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Abstract

BACKGROUND: In spite of the evident importance of suffering, the medical and psychological literature, with some exceptions, contains few contributions toward an understanding of its phenomenology, etiology, and alleviation.OBJECTIVE: To enhance understanding of suffering in chronic physical disease, the authors applied qualitative content analysis to semistructured interviews with 12 patients with systemic lupus erythematosus.METHOD: This study was intended to be exploratory, adopting a predominantly qualitative approach, supplemented with quantitative data. Case reports, complemented by psychometric and objective illness-related data, were used to elucidate a model of suffering and to explain its etiology and its interaction with personal growth.RESULTS: Findings were consistent with the concept of suffering as a psychological process triggered and sustained by an appraised threat to the "Self" or "Personhood."CONCLUSION: Results indicate that various types of suffering have to be differentiated. Recognizing personal growth in response to the illness-experience may reduce suffering.
Suffering and posttraumatic growth in patients with systemic lupus erythematosus (SLE) – a qualitative-quantitative case study

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Key words: Suffering, Posttraumatic Growth, Personal Development, Coping, Systemic Lupus Erythematosus (SLE), qualitative content analysis, case report

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Abstract

To enhance understanding of suffering in chronic physical disease, qualitative content analysis was applied to semi-structured interviews in 12 patients with systemic lupus erythematosus. Case reports, complemented by psychometric and objective illness-related data, were used to elucidate a model of suffering and to explain its aetiology and interaction with personal growth. Suffering, as a mental process reflecting a threat to the intactness of the person, under certain conditions linked with personal growth, appears to play a more central role than physical threats due to the disease. Improved comprehension of suffering is most relevant for its alleviation in health care.

Introduction

Alleviation of suffering is widely regarded as one of the main objectives of health care, along with the prevention and cure of diseases. In spite of the evident importance of suffering, medical and psychological literature reveal only few contributions towards an understanding of its phenomenology, aetiology, and possibilities for its alleviation. Phenomenological definitions of suffering are confined to descriptions of emotional states as “severe distress” [1, p. 640], “a feeling of displeasure which ranges from simple transitory mental, physical or spiritual discomfort to extreme anguish, and […] apathetic indifference” [2, p. 62] or to attributes as “emotional, unpleasant, and psychologically complex” [3, p. 6]. The yet unsolved difficulties in defining the experience of suffering may be partially responsible for the vast lack of empirical research on this subject. As to the aetiology of suffering, Cassel’s definition of suffering in his seminal 1982 paper [1] offers an intriguing explanation. Here, suffering is “associated with events that threaten the intactness of the person” (p. 640). Cassell stressed that in suffering associated with illness, the extent of suffering is determined not by the illness itself, but by the meaning for that individual of the threat to his or her ‘personhood’. In his own words, “suffering is experienced by persons, not merely by bodies” (p. 639). According to Cassel [1], a simplified description of a person comprises dimensions as relationships with others, the range of activities, life experiences, the body, and aspects of transcendence. Based on Cassell’s ideas we developed a model of suffering in chronic disease which is depicted in Fig. 1a. A person, which is defined as above, falls ill. If the illness is interpreted as a threat to the intactness of the person, suffering is experienced as a consequence. To our best knowledge, the explanatory value of Cassel’s assumption illustrated by Figure 1 has not yet been empirically tested.

Fig. 1a-b about here

Possible mechanisms to overcome chronic suffering can be derived from this model. As resolving the threat to the person (i.e., healing) often is impossible in chronic disease, two possibilities remain: one is to change the meaning of the disease, e.g., by meaning-based coping as a means of making sense or finding benefit [4]. The second possibility is the dynamic development of the person, e.g. a substitution of certain threatened aspects of the self by others. This latter process
can be called personal growth. It has been reported that chronic or life threatening illnesses such as cancer are not perceived by the affected patients as only a danger or loss but also as a chance for personal development and growth. Only recently has research begun systematically to evaluate these positive aspects of the aftermaths of trauma and develop instruments to assess these changes called posttraumatic growth [5, 6]. Posttraumatic growth is defined as subjectively perceived positive changes in the aftermath of a trauma including the dimensions of detection of personal strength, changes in attitudes and philosophy towards life, novel ways of relating to other people, appreciation of life and spiritual changes. Concerning the interaction of distress and posttraumatic growth, existing empirical evidence is contradictory. In a recent study [7] on bereavement in parents after the death of a preborn baby we found a positive correlation of bereavement and posttraumatic growth. On the other hand, Znoj (2005, submitted) detected a u-shaped association of distress and posttraumatic growth in parents with children who survived cancer, indicating, that a “medium” amount of distress was correlated with maximal posttraumatic growth, meanwhile little distress did not trigger a growth process and a high amount of distress seemed to block a posttraumatic growth. In summary, to date no convincing theory exists to explain the simultaneous existence of symptoms and personal development as well as its interaction in traumatized patients.

The first aim of this study was to provide a phenomenological description of suffering in chronic disease. Systemic lupus erythematosus (SLE) was chosen as its characteristics impose an illustrative burden to the patients: It is a chronic relapsing autoimmune disorder which predominantly affects young women. It can involve most organ systems, interferes with social role function and can have marked effects on life expectancy [8, 9]. In clinical practice, wide variation is observed in the adaptation of individual patients to SLE [10]. A second aim of this study was to test the value of the model after Cassel (Fig. 1), to explain the aetiology of suffering and to improve understanding of the interaction between suffering, coping resources and personal development. Due to the lack of specific information regarding the definition of suffering, its aetiology and interaction with further constructs, a mainly qualitative approach – complemented by quantitative data – appeared to be most adequate method.

**Methods**

This study was approved by the Institutional Review Board of the Canton of Zurich.

**Subjects and procedure**

Most patients were recruited at a meeting of the regional SLE patient’s organization. Additionally, participants were recruited via an announcement on this organization’s homepage. To be eligible, patients had to fulfil the American Rheumatology Association (ARA) classification criteria [11] and had to have a sufficient command of German for the interview. After giving informed consent,
subjects participated in an extensive interview which was audio recorded, completed a questionnaire and underwent a rheumatologic examination.

Measures

A. Interview

Semi-structured interviews focusing on the subjective experience of suffering and self-perceived changes due to illness were audio taped. To avoid interviewer bias, patients were always first asked open questions which eventually were followed by more specific questions. The first part of the interview focused on the illness. Subjects were asked to describe all kinds of changes they experienced due to their illness. If not mentioned by the participants, this question was specified for the domains of health, social-, professional-, and emotional life, self-perception, goals of life, and spirituality. In the following sequence, patients were asked about their concept of the term “suffering”. Relevant topics in this section were “What do you think suffering is like?”, “Which attributes does suffering have?”, „Is there any difference between being ill and suffering?“, and „How do you behave when you are suffering?“. Illness and suffering were then linked by a couple of questions like “Which aspects of the illness make you suffer?” and “Are there any symptoms of the illness that do not cause suffering?”. Later on, participants were asked to visualize their person before the onset of the illness as well as their current person by means of PRISM+ ([12], see below). After its development, the interview-structure was tested and refined by means of two interviews which were not considered for further analysis.

B. Assessment of suffering

Pictorial Representation of Illness and Self Measure (PRISM): PRISM is a novel, visual instrument to assess the perception of suffering caused by illness [13, 14]. Subjects are shown a white A4-sized metal board with a fixed, yellow disk 7 cm in diameter at the bottom right-hand corner. Each patient was asked to imagine that the board represented his/her life as it was currently, and the disk represented the patient’s “self”. Subjects were handed a red disk, 5 cm in diameter, with a magnetic strip on its underside so that it could be attached to the board. The patient was asked to imagine that the red disk represents her/his illness and is asked, “where would you put the (Illness) disk in your life at the moment?” The distance between the two disks, representing Illness and Self respectively, is inversely related to the burden of the illness. This distance, measured in centimetres, is the main quantitative measure derived from PRISM (for ease of description, this measure is called the Self-Illness Separation (SIS) ). The possible range of SIS is 0-27cm.

C. Assessment of the person

PRISM can also be used with multiple detachable disks. Further disks represent individually important dimensions of a person such as relationships with others, range of activities, or transcendent aspects, and help to assess comprehensive self-perceptions. In this extended PRISM task, called PRISM+ [12], these additional disks can be placed on the PRISM board to
reflect relationships between the illness and other aspects of the patient’s life. The closer a disk is put to the yellow “Self” disk, the more essential is the respective dimension of the person relative to other dimensions. At the end of the interview (s. above), participants were asked to retrospectively illustrate the most relevant aspects of their persons before illness onset and then to indicate how this picture has changed due to the illness.

D. Coping resources, Posttraumatic Growth, and Health Related Quality of Life

Perceived Coping Resources (SOC): Coping resources were measured using the 13-item Sense of Coherence scale [15]. The scale gives a measure of the individual’s appraisal of his/her resources available to cope with stressors. Total SOC scores (range 13-91) are calculated from the sum of individual item scores. Higher scores signify better coping resources.

Posttraumatic Growth Inventory (PTGI): The PTGI [6] is a 21-item self-rating instrument for assessing positive outcomes reported by persons who have experienced traumatic events. The scale includes factors of New Possibilities, Relating to Others, Personal Strength, Spiritual Change, and Appreciation of Life. Cronbach’s alpha is .90 for the total score. A reliable German version of the PGI has recently been validated [16]. Assuming that an incurable illness such as SLE may initiate processes of personal maturation in the same manner that traumatic events do, we adopted the questionnaire instruction to the circumstances of SLE-patients.

Medical Outcomes Study Short-Form (SF-36): The SF-36 has repeatedly proven excellent psychometric properties [e.g., 17] in the assessment of health-related quality of life. Two summary scores – Physical Component Scale and Mental Component Scale – are derived from eight domains (Physical function, role limitations, emotional problems, social function, mental health, general health perception, vitality, and pain). Higher values indicate better health (range 0-100).

E. Clinical investigation

SLICC / ACR (Systemic Lupus International Collaborating Clinic / American College of Rheumatology) Damage Score: Damage, i.e. irreversible impairment since the onset of SLE, is usually defined as a clinical feature that must be continuously present for at least 6 months to score [18, 19]. Briefly, damage is defined for 12 organ systems: ocular, neuropsychiatric, renal, pulmonary, cardiovascular, peripheral vascular, gastrointestinal, musculoskeletal, skin, gonadal, endocrine damage, and the occurrence of malignancy.

BILAG (British Isles Lupus Assessment Group Disease Activity Index): BILAG includes a total of 86 items and measures SLE-related disease activity in 8 organ-based components (general, mucocutaneous, neurological, musculoskeletal, cardiovascular/respiratory, vasculitis, renal, and hematological activity) [20, 21].

Laboratory investigation: Blood was taken to determine erythrocyte sedimentation rate, hemoglobin, leucocyte – and platelet count, serum creatinine, complement (C3 and C4), antinuclear antibodies (ANA), and antibodies against dsDNA by immunofluorescence (IF) and enzyme immuno assay (EIA). Proteinuria was measured by dipstick method and, where
appropriate, 24-hour urine protein and/or EDTA clearance was recorded. Except for ESR, complement- and antibody determinants all the blood tests are part of the BILAG score.

**Analyses**

The interview records were transcribed according to an adaptation of international criteria [22] and qualitatively analysed by means of summarizing content analysis [23] using the software ATLAS.ti (5.1). A categorization system was developed analysing three interviews. The final categorization system comprised the four codes “changes due to the illness”, “causes of suffering”, “quality of suffering”, and “coping with suffering”. After an interrater-reliability training, this system was independently applied to three new interviews by two of the investigators (LW, SB). Interrater-reliability was calculated and the remaining interviews (including the three utilized developing the categorization system) were analysed by LW. The quotations of any code were summarized through the steps of generating a paraphrase, generalisation of the paraphrases onto an equal level of abstraction and reduction (e.g., integration of related paraphrases) of the data [23]. The qualitative technique of summarization as a rather inductive approach was chosen due to the lack of specific information about the phenomenology of suffering in chronic disease. Psychometric and objective illness-related data allowed for comparison of our sample with the general population of SLE-patients as well as comparisons within our sample. In order to test the plausibility of our model in explaining the aetiology of suffering in SLE, all case reports of the participants were studied thoroughly and complemented by objective illness related data as well as psychometric information on posttraumatic growth and coping recourses. In particular, we thoroughly analysed the sequential visual processes of the individual patients before the onset of the illness up to the present by means of PRISM+. This ideographic paradigm was chosen as being able to consider all individual details possibly relevant for the assessment of the theoretical model saturation. Also, we aimed to derive hypotheses about the interaction of suffering with posttraumatic growth. We selected three cases for more in-depth presentation. At the beginning of the illness, all three patients retrospectively assessed their suffering under the illness as maximal (SIS 0-1cm). However, to best exemplify distinct patterns of adaptation in SLE we chose one subject each with high, medium, and low current suffering.

**Results**

**Description of demographic and illness characteristics**

Fourteen subjects fulfilled the inclusion criteria and gave written informed consent. As the interview-structure was redefined by means of the first two interviews, the final sample consisted of twelve participants. Mean age of the twelve subjects was 48.4 years (SD 12.0), mean disease duration from onset of symptoms amounted to 13.8 years (n=11, range 2-35). BILAG and SLICC/ACR total damage score was 14.5 (n=11, range 6-23) and 2.7 (n=11, range 0-9), respectively. Subjects fulfilled a mean of 5.6 (n=11, range 4-8) ARA classification criteria. Mean Physical and Mental Component Scale in the SF36 was 39.1 (SD 10.0) and 50.0 (SD 11.2),
respectively. Mean SOC was 68.0 (n=10, SD=13.6) and mean PTGI score was 2.2 (n=10, SD=0.5). Mean current SIS (PRISM) was 92mm (n=12, SD=97mm).

**Qualitative analysis of the interviews**
Mean duration of the interviews was 94 (SD 15) min. For all twelve interviews, 309 relevant quotations were identified. Both independent raters identified relevant quotations with an agreement of 69% and reached a interrater reliability of $\kappa=0.79$ in assigning codes to quotations.

1. **Changes due to the illness (188 quotations)**

Negative illness effects on physical, social and emotional well being as well as positive consequences were mentioned. All twelve subjects reported typical SLE-symptoms as pain, fatigue, or skin problems related to sun exposure. Eight of them stated that they were severely impaired in everyday activities, mainly due to musculoskeletal pains. Ten subjects reported interpersonal problems due to the illness, eight experienced work-related constraints. Eight subjects mentioned unpleasant emotions such as sadness or anxiety. Five patients noticed that they were no longer able to realize important life plans, for the same number of patients it was detected that they could no more dedicate themselves to hobbies they previously enjoyed.

Regarding positively evaluated changes, eight subjects reported elevated self-esteem or self-assurance. Five patients had altered their evaluation of what is important in life, and five patients reported spiritual developments. Four patients considered themselves as more sensitive. Furthermore, many individual dimensions of personal development were reported.

2. **Aetiology of suffering (41 quotations)**

All twelve patients reported on various causes of suffering. Among the causes shared by many patients were somatic reasons (9/12 patients), constraints in being or doing things of high personal value (7/12 patients), and the social environment (5/12 patients). Physical causes comprises pain and disability. The category “constraints in being or doing things of high personal value” can best be illustrated by two quotations: "[..] I feel that I have changed somehow as a person and that I no longer feel the same. Sure, it’s normal getting older and to have a different outlook on life, but I think illness has changed me more than I like to acknowledge." (P09/Q45). Another patient (P05/Q22) stated: “Illness is like an unexpected thief that attacks one’s life and destroys one’s life expectations. With illness, goals in life fade away or you are convinced that you won’t be able to achieve the old goals. One has to painfully reconstruct one’s expectations and which goals are important as energy is lacking to achieve them.” Other patients mentioned concrete wishes or important life aspects that could no longer be realized. Many subjects reported social or professional disadvantages and isolation due to the illness. Further factors related to suffering were loss of autonomy due to the illness (3/12 patients) and worries about the future (3/12 patients). Three subjects emphasized that they suffered particularly from changes they could not or did not want to accept. Also, illness-independent causes of suffering such as compassion with suffering family members or loss of beloved friends were reported.
3. Phenomenology of suffering (68 quotations)

Difference between illness and suffering
Nine subjects expressed their opinions about a relationship between the concepts of illness/pain and suffering. Eight of these patients explicitly mentioned that illness and pain are not identical with suffering. Patients experienced illness-independent suffering as well as periods without suffering; e.g. “The illness is always there. Suffering is not always there” (P01/Q159) or “But you can have a happy life with the illness more at the back of your mind” (P05, Q19). Suffering was considered to be a psychological aspect or perception of the somatic illness, assuming that certain factors mediate the relationship of illness and suffering. Examples of such factors were illness duration, degree of pain and disability, threat to life and curability. For instance, explaining why a flu does not make her suffer, one patient stated: “I know that I will get rid of it” (P08/Q67). Further moderating factors were social support and time of occurrence of symptoms (it was emphasized that symptoms occurring after a period without disturbances particularly caused suffering).

Kinds of suffering
Asked about their understanding of suffering, seven subjects stated that they perceive different types of suffering. Five of them differentiated two kinds of suffering – somatic and psychic suffering. Somatic suffering was closely associated with pain. However, pain does not automatically imply suffering. Rather, it became evident that – as for the more general relation between illness and suffering - also the relation between pain and suffering is mediated by factors as degree, duration, or time of occurrence of pain. The following quotation illustrates this latter point: “After a good time, when the pain returns, even if it is not very strong or restricting, I cannot bear it, I don’t want to bear it” (P01/Q158). Psychic suffering reduced life to a minimum; it was described by terms such as “to have no energy in the head, no faith, no trust, no hope any more” (P03/Q88). This difference is illustrated by the following quotation: “In my opinion, there is a somatic and a psychic suffering. Somatic suffering is only present when I have a pain. Psychic suffering is more like, how do I cope with the fact that I have this illness, that I will never again recover from it, that it will be there forever” (P12/Q20). Both types of suffering interact. Somatic suffering can prevent the fulfillment of important personal goals and thus cause psychic suffering. From the last quotation (P12/Q20) it is obvious that the pain associated with somatic suffering can also trigger psychic suffering by its signal character reminding a patient of the implications of the illness. The following quotation shows that also psychic suffering influences somatic suffering: “[…] suffering in the head is worse, as it also influences my body, my will to stay the course […].” (P5/Q78). Two patients stated that somatic suffering is less severe than its psychic equivalent, as it is treatable by analgesic medication and one can get used to the pain.

4. Coping with suffering (12 quotations)
Interestingly, the question „How do you behave when you are suffering?”, resulted in rather uniform answers. Nine patients responded with social withdrawal to suffering. One quotation illustrates this phenomenon: “When I was aware of feeling bad I retreat into my shell to avoid
Questions about whether I feel well and to avoid explaining why I feel awful. In these situations I do not have the energy to explain my situation or talk about pains or the reasons why I can't participate in many social activities." (P09/Q26). We subsumed several strategies as relaxation techniques, activating social support, activities and distraction to the term “behavioural coping” (4/12 patients). These were opposed by strategies such as trying to understand the own situation, ignoring problems, or repression of worries, which we called “cognitive coping” (3/12 patients). Behavioural and cognitive coping mostly occurred in a second step after social withdrawal. In two subjects, behavioural coping was associated with somatic suffering.

5. Suffering and posttraumatic personal growth – three case studies

Case reports including qualitative assessment of personal histories and quantitative measures on the three relevant dimensions of suffering (PRISM), personal growth (PRISM+, PTGI) and coping resilience (SOC) allowed for a first test of the explanatory value of the model of suffering according to Cassell. The relevant quantitative data of the three patients are presented in Table 1.

Table 1 about here

1. Mrs. D: high current suffering

Mrs. D. is a 35 year old occupational therapist who works part-time as her fatigue and pains due to SLE are too severe for her to be able to carry out a full-time job. After 6 years of severe symptoms for which doctors could not find a diagnosis, she was diagnosed two years ago as having SLE. This ended a very painful and humbling odyssey between doctors on her search for an explanation as to her many symptoms of which fatigue, joint pains, loss of hair and severe sensitivity to light were the most difficult to cope with. For Mrs. D. the most difficult aspect of SLE was the destruction of her life's plan. “No, at the moment I do not see any clear perspective for my future.” Many wishes such as having a family and a child were disrupted and she is afraid of losing her job due to weakness in her hands. She also lost several friends due to her physical problems as they disrupted her capacity to participate in regular social activities such as dancing or playing volleyball. Before SLE started she had many hobbies, liked sports and being outside in nature and was a curious and outgoing person. Now she often has a feeling of resignation. At her current point in life SLE has a central place (SIS=1cm). She also sees her dependency as a main stay of her life. Some friends still remain, but nevertheless she feels somewhat isolated. Earlier important aspects of her self such as “sports”, “nature” or “meeting people” are still existent but are negatively evaluated as compared to the qualities these aspects had in the past. At the end of the interview Mrs. D described SLE as an enemy or wild animal that wants to destroy her. Fig. 2a-b reveals the eye-catching difference between Mrs. D.’s person before illness onset and her current state. Only a pile of shards remains from the well-structured picture of the former person. Some aspects have turned to the contrary (e.g., dependency instead of independency), others have no
place any more in her life (e.g., sports), further aspects are intermingled with the discs representing illness and problems.

Here about Fig. 2 a-f.

2. Mrs. T: medium current suffering
Mrs. T. is a 30 year old woman. She lives with her husband and their two children in a large house in the countryside. In recounting her youth she sees the progressive cancer of her mother as a large shadow hanging over her childhood. As the oldest daughter she took all responsibility for her two sisters and was also very active in supporting her mother in many other aspects. The family lived in a small village where she felt under the watch of the villagers who expected her to be “the good girl”. Accordingly, Fig. 2c not only represents aspects typical for a school girl (as going out/having fun) but also the illness of the mother intruding into the disc representing the self of the patient. At the age of 19 the first symptoms of SLE arose: sensitivity to sunlight, shortness of breath, loss of hair and kidney problems, but currently she suffers little pain. Her disease changed her life markedly: her core-belief: “I am mature and do not have problems” was shattered. She started to recognise her own needs and dependencies. A few years later her physician told her she had a life expectancy of less than 5 years. This information resulted in huge changes in her life, reflected by Fig. 2d: she quit her job as a secretary in an insurance company (“Why should I sit around five years here just to die afterwards?”), married her boyfriend and decided rigorously on which activities and social encounters she wanted to pursue and which to stop. Some months later at the age of 24, she became pregnant and her first child was born after a very difficult pregnancy. A second child was born two years later. She also developed new interests. As a devout atheist she started to be interested in spirituality and became a religious person. She now feels much stronger and calmer than before the onset of SLE. As can be shown in Fig. 4a-b the self-perception as visualized in PRISM+ has changed markedly in the course of the disease. What is her attitude towards SLE? Mrs. T. talks about SLE as if it were a friend: “SLE somehow shapes my life and has a marked impact on most things that I do. It is difficult to accept that sunlight does so much harm to me and I also suffer from anxiety and have had several panic attacks. But on the other hand, SLE has guided my life positively in the last 10 years. I would not know life and myself as well and would not enjoy the transitoriness as well. Life is a precious gift”. The current SIS was 6cm and indicates an average level of suffering.

3. Mrs. U: low current suffering
Mrs. U. is an energetic 67 year old woman with a very positive outlook on life. She lives alone in a flat in the city of Zurich. Currently she describes many typical symptoms of SLE such as fatigue, pains, sensitivity to sunlight, loss of hair and problems with digestion. Her most difficult time was five years ago when she was so sensitive to sunlight that she had to stay inside for weeks. At this time she felt very depressed and overwhelmed by the illness (SIS=0). “At this time I was my illness!” During this severe crisis she heard of the suicide of Hannelore Kohl, the wife of the
German chancellor Helmut Kohl, and decided spontaneously to change her life and attitude to her illness radically. She stopped hiding her illness in front of her friends. They reacted very positively and started to go out regularly in the evenings and jokingly called her “our vampire”. Although she felt tired and suffered from pain she recognized the positive effects of her decision to live her life.

To give an impression of her life before the illness by means of PRISM+ Mrs. U. needed only two discs (Fig. 2e): one is called “Knowledge” and the second “Family”. When asked if she would like to represent other mentioned aspects within this picture she insisted that only knowledge and family were important enough to be essential parts of her person. She worked in the area of cultural history for a large Swiss publisher. Although she received a pension Mrs. U. still works as a freelancer in the company. The family was very important and she regularly looks after her nephews. Mrs. U. is a fighter: “I hate to be treated like a sick person. But sometimes, when my SLE is very active, I am ill. But I want for my friends – as I do- to reject seeing me as ill.” At the end of the interview the interviewer accompanied Mrs. U. to the physical exam. It was cold and most of the patients complained of an increase in pain. Mrs. U. was different: “I forget about my pains, they are not my main stay”. And laughed. Her current SIS was 24cm. As reflected by Fig. 2d, neither the Lupus nor the described crisis associated with disease onset caused any long-term changes of Mrs. U. person.

**Reasoning on the three case studies**

Explaining the different degrees of current suffering (SIS-PRISM, tab. 1) of these three patients, one might feel tempted to assume that Mrs. U. just benefits from a sound constitution, and that Mrs. D. suffers from an especially severe illness, in contrast to Mrs. T. who does not experience very restricting symptoms. However, the somatic data does not support such a hypothesis (see tab. 1). With the exception of Mrs. U.’s high BILAG total score, the three subjects can be regarded as comparable in terms of illness severity. According to the model of suffering by Cassell [1], a consideration of the whole person is more promising approach to understanding suffering than assessing the physical state alone.

Mrs. D. is one of the subjects in our sample who suffered most severely under the illness. Many aspects of her person – independency, new experiences, affinity with nature, sports – were strongly affected by the illness. Although not integrated in figure 3a, it became apparent in the course of the interview (see case report) that the wish to have children was one of the most essential aspects of Mrs. D’s identity. That the illness prevented her from realizing this plan seemed to have had severe implications for her identity as a woman. Figure 3b evokes the impression of a ruin of the original person: neither was it possible to maintain the old person under the changed condition, nor did Mrs. D. succeed in substituting the lost aspects of her person.

Another possible response to lupus was exemplified by Mrs. T. Mrs. T. underwent an impressive change of her person (fig. 4a-b). Instead of caring for her family and ill mother, she started to care for herself. She turned from what she calls superficiality to spirituality. She gave up her professional career and set up her own family. Her “new person” does not consider the lupus as a
fundamental threat, but as a companion. Nevertheless, a SIS (PRISM) of 6cm indicates that Mrs. T. is also suffering on her SLE. This finding makes it plausible that the relationship between suffering and personal development might be more complicated than initially assumed. A subject may seek to exchange or adapt threatened dimensions of the persons, but this development does not appear to necessarily prevent suffering altogether.

Retreated in her darkened flat, Mrs. U. suffered immensely (PRISM SIS = 0) under an almost complete destruction of her existence. There seemed to be no way to accommodate her person with the illness. Scared off by the destiny of Hannelore Kohl, Mrs. U. mobilized her coping resources (e.g., her social network, her willpower) in order to protect the central dimensions of her person. She integrated the illness into her life, ceased to deny it to her friends and allowed the pain to become a part of her existence: “Pains are there, that’s just a fact.” The two central aspects of her person – family and knowledge– could be maintained almost unchanged (figure 2e-f), nevertheless they showed some development: Mrs. U. started to take care of her grandchildren, and her striving for knowledge broadened from history to knowledge in a more generals – also spiritual – sense. Of course, Mrs. U. took advantage of the great social support she received.

Summarizing this interpretation on a more general level, there is evidence for three different constellations, all beginning with immense suffering at the time of the SLE diagnosis. Available coping recourses or attributes of the person may allow adaptation to the conditions of a chronic illness, i.e., integration of illness aspects into the person. In this case, neither a large amount of suffering nor large degree of personal development are to be expected. If a person’s attributes or coping mechanism do not allow such an adaptation, the hitherto person cannot exist in the known way. This may lead to the experience of enduring suffering or to a process of personal development resulting in a person less threatened by the illness.

**Discussion**

This is – to our best knowledge – the first empirical study performed to obtain a specific characterization of suffering in chronic disease and to test a model of the aetiology of suffering as well as its interactions with personal growth. The chosen ideographic paradigm combining qualitative, psychometric and objective illness-related data allowed a detailed illustration and understanding of the complex processes under consideration. The coding system developed proved reliably to summarize the subject’s statements. The present mean disease activity of 14.5 was comparable to other cohorts with rather high disease activity [24, 25]. However, most BILAG A scores in this cohort concerned the musculoskeletal system. Nevertheless, the participants covered the whole spectrum of disease activity from mild to active SLE (BILAG total score from 6 to 23). The present mean total SLICC/ACR damage score of 2.7 compared well to other published cohorts [26, 27]. Thus, comparison of our sample with the general SLE population allows the conclusion that our subjects showed typical illness characteristics [24-27] and psychosocial consequences [28].
Nevertheless, this study has a number of limitations which need to be addressed. First of all, the generalizability of the results of a case study remains unclear until replication by further studies. The study sample was confined to members of the Swiss SLE Association (SLEV) (or those patients accessing the SLEV-homepage) who volunteered for unpaid participation. Thus, our sample might reflect a selection bias, e.g. in personality characteristics such as social orientation. By not applying a purposive sampling strategy we risked excluding particular forms of suffering, for example associated with very severe or very mild forms of an illness. However, the broad range of illness severity reviewed above is what would be expected from a purposive sample. Further, as SLE affects mainly females, our sample consisted of only female patients. This is important to remember as some evidence suggests that the relation between suffering and growth might be different for female as compared to male subjects [7]. As subjects were asked for several retrospective statements, we cannot exclude that some of our results may be influenced by memory distortions or dominated by current mental states.

Nevertheless, the rather uniform answer pattern shown by our subjects lets us assume that our findings reflect central phenomenological aspects of suffering rather than influences of confounding variables. Illness and suffering are distinct, yet, related constructs. On the one hand, suffering is often caused by somatic reasons; on the other hand, constraints in being or achieving things of high personal value, and the social environment were often mentioned reasons of suffering. The latter finding fits well with Cassel's assumption that a threat to a central dimension of the person lies at the heart of suffering. Based on the obtained descriptions of suffering and reflecting the two kinds of causes of suffering (somatic reasons vs. threat to the person), two kinds of suffering can be postulated: psychic suffering and somatic suffering. This conclusion requires a specification of Cassel's model which will be presented below. Typically, patients cope with suffering by social withdrawal. We cannot, however, clarify if social withdrawal is specific to suffering or a general coping mechanism of our sample of SLE-patients. The coping mechanisms of social withdrawal as well as behavioural and cognitive coping seem to refer to a specific moment when suffering is experienced and aim at ceasing this sensation. However, none of them can prevent that the person will suffer under the disease again and again. With respect to chronic suffering, two possibilities as to how it can be overcome have been postulated based on Cassel's assumptions in the introduction: changing the meaning of the disease or a dynamic development of the person.

Compared to a somatic point of view, the three case reports yielded rich information necessary to assess the theoretical model saturation of Cassel's aetiological assumption. This ideographic approach considering as many details of the given cases as possible strongly supports the concept of a threat to central dimensions of persons lying at the heart of suffering. Furthermore, we were able to derive testable hypotheses on mechanisms of the interaction of suffering, personal development, and coping recourses. It is important to notice that the interaction by which personal
development modifies suffering appears to be more complicated than initially assumed based on the model according to Cassel. Personal growth is no guarantee to cease suffering completely. Most excitingly, our results implying three different kinds of outcome of this process closely meets the position of other authors. Joseph and Linley [29, p.1046] summarize “[…] three cognitive outcomes to the psychological resolution of trauma-related difficulties […]. First, that experiences are assimilated, leading to a return to pre-trauma baseline […]. Second, that experiences are accommodated in a negative direction, leading to psychopathology and distress. Third, that experiences are accommodated in a positive direction, leading to growth because the person has evolved and developed their world view in a light of the new traumatic information”. These three outcomes could well be labeled by the terminology suggested by O’Leary and Ickovics as recovery, survival, and thriving [30, cited according to 29].

Based on our results we suggest the following adaptation of the model of suffering in chronic disease (Fig. 1b). A perceived threat to the person results in the experience of psychic suffering. However, for a second type of suffering, somatic suffering, this interpretation process does not appear to be necessary. Here, a more direct pathway from the illness to suffering representing pain can be drawn. Under certain conditions (see above), suffering, in particular psychic suffering, is associated with a process of personal development. Of course, personal development does not automatically imply growth: as in the case of Mrs. D., losses that cannot be substituted (survival) are possible as well.

Longitudinal studies of representative samples will be needed to prove the validity of the results of this case study. Statistical techniques such as cluster analysis would be able to demonstrate whether the three detected ways of interaction between suffering and personal growth reflect general types of constellations of these constructs. In particular, the effect of personal development on suffering needs to be studied more carefully. It would be interesting to consider different types of suffering, e.g., suffering due to bereavement vs. suffering under chronic disease. Furthermore, the phenomenology of somatic and psychic suffering should be compared. As we did not anticipate this differentiation resulting from our qualitative analysis, the interviews did not elaborate on this important question. Finally, interventions based on the outlined nature of suffering could be developed and tested against treatment as usual.

Alleviation of suffering is one of the main objectives of health care. Which directions towards this aim are pointed out by our results? From the moment of the diagnosis onwards, the knowledge of being chronically ill causes a process of psychic suffering. Furthermore, constraints in being or achieving goals of high personal value and hampered social interactions add to or will add to this process. As long as scientific medicine restricts itself to the alleviation of physical symptoms it will have no satisfactorily understanding nor treatment of patients suffering as different as Mrs. B, who lost most of her loved self-aspects and suffers enormously or Mrs. T, who is guided by SLE in new
spheres of her existence. Thus, health professionals need to understand the interaction of the illness with a subject’s sense of her or his self. Derived from Cassel’s model (Fig 1a), alleviating suffering in SLE-patients consists of two major aspects: Either assistance in reducing and redefining the threat of SLE to their selves, or by redefining the selves. Based on this theoretical baseline specific therapeutic interventions to reduce suffering need to be developed.
### Tables

**Table 1: Burden of suffering and somatic parameters of three SLE-patients**

<table>
<thead>
<tr>
<th>Subject</th>
<th>SIS at illness onset</th>
<th>Current SIS (PRISM, cm)</th>
<th>SOC</th>
<th>PTGI</th>
<th>BILAG total</th>
<th>Damage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mrs. U.</td>
<td>0</td>
<td>24</td>
<td>72</td>
<td>1.9</td>
<td>14</td>
<td>2</td>
</tr>
<tr>
<td>Mrs. D</td>
<td>1</td>
<td>1</td>
<td>40</td>
<td>1.4</td>
<td>9</td>
<td>1</td>
</tr>
<tr>
<td>Mrs. T.</td>
<td>0</td>
<td>6</td>
<td>69</td>
<td>2.7</td>
<td>6</td>
<td>1</td>
</tr>
</tbody>
</table>

SIS: Self-Illness-Separation; PRISM: Pictorial Representation of Illness and Self Measure; SOC: Sense of Coherence; PTGI: Posttraumatic Growth Inventory
Figures
References


