Living with fatigue: how patients with Systemic Lupus Erythematosus describe and evaluate their way of coping with fatigue

Master thesis Health Psychology

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Abstract

Systemic lupus erythematosus (SLE) is a chronic, inflammatory, systemic autoimmune disease that can affect multiple organs and tissues. Of the symptoms related to this chronic disease, fatigue is often described as the most enduring and crippling. The impact of fatigue on patients has been extensively explored in the literature. However, the impact patients may have on their fatigue is scarcely examined. The aim of this study was thus to explore from a patient perspective, how patients with SLE live with and possibly influence and manage their fatigue.

Data for this study was collected using a qualitative cross-sectional research design. Participants for this study were recruited at a national congress in the Netherlands for patients with systemic autoimmune diseases. Inclusion criteria were: a diagnoses of Systemic Lupus Erythematosus (SLE) or a similar systemic autoimmune disease and experiencing severe disease related fatigue. This study contained 20 participants (19 female; 1 male). The patients were interviewed using a semi-structured interview scheme. The patients were asked to describe their way of coping with fatigue and how they evaluated their way of coping. All interviews were transcribed verbatim and themes and codes were identified through inductive and deductive coding.

SLE related fatigue is characterized by patients as an always present, crippling and fluctuating fatigue. In comparison to ordinary fatigue, SLE related fatigue is said to be more extreme. Fatigue causes patients to adapt their lifestyle to a slower pace, where rest, pausing, and making choices of what to do and when to do things is daily dilemma. Three general coping strategies were distinguished: one where patients choose to approach their fatigue with a fighting stance, a second where patients give in to the fatigue and a third where patients have an attitude which is a combination of these two positions. The patients in this study possess a broad range of coping tactics: resting and pausing, planning, dosing and prioritising activities, searching information, altering hobbies or adopting a healthy lifestyle and seeking practical help from their partner or social environment.

This study shows that the most effective coping strategy involves an attitude where patients find a balance between taking in account fatigue to the extent they still maintain physical functioning, the capability to perform activities and the ability to make choices of personal importance. SLE patients have acquired and utilize a wide range of problem-focused, emotion-focused an future orientated coping tactics to influence and manage their fatigue. The influence of patients on their fatigue seems to be marginal, only affecting if an how much their fatigue level rises. Future research should focus on examining which coping strategies and particularly tactics constitute adequate coping, as measured on psychological distress, physical health status, experienced fatigue and overall quality of life.

Samenvatting

Systemische lupus erythematosus (SLE) is een chronische, systemische auto-immuunziekte dat verscheidene organen en weefsels aan kan tasten. Van alle symptomen van deze chronische ziekte is vermoeidheid de meest aanwezige en beperkende. De impact van die vermoeidheid heeft op patiënten is veelvuldig onderzocht in de literatuur. Het effect dat patiënten op vermoeidheid kunnen hebben is nauwelijks onderzocht. Het doel van deze studie is te exploreren, door middel van het patiënt perspectief, hoe patiënten leren leven met en mogelijk hun vermoeidheid beïnvloeden en managen.

Data voor deze studie is verzameld door middel van een kwalitatief cross-sectioneel onderzoek. Participanten voor deze studie werden geworven op een nationaal congres voor patiënten met een systemische auto-immuunziekte. Inclusiecriteria bestonden uit de diagnose SLE of een andere systemische auto-immuunziekte en de ervaring van hevige vermoeidheid. In deze studie waren er 20 participanten (19 vrouw; 1 man). Deze patiënten werden geïnterviewd naar de wijze waarop zij omgaan (coping) met vermoeidheid, aan de hand van een semigestructureerd interviewschema. Alle interviews werden verbatim uitgeschreven en aan de hand van inductieve en deductieve codering werden er thema’s en codes geïdentificeerd.

SLE gerelateerde vermoeidheid wordt door patiënten omschreven als een altijd aanwezige, beperkende en fluctuerende vermoeidheid. Verder wordt de vermoeidheid als gevolg van SLE als meer extreem ervaren dan gewone vermoeidheid. Vermoeidheid leidt ertoe dat patiënten een langzamere leefstijl aannemen, waar rust, pauzes en het maken van keuzes wat en wanneer iets te doen elke dag opnieuw een vraag is. Drie algemene coping strategieën kunnen worden onderscheiden: het aannemen van een vechthouding jegens vermoeidheid, toegeven en zich niet meer verzetten tegen vermoeidheid en het zoeken van een attitude tussen deze twee posities in. De patiënten beschikken over een ruime hoeveelheid coping vaardigheden: rusten en pauzeren, plannen, doseren en prioriteiten stellen, informatie zoeken, hobby’s en leefstijl aanpassen en het zoeken van praktische hulp van de partner of de sociale omgeving.

Deze studie laat zien dat de meest effectieve coping strategie bestaat uit een attitude waarin er een balans wordt gezocht tussen het toegeven aan vermoeidheid, in zoverre men fysiek functioneren, het uitvoeren van activiteiten en het maken van belangrijke keuzes behoudt. SLE patiënten maken gebruik van een grote verscheidenheid aan probleemgerichte, emotie-gerichte en toekomstgerichte coping tactieken om hun vermoeidheid te beïnvloeden en managen. Deze invloed is slechts gering en gaat niet verder dan het bepalen of en in hoeverre vermoeidheid toeneemt. Toekomstig onderzoek zou zich moeten richten op het bepalen welke coping strategieën en in het bijzonder coping tactieken bijdragen aan adequate coping, zoals gemeten op psychische stress, fysieke gezondheidstoestand, ervaren vermoeidheid en algemene kwaliteit van leven.

1. Introduction

Systemic lupus erythematosus (SLE) is a chronic, inflammatory, systemic autoimmune disease that can affect multiple organs and tissues or the body as a whole (Gordon, Li & Isenberg, 2010). SLE is considered a rheumatic disease, of which rheumatoid arthritis (RA) is the most common and well known illness, but which also encompasses Sjögren's syndrome, mixed connective tissue disease (MCTD), among others (Cooper & Stroehla, 2003; Hooijkaas, Smeenk & Gmelig Meyling, 2006).

Estimates on the incidence of SLE in western countries range from approximately 1 to 10 per 100.000 person-years and the prevalence of SLE is estimated to range from 20 to 70 per 100.000 (Pons-Estel, Alarcón, Scofield, Reinlib & Cooper, 2010). Characteristic of SLE is the high incidence among females; 9 out of 10 patients with SLE are female (Cervera et al., 2014; Cooper & Stroehla, 2002; Ngo, Steyn & McCombe, 2014; See, Kuo, Chou, Chiou & Yu, 2013). This gender difference may indicate the role of hormones in the aetiology of the disease (Hooijkaas et al., 2006). SLE manifests itself generally in women at childbearing age; between the ages of 15 and 40 years (Cooper & Stroehla, 2003; See et al., 2013; Sutanto et al., 2013).

The immune system of patients with SLE fails to properly distinguish between the body's own cells and tissues and foreign microorganisms that might cause a disease (pathogens) (Hu & Deng, 2014). This failure results in the production of white blood cells (lymphocytes) and antibodies to target the body's own cells and tissues, resulting in cell and tissue damage and often causing inflammation in the process (Gordon et al., 2010; Hooijkaas, Smeenk & Gmelig Meyling, 2006). SLE is known for its wide variety of manifestations (Doria, Gatto, Zen, Iaccarino & Punzi, 2014; Pons-Estel et al., 2008; Ramsey-Goldman & Rothrock, 2010). As a result, SLE is often accompanied with many divergent symptoms, such as: pain, fever, malaise, painful or painless mouth ulcers, diffuse alopecia (hair loss), butterfly rash and photosensitivity (Gordon et al., 2010; Ramsey-Goldman & Rothrock, 2010; Schmeding & Schneider, 2013). Disease activity in SLE is known to change over time, alternating between more active periods of inflammation and less active periods of remission and quiescence (Cervera et al., 2014; Doria et al., 2014; Mosca, Ruiz-Irastorza, Khamastha & Hughes, 2001; Nutall & Isenberg, 2013). Some patients are reported to have multiple alternating periods of either inflammation or remission, where other patients have a more stable disease pattern (Doria et al., 2014). The fluctuation of disease activity influences the experience of symptoms in different SLE patients. One of the most prominent and debilitating symptoms of SLE is fatigue (Burgos, Alarcón, McGwin, Crews, Reveille, & Vilá, 2009; Chehab, Carnarius & Schneider, 2014; Da Costa et al., 2006; Dupond, 2010; Gordon et al., 2010; Ramsey-Goldman & Rothrock, 2010).

The fatigue experienced by SLE patients is different from ordinary fatigue and for many a cause of stress. The fatigue associated with the disease is a persisting and distressing physical and mental exhaustion, which is unrelated to recent activity, hindering the person's functioning (Lukkahatai & Saligan, 2013). Fatigue affects between 60 to 90% of SLE patients and is considered one of the main complaints; the majority of the patients with fatigue describe this symptom as severe or very severe (Dupond, 2010). The fatigue is often associated with disease activity, depression, pain, sleep disturbances and feelings of helplessness (Da Costa et al., 2006; Dobkin et al., 2001; Ramsey-Goldman & Rothrock, 2010; Schmeding & Schneider, 2013; Tayer, Nicassio, Weisman, Schuman, & Daly, 2001). The fatigue has a major influence on the patients' quality of life; affecting both physical and mental health (Chehab et al., 2014; Schmeding & Schneider, 2013; Sutanto et al., 2013). In a Dutch qualitative study among 29 patients with rheumatoid arthritis – fatigue is also a common symptom in other systemic autoimmune diseases – fatigue was described as influencing daily life, especially relationships, work, leisure and household activities (Repping-Wuts, Uitterhoeve, Van Riel & Van Achterberg, 2008). In short, fatigue was described in that study as a physical everyday experience with a variety in duration and intensity. The study of Repping-Wuts and colleagues (2008) supports findings of an earlier and similar study performed in the United Kingdom (Hewlett et al., 2005), which also pointed out that fatigue takes a toll on the ability to perform social roles and that it has a negative influence on self-esteem. Unlike other symptoms, fatigue is rarely a topic discussed with a health professional (Hewlett et al., 2005). Dupond (2010) notes that the complexity of the mechanisms that may lead to fatigue and the lack of a clear meaning when a patient reports fatigue may contribute to fatigue being dismissed by health professionals. Fatigue is often idiopathic (Balsamo & Dos Santos-Neto, 2011), and is as a result difficult to treat and impossible to measure clinically (Burgos et al., 2009).

Since fatigue is such a prominent symptom in SLE and is for many patients a source of stress, it is essential that patients learn to cope with and possibly influence the fatigue. Coping is a construct which can be described in terms of styles, strategies, tactics, cognitions, behaviours and resources (De Ridder & Schreurs, 2001; Schwarzer & Schwarzer, 1996). Coping is defined as the cognitive and behavioural efforts of an individual to manage stress (Stone, Kennedy-Moore, Newman, Greenberg & Neale, 1992). Lazarus (1991) defined stress as the "specific external or internal demands (and conflicts between them) that are appraised as taxing or exceeding the resources of the person" (p. 112). Coping is comprised as a process of appraising a situation as stressful, which motivates coping efforts and may change the stressful situation, leading to reappraisal (Stone et al., 1992). Essential for the use of coping strategies is the belief in effectively coping with the stressful situation (self-efficacy) (Hanley, as cited in Kozora et al., 2005). Self-efficacy refers to the person's belief about the degree to which they are able to behave in a certain way (efficacy expectations) and the belief that this behaviour results in a certain outcome (outcome expectations) (Bandura, 1977). Lowe and colleagues (2008) have shown that self-efficacy moderates the relationship between coping and emotion outcomes. High efficacy expectations of certain coping strategies make these strategies more likely to be enacted. Furthermore, patients' beliefs of their ability to control their disease (locus of control) seem to alter the way they experience the chronicity and acuity of their illness and the frequency of flare-ups and symptoms (Auerbach & Beckerman, 2012).

Since the number of coping responses to stress is endless, researchers have tried to conceptualize coping in basic styles or dimensions (Schwarzer & Schwarzer, 1996). Well-known is the classification by Lazarus and Folkman (1984), who suggested two types of coping: problem-focused or emotion-focused. The former aims to remove or reduce the cause of stress while the latter aims to reduce negative emotions associated with stress. Miller (1987) proposed a basic dimension of attentional style, where an individual either tunes in or out from information regarding the stressful situation. Monitoring is a vigilant attentional style, while an avoiding attentional style was named blunting by Miller (1987). Rothbaum, Weisz and Snyder (1982) suggested two types of control concerning coping. Primary control is the alteration of the environment to oneself, while secondary control is the alteration of oneself to the environment. The authors note that secondary control is most likely to occur after failed attempts of primary control. A decade later, Brandtstädter (1992) proposed two modes of coping: assimilative and accommodative coping. Individuals either try to actively change the situation so it conforms to personal goals or, when such efforts are proven ineffective, individuals may rescale their goals to situational constraints. Unlike Rothbaum et al. (1982), Brandtstädter and Rothermund (2002) do not assume rescaling goals to situational constraints (i.e. accommodative coping) is deliberately used as a means to maintain a sense of control. Goals give meaning and structure to our lives; the discrepancy between the current and an ideal or desired situation motivates people to attain their goal through assimilative processes. When goals remain out of reach, they give rise to helplessness and depression and may set in motion accommodative processes like disengagement of blocked goals, reorientation to new or adapted goals or a positive reappraisal of the status quo (Brandtstädter, 2009). Coping can also be regarded in terms of reactions to stressful events that have occurred in the past (reactive coping) or taking action in advance of stressful events that might occur in the future (proactive coping and anticipatory coping). According to Aspinwall & Taylor (1997), anticipatory coping is characterized by preparation for the occurrence of likely events in the near future. Proactive coping efforts occur prior to anticipatory and reactive coping, as they are not directed to a particular event. Both proactive and anticipatory coping are future-orientated and involve preliminary coping efforts to mute the impact of a stressful event or averting a stressful event from happening.

Coping with fatigue can be achieved by employing one or multiple coping strategies. Problem-focused coping is generally regarded as the most adaptive form of coping and has the most positive effects on reducing fatigue (Dobkin et al., 2001; Kozora, Ellison, Waxmonsky, Wamboldt & Patterson, 2005; McCracken, Semenchuck & Goetsch, 1995; Oliveira, Avelino, Paixão, Agostinho, Jara & Bento, 2013; Savelkoul, Post, De Witte & Van Den Borne, 1999). Emotion-focused coping is mostly viewed as an maladaptive form of coping during inactive disease (Kozora et al., 2005). However, it is suggested that emotion-focused coping may result in better physical health during active disease (Dobkin et al., 2001). Disease activity may hinder or even prevent patients to employ problem-focused coping strategies, thus making them rely more on emotion-focused coping and other coping strategies to deal with fatigue (Dobkin et al., 2001). In a Canadian study by Dobkin and colleagues (2001), it was found that the majority of the 120 SLE patients included in that study had found a way of adapting to the fatigue over a period of 15 months. Noteworthy is the decrease of emotion-focused coping (e.g. self-blaming, daydreaming) of the subjects in that study, indicating that patients could have learned that these are inadequate coping responses to fatigue. In a Dutch study concerning management strategies, goal readjustment and striving to attain goals were better strategies in adapting to a life with polyarthritis – a disease with roughly similar symptoms to those found in SLE – than goal disengagement or striving for alternative goals (Arends, Bode, Taal, Van De Laan, 2013). McCracken, Semenchuck & Goetsch (1995) stated that passive coping strategies (e.g. avoidance, self-blaming or wishful thinking) were associated with higher depression as well as physical and social disabilities and may lead to less social support. According to the literature, coping with fatigue encompasses accepting physical limitations, adopting a healthy lifestyle and maintaining a positive attitude, amongst other things (Sutanto et al., 2013). Some studies also emphasize the importance of physical activity in managing fatigue, because SLE patients often have an overall reduced physical fitness – lower cardiovascular capacity and muscle strength – when compared to women without SLE (Balsamo & Dos Santos-Neto, 2011; Burgos et al., 2009).

Coping is generally described in the literature as adequate in SLE when it positively affects parameters like fatigue, pain, depression or physical functioning as assessed in routine clinical outcome measurement (e.g. Burgos et al., 2009; Dobkin et al., 2001; Kozora et al., 2005). However, few studies regarding effectively coping with fatigue have taken in account the point of view of the patients themselves. The question what patients themselves consider adequate coping with their fatigue is rarely answered in the above mentioned studies. And although there have been a number of studies regarding the patient perspective on fatigue in SLE (for an overview, see Sutanto et al., 2013) and rheumatoid arthritis (e.g. Hewlett et al., 2005; Repping-Wuts et al., 2008), most of these studies have solely focused on the reported impact the systemic autoimmune disease and fatigue have on the lives of the patients. The influence patients could have on fatigue is less extensively explored in the literature. It is therefore interesting to explore how patients describe the way they live with and possible influence and manage their fatigue. Qualitative research enables the exploration of the patients' perspective on fatigue: the experiences and beliefs patients have regarding coping with their fatigue. This qualitative study aimed to explore and describe the way SLE patients in the Netherlands cope with their fatigue; to learn more about the coping strategies and tactics they have acquired, adopted and employ in their daily lives. The perspective of a patient is paramount in understanding fatigue, which is a highly subjective and still poorly understood symptom (Dupond, 2010). Furthermore, these findings were put in perspective of the theoretical framework of Brandtstädter (1982; 2009) on accommodative and assimilative coping and the theoretical approach of Aspinwall and Taylor (1997) on reactive, anticipatory coping and proactive. The literature pointed out that patients often keep struggling with their fatigue and that it affects many spheres of life (e.g. Hewlett et al., 2005; Repping-Wuts et al., 2008), hence the use of the theory of Brandtstädter was found appropriate; patients may experience their fatigue as a serious constraint in achieving personal goals, which in turn may result in a shift from assimilative to accommodative processes. Since fatigue is such a prominent and enduring symptom that may vary in duration and intensity (Repping-Wuts et al., 2008), it is of importance to look at how patients react in advance of times of prolonged and more intense fatigue, in addition to how they react to fatigue in general. This study tried two answer the following two research questions: How do patients describe their own way of coping with SLE associated fatigue? And how do patients evaluate their own way of coping?

2. Methods

2.1 Participants & Procedure

Twenty-five Dutch patients diagnosed with SLE or/and another systemic autoimmune disease (24 women, 1 man, M_{age} = 52.92 years, age range: 26-71 years), who reported experiencing disease related fatigue and found willing to voluntarily participate in this study, were recruited at the congress on May 10 2014 of the World Lupus Day 2014 (*Wereld Lupus Dag 2014*) in Ede (The Netherlands). Patients diagnosed with a systemic autoimmune disease other than SLE were also included into this study, as fatigue is a common complaint in many systemic autoimmune diseases (Chehab, Carnarius & Schneider, 2014), such as in rheumatic arthritis (Hewlett et al., 2005; Repping-Wuts et al., 2008; Ramsey-Goldman & Rothrock, 2010) and Sjögren syndrome (Fox, 2005). The inclusion criteria were: a diagnosis of a systemic autoimmune disease, such as: systemic lupus erythematosus (SLE) and/or subacute cutaneous lupus erythematosus (SCLE), Sjögren's syndrome, antiphospholipid syndrome (APS), mixed connective tissue disease (MCTD) or scleroderma; experiencing fatigue; being ≥18 years of age; willingness to participate in the study. The participants gave their contact information and other necessary information (name, e-mail address, phone number, place of residence, their diagnosed systemic autoimmune disease(s) and age), so they could be contacted for scheduling an interview at a later moment. In the months June and July 2014, the patients were contacted – either by e-mail, phone or both – for making an arrangement for conducting the interview. The interviews were held in the same time period (June and July 2014). The interviews were conducted by two interviewers (MB and LH); each interviewer separately interviewed half of the participants. All interviews were conducted at the homes of the participants. Participants were offered to come to the University of Twente to be interviewed, but all participants preferred to be interviewed at their residence. Prior to the interview, the participants signed an 'informed consent' form (Appendix A) in which they confirmed that they were informed of the research subject and its procedure.

The sample was used for the collection of data for two separate, yet related studies. The other study for which the interviews provided data aimed on describing the impact of fatigue on the quality of life of SLE patients and their partners. Because of this other study, eleven patients (10 women, 1 man, Mage = 55.27 years, age range: 32-71 years) indicated their partners were also willing to participate as part of the other study. Of the initial 25 patients and 11 partners recruited, 5 patients and 1 partner were not interviewed, because they either declined to further participate in the study at a later moment or the interviewers did not succeed in contacting them or making an arrangement for an interview. Eventually, 20 patients (80%) and 10 partners (91%) were interviewed for this study. Table 1 shows an overview of the demographics of the 20 patients. The sample consisted of a varied group of patients regarding age, education level and employment. Systemic Lupus Erythematosus is a disease that affects more females than men, which explains why there was just one male patient participating in this study, along 19 female patients.

The study proposal was presented to the Ethics Committee of the University of Twente (Enschede). The proposal was approved. The study proposal was not presented to a Medical Ethics Committee (METC), as the study did not affect medical treatment, nor was the study considered burdensome to the participants.

Table 1.

Demographic Characteristics of Participants (N = 20)

	n	**%**
Systemic autoimmune disease(s)		
SLE	13	65
SLE, Sjögren's syndrome and Hashimoto thyroiditis	2	10
SLE and Sjögren's syndrome	1	5
SLE, scleroderma and myositis	1	5
SLE and APS	1	5
APS	1	5
MCTD	1	5
Gender		
Female	19	95
Male	1	5
Age		
30-39	3	15
40-49	2	10
50-59	7	35
60-69	7	35
70+	1	5
Education*		
Lower	7	35
Middle	5	25
Higher	7	35
Unknown	1	5
Employment		
Fulltime	2	10
Part-time	4	20
Disabled	7	35
Retired	5	25
Homemaker	2	10
Marital status		
No partner (e.g. single, divorced, widowed)	5	25
Partner (e.g. in a relationship, engaged, married)	15	75
Children		
No children	4	20
Living in parental home	3	15
Living separate from parental home	9	45
Living both in parental home and separate	4	20

*Lower: Elementary school;
Middle: Vocational Education/High School;
Higher: College/University

2.2 Materials

The Fatigue Severity Scale (FFS) (Appendix B) was used, preceding the interview. This instrument was used to measure the fatigue, as to distinguish between patients with a less or more severe fatigue. An Ad Hoc Committee on Systemic Lupus Erythematosus Response Criteria for Fatigue (2007) has reviewed the FSS, recommending its use to measure fatigue in SLE. A translated (Dutch) version of the FSS was used in this study. The FSS consists of nine items, measuring fatigue on specific types of functioning in the past two weeks. For example, items include how easily one is fatigued, if fatigue is among the three most disabling symptoms and if fatigue interferes with certain tasks and responsibilities. The instrument uses a 7 point Likert scale. Each item is scored from 1 (strongly disagree) to 7 (strongly agree). A mean score is calculated based on all items to determine the extent wherein the patient is experiencing fatigue. A mean score of < 4 is considered normal. A mean score of ≥ 4 means the fatigue is more severe. This score was used to examine if a participant has severe disease related fatigue (score of at least 4). A summary of the FSS scores as expressed by the patients are presented in table 2. It is clear the majority of the patients experience severe fatigue. Only two patients reported experiencing less fatigue. One such patient said she did not want to concede to the fatigue, explaining her lower mean score.

A short questionnaire was used to gain demographic information of the participant (Appendix C), to further relate findings in the interviews. This questionnaire consisted of seven questions, asking the participant about their gender, age, highest education level attained, employment, the duration of the relationship with their partner and if the participant has children, either living in or away from the parental home. An overview of the demographic information of the patients that participated in the study are presented in table 1.

Table 2.

Fatigue Severity Scale (FSS) mean scores (N = 20)

Mean score range	*Number of patients with mean score*	
1,0-1,9		
2,0-2,9		
3,0-3,9	2	
4,0-4,9	2	*severe fatigue >4*
5,0-5,9	13	
6,0-6,9	3	
7,0		

2.3 Interviews

Participants participated in a semi-structured individual interview. Prior to the interview, participants were asked if they had reservations against the interview being audiotaped. Participants were told that the audio-tape would be used to transcribe the interviews, and would help the researchers during the interview and in the analysing process afterwards. They were reminded about the anonymity of the findings. The participants were informed about the goal of the study and that they could not give false answers; the purpose of the study was to hear their story, ideas and opinion toward coping with fatigue. Furthermore, the participants were told they were free to interrupt the interview or end it prematurely if they wanted to. The interviewers used an interview protocol, consisting of a list of questions and topics to structure the interview (see table 3 for a translated interview schedule or table D1 in appendix D for the original Dutch version). The first four questions of the interview were focused on the impact of fatigue on certain life-domains (e.g. emotions, personality, daily activities, work, leisure activities) of the patient. These questions are primarily relevant for the other study for which the interviews also provided data. The last three questions of the interview were focused on the patients' idea of being able to cope with and influence their fatigue. Especially, but not exclusively, those latter questions resulted in much of the data for use in this study. At the end of the interview there was the opportunity for additional comments.

The first interview of both interviewers was used as a pilot and resulted in slight adjustments and minor additions to the questions and topics of the interview protocol. The piloted interviews were used in the analyses, as there were only slight adjustments to the interview protocol. The interviews duration ranged from 25 minutes to 90 minutes, while most interviews lasted around 45 minutes. All interviews were conducted successfully. One interview was found to be less useful afterwards, since the participant was unwilling or unable to keep focused and her responses were mainly focused on other topics. Also, only a few questions on the impact of the fatigue were asked, resulting in a marginal amount of data, hence this particular interview is excluded from the analysis.

Table 3.

Translated interview schedule

1. Can you describe the way you experience your fatigue?
2. Do you experience fatigue as invariable?
3. What does fatigue mean to you?
4. Can you tell me how fatigue influences your life?
   a. Emotional impact; Personality; Cognitive impact; Daily activities; Leisure time, social contacts and family; Work/Employment
5. Do you think you have influence on your fatigue?
   a. Activities which have a negative effect on fatigue
   b. Activities which have a neutral or positive effect on fatigue
6. How do you learn or have you learned to live with your fatigue?
7. How do you evaluate the way you manage your fatigue?

2.4 Data analyses

All audio-taped interviews were manually transcribed *verbatim* by the interviewers. This resulted in transcriptions where every word, pause and audible cue (e.g. cough, humming, thinking out loud) was written down. Each interview was given a distinctive number, to keep the transcriptions apart from one another and to anonymize the data (i.e. preventing a transcribed interview to refer to a certain participant). For the data analysis *ATLAS.ti* was used, a qualitative data analysis computer program. After the literature research, a number of codes and themes were identified concerning coping with fatigue. During analysing, new codes emerged or codes identified in the literature were refined or renamed to better suit the data and the research questions. After analysing five randomly selected interviews, nearly all codes and all themes were identified by this inductive and deductive coding techniques, which is indicative of conceptual saturation. An example of a theme is *coping tactics*, where a code is a more specific label as part of that theme, for example *planning*, *pausing/resting* or *dosing of activities* are all considered behaviours belonging to the theme *coping tactics*. The codes and code scheme used in this study can be found in Appendix E. All patient transcripts were analysed by the author of this paper. The coding and analysing process was regularly reviewed by and discussed with the supervisors of this study. The analysis focused on information concerning the thoughts, intentions, behaviours, perceptions and decisions of the patients related to fatigue. Furthermore, information concerning relationships and social support were also gathered. This study was performed in the Netherlands, hence the quotes mentioned in the *Results* section of this paper are in Dutch; a proper translation of the quotes to English by a translator was not possible due to time constraints.

3. Results

3.1 Perception of fatigue

When asked to describe their perception of SLE related fatigue, nearly all patients described their fatigue as fluctuating and as a result of that as unpredictable. This unpredictability makes it harder to plan and anticipate on fatigue, as it changes from day to day, even from moment to moment. Sometimes patients experienced less fatigue, while on other times they felt more lethargic.

> *Als ik me een beetje vermoeid [voel], als het een klein beetje is, dan denk ik: 'Hup, aankleden en hup we gaan wat doen'. Maar als het die [extremere] vermoeidheid toch wordt, dan merk ik snel dat ik heel vermoeid raak en dan [moet ik een] pas op de plaats [maken]. (P6, 51 years male)*

> *Er is moeilijk om daarop te plannen, omdat je van tevoren niet weet hoe je je voelt. Ik kan niet zeggen: 'Morgen ga ik vermoeid opstaan'. Ik heb in een week lang, in zeven dagen heb ik goede en minder goede dagen. Dan weet ik van tevoren niet welke dag dat is. (P10, 38 years female)*

Some patients went as far to observe multiple distinguishable stages of fatigue, which may alternate depending on exertion or rest. As illustrated in the following quote, this patient experiences an always present base stage of fatigue that may increase to higher stages when exerting herself:

> *Die vermoeidheid die ik vanmorgen voelde: 'Ga nou maar liggen, anders kun je vanmiddag niets meer'. Maar dat is de tweede moeheid die ik noem. Maar dan heb je nog de derde moeheid. Want soms heb je dingen die ik toch wil afmaken, toch wil doen of toch een dagje weg. (P5, 55 years female)*

Only two of the 19 patients described their fatigue as being mostly constant. Nearly half of the patients in the study explicitly mentioned that SLE related fatigue is very different from ordinary fatigue: SLE related fatigue is characterized as a more extreme, always present and crippling fatigue.

> *Ik krijg het aan een doorsnee burger niet uitgelegd hoe moe, moe kan zijn. Te moe om je tanden te poetsen – je doet het wel, maar eigenlijk ben je te moe. Te moe om te koken – dat doe ik dan weleens niet; broodje smeren, gauw. Ja… het is duizend keer vermoeiender dan moe. (P4, 50 years female)*

> *En deze vermoeidheid – ja, dat is er dan – en je kan er geen naam [aan geven], maar die is veel slopender [dan] een vermoeidheid die je hebt als je […] echt een bepaalde inspanning ervoor geleverd hebt. (P16, 54 years female)*

3.2 Impact of fatigue

Fatigue impacts all aspects of a patients' life; from imposing a physical limitation, forcing patients to make decisions concerning daily activities and work and affecting the social relationships of the patient.

3.2.1 Physical limitations

Fatigue impairs patients physically. A majority of the patients described actively searching their physical limits to see to which extent they are hindered by their fatigue in performing daily activities. A majority of the patients may even try to go beyond their perceived physical restrictions. The consequences – even more fatigue, irritability, physical complaints or worsened sleep quality – are often taken for granted, as it enables patients to perform beyond the limitations and may sometimes be necessary to accomplish something of importance.

> *Maar soms loop ik nog zo hard tegen de lamp. En eigenlijk vind ik dat… ik weet niet of ik dat zo nadelig vind, want als ik altijd naar mijn lichamelijke conditie zou luisteren, zou ik nergens meer komen. (P2, 37 years female)*

> *…ik probeer wel mezelf uit te dagen op momenten. Ik zal het niet doen op momenten dat ik weet dat ik zaterdags naar een verjaardag moet, bij wijze van spreken, dan zal ik het niet doen, vrijdags de zaken te torpederen, maar op een andere dag – dat ik weet, morgen is er niks bijzonders – dan probeer ik wel die grens te overschrijden. (P6, 51 years male)*

> *…af en toe ga je gewoon over je grens heen, dat je denkt: 'Morgen komt weer een dag'. Nou goed, omdat je je energie zo moet verdelen en je daar altijd van bewust bent, dat dat gewoon moet, heb je weleens de neiging [om] wat minder braaf te zijn. (P18, 65 years female)*

A couple of patients described experiencing a positive feeling of being tired and having fatigue caused by physical activity. For them, it is motivation to keep pushing their limits.

> *…ik doe veel meer dan dat ik eigenlijk zou moeten doen volgens de artsen en volgens de boekjes. Maar daar hou ik me niet aan want ik heb gemerkt dat ik heel vaak en heel lang over mijn grenzen heen kan gaan, zonder ook weleens helemaal vermoeid te worden dus dat ben ik ook weleens lekker moe. Dan denk ik van he, ja dat is een andere, dat is die andere moeheid. (P19, 67 years female)*

Being hindered by fatigue often results in a conflict between the will to do something and the possibility to act upon that will. It requires patients to accept that they are not able to do certain strenuous activities anymore or should not try to do multiple arduous tasks all at once.

> *…ik wil gewoon een explosief leven hebben, dat ben ik ook. En mijn hersens denken meer over dingen wat je wil, maar je lichaam wil niet mee. En dat vind ik weleens een confronterend feit. (P15, 47 years female)*

> *…soms dan heb je van die plannen hè, 's avonds in bed dan denk ik weleens van nou, het wordt tijd dat ik morgen weer iets ga doen, want het ziet er gewoon niet uit. En dan sta je 's ochtends op met je goede voornemens en dan voel je al van nou, dat wordt niks. Dus alles wat je plant, dat kan gewoon de mist ingaan daarmee dat je zo moe bent, dat dat niks wordt. (P12, 57 years female)*

Ultimately, fatigue may hamper patients in self-regulation; undermining efforts to control their own health, their own actions and their own life. Fatigue even gave some patients the feeling that their lives are controlled by their fatigue.

> *Het beheerst ons leven en bepaalt ons leven en begrenst ons leven, maar toch probeer ik dat niet te laten overheersen in mijn bewustzijn van mijn bestaan. (P2, 37 years female)*

> *…dat frustreert me weleens. Dat het gewoon een deel van je leven ontneemt. Zo zie ik dat in ieder geval. Ja, ik ben mijn leven gewoon aan het verslapen en dat vind ik niet leuk. Ik wil gewoon mijn, gewoon midden instaan en meemaken. (P11, 50 years female)*

Others regarded themselves, not their fatigue, as in control of their own life and their own choices.

> *Voor de rest. Je moet zoveel mogelijk doen, wat je altijd doet. Zien dat je het volhoudt. (P7, 66 years female)*

> *…dan is het gewoon voor mij een knop omzetten: 'Weg moeheid!'. Ik moet me aankleden, ik moet gaan werken en als ik thuiskom, dan ga ik dan wel even zitten en… dan ga ik slapen. En ik moet een heleboel dingen doen, dus het is gewoon die vermoeidheid achter je gooien; niet meer aan denken, klaar doorgaan. (P9, 51 years female)*

3.2.2 Activities and work

Most patients reported that fatigue has a major influence on their ability to perform day to day activities, mandatory tasks and on social roles. Some patients have even stopped such activities, such as shopping, doing the groceries, cleaning windows and hobby's or sports as a result of their fatigue.

> *Wij gingen toch wel graag op vakantie, maar we zijn de afgelopen jaren niet meer op vakantie geweest. Want je kunt niet van jezelf op aan. (P1, 66 years female)*

> *…we deden nogal veel. We gingen altijd naar Amsterdam; het concertgebouw. En met de trein naar steden. … Maar dat is ook allemaal veel minder geworden. (P7, 66 years female)*

Housekeeping and gardening are often described as difficult, but mandatory chores. Five patients mentioned gardening as a nice distraction from thinking about fatigue.

> *…het is ontspanning voor mij, in de zin dat ik het prettig ervaar om te doen. […] Een soort ontspanning, omdat je niet met je hersens aan het denken bent: 'Wat gaan we koken? Wat gaan we dit doen? Oh ja, we moeten naar de specialist?'; je bent niet aan het denken. Zo ervaar ik die ontspanning. (P5, 55 years female)*

Five patients have quit their job, as they were unable to handle their duties and responsibilities at work due to their fatigue. Of those who still work, most do so part-time to have enough days off from work to recover properly.

> *…dat is de reden dat ik van vijf naar vier dagen [ben gaan] werken. Vrijdags vrij. Vier dagen werken en drie dagen vrij. Dan kan ik even bijkomen, rust. (P4, 50 years female)*

The only patient in this study who still worked fulltime hinted that having a hectic fulltime job creates an imbalance between her work, private life and time to recover from fatigue.

> *…ik ga op den duur een andere baan zoeken. Die maak ik ook echt voor mezelf, omdat het zo stressvol is binnen dit bedrijf om te werken, dat ik zoiets heb: ik ga hier onderdoor. In combi met wat ik heb en de vermoeidheid die ik heb is dit niet de juiste match meer. Dat is een keuze die ik heb gemaakt, nou moet ik er nog naar handelen, maar het is een keuze die ik heb gemaakt. (P10, 38 years female)*

While most activities are a cause of fatigue, many patients described hobby's and even physical activity and sports as a way to gain renewed energy, despite getting more tired. Patients reported feeling satisfied and seeing thinks positively when getting fatigued through exercise and accomplishing a physical feat.

> *…meestal ga ik gewoon wel de leuke dingen doen hoor. Dat geeft ook weer energie, als je naar iemand toe gaat. Het kost energie, maar het geeft ook energie. Of als je hier een wandeling maakt door het bos. Je krijgt weer een ander soort energie. Je bent lekker in beweging. (P3, 34 years female)*

> *…dan kan je ook best wel moe zijn, maar dat is een energie die je daarin steekt maar dat is gewoon, ja dan is je hoofd vrij, lekker. Ja, daar haal ik dan ook wel weer energie uit. (P13, 63 years female)*

> *[Moe,] na zo'n dag wandelen, maar wel positief moe. Dat is wel lekker. Wel een stukje trots: 'Nou, dat heb ik toch maar weer even gelopen'. (P4, 50 years female)*

3.2.3 Social environment and support

As with daily activities and work, relationships with other people can be affected by the presence of fatigue. While some patients viewed their relationships with family and friends as unchanged due to the fatigue, a few patients stated their contact with friends and colleagues has decreased as a result of fatigue. One patient articulated that her environment had difficulty in understanding what her fatigue compels:

> *Ik probeer met voorbeelden [mijn vermoeidheid uit te leggen]… en dan zie ik aan hun gezicht dat ze het toch niet snappen en dan denk ik: 'Laat maar'. […] Dan denk ik: 'Ik heb mijn best gedaan, maar ik denk niet dat ze me gaan snappen'. Nee. Dus ik begin er maar niet zo vaak over, want men snapt het toch niet. (P4, 50 years female)*

A few other patients noted they felt treated differently because of their fatigue.

> *Ik heb een aantal collega's erbij: 'Ach, ga jij maar ergens anders zitten'. En als die het zeggen, dat doet me niets. Maar zouden mensen die… Ja, je krijgt weleens opmerkingen, dat ik denk: 'Auw', maar ze maken geintjes of zo. Maar dat kan ik ook keihard terugzeggen nu, zo van: 'Dat doet pijn! Ga jij eens een dag in mijn huid leven, dan praten we verder' (P9, 51 years female)*

> *En als mensen me dan zien met boodschappen doen, van: "Hey, ben je lekker thuis? Hoef je niet te werken?" Ik zeg: "Nee, ik hoef niet te werken. "Oh lekker he? Lekker genieten, kun je lekker doen wat je zelf wilt". Waar ik in het begin zoiets had van: ik moet me verantwoorden, ik [moet] dat allemaal uitleggen. Ik [denk nu:]nee ik stop er ook helemaal geen energie meer in. (P16, 54 years female)*

Some patients said making arrangements and promises is very difficult, as the unpredictability of the fatigue may make it hard to adhere to those promises.

> *Maar mensen kunnen van mij niet op aan. En dat vind ik erg vervelend. Ik kan mijn eigen niet op aan en… kijk… ik kan mijn afspraken vaak niet nakomen. (P1, 66 years female)*

> *Ben je vrijwilliger, wil je een afspraak maken, ik ga helpen of ik ga iets doen; dan verwacht men ook dat je er bent. En dat is het grootste euvel, dat kan ik nooit garanderen. Dat weet ik niet. Ik ga er wel vanuit dat ik dat ga doen, maar als op de dag blijkt dat dat niet zo is, dan moet ik dan toch afbellen. (P6, 51 years male)*

Another issue is independence and asking social support. Some patients felt uneasy with their reliance on other people for helping them out.

> *Ik was niet meer in staat om dat [ingezakte schuurtje]weg te halen, dus ik bel mijn schoonzoon op: 'Kun je me even helpen?', [schoonzoon]: 'Tuurlijk, ik kom eraan!'. En dan raak ik zo gefrustreerd dat hij daar – hij heeft een hele drukke baan, weet je wel – 's avonds laat nog loopt te sjouwen met planken, omdat ik dat weg wil hebben en ik dat niet meer kan. Ja, daar kan ik gewoon heel verdrietig van worden, tot tranen toe. Zo gefrustreerd kan ik zijn! (P18, 67 years female)*

One patient explained that her role as mother has become harder as a result of her fatigue. Still, as the following quote expresses, she refuses to let the fatigue come between her relationship with her children:

> *Ik voel heel duidelijk in mezelf dat ik weiger het domein van mijn moederschap te verpesten door mijn ziekte. Alles… voor mijn gevoel is bijna alles aangetast, maar dat moederschap is mijn grote geluk. Dus daar voel ik ook echt een soort eigenwijsheid in. Ik laat me gewoon niet kisten. En ik moet ook eerlijk zeggen, mijn kinderen en met mijn man… als gezin zijn wij buitengewoon gelukkig. (P2, 37 years female)*

Patients with a partner described their relationship as mostly unaffected by fatigue. Although many patients with a partner gained social support and practical help in doing chores in and around the house, like vacuum cleaning and doing groceries, this wasn't considered as affecting the relationship.

> *Ik denk ook dat mijn man er goed bij helpt, want die is zo van: 'Nou, morgen is er weer een dag. Doe rustig aan!'. Dus dat is eigenlijk iets van: dat is ook eigenlijk goed. (P8, unknown age, female)*

> *En mijn dochter komt of mijn zoon helpt me of hij helpt me weleens… Dan komen ze stofzuigen voor mij of dweilen, het ligt eraan, soms doe ik het zelf. (P5, 55 years female)*

There were however a few exceptions, where one patient became very reliant on her husband and another patient stating her sex life was affected unfavourable by the fatigue.

3.3 Learning to cope with fatigue

The process of learning to cope with fatigue is for the majority of the patients a matter of gradually adapting to a life that is to a certain degree constraint by fatigue.

> *…je moet gewoon een heel nieuw leven opbouwen. Alles wat je in het begin deed, dat gaat gewoon niet meer. (P3, 34 years female)*

After the diagnosis or the manifestation of systemic autoimmune disease related symptoms – for almost all patients the symptoms appear a considerable time prior to the diagnosis; a diagnose following a few years after the first signs of a systemic autoimmune disease is not uncommon – many patients try to do things as they would normally do. Sooner or later, however, they may be stumbling upon the limitations imposed by the fatigue.

> *Dat is met gewoon een paar keer vallen. Gewoon merken dat iets niet kan. Gewoon uitproberen. Ze kunnen wel tegen me zeggen, maar stronteigenwijs dat ik ben ga ik het toch uitproberen. (P4, 50 years female)*

Many patients thought a major skill to learn is making choices; *what* is of importance (and what is of less or no importance) and *when* something is of most importance.

> *Wat ik beter zou moeten doen, is beter balanceren inderdaad. Door niet te zeggen: 'Ik kan nu en ga door en ga door in mijn piek met werken'. Nee: 'Ik kan nu, dus ik moet ook op tijd zorgen dat ik ook thuis balans heb en ik moet dat balans beter gaan vinden'. (P10, 38 years female)*

> *…ik ben vorig jaar drie dagen naar een revalidatiecentrum geweest, waar ik… wat ook een onderdeel van de behandeling was, was leren doseren. En dat… Daar heb ik het wel geleerd: 'Nu ga ik even zitten', of 'Ik doe het op mijn eigen tempo, want anders kom ik straks mezelf weer tegen'. (P18, 65 years female)*

> *Ik heb laatst een serie oude kastjes geverfd, en dan heb ik de neiging: het moet het eigenlijk allemaal in rap tempo af. Maar dan weet ik gewoon, dat kan gewoon niet. Dan zou mijn man zeggen: 'Verdeel het over de hele week, het hoeft niet in één dag af'. En dan denk ik: 'Dat is eigenlijk ook wel zo'. En dan voel je je er eigenlijk beter bij. En dat zijn dat soort dingen die moet je denk ik leren. (P8, unknown age, female)*

3.4 Coping with fatigue

Coping with fatigue includes all the thoughts, intentions, behaviours, perceptions and decisions of the patients related to fatigue. Coping *strategies* comprises the attitude towards fatigue, a general style of approach a patient primarily adopts in managing their fatigue. Coping *tactics* encompasses the many different ways of acting and reacting in regard to fatigue. Often, a coping strategy dictates which tactics are utilized by the patient.

3.4.1 Strategies: attitude towards fatigue

Some patients approach their fatigue primarily as an enemy and as a result adopt a fighting stance; often wilfully ignoring to listen to their fatigue and acting without concern of whether it may negatively influence their fatigue.

> *Want dan denk ik: 'Daag, vermoeidheid. Jou heb ik iedere dag naast mij. Bekijk het maar! Ik wil dit nou vandaag doen, klaar!', en dan ga ik door. (P5, 55 years female)*

> *…als ik echt naar mijn natuurlijke conditie zou luisteren, dan zou ik nergens meer komen. Dus weiger om me daarbij neer te leggen. (P2, 37 years female)*

Other patients, however, regard fighting against fatigue as counterproductive, as it may as well result in even more fatigue.

> *…toen heb ik ook gezegd: 'Ik kan wel vechten' en dat heb ik ook lang genoeg gedaan om ook weer mijn oude patroon op te kunnen starten, dat heeft geen resultaat gehad. Alleen dat ik nog zieker werd. Dus op die manier heb ik het leren accepteren. Want op het moment dat je het accepteert en daarna gaat kijken, kun je ook meer. Niet vechten tegen iets waar niet tegen te vechten is. Dat is verloren energie. (P6, 51 years male)*

Even patients that generally adopt a fighting stance to fatigue seem aware of the adverse effects of acting without taking fatigue in account.

> *Maar het is eigenlijk, je vecht er tegen, maar ook doordat je ook weer vecht tegen [de vermoeidheid], maak je jezelf ook weer moeër. (P5, 55 years female)*

A few patients approach their fatigue mostly as inevitable and unalterable; regarding giving in to fatigue the best way to avoid getting even more fatigued.

> *…ik ben meer aan toegeven aan mijn vermoeidheid, laat mij dan maar eventjes, weet je wel, dan ga ik gewoon zitten, beetje dom televisie kijken, dan ben ik zelfs niet in staat om te lezen, ik zou het wel kunnen maar dan ben ik te moe om te concentreren in mijn hersenen. […] Laat mij maar gewoon even.. (P15, 47 years female)*

Most patients in this study tried to approach their fatigue by neither fully fighting against their fatigue nor fully giving in to it. For these patients, it was searching for a balance of taking in account fatigue to the extent that they were still free to make certain choices and do the things that they consider important.

> *Ik probeer er een beetje naar te luisteren, maar ook regelmatig die grenzen te tarten. Om te kijken hoeveel rek erin zit. Dus niet teveel er tegen vechten, want dat levert stress en spanningen op. Maar er ook niet klakkeloos bij neerleggen. (P2, 37 years female)*

> *Iedereen heeft invloed [op vermoeidheid]. Het is het zoeken van de juiste balans en de balans wat je accepteert. En daar heb ik heel veel moeite mee. En die uitdaging zal ik ook altijd blijven aangaan. (P10, 38 years female)*

> *Ook wel even op een rij te zetten, als je die balans niet goed hebt, heb je ook meer last van die vermoeidheid. Dat je voor jezelf ook eigenlijk wel probeert je dingen zo in te delen… en dat hoeft dan ook niet heel beperkend te zijn. Want ik vind ook, je moet soms even wennen aan een bepaalde manier, die je misschien anders doet, maar dat hoeft niet per se iets te zijn, dat het van mindere kwaliteit is. (P8, unknown age, female)*

3.4.2 Coping tactics: behaviours to manage fatigue

Coping with fatigue encompassed many different tactics that patients employed to live, act and think as unhindered by fatigue as possible. Many tactics fall in line with the general strategy a patient has adopted in regard to their fatigue.

Nearly all patients in this study stressed the importance of proper pausing and resting to recover from fatigue. Fatigue tends to build up and when the patient does not pause or rest often and at the right times, the fatigue can get excruciating.

> *Nou, dat heb ik sinds de laatste tijd dat ik dus echt bewust van mezelf moet gaan rusten. Gewoon een pauze inlassen. Nou ja… een half uurtje gaan liggen of zo. En dat voelt wel beter. (P1, 66 years female)*

> *Als je vaker een rustmoment neemt, echt even uitrust, echt even gaat liggen, dan heb je daarna meer energie om die dingen wel te doen. (P8, unknown age, female)*

In combination with pausing and resting, planning activities and anticipating on fatigue are mentioned by a large portion of the patients in this study. Most patients try to plan tiresome activities on days where they know they have enough time to recover, preferably the day after.

> *Ik ga graag naar het theater, maar dat plan ik niet op een avond als ik de volgende ochtend weer naar mijn werk moet. Daar ben ik bewust mee bezig. Ik ben vrijdag's vrij, dus ik wil donderdag best wel een avondje weg. Maar ik zal dus maandag,*

> *dinsdag, woensdag niet plannen. Dat doe ik bewust niet, nee. In die zin ben ik daar wel mee bezig. […] Theater kun je plannen. Een avond kun je plannen. Nou, dan ga ik bewust bepaalde avonden niet plannen. Dat weet ik. Dat ga ik heel bewust niet doen, nee. (P4, 50 years female)*

Of importance when planning activities, is making choices when and how long these activities should be executed to have minimal negative repercussions in the form of increased fatigue. Dosing activities and cutting strenuous tasks up in smaller and more manageable portions may help do the activity or task more effectively, while maintaining a tolerable level of fatigue.

> *…dat je altijd rekening ermee moet houden met alles wat je doet; dat moet je gewoon doseren, je moet [er] rekening mee houden dat als je vandaag iets doet – naar de stad bijvoorbeeld eventjes – dat je dan de volgende dag gewoon een rustdag moet inlassen. (P12, 57 years female)*

> *Alles gefaseerd doen. Dus als ik zeg maar… ik heb een goede dag en dan voor mezelf in de tuin iets doen, dan hak ik de tuin in een aantal partjes en dan zeg ik: 'Vandaag doe ik dit hoekje'. En gaat het goed, dan heb ik het hoekje klaar. [Ik] neem er ook een hele week voor en dan doe ik elke dag een stukje. (P6, 51 years male)*

> *Ik moet er echt aan werken, omdat je van nature misschien heel veel wilt, maar moet zorgen: dat kan wel, maar in een ander tempo. (P8, unknown age, female)*

Acceptance is a topic where some patients see no other way than to accept fatigue will most likely not go away, while others cannot fully accept that fatigue plays a major role in the further defining of their lives and who they are.

> *Je kan het niet accepteren, omdat het teveel dingen beïnvloed in je leven, maar je zal wel moeten, ermee omgaan. Want het is er. Je kan het niet wegdenken. Je kan het niet wegsturen. Je kan het niet wegtoveren, zeg maar. Dus je gaat ermee om naar de omstandigheden van het moment. (P5, 55 years female)*

> *Als jij je vermoeidheid accepteert, dan moet je ook accepteren dat je ook niet met vrienden aan de zwier kunt gaan. Of niet meer op vakantie kunt gaan of niet meer... hè. Het zal altijd een beladen iets blijven, van het innige. (P18, 65 years female)*

Fatigue limits the amount of energy for most patients, hence the importance for most patients to set priorities. A few patients mentioned they are willing to make time for spontaneous events, even if they can have adverse effects on their fatigue level.

> *Mijn zoon kan eens bellen: 'Mam, ik kom even een kopje koffie drinken'. Oké, dan slaap ik niet 's middags als hij komt. Dan vind ik het leuker als hij komt, dan dat ik toegeef: 'Ik moet eigenlijk een uurtje gaan slapen'. (P9, 51 years female)*

> *Maar sommige dingen kan je niet afzeggen of niet plannen. Maar dan weet je dat je daardoor dus moeër bent. Dan heb je dat er ook een soort van voor over. (P3, 34 years female)*

While some patients prioritised work over private, one patient had made the choice to spend less energy on work to have more energy left at home.

> *…ik wil ook nog een beetje genieten van het leven en dat kan anders niet. dan kom ik weer terecht in dat ik weer ga werken en voor de rest thuis dan weer aan het slapen ben, moe ben, niet meer scherp ben, dan ga ik weer inderdaad alles inzetten om het werk te presteren en ja. Ik heb niet genoeg en dan gaat het ten koste van mij en het gezin. (P11, 50 years female)*

Some patients adopted a healthy lifestyle (diet, physical exercise and sleep) to more effectively deal with their fatigue.

> *En ik pas héél goed op of ik euh… genoeg slaap krijg, gezond eet, of ik niet over mijn grenzen heenga… ik beweeg ontzettend veel – ik probeer op allerlei manieren in beweging te blijven: dus met de fysiotherapeut, ik doe alles op de fiets, ik probeer genoeg mensen nog te spreken – op die manier alles in beweging te houden in mijn leven. (P2, 37 years female)*

> *Daar ben ik eigenlijk mee begonnen in het begin. Toen had ik wat vermoeidheidsklachten en toen zeiden ze al van het is wel goed om daar ook lichamelijke vermoeidheid tegenover te stellen. dus toen ben ik eigenlijk al lid geworden van de sportstudio, ben ik gaan sporten. Op een gegeven moment zat er een beetje de klad in dat ik er echt geen puf aan had. Maar sinds vier, vijf maand of zo ben ik weer echt toch wel weer goed daar mee bezig. (P11, 50 years female)*

> *…ik probeer zo gezond mogelijk te leven ook met mijn voeding en ook weer niet heel overdreven, ik drink één kop koffie op een dag, heel veel groene thee, oliën, olijfolie, want voor reuma is dat op zich heel goed en ik noem het altijd smeerolie, ja weet je, dat is wel een levensstandaard dat ik denk van wat je er aan kan doen, doe er aan… (P15, 47 years female)*

Others altered their hobby's or holiday's to accommodate a lifestyle that is more or less imposed by their fatigue.

> *Ik doe langeafstandslopen, dus ik ben heel trots dat ik nog steeds rond de 20 kilometer loop, maar dat doe ik dan niet drie dagen natuurlijk. Ik rende eerst, maar dat wilden mijn knieën niet meer; mijn knieën protesteerden. Dus nu loop ik. (P4, 50 years female)*

Keeping a positive attitude is mentioned by a few patients to not fall into despair and depression. Focusing on things you have or can do is more effective than focusing on that which is lost or is not feasible anymore, according to one patient.

> *Als je alleen maar denkt: 'Oh, ik ben moe… ik ben moe', je hebt die mensen die dat doen. En kijk, ik doe het ook af en toe. Maar dan raak je zelf de put in, dan word je alleen maar moe. Maar als je denkt: 'Ik ben moe, maar ik ga nu iets leuks doen'. Dan ben ik daarna wel moe, maar dat geeft energie. Dan sta je er anders in. (P3, 34 years female)*

Together with having a positive attitude, distraction can help for some patients to divert their attention away from the feeling of fatigue.

> *Als ik schilder. Als ik wel eens schilder, dan concentreer ik me zo op dat schilderen, ik weet het niet, het zuigt je op, zeg maar, dat je op dat moment daarmee bezig bent… (P5, 55 years female)*

Some patients mentioned they have searched on the internet or by other means acquired information concerning SLE or another autoimmune disease and the accompanying fatigue. Although it helped some to learn more about their illness, a few patients stated they did not want to be informed as the overwhelming amount of negative information could be harmful.

> *Ik heb geen idee waar dit me uit gaat brengen. Ik ben ook niet iemand die zich gaat verdiepen in de probleemgebieden, omdat ik van mening ben dat je het voor jezelf makkelijker kan maken of moeilijker kan maken. En als ik alleen de ellende zie, dan heb ik zoiets van: 'Ja…'. Het kan heel naïef zijn, hoor. (P10, 38 years female)*

Finally, a few patients keep up their hopes that their fatigue may subside over time.

> *Ik ben nog in een zoektocht. Dat is echt voor mij nog, want ik hoop niet dat het erger word. Dat is het enige, ik hoop dat het minder wordt. Ik hoop dat het altijd, dat het ooit van hey er is helemaal niks meer aan de hand. (P15, 47 years female)*

3.5 Evaluation of coping with fatigue

Most patients thought that their own actions had an effect on the level of fatigue they experience. A few patients said they only had negative influence on the fatigue of their actions; everything they do causes an increasing experience of a fatigue. More patients, however, indicated they can have at least some positive influence on their fatigue by noticing when it fluctuates to highs and lows and acting accordingly. Having lower levels of fatigue allows for greater physical efforts, while higher levels subsequently offer less room to perform demanding activities and encourage patients to take rest.

> *Ik kan er zeg maar aan toe geven en het even over me heen laten komen en denken van als het weer wat gezakt is of ik voel me weer wat beter, dat ik andere dingen wel weer kunnen op pakken. In die zin heb ik er invloed op. En soms heb ik als ik het gewoon hetgeen wat ik wil doen, wat [meer gespreid] doe, dat ik die vermoeidheid dan ook minder voel als een soort druk. (P16, 54 years female)*

Some patients were negative in their evaluation of their own way of coping with fatigue. They tended to keep upwards comparing their own capabilities to those of healthy others or their former selves, when they were still unaffected by SLE related fatigue. Many patients were however mildly positive about their way of coping with fatigue, although stating their influence was but minor and stopped at affecting if and how much their fatigue severity builds up in intensity or duration.

> *…tevreden ben ik wel. Ja, je moet het aanvaarden dat het zo beter is. Dat het daardoor wel een plek heeft gekregen, omdat je het noodzakelijke ervan inziet, dat het anders te bepalend wordt. Dat je wel op een realistische manier ermee om moet gaan. Dat je zegt: 'Nou goed, dan kan ik niet meer een grote berg verzetten, maar het bergje elke keer een beetje kleiner wordt'. (P8, unknown age, female)*

4. Discussion

The results of this explorative study showed that fatigue is perceived by SLE patients as the most debilitating symptom of their systemic autoimmune disease. SLE related fatigue is generally described as a fluctuating and unpredictable symptom. And when compared to ordinary fatigue, SLE related fatigue is characterized as a more extreme, persistent and crippling form of fatigue. Most patients experience their fatigue as a physical limitation, restricting them to live their life as they once did in a past without fatigue or they planned to for a future without fatigue.

Coping strategies comprises a general style of approach a patient primarily adopts or tries to adopt in managing their fatigue. It was found that there were three distinguishable strategies, which could be defined as an attitude. While some patients chose to primarily adopt a fighting stance, not swaying for the influence of fatigue, some others did the exact opposite and tended to give in with the limits imposed by their fatigue. Most patients, however, had acquired or tried to acquire an attitude that combines these strategies. This attitude is the middle between the two extremes of fighting and giving in. With this attitude, patients tried to take their fatigue in consideration, but only to the extent that they were still able to make important choices and do those things they deem important and necessary. It is this attitude where patients aimed to cope in such a way as to attain a tolerable level of fatigue, while maintaining much of their physical functioning, their ability to perform activities and ability to make choices they deemed important. Pushing their physical limits occasionally and thoughtfully may be the most rewarding, in comparison to patients that always fight to push their limits or those that never try to do so and give in. Nearly all of the patients who had a greater tendency to fight against or give in to the fatigue also noted that the balanced attitude could be the most optimal coping strategy.

The general coping strategies adopted by the patients in this study can be regarded from the theory of Brandtstädter (1982; 2009) and Brandtstädter and Rothermund (2002) on assimilative and accommodative coping. Whereas assimilative coping comprises the mechanisms to adjust the situation to personal goals, accommodative coping comprises the mechanisms to adjust personal goals to the situation. Accommodative efforts results in “rescaling of aspirations, the dissolving of barren attachments, and the channelling of assimilative energies toward new, feasible goals (Brandtstädter & Rothermund, 2002, p.123)”. The fighting stance some patients adopted can be regarded as part of assimilative coping strategies. Brandtstädter (2009) describes the assimilative mode of coping as follows: “the assimilative mode supports persistence in action paths, the tenacious maintaining of commitments even against obstacles, and the shielding of goal pursuit against enticements and distractions (p.55)”. Interesting was that patients that expressed this attitude were aware of the negative effects this attitude and the compensatory efforts they had to make had on their fatigue and their ability to reach their goals. With enduring commitment to unreachable goals, compensatory efforts mark the late phase of assimilation. The patients realise their efforts are giving diminishing returns and, according to Brandtstädter and Rothermund (2002), accommodative coping should be engaged and assimilative coping disengaged. On the opposite, patients that gave in to their fatigue could be seen as giving up many of their personal goals to live with fatigue. These patients adhere strongly to accommodative coping strategies, but seem incapable of properly engaging assimilative coping; to gain a reorientation to new or adapted goals. According to Brandtstädter (2009), this is partly due to a lack of self-beliefs of control: a lack of self-regulation and the feeling fatigue controls their life and personal choices. Brandtstädter and Rothermund (2002) stated that both modes of coping may operate synergistically and complement each other. The patients that tried to find a balance in fighting and giving in to the fatigue may be those that have the most advantageous coping strategy. They likely are the most flexible and have the broadest range of coping tactics. They altered or readjusted their goals to the new situation, but also tried to find ways of reaching goals that are important to them. This finding is in line with research by Arends and colleagues (2013), who showed in their study on goal management that readjustment of goals to personal capabilities and circumstances, which may be hindered or altered by disease related symptoms, was the most effective strategy to adapt to living with polyarthritis, an autoimmune disease with roughly similar symptoms as SLE. They also noted that patients maintaining their personal goals and aim to achieve those goals were better adapted to their chronic disease than patients that abandoned their personal goals.

Coping tactics are the tangible efforts of patients to manage their fatigue; the actual intentions, behaviours, perceptions and thoughts concerning fatigue. The coping tactics utilized by patients fall within the larger coping strategy. The always present fatigue required patients to make hard choices regarding their day to day activities, work and even relationships. Most notably patients need to learn to weigh the importance of activities. An essential consideration many patients with SLE had to make is *what* activities were of importance and *when* they should do these activities. This is why planning, prioritising and dosing activities were important tactics of coping with fatigue. To keep fatigue at a tolerable level, many patients tried to rest and pause during the day and in between activities. These coping tactics were also found important in studies with patients with rheumatoid arthritis related fatigue (Hewlett et al., 2005; Repping-Wuts et al., 2008). As a result of fatigue, many patients had to give up on certain activities, such as work, volunteerism or a hobby. Others found ways to continue doing them, albeit in a different and adapted form.

These results on coping tactics can be regarded as confirming the ideas proposed by Aspinwall and Taylor (1997), who argued that the construct of coping would benefit with the addition of an understanding how people cope with stressors in the near (anticipatory coping) or far future (proactive coping). Planning was mentioned to be an integral part of coping with fatigue for the majority of the patients. Many patients thought their actions were a factor in the intensity and/or duration of their fatigue, hence they planned, prioritised and dosed their activities. The tactics mentioned were not used as reaction to their current level of fatigue, but were an action in advance, to prevent their fatigue from increasing to a higher intensity or longer duration. Patients have learned with time and experience to make use of anticipatory coping: by doing certain activities the fatigue may become more intense, so these particular activities need to be planned accordingly to maintain a tolerable level of fatigue. Concerning the level of fatigue, it was found that some patients distinguished different stages of fatigue and could monitor those stages, while others did not make such a distinction. For the latter group of patients, fatigue was more or less always constant and the fluctuations not nearly as noticeable. It is assumed that the patients who discerned and monitored their stages of fatigue more easily should be able to utilize anticipatory coping tactics, like planning and dosing activities, more efficiently.

Many studies point out that problem-focused, active and engaging coping is overall the most adaptive form of coping and has the most positive effects on reducing fatigue (Dobkin et al., 2001; Kozora, Ellison, Waxmonsky, Wamboldt & Patterson, 2005; McCracken, Semenchuck & Goetsch, 1995; Oliveira, Avelino, Paixão, Agostinho, Jara & Bento, 2013; Savelkoul, Post, De Witte & Van Den Borne, 1999). Problem-focused coping is generally regarded as the best way of coping, as it affects the source of the stressor, unlike emotion-focused coping, which addresses the way one thinks and feels about a stressor. Patients in this study made use of a wide range of problem-focused coping tactics like: resting and pausing, planning, dosing and prioritising activities, searching information, altering hobbies or adopting a healthy lifestyle and seeking practical help from their partner or social environment. It must be noted that the effects of these coping tactics on the stressor (fatigue) were minor. These coping tactics were used by patients as a means to affect if and how much their fatigue severity or duration builds up. Patients made no mention of an ability to directly decrease their fatigue severity or duration.

Emotion-focused coping is generally associated in the literature (e.g. McCracken et al., 1995; Savelkoul et al., 1999) with passive and negative coping styles, such as avoidance, wishful thinking, accepting responsibility and self-blaming. However, as found in this study, acceptance, distraction and hoping for a better future are ways patients coped in an emotion-focused way. None of these patients solely relied on these emotion-focused coping and also employed numerous problem-focused coping tactics. Since the patients in this study adopt such a wide variety of coping tactics, it is not possible to say if having hopes for a better future, seeking distraction from thinking about fatigue or accepting that fatigue is part of their life is maladaptive coping. In isolation these tactics might be maladaptive, but they are part of a repertoire of coping tactics and skills the patient has developed in the years trying to manage and influence their fatigue. It is just as likely that acceptance, for example, is a necessity for some patients to adopt an attitude of fighting less against their fatigue and enabling the use of other coping tactics. If so, acceptance could have an indirect positive effect on the experience of fatigue. In another Dutch study, respondents mentioned different kinds of relaxation and acceptance as part of self-management (Repping-Wuts et al., 2008), so emotion-focused coping is found useful to patients and utilized to manage fatigue aside from active coping tactics.

The research questions central in this study necessitated a qualitative research design, as this was the most suitable way of gaining data from a patient perspective. An open, semi-structured interview as research setting allowed patients to share their experiences regarding coping with fatigue, without being largely restricted by the interview scheme or the questions. The questions asked during the interview were intended to be a starting point for the patient to begin his or her story and were thus used as indication of the overarching topic the patient should talk about. This study had a sizeable number of participants for a qualitative study. This helped in identifying less common coping tactics and allowed for a better evaluation of conceptual saturation in the data. A limitation of the sample of this study was the way the participants were recruited. Aside from the patient reporting experiencing severe SLE related fatigue, there were no hard exclusion criteria. The patients that participated in this study were all contacted at the World Lupus Day 2014 (*Wereld Lupus Dag 2014*) in Ede (The Netherlands). It could be argued such an event attracts a rather homogenous group of patients, so the sample in this study might not give a good representation of Dutch SLE patients in general. The fact all patients in this study coped fairly well with their fatigue could be considered an indication that patients that are more maladaptive in coping with fatigue are not included in the sample of this study. However, all except two patients were identified having severe fatigue, as measured with the Fatigue Severity Scale (see table 3). So it is clear that the majority of the patients in this study were heavily affected by their fatigue. Two patients had a different systemic autoimmune disease than SLE. Five patients had more than one systemic autoimmune disease. However, since this study solely focused on one particular symptom of SLE and other systemic autoimmune diseases share this symptom, it should not have made much difference, if any.

Half of the participants were interviewed by the author of this paper, while the other half were interviewed by another interviewer. Although both interviewers used the same interview protocol and reviewed and discussed the interviews/transcripts on a regular interval, the focus of the other interviewer was primarily on the first half of the interview, whereas the most useful data for this study came from the second half of the interview. The use of two interviewers might have had a slight effect on the overall quantity of data acquired, but there is no indication that the data is of lower quality. Although the results of this study are certainly useable for the purpose of this study, the design of the interview was not exclusively set on actual modes of being. It is therefore likely some phrases of patients may have been interpreted as actual behaviour, thoughts, attitudes and ideas of the participant, while the patient wanted to articulate he or she wanted to act or think that way or did so in the past. For example, a patient who mentioned she should spread an activity over multiple days, but in other instances mentions she does spread other activities on some occasions. It is difficult to state if this patient does or does not generally spread her activities. The process of being interviewed had an unfavourable effect on the fatigue of patients. This can have affected the quality or quantity of the data acquired, especially at more difficult questions and as the interview progressed. Also, sometimes the interviewer tried to paraphrase or help the patients find words, often resulting in short answers that are difficult to interpret outside of the context of the interview setting.

The use of a patients perspective gave new insights and resulted in findings that would not have been acquired if a different research method was used. In all the unique and personal stories of the patients that were gathered with the interviews, were found intriguing similarities and occasionally differences. Despite this, the patient perspective is also a limitation of this study. It was clear some patients were more capable of self-reflecting than others. Also, some patients were more expressive in their choice of words and what they were willing to share with the interviewer than others. People who are better narrators of their experience may provide more data and people who give short and less extensive answers provide harder to analyse data. To remedy this, at least for a part, topics mentioned by a sole or a small number of patients and related to the research question are also mentioned in the results of this paper.

A small flaw of the demographic questionnaire was the absence of a question about when the patient was diagnosed with their systemic autoimmune disease and which systemic autoimmune disease or diseases they are diagnosed with. Although in nearly all interviews it was discussed with the patient, it could have been more convenient if it was a question on the aforementioned questionnaire.

The use of the Fatigue Severity Scale was not clear from the start of the study and served no real purpose, aside from describing the population. Post hoc it was rationalized it could have served as inclusion criteria for patients participating in this study. Two out of the 20 patients would have been excluded, had it been used in such a manner. It nonetheless confirmed that nearly all patients in the sample of this study experienced severe fatigue levels.

This qualitative study aimed to explore, through a patient perspective, the way SLE patients in the Netherlands cope with their fatigue; to learn more about the coping strategies and tactics they have acquired, adopted and employ in their daily lives. It has been shown that SLE patients learn a large variety of coping tactics aimed to improve their ability to do and act as they want, while limiting the negative impact of fatigue as much as possible. Fatigue causes patients to adapt their life to a slower pace, where rest, pausing, and making choices of what to do and when to do things is a daily dilemma. SLE patients possess a broad repertoire of coping tactics, with which the patients in this study tend to cope quite well. The influence patients have on their fatigue is but marginal. Most patients stated their influence on their fatigue experience can be both positive as well as negative. But according to the patients their influence generally stops at affecting if and how much their fatigue severity rises to higher levels; patients in this study had not found ways of directly lowering the intensity or duration of fatigue.

Future research should focus on the learning process in adapting to a life with fatigue. A longitudinal study should give insight in the factors that constitute the adaptation of patients that are recently diagnosed with SLE to their disease and disease related fatigue. Furthermore, future research should examine which coping tactics constitute adequate coping. A study with a quantitative research design could possible test which coping strategies and particularly tactics SLE patients generally employ and which effects this coping has on psychological distress, physical health status, experienced fatigue and overall quality of life. It might give clues to what extent certain coping tactics, as described in this study, constitute adequate coping.

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Appendix A

Informed consent form (Toestemmingsverklaringsformulier)

Titel onderzoek: “Vermoeidheid en de kwaliteit van leven van patiënten met een systemische auto-immuunziekte en hun partners”
Verantwoordelijke onderzoeker: Marc Bouma

In te vullen door deelnemer:

‘Ik verklaar hierbij op voor mij duidelijke wijze te zijn ingelicht over de aard en methode van het onderzoek, zoals uiteengezet in de bovenstaande informatiebrochure. Mijn vragen zijn naar tevredenheid beantwoord. Ik stem geheel vrijwillig in met deelname aan dit onderzoek. Ik behoud daarbij het recht deze instemming weer in te trekken zonder dat ik daarvoor een reden hoef op te geven en besef dat ik op elk moment mag stoppen met het interview. Indien mijn antwoorden gebruikt zullen worden in wetenschappelijke publicaties, dan wel op een andere manier openbaar worden gemaakt, zal dit volledig geanonimiseerd gebeuren. Mijn persoonsgegevens zullen niet door derden worden ingezien zonder mijn uitdrukkelijke toestemming. Als ik nog verdere informatie over het onderzoek zou willen krijgen, nu of in de toekomst, kan ik me wenden tot de verantwoordelijke onderzoeker, Marc Bouma (telefoon: 06-21496869; e-mail: m.k.bouma@student.utwente.nl).’
Voor eventuele klachten over dit onderzoek kunt u zich wenden tot de secretaris van de Commissie Ethiek van de faculteit Gedragswetenschappen van de Universiteit Twente, mevr. J. Rademaker (telefoon: 053-4894591; e-mail: j.rademaker@utwente.nl, Postbus 217, 7500 AE Enschede).

Aldus in tweevoud getekend op: ... - ... – 2014

……………………………	……………………………
Naam deelnemer	Handtekening

In te vullen door verantwoordelijke onderzoeker:

Ik heb toelichting verstrekt op het onderzoek. Ik verklaar mij bereid nog opkomende vragen over het onderzoek naar vermogen te beantwoorden.

……………………………	……………………………
Naam onderzoeker	Handtekening

Appendix B

Fatigue Severity Scale (FSS)

1. Als ik moe ben, ben ik minder gemotiveerd

Helemaal mee oneens 1 2 3 4 5 6 7 Helemaal mee eens

2. Mijn vermoeidheid wordt opgeroepen door lichaamsbeweging

Helemaal mee oneens 1 2 3 4 5 6 7 Helemaal mee eens

3. Ik ben snel vermoeid

Helemaal mee oneens 1 2 3 4 5 6 7 Helemaal mee eens

4. Moeheid belemmert mijn lichamelijk functioneren

Helemaal mee oneens 1 2 3 4 5 6 7 Helemaal mee eens

5. Mijn moeheid zorgt vaak voor problemen

Helemaal mee oneens 1 2 3 4 5 6 7 Helemaal mee eens

6. Langdurig lichamelijk inspannen kan ik niet door de vermoeidheid

Helemaal mee oneens 1 2 3 4 5 6 7 Helemaal mee eens

7. Moeheid belemmert mij bij het uitvoeren van bepaalde taken en verantwoordelijkheden

Helemaal mee oneens 1 2 3 4 5 6 7 Helemaal mee eens

8. Van de klachten die mij het meest hinderen, is vermoeidheid één van de drie ergste

Helemaal mee oneens 1 2 3 4 5 6 7 Helemaal mee eens

9. Bij mijn werk, gezinsleven of sociale contacten word ik belemmerd door mijn vermoeidheid

Helemaal mee oneens 1 2 3 4 5 6 7 Helemaal mee eens

Appendix C

Demographic Questionnaire

<u>PERSOONLIJKE GEGEVENS</u>

1. Wat is uw geslacht?   Man/Vrouw

2. Hoe oud bent u? …………. jaar

3. Wat is uw hoogst afgeronde opleiding?

- ○ Lager onderwijs
- ○ Mavo/Lbo/Vmbo
- ○ Havo/Vwo/Atheneum/Gymnasium
- ○ Mbo
- ○ Hbo/Bachelor Wo
- ○ Master Wo

4. Welke van onderstaande antwoorden omschrijft uw huidige situatie het best?

- ○ Ik werk fulltime
- ○ Ik werk parttime
- ○ Ik ben werkzoekend
- ○ Ik ben gepensioneerd
- ○ Ik ben huisvrouw/huisman
- ○ Ik ben arbeidsongeschikt
- ○ Ik ben student
- ○ Anders, namelijk ……………………………………………

5. Bent u werkzaam als vrijwilliger?

- ○ Ja
- ○ Nee
- ○ Niet meer

(Indien van toepassing)

6. Hoe lang bent u samen met uw partner?

……

7. Hebt u kinderen?

- ○ Ja, thuiswonend: …………… (aantal)
- ○ Ja, uitwonend: ………………. (aantal)
- ○ Nee

Appendix D

Table D1.

Interview Schedule (Dutch version)

1. Kunt u mij uw gevoel van vermoeidheid beschrijven?
2. Ervaart u de vermoeidheid altijd hetzelfde?
3. Wat betekent vermoeidheid voor u?
4. Kunt u mij vertellen welke invloed vermoeidheid heeft op uw leven?
    a. Emotionele impact; Persoonlijkheid; Cognitieve impact; Dagelijkse activiteiten; Vrije tijd, sociale leven en familie; Werk
5. Heeft u het idee dat u zelf uw vermoeidheid beïnvloed?
    a. Zijn er activiteiten waardoor u meer vermoeidheid ervaart?
    b. Zijn er activiteiten waardoor u minder of niet nog meer vermoeidheid ervaart?
6. Hoe heeft u leren of leert u omgaan met de vermoeidheid?
7. Zou u kunnen beschrijven hoe u aankijkt tegen de manier waarop u met uw vermoeidheid omgaat?

Appendix E

Code Scheme

Activiteiten - die energie geven (positief)

Families (1): Activiteiten
Quotations: 24
Comment:

> Activiteiten en handelingen (werk, hobby's, sociaal contact e.d.) die energie geven; positief worden beschouwd in het licht van vermoeidheid. Activiteiten die vermoeiend zijn, doch voor voldoening en positief affect zorgen.

Activiteiten - die energie kosten (negatief)

Families (1): Activiteiten
Quotations: 27
Comment:

> Activiteiten en handelingen (werk, hobby's, sociaal contact e.d.) die energie kosten; negatief worden beschouwd in het licht van vermoeidheid

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Activiteiten - stoppen c.q. starten

Families (1): Activiteiten
Quotations: 30
Comment:

> Activiteiten die niet of moeilijk met de vermoeidheid samengaan niet beginnen of niet continueren, maar staken of plannen daartoe opzeggen. Of activiteiten die nu juist meer worden ontplooid, doordat de vermoeidheid ruimte laat voor nieuwe activiteiten of het verder gaan in activiteiten waarvoor tijd en ruimte is vrijgekomen (bijv. door verlies baan, opgeven andere activiteiten). Hangt samen met werk, prioriteiten stellen en structuur in dagelijkse bezigheden.

Attitude vermoeidheid - Leven naast vermoeidheid

Families (1): Attitude op vermoeidheid
Quotations: 48
Comment:

> Proberen ondanks vermoeidheid zoveel mogelijk te blijven willen en kunnen. Doorzetten, zoveel mogelijk leven zoals normaal, binnen de fysieke begrenzing van de vermoeidheid. Proberen de vermoeidheid te omzeilen als dat mogelijk is en niet teveel de grens te overschrijden. Compromis tussen vechten en overgeven. Tevredenheid met omgang.

Attitude vermoeidheid - Toegeven aan vermoeidheid

Families (1): Attitude op vermoeidheid
Quotations: 37
Comment:

De vermoeidheid zien als bepalend in de verdere loop van het leven. Berusten in de beperkingen en limitaties die vermoeidheid met zich meebrengt. Los laten van wat niet als haalbaar c.q. behoudbaar wordt beschouwd.
Niet opzoeken van mogelijkheden, maar berusten in de limitaties en begrenzing van vermoeidheid. Opzien tegen vermoeidheid, weinig tevredenheid met omgang.

Attitude vermoeidheid - Vechten tegen vermoeidheid

Families (1): Attitude op vermoeidheid
Quotations: 40
Comment:

Ondanks vermoeidheid alles blijven willen en kunnen, zelfs als dat niet mogelijk is. Vermoeidheid wordt gezien als een blokkade die (soms) overwonnen moet worden.
Niet luisteren naar fysieke grenzen en grenzen overschrijden. Vijandige en opstandige houding t.o.v. fysieke limitaties. Ontevredenheid met omgang.

Diagnose - Duur ziekte en vermoeidheid

Families (1): Diagnose
Quotations: 20
Comment:

Tijd sinds klachten/diagnose SLE.

Eigen invloed vermoeidheid - negatief

Families (1): Invloed eigen handelen
Quotations: 13
Comment:

Eigen invloed op vermoeidheid is negatief; eigen doen en laten verergerd de ervaren vermoeidheid.

Eigen invloed vermoeidheid - neutraal (of geen invloed)

Families (1): Invloed eigen handelen
Quotations: 13
Comment:

Eigen invloed op vermoeidheid is neutraal; eigen doen en laten verergerd noch verlicht de ervaren vermoeidheid (i.e. de vermoeidheid blijft gelijk)

Eigen invloed vermoeidheid - positief

Families (1): Invloed eigen handelen
Quotations: 20
Comment:

Eigen invloed op vermoeidheid is positief; eigen doen en laten verlicht de ervaren vermoeidheid.

Grenzen - opzoeken/aftasten

Families (1): Fysieke grenzen
Quotations: 17
Comment:
Opzoeken en verkennen van fysieke grenzen, mogelijkheden en eigen kunnen

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Grenzen - overschrijden

Families (1): Fysieke grenzen
Quotations: 31
Comment:
Fysieke grenzen overtreden, met als gevolg meer vermoeidheid en/of andere fysieke consequenties

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Grenzen - willen versus kunnen

Families (2): Controle over eigen leven, Fysieke grenzen
Quotations: 36
Comment:
Strijd tussen het willen en het fysiek kunnen. Botsing tussen ideeën hebben en het realiseren daarvan.

Grenzen - zelfregie/grip en controle vermoeidheid en leven

Families (1): Controle over eigen leven
Quotations: 35
Comment:
Controle krijgen op de vermoeidheid en daarmee weer grip op en regie over eigen levensinvulling. Vermoeidheid of patiënt bepaald de levensweg.

Leren omgaan met vermoeidheid

Families (1): Leren omgaan met vermoeidheid
Quotations: 83
Comment:
Beschrijving van proces van vallen en opstaan met betrekking tot het omgaan met vermoeidheid. Proces van zingeving aan leven dat in meer of mindere mate beperkt is door vermoeidheid.

Omgang - Aanpassen van leefstijl

Families (1): Omgaan met vermoeidheid (tactieken)
Quotations: 22
Comment:
Gezonder, bewuster of anders leven voor betere omgang met de vermoeidheid. Op een andere manier activiteiten ontplooien of verwante activiteiten ontplooien. Stoppen met activiteiten die niet meer kunnen. Adaptief proces voor betere omgang met de vermoeidheid.

Omgang - Acceptatie vermoeidheid

Families (2): Omgaan met vermoeidheid (tactieken), Acceptatie van vermoeidheid
Quotations: 35
Comment:

Accepteren van vermoeidheid/plaats geven van vermoeidheid/loslaten van hetgeen door vermoeidheid verloren is gegaan

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Omgang - Afleiding

Families (1): Omgaan met vermoeidheid (tactieken)
Quotations: 13
Comment:

Denken aan andere zaken dan vermoeidheid, opdat vermoeidheid even niet een rol speelt in het dagelijks leven.

Omgang - Doseren van activiteiten

Families (2): Omgaan met vermoeidheid (tactieken), Activiteiten
Quotations: 40
Comment:

Activiteiten doseren, opdat ze gemakkelijker met de vermoeidheid uitgevoerd kunnen worden. Bijv. Minder lange tijdsduur, activiteit opdelen in kleinere onderdelen, activiteit spreiden over meerdere momenten etc.

Omgang - Emoties ventileren

Families (1): Omgaan met vermoeidheid (tactieken)
Quotations: 6
Comment:

Emoties ventileren van boosheid en woede tot verdriet en angst.

Omgang - Hopen op verbetering

Families (1): Omgaan met vermoeidheid (tactieken)
Quotations: 13
Comment:

Hopen/verwachten dat SLE of vermoeidheid met den duur verbeterd.

Omgang - Informatie zoeken

Families (1): Omgaan met vermoeidheid (tactieken)
Quotations: 10
Comment:

Zoeken naar informatie over ziekte/vermoeidheid.

Omgang - Pauze/rusten

Families (1): Omgaan met vermoeidheid (tactieken)
Quotations: 71
Comment:

Activiteiten en handelingen onderbreken voor rustmomenten/pauzes, om even op adem te komen en niet te vermoeid te worden.

Omgang - Plannen/Anticiperen op vermoeidheid

Families (1): Omgaan met vermoeidheid (tactieken)
Quotations: 42
Comment:

Voortijdig plannen van activiteiten en anticiperen op toenemende vermoeidheid. Inbouwen van buffers of rustperiodes.

Omgang - Positief blijven

Families (2): Omgaan met vermoeidheid (tactieken), Acceptatie van vermoeidheid
Quotations: 17
Comment:

Positief ingesteld blijven, ondanks de beperkende vermoeidheid.

Omgang - Prioriteiten stellen

Families (2): Omgaan met vermoeidheid (tactieken), Activiteiten
Quotations: 30
Comment:

Bewust afwegen wat belangrijk is en wat minder belangrijk is. Door vermoeidheid keuzes maken wat wel en wat niet.

Omgang - Ruimte voor tegenslag

Families (1): Omgaan met vermoeidheid (tactieken)
Quotations: 4
Comment:

Mentale weerbaarheid voor tegenslagen in de omgang met de vermoeidheid. Rekening houdend met een mogelijke tegenslag of verergering van de vermoeidheid.

Omgang - Structuur/ritme daginvulling

Families (1): Omgaan met vermoeidheid (tactieken)
Quotations: 23
Comment:

Een duidelijke agenda en dagstructurering, opdat vermoeidheid zo weinig mogelijk activiteiten en dagelijks leven in de weg staat. Hangt samen met plannen en organiseren van activiteiten.

Omgang - Toekomstplannen

Families (1): Omgaan met vermoeidheid (tactieken)
Quotations: 10
Comment:

> Ideeën over de toekomst die veranderd zijn als gevolg van de vermoeidheid.

Perceptie vermoeidheid - Algemeen

Families (1): Perceptie van vermoeidheid
Quotations: 81
Comment:

> Algemeen. Ideeën over vermoeidheid. Waardeoordelen en beschrijving van vermoeidheidsklachten en de ervaring daarvan. Ook mogelijke ideeën over de oorzaken van de vermoeidheid.

Perceptie vermoeidheid - Anders dan “normale” moeheid

Families (1): Perceptie van vermoeidheid
Quotations: 19
Comment:

> Onderscheid tussen normale (fysieke/mentale) vermoeidheid na inspanning (of stress) en vermoeidheid als gevolg van SLE.

Perceptie vermoeidheid - Onvoorspelbaar

Families (1): Perceptie van vermoeidheid
Quotations: 18
Comment:

> Onvoorspelbaarheid van vermoeidheid en omgang met vermoeidheid. Wispelturigheid, wisselvalligheid, ...

Perceptie vermoeidheid - Stabiel

Families (1): Perceptie van vermoeidheid
Quotations: 2
Comment:

> Vermoeidheid is altijd gelijk, stabiel en/of op één niveau aanwezig.

Perceptie vermoeidheid - Wisselend

Families (1): Perceptie van vermoeidheid
Quotations: 36
Comment:

> Vermoeidheid is niet altijd gelijk en is wisselend, fluctuerend en wordt op tijden als minder of meer "moe" ervaren.

Sociale omgeving - Afhankelijkheid

Families (1): Sociale omgeving en vermoeidheid
Quotations: 6
Comment:
Gevoel van afhankelijkheid van anderen (familie, vrienden, artsen, apothekers (medicatie), etc.) in de omgang met vermoeidheid en het verrichten van algemene dagelijkse levensverrichtingen.

Sociale omgeving - Beloftes/afspraken

Families (1): Sociale omgeving en vermoeidheid
Quotations: 25
Comment:
Afspraken en beloftes maken tegenover zelf c.q. een ander die naderhand - door vermoeidheid - gebroken worden.

Sociale omgeving - Delen informatie vermoeidheid

Families (2): Sociale omgeving en vermoeidheid, Fysieke grenzen
Quotations: 44
Comment:
Delen van informatie over vermoeidheid met naasten en fysieke mogelijkheden c.q. limitaties aangeven. De mate waarin de naasten op de hoogte zijn en worden gehouden over de vermoeidheid van de patiënt.

Sociale omgeving - Lotgenoten

Families (2): Sociale steun, Sociale omgeving en vermoeidheid
Quotations: 7
Comment:
Contact zoeken met lotgenoten (andere SLE patiënten, NVLE e.d.)

Sociale omgeving - Relaties/contacten

Families (1): Sociale omgeving en vermoeidheid
Quotations: 81
Comment:
Veranderingen in de sociale omgeving. Verloren/verbroken contacten, nieuwe contacten, versterkte of verzwakte relaties met naasten, vrienden en kennissen.

Sociale omgeving - Sociale vergelijking

Families (1): Sociale omgeving en vermoeidheid
Quotations: 6
Comment:
Vergelijking met andere patiënten die het slechter hebben met vermoeidheid (neerwaarts) of die het beter hebben met vermoeidheid (opwaarts).
Of vergelijking tussen zelf en gezonde mensen of tussen huidige (met vermoeidheid) en voormalige (geen vermoeidheid en geen SLE) situatie.

Sociale omgeving - Stigma

Families (1): Sociale omgeving en vermoeidheid
Quotations: 26
Comment:
Gevoel benadeelt/anders behandeld te worden door de sociale omgeving als gevolg van SLE of vermoeidheidsklachten

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Sociale steun - Algemeen

Families (1): Sociale steun
Quotations: 43
Comment:
Sociale steun in instrumentele, emotionele of informatieve vorm van partner, kinderen, vrienden, arts en anderen.

Sociale steun - Arts/Gezondheidszorg

Families (1): Sociale steun
Quotations: 21
Comment:
Aandacht van arts/reuma-specialist, huisarts en andere gezondheidsprofessionals voor vermoeidheidsklachten

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Sociale steun - Psychologische begeleiding/maatschappelijke ondersteuning

Families (1): Sociale steun
Quotations: 13
Comment:
Psychologische hulpverlening of maatschappelijke ondersteuning gezocht in het leren omgaan met de vermoeidheid

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Werk

Families (2): Werk, Activiteiten
Quotations: 55
Comment:
Veranderingen in (vrijwilligers)werk als gevolg van vermoeidheid c.q. voor betere omgang met vermoeidheid. Bijv. Stoppen met werk, minder werken, ander werk, etc.
Ideeën over het belang van werk en de relatie werk en privé met vermoeidheid.