

**The partners' perspective on giving  
social support and coping with fatigue  
in systemic lupus erythematosus:**

*A qualitative study*

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## **Samenvatting**

*Achtergrond:* Doel van dit kwalitatief onderzoek was het exploreren van het perspectief van de partner op het geven van sociale steun en de eigen omgang met betrekking tot vermoeidheid bij systemic lupus erythematosus (SLE). SLE is een chronische ziekte en ernstige vermoeidheid lijkt één van de symptomen te zijn die de patiënt het meest belemmert. Mensen met SLE hebben veel steun nodig en hun partner representeert een belangrijk bron voor sociale steun. Verder moet de partner ook zelf leren hoe hij/zij met de vermoeidheid van zijn/haar partner omgaat. Eerdere studies richtten zich echter alleen op het perspectief van de patiënt. *Methode:* De semi-gestructureerde interviews met negen partners van mensen met SLE zijn afgenomen door twee Masterstudenten psychologie van de Universiteit Twente en ze zijn door een codeerschema dat in combinatie van een inductieve en deductieve aanpak tot stand is gekomen geanalyseerd. *Resultaten:* De meeste partners bleken een breed handelingsrepertoire te hebben om met de vermoeidheid van hun partner om te kunnen gaan en om steun te kunnen geven. Het overnemen van taken (instrumentele steun) en het adviseren om rust te nemen (informationele steun) beleven de partners als heel effectief. De meeste partners verklaren dat ze de vermoeidheid van hun partner kunnen accepteren en dat ze tevreden zijn met hun omgang en met het geven van sociale steun. Alleen de twee van de negen partners die de vermoeidheid van hun partner niet kunnen accepteren, verklaren dat ze ook niet tevreden zijn met hun omgang en het geven van sociale steun. *Conclusie:* Dit onderzoek ondersteunt het dynamisch karakter van de partners' omgang met SLE gerelateerd vermoeidheid en het geven van sociale steun en het ondersteunt de belangrijke rol die acceptatie erin speelt. Vervolgonderzoek zou zich daarom richten op het verdiepen van kennis over de relatie tussen acceptatie, de omgang en het geven van sociale steun in de context van SLE gerelateerde vermoeidheid. Ten slotte, interventies die de acceptatie en het welbevinden van de partners van mensen met SLE bevorderen zouden ontwikkeld moeten worden.

### Abstract

*Background:* This qualitative study aimed to explore the partner's perspective on giving social support and coping with his/her spouse's SLE related fatigue. SLE is a chronic disease and severe fatigue seems to be one of the most debilitating symptoms. Since the partner is an important source of social support and also has to cope with his/her spouse's fatigue for his/her own, it is important to gain insight into his perspective on the spouse's fatigue

*Method:* The study population consisted of 1 female and 8 male respondents who had a partner suffering from SLE related fatigue. Respondents were recruited at the World Lupus Day 2014 and interviewed by two master students. The semi-structured interviews were recorded and transcribed verbatim. The data were then analyzed using a code scheme that was developed by an inductive and deductive approach. *Results:* Most of the partners had a broad behavioral repertoire in order to cope with the spouse's fatigue and offer support. Taking over household duties (instrumental support) and advising the partner to stop doing tasks (informational support) were perceived as most effective by the partners regarding their spouse's SLE related fatigue. Most of the partners reported that they could accept their spouse's fatigue and that they were satisfied with their way of coping and giving support. Only the two partners who reported not being able to accept their spouse's fatigue, also reported being unsatisfied with their way of coping and giving support. *Conclusion:* This study highlights the dynamic process of supporting the spouse and coping with his/her SLE related fatigue and the importance of the partner's acceptance. Therefore, future research should further investigate the relation between the partner's acceptance, coping and social support in the context of SLE related fatigue. Finally, interventions that enhance the acceptance and well-being should be targeted at partners of people with SLE related fatigue.

*Keywords:* coping, social support, partner, fatigue, systemic lupus erythematosus, qualitative

*The partners' perspective on giving social support and coping with the spouse's SLE related fatigue: A qualitative study*

Systemic lupus erythematosus (SLE) is a prototypical autoimmune disease which can affect almost every organ (Jump et al., 2005). The etiology of the disease is unclear but it seems that it develops through an interaction of multiple genes and various environmental factors (Mazzoni & Cicognani, 2011). The disease is chronic but its process is unstable as there are intense batches and periods of remission (NVLE, 2015). Worldwide there are about 5 million people living with SLE which is a low incidence compared to other inflammatory rheumatic diseases (Connolly, McNally, Moran and Ryan, 2014). Mostly, SLE is diagnosed between the age of 15 and 45 and 90% of the affected people are women (Medical News Today, 2015). Treatment advances have reduced mortality rates in SLE but still people with SLE have a long-term morbidity and an impaired quality of life (Sutanto et al., 2013). The disease is very complex and its expression is diverse. In general, the immune system of an affected person works against his own body and some of the symptoms are fever, swollen glands, anemia and eruption in the form of a butterfly (NVLE, 2015). However, one of the most frequently reported symptoms of SLE is fatigue (Jump et al., 2011).

According to Connolly et al. (2014) fatigue was reported by 81% of people with SLE and it had a huge impact on their lives. In their cases fatigue was particularly described as debilitating (Sutanto et al., 2013). In the literature there seems to be no deeper exploration of fatigue in SLE yet, but from studies with other chronic diseases it is known that fatigue leads to limitations in the fulfillment of roles such as employee or family member (Jump, 2011). Therefore, people with SLE require support in many different domains. According to Mazzoni and Cicognani (2011) it is crucial for people with SLE to have a constant support in order to deal with the varying range of unpredictable symptoms. Support from their spouse or partner consequently represents an important source of social support for them (Rosland, Heisler, & Piette, 2012). However, the partner does not only support his spouse with regard to SLE related fatigue but also has to deal with the consequences for him/herself. Dealing with the spouse's SLE related fatigue can be described as coping. In the following the two concepts of social support and coping are analyzed in the context of SLE related fatigue.

In the context of the partner's perspective on SLE related fatigue social support relates to the way of how the partner tries to support his/her spouse in dealing with the consequences

of the SLE related fatigue. Social support is a complex and multifaceted construct, and depending on its function it can be differentiated between different types of support. In the current literature there are different distinctions but the most common types are emotional (understanding/empathy), informational (advice) and instrumental (e.g. physical assistance) support (Luszczynska, Pawlowska, Cieslak, Knoll, & Scholz, 2013). Gottlieb and Bergen (2010) additionally differentiate between esteem (reassurance of worth) and companionship (giving a sense of belonging) support.

Mazzoni and Cicognani (2011) found that social support has a positive influence on the health of people with SLE as it improves their quality of life, is positively correlated with disease activity and negatively correlated with disease damage. As there is spoken of correlations no causal linkages can be made, thus the precise ways of how social support operates on health are not yet completely understood (Mazzoni & Cigognani, 2011). However, Mazzoni and Cigognani (2011) summarized three different ways of how social support could enhance SLE outcomes such as disease activity or fatigue. Firstly, the *direct effects hypothesis* states that social support always has a beneficial effect and that more support is associated with better health respectively less fatigue. The *stress-buffering hypothesis* includes the assumption that social support acts as a protective factor or cushion against the negative effects of stress. Thirdly, *seeking social support* is described as a *coping strategy* that has got beneficial effects due to the challenges that people with SLE cannot easily face alone. Mazzoni and Cicognani (2011) concluded that the psychological health of people with SLE might be enhanced by social support through the development of more active coping strategies. Sutanto et al. (2013) supported the positive effects of social support for people with SLE as they found that it helps them to gather resilience and optimism. Nevertheless, only a few studies have focused on the direct relationship between social support and fatigue in SLE but Jump et al. (2011) found a significant inverse relationship between the two variables. This means that lower scores of perceived social support were modestly associated with higher levels of perceived fatigue. In concrete terms this means that if people with SLE only felt little social supported they slightly tended to feel more tired in comparison to people with SLE that felt more social support. Nevertheless, Jump et al. (2011) focused on the perspective of the patient rather than exploring the perspective of the partner as it was the intention of this paper. Still, their findings illustrated that the behavior of the partner has an impact on the SLE related fatigue of the patient and consequently they underline the

importance of exploring the partner's perspective on social support in the context of SLE related fatigue.

However, there are also indications from recent research that social support can also have a negative influence on people with SLE. According to Mazzoni and Cicognani (2015) social support can lead to negative outcomes if it is provided too frequent or at wrong moments. From research about patients with rheumatoid arthritis it is further known that problematic social support is related to increased fatigue and depression (Riemsma et al., 1998). Therefore, it could be assumed that problematic social support also might lead to increased fatigue in patients with SLE. This assumption is confirmed by Mazzoni and Cicognani (2015) who found that in the context of SLE problematic social support can be characterized as "denying/uninformed" support or as "oppressive" support.

"Denying/uninformed" support describes supportive actions that ignore the disease manifestations or consequences such as *avoiding talking about the illness* with the patient or *giving wrong advice about the illness management* and actions that are characterized by a lack of understanding or critique (Mazzoni & Cicognani, 2015). "Oppressive" support by contrast describes supportive actions that are perceived by the patient as excessive and too focused on the illness such as being overprotective or checking the physical conditions too often (Mazzoni & Cicognani, 2015). This means that if the spouse is intending to support his partner by *protecting him too much* the patients SLE related fatigue could increase instead of decrease. Mazzoni and Cicognani (2015) concluded that programs aiming at an improvement of the patient-supporter communication could prevent problematic social support by providing accurate and reliable information about SLE without overemphasizing or hiding consequences of SLE. From the information described above it gets obvious that social support can significantly affect the health of people with SLE and therefore it represents an important issue to focus on.

As the partner does not only try to support his spouse with regard to SLE related fatigue but also has to deal with it on his/her own, it is further important to have a closer look on his/her way of coping. This is so important, since current literature (Hamama & Sharon, 2013; Cadell, 2007) emphasized that caregivers are exposed to stressful experiences and an increased vulnerability to medical and psychological distress. Consequently, the partner's well-being and quality of life is heavily affected by the spouse's SLE related fatigue.

On top of that, studies with cancer patients (Green, Wells, & Laakso, 2011) demonstrated that there are relationships between the coping style of the partner and the fatigue of the ill person which underlines the importance of considering both perspectives. In the context of this paper coping refers to the way of how the partner deals for himself with the SLE related fatigue of his spouse. Coping can be understood as adjustment to a stressor such as cancer or in this case as adjustment of the partner to the SLE related fatigue of his spouse. The concept of coping can be explained in terms of Folkman and Lazarus' Stress and Coping model (Folkman & Lazarus, 1986). In this model, the individual's cognitive appraisals and coping mediate the emotional responses to a potential stressor. Furthermore, it is differentiated between two main functions of coping: *Emotion-focused coping*, which means regulating the emotions that are perceived as stressful and *problem-focused coping*, which is characterized by changing the distress-causing environment (Folkman & Lazarus, 1986).

Green et al (2011) differentiated between *approach coping* (strategies directed towards a threat, such as seeking information or using emotional or instrumental support) and *avoidant coping* (strategies deflected from a threat, such as self-distraction or behavioral disengagement). In the context of SLE related fatigue the partner of a patient would for example use *approach coping* if he seeks information about SLE related fatigue on the internet or if he talks with his partner about his feelings with regard to fatigue. In contrast, an instance of *avoidant coping* would be a partner that smokes cigarettes or drinks alcohol in times where his partner is affected by SLE related fatigue. According to Green et al. (2011) higher avoidant coping of the partner is associated with higher fatigue of the patient and with worse patient role functioning. This means that the patient gets more tired and more limitations in fulfilling his roles as his partner deflects from the problems due to fatigue. These examples show clearly that the coping strategy of the partner also affects the patient as his actions can increase respectively decrease the fatigue of the patient. On top of that, Green et al. (2010) found that partners use multiple coping strategies but that *seeking instrumental* and *emotional support* were used most (Green et al., 2011). Overall, Green et al. (2011) emphasized the importance of considering the coping strategies of the partner and not only the ones of the patient as they also have an impact on their fatigue. As Green et al. (2011) had a sample of cancer patients their findings cannot simply be generalized to patients with SLE. However, as they also focused on the symptom fatigue the assumption can be drawn that the coping strategies of the partner also affect the fatigue of patients with SLE. Furthermore, Berg and Upchurch (2007) introduced a developmental-contextual model on couples coping with



chronic illnesses. Dyadic coping is characterized as a “process in which the coping reactions of one partner take into account the stress signals of the other partner” (Bodenmann, Pihet & Kayser, 2006). Since Berg and Upchurch (2007) focused on the couples' coping and regarded it as dyadic, they did not examine the partners' coping efforts separately but in relation to the spouse. Additionally, they described dyadic coping in terms of a continuum of involvement ranging from uninvolvement of the spouse (patient seems to cope individually) to overinvolvement of the spouse (patient perceives spouse as controlling or engaging in miscarried help). Berg and Upchurch (2007) concluded that the coping strategies used by the patient influence the coping strategies of the partner and vice versa and that the dyadic process of coping might be affected by the specific chronic illness. Therefore, the importance of considering the partners' perspective on coping with the spouses' SLE related fatigue is further underlined and the relation between the partners' coping style and his/her way of giving support becomes visible. On top of that, a study of cancer patients with pain (Morgan, Small, Donovan, Overcash, & McMillan, 2011) explored the partner relationship and the partners' coping style in order to use it as a mediator for the couples' quality of life. Their findings were helpful with regard to this study as they found that “positive supportive coping” includes the *expression of solidarity, words of wise counsel, communicating belief in the capabilities of the patient, empathy and self-sacrifice* such as taking over more tasks e.g. in the household. Moreover, “negative dyadic coping” was characterized by a *minimization of the illness and its consequences, forced cheerfulness, physical avoidance and avoidance of open communication*. Morgan et al. (2011) concluded that negative effects of pain were reduced by a high quality relationship and that the partners' influence impacted patients' pain negatively in low quality relationships. As pain and fatigue are both psychophysical symptoms these findings might be applicable to SLE related fatigue (Neu et al., 2014)

As the spouse or partner of a patient with SLE is an important source of social support and as his daily life is also heavily affected by the SLE related fatigue of his partner, it is not only important to consider his perspective on how he tries to support his spouse but also his way of coping with his spouse's SLE related fatigue. This perspective does not only include the partner's coping strategies and styles of social support, but also the emotional consequences for the partner and his/her well-being. It seems that the previous studies with SLE rather focused on the patient's perspective. Therefore, this paper tried to explore the perspective of the partner on coping with his spouse's SLE related fatigue and his way of

giving support. This led to the following research questions: “*How do partners cope with their spouses' SLE related fatigue?*”, and “*How do partners support their spouses regarding their SLE related fatigue?*” In order to answer these questions the following sub questions had to be answered:

**1. How do partners cope with their spouses' SLE related fatigue?**

- Which coping strategies do partners report with regard to their spouse's SLE related fatigue?
- Do partners experience difficulties with accepting their spouse's SLE related fatigue?
- Which emotional consequences do partners report with regard to their spouse's SLE related fatigue?
- How satisfied are partners with their way of coping with their spouse's SLE related fatigue?

**2. How do partners support their spouses with regard to their SLE related fatigue?**

- Which types of social support do the partners offer?
- Which type of support do the partners regard as the most effective?
- How satisfied are partners with their way of giving support?

## **2. Method**

### **Participants**

Participants were recruited with admission of the Ethics Committee of the Faculty of Behavioral Sciences at the University of Twente by Linda Hoek in the context of writing her master thesis (Hoek, 2015). With support of the Dutch patient organization for people with SLE, APS, scleroderma and MCTD, the NVLE, nine patients and their partners were recruited by convenience sampling. In order to make possible participants aware of the study, patients and partners were informed about it at the World Lupus Day-congress on the 10<sup>th</sup> of May 2014 by brochures, posters and by approaching them directly. If they were interested in voluntarily participating in the study, patients and their partners could register for it by filling

in a form that included information about their name, phone number, email address, residence, age, and illness. Further, they were asked if they had a partner who would be willing to join the study. An additional way of subscribing to the study was to register afterwards via email or telephone. Subsequently, the patients were checked by means of the following inclusion criteria: participants or their partner are diagnosed by a medical specialist with either SLE, or MCTD, and/or the Sjögren Syndrome; participants or their partner experience fatigue on a regular basis; they are at least 18 years old; and they are able to communicate in Dutch. Within two weeks, suitable participants were contacted in order to fix a date for the interview. Based on other study samples it was concluded that conducting interviews with nine patients with a systemic auto-immune disease and their partners was sufficient. Moreover there was a convenient reflection of the population of people with a systemic auto-immune disease, since 90% of those affected are female and the study included eight female and one male patient (Hoek, 2015).

### **Materials and Procedure**

The materials used to study the perspective of the partner on his way of giving social support and coping with regard to the spouse's SLE related fatigue were the audio files of the interviews conducted by the two master students and the interview scheme of Linda Hoek's master thesis (2015). Depending on the participants' preference, the two master students (Hoek, 2015) conducted the individual interviews either at the University of Twente or at the participant's home. At the beginning of the meetings the participants were debriefed about the study, the processing of data, the anonymity, the confidentiality and the possibility of withdrawing from the study at any moment. After the debriefing the participants were asked to sign an informed consent that stated that the participants were informed about the study, understood the expectations and were aware of the collection and analysis of the anonymous data. The partners' perspective on social support and coping with their spouse's SLE related fatigue was examined by using the second part of the mentioned above semi-structured interviews of the partners. The questions were developed by the two master students and they were formulated in Dutch. The focus of this study was on the second part of the interviews with the partners which consisted of questions with regard to offering social support and coping with the spouse's SLE related fatigue. This part included the following three open questions which enabled the participants to describe their perspective unbiasedly: "Are there situations in which you have the feeling of supporting your spouse effectively when he/she

experiences fatigue?”, “Are the situations in which you have the feeling of supporting your spouse less effectively or ineffectively when he/she experiences fatigue?” and “How did you or do you learn to deal with your spouse’s fatigue?”. The last scheduled question was a closed question: “Are you satisfied with the way of how you cope with your spouse’s fatigue?”. Due to the semi-structured interviews the interviewers (Hoek, 2015) had the possibility to go into detail or to ask topic related questions dependent on the emerging answers such as: “Do you often react to the situation like this?”. Therefore, the partners’ perspective could be explored by following relevant topics that spontaneously arose (Cohen & Crabtree, 2006). The duration of the interviews with the partners varied from fifteen to forty-five minutes. At the end the partners were asked if there were relevant aspects that were not covered during the interviews and they were thanked for their participation.

### **Analysis**

The focus of this study was on the partners’ perspective on their way of giving support and coping with their spouse’s SLE related fatigue. Therefore, the second parts of the partners’ interviews were transcribed verbatim on the basis of the audio-records from the interviews conducted by the two master students (Hoek, 2015). Afterwards meaningful units that related to the research questions were identified and provided with a code which can be referred to as open coding (Corbin & Strauss, 1990). For the attribution of codes an inductive as well as deductive approach was used. In order to conduct the qualitative analysis it was made use of Atlas.ti (Muhr, 1992). After coding four interviews the identified codes were compared and related to each other in an inductive as well as deductive manner. This step can also be referred to as axial coding (Corbin & Strauss, 1990). Afterwards the categorized codes were applied to the remaining interviews and adjusted when necessary. Finally, all interviews were checked again by means of the developed code scheme. Therefore, it can be spoken of an iterative process which is the key to deep insight and generating meaning according to Srivastava & Hopwood (2009). In order to answer the research questions all findings related to the specific topic were described and compared among the partners.

### **Inter-rater reliability**

In order to assess the rigor of the conducted analysis an inter-rater reliability was calculated. In this case it was made use of a consensus estimate that was based on the assumption that researchers should be able to come to the same attribution of codes (Stemler,

2004). Therefore an independent researcher, Dr. Christina Bode, who is an expert in qualitative data analysis, coded two of the transcripts by means of the developed code scheme. In order to increase the reliability those two interviews were chosen randomly. Afterwards, the coded versions of the transcripts were compared with regard to differences and similarities in coding between the two researchers. Strikingly, most of the meaningful units were given the same code by the two researchers. The few units that were coded differently were for example cases in which the author assigned two codes to a unit and the other researcher assigned only one code. In another case where the interviewer asked about the respondents' coping but the respondents' answer was related to social support, the author assigned a code related to social support, whereas the other researcher assigned a code related to coping. Finally, the percent agreement was assessed by adding up the number of cases upon which both researchers assigned the same code and by dividing that number by the total number of cases coded by the two researchers. In order to evaluate the quality of the inter-rater reliability based upon consensus estimates it has to be considered that this estimate should be 70% or greater (Stemler, 2004). As the percent agreement was 77,5 % ( $31/40 \times 100$ ), it can be concluded that the conducted analysis was reliable.

### **3. Results**

In the following section the results of the interviews with the patients' partners are presented. At first the questions with regard to the partners' coping are answered which include the utilized coping strategies, the learning experience of coping with the spouse's fatigue, the emotional consequences and the partners' satisfaction with their way of coping. Afterwards, the research questions with regard to social support are answered which include the different types of social support, the effectiveness of their support and the partners' satisfaction with it.

#### **3.1 Coping**

When confronted with the spouse's SLE related fatigue, the partners did not only report that they support their spouse with regard to it, but they also described how they cope with it for themselves. Next to the use of coping strategies, the partners reported experiencing acceptance or unacceptance of their spouse's fatigue, experiencing a variety of emotional consequences and either being satisfied or unsatisfied with their way of coping. Figure 2a

visually represents the different aspects of the partners' perspective on coping with their spouse's fatigue.



*Figure 2a.* The different aspects of the partner's perspective on coping with the spouse's fatigue

### **3.1.1 Coping strategies**

In order to answer the question which coping strategies the partners do report with regard to their spouse's SLE related fatigue they were directly asked how they have learned to cope with their spouse's fatigue. The patients' partners reported two different main types of coping strategies: *problem focused coping* and *emotion focused coping*.

#### ***Problem focused coping***

Since every partner reported at least one strategy that could be characterized as *problem focused coping* this strategy was the one reported most regarding dealing with the spouse's SLE related fatigue. *Problem focused coping* means that the partners cope with the SLE related fatigue in an *adaptive behavioral* manner by dealing with the cause of the

problem. Thus the partners' reported coping strategies were directed at actively approaching the cause of their spouse's fatigue. They reported doing this by 'observing the current situation in order to be able to react to it', by 'rearranging tasks', 'relenting' and 'using common sense in order to know how to behave'.

A strategy that was used by all of the partners was to 'observe the current situation and react to it': "*Je moet altijd kijken hoe het gaat en je aanpassen*" (PR 9), "*Ik zit altijd goed te kijken hoe iemand doet of hoe iemand is*" (PR 7), "*Je moet wel een beetje op de loer blijven*" (PR 8).

On top of that, all of the partners explained that they 'rearranged tasks' for example in the household in order to deal with their partner's SLE related fatigue: "*Ja, mijn generatie is nog wel van de oude stempel, van niet per definitie de karakteristieke rolverdeling, vrouw thuis, man werk, zo maar toch nog wel z'n kleine eind slag. Dus dat moet je dan helemaal los laten*" (PR 2), "*Ja, ik ben eigenlijk heel systematisch dus ik heb een lijstje gemaakt met wat is eigenlijk het huishoudelijk werk en wat zou ik daarin kunnen doen. En ik zei wat zou ik dan eigenlijk erin maken, maar ik moet weten wat ik moet doen, dan plan ik het ook op mijn manier in*" (PR 4).

Furthermore, a third of the partners concreted that they 'always take the SLE related fatigue of their partner into account': "*Je moet er altijd rekening mee houden, ik houd er altijd rekening mee*" (PR 6).

Moreover a minority reported coping with their partner's SLE related fatigue by 'using common sense': "*Hoe ga je ermee om? Ja, gezond verstand gebruiken*" (PR 4). Finally, a strategy that was also only reported by a minority of the partners was to cope with their spouse's SLE related fatigue by 'relenting': "*Afen toe ook toegeven 'tuurlijk. Als ik iets zit te doen en ik word onderbroken, dan vind ik het vervelend maar ja, als ik het kan, dan doe ik het ook*" (PR 4). All in all, those reported strategies underlined that the partners generally direct their coping efforts at tackling situations that could increase their spouse's SLE related fatigue.

### ***Emotion focused coping***

Another coping strategy that was mentioned by all of the interviewed partners in order to cope with their partner's SLE related fatigue was *emotion focused coping*. This means that the partners also tried to deal with their spouse's SLE related fatigue in an *adaptive emotional* manner. Therefore, partners generally try to regulate the emotional consequences due to their

spouse's fatigue by either changing the meaning of it or by transferring their attention away from it. Strikingly, most of the reported *emotion focused coping strategies* were *active* which means that the partners mostly tried to actively change their thoughts about their spouse's SLE related fatigue.

The following *emotion focused coping strategies* could be characterized as *active*: The majority of the respondents explained that they had the feeling of 'not having a choice' or 'just having to accept their partner's SLE related fatigue' and that they therefore 'just accept their spouse's fatigue and the consequences': "*Ja, je komt daar voor te staan; je moet. Ik denk dat daar geen leerschool voor is, het is gewoon... ehm... meegaan...je hebt geen keuze, je moet gewoon meegaan*" (PR 7), "*Kijk, als wij op een feestje zitten bij kennissen, vrienden, en zij geeft aan van: 'Ik ben nu zat', dan gaan we naar huis, klaar. Dan pas je je in principe aan. Ik zou de hele nacht wel door willen feesten, maar dan pas je jezelf aan*" (PR 9).

Half of the partners mentioned that they dealt with their partner's SLE related fatigue by 'making the best of it': "*Ja, je gaat met de situatie om en je maakt er gewoon het beste van*" (PR 7), "*Maar je moet toch maar proberen om zo goed mogelijk door te gaan. Dat is het beste wat je kunt doen. Ja, en dat doen we ook wel*" (PR 8). One partner concretized that he makes the best of the whole situation since he does nice things alone in cases where his spouse is not able to join him for example at a cycling tour. He even tried to see an advantage in this situation as his spouse could use the time to work at home: "*Ik ga dan ook vaak alleen (...)* daar zie ik dan ook weer de combinatie met het werk. Zij zag wat achter de computer moest gebeuren en in de tussentijd ging ik dan weg. Ja en dat is eigenlijk het voordeel" (PR 3). This example underlined the *active* manner by which the partners generally try to regulate the emotional consequences that occur due to their spouse's SLE related fatigue by changing the meaning of it.

A few of the partners reported a strategy that was also directed at changing the meaning of the stressor, namely 'relativizing': "*Hoe leer je daarmee omgaan? Gewoon relativeren*" (PR 9). Another strategy derived from the interviews that was described by a few of the partners and that could be characterized as *active emotion focused coping* was 'having patience': "*En het is soms heel moeilijk, ja, geduld misschien*" (PR 6). Therefore, the partners tried to cope with their spouse's SLE related fatigue by also regulating the emotional consequences of it.

Only one of the partners reported that 'talking with others who also know the problem' helped him to cope with his spouse's SLE related fatigue. However, he explained that only



people who were also affected by it or who had partners with the same illness could really understand him. Therefore, he explained that he valued the lupus congresses enormously: *“Ja, ik kan het daar eigenlijk alleen met mensen over hebben die hetzelfde kennen eigenlijk. Voor de anderen is het heel moeilijk voor te stellen, ja hoe het lijden van een ander person is eigenlijk (...) Dus daarom zijn de congressen ook zo goed. Want daar kom je dan met mensen in aanraking die ook de partners hebben, die ook een impact hebben”* (PR 6).

Only a minority of the *emotion focused coping strategies* could be characterized as *avoidant* which means that partners rather tried to escape in thoughts or activities that transfer their attention away from their spouse's SLE related fatigue. In this category a minority of the partners reported making use of 'distancing' in order to keep their thoughts away from directly addressing the problem. This strategy was represented by 'regarding the illness as belonging to the partner' and by 'trusting into the patient's ability of knowing when having to rest': *“En dat doet ze en in hoeverre het nou echt helpt, ik weet het niet (...) het is iets van haar en ik kan daar zelf niet zoveel invloed op uitoefenen”*(PR1); *“Ik moet ook erop vertrouwen dat ze ook zelf weet wanneer ze iets niet kan, dus daar vertrouw ik dan ook wel op”* (PR 6). Through these thoughts the partners generally distance themselves from their spouse's fatigue and thereby avoid negative emotional consequences. Another way of distancing themselves and thereby reducing the negative emotional consequences that was reported by a minority of the partners was to 'use denial'. Those partners explained that they had 'learned to deny their spouse's SLE related fatigue and to act as normal': *“En soms ga ik daar ook overheen en doe ik zo alsof het niet aanwezig is, misschien is dat ook negeren af en toe. Net zoals ik al zei aan het begin van de dag probeer je gewoon ook een normaal leven te leiden eigenlijk. Je doet alsof alles normaal is en doet de dingen die normaal zijn”* (PR 6).

A minority mentioned 'exerting self-control' in order to cope with the negative emotions that arise due to their partner's SLE related fatigue: *“Ja, je wordt emotioneel daarvan en ga je de grond op drukken en daar heb ik voor mezelf besloten dat ga ik niet doen”* (PR 7). This strategy represented that some of the respondents generally suppress the emotional consequences in order to cope with their spouse's SLE related fatigue.

### **3.1.2 Learning to cope with the spouse's SLE related fatigue**

With regard to how the partners have learned to cope with their spouse's SLE related fatigue nearly all respondents reported that it had been a 'process of gradually growing into the situation': "*Ja, ik ben nog aan het leren denk ik wel ook. Het gaat ook geleidelijk*" (PR 6), "*Dus wat dat betreft maak je dan wel een ontwikkeling door*" (PR 2), "*Dat is, ja zeg maar langzaam ingegroeid*" (PR 3). By other respondents this process was described as 'finding a way that fits': "*Op één moment denk je dan ja dat is een weg die bij me past en dat denk ik wel op dit moment*" (PR 2). The only female respondent did not describe a process, she rather reported that she had learned to cope with her partner's SLE related fatigue by 'pressing a button' and that it did not take her much time to do that: "*En ja hoe doe je zoiets? Ja, dat weet ik niet (...) Ja, ik vind het gewoon een knop omzetten, zo gaat het leven eruit zien en dan kun je mee dealen of niet mee dealen...Nee, nee(niet veel tijd gekost om knop om te zetten). Ik kan heel snel situaties, eh...*" (PR 7).

When the partners were asked how they have learned or how they learn to cope with their spouse's fatigue, it was underlined by their answers that acceptance plays a major role in learning to cope with the spouse's SLE related fatigue. With regard to the question if partners experience difficulties with accepting their spouse's SLE related fatigue it was found that the majority of the partners experienced acceptance of fatigue and only a minority reported non-acceptance of fatigue.

#### ***Acceptance of SLE related fatigue***

A minority of the respondents reported experiencing no difficulties with accepting their spouse's SLE related fatigue at all.

The main reason for the total acceptance was that the partners could 'give fatigue a place in their relationship': "*Ja, dat heb ik wel een plaats kunnen geven, natuurlijk. Ik ben zelf ook doodmoe als ik 's avonds thuiskom*" (PR 9). One of the partners explained his ease of acceptance with his 'choice of a joint path with his spouse through life': "*Daar heb ik geen moeite mee (...) Je bent samen een weg ingeslagen en die probeer je samen goed mogelijk af te maken*" (PR 9). On top of that, he explained that 'there was no other solution' and that no acceptance would even make it worse: "*Er is geen andere oplossing voor (...) Anders gaat het jezelf tegenstaan en dan ga je tegenover elkaar staan en dat is niet de bedoeling*" (PR 9). Another partner described that he did not experience difficult moments with acceptance since

his 'spouse is still doing well': "*Wij gaan nog redelijk vaak weg, gaan lekker s'avonds naar het toneel en dat soort dingen, films en dat gaat dan ook gewoon. (Moeilijke momenten?) Nou, ik ervaar het niet zo*" (PR 8).

The majority of the respondents reported that they accepted their spouse's SLE related fatigue but that they also experienced difficulties due to the related constraints. Remarkably, the mentioned constraints were mainly experienced among all respondents. They explained that they had 'difficulties with switching if their plans have changed and with long term planning': "*Als je van plan bent weg te gaan bijvoorbeeld. En dan kan zij gewoon even helemaal niet meer. Dat is toch altijd even moeilijk, die omschakeling*" (PR 5), "*Dat is moeilijk (lange termijn plannen). Ik ga volgende week... noem maar iets... als we op vakantie gaan*" (PR 5). Other mentioned constrained activities which caused difficulties with accepting their spouse's SLE related fatigue were 'going out' and 'riding the bike': "*Als we plannen hadden (zoals fietsen), of dingen die we graag wilden doen, maar dan ging dat op dat moment niet*" (PR 3). Finally, the 'unpredictable course of the disease' was described as leading to difficulties with accepting the spouse's SLE related fatigue: "*Het probleem is natuurlijk ook dat het niet zo blijft als het nu is*" (PR 2).

### ***Non-acceptance of SLE related fatigue***

Only two of the partners reported not being able to accept their spouse's SLE related fatigue. The reasons that one of the partners named for this were that he was 'struggling with it' and that it 'impaired his way of living' since his 'plans could not be realized': "*Nee, niet echt. Ik worstel ermee. Het tast heel erg mijn levenswijze aan (...)wij wonen nog steeds in dit huis, maar ik had hier wel 15 jaar geleden weg gewild, had andere ideeën gehad (...) ik wilde naar Spanje gaan*" (PR 4). The other partner that reported not being able to accept his spouse's fatigue explained that he struggled with the 'constant presence of fatigue': "*Oh ja, of u de vermoeidheid kunt accepteren. Ehm, in de basis niet (...)Het is er gewoon altijd aanwezig*" (PR 6).

### **3.1.3 Emotional consequences**

In the following part the partners' reported feelings are described. These feelings can be regarded as the emotional consequences that the partners experience due to their spouse's SLE related fatigue.

### ***Positive feelings***

Strikingly, only two positive feelings were reported by two of the respondents. One of the partners reported feeling 'admiration' for how his spouse deals with the SLE related fatigue "*Zij is toch wel ondanks de ziekte, ja het is wel een vermoeidheidsziekte, vind ik toch dat ze zich behoorlijk goed in stand houdt. Ja, daar heb ik echt een bewondering voor*" (PR 8).

Another partner mentioned being 'grateful' for talks with other affected people: "*Het heeft ook een impact op mij (de vermoeidheid). Dus daarom zijn de congressen ook zo goed. Want daar kom je dan met mensen in aanraking die ook de partners hebben, die ook een impact hebben*" (PR 6). Remarkably, these positive feelings were related to dealing with the SLE related fatigue and not to fatigue directly.

### ***Negative feelings***

The majority of the respondents only reported negative emotional consequences such as frustration, anger, fear and sadness. However, it has to be mentioned that most of the partners reported acceptance and a focus on making the best of the situation in order to deal with those negative feelings: "*Ik heb nog niets gehoord van dat daar iets op de markt komt wat echt helpt, heel vreemd eigenlijk. Dus blijkbaar een heel moeilijke ziekte. Maar je moet toch maar proberen om zo goed mogelijk door te gaan. Dat is het beste wat je kunt doen*" (PR 8).

The emotional consequence of their spouse's fatigue that was most common among all partners was 'frustration' for which different reasons were reported: a 'lack of healing', 'constant presence of fatigue', 'struggle with the whole situation' and 'plans that cannot be realized anymore'. Most of the partners explained that they were frustrated due to 'plans that could not be realized' because of the SLE related fatigue: "*Dat is bij mij toch wel wat gaan opspelen. Dat je zegt: potverdomme, na al die jaren, ik zit hier nog een beetje te zitten. Het boeiende is eraf, er is niks boeiends meer (...) Ja, ik had graag veel wisselingen. En dat zit daar niet in*" (PR 4). Another reported feeling that was close to frustration was 'anger'. However, only a minority of the partners reported that their spouse's SLE related fatigue sometimes made them angry: "*Soms zijn er momenten dat ik boos op haar ben en eigenlijk daarna heb ik er ook wel weer spijt van, want dan denk ik: het klopt eigenlijk niet, want zij kan er ook niets aan doen. Maar ik kan er ook niets aan doen dat ik me zo voel, dat ik het heel klote vind dat zij altijd zo ziek is en dat het altijd aanwezig is*" (PR 6). Another partner

expressed his 'anger' by 'swearing about the illness and the related fatigue': "*Het blijft een rotziekte*" (PR 8).

Another emotional consequence that was reported by some of the partners was 'fear'. A few of the partners reported feeling 'fear about the future' due to the 'changes' that might be necessary such as moving or a change of their role from husband into that of a caregiver: "*Ja, daar zie ik wel tegen op. Want dat zou misschien betekenen van ja kun je blijven wonen? Dat soort dingen*" (PR 2), "*Je verzorgers rol wordt nog heel anders dan (...). Ik ben er eigenlijk geen mantelzorger, vind ik*" (PR 2). Furthermore, one of the partners expressed his fear about the future by reporting 'uncertainty' about the impact of the SLE related fatigue on the relationship: "*Er is tijd nodig om te zien of het veranderd, wat doet het met de relatie*" (PR 1).

Finally, a few of the partners reported being 'sad': "*Ja, daar wordt het heel zwaar, daar krijg ik ook tranen in mijn ogen*" (PR 6).

### **3.1.4 Partners' satisfaction with coping**

In order to answer the question how satisfied the partners are with their way of coping with regard to their spouse's SLE related fatigue, they were directly asked about their satisfaction. Initially, some of the respondents confused their satisfaction with coping with their satisfaction with their way of giving support but finally their answers could be classified correctly.

#### ***Satisfied with way of coping***

The majority of the partners reported that they were satisfied with their way of coping. It was found that their satisfaction was 'related to their acceptance' of their spouse's SLE related fatigue: "*(heeft tevredenheid te maken met acceptance?) Ja, je probeert er toch een weg in te vinden. Op één moment denk je dan ja dat is een weg die bij me past en dat denk ik wel op dit moment*" (PR 2), "*Ja het idee heb ik wel(echt om kunnen gaan met de vermoeidheid). Het is een stuk van ons leven geworden*" (PR 2).

A few of the respondents explained that they were satisfied with their way of coping because they had the 'idea to handle it well': "*Ja, dat hoef ik niet toe te lichten. Ik vind dat ik*

*het goed doe ja. Ik zit niet in het hoekje te kniezen of te huilen dat het zo is (...) Absoluut (het idee het samen goed te kunnen handelen). Ja” (PR 7).*

A minority explained their satisfaction with the fact that they found it ‘easy to adapt to their spouse’s fatigue’: *“Daar heb ik totaal geen moeite mee (aanpassen). Vanaf het begin al niet” (PR 9).*

### ***Unsatisfied with way of coping***

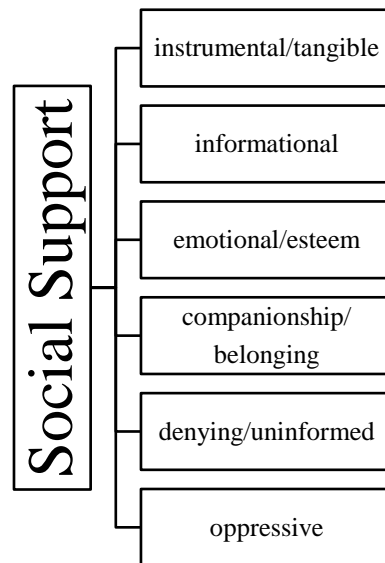
Only two of the respondents reported that they were not satisfied with their way of coping with their spouse’s SLE related fatigue. Strikingly, those respondents were the partners who also reported that they could not accept their spouse’s SLE related fatigue. The respondents mentioned different reasons for that. One of them thought that his way of coping ‘could be better’ since he still struggled with it: *“Nee, niet echt (vermoeidheid kunnen accepteren). Ik worstel ermee...Nee, natuurlijk niet (tevreden zijn met omgang). Als ik zou worstelen ermee, he, dan moet het vast beter kunnen, denk ik dan” (PR 4).* Another mentioned reason for dissatisfaction with his way of coping was ‘unjustified anger’ due to fatigue: *“Soms zijn er momenten dat ik boos op haar ben en eigenlijk daarna heb ik er ook wel weer spijt van, want dan denk ik: het klopt eigenlijk niet, want zij kan er ook niets aan doen.” (PR 6).* The same respondent additionally reported being unsatisfied with his way of coping since he had the feeling that he ‘should talk more about it with others’: *“Ja, maar dat is met haar (dingen altijd bespreken), maar naar buiten ben ik veel minder open eigenlijk” (PR 6).* The partner related the fact that he did not talk much with others about his spouse’s SLE related fatigue to a ‘lack of understanding from others’: *“Ja, het is ook wel moeilijk te begrijpen, de mensen begrijpen het helemaal niet (...) als ik er met iemand op mijn werk, mijn collega’s over zou praten, ja zij ligt gewoon in bed en is alleen aan het slapen, ja erg, maar voor hen gaat het dan normaal verder” (PR 6).*

## **3.2. Social support**

### **3.2.1 Types of social support**

In order to explore the partner’s perspective on his spouse’s SLE related fatigue, the other focus of this study was on how the partner tries to support his spouse. After asking if there were situations in which the partner has the feeling of being able to effectively support

his spouse regarding SLE related fatigue, different types of social support were reported. On the one hand many examples of *emotional/esteem support*, *instrumental/tangible support*, *informational* and *companionship/belonging support* were found. On the other hand two types of problematic social support, *denying/uninformed support* and *oppressive support* were reported by two partners.



*Figure 2b.* The partner's reported types of social support

### ***Instrumental/tangible support***

The most reported type of social support was *instrumental/tangible support*. This means that many partners generally try to support their spouse with regard to the SLE related fatigue by offering help or assisting them. All respondents described situations in which they supported their spouses with regard to their SLE related fatigue by 'taking over tasks' such as household duties, 'helping with work', 'doing tasks together' and 'earning a living'. It was striking that all of the respondents reported that they supported their spouse with regard to SLE related fatigue by 'taking over tasks or doing tasks together': "*Ik neem weleens wat dingetjes van haar over*" (PR 3), "*Als zij hier bij Albert Heijn boodschappen doet en dan komt ze met de auto aan, als ik dat zie dan haal ik die tassen daar eruit*" (PR 8). The majority of the partners mentioned that the tasks they took over were 'household duties': "*Het komt*

*erop neer dat ik haar help met de huishoud, ik stofzuig en ik doe de afwas en de tuin, maak het bed op*” (PR 4), *“Ja, zoveel mogelijk helpen eigenlijk. Ja, laat zeggen de afwasmachine inruimen en ook weer uitruimen en dat soort dingen, stofzuigen, bed opmaken”* (PR 8), *“Gewoon het huishoudelijk werk”* (PR 5). Only one partner did not mention to take over household duties but he explained that he rather helped his spouse by assisting at work on the computer. Since this spouse with SLE related fatigue works from home her partner generally offers support by ‘helping with work on the computer’: *“Nou ik neem weleens wat dingetjes van haar over. Qua computer ofzo. En wat lijsten invullen en dergelijke (...) dat wordt dan wel een combinatie, de vermoeidheid en zij heeft het druk. Dan probeer ik het op z'n manier en denk dat kan ik even voor haar doen”* (PR 3).

Another way found by which the partners offer *instrumental/tangible* support was by ‘earning a living’. This type of social support was not mentioned directly by the respondents but it could be derived from the descriptions that most of the spouses with SLE related fatigue could not work anymore, thus their partners were the only ones who earned the families living and therefore ‘supported their partner financially’: *“En verder werk ik fulltime (...) Want hij probeerde ook heel lang een paar uurtjes te werken. Daar heb ik hem dan van afgeraden, omdat het echt niet kon ”* (PR 7).

*Instrumental support* seemed to be experienced as very effective by the partners since strikingly all of them reported examples of ‘taking over tasks’ after being asked if there were situations in which they had the feeling of effectively supporting their spouse regarding SLE related fatigue

### ***Emotional/esteem support***

The majority of the partners also reported situations in which they could support their spouse with regard to their SLE related fatigue via offering *emotional/esteem support*. This means that the partners generally try to support their spouse by offering understanding and showing concern. The *emotional/esteem support* that the partners reported was mainly characterized by ‘mutual understanding’, ‘concern’, ‘empathy’, ‘caring’, ‘extra attention’ and ‘standing by the spouse with love’. The most commonly reported way of supporting their spouses with regard to their SLE related fatigue was ‘being concerned about the spouse’s feelings and the entire situation’: *“Nou we bespreken dingen altijd samen”* (PR 5), *“Wij hebben wel genoeg tranen gesprekken gehad. Ja zeker, als iets is gebeurd, of je heel ziek bent geweest, soms zitten we ook wel allebei met traantjes daarbij”* (PR 6), *“Dus ja, daar*



*hebben wij dan bij voorbaat ook veel over gesproken voordat de eigenlijke uitspraak was dat de diagnose SLE was” (PR 7). One of the partners also showed his concern via ‘calling his spouse from work’ in order to ask how she felt and how it was going: “Een belletje is vaak al een goede ondersteuning om even te informeren: hoe en wat” (PR 9).*

Two partners explicitly reported that a way of supporting their spouse was having ‘mutual understanding’: “De verstandhouding naar elkaar is er gewoon” (PR 3), “Ja en heel veel praten met elkaar(...)Altijd duidelijk aangeven waar grenzen zijn, wat je wilt, wat jou doel is, ja en praten of je dat samen kunt, of je dat samen kunt bereiken” (PR 7). One of the partners reported that he supported his spouse by ‘standing by her with love’ and by ‘giving her extra attention’: “haar met gewoon... liefde bijstaan”, “Extra aandacht schenken, dat helpt zeker” (PR 5). Another partner expressed his *emotional/esteem support* by ‘caring’ for his spouse when she suffered from SLE related fatigue: “En ook als ze vanwege vermoeidheid in bed ligt, dan ga ik haar een lekker kopje koffie naar het bed brengen. Dus op die manier kan ik haar ook ondersteunen”.

This type of support also was experienced as effective by the partners since most of them mentioned examples of it after being asked about other effective ways of support next to *instrumental/tangible support*.

### ***Informational support***

Another common type of social support that was described by more than the half of the respondents was *informational support*. This means that partners generally try to support their spouse with regard to the SLE related fatigue by discussing related information and giving advice for how to cope with it. Strikingly, all descriptions of the partners’ *informational support* could be characterized as ‘giving advice or guidance’ since the partners explained that they always discussed new information about the SLE related fatigue with their spouse or that they advised him/her with regard to daily activities.

The majority of the partners that offered *informational support* described to express this by ‘advising their partner to stop doing tasks’ when they experience SLE related fatigue: “Als ik zie dat ze te veel wil doen en, uhm, eigenlijk veel te moe is dan zeg ik tegen haar laat het maar liggen en doe het morgen” (PR 4), “Ik heb natuurlijk wel altijd gezegd van denk aan jezelf en heer kijk nou leg je daar drie dagen uit om de drie uurtjes te gaan werken” (PR 7). Some of the partners did not only explain that they gave advice but also that they ‘persuaded their spouse to stop doing tasks’. Since ‘persuasion’ is a very extreme type compared to an

'advice', it could better be characterized as *oppressive support* which is further explained later.

On top of that, it was found that a few partners give their spouse advice by 'talking with them about how tasks that occur due to SLE related fatigue could be solved': "*Dat zijn wel dingen waar je heel veel over praat. Hoe gaan we dit doen en hoe kunnen wij het best allemaal oplossen*" (PR 7). Moreover, one partner described that he guided or advised his spouse by 'discussing new information' that he gathered via de lupus website or via the doctor: "*We bespreken dingen altijd samen. Als er iets nieuws is op de Lupussite. Toch samen er even overheen kijken. Dat zijn toch wel dingen waar we samen dingen... overleggen. En even bepraten als er iets nieuws is. 'Zullen we dat toch niet proberen' of... toch dingen in de gaten houden*", "*En als we naar de dokter gaan, toch dingen samen doorspreken*" (PR 5).

Strikingly, 'advising the partner to stop doing tasks' was commonly described as effective by the partners, which demonstrated that *informational support* was generally experienced as effective type of support.

### ***Companionship/belonging support***

Only one partner explicitly described that he supported his spouse with regard to her SLE related fatigue via *companionship/belonging support*. This means that he tried to support his spouse by giving her the sense of belonging. Characteristically the focus of this type of support lay on providing this sense via actively doing nice things together. In this case the partner reported that he supported his spouse by 'providing alternation': "*Ik probeer wel zoveel mogelijk verzetjes of zo te maken en ja wat dat betreft niet in het huis te blijven zitten en dat we daar nog een beetje afleiding hebben*" (PR 2). Furthermore, he described that there was a 'mutual stimulation to do nice things together': "*Maar dat wil ze zelf ook, hoor. Dus wat dat betreft (dingen samen doen) stimuleren we elkaar*" (PR 2).

### **Problematic social support**

It has to be mentioned that only a minority of the partners seemed to exert problematic social support which could be divided into *uninformed/denying* and *oppressive social support*.

### ***Uninformed/denying social support***

Only two descriptions of the respondents could be classified as *uninformed/denying support*. This means that the partner exerted actions that expressed his misunderstanding or

denial of the SLE related fatigue. However, in one of those cases the partner only described the *uninformed/denying social support* to be present at the very beginning of the illness since he 'did not realize the severity' of SLE related fatigue, thus there was a 'lack of understanding': "*Ja helemaal aan het begin was het ook een beetje ongeloof. Toen wisten we ook nog niet wat ze had, toen gingen we fietsen en toen kon ze niet meer fietsen want ze was moe. En ik dacht, ha het is wat over niets en ging weer fietsen dus het is ook wat moeilijk in te schatten soms. Die vermoeidheid is ook niet voor te stellen eigenlijk*" (PR 6).

Another partner also described that he 'did not realize the severity' of his spouse's SLE related fatigue: "*Ik heb het nooit zo gemerkt, ik moest het uit verhalen horen. Want eerlijk gezegd, in het begin drong het helemaal niet tot mij door*" (PR 1). In contrast to the other partner that exerted *uninformed/denying social support* only at the beginning of the illness, this partner 'still not seemed to realize the severity' as he described that he once countered his spouse that he was also tired sometimes and that he believed that she did not need support: "Ja ik zei ja ik vergeet ook weleens wat, ja ik onthoud ook niet meer alles", "(Is het iets van haar dat ze niet snel om hulp vraagt of is het niet nodig?) Het is niet nodig" (PR 1). However, it has to be mentioned that this partner later also explained that he still sometimes 'took over tasks' that his spouse could not do but he 'did not relate this to his spouse's fatigue': "*Er zijn dingen daar is ze niet goed in, dan komt het op mij aan (...) Dus ja, dat is dan toch logisch. Maar dat was vroeger ook al zo*" (PR 1).

### ***Oppressive social support***

Only two of the nine partners reported actions that could be identified as *oppressive social support*. This means that the partners oppressed instead of supported their spouse with their support efforts.

One of the partners explained that he 'wanted to take over more tasks' in order to relieve his spouse but that 'she did not want to hand off tasks': "*Maar de grote klussen, wassen, strijken, dat wil ze samen maken of alleen. En zo ook met het koken. Dat is ook zo iets waar ik van dacht ja, ik vind het niet erg leuk, heb ook geen talent, maar ik dacht laat mij maar een paar weken koken, maar nee. Ze geeft niets af*" (PR 4).

As was already mentioned above, another partner reported an extreme type of advising that had a paternalistic character and could not be characterized as informational support anymore, namely 'persuading the partner to stop doing tasks': "*Soms is zij zo enthousiaste en*

*wil van alles, maar dat is gewoon niet mogelijk in de werkelijkheid, wat ze wil is niet altijd wat ze kan. En dan zeg ik gewoon dat doen we niet of zet dat maar af of zo” (PR 6).*

### **3.2.2 Partners' satisfaction with way of giving support**

In order to answer the question how satisfied the partners are with their way of giving support they were explicitly asked about their satisfaction. The majority of the partners reported that they were satisfied with their way of giving support. Only a minority reported that they were not satisfied with their way of giving support.

#### ***Satisfied with way of giving support***

Two-thirds of the partners reported being satisfied with their way of giving support. The main reasons they mentioned for this were that they did not experience situations in which they could not support their partners and that they perceived that it was going well. Only one partner who reported not being satisfied with his way of giving support however described one exception namely that he had ‘the idea that his spouse expects more support of him’: *“Voor mij in ieder geval (satisfied with social support). Voor haar misschien... denkt ze dat het te weinig is. Gisteren was ik te laat thuis. Het is gewoon niet anders. Dan bel ik op: ‘Shit’. Die mensen moeten ook geholpen worden... die in de parkeergarage staan en niet wegkunnen. Dan ga je toch maar weer op pad. De vrouw komt dan toch effe als tweede” (PR 5).*

The reason for their satisfaction with support that most respondents had in common was the fact that they did ‘not perceive any situations in which they could not support their partners’: *“Ik denk dat ik haar wel ergens mee kan ondersteunen emotioneel en ook gewoon de praktische dingen” (PR 2), “Er komen geen situaties voor waarin ik haar niet kan ondersteunen. Meestal wel” (PR 9).* The only female partner explained that there were no situations in which she could not support her partner among others due to the fact that her ‘spouse tries to hide the severity’ of his fatigue in order to spare her: *“Alleen denkt Meneer ook vanuit mijn winst (...)Ja, ik neem aan als je patient bent, dat je altijd probeert, zo is mijn man zijn karakter ook, hij probeert altijd het best eruit te halen. En ik denk dat daardoor, dat je ook wel regelmatig, zich misschien iets wat beter voelt (...)hij probeert altijd denk ik wel, mensen te sparen” (PR 7).*

Many of the satisfied respondents also mentioned their ‘perception that it was going well’ as reason for their satisfaction: *“Op zich valt het, het is niet zozeer dat ze niet alles meer*

*kan hoor” (PR 1), “Dus ja ik vind eigenlijk dat het redelijk goed gaat, maar zij maakt op mij ook helemaal niet... dat ze daar ja, wat ongelukkige, dat het niet goed gaat. En ik heb het idee dat ze zichzelf eigenlijk redelijk goed kan vinden” (PR 8).*

There was one partner who fell out of alignment. He well described that he was satisfied with his way of giving support due to the fact that it was going well, but he was the only partner who reported that the couples' 'early distribution of tasks stayed' and that his 'spouse did not explicitly request help': *“Nee, dat is niet aan de orde (dingen van haar opgepakken). Dan heb je nog typisch mannendingen, maar dat deed ik toch al, zoals klussen en tuin”, “Nee, dat speelt nog niet (wou om haar meer te ondersteunen). Maar op het moment dat ze zegt van ik zit ergens mee, dan is het, kan ik meedenken en haar ontlasten of zoiets, maar dat is er niet. Daar is geen hulpvraag echt van haar kant uit” (PR 1).*

### ***Unsatisfied with way of giving social support***

Only a minority of the partners reported that they were unsatisfied with their way of giving social support. The reasons they mentioned for this were that they experienced several situations in which they could not support their spouse with regard to SLE related fatigue, that they did not have the feeling of having an influence on their spouse's SLE related fatigue and that they had the idea that their support could be better.

The idea that the partners 'support could be better' was related to 'showing more empathy' and to 'talking more with the spouse': *“Nee, kan altijd wel beter. Nog meer begrip tonen eigenlijk, soms heb ik wel te weinig begrip zoals ik al zei en neger het. Ja, of misschien nog meer over praten, nog specifiekere vragen stellen, maar soms heb ik daar ook geen zin in” (PR 6).*

Another partner reported that his 'spouse did not accept more help' and that he had 'no idea of how this acceptance could grow': *Maar wat ik me wel afvraag, als ik heel veel eigen initiatief zou doen, bijvoorbeeld met werk, ik geloof niet dat zij het zou waarderen. Dan ga ik toch door haar domeinen zitten, waar couples het over hebben, je kent toch deze grafiekjes (...). Ja, dit is jouw taakgebied en daar moet ik me niet mee bezig houden, behalve als je vraagt. En ja ik geloof niet dat dat goed zou vallen, nee, nog niet” (PR 4).*

The situations described in which the partners could not support their spouse were related to 'tasks that only the patient can do', were situations in which 'difficulties occur with combining work and support' and situations 'when the spouse cries and the partner is angry': *“Dingen die ze eigenlijk maar alleen kan. Daar kan ik niets aan doen. Niet... Ik kan daarbij*

*niet assisteren. Dat zijn toch dingen waar ik geen verstand van heb, of geen kijk op heb” (PR 6), “En als er twee dingen tegelijkertijd komen, twee verschillende botsingen, bijvoorbeeld als ik moet werken en zij doodziek is, dan is daar mijn vrouw en op de andere kant mijn werk en daar zitten mijn collega's en dan wordt het moeilijk voor hen en op de andere kant is mijn vrouw dan ook niet lekker (PR 6), “Nee, dat vind ik dan heel moeilijk en ook als ze ziek is en dan gaat ze huilen, dan heb ja daar een huilende vrouw, puh, ah, dat hebben we lekker helemaal gehad. En dan kan ik ook een beetje boos worden, dat is wel gek, dat hoeft eigenlijk niet, maar dan merk ik wel dat ik soms boos word of zoiets” (PR 6).*

Strikingly, those two partners who reported that they were unsatisfied with their way of giving support were the same partners who reported being unsatisfied with their way of coping and not being able to accept their spouse's SLE related fatigue.

#### **4. Discussion & Conclusion**

This study aimed to give insight into the partner's perspective on the spouse's SLE related fatigue. The main findings were that the partners utilized a variety of coping strategies in order to deal with their spouse's SLE related fatigue. However, this variety could be either characterized as emotion focused or as problem focused coping. This finding is consistent with prior studies which indicated that emotion focused and problem focused coping were used most by partners whose spouse is suffering from the symptom fatigue (Green et al., 2010). Strikingly, all of the partners reported that they rearranged tasks and observed the current situation and reacted to it in order to deal with the cause of the stressor, namely more fatigue due to overload. Therefore, problem focused coping was used most by the partners in order to deal with their spouse's SLE related fatigue.

With regard to emotion focused coping the most utilized strategies were *active* which shows that the partners mostly actively change their thoughts about their spouse's SLE related fatigue and give another meaning to it. Furthermore, it was found that the majority of the partners reported that they just accepted their spouse's SLE related fatigue in order to regulate the emotional consequences of it. This fact underlines the finding that the emotion focused coping strategies partly overlapped with acceptance. This result might be explained by the major role that acceptance plays in dealing with a chronic disease (McCracken, & Eccleston, 2003) and by the findings of Folkman & Lazarus (1988) who explained that the “acceptance of the own responsibility” could be characterized as emotion focused coping strategy.

Therefore, accepting the spouse's SLE related fatigue and the consequences could be characterized as emotion focused coping strategy.

Another important finding was that the majority of the partners perceived the experience of learning to cope with their spouse's SLE related fatigue as process. Only one partner reported that this experience was more like pressing a button and directly adapting to the situation for her.

As was already mentioned above the results revealed that acceptance plays a major role in learning to cope with the spouse's SLE related fatigue. It was found that only a minority either reported not to accept their spouse's fatigue or to experience no difficulties with acceptance at all. The majority explained to accept their spouse's fatigue but also to experience difficulties with the constraints that were caused by the fatigue. Most of the reported constraints were common among all of the respondents, such as having difficulties with long-term planning or with switching if the plans suddenly changed due to fatigue.

Further, the results revealed that the partners only described negative emotional consequences such as frustration, anger, fear and sadness that were caused by their spouse's SLE related fatigue. However, it has to be mentioned that with admiration and gratefulness also two positive feelings were reported. These feelings were though not reported as direct emotional consequence due to fatigue but rather described in relation to coping, namely admiration for how the spouse copes with his/her fatigue and gratefulness for talks with other affected people. The fact that only negative direct emotional consequences were reported underlines the negative impact that SLE related fatigue has on the emotions of the partners.

On top of that, it was found that the majority of the partners were satisfied with their way of coping and that this satisfaction correlated with their acceptance of their spouse's fatigue. Further reasons for the partners' satisfaction were that they perceived to handle the situation well and to easily adapt to their spouse's fatigue. Remarkably, the partners who reported that they were not able to accept their spouse's fatigue were the only partners who recounted that they were unsatisfied with their way of coping. Other reasons named for the partners' dissatisfaction were that they still struggled with their spouse's fatigue and the idea that they should talk more about it with others in order to deal with the emotional consequences of it. Literature (Sales, Schulz & Biegel, 1992; Berg & Upchurch, 2007) indicated that the age, the duration of the relationship and the marital satisfaction were factors that have an influence on the partner's adjustment to the spouse's illness. Those findings only

partly overlap with the results of this study. Sales et al. (1992) found that younger partners were more likely to experience adjustment problems to the spouse's illness, which is consistent with the finding that one of the two partners was 43 years old. However, the other partner who reported unacceptance and dissatisfaction was 69 years old which is in contrast to the hypothesis that the age plays an important role. Further the two partners differed in the duration of their relationships with their spouses and their marital satisfaction was not examined in this study.

In conclusion, partners utilize different coping strategies in order to deal with their spouse's fatigue and they generally learn to cope with it by a process of gradually growing into the situation and finding a way that fits them. Most of the partners were able to accept their spouse's fatigue despite the difficulties they experience due to the related constraints. Since acceptance and satisfaction with coping were related to each other, most of the partners also reported being satisfied with their way of coping. Prior studies (Eton, Lepore & Helgeson, 2005) also underlined the important role of acceptance in coping with the spouse's fatigue, since they found that greater acceptance of the spouse's illness was associated with lower general distress. From the author's general impression, the two partners who explained that they were not able to accept their spouse's fatigue and also were not satisfied with their way of coping differed from the other partners in the following points: they seemed inflexible and holding on to old plans and ideas of daily living that could not be realized anymore due to their spouse's fatigue, while the other partners seemed to have a broad behavioral repertoire that they flexibly applied in their daily lives in order to adapt to the whole situation. Moreover, those two partners were the only ones who exerted oppressive social support. This impression is underlined by current literature (Arends, Bode, Taal & Van de Laar, 2013) that emphasized the importance of goal management strategies in successfully adapting to a chronic disease. Particularly, their finding that the "adjustment of goals to the circumstances" and "striving goals" were the most beneficial strategies in adapting to a chronic disease (Arends et al, 2013), fits the results of this study.

With regard to how the partners offer social support the following results were found. Different types of social support were recounted by the partners which included instrumental/tangible support, emotional/esteem support, companionship/belonging, denying/uninformed and oppressive support. Remarkably, instrumental/tangible support was offered most since all of the partners reported to take over tasks in order to support their



spouse. Strikingly, problem focused coping strategies such as rearranging tasks overlap with instrumental/tangible support. This is not surprising when earlier studies (Carver & Vargas, 2011) who characterized the mobilization of instrumental assistance as problem focused coping are considered. Making a difference between the two concepts of coping and social support is however very important since they still help to differentiate between “internal” emotional adjustment to a stressor (coping) and external adjustment (social support).

Next to instrumental/tangible support most of the partners also mentioned supporting their spouse by offering emotional support. Here the partners especially reported that they showed concern about their spouse's feelings and the entire situation in order to support their spouse. This result is in line with the prior description that an emotional approach is particularly effective in cases where the person is affected by unchangeable conditions such as a chronic disease.

On top of that, half of the partners offered informational support by advising their partner to stop doing tasks or activities such as household duties or keeping multiple appointments. Considering prior studies (Ayan & Martin, 2007; Ramsey et al., 2000) who found beneficial effects of physical exercise on the fatigue level of patients with SLE, it seems surprising that partners stopped their spouse to be active. However, it seems reasonable from the partners point of view since they described that their spouse got even more tired after long lasting or several activities. Moreover, it must be recognized that physical exercise and doing many or long lasting activities are not the same. While physical exercise/sport is proved leading to an increase of cardiovascular fitness and reduced fatigue in SLE patients (Ayan, 2007), gardening or fulfilling household duties were rather associated with more stress and fatigue for SLE patients. The other types of social support were only reported by a minority of the partners. The fact that types of problematic social support were scarcely reported could be explained by the perspective of the respondents, namely that of the partners. They generally might not perceive some of their own specific support efforts as problematic or may not want to admit that, while their spouses would do that.

Remarkably, the partners' strategy of *advising* their spouse to stop doing tasks could be characterized as informational support, while their strategy *persuading* the spouse to stop doing tasks could rather be assigned to oppressive support. This result draws attention to the very narrow boundary between positive and problematic social support. Further, it demonstrated that no matter how conscientious researchers try to analyze the different types

of social support that the partners offer, the effectiveness of their support is heavily dependent on the receiver of that support and many other factors.

Another important finding was that the majority of the partners were satisfied with their way of giving support. The main reported reason for their satisfaction was that they did not perceive any situation in which they could not support their spouse with regard to their SLE related fatigue. Only the two partners who already explained that they were not able to accept their spouse's fatigue and were unsatisfied with their way of coping also explained to be unsatisfied with their way of giving social support. This result might be explained by the fact that SLE related fatigue of the spouse is a condition over which the partners do not have much control. From the authors' perception, acceptance of the circumstances could give them the possibility of getting rid of the permanent struggle against it. Since those two partners have not yet succeeded in accepting their spouse's fatigue, they consequently struggle permanently with it and therefore are dissatisfied with their way of coping. If they are not able to adequately cope with it for themselves it is comprehensible that they also did not have the idea of giving adequate support and therefore be satisfied with it. Further, current literature (Bodenmann et al., 2004 In: Berg and Upchurch, 2007) states that poor adjustment might limit the spouse's ability to support his spouse with a chronic disease. That finding is consistent with the result of this study that exactly the partners who reported unacceptance of the spouse's fatigue and dissatisfaction with their coping were the ones who reported being unsatisfied with their way of giving support.

Putting all findings together, it was found that the behavior of the partners had a dynamic character. Every partner reported that he always observed the current situation and reacted to it. This did not only represent the dynamic character of the partners' behavior in the long term, but also the situational dynamic process. Regarding the long term, the partners reported having to keep observing the situation due to the unpredictable course of the disease and to constantly adapting to new situations. Regarding the situational process, the dynamic lay in firstly observing the current state of the spouse's fatigue, then trying to form an adequate reaction and thirdly in accepting the situation and the consequences. These findings remind at Leventhal's Self-Regulation Model (Leventhal, Brissette & Leventhal, 2003), which explains how people's self-regulation processes help them to cope with illnesses. It is argued that self-regulation is based on a feedback loop or "TOTE (test, operate, test, exit)"

(Leventhal et al. 2003) which reminds at the observation and adaptation of the partners. The results revealed that most of the partners succeeded in combining emotion focused and problem focused coping strategies and in applying their broad behavioral repertoire very flexible to the requirements of the current situations. Conclusively, the partners did not only observe and adapt in situational moments but also in the long term to the whole situation. This dynamic process is also underlined by the partners' descriptions that learning to cope with the spouse's fatigue is like a process of gradually growing into the situation. Berg and Upchurch (2007) also described the couples' coping with a chronic illness as process in which the patient and the spouse were placed in a context where their adjustment and coping efforts exist in a relation to each other. Further, they found that problem-focused coping such as a division of tasks was associated with better adjustment for multiple-sclerosis patients and their spouses (Berg & Upchurch, 2007) and this study adds that a rearrangement of tasks is also perceived as effective by SLE couples.

According to current literature (Rosland, Heisler, Piette, 2012), the management of chronic diseases often includes a change of daily routines, such as changes in physical activity, eating patterns and regular self-testing. The results of this study confirmed some of those findings since the partners mentioned a rearrangement of tasks and a lower physical activity level due to the spouse's SLE related fatigue.

Egberg, Andreassen & Mattiasson (2012) found that living with a person with a chronic disease leads to frustration not to meet intentions, changes in social life, being a person on the side of things and intertwining of circumstances. With regard to frustration this study also found that partners explained feeling frustrated but this frustration was rather related to plans that could not be realized and not to effects on the relationship or the perception of consideration as demanding as Egberg et al. (2012) found. What this study nevertheless confirmed was that partners experienced a limitation of their possibilities and changes of their roles. Moreover, Egberg et al. (2012) reported that partners felt powerless and experienced discomfort and coexisting symptoms. Contrary, the results of this study revealed that the majority of the partners reported that they were satisfied with their way of coping and giving support and from the authors' impression they rather resembled a strong and supportive counterpart to their fatigued spouse. However, this impression has to be regarded with caution, since this study did not explicitly examine the partners' health status.

With regard to the partners' well-being, prior studies (Sawatzky & Fowler-Kerry, 2003) found that the identity of partners is partly reduced to the caregiver role since they perceive that they do not have a choice with regard to their caregiver role, that their own lives are put on hold and that there is a lack of time for themselves and spontaneity. Those findings are in accordance with the results of this study. According to Hoek's study (2015), however, the patients with SLE related fatigue felt guilty for being a burden for their partner and also for impacting their partners life due to fatigue. Therefore, the conclusion could be drawn that they might want their partners to take time for themselves and not only to focus on caring for them. Additionally, other research (Barbosa, Figueiredo, Sousa and Demain, 2011) emphasized the importance for caregivers of keeping time for themselves and holding on to interests outside caregiving in order to maintain their own health and ability to provide support. Contrary to that, the results of this study revealed that the partners scarcely do something for themselves. The author expected to find examples of doing sports or meeting friends in the interview transcripts as ways of distracting themselves from their spouse's fatigue or as possibility to recharge their bodies with energy. But instead, the partners mostly described behavior related to the spouse's fatigue after being asked how they cope with it. Remarkably, the only activity they recalled next to supporting the spouse was their work. A possible explanation drawn from the interviews and also from current literature (Sutanto et al., 2013) could be that their work is something that the partners have to retain since their spouses cannot work anymore due to fatigue and that there is no time left for other activities. However, it has to be considered that the partners might have recalled activities they do for themselves, if they were asked more directly about it.

Furthermore, Senden et al. (2015) found that a typical coping strategy of caregivers of cancer patients was the "normalization of their own caregiving" by understating their efforts and denying the changes to their daily lives. Though that study focused on cancer patients, the results can be compared with this study since Sender et al. (2015) described that fatigue was predominant among complaints of the patients. Further findings were that the caregivers adjusted their expectations and used downwards comparison in order to cope with the situation (Senden et al., 2015). Those findings partly overlap with the results of this study since most of the partners found it natural to support their spouse and adjusted their expectations by adapting to the situation. In contrast to those findings, this study found that partners recognized and talked about the changes to their daily lives and they did not mention downward comparison in order to cope with their spouse's fatigue. With regard to social

support Senden et al. (2015) reported that patients were given a “central position in the relationship”, that partners were sensitive in order to recognize the patients' needs and that they adapted to the patient. Those results remind at the finding of the dynamic situational process that partners in this study described in relation to adapting to their spouse's SLE related fatigue.

Certain strengths and limitations of this study should be considered. On the one hand, this study was one of the first who intensively explored the partners' perspective on their spouse's SLE related fatigue. Therefore, this study has a high scientific value since it did not only underline the importance of considering the partner's perspective on his/her spouse's fatigue but also could help to increase the knowledge and understanding of the partner's perspective on his/her spouse's SLE related fatigue. Especially for the field of chronic diseases, fatigue and partner relationships the scientific value is high since an understanding of the partner's experience with the spouse's SLE related fatigue enables a holistic approach in all fields mentioned above. The importance of such a holistic approach was already underlined by other studies with other chronic diseases (Egberg, et al., 2012). In this study particularly problems of the partner with accepting the spouse's SLE related fatigue could be identified as leading to dissatisfaction with coping and social support. The value of this study was also emphasized by the partners themselves since they reported that their spouse's fatigue also had an impact on them and that they unfortunately rarely talked about it due to a lack of understanding from others.

On the other hand, it has to be considered that the interviews with the partners that were subject to the analysis of this study were conducted by two master students and not by the author herself. Consequently, the author of this study did not have the possibility of asking the partners upcoming questions herself but was restricted to the interview data that was already gathered. Questions that the author would have liked to asked were related to things that the partners do for themselves and to the sources from which the partners get the energy for coping and supporting their spouse. Some of the answers of the partners were quite short and as there was no possibility to ask further questions it has to be taken into account that some details of the partner's perception might not have been considered. Moreover, a questionnaire assessing the well-being of the partners could have provided important insight into the perspective of the partner. Therefore, a suggestion for future research would be to integrate such a questionnaire and the questions mentioned above in the interview scheme of

follow up research. It has to be kept in mind that some of the respondents related their answers to social support when asked about their way of coping. This could have given a distorted image of their perspective, however, the author tried to analyze their answers by means of the context. That the conducted analysis was reliable, was confirmed by the percent agreement of 77, 5 %, which was more precisely described in the method section.

Additionally, the fact that coping was sometimes confused with giving support gives rise to the author's assumption that some of the partners were not even explicitly aware of the meaning of coping and the fact that doing things for themselves is essential for being able to support the spouse in the long run. This assumption is also underlined by literature (Barbosa et al., 2011) which was already described above.

Furthermore, the sample characteristics could be subject to some criticism. With nine respondents that were collected at the World Lupus Day-congress, the study sample could be described as small and self-selected. Participants differed from individuals not included in the study in the following characteristics: they actively searched for information about the disease, their spouse experienced severe fatigue but was not too tired to visit the Lupus World Day-congress, and their spouse had SLE. Therefore, the results can neither be generalized to the whole SLE population, nor to other chronic illnesses. Since this study was however qualitative, it did not aim at finding generalizable results, but at giving insight into the perspective on SLE related fatigue of a specific population: the partners of the people suffering from SLE related fatigue.

The results of this study do not only have implications for future research but also for interventions in the primary health care sector. Regarding the research sector, future research should further investigate the partners' reasons for their unacceptance of SLE related fatigue in order to help the partners with accepting their spouse's fatigue and therefore enable them to better cope with it. This would shed more light on possibilities of the primary health care sector of how to enhance the partners' acceptance of their spouse's SLE related fatigue. Ideas about how to enhance the partners' adjustment to his/her spouses fatigue could be based on the findings of Arends et al. (2013). Since they emphasized the beneficial effects of strategies like "adjusting goals to circumstances" and "striving new goals" (Arends et al., 2013), interventions targeted at the partner and his/her implementation of those beneficial strategies could be helpful. Furthermore, the relationship between acceptance, coping and social support could be investigated more deeply. On top of that, it should be more deeply explored whether interventions directed at the implementation of effective coping strategies and adequate types

of social support could increase the partners' acceptance of their spouse's fatigue or if this might function vice versa. Moreover, it might be interesting to further explore the differences between the partners who succeeded and the ones who did not succeed in accepting the spouse's fatigue and in being satisfied with their coping and giving social support. In this context, future research could investigate whether personality traits such as Extraversion, Neuroticism or Openness have a strong influence on accepting the spouse's SLE related fatigue. This relation is assumed since prior studies (David & Suls, 1999) found that individual differences in personality were related to the use of coping strategies and the results of this study revealed that both partners who could not accept their spouse's fatigue seemed inflexible in contrast to the other partners. Therefore, it could be assumed that personality traits such as Openness also have an influence on the partners' coping and acceptance of their spouse's SLE related fatigue.

Furthermore, information campaigns could be designed in order to address the lack of understanding from others with that the partners felt confronted. Regarding the costs and the low incidence of the disease it might be most efficient to target those information campaigns at the close environment of those affected, for example via brochures that contain the most important facts about SLE and the impact of the severe fatigue.

With regard to the immense impact of SLE related fatigue on the partners' life, interventions should be designed in which the partners' well-being is central. Prior studies (Diehl, Mayer, Förstl & Kurz, 2003) emphasized the effectiveness of group programs for caregivers since sharing their experiences and needs was associated with a feeling of relief, the establishment of new social contacts and the learning experience of new coping strategies. Consequently, interventions targeted at the partners of patients with SLE should be designed as group program. Regarding the low incidence of SLE it might be hard to find a suited location for group programs for the partners. The author therefore suggests health care providers to search for ways of successfully realizing those group programs via internet, for example via conferences on skype. In general, the author of this study joins the call of other researchers (Sawatzky & Fowler-Kerry, 2003) for involving caregivers in the development and implementation of policies that give them a voice and consider their needs.

## 5. References

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## **6. Appendices**

### **A - Interview scheme of Linda Hoek's interviews with the partners**

#### Deel 2 Omgang met de vermoeidheid van partner en bieden van sociale steun

- Dan komen we nu aan bij het tweede deel van het interview. Bij de vorige vragen ging het om de invloed van vermoeidheid van uw partner op uw leven. Bij de volgende vragen gaat het over hoe u zelf invloed heeft op vermoeidheid van uw partner en hoe u daar mee omgaat.

1. Zijn er situaties waar u het idee heeft uw partner goed te kunnen ondersteunen wanneer zij vermoeidheid ervaart?

- voorbeelden
- invloed van partner op vermoeidheid, preventief of actief
- coping strategieën, probleemgericht (actief) / emotiegericht (passief)
- de gegeven sociale steun (emotioneel, instrumenteel, informatieel...)

2. Zijn er situaties waar u het idee heeft niet of minder goed uw partner te kunnen ondersteunen wanneer zij vermoeidheid ervaart?

- voorbeelden
- coping strategieën, probleemgericht (actief) / emotiegericht (passief)
- de gegeven sociale steun (emotioneel, instrumenteel, informatieel...)

3. Hoe heeft u leren of leert u omgaan met de vermoeidheid van uw partner?

- momenten van kracht en momenten van zwakte
- acceptatie van vermoeidheid
- vermoeidheid plaats geven in leven

- veranderde relatie tot de partner met systemische auto-immuunziekte
- rol van naasten (sociale steun)

4. Bent u tevreden met de manier hoe u met de vermoeidheid van uw partner omgaat?

- acceptatie van vermoeidheid
- coping strategieën, probleemgericht (actief) / emotiegericht (passief)

- Ik heb nu alles gevraagd wat ik graag wil weten voor het onderzoek, dus we zijn aan het einde van het interview gekomen. Heeft u nog vragen of opmerkingen over het interview of het onderzoek? (...)

- Dan zal ik nu de opname stil zetten.

- Dan ga ik het interview uittypen en analyseren, samen met de interviews van uw partner en die van de andere deelnemers aan het onderzoek. Als u interesse heeft, kan ik de resultaten van het onderzoek per mail naar u toe sturen?

- Als laatste wil ik u van harte danken voor uw openheid over de besproken onderwerpen. Ik kan me voorstellen dat het niet altijd even makkelijk is om hier over te praten, daarom wil ik u laten weten dat ik uw deelname ontzettend op prijs stel.

**B – Code scheme**

Research questions	Interview questions	Codescheme	Problems
<p>Which coping strategies do partners report with regard to their spouses' SLE related fatigue?</p>	<p>-Hoe heeft u leren of leert u omgaan met de vermoeidheid van uw partner?</p>	<p><b>coping strategies:</b></p> <ul style="list-style-type: none"> <li>-<b>appraisal focused coping:</b></li> <li>-<b>distancing:</b> regarding illness as belonging to the partner, trust in patients ability when to rest</li> <li>-<b>denial:</b> learned to deny it and think about other things</li> <li>-relativizing</li> <li>- having patience</li>   <li>- <b>problem focused coping :</b></li> <li>-taking fatigue into account/observing situation and adapt</li> <li>-using common sense</li> <li>- making the best out of it</li> <li>-relenting</li> <li>-rearranging tasks</li>   <li>- <b>emotion focused coping :</b></li> <li>-<b>accepting responsibility/blame:</b> just having to accept it</li> <li>-self-control</li> <li>-doing nice things alone</li> <li>-talking with others who also know the problem</li>   <li>-<b>general procedure:</b></li> <li>-process of gradually growing in</li> <li>- finding a way that fits</li> <li>- easily switching the gear</li> </ul>	
<p>Do partners experience difficulties with accepting their spouses' SLE related fatigue?</p>	<p>-Hoe heeft u leren of leert u omgaan met de vermoeidheid van uw partner?</p> <p>-Dus is er acceptatie?</p>	<p><b>acceptance of fatigue:</b></p> <ul style="list-style-type: none"> <li>-<b>acceptance of fatigue</b></li> <li>-<b>reasons:</b></li> <li>-no other way</li> <li>-choice of common path through life</li> <li>- it's going well</li> <li>-giving fatigue a place in the relationship</li>   <li>-acceptance of fatigue but difficulties with constraints/problems:</li> <li>-switching if you're plans have</li> </ul>	

		<p>changed</p> <ul style="list-style-type: none"> <li>-going out on parties</li> <li>-riding the bike</li> <li>-long-term planning</li> <li>-unpredictable future</li> </ul> <p><b>-non-acceptance</b></p> <p><b>-reasons:</b></p> <ul style="list-style-type: none"> <li>-sometime moments of grief because of difficulties</li> <li>-struggle with fatigue</li> <li>-impairs way of living</li> <li>-plans can't be realised</li> </ul>	
How satisfied are partners with their way of coping regarding their spouses' SLE related fatigue?	-Bent u tevreden met de manier hoe u met de vermoeidheid van uw partner omgaat?	<p><b>satisfaction with coping:</b></p> <p><b>-satisfied</b></p> <p><b>-reasons:</b></p> <ul style="list-style-type: none"> <li>-related to acceptance</li> <li>-it's going well</li> <li>-easy to adapt</li> </ul> <p><b>-unsatisfied</b></p> <p><b>-reasons:</b></p> <ul style="list-style-type: none"> <li>-unpredictable change of symptoms</li> <li>-could be better</li> <li>-should talk more with others</li> <li>-lack of understanding from others</li> <li>-unjustified anger</li> </ul>	related to acceptance, sometimes impression that partners confused coping with giving social support
Which feelings do partners report with regard to their spouses' SLE related fatigue?	-all questions	<p><b>feelings:</b></p> <p><b>-positive feelings</b></p> <ul style="list-style-type: none"> <li>-admiration of spouse's coping</li> <li>-gratefulness for talks with other affected people</li> </ul> <p><b>-negative feelings:</b></p> <ul style="list-style-type: none"> <li>-sadness</li> <li><b>-fear:</b> of future, of change of role into that of caregiver, uncertainty about impact on relationship</li> <li><b>-frustration:</b> due to lack of healing, constant presence, struggle with whole situation, plans that can't be realized</li> <li><b>-anger:</b> swearing about illness</li> </ul>	

<p>Which type of social support do the partners offer?</p>	<p>-Zijn er situaties waar u het idee heeft uw partner goed te kunnen ondersteunen wanneer zij vermoeidheid ervaart?</p>	<p><b>social support:</b></p> <ul style="list-style-type: none"> <li>-<b>emotional/esteem</b></li> <li>-mutual understanding</li> <li>-stand by spouse with love</li> <li>-giving extra attention</li> <li>- concern</li> <li>- caring</li> <li>-empathy</li> </ul> <p><b>instrumental/tangible</b></p> <ul style="list-style-type: none"> <li>-<b>taking over tasks:</b></li> <li>- household duties</li> <li>- help at work</li> <li>- earn a living</li> <li>- doing tasks together</li> </ul> <p><b>-informational</b></p> <ul style="list-style-type: none"> <li>-<b>advising/guiding:</b></li> <li>-gather information about illness and fatigue on website</li> <li>- gather information via the doctor</li> <li>- advising</li> </ul> <p><b>-companionship/belonging: - doing things together:</b></p> <ul style="list-style-type: none"> <li>-providing alternation</li> <li>- mutual stimulation to stay active</li> </ul> <p><b>problematic social support:</b></p> <ul style="list-style-type: none"> <li>-<b>denying/uninformed:</b></li> <li>-lack of understanding: no realization of severity</li> <li>-<b>oppressive:</b></li> <li>-taking over more tasks than patient wants</li> <li>- persuading partner to stop fulfilling tasks</li> </ul>	
<p>How satisfied are partners with their way of giving support?</p>	<p>-Bent u tevreden met de manier hoe u met de vermoeidheid van uw partner omgaat?</p> <p>-Zijn er situaties waar</p>	<p><b>satisfaction with social support:</b></p> <ul style="list-style-type: none"> <li>-<b>satisfied</b></li> <li>-<b>reason:</b></li> <li>- it's going well</li> <li>-easy to adapt</li> </ul>	<p>-interview question related to coping and not to social support but</p>

	<p>u het idee heeft uw partner niet of minder goed te kunnen ondersteunen wanneer zij vermoeidheid ervaart?</p>	<ul style="list-style-type: none"> <li>- otherwise it's going worse</li> <li>- partner tries to hide severity</li> <li>- no situation where partner can't support</li> <li>-<b>exception</b>: feeling that patient expects more support, earlier distribution of tasks stayed, no concrete request for help</li>   <li>-<b>unsatisfied</b></li> <li>-<b>reasons</b>: <ul style="list-style-type: none"> <li>-could be better</li> <li>-doubts about spouse's acceptance of more help/no precise idea of how acceptance of support could grow</li> </ul> </li> <li>-<b>situation where partner can't support</b>: difficult to combine support and work, difficult when she cries and partner is angry, no support in tasks that only patient can do</li> </ul>	<p>partners often relate question to support</p>
<p>Other (relevant for research question but not fitting into categories) only named once</p>			<p>I tried to assign' Other' to related topics and mentioned in results that only one partner reported it</p>