A Taxonomy of Disease Experiences of Dutch Women with Sjögren's Syndrome from the Perspective of the Patient

Master thesis

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ABSTRACT

The aim of this study was to explore, structure and summarize life experiences of women with Sjögren's Syndrome (SS) from the perspective of patients. The expectation was that illness experiences, psychological response, social interaction and management are important life domains in SS. Additionally, the expectation was that experiences of patients reflect consequences of common symptoms of Sjögren's syndrome such as dryness of mouth and eyes, that involvement with the disease of family, partner and social network will be experienced by the patients and that not only outcomes but also management is represented in the taxonomy.

A concept mapping technique was used. Interviews in a previous study yielded 75 experiences of living with SS. A sample of 52 women, sorted these experiences by content and filled out questionnaires regarding the health-related quality of life and experiences of living with SS. A hierarchical cluster analysis was used to structure the experiences. Descriptive analyses were used to examine the agreement of patients with these experiences.

In line with the expectation, cluster analyses showed a main clustering of primary symptoms, emotional processing, social interaction and self-management. Besides, clusters of experiences with ignorance and doctors were found. The results of the second part of the study gave more individual descriptions about the experiences. All primary symptoms are identifiable and there is little ignorance about the disease. The diagnosis is a relief for the patients, it takes the uncertainty away. Besides, management seems important in dealing with the disease. Participants show that acceptance, calmness and control over medical treatment contributes positively. Lastly, understanding of the disease and attention from family, partner and social network is essential for the patient.

Future research should try to overcome the limitations of current research by examining cultural differences in the experiences including management of SS and by doing qualitative research on experiences of Dutch women with SS. The current findings highlight the patient's view in quick insight in the problem domains. The findings could be considered in the construction of a screening instrument for SS, in the development of intervention- and education programs of SS and in the construction of a questionnaire.

Content

Preface 4
1. Introduction 5
2. Methods 8
  2.1 Procedure 8
  2.2 Sample 9
  2.3 Measures 10
  2.4 Statistical analyses 11
3. Results 11
  3.1 EQ-5D-5L 11
  3.2 Card sorting task 13
  3.3 Checklist experiences with SS 16
4. Discussion 20
  4.1 Main findings 20
  4.2 Strengths, limitations and future directions 21
  4.3 Implications 22
  4.4 Conclusion 23
5. References 24
6. Appendix 28
  6.1 Questionnaires 28
  6.2 Syntaxes IBM Statistical Software Package for the Social Sciences 22 37
    6.2.1 Syntax Cluster analyses 37
    6.2.2 Syntax descriptive- and non-parametric statistical tests for one sample 40

Preface

Presented here is the final version of my master thesis, which is submitted as a fulfillment for the Master's Degree in Clinical and Health Psychology at Utrecht University. The thesis is about disease experiences of Dutch women with Sjögren's syndrome. This subject has been of interest to me because of experiences with Sjögren's syndrome in my family. I appreciated to learn more about the subject and its consequences. The execution of the research progressed smoothly because of the fast data collection and good cooperation with R. Geenen and volunteers.

First of all, I would like to thank R. Geenen for his guidance and feedback throughout the completion of my thesis. He made me enthusiastic in doing research and was always, even abroad, available to answer my questions. Next, I would like to thank all of the participants who were willing to help me to conduct this study. Lastly, I want to thank Marianne Visser and Marjan Schipper, volunteers of the national association of Sjögren patients of the Netherlands, for the collaboration in recruiting participants and interpreting the cluster analysis.

1. Introduction

Symptoms of Sjögren's Syndrome (SS), a chronic autoimmune disease, have effect on physical activity, intimacy, work, daily activities and social life (Segal et al., 2008). However, most studies have only focused on one single physical consequence of the syndrome even though SS has influence on much more domains (Chai & Logigian, 2010; Leeuwen et al., 2016; Valtýsdóttir, Gudbjörnsson, Lindqvist, Hällgren, & Hetta, 2000; Rojas-Algayaga et al., 2016). Furthermore, previous research paid no attention to the patient's perspective of the impact of the disease on quality of life. There is need for a comprehensive overview of the consequences of SS from the patient's view. This is necessary for further research in treatment options of SS, screening of SS in health care and education about SS for patients and social network. The expectactions of the current study are guided by the existing literature, which is described in this introduction.

Sjögren's Syndrome has been defined as a disease that primarily involves the exocrine glands (Tincani et al., 2013). In primary Sjögren's Syndrome (pSS), the syndrome with symptoms as dry mouth, eyes and other parts of the body occurs on its own. In secondary Sjögren's Syndrome (sSS) the disease occurs in association with another autoimmune disease (Peri, Agmon-Levin, Theodor & Shoenfeld, 2012). PSS has an estimated prevalence of 0.019 – 0.6% in European women (Anagnostopoulos et al., 2010; Bowman et al., 2004; Maldini et al., 2014). The preponderance of pSS in women is 90% (Vitali et al., 2002). Diagnosis of SS is difficult because it affects many different areas and therefore many different specialists are involved. In addition, there is lack of agreement about the diagnostic criteria and specialists see associations of the complaints of SS in women with the menopause (Carsons, 2001).

A couple of studies describe multiple negative consequences of SS. Patients in these studies mainly report low physical- and mental well-being and high fatigue (Champey et al., 2006; Goto, Yagi, Matsumoto & Tsubota, 2002; Vitali et al., 2002). Compared to healthy individuals, patients have a diminished general functional capacity, joint problems, a decreased ability to engage in aerobic exercises and higher levels of fatigue, pain, anxiety and depression (Bowman et al., 2004, Strömbeck et al., 2003, Westhoff et al., 2011). SS, and specifically dry mouth symptoms, have an obvious negative influence on the quality of life of patients (Ikebe et al., 2007; Locker, 2003; Segal et al., 2009; Thomson, Lawrence, Broadbent & Poulton, 2006). Enger, Palm, Garen, Sandvik and Jensen (2011) have found that patients with high levels of oral distress scored significantly lower on health-related quality of life than patients with low levels of oral distress, indicating that oral problems have a marked impact. Also in comparison to control groups, patients with dry eyes due to suffering of SS have a decreased quality of everyday life (Mertzanis et al., 2005).

The experiences of the symptoms in SS, as described before, cannot be understood on its own (Ngo, Thomson, Nolan & Ferguson, 2015). The authors state that the disease needs to be understood in a holistic manner for better understanding and treatment. According to this study, it must be examined in the context of individual characteristics (such as coping style, lifestyle, and perceptions) and in the environment in which the person lives (and which healthcare professionals and social network are part of) (Ngo, Thomson, Nolan & Ferguson, 2015). For this reason, the current study goes beyond a description of the impact of 'primary symptoms' of SS and is about how people see, cope with and interpret their disease.

Although the findings in previous studies on symptom experiences of SS have made important contributions to clinical strategies, medicines and other research, not many studies were able to give a comprehensive overview of all domains of consequences women with SS experience. A study of Rojas-Alcayaga et al. (2016), which had in-depth interviews with twelve Chilean women with pSS, identified three categories in pSS by selective coding, which are more than only physical symptoms, namely: illness experience, psychological response and social interaction. In addition to the impact of dryness symptoms, concerning the category illness experience, the study found pSS is hardly recognized by the patient which also has consequences for emotional reactions and understanding of the disease by others. The psychological response to pSS is related to loss of health, but also to 'ignorance' of the disease and problems within social interaction (Rojas-Alcayaga et al., 2016). This produces feelings of sadness, abandonment and powerlessness in patients. Concerning social interaction, patients experience difficulties in maintaining social relationships while social support is fundamental to maintaining activities and sustaining social networks (Rojas-Alcayaga et al., 2016). These results are considered as a basis for the domains in the comprehensive overview the current study will give. The overview will be a completion of experiences that women with SS have, of which Rojas-Alcayaga and coworkers (2016) described a part.

Huber et al. (2011) defined illness experience, psychological response and social interaction like Rojas-Alcayaga et al. (2016), as three domains of health: physical, social and mental. Following the physical domain, a healthy organism is able to mount a prospective response, to reduce the potential for harm and restore an equilibrium when confronted with stress (Huber et al., 2011). According to the mental domain, the sense of coherence is a factor that contributes to the capacity to cope with and recover from psychological stress. Health in the social domain is a balance between opportunities and limitations affected by social and environmental challenges. People are able to participate in work and social activities by successfully adapting to their illness. In short, Huber et al. (2011) say: "Health is the ability to adapt and to self-manage". According to this view, the domains of SS the current study will find, are considered to also reflect the degree to which a person is able to adapt to deteriorated conditions instead of the status of health as a result of the consequences of SS per se.

Besides the more holistic view on SS as compared to previous studies, in the current research the participating patients have a large share in the interpretation of the study. The way one see and interpret things determines how you respond and no one else can assume another person's internal frame of reference (Rogers, 1951). In order to do research on consequences of a disease for a patient, the best information comes from the patient itself. Kelly (1955) emphasizes that every person is a scientist: they construe their own behavior by categorizing, interpreting, labeling and judging themselves and their surroundings. In the current study the patients need to interpret, structure, criticize and sort statements about SS, the researchers are non-evaluative (Rogers, 1951).

First, the aim of the present qualitative study is to structure and summarize life experiences of women with SS in an integrated model. This study contributes to the existing literature by focusing on a holistic view of the consequences of SS and as the interpretation is from the perspective of the patient instead of the researchers. A structured and integrated model about disease experiences is important for screening of SS and education about SS because it offers a quick impression of the consequences. Based on previous research, the expectation is that multiple life domains are influenced by SS; especially in illness experience, psychological response and social interaction (Rojas-Alcayaga et al., 2016). Besides, the expectation is that management of the disease has consequences on life experiences of the patients (Huber et al., 2011). A valid and reliable method to generate and structure patient's individual experiences with SS is concept mapping. The patients structure 75 statements about SS, derived from detailed interviews with twelve women who had pSS (Rojas-Alcayaga et al.,2016). A statistical technique, described in the methods, structures the sorting of the patients.

Secondly, a hierarchical overview of the opinion on the statements that participants have sorted provides information about the importance of each cluster for the participants and is relevant for the screening and handling of SS patients. Most of all, it is a contribution to future research on treatment options. Based on previous research, the expectation is that experiences of patients reflect consequences of common symptoms of Sjogren's syndrome such as dryness of mouth and eyes (Baldini, Talarico, Tzioufas & Bombardieri, 2012; Leeuwen, Schipper, Schueler-de Kort & Geenen, 2013; Tincani et al., 2013; Vitali et al., 2002), that involvement with the disease of family, partner and social network will be mentioned by the patients (Rojas-Algayaga, 2016) and that management is represented in the taxonomy (Huber et al., 2011).

2. Methods

2.1 Procedure

The ethics committee of the faculty of social and behavioral sciences (FETC) approved the research proposal. All participants provided written informed consent. Participants were recruited through an announcement in ‘n’ Ogenblikje’, a national magazine for patients with Sjögren’s syndrome, and through a message on Facebook by the national association of Sjögren patients of the Netherlands. The interested participants could send an e-mail to register. This resulted in 61 women with SS who wanted to participate. The registered participants received an envelope on their postal address with an information letter, informed consent, instruction booklet with questionnaires, 75 cards with statements about SS and a response envelope to send the questionnaires back. The card sorting task and questionnaires were performed at the participants’ homes.

This study employed a concept mapping design for the card sorting task. Quantitative analyses were used to structure qualitative materials. The concept mapping technique consisted of three steps. First, the participants individually sorted 75 cards with statements about SS into piles, each pile was later labeled by the participants. The participants wrote the numbers of the cards and the labels of the piles down on a score form. Secondly, to classify the statements sorted by the participants, a hierarchical cluster analysis is done in a statistical software program (see 2.4 Statistical analyses). Lastly, a project group consisting of two patient representatives (M.V.) (M.S.), one professional in rheumatology and psychology (R.G.) and one master student clinical psychology (V.H.), analyzed the hierarchical cluster analysis and discussed about the amount of clusters. The cluster analysis was used to structure the experiences of the participants with SS in a comprehensive overview.

Besides the card sorting task, the participating women completed additional questionnaires: EuroQol 5 dimensions 5 levels (EQ-5D-5L), the Checklist experiences with SS and some demographic questions. For questions or help with the card sorting task or additional questionnaires, participants could contact the researchers by e-mail and telephone, the researchers were available to help at the participant’s home. The participants had the opportunity to give comments on paper to the researchers about the participation. 52 participants returned the questionnaires free by post.

2.2 Sample

The sample consisted of 52 women with SS. Five participants were excluded because they did not understand the instruction that asked to sort the cards by content of the statements instead of giving a personal value on the statement as the labels of the piles indicated. One participant was excluded because she placed too much cards in one pile and most of the cards in more piles than one. Based on these exclusions, six participants were excluded, leaving a sample of 46 women with SS. This sample is analyzed in the research. The socio-demographic characteristics of the participating individuals are shown in Table 1. The sample is a representative group of women in gender and age (M = 60.6, *SD* =12.3). SS has female preponderance (90%) and manifests most frequently over age of 55 (Kvärnstrom, Ottosson, Nordmark, & Wahren-Herlenius, 2015; Mavragani & Moutsoupoulos, 2010; Vitali et al., 2002). However, symptoms were much longer present (M=10.6 years) before the diagnosis took place.

Table 1
The mean scores (M) and standard deviation (SD) or percentage (%) and range of the sociodemographic variables.

Characteristic (n=46)	*M* (*SD)* and range or percentage (%)
Age in years	60.6 (12.3), range = 24 – 85
Diagnosis duration in years	13.2 (11.3), range = 1 - 61
Symptom duration in years*	23.8 (16.6), range = 4 - 64
Symptom duration before Diagnosis	10.6
Marital status	65.2%
Married or co-habiting	6.5%
Divorced	28.3%
Single	
Highest level of completed education	
Primary education	0%
Lower vocational education	6.5%
Medium general education	34.8%
Medium vocational education	13%
Higher general education	2.2%
University of Applied Sciences	28.3%
University	15.2%

*missing values: two patients did not fill out this question

Twelve participants had missing values in the card sorting task. When a card was placed in two piles instead of one (5 cards in this study) or when a card was not placed in any pile at all (23 cards in this study), a new pile without label was formed by the researcher.

2.3 Measures

Card sorting task

The participants categorized 75 cards into piles according using similarity of contents as a criterion. After categorizing the cards with statements, each pile with relatively similar statements was labeled by the participant. The card sorting task was performed individually by the participants at home. There were no specific conditions that influences the task, except for the possibility of the presence of a partner, family member or other person. The following instruction was given in Dutch: 1 "Look at all 75 cards on the table" 2. "We ask you to organize these statements by placing the cards together by content. You decide how to do this. There are no right or wrong ways." 3. "Place the cards that belong, in your opinion, together in a pile on the table. Please ensure that: all statements are classified, each statement is only used once, a minimum of four and a maximum of twelve piles are created and each pile has at least two and up to 25 cards. Try to come up with a name for each pile you created. When you are ready, complete the table by writing down the name of the pile and the numbers of the cards which belong to this pile." No research has been done into the validity and reliability of the task. The instruction of the task for the patients can be found in appendix 6.1

The EuroQOL – five dimensions– five level response (EQ-5D-5L)

The EuroQOL – five dimensions– five level response (EQ-5D-5L) was employed as a questionnaire to measure the health related quality of life of patients with SS (Versteegh, Vermeulen, Evers, de Wit, Prenger & Stolk, 2016). The five dimensions of the EQ-5D-5L are: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. The five response options were different between the five dimensions, they are all built up as follows: no problems, slight problems, moderate problems, severe problems and extreme problems. The EQ-5D-5L includes furthermore a visual analogue scale from 0 to 100 with endpoints: 0 = 'the worst health you can imagine' and 100 = 'the best health you can imagine'. This recorded the self-rated health of the women. The convergent validity of the EQ-5D-5L is high (range: 0.90 - 0.99), inter-observer reliability (0.57) and test-retest reliability are good (0.69) (Janssen, Birnie, Haagsma & Bonsel, 2008). The questionnaire can be found in appendix 6.1.

Checklist experiences with SS

The Checklist experiences with SS was developed to measure the agreement of the patients with the experiences that were included in the card sorting task. The patients in this study gave their agreement with each experience on a 4-point Likert scale (agree, mildly agree, mildly disagree, disagree). Information about the reliability and validity of the checklist is not available. The Checklist can be found in appendix 6.1.

2.4 Statistical Analyses

IBM Statistical Software Package for the Social Sciences (SPSS) version 22 for Windows is used for all analyses and syntaxes can be found in appendix 6.1. Descriptive statistics (mean, standard deviation, minimum, maximum*)* were performed to describe the socio-demographics (age, diagnosis, symptom duration, marital status and education level) of participants. Frequency table and descriptive statistics (mean, standard deviation, minimum, maximum) were performed to describe the EQ-5D-5L health profiles of participants. Hierarchical cluster analysis (Ward's method, squared Euclidian distances) was used to analyze the statements sorted by the participants according to similarity of meaning in a hierarchy of clusters. Cluster analysis is a method to classify statements of a similar kind into clusters (Clatworthy, Buick, Hanins, Weinman & Horne, 2005). The cells of the input matrix of statements comprised the number of times that two statements were not sorted in the same pile. The dendogram and agglomeration schedule using Ward linkage were used to see the combination of statements in each amount of clusters that could be chosen. A non-parametric statistical test for one sample (Wilcoxon Signed Rank Test) compared the response of the participants with the median (2.5) of the response possibilities. A *p*-value of less than .05 was considered to indicate statistical significance. Frequencies (minimum, maximum, median) were performed to describe the responses of the participants on the items.

3. Results

3.1 EQ-5D-5L

In Table 2 are the results of the EQ-5D-5L (Versteegh, Vermeulen, Evers, de Wit, Prenger & Stolk, 2016) shown.

Table 2

The frequency and percentage of the EuroQOL - five dimensions (5D) – five level response (5L): the health-related quality of life of patients with SS.

ITEM	Frequency	Percentage (%)
MOBILITY, n[a]		
I have no problems in walking about	22	47.8%
I have slight problems in walking about	12	26.1%
I have moderate problems in walking about	7	15.2%
I have severe problems in walking about	4	8.7%
I am unable to walk about	0	0%
Missing	1	2.2%
SELF-CARE, n[a]		
I have no problems washing or dressing myself	35	76.1%
I have slight problems washing or dressing myself	6	13%
I have moderate problems washing or dressing myself	3	6.5%
I have severe problems washing or dressing myself	1	2.2%
I am unable to wash or dress myself	0	0%
Missing	1	2.2%
USUAL ACTIVITIES		
I have no problems doing my usual activities	8	17.4%
I have slight problems doing my usual activities	11	23.9%
I have moderate problems doing my usual activities	16	34.8%
I have severe problems doing my usual activities	11	23.9%
I am unable to do my usual activities	0	0%
PAIN / DISCOMFORT, n[a]		
I have no pain or discomfort	2	4.3%
I have slight pain or discomfort	14	30.4%
I have moderate pain or discomfort	17	37%
I have severe pain or discomfort	12	26.1%
I have extreme pain or discomfort	0	0%
Missing	1	2.2%
ANXIETY / DEPRESSION, n[b]		
I am not anxious or depressed	24	52.2%
I am slightly anxious or depressed	14	30.4%
I am moderately anxious or depressed	6	13%
I am severely anxious or depressed	0	0%
I am extremely anxious or depressed	0	0%
Missing	2	4.3%

[a] missing values: one patient did not fill out this question

[b] missing values: two patients did not fill out this question

Women with SS have, according to the EQ-5D-5L, little or no problems with mobility and self-care, moderate problems with usual activities and pain/discomfort and mostly no problems with anxiety and depression. In comparison to Dutch general population with age of 60 through (M=0.839, *SD = 0.179)*, women with SS have, following this study, a lower health status (M = 0.631, *SD* = 0.269), d = 1.16 (Versteegh, Vermeulen, Evers, de Wit, Prenger & Stolk, 2016).

3.2 Card Sorting Task

The mean number of piles participants created was 8, with a range of 4 to 16. The number of cards per pile varied from 1 to 25.

The number of clusters was set to 14. Increasing the number of clusters to 15 divided the cluster 'psychological vulnerability' in two clusters: 'symptoms as a consequence of mood' and 'insecurity as a consequence of complications'. Although the division was evident, both clusters contained psychological vulnerability, therefore there was no need to divide these clusters. Increasing the number of clusters to 16 divided the cluster 'role functioning barrier' into two different clusters. Because both clusters had same items concerning content, it was decided not to split this cluster. Furthermore, decreasing the number of clusters to 13 combined the clusters 'lack of understanding' and 'psychologizing' although these were two different topics according to the discussion. Decreasing the number of clusters to 12 clusters combined the clusters 'psychological vulnerability' and 'crying difficulties'. Psychological vulnerability and crying difficulties were, according to our discussion, two different topics because crying difficulties can be a psychological consequence but also a physical problem in SS. Figure 1 'Hierarchical Cluster Analysis of the Experiences of having SS' shows the overview of the outcome of cluster analysis.

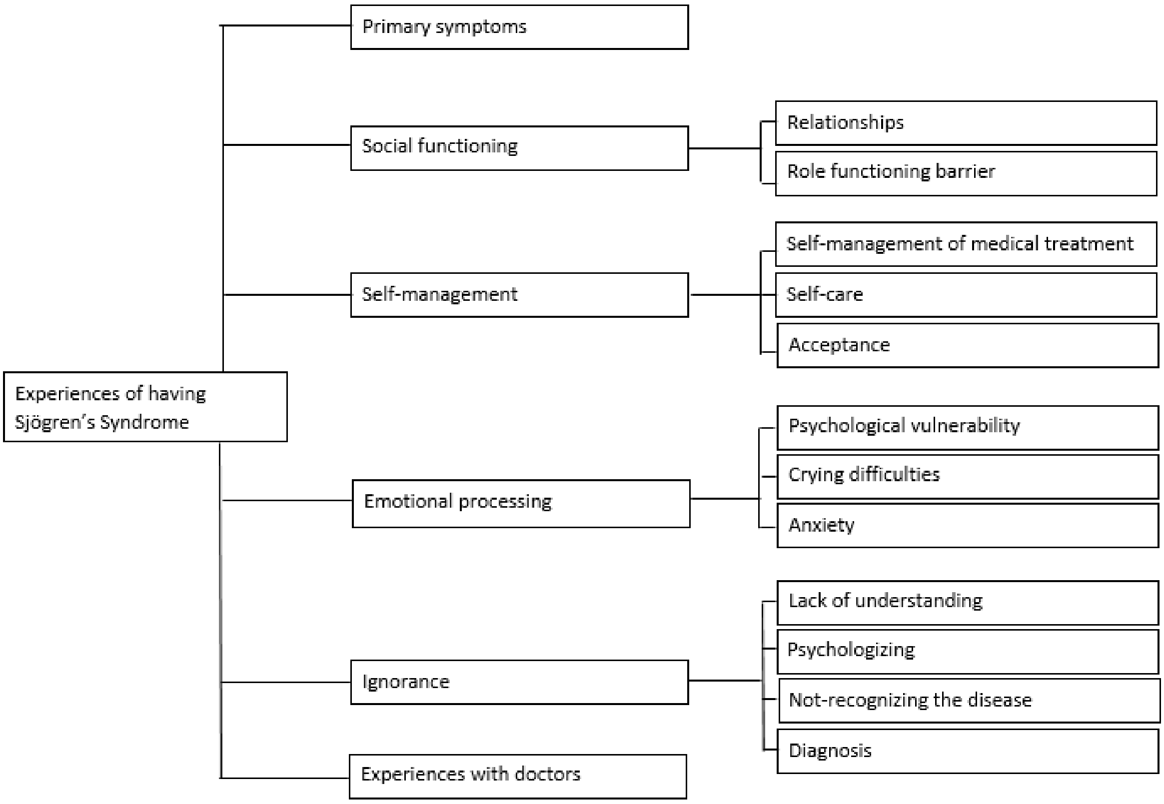

Figure 1. Schematic overview of the outcome of Hierarchical Cluster Analysis grouping 75 Experiences of having SS.

The experiences of having SS were on the highest-order level divided into six domains: ‘primary symptoms’, ‘social functioning’, ‘self-management’, ‘emotional processing’, ‘ignorance’ and ‘experiences with doctors’. Social functioning included two clusters: ‘relationships’ and ‘role functioning barrier’. The lowest-order clusters ‘relationships’ and ‘role functioning barriers’ contains both six statements which are of a similar kind. ‘Self-management’ is in lower order divided in three clusters: ‘self-management of medical treatment’ (three statements), ‘self-care’ (five statements) and ‘acceptance’ (five statements). ‘Emotional processing’ is divided into three clusters; ‘psychological vulnerability’ (four statements), ‘crying difficulties’ (three statements) and ‘anxiety’ (five statements). ‘Ignorance’ is divided into four clusters in lower order; ‘lack of understanding’ (three statements), ‘psychologizing’ (three statements), ‘not-recognizing the disease’ (three statements) and ‘diagnosis’ (four statements). The experiences as included in the clusters are shown in Table 3.

Table 3

The fourteen clusters of experiences with having SS. All statements started with: 'My experience with the disease is that...'

Cluster	*Statements*
1	*Primary symptoms*
	7. The oral mucosa and the lips stick and become irritated
	9. I feel a sensation of burning or sensitive oral mucosa
	26. The sense of taste is lost or decreased
	5. There is teeth loss or teeth damage by the dry mouth
	72. You cannot eat without drinking
	49. It is difficult to talk clearly and for a long time
	16. Eyes become red and sore by lack of tears
	75. The sense of smell is lost or decreased
	4. There is deterioration of the physical appearance
	36. There is weakness, tiredness and permanent apathy. The energy does not last long
	17. The quality of sleep is poor
2	*Relationships*
	12. The SS disease draws attention of the family and causes concern in the family
	28. The understanding of the partner is essential to maintain the relationship
	43. The social environment is unwelcoming for SS sufferers and does not consider the limitations of the disease
	70. The social environment does not either know or understand the disease
	38. The family minimizes the illness of the patient
	23. Relationship break-up due to physical problems
3	*Role functioning barrier*
	40. Social roles (mother, housewife, wife) are affected
	52. Physical difficulties (pain, fatigue, dry mouth) cause a withdrawal from social network
	32. Sexual intercourse is avoided because of the vaginal dryness, body ache or dry mouth
	57. It is difficulty to have a job which involves talking
	10. This disease implies spending a lot of money
	69. Physicians do not consider expectations, fears and preferences of patients
4	*Self-management of medical treatment*
	14. I abandon the treatment when it causes unpleasant symptoms.
	25. If the medicine puts my health at risk, I stop taking it
	21. The symptoms are the same, with or without treatment
5	*Self-care*
	13. Herbs and natural foods are part of the self-care
	15. Taking self-care measures (diet, relaxation, following medical advice) is very helpful
	64. Alternative medicine (Reiki, acupuncture, apitherapy and so on) helps to control the symptoms
	46. I try to maintain a normal life despite the symptoms
	48. The patient is able to actively participate in the diagnosis and treatment
6	*Acceptance*
	66. It is better not to think about what could happen. Whatever has to happen, let it happen.
	67. Being calm and in a good mood helps for a better health status
	19. It is better to accept that you have to live with SS because there are worse diseases
	47. The faith in God helps to face the disease
	51. The disease is an opportunity for personal growth
7	*Psychological vulnerability*
	8. My mood changes according to my symptoms
	24. The disease gets worse because of daily stress
	61. There is uncertainty in the face of future events (complications)
	73. Confusion when facing unexpected symptoms
8	*Crying difficulties*
	31. I feel sadness but I cannot cry with tears
	45. I prefer to avoid speaking about sad issues to avoid crying
	2. An intense muscle contraction (neck, face, shoulders) happens when you cannot cry
9	*Anxiety*
	62. I feel embarrassed for the state of my mouth
	68. I am afraid of losing teeth because of dry mouth

	11. I am afraid of possible blindness because of SS
	27. I am afraid that the drugs can cause other diseases
	39. I feel sadness for having an irreversible and complex disease
10	*Lack of understanding*
	37. The SS diagnosis is uncertain and provisional
	65. I do not understand what the disease is about
	3. SS is a disease, whose name is hard to read, write and pronounce
11	*Psychologizing*
	33. Emotions like sadness, blame, rage and resentment may be the cause of SS
	50. Past sad or traumatic experiences may initiate SS
	34. The inability to cry with tears can lead to a nervous breakdown or depression
12	*Not-recognizing the disease*
	53. Patients do not recognize dry mouth as a symptom of a disease
	58. We do not recognize dry eyes as a symptom of a disease
	35. SS is a hereditary disease; it is part of our body
	54. The symptoms of SS are common with other diseases
13	*Diagnosis*
	56. The symptoms of SS appear many years before the diagnosis
	60. The SS diagnosis can be a relief, as it ends the uncertainty of not having a diagnosis
	18. I had never heard about SS
	30. It is necessary to search for additional information, either on the internet or in books
14	*Experiences with doctors*
	29. Before arriving to the diagnosis of SS, one visits a lot of doctors
	41. It is exhausting to go to the doctor again and again, to complete health checks and to face bureaucratic procedures
	22. It is extremely difficult to get an appointment with the doctor when it is required
	74. I drop-out of treatment because it is impossible to get an appointment for medical check-up
	42. I Fear being admonished by physician for not following the instructions
	6. You must fully trust in the decisions and instructions of the rheumatologist
	1. The doctors have little time to spend with patients
	55. Doctors do not provide sufficient and clear information to guide the patient
	44. Even the physicians from other medical specialties do not know much about SS
	69. Physicians do not consider expectations, fears and preferences of patients
	20. The doctors think that other diseases are more important than SS
	63. It is comforting for the patient that the doctor considers the human side of the patient
	71. Some limitations of the medical care are responsibility of the institution and not of the doctors

3.3 Checklist experiences with SS

In Table 4 an overview is provided of the opinion of the patients about the statements they sorted, this is shown for each item separately categorized by the cluster.

Table 4

Results (median, P median and frequency (n, %) of answer possibilities) of participants on Checklist experiences with SS.

Cluster	Item	Median	P median	Agree, n (%)	Mildly agree, n (%)	Mildly disagree, n (%)	Disagree, n (%)
Primary symptoms	7, n[a]	1	*P*<.001	36 (78,3%)	8 (17,4%)	1(2,2%)	0 (0%)
	9, n[a]	1	*P*<.001	23 (50,0%)	15 (32,6%)	3 (6,5%)	4 (8,7%)
	26	2	.011	20 (43,5%)	14 (30,4%)	3 (6,5%)	9 (19,5%)
	5, n[a]	1	*P*<.001	33 (71,1%)	9 (19,6%)	2 (4,3%)	1 (2,2%)
	72	1	*P*<.001	30 (65,2%)	10 (21,7%)	3 (6,5%)	3 (6,5%)
	49, n[a]	1	*P*<.001	29 (63,0%)	11 (23,9%)	3 (6,5%)	2 (4,3%)
	16, n[a]	1	*P*<.001	33 (71,7%)	8 (17,4%)	3 (6,5%)	1 (2,2%)
	75, n[a]	2	.044	16 (34,8%)	14 (30,4%)	7 (15,2%)	8 (17,4%)
	4	1	*P*<.001	35 (76,1%)	9 (19,6%)	1 (2,2%)	1 (2,2%)
	36	1	*P*<.001	27 (58,7%)	12 (26,1%)	3 (6,5%)	4 (8,7%)
	17	2	.003	22 (47,8%)	11 (23,9%)	6 (13,0%)	7 (15,2%)
Relationships	12	2	.092	15 (32,6%)	15 (32,6%)	7 (15,2%)	9 (19,6%)
	28, n[c]	1	*P*<.001	36 (78,3%)	6 (13,0%)	0 (0%)	1 (2,2%)
	43	3	.181	11 (23,9%)	9 (19,6%)	7 (15,2%)	19 (41,3%)
	70	1.5	*P*<.001	23 (50,0%)	16 (34,8%)	3 (6,5%)	4 (8,7%)
	38	3	.209	10 (21,7%)	11 (23,9%)	7 (15,2%)	18 (39,1%)
	23, n[b]	3	.072	8 (17,4%)	9 (19,6%)	10 (21,7%)	17 (37,0%)
Role functioning barrier	40, n[d]	1	.001	22 (47,8%)	12 (26,1%)	2 (4,3%)	6 (13,0%)
	52	1	*P*<.001.	34 (73,9%)	6 (13,0%)	4 (8,7%)	2 (4,3%)
	32, n[b]	2	.008	15 (32,6%)	17 (37,0%)	6 (13,0%)	6 (13,0%)
	57, n[a]	1	*P*<.001	28 (60,9%)	12 (26,1%)	4 (8,7%)	1 (2,2%)
	10, n[a]	2	.004	15 (32,6%)	18 (39,1%)	7 (15,2%)	5 (10,9%)
	69, n[a]	2	.698	5 (10,9%)	19 (41,3%)	11 (23,9%)	10 (21,7%)
Self-management of medical treatment	14	2	.005	17 (37,0%)	15 (32,6%)	9 (19,6%)	5 (10,9%)
	25	1	*P*<.001	35 (67,4%)	8 (17,4%)	4 (8,7%)	3 (6,5%)
	21	2	.055	12 (26,1%)	19 (43,3%)	8 (17,4%)	7 (15,2%)
Self-care	13	2	.011	17 (37,0%)	17 (37,0%)	4 (8,7%)	8 (17,4%)
	15	1	*P*<.001	29 (63,0%)	15 (32,6%)	1(2,2%)	1 (2,2%)
	64, n[c]	3	.118	6 (13,0%)	13 (28,3%)	9 (19,6%)	15 (32,6%)
	46	1	*P*<.001	39 (84,8)	7 (15,2%)	0 (0%)	0 (0%)
	48	1	*P*<.001	29 (63,0%)	12 (26,1%)	4 (8,7%)	1 (2,2%)
Acceptance	66	2	.059	15 (32,6%)	18 (39,1%)	3 (6,5%)	10 (21,7%)
	67, n[a]	1	*P*<.001	30 (65,2%)	11 (23,9%)	3 (6,5%)	1 (2,2%)
	19	2	*P*<.001	20 (43,5%)	16 (34,8%)	5 (10,9%)	5 (10,9%)
	47, n[c]	4	.002	8 (17,4%)	7 (15,2%)	1 (2,2%)	27 (58,7%)
	51	2	.092	13 (28,3%)	21 (45,7%)	1 (2,2%)	11 (23,9%)
Psychological vulnerability	8	1	*P*<.001	26 (56,5%)	12 (26,1%)	4 (8,7%)	4 (8,7%)
	24, n[a]	2	.005	19 (41.3%)	14 (30.4%)	5 (10.9%)	20 (21.7%)
	61	1	*P*<.001	31 (67,4%)	12 (26,1%)	2 (4,3%)	1 (2,2%)
	73, n[a]	2	*P*<.001	21 (45,7%)	16 (34,8%)	5 (10,9%)	3 (6,5%)
Crying difficulties	31, n[a]	2	.525	19 (41,3%)	7 (15,2%)	3 (6,5%)	16 (34,8%)
	45, n[a]	4	*P*<.001	4 (8,7%)	3 (6,5%)	5 (10,9%)	33 (71,7%)
	2, n[c]	3	.006	5(10,9%)	11 (23,9%)	6 (13%)	21 (45,7%)
Anxiety	62, n[a]	4	.003	6 (13,0%)	10 (21,7%)	5 (10,9%)	24 (52,2%)
	68, n[a]	2	*P*<.001	21 (45,7%)	15 (32,6%)	5 (10,9%)	4 (8,7%)
	11	4	*P*<.001	4 (8,7%)	10 (21,7%)	5 (10,9%)	27 (58,7%)
	27, n[a]	2	.398	7 (15,2%)	16 (34,8%)	8 (17,4%)	14 (30,4%)
	39	3	.256	10 (21,7%)	11 (23,9%)	8 (17,4%)	17 (37,0%)
Lack of understanding	37, n[a]	3	.015	7 (15,2%)	10 (21,7%)	7 (15,2%)	21 (45,7%)
	65	4	*P*<.001	1 (2,2%)	1 (2,2%)	6 (13,0%)	38 (82,6%)
	3	4	*P*<.001	3 (6,5%)	7 (15,2%)	7 (15,2%)	29 (63%)
Psychologizing	33	4	*P*<.001	3 (6,5%)	8 (17,4%)	4 (8,7%)	31 (67,4%)
	50, n[a]	4	*P*<.001	4 (8,7%)	5 (10,9%)	5 (10,9%)	31 (67,4%)
	34, n[a]	4	*P*<.001	4 (8,7%)	6 (13,0%)	10 (21,7%)	25 (54,3%)

Not-recognizing the disease	53, n[c]	2	.470	12 (26,1%)	14 (30,4%)	6 (13,0%)	11 (23,9%)
	58, n[b]	2	.791	10 (21,7%)	17 (37,0%)	4 (8,7%)	13 (28,2%)
	35, n[a]	3	.064	8 (17,4%)	9 (19,6%)	11 (23,9%)	17 (37,0%)
	54	2	P<.001	18 (39,1%)	21 (45,7%)	4 (8,7%)	3 (6,5%)
Diagnosis	56	1	*P*<.001	35 (76,1%)	10 (21,7%)	1 (2,2%)	0 (0%)
	60	1	*P*<.001	34 (73,9%)	9 (19,6%)	1 (2,2%)	2 (4,3%)
	18	1	*P*<.001	36 (78,3%)	1 (2,2%)	2 (4,3%)	7 (15,2%)
	30	1	*P*<.001	27 (58,7%)	11 (23,9%)	2 (4,3%)	6 (13,0%)
Experiences with doctors	29	2	.023	22 (47,8%)	9 (19,6%)	5 (10,9%)	20 (21,7%)
	41, n[a]	2	.629	13 (28,3%)	10 (21,7%)	5 (10,9%)	17 (37,0%)
	22	4	*P*<.001	3 (6,5%)	7 (15,2%)	10 (21,7%)	17 (37,0%)
	74, n[a]	4	*P*<.001	1 (2,2%)	0 (0%)	3 (6,5%)	41 (89,1%)
	42	4	.000	3 (6,5%)	4(8,7%)	4 (8,7%)	35 (76,1%)
	6	2	.230	14 (30,4%)	11 (23,9%)	14 (30,4%)	7 (15,2%)
	1	3	.012	4 (8,7%)	14 (30,4%)	10 (21,7%)	18 (39,1%)
	55	2	.977	7 (15,2%)	19 (41,3%)	9 (19,6%)	11 (23,9%)
	44	2	.020	14 (30,4%)	20 (43,5%)	4 (8,7%)	8 (17,4%)
	69, n[a]	2	.698	5 (10,9%)	19 (41,3%)	11 (23,9%)	10 (21,7%)
	20, n[a]	3	.043	6 (13,0%)	13 (28,3%)	8 (17,4%)	18 (39,1%)
	63, n[a]	1	*P*<.001	37 (80,4%)	7 (15,2%)	1 (2,2%)	0 (0%)
	71, n[e]	2	.341	8 (17,4%)	19 (41,3%)	5 (10,9%)	9 (19,6%)

Note: Median = 2.5.

[a] missing values: one patient did not fill out this question

[b] missing values: two patients did not fill out this question

[c] missing values: three patients did not fill out this question

[d] missing values: four patients did not fill out this question

[e] missing values: five patients did not fill out this question

Table 5 shows an overview of the findings and the interpretation of these findings of the Checklist experiences with SS, categorized into clusters.

Table 5

Findings of the experiences of the patients with SS and the interpretation of these findings by each cluster.

Cluster	Findings	Interpretation
Primary symptoms	On all statements about symptoms in mouth, eyes and fatigue the majority agreed.	All primary symptoms, as described in Table 3 were experienced by the patients and therefore recognized as consequences of SS.
Relationships	The results of the participants on the statements in this cluster were in content in line with each other, they reflect the importance of relationships.	The patients prove the importance of understanding and involvement of the partner and notice that it is hard for the social environment to understand SS.
Role functioning barrier	Most women mildly agreed or agreed with the statements about the negative influence of the disease on role functioning.	The physical difficulties appear to have influence on the role of being mother and partner, on practicing jobs, on sexual intercourse and on participating in social networks.
Self-management of medical treatment	Most participants agreed or mildly agreed with all statements about 'self-management of medical treatment'.	The participants show to manage individually their own medical treatment by deciding not taking medicines or treatment if they put health at risk.
Self-care	On most statements participants show a positive attitude towards self-care measures.	The participants take self-care activities, try to life a normal life and are able to actively participate in diagnosis and treatment.
Acceptance	Most participants agreed with the statements about accepting the disease and its development.	According to the patients, calmness, good mood and acceptance contribute to health status.
Psychological vulnerability	Most participants agreed with statements about the interaction between psychological themes and the disease. The opinions were divided about the influence of stress.	Participants experience their mood changes when symptoms change, they feel insecure about future complications and are confused when they have unexpected symptoms.
Crying difficulties	This cluster showed no consistent results	Participants try to avoid crying. Opinions are divided about muscle contractions and the ability to cry when feeling sad.
Anxiety	Participants showed to have a different opinion on various situations which can provoke anxiety	Participants are afraid of losing teeth because of dry mouth and are afraid of becoming blind because of dry eyes.
Lack of understanding	The statements were quite different, but the participants show to agree with each other about the statements	The diagnosis is for the most participants not uncertain and provisional and the participants know what the content of the disease is about.
Psychologizing	The results of this cluster show that participants agree with each other about psychological themes and the disease.	The participants do not think emotions or traumatic experiences could be the cause of SS. Besides, they do not experience a depression or nervous breakdown as a result of the inability to cry.
Not-recognizing the disease	The participants had no consistent opinion about what symptoms they recognize in SS.	The experience of the participants is that symptoms of SS correspond to other diseases.
Diagnosis	The results on the statements were very similar between the participants, they strongly agreed with each other.	The symptoms appear many years before the diagnosis and the diagnosis can be a relief for the participants. The participants had never heard about SS before diagnosis and had to search for information about it.
Experiences with doctors	The opinion about most statements varied between participants.	There is no negativity with respect to the attitude and availability of doctors from most of the participants.

4. Discussion

4.1 Main findings

This study examined the experiences of women with SS from the patient's perspective. It offered a comprehensive hierarchical overview of the themes those women deal as a consequence of having SS. In collaboration with two patient representatives, fourteen clusters classified over six high-order clusters were identified in a cluster analyses.

The expectations about which clusters could be formed in a hierarchical overview in this study were mainly based on research of Rojas-Alcayaga et al. (2016). In line with the study of Rojas Alcayaga et al. (2016) and the health definition found by Huber et al. (2011), the domains illness experience, psychological response and social interaction were found in the analyses of the current study. They were defined as: 'primary symptoms', 'emotional processing' and 'social functioning'. Also the clusters 'ignorance' and 'experiences with doctors' were found to play a role in the experiences of SS. The existence of the cluster 'experiences with doctors' is probably explained by the medical content of a lot of statements because these were formed in a hospital environment (Rojas-Alcayaga et al., 2016). The cluster 'ignorance' could be formed because some consequences of SS were unknown or the statements, formed by Chilean patients, were not recognizable for Dutch patients (Rojas-Alcayaga et al., 2016).

Another expectation of the clusters was based on research of Huber et al. (2011). According to Huber et al. (2011) and the results of this investigation, 'management' also has a role in the experiences of women with SS. This resulted in a cluster defined as 'self-management'. The statements in the low-order clusters of self-management: 'self-management of medical treatment', 'acceptance' and 'self-care' describe the behavior patients could have to adapt and to self-manage the disease. Huber et al. (2016) state that this is an integral part of health.

Besides a hierarchical overview, this research gave an overview of the opinion of the patients about the statements they sorted. First about the disease itself: all primary symptoms as dryness in mouth and eyes and fatigue were, as expected, identifiable for the patients. This indicates that these symptoms are common in SS as described in previous research (Baldini, Talarico, Tzioufas & Bombardieri, 2012; Van Leeuwen, Schipper, Schueler-de Kort & Geenen, 2013; Tincani et al., 2013; Vitali et al., 2002). Besides, there is little ignorance about SS among patients: they know what SS is about, do not psychologize it and disagree SS is uncertain and provisional. The diagnosis is a relief for the patients: it takes the uncertainty away. According to the participants of current study, the symptoms of SS were present for on average 10.6 years before the diagnosis took place. This reflects the effort it takes to diagnose the disease (Carsons, 2001). These findings indicate that SS itself is not undefinable for the patients when they were diagnosed, but the life before the diagnosis was uncertain. Findings of the research of Rojas-

Algayaga et al. (2016) found that when pSS was hardly recognized. Chilean patients were confused and the uncertainty and ignorance led to emotional reactions. Thus, better diagnosis of the disease contributes to a better understanding and reduces uncertainty and emotional reactions. Therefore, better quality of screening of SS and more education about the disease is necessary to get faster diagnoses. The hierarchical overview and the information from the patient's perspective is useful for research in screening instruments and education materials.

The participants of current study show to have control over medical treatment, are actively participating in treatment and do belief in use of self-care measures. In terms of 'self-management', participants show acceptance of the disease and they believe that calmness contributes positively. Management seems important in dealing with the disease, which is in line with the expectations based on findings of Huber et al. (2011). Within the high-order cluster 'emotional processing', patients think, as previous research, there is an interaction between complications of SS and well-being (Champey et al., 2006; Goto, Yagi, Matsumoto & Tsubota, 2002; Vitali et al., 2002). The positive results of self-management and the indicated interaction between complications and well-being are the basis for new treatment options of SS. In the case that adequate self-management, acceptance, calmness and handling with disease as a result of complications is of importance in the treatment of SS, participants would feel better and be more able to participate in society.

The findings about the social environment of the patients and the disease showed the importance of attention and understanding from family, partner and social network even though it is hard for them to understand the disease. This is in line with previous research (Rojas-Algayaga et al., 2016). Besides, participants experienced a role functioning barrier as the disease limited participation in social life and performing a job of the patients. This could be a consequence of the lower physical activity in women with SS, which in turn is due to fatigue or problems with speaking (Segal et al., 2009; Rojas-Algayaga et al. 2016). It can also be a result of the feelings that participants have about their disease in relation to their social environment, for example: anxious thoughts or senses of shame. These findings indicate that education about the disease is also important for society and social environment of the patient. Based on this information, future research could focus on the development and evaluation of education programs about SS.

4.2 Strengths, limitations and future directions

This research has several strengths. First of all, it is the first structured study about virtually all disease experiences in Sjögren's syndrome from a patient's perspective. There was hardly any interpretation by the researchers of the results from the participants as is the case in interpretation of interview data. Besides, although it is a qualitative method to analyze, this study gave a structured taxonomy of experiences women with pSS have. The study of Rojas-Alcayaga (2016) could not give a structured taxonomy of the results. The cluster analyses of research of Van Leeuwen, Schueler-de Kort, Schipper & Geenen (2014) was limited to the consequences of dryness. Furthermore, this research has a large sample of intrinsically motivated participants (n=52) which are representative in gender and age.

However, the current research also has some limitations. First, the way the participants were recruited could be influenced by a selection bias and volunteer bias because of the announcements on Facebook and in a magazine for Sjögren's patients (Hernán, Hernández-Diaz, Robins, 2004). This meant that the study received a lot of reactions, but that only a selective group of participants could actually participate in the study: those that participate in alliances and/or are able to read a magazine or go online. Besides, the questionnaires were filled out at participants' homes. Completing the card sorting task and additional questionnaires with perhaps a partner or family member present could have influenced the answers on some statements. This was not checked due to time constraints of the researchers. Furthermore, the performance of the card sorting task was perhaps too difficult for some participants. Data of five participants were not included in the analysis because these participants did not sort the cards in content of the statements. This may have led to a non-representative sample in terms of intelligence level. Lastly, the statements used in the card sorting task and checklist experiences with SS was derived from research with participants living in Chili. This could have manipulated the cluster analysis of the sorting of the participants because they had predetermined themes to sort. Furthermore, these themes are based on experiences Chilean women have, these could be different from experiences of Dutch women. Despite the above-mentioned limitations that readers need to consider in interpreting the findings, this research provides additional insight in the life experiences of women with SS.

Future research should examine the cross-cultural sustainability of the findings of experiences with SS and investigate which experiences of SS are more culture related and which are more general. Additionally, future qualitative research could have open interviews with Dutch women with SS for better understanding of all experiences of the Dutch population.

4.3 Implications

Despite these limitations, several implications can be made based on the results. This study took notice of the uniqueness of patients and is no generalizability of a whole group of participants. It is therefore a valuable description of the disease for clinical screening of SS patients in the future. That is, the findings can guide the interview and help to find out what are important experiences for individual patients. Besides, with the knowledge found in this study that social relationships and (self-)management may have an effect on the degree of suffering of the disease, this study recommends that treatment and research of treatment options focus on these domains. Moreover, the findings from this study can be used in briefings and education programs to patients and social environment about SS, the consequences of SS and the possibilities to adapt in the society. Finally, the findings could be used to develop a questionnaire.

4.4 Conclusion

The aim of this study was to structure and summarize life experiences of women with SS in an integrated model and to give an overview of the opinion of the participants about the consequences of SS. In summary, it can be concluded that SS has fourteen clusters classified over 6 high-order domains, defined as: primary symptoms, social functioning, emotional processing, management, ignorance and experiences with doctors. Furthermore, the more general and more individual descriptions of experiences with SS of the participants has led to implications and information for future research. The hierarchical overview and the descriptions of the experiences from the patient's view could be used for the development of better screening of SS in clinical consults, resulting in faster diagnose. It also contributes to future research of treatment options for SS, where self-management would have an important role. At last, it is useful for the development of briefings and education programs of SS to patients and their social environment.

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6. Appendix

6.1 Questionnaires

Tabel groeperen uitspraken (vul de nummers van de kaartjes in)

Naam												
Kolom	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**
Nr.												

Algemene gegevens

1. Wat is de datum vandaag? ______________________________

2. Wat is uw geboortedatum? ______________________________

3. In welk jaar is bij u het syndroom van Sjögren gediagnosticeerd? ______________________________

4. Wie stelde de diagnose syndroom van Sjögren (bijvoorbeeld: een reumatoloog, de huisarts? ______________________________

5. In welk jaar had u voor het eerst klachten die te maken hadden met het syndroom van Sjögren? ______________________________

6. Wat is op dit moment uw burgerlijke staat?

☐ Gehuwd/samenwonend

☐ Gescheiden

☐ Weduwe

☐ Alleenstaand

☐ Anders, namelijk ______________________________

7. Wat is uw hoogst <u>voltooide</u> opleiding?

☐ Lager onderwijs (basisschool),

☐ Lager beroepsonderwijs (LHNO/huishoudschool/LTS/VBO/VMBO-p))

☐ Middelbaar algemeen onderwijs (MULO/MAVO/VMBO-t/ 3 jaar HAVO/VWO)

☐ Middelbaar beroepsonderwijs (MTS,MEAO etc.)

☐ Voortgezet algemeen onderwijs (HBS/MMS/HAVO/VWO/Gymnasium/Atheneum)

☐ Hoger beroepsonderwijs (HTS,HEAO etc.)

☐ Wetenschappelijk onderwijs (universiteit, ingenieursexamen)

☐ Anders, namelijk ______________________________

Vragenlijst over gezondheid en kwaliteit van leven: EQ-5D-5L

Zet bij iedere groep in de lijst hieronder een kruisje in het hokje dat het best past bij uw gezondheid VANDAAG.

MOBILITEIT

Ik heb geen problemen met lopen ☐
Ik heb een beetje problemen met lopen ☐
Ik heb matige problemen met lopen ☐
Ik heb ernstige problemen met lopen ☐
Ik ben niet in staat om te lopen ☐

ZELFZORG

Ik heb geen problemen met mijzelf wassen of aankleden ☐
Ik heb een beetje problemen met mijzelf wassen of aankleden ☐
Ik heb matige problemen met mijzelf wassen of aankleden ☐
Ik heb ernstige problemen met mijzelf wassen of aankleden ☐
Ik ben niet in staat mijzelf te wassen of aan te kleden ☐

DAGELIJKSE ACTIVITEITEN *(bijv. werk, studie, huishouden, gezins- en vrijetijdsactiviteiten)*

Ik heb geen problemen met mijn dagelijkse activiteiten ☐
Ik heb een beetje problemen met mijn dagelijkse activiteiten ☐
Ik heb matige problemen met mijn dagelijkse activiteiten ☐
Ik heb ernstige problemen met mijn dagelijkse activiteiten ☐
Ik ben niet in staat mijn dagelijkse activiteiten uit te voeren ☐

PIJN / ONGEMAK

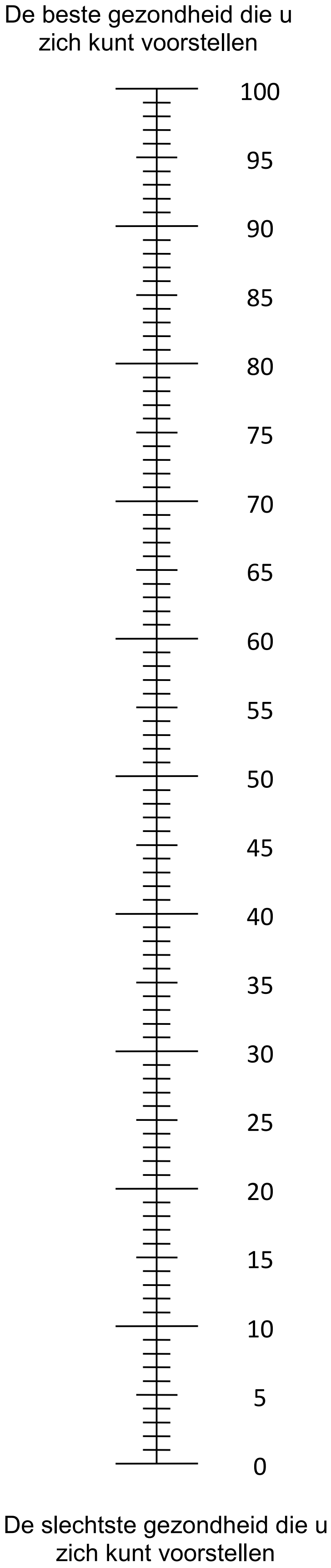
Ik heb geen pijn of ongemak ☐
Ik heb een beetje pijn of ongemak ☐
Ik heb matige pijn of ongemak ☐
Ik heb ernstige pijn of ongemak ☐
Ik heb extreme pijn of ongemak ☐

ANGST / SOMBERHEID

Ik ben niet angstig of somber ☐
Ik ben een beetje angstig of somber ☐
Ik ben matig angstig of somber ☐
Ik ben erg angstig of somber ☐
Ik ben extreem angstig of somber ☐

- We willen weten hoe goed of slecht uw gezondheid VANDAAG is.
- Deze meetschaal loopt van 0 tot 100.
- 100 staat voor de <u>beste</u> gezondheid die u zich kunt voorstellen.
  0 staat voor de <u>slechtste</u> gezondheid die u zich kunt voorstellen.
- Markeer een X op de meetschaal om aan te geven hoe uw gezondheid VANDAAG is.
- Noteer het getal waarbij u de X heeft geplaatst in onderstaand vakje.

UW GEZONDHEID VANDAAG = ☐



Hieronder staan opnieuw de uitspraken weergegeven die u zojuist op stapels heeft gelegd. We vragen u om aan te geven **hoezeer u het eens bent met deze uitspraak**.

U doet dat door een kruisje in het juiste vakje te zetten

Mijn ervaring met het Sjögren syndroom is dat…	**Mee eens**	**Een beetje mee eens**	**Een beetje mee oneens**	**Mee oneens**
1) de artsen weinig tijd voor hun patiënten hebben				
2) wanneer je niet kunt huilen, er een spiersamentrekking ontstaat in nek of schouders				
3) het syndroom van Sjögren een ziekte is waarvan de naam moeilijk te lezen, te schrijven en uit te spreken is				
4) er een achteruitgang van de fysieke gesteldheid optreedt				
5) er tandverlies of bederf optreedt als men een droge mond heeft				
6) je de beslissingen en aanbevelingen van de reumatoloog volledig moet vertrouwen				
7) het slijmvlies in de mond en de lippen geïrriteerd raken				
8) mijn humeur verandert als de symptomen toe- of afnemen				
9) mijn mond branderig of pijnlijk aanvoelt				
10) deze ziekte hoge kosten met zich mee brengt				
11) ik bang ben dat ik misschien blind word door het syndroom van Sjögren				
12) de ziekte aandacht vraagt van de familie en hen bezorgd maakt.				
13) natuurlijke kruiden en voeding onderdeel van zelf management zijn				
14) ik de behandeling staak als deze hinderlijke bijwerkingen geeft				
15) het helpt om zelfzorg maatregelen toe te passen (dieet, ontspanning, medisch advies opvolgen)				

Mijn ervaring met het Sjögren syndroom is dat…	**Mee eens**	**Een beetje mee eens**	**Een beetje mee oneens**	**Mee oneens**
16) de ogen rood worden en pijn doen bij gebrek aan tranen				
17) ik slecht slaap				
18) ik nog nooit van het syndroom van Sjögren gehoord had				
19) het beter is om de gevolgen van het syndroom van Sjögren te accepteren, omdat er veel ergere ziektes zijn				
20) de artsen denken dat andere ziektes belangrijker zijn dan het syndroom van Sjögren				
21) de symptomen niet veranderen of ik nou behandeld word of niet				
22) het uitermate lastig is om een afspraak met de arts te maken als dat noodzakelijk is				
23) relaties stuk lopen door lichamelijke problemen				
24) de ziekte door stress erger wordt				
25) ik stop met medicijnen innemen als ze mijn gezondheid in gevaar brengen				
26) de smaak weg is of verminderd is				
27) ik bang ben dat de medicatie die ik slik andere ziektes kan veroorzaken				
28) het voor het in stand houden van onze relatie van belang is dat mijn partner mij begrijpt				
29) voordat de diagnose syndroom van Sjögren gesteld werd, ik al veel artsen geconsulteerd had				
30) ik aanvullende informatie over de ziekte uit boeken of van internet moet halen				
31) ik verdrietig ben en zou willen huilen, maar ik heb geen tranen				

Mijn ervaring met het Sjögren syndroom is dat…	**Mee eens**	**Een beetje mee eens**	**Een beetje mee oneens**	**Mee oneens**
32) geslachtsgemeenschap wordt vermeden omdat er sprake is van een droge vagina, lichamelijke pijn of een droge mond				
33) emoties zoals droefheid, schuldgevoel, woede en wrok de oorzaak van het syndroom van Sjögren kunnen zijn				
34) een zenuwinzinking of depressie kan ontstaan, doordat men niet kan huilen				
35) het syndroom van Sjögren een erfelijke ziekte is, het is onderdeel van onze lichamelijke gesteldheid				
36) er een gevoel van zwakheid, moeheid en permanente lusteloosheid is. De energie is snel op.				
37) de diagnose syndroom van Sjögren onzeker en voorlopig is				
38) de familie de ziekte van de patiënt bagatelliseert				
39) ik verdrietig ben omdat ik een ongeneeslijke en complexe ziekte heb				
40) de ziekte invloed heeft op mijn rol als moeder, huisvrouw of echtgenote				
41) ik er zo moe van word om telkens weer naar de dokter te gaan voor gezondheidscontroles en alle bureaucratische rompslomp				
42) ik vrees om op mijn kop te krijgen van de arts als ik de instructies niet opvolg				
43) de (sociale)omgeving onwelwillend tegenover het syndroom van Sjögren staat en geen rekening houdt met de beperkingen van de ziekte				
44) zelfs de andere medisch specialisten niet weten wat het syndroom van Sjögren inhoudt				
45) ik probeer te voorkomen om over droevige dingen te praten, zodat ik niet hoef te huilen				

Mijn ervaring met het Sjögren syndroom is dat…	**Mee eens**	**Een beetje mee eens**	**Een beetje mee oneens**	**Mee oneens**
46) ik ondanks de symptomen die ik ondervind, een zo normaal mogelijk leven probeer te leiden				
47) het vertrouwen in God mij helpt om met de ziekte om te gaan				
48) de patiënt in staat is om actief deel te nemen aan de diagnose en de behandeling				
49) het moeilijk is om duidelijk en lange tijd achter elkaar te spreken				
50) verdriet of een traumatische gebeurtenis in het verleden oorzaken van het syndroom van Sjögren zouden kunnen zijn				
51) de ziekte een mogelijkheid voor persoonlijke groei is				
52) lichamelijke klachten (pijn, moeheid, droge mond) mijn sociale leven beperken				
53) patiënten een droge mond niet als een symptoom van de ziekte herkennen				
54) de symptomen van het syndroom van Sjögren overeenkomen met die van andere ziektes				
55) artsen geen toereikende en duidelijke informatie verstrekken om de patiënt bij te staan				
56) de symptomen van het syndroom van Sjögren al jaren voordat de diagnose gesteld wordt aanwezig zijn				
57) het lastig is om een beroep uit te oefenen waarbij men veel moet praten				
58) wij droge ogen niet herkennen als een symptoom van een ziekte				
59) dagelijkse bezigheden zoals het huishouden of boodschappen doen vermeden worden				
60) de diagnose syndroom van Sjögren een opluchting kan zijn, omdat het de onzekerheid (van het niet weten wat er aan de				

Mijn ervaring met het Sjögren syndroom is dat…	**Mee eens**	**Een beetje mee eens**	**Een beetje mee oneens**	**Mee oneens**
hand is), wegneemt				
61) er onzekerheid bestaat over toekomstige complicaties				
62) ik me schaam voor de toestand van mijn mond				
63) het voor de patiënt geruststellend/troostend is als de arts de menselijke kant van de patiënt ziet				
64) alternatieve geneeswijzen helpen om de symptomen onder controle te houden (Reiki, acupunctuur, therapie met producten van bijen, etc.)				
65) ik niet begrijp wat de ziekte inhoudt				
66) het beter is om er niet aan te denken wat zou kunnen gebeuren. Ik laat het over mij heen komen wat er gaat gebeuren				
67) dat kalmte en een goed humeur bijdragen aan een betere gezondheid.				
68) ik bang ben om door een droge mond mijn tanden te verliezen				
69) medici geen rekening houden met de verwachtingen, angsten en voorkeuren van de patiënten				
70) de sociale omgeving geen idee heeft van wat de ziekte inhoudt of de ziekte niet begrijpt				
71) sommige beperkingen in de medische zorg onder verantwoordelijkheid vallen van de instelling en niet van de artsen				
72) je niet kunt eten zonder te drinken				
73) er verwarring is als er onverwachte symptomen optreden				
74) ik met de behandeling stop, omdat het onmogelijk is om een controle afspraak met de arts te krijgen				
75) het reukvermogen weg is of afneemt				

6.2 Syntaxes

6.2.1. Syntax Cluster analyses

```
** Make a file with all subjects and items in one column.
** With RESTRUCTURE (Data) another matrix is made only consisting of 0 and 1.
** Step 1 --- Kies de eerste regel VARIABLES into CASES.
** Step 2 --- Kies 'One' for example w1 w2 w3.
** Step 3 --- Kies het volgende.
** Use selected variable --- ID
** Target variable --- geef een label zoals ‘stapel’.
** Step 4 en 5 --- Next.
** Step 6 --- Fixed variable --- Eerste regel: keep al seen fixed variable.
** DAN IS DIT DE SYNTAX.

VARSTOCASES
 /ID=id
 /MAKE pile FROM V01_artsen_weinig_tijd_voor_patienten

V02_niet_huilen_spiersamentrekking_nek_schoud
V03_Sjögren_moeilijk_lezen_schrijven_uitspre
V04_achteruitgang_fysieke_gesteldheid
V05_tandverlies_bederf_droge_mond
V06_beslissingen_reumatoloog_vertrouwen
V07_slijmvlies_mond_lippen_geïrriteerd
V08_humeur_verandert_symptomen_toeafnemen
V09_mond_branderig_of_pijnlijk
V10_ziekte_hoge_kosten
V11_bang_blind_door_Sjögren
V12_aandacht_familie_en_bezorgd
V13_kruiden_voeding_zelfmanagement
V14_behandeling_staak_bijwerkingen
V15_helpt_zelfzorgmaatregelen_toepassen
V16_ogen_rood_en_pijn_gebrek_tranen
V17_ik_slecht_slaap
V18_nooit_Sjögren_gehoord
V19_gevolgen_Sjögren_accepteren
V20_artsen_andere_ziektes_belangrijker
V21_symptomen_niet_veranderen_behandeld
V22_lastig_afspraak_arts_noodzakelijk
V23_relaties_stuk_lichamelijke_problemen
V24_ziekte_door_stress_erger
V25_stop_medicijnen_gezondheid_gevaar
V26_de_smaak_weg_of_verminderd
V27_bang_medicatie_ziektes_veroorzaken
V28_stand_houden_relatie_partner_begrijpt
V29_voor_diagnose_veel_artsen_geconsulteerd
V30_aanvullende_informatie_boeken_internet
V31_verdrietig_willen_huilen_geen_tranen
V32_geslachtsgemeenschap_vermijden
V33_emoties_oorzaak_Sjögren
V34_inzinking_depressie_ontstaan_niet_huilen
V35_erfelijk_onderdeel_lichamelijk_gesteldhei
V36_zwakheid_moeheid_lusteloosheid
V37_Sjögren_onzeker_en_voorlopig
V38_familie_ziekte_bagatelliseert
V39_verdrietig_ongeneeslijke_complexe_ziekte
V40_invloed_rol_moeder_huisvrouw_echtgenote
V41_moe_gezondheidscontroles_rompslomp
V42_vrees_arts_instructies_niet_opvolg
V43_omgeving_onwelwillend_Sjögren
V44_specialisten_niet_weten_Sjögren_inhoudt
V45_voorkomen_droevige_dingen_niet_huilen
V46_ondanks_symptomen_normaal_leven
V47_vertrouwen_God_helpt
V48_actief_deelnemen_diagnose_behandeling
V49_moeilijk_duidelijk_lang_spreken
V50_verdriet_trauma_oorzaken_Sjögren
V51_ziekte_mogelijkheid_persoonlijke_groei
V52_klachten_sociale_leven_beperken
V53_droge_mond_niet_herkennen
V54_symptomen_overeenkomen_ziektes
V55_artsen_geen_duidelijke_info
V56_symptomen_jaren_voor_diagnose_aanwezig
V57_lastig_beroep_veel_praten
V58_droge_ogen_niet_herkennen_symptoom
V59_dagelijkse_bezigheden_vermeden_worden
V60_diagnose_opluchting_onzekerheid_weg
V61_onzekerheid_toekomstige_complicaties
V62_schaam_toestand_mond
V63_geruststellend_troostend_arts_menselijk
V64_alternatieve_geneeswijzen_helpen
V65_niet_begrijp_wat_ziekte_inhoudt
V66_beter_niet_denken_over_heen_komen
V67_kalmte_humeur_betere_gezondheid
V68_bang_tanden_verliezen
V69_geen_rekening_verwachtingen_angsten
V70_omgeving_geen_idee_ziekte_niet_begrijpt
V71_beperkingen_verantwoordelijkheid_instelli
V72_je_niet_kunt_eten_zonder_te_drinken
V73_verwarring_onverwachte_symptomen
V74_onmogelijk_controle_afspraak
V75_het_reukvermogen_weg_afneemt
 /INDEX=Index1(75)
 /KEEP=ppnr
 /NULL=KEEP.

** next step ---- make a file with zero and 1.
* Sorteer nu eerst per uitspraak stapel en respondentnummer.
SORT CASES BY ppnr(A) pile(A) Index1(A) .
EXECUTE.
** Eerst met TRANSFORM een dummy variabele maken voor Index1.
** of hoe die verder ook heet.
```

```
** Het gaat om de uitspraken.
** Kies onder TRANSFORM --- Create dummy variable.
** Sleep de naam van de variabele naar rechts.
** Kies bij Rootnames bijvoorbeeld de letter V voor variabele.
** IN SYNTAX ZIET DAT ER ZO UIT.

SPSSINC CREATE DUMMIES VARIABLE=Index1
ROOTNAME1=V
/OPTIONS ORDER=A USEVALUELABELS=YES USEML=YES OMITFIRST=NO.

** Save het bestand eventueel onder een andere naam.
** Bijvoorbeeld.
** DOEL 3 ---- HET BESTAND MAKEN PER PERSOON PER STAPEL ORDENEN.
* Eerst weer even sorteren per respondentnummer en per stapel.

SORT CASES BY ppnr(A) pile(A) .
EXECUTE.

** Nu met behulp van aggregatie ordenen in een bestand per persoon en per stapel.
** Kies DATA en dan AGGREGATE.
** Breek per Respondentnummer en per Stapel (die kan een vreemde naam hebben).
** Zet alle variabelen (de uitspraken) bij de Aggregated Variables.
** Kies als function de SUM.
** Create e new dataset en geef die een naam.
** DAT ZIET ER ALS SYNTAX DAN ZO UIT.

DATASET DECLARE databestand_3.sav.
AGGREGATE
 /OUTFILE='databestand_3.sav'
 /BREAK=ppnr pile

 /V_1_sum=SUM(V_1)
 /V_2_sum=SUM(V_2)
 /V_3_sum=SUM(V_3)
 /V_4_sum=SUM(V_4)
 /V_5_sum=SUM(V_5)
 /V_6_sum=SUM(V_6)
 /V_7_sum=SUM(V_7)
 /V_8_sum=SUM(V_8)
 /V_9_sum=SUM(V_9)
 /V_10_sum=SUM(V_10)
 /V_11_sum=SUM(V_11)
 /V_12_sum=SUM(V_12)
 /V_13_sum=SUM(V_13)
 /V_14_sum=SUM(V_14)
 /V_15_sum=SUM(V_15)
 /V_16_sum=SUM(V_16)
 /V_17_sum=SUM(V_17)
 /V_18_sum=SUM(V_18)
 /V_19_sum=SUM(V_19)
 /V_20_sum=SUM(V_20)
 /V_21_sum=SUM(V_21)
 /V_22_sum=SUM(V_22)
 /V_23_sum=SUM(V_23)
 /V_24_sum=SUM(V_24)
 /V_25_sum=SUM(V_25)
 /V_26_sum=SUM(V_26)
 /V_27_sum=SUM(V_27)
 /V_28_sum=SUM(V_28)
 /V_29_sum=SUM(V_29)
 /V_30_sum=SUM(V_30)
 /V_31_sum=SUM(V_31)
 /V_32_sum=SUM(V_32)
 /V_33_sum=SUM(V_33)
 /V_34_sum=SUM(V_34)
 /V_35_sum=SUM(V_35)
 /V_36_sum=SUM(V_36)
 /V_37_sum=SUM(V_37)
 /V_38_sum=SUM(V_38)
 /V_39_sum=SUM(V_39)
 /V_40_sum=SUM(V_40)
 /V_41_sum=SUM(V_41)
 /V_42_sum=SUM(V_42)
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 /V_44_sum=SUM(V_44)
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 /V_52_sum=SUM(V_52)
 /V_53_sum=SUM(V_53)
 /V_54_sum=SUM(V_54)
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 /V_56_sum=SUM(V_56)
 /V_57_sum=SUM(V_57)
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 /V_61_sum=SUM(V_61)
 /V_62_sum=SUM(V_62)
 /V_63_sum=SUM(V_63)
 /V_64_sum=SUM(V_64)
 /V_65_sum=SUM(V_65)
 /V_66_sum=SUM(V_66)
 /V_67_sum=SUM(V_67)
 /V_68_sum=SUM(V_68)
 /V_69_sum=SUM(V_69)
 /V_70_sum=SUM(V_70)
 /V_71_sum=SUM(V_71)
 /V_72_sum=SUM(V_72)
 /V_73_sum=SUM(V_73)
 /V_74_sum=SUM(V_74)
```

```
 /V_75_sum=SUM(V_75).

* bewaar het bestand als Databestand_3.sav.

DATASET ACTIVATE databestand_3.sav.
DATASET DECLARE D0.7933626911670203.
PROXIMITIES V01_artsen_weinig_tijd_voor_patienten

 V02_niet_huilen_spiersamentrekking_nek_schouders V03_Sjögren_moeilijk_lezen_schrijven_uitspreken
 V04_achteruitgang_fysieke_gesteldheid V05_tandverlies_bederf_droge_mond
 V06_beslissingen_reumatoloog_vertrouwen V07_slijmvlies_mond_lippen_geïrriteerd
 V08_humeur_verandert_symptomen_toeafnemen V09_mond_branderig_of_pijnlijk V10_ziekte_hoge_kosten
 V11_bang_blind_door_Sjögren V12_aandacht_familie_en_bezorgd V13_kruiden_voeding_zelfmanagement
 V14_behandeling_staak_bijwerkingen V15_helpt_zelfzorgmaatregelen_toepassen
 V16_ogen_rood_en_pijn_gebrek_tranen V17_ik_slecht_slaap V18_nooit_Sjögren_gehoord
 V19_gevolgen_Sjögren_accepteren V20_artsen_andere_ziektes_belangrijker
 V21_symptomen_niet_veranderen_behandeld V22_lastig_afspraak_arts_noodzakelijk
 V23_relaties_stuk_lichamelijke_problemen V24_ziekte_door_stress_erger
 V25_stop_medicijnen_gezondheid_gevaar V26_de_smaak_weg_of_verminderd
 V27_bang_medicatie_ziektes_veroorzaken V28_stand_houden_relatie_partner_begrijpt
 V29_voor_diagnose_veel_artsen_geconsulteerd V30_aanvullende_informatie_boeken_internet
 V31_verdrietig_willen_huilen_geen_tranen V32_geslachtsgemeenschap_vermijden
 V33_emoties_oorzaak_Sjögren V34_inzinking_depressie_ontstaan_niet_huilen
 V35_erfelijk_onderdeel_lichamelijk_gesteldheid V36_zwakheid_moeheid_lusteloosheid
 V37_Sjögren_onzeker_en_voorlopig V38_familie_ziekte_bagatelliseert
 V39_verdrietig_ongeneeslijke_complexe_ziekte V40_invloed_rol_moeder_huisvrouw_echtgenote
 V41_moe_gezondheidscontroles_rompslomp V42_vrees_arts_instructies_niet_opvolg
 V43_omgeving_onwelwillend_Sjögren V44_specialisten_niet_weten_Sjögren_inhoudt
 V45_voorkomen_droevige_dingen_niet_huilen V46_ondanks_symptomen_normaal_leven
 V47_vertrouwen_God_helpt V48_actief_deelnemen_diagnose_behandeling
 V49_moeilijk_duidelijk_lang_spreken V50_verdriet_trauma_oorzaken_Sjögren
 V51_ziekte_mogelijkheid_persoonlijke_groei V52_klachten_sociale_leven_beperken
 V53_droge_mond_niet_herkennen V54_symptomen_overeenkomen_ziektes V55_artsen_geen_duidelijke_info
 V56_symptomen_jaren_voor_diagnose_aanwezig V57_lastig_beroep_veel_praten
 V58_droge_ogen_niet_herkennen_symptoom V59_dagelijkse_bezigheden_vermeden_worden
 V60_diagnose_opluchting_onzekerheid_weg V61_onzekerheid_toekomstige_complicaties
 V62_schaam_toestand_mond V63_geruststellend_troostend_arts_menselijk
 V64_alternatieve_geneeswijzen_helpen V65_niet_begrijp_wat_ziekte_inhoudt
 V66_beter_niet_denken_over_heen_komen V67_kalmte_humeur_betere_gezondheid V68_bang_tanden_verliezen
 V69_geen_rekening_verwachtingen_angsten V70_omgeving_geen_idee_ziekte_niet_begrijpt
 V71_beperkingen_verantwoordelijkheid_instelling V72_je_niet_kunt_eten_zonder_te_drinken
 V73_verwarring_onverwachte_symptomen V74_onmogelijk_controle_afspraak
 V75_het_reukvermogen_weg_afneemt

 /MATRIX OUT(D0.7933626911670203)
 /VIEW=VARIABLE
 /MEASURE=SEUCLID
 /PRINT NONE
 /STANDARDIZE=VARIABLE NONE.
RECODE V01_artsen_weinig_tijd_voor_patienten

 V02_niet_huilen_spiersamentrekking_nek_schouders V03_Sjögren_moeilijk_lezen_schrijven_uitspreken
 V04_achteruitgang_fysieke_gesteldheid V05_tandverlies_bederf_droge_mond
 V06_beslissingen_reumatoloog_vertrouwen V07_slijmvlies_mond_lippen_geïrriteerd
 V08_humeur_verandert_symptomen_toeafnemen V09_mond_branderig_of_pijnlijk V10_ziekte_hoge_kosten
 V11_bang_blind_door_Sjögren V12_aandacht_familie_en_bezorgd V13_kruiden_voeding_zelfmanagement
 V14_behandeling_staak_bijwerkingen V15_helpt_zelfzorgmaatregelen_toepassen
 V16_ogen_rood_en_pijn_gebrek_tranen V17_ik_slecht_slaap V18_nooit_Sjögren_gehoord
 V19_gevolgen_Sjögren_accepteren V20_artsen_andere_ziektes_belangrijker
 V21_symptomen_niet_veranderen_behandeld V22_lastig_afspraak_arts_noodzakelijk
 V23_relaties_stuk_lichamelijke_problemen V24_ziekte_door_stress_erger
 V25_stop_medicijnen_gezondheid_gevaar V26_de_smaak_weg_of_verminderd
 V27_bang_medicatie_ziektes_veroorzaken V28_stand_houden_relatie_partner_begrijpt
 V29_voor_diagnose_veel_artsen_geconsulteerd V30_aanvullende_informatie_boeken_internet
 V31_verdrietig_willen_huilen_geen_tranen V32_geslachtsgemeenschap_vermijden
 V33_emoties_oorzaak_Sjögren V34_inzinking_depressie_ontstaan_niet_huilen
 V35_erfelijk_onderdeel_lichamelijk_gesteldheid V36_zwakheid_moeheid_lusteloosheid
 V37_Sjögren_onzeker_en_voorlopig V38_familie_ziekte_bagatelliseert
 V39_verdrietig_ongeneeslijke_complexe_ziekte V40_invloed_rol_moeder_huisvrouw_echtgenote
 V41_moe_gezondheidscontroles_rompslomp V42_vrees_arts_instructies_niet_opvolg
 V43_omgeving_onwelwillend_Sjögren V44_specialisten_niet_weten_Sjögren_inhoudt
 V45_voorkomen_droevige_dingen_niet_huilen V46_ondanks_symptomen_normaal_leven
 V47_vertrouwen_God_helpt V48_actief_deelnemen_diagnose_behandeling
 V49_moeilijk_duidelijk_lang_spreken V50_verdriet_trauma_oorzaken_Sjögren
 V51_ziekte_mogelijkheid_persoonlijke_groei V52_klachten_sociale_leven_beperken
 V53_droge_mond_niet_herkennen V54_symptomen_overeenkomen_ziektes V55_artsen_geen_duidelijke_info
 V56_symptomen_jaren_voor_diagnose_aanwezig V57_lastig_beroep_veel_praten
 V58_droge_ogen_niet_herkennen_symptoom V59_dagelijkse_bezigheden_vermeden_worden
 V60_diagnose_opluchting_onzekerheid_weg V61_onzekerheid_toekomstige_complicaties
 V62_schaam_toestand_mond V63_geruststellend_troostend_arts_menselijk
 V64_alternatieve_geneeswijzen_helpen V65_niet_begrijp_wat_ziekte_inhoudt
 V66_beter_niet_denken_over_heen_komen V67_kalmte_humeur_betere_gezondheid V68_bang_tanden_verliezen
 V69_geen_rekening_verwachtingen_angsten V70_omgeving_geen_idee_ziekte_niet_begrijpt
 V71_beperkingen_verantwoordelijkheid_instelling V72_je_niet_kunt_eten_zonder_te_drinken
 V73_verwarring_onverwachte_symptomen V74_onmogelijk_controle_afspraak
 V75_het_reukvermogen_weg_afneemt

(2=1)
(4=4)
(6=9)
(8=16)
(10=25)
(12=36)
(14=49)
(16=64)
(18= 81)
(20=100)
(22=121)
(24=144)
(26=169)
(28=196)
(30=225)
(32=256)
(34=289)
(36=324)
```

```
(38=361)
(40=400)
(42=441)
(44=484)
(46=529)
(48=566)
(50=625)
(52=676)
(54=729)
(56=784)
(58=841)
(60=900)
(62=961)
(64=1024)
(66=1089)
(68=1156)
(70=1225)
(72=1296)
(74=1369)
(76=1444)
(78=1521)
(80=1600)
(82=1681)
(84=1764)
(86=1849)
(88=1936)
(90=2025)
(92=2116).
EXECUTE.

CLUSTER
 /MATRIX IN(D0.7933626911670203)
 /METHOD WARD
 /PRINT SCHEDULE CLUSTER(8,20)
 /PLOT DENDROGRAM VICICLE.
Dataset Close D0.7933626911670203.
```

6.2.2 Syntax descriptive- and non-parametric statistical tests for one sample

```
USE ALL.
compute leeftijd=2016-geboortejaar.
compute duur_diagnose=2016-jaar_diagnose.
compute duur_klachten=2016-jaar_eerste_klachten.
execute.

DESCRIPTIVES VARIABLES=leeftijd duur_diagnose duur_klachten
 /STATISTICS=MEAN STDDEV MIN MAX.
Value labels burgerlijke_staat 1 'gehuwd samenwonend' 2 'gescheiden' 3 'weduwe' 4 'alleenstaand' 5 'anders'.

FREQUENCIES VARIABLES=burgerlijke_staat
 /STATISTICS=MINIMUM MAXIMUM MEDIAN
 /ORDER=ANALYSIS.

FREQUENCIES VARIABLES=ek1 ek2 ek3 ek4 ek5 ek6 ek7 ek8 ek9 ek10 ek11 ek12 ek13 ek14 ek15 ek16 ek17 ek18 ek19 ek20 ek21 ek22 ek23 ek24 ek25 ek26 ek27 ek28 ek29 ek30 ek31 ek32 ek33 ek34
ek35 ek36 ek37 ek38 ek39 ek40 ek41 ek42 ek43 ek44 ek45 ek46 ek47 ek48 ek49 ek50 ek51 ek52 ek53 ek54 ek55 ek56 ek57 ek58 ek59 ek60 ek61 ek62 ek63 ek64 ek65 ek66 ek67 ek68 ek69 ek70 ek71 ek72
ek73 ek74 ek75

 /STATISTICS=MINIMUM MAXIMUM MEDIAN
 /ORDER=ANALYSIS.

*Nonparametric Tests: One Sample.

NPTESTS
 /ONESAMPLE TEST (ek1 ek2 ek3 ek4 ek5 ek6 ek7 ek8 ek9 ek10 ek11 ek12 ek13 ek14 ek15 ek16 ek17 ek18 ek19 ek20 ek21 ek22 ek23 ek24 ek25 ek26 ek27 ek28 ek29 ek30 ek31 ek32 ek33 ek34 ek35 ek36
ek37 ek38 ek39 ek40 ek41 ek42 ek43 ek44 ek45 ek46 ek47 ek48 ek49 ek50 ek51 ek52 ek53 ek54 ek55 ek56 ek57 ek58 ek59 ek60 ek61 ek62 ek63 ek64 ek65 ek66 ek67 ek68 ek69 ek70 ek71 ek72 ek73 ek74
ek75) WILCOXON(TESTVALUE=2.5)
 /MISSING SCOPE=ANALYSIS USERMISSING=EXCLUDE
 /CRITERIA ALPHA=0.05 CILEVEL=95.
DESCRIPTIVES VARIABLES=leeftijd
 /STATISTICS=MEAN STDDEV MIN MAX.
FREQUENCIES VARIABLES=burgerlijke_staat
 /STATISTICS=MINIMUM MAXIMUM MEDIAN
 /ORDER=ANALYSIS.

* syntax eq-5d-5l.

IF (eq5d01 < 1 OR eq5d01 > 5) eq5d01 = 9 .
IF (eq5d02 < 1 OR eq5d02 > 5) eq5d02 = 9 .
IF (eq5d03 < 1 OR eq5d03 > 5) eq5d03 = 9 .
IF (eq5d04 < 1 OR eq5d04 > 5) eq5d04 = 9 .
IF (eq5d05 < 1 OR eq5d05 > 5) eq5d05 = 9 .
MISSING VALUE eq5d01 TO eq5d05 (9) .

* Frecuency tables and Descriptive Statistics *.

FREQUENCIES
 VARIABLES= eq5d01 eq5d02 eq5d03 eq5d04 eq5d05 .
DESCRIPTIVES
 VARIABLES=eq5dvas
 /FORMAT=LABELS NOINDEX
 /STATISTICS=MEAN STDDEV MIN MAX .
* SOCIAL TARIFF CALCULATE EQ5D (UTILITY)*
COMPUTE UTIL5D=0.1502+((eq5d01-1)*0.0897)+((eq5d02-1)*0.1012)+((eq5d03-1)*0.0551)+((eq5d04-1)*0.0596)+((eq5d05-1)*0.0512)
IF (eq5d01=1 AND eq5d02=1 AND eq5d03=1 AND eq5d04=1 AND eq5d05=1) UTIL5D=0
IF (eq5d01=3 OR eq5d02=3 OR eq5d03=3 OR eq5d04=3 OR eq5d05=3) UTIL5D=UTIL5D+0.2119
COMPUTE UTIL5D=1-UTIL5D
VARIABLE LABEL UTIL5D "UTILIDAD" .
FORMATS UTIL5D (F8.4)
DESCRIPTIVES
 VARIABLES=UTIL5D
 /STATISTICS=MEAN STDDEV MIN MAX
```