Individual goals of patients with somatic symptom and related disorders from the perspective of experienced clinicians: a concept mapping study.

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Contents

Preface 3
Abstract 4
Introduction 5
Methods 8
Results 11
Discussion 20
Reference list 23
Appendixes 28

Preface

This thesis is written as part of the graduation of the Master of Clinical and Health Psychology at Utrecht University. Firstly, thank you Rinie Geenen, for your intensive supervision, your patience and ethousiasm. And a big thank to the project group: Saskia van Broekhuysen-Kloth, Peter Lucassen, Michel Reinders and Saskia van Es. I did this thesis in collebortation with Luisa Kühlmann, I also would like tot thank her, I learned a lot from our colleboration. Lastly thank you to everyone who participated in the research.

Abstract

Background:

In order to personalize the treatment for somatic symptom disorder (SSD), an extensive overview of treatment goals is needed. The individualization of therapy goals may improve the small to moderate effect sizes of psychotherapeutic treatment of patients with somatic symptom disorder. The aim of the current study is to identify and structure an encompassing set of individual goals from the perspective of experienced clinicians.

Method:

To obtain an overview of the treatment goals, seventeen experienced clinicians were interviewed. Eventually, 136 goals were derived from the interviews. These goals were sorted by fifteen clinicians independently in a card-sorting task. In the first card sorting task, clinicians sorted the goals based on similarity of meaning. In the second card-sorting task, the clinicians sorted the goals from individual to general. Hierarchical cluster analysis was used to structure the goals. For the second card-sorting task, descriptive statistics were computed.

Results:

Hierarchical cluster analysis showed ten clusters classified in three broad categories: activation (physical complaints, balance daily schedule, activaties), mental functioning (resilience, cognitive, psychopathology) and positive psychology (emotion regulation, body relatedness, self-esteem and coping). The clusters physical complaints, activaties, psychopathology and self-esteem were rated as more individual clusters.

Conclusion:

This study revealed an encompassing hierarchical structure of treatment goals based on the perspective of experienced clinicians. These treatment goals can be used as a screening tool in the intake with somatic symptom disorder patients. Patient-based measures can promote shared decision making and help to adjust the therapy to the preferences of the individual patient.

Introduction

Somatic symptom disorder (SSD) is a common disease. In the general population prevalence is estimated at 5% to 7% (Kurlansik & Maffei, 2016). SSD is characterized by somatic symptoms that are either very distressing or result in significant disruption of functioning, and includes excessive and disproportionate thoughts, feelings and behaviors regarding those symptoms (DSM-IV-TR; American Psychiatric Association, 2000). The treatment of choice for patients with SSD is Cognitive Behavior Therapy (Koelen et al., 2014). This treatment was shown to be effective in the treatment of the precursor diagnostic category somatoform disorder, but the effect-sizes of treatment outcomes are generally small to moderate (Abbas, Kisely &, Kroenke, 2009; Koelen et al., 2014; Kleinsträuber, Witthöft &, Hiller, 2010; Lakhan & Schofield, 2013).

Moderate effect sizes can be explained by ineffective treatment but can also be related to the formulated treatment goals. These may not be the appropriate goals to measure change.Therapy goals can be defined as desired changes in behavior, agreed upon by patient and therapist at the beginning of treatment (Grosse & Grawe, 2002; Schulte-Bahrenberg & Schulte, 1993). Goal setting is an effective way of achieving behavioral change (Bovend'Eerdt, Botell & Wade, 2009). Goals drive treatment planning, ensure that attention is focused on certain components and have a therapeutic effect on their own (Grosse Holtforth & Castonguay, 2005).

In the treatment of SSD, many different goals or outcome measures have been formulated. When therapy goals were compared between diagnostic groups, the most common goal for SSD appears to be a reduction of somatic symptoms such as pain, fatigue and vegetative symptoms (Dirmaier, Harfst, Koch &, Schulz, 2006). Compared to other diagnostic groups, goals are also more related to rest and recovery or stress-related goals (Lind, Delmar &, Nielsen, 2014). Other goals focus on the daily schedule of these patients (Rief et al., 2017). Psychotherapy for SSD often focuses on improving coping strategies rather than curing patients from their physical symptoms (Kleinsträuber,Witthöft & Hiller, 2011).

Most outcome measures are related to the received type of treatment, rather than to the goals that are important for a specific patient (Janssens et al., 2017). They are mainly therapy goals instead of personal goals. For example, Cognitive behavioral therapy mainly focuses on cognitive fields such as ’challenging unhelpful thoughts’(Dirmaier et al., 2006). Graded-exercise therapy focuses on ‘increasing activity level’. Psychoanalytic oriented therapy emphasizes improvements in goal categories such as ‘intrapsychic conflicts’ and ‘self-worth’ (Dirmaier et al., 2006).

Part of the SSD patients seem not to be satisfied with their treatment. It is not certain whether the outcome measures that are currently used, reflect the results patients prefer (Hartman et al., 2008). When SSD patients are asked which goals they find most important, they first mention problem and symptom related goals followed by goals related to well-being, interpersonal and personal growth (Berking, 2004).

Currently used general outcome measures are not comprehensive enough, patients value other outcome measures. General measures consist of the domains 'improved health', 'better quality of life' and 'reduction of common SSD symptoms' (Behandelvisie Eikenboom, 2017). These measures do not take into account the heterogeneity of the patients with SSD (Epstein, Quill &, McWhinney, 1999). Within the group of SSD patients different subgroups can be distinguished, this population is heterogeneous (Özçulha, 2015).

An alternative to general measures is the use of individual goal setting or goal attainment scaling (GAS). GAS assumes that goals cannot be described in one global definition, but can be defined as the individual needs of a patient at a certain moment (Hurn, Kneebone, &, Cropley, 2006). There is a moderate relationship between GAS and standardized measures, which indicates that patients value goals other than general goals (Turner-Stokes, Williams &. Johnson, 2009). Michalak and Holforth (2006) mention also the importance of pursuing individual goals in therapy. Pursuing individual goals increases motivation in therapy and achieving individual goals is essential for well-being (Michalak & Holforth, 2006).

A theory consistent with the assumption that more attention is needed for the experience and motivation of the individual patient is the Self Determination Theory (SDT) (Deci & Ryan, 2000). According to SDT, effective goal pursuit and attainment is related to the extent to which people are able to fulfill their basic psychological needs (Deci et al., 2000). SDT distinguishes three basic psychological needs: the needs for autonomy, competence and relatedness. The need for autonomy is the feeling of a sense of willingness and choice when acting (Deci & VanSteenkiste, 2004). The need for competence concerns the desire to deal effective with the environment (Deci et al., 2004). Finally, the need for relatedness is the feeling to be connected to and the need to interact with other people (Deci et al., 2004). These needs are interdependent, and must all be present for optimal development (Vansteenkiste & Sheldon, 2006). For example, optimal development is only possible if an individual sets a goal that he/she considers important (autonomy) and is able to realize this goal (competence). SDT suggests these needs should be optimal reflected in the formulation of goals in order for patients to be able to internalize goals. With internalisation of goals, behaviour change is more likely

maintained (Williams, Deci &, Ryan, 1998). In particular, behavior that is autonomously regulated instead of controlled leads to a variety of more positive outcomes. Controlled behavior is pressuring someone toward specific outcomes, autonomously regulated behavior is self motivated and based on choice (Deci & Ryan, 1987). Autonomously regulated behavior leads to positive outcomes like higher quality performance, behavioral persistence and better mental health (Deci et al., 2000).

Another theory consistent with this assumption is the value expectancy model of motivation. The value expectancy model argues that individuals' choice, persistence, and performance can be explained by their beliefs about the extent to which they value the activity and how well they will do on the activity (Wigfield & Eccles, 2000).When individuals consider a goal as meaningful and attainable, the person will strive longer to reach the goal, even when there are obstacles (Affleck et al., 2001). For instance, a study of women with fibromyalgia showed that health and social goals were pursued more successfully if they were valued more by these patients (Affleck et al., 2001).

The current study uses the experience of clinicians to formulate personal treatment goals of SSD patients. The clinician is an experienced observer who is available to provide firsthand information about the clinical status of the patient (Lyons, 1997). The aim of the current study is to identify and structure a wide and varied set of goals in the treatment of SSD. A first expectation is to find commonly used general outcome measures, such as improved health, better quality of life and the reduction of common SSD symptoms. A second expectation is to find more individual goals, goals related to the needs for autonomy, competence and relatedness.

Methods

Procedure

In this study a concept-mapping technique was used, consisting of four steps. The first step consisted of interviewing experienced clinicians on possible individual goals of patients in the treatment of SSD, and a review of the literature on possible goals. Second, the project group (a group of experts) and the researchers selected a representative set of goals from the interviews. Third, the selected items were sorted by experienced clinicians in two card-sorting tasks. In the first card-sorting task the items were categorized based on content. In the second card-sorting task the items were sorted by indicating whether the treatment goals were more individual or more general. Fourth, the sortings were structured with a hierarchical cluster analysis.

This study was approved by the ethics committee of the faculty of social and behavioral sciences of Utrecht University, the Netherlands (FETC17-099). All participants have signed an informed consent before taking part in the interview and the card-sorting tasks.

Participants

Eligible participants were experienced clinicians working with patients with SSD. Clinicians with a diversity of professions and orientations were selected. These clinicians came from different institutions, namely Altrecht Psychosomatics, Psyq, GGZinGeest, Dimence and de Gezonde zaak. The participants have been approached by email.

For the interviews, a minimum of 10 interviews was required and more if saturation was not reached during the last two interviews. Eventually, 17 clinicians have been taking part in the interviews.

For the card sorting task, a minimum of 30 experienced clinicians was aimed for. A sample size of 10/20 people is considered a workable number for a card sorting task by Trochim (1989). A group of 62 clinicians received the card sorting task in their mailbox. Eventually, the sortings of 15 clinicians that have been taking part in the card-sorting task were analyzed.

Interviews

The first step consisted of interviewing experienced clinicians about goals in the treatment of SSD. The interviews consisted mainly of open questions via email. There was one live interview and one interview was done by phone. Completing the questions has been taking about 60 minutes.

Examples of questions are: ‘If you consider the last five patients that you worked with, what types of goals did you set with them?’or ‘Which goals did you set with your most complex patients?’ For a full set of questions see appendix C.

Reduction of statements

After interviewing the clinicians and a review of the literature, a set of 136 goals in total was collected. Exact and obvious duplications in the formulation of goals were removed or goals were merged, and a list of 123 goals remained. These changes were done by the researchers RG and IB.

Next a stepwise Delphi procedure was used to select a set of goals. The goals were evaluated by four members of the project group (SvE, SvB, PL, MR) independently. The project group consisted of four specialists from three different institutions. The members of the project group were instructed to reduce the goals of the interviews to a manageable set of 55/60 goals. The members had to give a mark to each goal. This mark varied from three (leave the goal in the set), two (a doubtful case) to one (remove the goal). The members were asked to give an equal amount of ones, twos and threes. After the experts made a selection of the goals, the scores from all the assessors were added. The sum score determined which goals remained in the set. A sum of 10 or higher was marked green (leave the goal in the set) and a sum of 7 or lower was marked red (remove the goal from the set), the rest of the goals were left white (doubtful case). Eventually, 22 goals were marked green, 47 goals were marked red and 54 goals were left white.

The project group made a second selection after the first selection of goals. Three of the four project group members participated in the second selection (SvB, PL, MR). The project group received an overview of the green, red and white goals. The project group members had to put an ‘X’ behind a goal if they wanted to keep the goal. The members were instructed not to select the goals that they found important, but to make a varied as possible list of goals. Furthermore, the group members were also able to comment on the goals to motivate their choice.

For the final selection of goals, the goals of round 1 were organized by the researchers from the highest sum score to the lowest. There were 67 goals with a sum score of 8 or higher, these goals were included in the final set of goals. Hereafter, the comments of the project members at the goals in round two were taken into consideration. If there was a convincing comment that the goal should remain, this goal was also included by the researchers.

Finally, the goals with three times an ‘X’ behind it in the second slection round were included in the final set. After this procedure, a list of 74 goals remained.

From the final list of goals, the researchers (RG, IB, LK) selected 55 goals based on variety. The researchers did independently a trial of a card-sorting task. In this card-sorting task, the researchers sorted the cards according to content.

Some cards were sorted in similar piles by the three researchers. When the content of these cards was more or less the same, a card was removed or merged. Eventually, 19 items were removed. Some changes were made to the formulation of the goals. Negative words and non-indicative words were removed. When two goals had a similar content, they were combined in one card. For example, the card with the goal ‘activating’ and the card with the goal ‘building up activities’ was combined in one card.

Sorting task

In this step, the 55 goals were independently sorted by clinicians in two card-sorting tasks. The eventually selected goals were written on numbered cards in a random order. Each card started with “An individual goal in treatment is..” (In Dutch: ‘een individueel doel in de behandeling is..’) followed by one of the goals. The task took about 60 minutes to complete.

In the first card sorting task, clinicians individually sorted the goals based on content into piles. The clinicians gave each pile a label that could be used by the researchers to interpret the sortings. There were a number of rules for sorting the cards: 1) each goal had to be placed on a pile, 2) each goal could be placed on one pile only, 3) a minimum of four and a maximum of twelve piles had to be formed and 4) each pile could contain two to twenty-five goals.

For the second card sorting task, the clinicians individually sorted the items by indicating whether the treatment goals were more individual or more general. In other words, goals that are very uncommon but very particular for an individual, to goals that are applicable to many people with SSD. These categories varied from 1 (more individual) to 5 (more general). Goals had to be equally allocated in five piles.

In case a clinician did not group cards in the first card-sorting task, these cards were considered as a separate pile consisting of one card. In case a clinician sorted a card in two various piles, these cards were considered as a separate pile.

In case a clinician did not group a card in the second card-sorting task, it was reported as a missing value. In case a clinician sorted a card in two various piles, the mean from this two piles was used.

Analysis

Hierarchical cluster analysis was used to structure the goals from the first card-sorting task. With hierarchical cluster analysis, the goals that are often grouped together by participants are grouped together in clusters.The data was analyzed with software of SPSS version 24. Squared Euclidean distances were computed between each pair of goals and Ward's method was used to define the hierarchical structure of the goals. The final numbers of clusters was decided by the researchers, guided by the dendrogram and the agglomeration schedule. The main criterion to decide on the number of clusters was that the clusters should reflect distinct goals. The researchers also gave a name to the clusters. For the second card-sorting task, descriptive statistics (mean and standard deviation) were computed for each of the 55 goals and for the clusters. In order to determine the average score of a cluster, the average score of all goals in the cluster were first calculated for each clinician. To determine the standard deviation of a cluster, the standard deviation was calculated over the averages for each participant.

Results

Participants

Seventeen clinicians were interviewed and fifteen clinicians completed the card-sorting task. Saturation was not reached during the interviews. Eleven women and six men participated in the interviews, and nine women and six men participated in the card sorting task. Most of the participants were psychologists. Table 1 presents the characteristics of the participants.

Table 1

Characteristics of Participants

	Interview (*N*=17)	Card-Sorting (*N*=15)
Seks		
Female	11	9
Male	6	6
Mean age in years (min-max)	47.5 (32-65)	47.4 (24-65)
Place of work		
Altrecht Psychosomatic Medicine, Zeist	6	11
Other health institutions in the NL	11	4
Profession		
Psychologist	10	9
Psychiatrist	2	2
Medical doctor	3	2
Physical therapist	1	1
Occupational therapist	1	0
Mean number of hours working with SSD patients every week (min-max)	21.4 (0.5-36)	24.0 (2.5-36)
Years of experience working with SSD patients (min-max)	13.1 (6-35)	12.3 (2-30)

Note. Missing values for demographic information. One participant in the interview did not fill in any demographic information. Three participants in the card-sorting tasks did not respond to hours working with Somatic Symptom Disorder (SSD) patients.

Selection of goals

The 136 goals were reduced to a manageable set of 55 goals, see Figure 1.

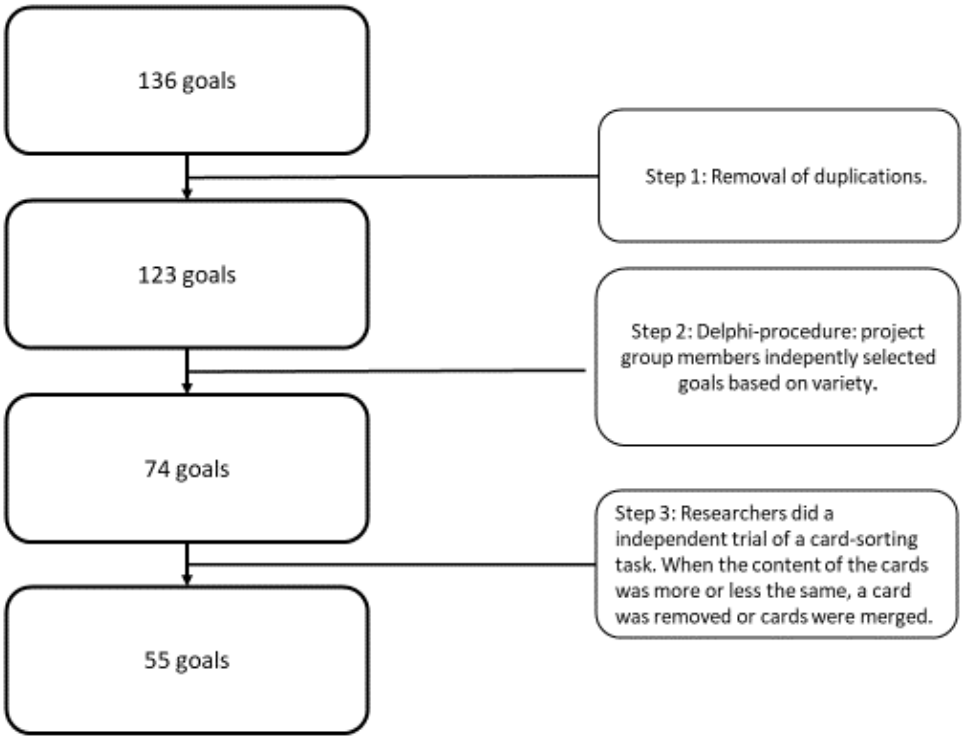

Figure 1. Selection of treatment goals by the project group and the researchers

First card-sorting task (content)

The number of cards per pile varied from 2 to 20. The mean number of the piles was 7.6 (range of 4 to 12 piles). No participants were excluded from the analysis. One participant did not group two cards in the first card- sorting task, those two cards were placed on two separate piles.

Hierarchical card sorting solution

Based on the dendrogram that was produced by the hierarchical cluster analysis, the number of clusters was set to ten. First, a visual inspection of the dendrogram was done. Second, the content of both a lower and a higher number of clusters were compared to finally decide on the number of clusters, based on consensus of the researchers about the content of the clusters. A schematic drawing of the dendrogram is shown in Figure 2 and Appendix D.

The dendrogram showed that the goals of SSD patients can be subdivided in three main domains, aclowest level of the hierarchy. The cluster *'activation'* was subdivided in the clusters 'physical complaints', 'balance daily schedule' and 'activaties'. The cluster *'mental functioning'* consisted of the clusters 'resilience', 'cognitive' and ' psychopathology'. Finally, the cluster *'positive psychology'* consisted of the clusters 'emotion regulation', 'body relatedness', 'self-esteem' and 'coping'.

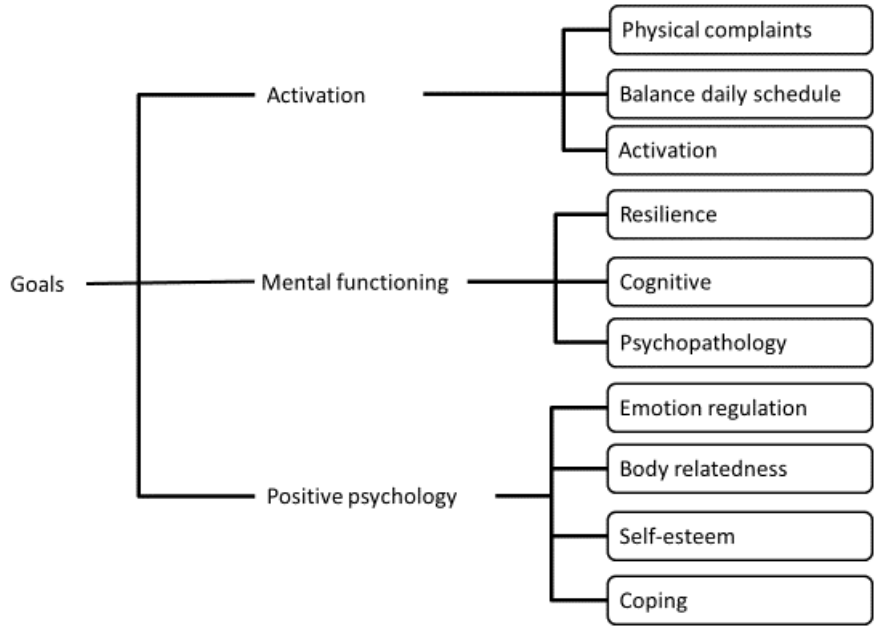

Figure 2. Schematic representation of the hierarchical structure of the goals

Number of clusters

A visual inspection was done of the dendrogram, this gave an indication of the number of clusters, but the final number of clusters was decided by the researchers based on the content. Increasing the number of clusters from ten to eleven, created a separation of the cluster 'coping' into two clusters: item 39,44, 38, 55 and item 2 and 14. This division made no sense because item 2 (come up with customized solutions for things the patient likes to do) and item 14 (learn to deal differently with physical complaints and limitations) together do not have a clear meaning that makes them stand out from the other four items. Increasing the number of clusters from eleven to twelve, created a seperation of the cluster 'coping' and the cluster 'psychopathology'. The cluster "psychopathology" was divided into two clusters: item 17 and 40 and items 33, 34, 23, 48. This division could not be done because the previous division (from 10 to 11 clusters) was meaningless. Moreover, there is no need to split the cluster psychopathology, because all the items fit into the psychopathology cluster.

Decreasing the ten clusters to nine combined the clusters ‘daily schedule’and ‘activity’, which are clearly different groups of goals. The "activity" cluster requires more effort from the patient and also requires effort from other people. For example, the goals "labor reintegration” and “building up social contacts”, require help from others. Information would be missed when combining those two clusters. When decreasing the number of clusters from nine to eight, the clusters “daily schedule” and “activity” and the clusters “emotion regulation” and “body relatedness ” would be combined. The clusters “emotion regulation” and “body relatedness” have no overlap. The cluster "body relatedness" is about the primary recognition of the patient's body signals and is a more passive cluster. This means that the patient does not yet have to perform any actions, but only needs to recognize bodily functions. The “emotion regulation” cluster goes a step further. This involves recognizing stress and also being able to regulate emotions.

Second card-sorting task (individual to general)

The mean ratings in table 2 show how the goals were rated by the clinicians from individual to more general goals. Lower means represent goals that are more individual. Higher means represent goals that are more general.The mean ratings for the 10 clusters ranged from 2.43 (psychopathology, *SD*= .72) to 3.78 (relation to the body, *SD*= .83). The mean ratings for the 55 individual goals ranged from 1.67 (decrease headache complain, *SD*= 1.29) to 4.33 (acceptance of the complaints, *SD*= 1.23).

A one-tailed analysis of variance (ANOVA) indicated a significant difference of means between groups, F (9, 808)= 6.10, $p < .001$ Post-hoc analyses with Student-Newman-Keuls revealed a distinction between the more individual clusters and more general clusters, see table 3. The clusters physical complaints (6) , activaties (3) , psychopathology (9) and self-esteem (1) were rated as more individual clusters. The clusters body relatedness (10), coping (4) , resilience (5), cognitive (2), balance daily schedule (7) and emotion regulation (8) were rated as more general clusters.

Table 2

The Mean Individual-General Rating and Standard Deviation of Each Treatment Goal as well as the Mean of the Overarching Clusters. The Lowest Possible Score is 1(Highly Individual) and the Highest Possible Score is 5 (Highly General).

	Individual vs. General Rating by Clinicians	
An individual goal in treatment is…	**Mean**	**Standard deviation**
Cluster 1: Physical complaints (fysieke klachten)	2.84	0.77
35 decrease headache complains (afname van hoofdpijnklacht)	1.67	1.29
36 decrease of conversive breakdowns and relapse (afname van conversieve wegrakingen en terugval)	1.93	1.33
25 decrease chronic pain (verminderen chronische pijn)	3.27	1.33
8 improve physical functioning (fysiek functioneren verbeteren)	4.07	1.03
49 improve general health (algemene gezondheid verbeteren)	3.73	1.44
45 sleep better (beter slapen)	2.87	1.19
18 tapering of addictive drugs (pain medication, cannabis, benzodiazepines) (afbouw verslavende middelen (pijnmedicatie, cannabis, benzodiazepinen))	2.20	1.32
Cluster 2: Balance daily schedule (balans dagindeling)	3.38	.62
15 better daily schedule (betere dagindeling)	3.07	1.10
42 improve day and night rhythm (verbeteren dag en nachtritme)	2.93	1.22
7 learn to have more balance between activity and rest (leren meer balans te hebben tussen activiteit en rust)	4.13	1.06
Cluster 3: Activaties (activiteiten)	2.71	.80
4 labor re-integration (arbeids re-integratie)	2.07	1.53
47 building up social contacts (opbouw van sociale contacten)	2.36	1.28
16 activating/building up activities (activeren/opbouw van activiteiten)	3.53	1.30
27 building up condition (conditie opbouwen)	3.20	1.26
24 laying less in bed or on the couch (minder in bed of op bank liggen)	2.27	.96
5 hierarchy of priorities in daily activities (hiërarchie maken van prioriteiten in dagelijkse activiteiten)	2.67	1.35
Cluster 4: Resilience (veerkracht)	3.17	.57
1 acceptance of the complaints (acceptatie van de klachten)	4.33	1.23
19 finding a new therapeutic perspective (nieuw therapeutisch perspectief	2.42	1.60

vinden)		
6 investigate what is worth focusing on in life (onderzoeken wat de moeite waard is om op te focussen in het leven)	2.53	1.46
9 increasing the quality of life by setting and implementing goals that fit with values (vergroten van de kwaliteit van leven door het stellen en uitvoeren van doelen passend bij waarden)	3.73	1.23
46 discover who the patient is and what makes him/her happy (ontdekken wie de patiënt is en waar die blij van wordt)	3.00	1.56
32 have fun and have fun activities (weer genieten en plezierige activiteiten ondernemen)	3.07	1.44
Cluster 5: Cognitive (cognitief)	3.20	.60
10 change in illness beliefs (verandering in ziekte cognities)	3.40	1.18
37 reduce negative thoughts associated with the complaint, for example, illness beliefs on trauma-related thoughts (verminderen negatieve gedachten samenhangend met de klacht, bijvoorbeeld illness beliefs op trauma gerelateerde gedachten)	2.93	1.03
22 pay less attention to the complaints (minder aandacht hebben voor de klachten)	3.13	1.36
29 pay less attention to health concerns (minder aandacht besteden aan gezondheidszorgen)	3.27	1.10
28 stop seeking medical statement for complaints (stoppen met zoeken naar medische verklaring voor klachten)	3.27	1.44
Cluster 6: Psychopathology (psychopathologie)	2.43	.72
17 exposure with anxiety (exposure bij angst)	1.93	.96
40 break through avoidance behavior (doorbreken vermijdingsgedrag)	2.87	1.19
33 improve mood (verbeteren van de stemming)	2.60	1.30
34 co-morbid psychopathology (depression, anxiety, posttraumatic complaints) (co-morbide psychopathologie (depressie, angst en posttraumatische klachten)	2.50	1.09
23 reduction of excessive worrying (vermindering van overmatig piekeren)	2.60	.99
48 goals focused on state, for example "I want more peace in my head" (doelen gericht op toestand bijvoorbeeld “ik wil meer rust in mijn hoofd”)	2.07	1.33
Cluster 7: Emotion regulation (emotieregulatie)	3.45	.97
3 reducing tension through relaxation exercises (verminderen van spanning door middel van ontspanningsoefeningen)	3.73	1.33
43 recognize tension (spanning leren herkennen)	3.46	1.39
51 improve emotion regulation (verbetering emotieregulatie)	3.27	1.28

54 improve stress regulation (verbeteren stressregulatie)	3.60	1.24
41 to recognize and express feelings and emotions (gevoelens en emoties leren herkennen, uiten en verwoorden)	3.20	1.37
Cluster 8: Body relatedness (relatie met het lichaam)	3.78	.83
13 learn to recognize early signs of getting away or pain attack (leren herkennen van vroege signalen van wegraking of pijnaanval)	3.27	1.44
31 learn to recognize the interaction between emotions and physical complaints (leren herkennen van wisselwerking tussen emoties en lichamelijke klachten)	4.13	1.30
21 learn to trust your body (leren vertrouwen van je lijf)	3.93	1.22
Cluster 9: Self-esteem (zelfvertrouwen)	2.80	.87
52 strengthen identity and sense of self (verstevigen identiteit en zelfgevoel)	2.20	1.42
53 to promote autonomy (autonomie bevorderen)	2.40	1.35
12 learning to put less demands on myself (leren minder hoge eisen te stellen aan mezelf)	3.53	1.55
50 lower the bar (de lat lager leggen)	3.13	1.41
26 learn to be satisfied (tevreden leren zijn)	2.67	1.54
30 learn self-compassion (zelfcompassie aanleren)	2.80	1.47
11 having self-esteem despite the handicap of physical complaints (zelfwaardering hebben ondanks de handicap van lichamelijke klachten)	2.73	1.22
20 get a better eye for things that I can be satisfied with (beter oog krijgen voor dingen waar ik tevreden over kan zijn)	2.93	1.33
Cluster 10: Coping	3.18	.56
39 improve interpersonal skills such as communicating (verbeteren interpersoonlijke vaardigheden zoals communiceren)	2.60	1.24
44 learn to ask for support (steun leren vragen)	2.93	1.33
38 learn and set limits (grenzen leren kennen en stellen)	3.80	1.47
55 improve coping skills (het verbeteren van copingvaardigheden)	3.33	1.29
2 come up with customized solutions for things that the patient likes to do (aangepaste oplossingen bedenken voor dingen die de patiënt graag doet)	2.30	.96
14 learn to deal differently with physical complaints and limitations (anders om te leren gaan met lichamelijke klachten en beperkingen)	4.07	1.10

Note. For the purpose of this thesis, translations of the treatment goals have been made. Treatment goals were translated solely by the researchers, without forward or backward translation.

Table 3

Student Newman Keuls comparison. The Output Shows a Distinction Between More Individual and More General Goals.

Cluster	N	1	2	3	4
6	88	2.432			
3	89	2.685	2.685		
9	120	2.800	2.800	2.800	
1	104	2.827	2.827	2.827	
10	90		3.172	3.172	3.172
4	89		3.191	3.191	3.191
5	75		3.200	3.200	3.200
2	45			3.378	3.378
7	73			3.452	3.452
8	45				3.778
Sig.		.292	.196	.057	.076

Discussion

In order to personalize the treatment for SSD, a concept mapping study was done to provide an overview of treatment goals. Ten clusters were found, organized in three main domains labeled as activation, mental functioning and positive psychology. *Activation* consists of the clusters physical complaints, balance daily schedule and activaties. *Mental functioning* consists of the clusters resilience, cognitive and psychopathology. *Positive psychology* consists of the clusters emotion regulation, body relatedness, self-esteem and coping. Goals differed in terms of individual to general. Two groups of clusters were found, one cluster consisted of more individual goals and the other of more general goals.The first hypothesis was met: commonly used generic outcome measures were found. The second hypothesis was partially met, because no relatedness goals were found.

Firstly, in line with previous studies, commonly used generic outcome measures were found. Common outcome measures used with patients with SSD address outcomes such as better quality of life, improved health and reduction of common symptoms of SSD (Behandelvisie Eikenboom, 2017). Examples of generic outcome measures mentioned in this study were goals such as ‘improve general health’, ‘decrease chronic pain’ and ‘learn to deal differently with physical complaints’.

Secondly, goals related to the needs for competence and autonomy were found. Competency goals were found most frequently, namely in the clusters resilience, cognitive, emotion regulation, body-relatedness and coping. An example of a competency goal mentioned in this study is:‘improve interpersonal skills’. Goals related to the need of autonomy were also found, namely in the clusters resilience and self-esteem. An example of a autonomy goal mentioned in this study is:‘promoting autonomy’.

Contrary to what was expected, no relatedness goals were mentioned by the professionals. A possible explanation is that most outcome measures for patients with SSD are related to the received type of treatment. Cognitive behavioral therapy, for example, may not involve the interpersonal environment in the treatment. However, studies emphasize the importance of social support for patients with SSD. Social support has a favorable impact on pain and may inhibit avoidance of physical and social activities (Cohen &Wills, 1985; Keefe, Buffington, Gibson, Studts & Caldwell, 2002; Uchino, Cacioppo, &, Kiecolt-Glaser, 1996). Because of the invisibility of their symptoms, many patients with SSD feel a lack of understanding from their social network (Kool, van Middendorp, Boeije &, Geenen, 2009). These patients often feel lonely and this feeling has negative effects on their functioning, health and well-being on top of the disease itself (Kool & Geenen, 2012).

The formulation of relatedness goals could be beneficial for treatment results, and has a positive effect on the needs for autonomy and competence. SDT (Deci & Ryan, 2000) states that the needs for autonomy, competence and relatedness are interdependent, and must all be present for optimal development. It is interesting that professionals did not mention relatedness goals. In the future, relatedness goals could be mentioned with these patients, for example goals such as ‘less negative social interactions’ and ‘more social support’(Kool et al. 2012).

A notable observation in this study is that many goals were formulated positively, namely as approach goals. Approach goals are positively oriented, when an individual strives to attain success (Elliot, 1999). In contrast, avoidance goals are goals to avoid a negative possibility (Elliot,1999). A domination of avoidance goals contributes to psychopathology and low well-being (Michalak et al., 2006). Pöhlmann (1999) compared the personal goals of psychosomatic patients with the goals of a psychologically healthy sample. Compared to psychologically healthy people, patients with SSD pursue more avoidance goals rather than approach goals (Pöhlmann, 1999). In the current study, more positive goal clusters were identified, namely the clusters activaties, resilience, self-esteem and coping. A positive formulation of goals and the formulation of approach goals fits with the perspective of positive psychology. Postive psychology suggests that focusing on individual's strengths, virtues and development can increase well-being and functioning of the patient (Deci et al., 2004). Therapy that is more focused on positive goals initiates a upward spiral of positive beliefs, affects and behaviors (Gilham & Seligman, 1999).The treatment goals reported by clinicians in this study, reflect more positive goals than are commenly used in the treatment of patients with SSD. It is possible that approach goals, will show higher therapy effects than the commonly used avoidance goals.

Another finding of this study is the division of the clusters into two groups, ranging from general to individual. The clusters physical complaints, activaties, psychopathology and self-esteem were rated as more individual. The clusters body relatedness, coping, resilience, cognitive, balance daily schedule, and emotion regulation were rated as more general. Remarkably, the cluster 'physical complaints' was rated as a more individual cluster. This is in contrast to a previous study, were physical complaints were rated as typical and more general symptoms of SSD (Dirmaier et al., 2006). Perhaps this cluster was seen as more individual because there are a large variety of complaints that are covered by SSD.

A strength of this study is that the clinicians who participated in the interviews and card-sorting tasks were highly experienced. They came from different institutions with a variety of professions. They were also involved in reducing the set of goals to a manageable set. Another strength is that both qualitative and quantitative methods have been applied. The subjective interpretation of the researchers was limited, because the clinicians categorized the goals in meaningful clusters in the card-sorting task. This provided a hierarchically structured overview of goals from the perspective of the clinician.

However, this study also shows some methodological weaknesses, which may limit the generalizability of findings in this study. One limitation of this study is the small sample size. Another was that not all clinicians opted for a personal interview. As a consequence, most of the interviews were done via email and therefore not profound. Furthermore, in the interviews saturation of goals was not reached. For the card-sorting task, a minimum of 30 experienced clinicians was aimed for. Only 15 clinicians participated in the card-sorting task, and this affected the validity and reliability of the

results of the cluster analysis. To show whether the hierarchical structure of goals will be replicated, further investigations need to be done with a larger sample of SSD patients. As an additional population, future research should repeat this study with SSD patients instead of with clinicians as intended by the research group. Maybe patients will mention goals that have not been named by clinicians. In addition, this study was only performed in the Netherlands and in the future cultural specific processes also need to be studied.

Specific adjustments in a replication study will be necessary to validate the findings of this pilot study. The instructions in the Delphi procedure should be made more complete. In the current study, criteria for selecting goals were not clearly enough communicated to the clinicians. The aim of the procedure was that project group members chose a set of goals as varied as possible. Due to insufficient instruction, the experts selected mainly goals they considered most important and/or more generally applicable. For example, a goal like ‘learn to recognize anger and express it’ did not reach the definitive set of goals while this could be an example of a more individual goal.

A suggestion for follow-up research is an expansion of the Delphi procedure. The selection of goals was based on variation. The formulation of goals was not reviewed. Some goals were formulated as a tool to achieve a goal. One goal, for example, was exposure. But exposure is more a method to counteract avoidance than a goal in itself. Therefore, it is recommended that items that are more a tool to achieve a goal are removed.

The main contribution of this study is that a preliminary encompassing overview of goals is offered that can be used as a screening tool in the intake with patients with SSD. This screening tool can help to initiate the client's thought process about his or her treatment goals and therapy can be adjusted to the preferences of the individual patient. Measuring outcomes on irrelevant variables is avoided and there is no restriction on possible goals. Patient-based measures can promote shared decision-making and facilitate communication between clinicians and patients. A one way (top-down) communication about goal setting between clinicians and SSD patients can develop to be more a dialogical (bottom-up) character.

In conclusion, this study has provided further input for personalized outcome measures. This study adds to previous studies, with an overview of possible individual treatment goals. This overview can be used as a starting point for the development of an assessment tool. It can help to adjust the therapy more to the preferences of the individual patient and contributes to shared decision making, which promotes patient-centered care.

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Appendixes

Appendix A
Results of the Literature Review

Search Method

Searches were performed on WebofScience and Google Scholar. Searches were mainly focused on patients with Somatic Symptom Disorder. The following combination of terms were used: *'somatic symptom disoder', 'somatoform', 'outcome measures', 'treatment goals', 'personal goals' 'therapy goals', 'patient based measures'.*

Appendix B
Overview of 55 goals in the treatment of somatic symptom disorder
Een individueel doel in de behandeling is..

1) acceptatie van de klachten (acceptance of complaints)

2) aangepaste oplossingen bedenken voor dingen die de patiënt graag doet (come up with customized solutions for things that the patient likes to do)

3) verminderen van spanning door middel van ontspanningsoefeningen (reducing tension through relaxation exercises)

4) arbeids re-integratie (labor re-integration)

5) hiërarchie maken van prioriteiten in het dagelijkse activiteiten (hierarchy of priorities in daily activities)

6) onderzoeken wat de moeite waard is om op te focussen in het leven (investigate what is worth focusing on in life)

7) leren meer balans te hebben tussen activiteit en rust (activity pacing) (learn to have more balance between activity and rest)

8) fysiek functioneren verbeteren (improve physical functioning)

9) vergroten van de kwaliteit van leven door het stellen en uitvoeren van doelen passend bij waarden (increasing the quality of life by setting and implementing goals that fit with values)

10) verandering in ziekte cognities (illness beliefs) (change in illness cognitions)

11) zelfwaardering hebben ondanks de handicap van lichamelijke klachten (having self-esteem despite the handicap of physical complaints)

12) leren minder hoge eisen stellen aan mezelf (learning to put less demands on myself)

13) leren herkennen van vroege signalen van wegraking of pijnaanval (learn to recognize early signs of getting away or pain attack)

14) anders om te leren gaan met lichamelijke klachten en beperkingen (learn to deal differently with physical complaints and limitations)

15) betere dagindeling (improve daily schedule)

16) activeren/ opbouw van activiteiten (activating/building up activities)

17) exposure bij angst (exposure with anxiety)

18) afbouw verslavende middelen (pijnmedicatie, cannabis, benzodiazepinen) (tapering of addictive drugs (pain medication, cannabis, benzodiazepines))

19) nieuw therapeutisch perspectief vinden (finding a new therapeutic perspective)

20) beter oog krijgen voor dingen waar ik tevreden over kan zijn (get a better eye for things that I can be satisfied with)

21) leren vertrouwen van je lijf (learn to trust your body)

22) minder aandacht hebben voor de klachten (pay less attention to the complaints)

23) vermindering van overmatig piekeren (reduction of excessive worrying)

24) minder in bed of op bank liggen (laying less in bed or couch)

25) verminderen (impact van) chronische pijn (decrease chronic pain)

26) tevreden leren zijn (learn to be satisfied)

27) conditie opbouwen (building up condition)

28) stoppen met zoeken naar medische verklaring voor klachten (stop seeking medical explanation for complaints)

29) minder aandacht besteden aan gezondheidszorgen (pay less attention to health concerns)

30) zelfcompassie aanleren (learn self-compassion)

31) leren herkennen van wisselwerking tussen emoties en lichamelijke klachten (learn to recognize the interaction between emotions and physical complaints)

32) weer genieten en plezierige activiteiten ondernemen (have fun and have fun activities)

33) verbeteren van de stemming (improve mood)

34) co-morbide psychopathologie (depressie, angst en posttraumatische klachten) (co-morbid psychopathology (depression, anxiety, posttraumatic complaints))

35) afname van hoofdpijnklacht (decrease headache complaints)

36) afname van conversieve wegrakingen en terugval (decrease of conversive breakdowns and relapse)

37) verminderen negatieve gedachten samenhangend met de klacht, bijvoorbeeld illness beliefs of trauma gerelateerde gedachten (reduce negative thoughts associated with a complaint, for example, illness beliefs on trauma-related thoughts)

38) grenzen leren kennen en stellen (learn and set limits)

39) verbeteren interpersoonlijke vaardigheden zoals communiceren (improve interpersonal skills such as communicating)

40) doorbreken vermijdingsgedrag (break through avoidance behavior)

41) gevoelens en emoties leren herkennen, uiten en verwoorden (recognize and express feelings and emotions)

42) verbeteren dag en nachtritme (improve day and night rhythm)

43) spanning leren herkennen (recognize tension)

44) steun leren vragen (learn to ask for help)

45) beter slapen (sleep better)

46) ontdekken wie de patiënt is en waar die blij van wordt (discover who the patient is and what makes him/her happy)

47) opbouw van sociale contacten (building up social contacts)

48) doelen gericht op toestand bijvoorbeeld “ik wil meer rust in mijn hoofd” (goals focused on state, for example "I want more peace in my head")

49) algemene gezondheid verbeteren (improve general health)

50) lat lager leggen (lower the bar)

51) verbetering emotieregulatie (improve emotion regulation)

52) verstevigen identiteit en zelfgevoel (strengthen identity and sense of self)

53) autonomie bevorderen (promote autonomy)

54) verbeteren stressregulatie (improve stress regulation)

55) het verbeteren van copingvaardigheden (improve coping skills)

Appendix C
Interview with experienced clinicians on possible individual goals of patients in the treatment of somatic symptom disorder.

1.Welke individuele doelen zou u in samenspraak met een patiënt kunnen stellen?

What individual goals would you set in consultation with a patient?

2.Welke soort doelen heeft u met de laatste vijf patiënten afgesproken?

If you consider the last five patients that you worked with, what types of goals did you set with them?

3.Als u aan uw meest complexe / zwaarste patiënten terugdenkt, welke doelen heeft u met hen afgesproken?

If you consider your most complex patients, what types of goals did you set with them?

4. Als u aan uw makkelijkste patiënten terugdenkt, welke doelen heeft u met hen afgesproken?

If you consider your easiest patients, what types of goals did you set with them?

Appendix D Dendrogram produced by the hierarchical cluster analysis