



Longing for existential recognition: A qualitative study of everyday concerns for people with somatoform disorders



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ABSTRACT

Objective: Patients with somatoform disorders could be vulnerable to stressors and have difficulties coping with stress. The aim was to explore what the patients experience as stressful and how they resolve stress in everyday life.

Methods: A cross-sectional retrospective design using 24 semi-structured individual life history interviews. Data-analysis was based on grounded theory.

Results: A major concern in patients was a longing for existential recognition. This influenced the patients' self-confidence, stress appraisals, symptom perceptions, and coping attitudes. Generally, patients had difficulties with self-confidence and self-recognition of bodily sensations, feelings, vulnerability, and needs, which negatively framed their attempts to obtain recognition in social interactions. Experiences of recognition appeared in three different modalities: 1) "existential misrecognition" covered the experience of being met with distrust and disrespect, 2) "uncertain existential recognition" covered experiences of unclear communication and a perception of not being totally recognized, and 3) "successful existential recognition" covered experiences of total respect and understanding. "Misrecognition" and "uncertain recognition" related to decreased self-confidence, avoidant coping behaviours, increased stress, and symptom appraisal; whereas "successful recognition" related to higher self-confidence, active coping behaviours, decreased stress, and symptom appraisal.

Conclusion: Different modalities of existential recognition influenced self-identity and social identity affecting patients' daily stress and symptom appraisals, self-confidence, self-recognition, and coping attitudes. Clinically it seems crucial to improve the patients' ability to communicate concerns, feelings, and needs in social interactions. Better communicative skills and more active coping could reduce the harm the patients experienced by not being recognized and increase the healing potential of successful recognition.

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Introduction

Physical complaints not attributable to conventionally defined diseases are prevalent in all medical settings [1]. When the symptoms become chronic they are diagnosed as somatoform disorders (SD). Patients with SD are often vulnerable to stressors and may find it difficult to cope with stress. However, little is known about the nature, mechanisms, and effects of stress and the exact interaction with coping [2–6]. Much research shows how the stress experience could be

aggravated by the often troublesome nature of the patients' encounters with the health care system, which are marked by diagnostic confusion, lacking etiology, uncertain illness perceptions, troublesome doctor–patient relationships, and insufficient treatment [7–16]. Less is known of stress triggers and management in non-clinical social spheres. Although patients seem to fight to overcome their illnesses and to interact with relatives, friends, colleagues, and health care professionals in order to create meaningful relations and manage a life in distress [17], they experience role constraints, social isolation and de-legitimization processes [18,19]. The struggle these patients experience fighting for being recognized as "legitimately ill" makes it especially relevant to bring in Honneth's concept of recognition. Honneth emphasises how the individual's need for social recognition is crucial to identity-formation and development of self-confidence, self-esteem, self-respect, and social- and physical integrity. Human

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identity depends on mutual recognition involving cognitive respect, social esteem and emotional support in social interactions [20].

Emotions are found to play a central role within the physiological stress response, emphasising the importance of subjective experience [21,22]. Further stress is considered to be dependent on the meaning the stimulus holds to the perceiver and the perceiver's coping behaviour [23–26]. The cognitive-activation theory of stress points out that when sustained cognitive stress is activated and met by a negative expectancy of coping, the stress-response is maintained [27]. Thus, the experience of stress is highly subjective and dependent on people's experiences of stressors, how they resolve stress, and how they had resolved stress earlier in their lives, which all affect their expected coping possibilities and behaviours. Therefore, the aim of this paper is to explore what patients with SD experience as stressful in their daily life and how they react when confronted with stressful challenges like e.g. misrecognition or lack of recognition in social interactions with significant others.

Method

Study design and data sampling

The study used a cross-sectional retrospective design using semi-structured individual life history interviews with 24 patients. Data was based on a purposeful sample collected among referred patients newly diagnosed with severe SD, recruited from “The Research Clinic for Functional Disorders and Psychosomatics” at Aarhus University Hospital, Denmark. Inclusion-criteria: Newly diagnosed with severe multi organ somatoform disorder/bodily distress syndrome [1], moderate to severe impairment for at least 6 months, 20–50 years, in case of co-morbid mental disorders e.g. depression/anxiety or co-morbid medical condition e.g. asthma/diabetes it should be clearly differentiated from the SD symptoms. Exclusion-criteria: Current alcohol or drug abuse, pregnancy and not fluent in the Danish language. The study included 24 patients, 21 female, purposefully sampled in order to obtain demographic variation and saturation [28]. Saturation is the point in qualitative data collection, when no new information emerges in relation to the target phenomenon/the newly constructed theory [28]. An uneven gender-balance was accepted, because this reflected the population generally referred to “The Research Clinic”, approximately 80% women, and gender was not a target of the study. Another paper (in preparation) deriving from the same study addresses the results related to patterns of experienced stress and coping in the patients' life histories before the onset of illness [29].

Interviews lasted between 2 and 4 h covering diverse aspects related to the patients major concerns and related experiences of stress, reactions to stress and coping with both external and internal stressful conditions (see topic guide on daily life Table 1). A confidential and relaxed atmosphere was created e.g. by responding to patients saying “yes” “interesting, can you tell me more” or nodding and carefully creating “emotional reciprocity”, meaning being emotionally emphatically, in order to make the patients comfortable telling in detail about painful experiences. Twenty-one of the interviews took place in the patients' homes and three at “The Research Clinic”. Interviews were done by one of the researchers, supervised by a senior researcher. The interviews were recorded digitally and subsequently transcribed verbatim.

Data analysis and generation of theory

The methodological framework was based on a constructivist grounded theory approach in order to capture the patients' individual experiences and attitudes as well as their social processes [30,31]. Data collection and analysis were done according to constructivist grounded theory procedures using theoretical sampling [32,33]. After each interview, memos were made with significant observations, analytic and theoretical reflections on the data, guiding further data collection and interviewing. All interviews were subsequently read

Table 1
Topic guide.

How stressful events and circumstances are experienced and influence the patient's major concerns, self-image and social identity in everyday life. And how the patient reacts and cope with daily challenges were explored in relation to:
The daily environment at home presently
A typical day in life presently (activities/relaxation)
Sleep quality and duration
Attachment with significant others like intimate partners or children
Communication with intimate partners of stressful events and related needs and feelings
Experience of social support related to stressful events and conditions
Atmosphere in the home
The relation to body and self
Body-awareness (sense of body, body-image and symptom appraisal)
Emotional awareness (emotional connection/disconnection)
Cognitive awareness (negative automatic thinking self-stigma processes, positive reframing)
Self-recognition/awareness of needs, feelings, vulnerability and distress
Self-image (self-esteem, self-confidence, strengths and limitations)
Self-care ability (How do you take care of yourself in your daily life?)
Other close relations
Relation and communication with other family relatives
Relation and communication with close friends
Expression of feelings, needs, distress and vulnerability in social interactions
Reactions to help offered by others/ability to ask for help/social network
Other significant relations (e.g. neighbours/people related to their children/colleagues)
Stressful experiences related to work/education
Identity and work (how important is your work/education to you?)
The illness affection on the ability to work/study and social relations at work/study
Reactions to these stressful conditions (thoughts, feelings, bodily reactions)
Coping strategies dealing with work/study-related challenges (how is this resolved?)
Related to leisure time environment
Stress relieving circumstances – e.g. physical exercise or creative activities
Atmosphere and social interactions
Importance to self-image and social identity
Relation to social worker, health professionals and illness perception
Relation to social worker and experience of the social system in general
Relation to the GP (do you experience your GP to understand your illness?)
Experience of the health care system in general (do you receive the help you need?)
Reactions to these challenges and coping strategies to resolve these challenges
Illness perception (can you explain the nature/cause/consequence of your illness?)
Illness-management (how do you react to symptoms/how do you cope to resolve this?)
Sense of coherence and expectations of the future
Do you experience your life to be: comprehensible, manageable and meaningful right now?
Do you see any positive consequences in relation to your illness?
How do you expect your future to be in one/five years? (illness/work/social life)

inductively and open-mindedly to obtain a general impression of the field. Data was systematically coded to identify the patients' main concerns and their reactions and behaviours with regard to resolving stressful experiences and circumstances. The coding was done (using NVivo 8) by the first author ABL systematically supervised by the senior researchers. Thus the coding of central transcripts was elaborated and discussed within the research-group to ensure accuracy and achieve consensus of the essential codes and the conceptualisation of the findings. Hypotheses, concepts and the grounded theory were in the same way developed in co-work in the research group. The core-concept and interrelated categories were identified and tested by axial/selective coding-procedures. Comparison between codes, concepts, and themes was constantly made. The study was carried out in accordance with the Declaration of Helsinki, and presented to the local Ethics Committee, who decided it should not be notified, because no human biological material was involved. All patients gave informed consent.

Results

The study included 24 patients – 21 female. The mean age was 35 (range 20–47). All patients had recently been diagnosed with severe multi-organ SD/bodily distress syndrome [1] affecting at least three out of four bodily systems with functional

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