disruption. If the illness upsets family relations to the point of a relational disruption (Gibson et al., 2018), it is mainly due to insufficient emotional support. To the contrary, the negotiation of practical support makes it possible to normalize everyday life and the maintenance of an identity valued by many of the interviewed women (Richardson et al., 2007). As Gregory (2005) has pointed out, illness has little impact on the distribution of housework, except for the most physically affected. This normalization work for oneself and even more so for others may furthermore act as a barrier to receiving care from others, tying back to the previously studied dilemmas between self-care and care for others, where gender norms are especially heavy (Gibson et al., 2018; Sulik, 2007).

Of course, such trends and observations must be interpreted with caution. This distinction between male and female behavior must not be considered clear-cut. Indeed, not all of our female ILPs voiced such frustration: half of our population did not even mention such issues, claiming that they had satisfactory support from their loved ones, and especially their partners (Emslie et al., 2009). Moreover, a minority of female ILPs even felt that the experience had



strengthened their relationship (Hudson, 2016). There are multiple configurations, which can change over time, leaving radical differences between ILPs' experiences with pemphigus. This article, especially its second section, examined criticism to shed light on processes within gender dynamics. Although the focus on gender is pertinent to our analysis, it is important to remain prudent, especially since the interview context could be propitious to the expression of gender performance, as Emslie and Hunt (2009), among others, have indicated.

In conclusion, our research concurs with the previously cited literature as to the importance of gender dynamics in the experience of illness and care relations. In order to provide a more precise account of these aspects, we committed to two analytical principles: to take account of past family configurations and to distinguish between practical and emotional support. These analytical principles made it possible for us to demonstrate that these care relations contribute significantly to the biographical disruption, especially for women. It is a painful experience when reciprocity, a cornerstone of family and emotional support, is called into question, akin to a relational disruption (Gibson et al., 2018). All this goes to show that biographical disruption also plays out in the family.

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## **References**

Aasbø, G., Solbrække K.N., Kristvik E. & Werner A. (2016). Between disruption and continuity: challenges in maintaining the 'biographical we' when caring for a partner with a severe, chronic illness. *Sociology of Health & Illness*, 38(5), 782–796.

Anderson, R. & Bury, M. (1988). *Living With Chronic Illness: The Experience of Patients and their Families*. London: Unwin Hyman.

Baldassar, L. (2007). Transnational families and the provision of moral and emotional support: the relationship between truth and distance. *Identities: Global Studies in Culture and Power*, 14(4), 385-409.

Bertaux, D., & Kohli M. (1984). The life story approach: a continental view, *Annual Review of Sociology*, 10, 215-237.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*, 4(2), 167–82.

Cahill, S. (2000). Elderly husbands caring for wives diagnosed with alzheimer's disease: are male caregivers really different?. *Australian Journal of Social Issues*, 35, 1, 53-72.

Casey, R., & Stone, S. (2010). Aging with Long-term Physical Impairments: The Significance of Social Support *Canadian Journal on Aging / La Revue Canadienne du Vieillissement*, 29 (3), 349-359.

Emslie, C., Ridge, D., Ziebland, S., & Hunt, K. (2007). Exploring men's and women's experiences of depression and engagement with health professionals: More similarities than differences? A qualitative interview study. *BMC Family Practice*, 8(43). doi:10.1186/1471-2296-8-43.

Emslie, C., Browne, S., Macleod, U., Rozmovits, L., Mitchell, E., & Ziebland, S. (2009). 'Getting through' not 'going under': a qualitative study of gender and spousal support after diagnosis with colorectal cancer. *Social Science Medicine*, 68 (6),1169-1175.

Ferrand, M. (2004). *Féminin, masculin*. Paris: La Découverte.

Gibson, A., Broom, A., Kirby, E., Wyld, D. & Lwin, Z. (2018). '... My biggest worry now is how my husband is going to cope': women's relational experiences of cancer 'care' during illness. *Journal of Gender Studies*, 27(8), 901-913.

Glaser, B.G., & Strauss, A.L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. London: Aldine Transaction.

Gregory, S. (2005). Living with chronic illness in the family setting. *Sociology of Health & Illness*, 27 (3), 372–392.

Hayes, J., Zimmerman, M. & Boylstein, C. (2010). Responding to Symptoms of Alzheimer's Disease: Husbands, Wives, and the Gendered Dynamics of Recognition and Disclosure. *Qualitative Health Research*, 20(8), 1101–1115.

Hudson, N., Law, C., Culley, L. L., Mitchell, H., Denny, E., Norton, W. & Raine-Fenning, N. (2020). Men, chronic illness and healthwork: accounts from male partners of women with endometriosis. *Sociology of Health & Illness*, 42(7), 1532–1547.

Hurd Clarke, L., & Bennett, E. (2013). "You learn to live with all the things that are wrong with you": Gender and the experience of multiple chronic conditions in later life. *Ageing and Society*, 33, 342-360.

Joachim, G., & Acorn, S. (2003). Life with a rare chronic disease: the scleroderma experience. *Journal of Advanced Nursing*, 42(6), 598-606.

Joly, P., & Sin, C. (2011). Pemphigus : revue de la littérature. *Annales de dermatologie et de vénéréologie*, 138, 182-200.

Le Hénaff, Y. & Héas, S. (2019). Individuals with the Rare Disease Pemphigus: A Quest for Diagnostic. *Qualitative Health Research*, 29, 6, p.889-899.

Le Hénaff, Y., Héas, S. & Joly P. (2022). Taking care of oneself and others: the emotion work of women suffering from a rare skin disease. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, first published online, DOI: [10.1177/13634593211064127](https://doi.org/10.1177/13634593211064127)

Macleod, R., & Mcpherson, K.M. (2007). Care and compassion: Part of person-centred rehabilitation, inappropriate response or a forgotten art?. *Disability and Rehabilitation*, 29(20-21), 1589-1595.

Plage, S., Gibson, A., Burge, M., & Wyld, D. (2018). Cancer on the margins: experiences of living with neuroendocrine tumours. *Health Sociology Review*, 27(2), 153-167.

Richardson, J.C., Nio Ong, B., & Sim, J. (2007). Experiencing chronic widespread pain in a family context: giving and receiving practical and emotional support. *Sociology of health and Illness*, 29(3), 347-365.

- Seale, C., Ziebland, S., & Charteris-Black, J. (2006). Gender, cancer experience and internet use: A comparative keyword analysis of interviews and online cancer support groups. *Social Science & Medicine*, 62, 2577–2590.
- Seale, C., & Charteris-Black, J. (2008). The interaction of age and gender in illness narratives. *Ageing and Society*, 28 (7), 1025-1045.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: techniques and procedures for developing grounded theory*, Sage Publication.
- Strazdins, L., & Broom, D. H. (2004). Acts of love (and work). Gender imbalance in emotional work and women's psychological distress. *Journal of Family Issues*, 5(3), 356–378.
- Sulik, G.A. (2007). The balancing act. *Care Work for the Self and Coping with Breast Cancer*. *Gender & Society*, 21(6), 857-877.
- Thomeer M.B., Reczek, C., Umberson, D. (2015). Gendered emotion work around physical health problems in mid- and later-life marriages. *Journal of Aging Studies*, 32, 12-22.
- West, C. & Zimmerman, D. (1987). *Doing Gender*. *Gender and Society*, 1(2), 125-151.
- Williams, S. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness?. *Sociology of Health and Illness*, 22(1), 40-67.
- Wilson, S. (2007). 'When you have children, you're obliged to live': motherhood, chronic illness and biographical disruption. *Sociology of Health & Illness*, 29 (4), 610–626.