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On parole: The natural history of recovery from fibromyalgia in women: A grounded theory study

Kerstin AH Wentz, PhD[*], Christopher Lindberg, MD, PhD and Lillemor R-M Hallberg, RN, PhD
Department of Internal Medicine
and Neuromuscular Centre, Department of Neurology,
Sahlgrenska University Hospital, Mölndal,
Health Care Science, Halmstad University
and Sahlgrenska Academy, Gothenburg University,
Gothenburg, Sweden

Abstract

Full remission of fibromyalgia symptoms is unusual and this course is unknown. The aim of this study was to elucidate psychological functioning and psychosocial processes expressed by women originally diagnosed with fibromyalgia and presently recovered. Eight women, earlier diagnosed with fibromyalgia but presently subjectively and objectively recovered, were interviewed in-depth. The interviews were analysed in line with Grounded Theory. Result: The women were as children exposed to high levels of mental load. Adult psychological functioning, prior to the onset of fibromyalgia, was characterised by insufficient definition of self and dissociation; psychological strengths were used to cover up or desert psychological 'weaknesses' as negative effects. Later in process an increase in mental load was accompanied by development of fibromyalgia symptoms. The phase of fibromyalgia held three dimensions; a maintained high level of load, mastering strategies as seeking alternative treatment and use of support from others. The stage of recovery or remission was reached proceeded by a pronounced decrease in mental load as improved life conditions or cease of overexertion of body and mind. The stage of conditional recovery was mirrored by the core concept 'on parole –strengthened enough to be weak'. At this stage of process, absence of symptoms was secured by personal growth and less dissociative functioning including careful management of health needs as pacing of activity. Conclusions: Recovery from fibromyalgia seems to be a recovery on parole. Recovery appears to rely on improved self-regulation including less dissociative psychological functioning and ways of living allowed by prosperous conditions of life.

Keywords: Fibromyalgia, grounded theory, dissociation, negative effect, self-regulation, personal growth, recovery.

Introduction

Fibromyalgia is a pain syndrome without an established pathogeneses. Diagnosis is based on criteria including a history of widespread pain lasting

[*] **Correspondence:** Kerstin Wentz, Department of Internal Medicine, Sahlgrenska University hospital/Mölndal, Göteborgsvägen 31, 431 80 Mölndal, Sweden. E-mail: kerstin.a.wentz@vgregion.se

for three or more months and elicitation of pain by digital palpation of at least 11 of 18 predetermined bilateral tender points (1). The prevalence of fibromyalgia is estimated to 2% of the population and has an obvious dominance in females (2). The course of the disorder is regarded by Felson and Goldenberg (3) as chronic with few generally transitory remissions. Ledingham, Doherty and Doherty (4) reported full remission of symptoms in 3 % of patients in a 4-year follow-up study whereas Bengtsson, Bäckman, Lindblom and Skogh (5) found full remission of symptoms in 2% of patients 8 years after diagnosis. A more positive prognosis is described for children (6).

Griep, Boersma and de Kloet (7) suggested that fibromyalgia is related to a documented neuroendocrine dysregulation characterized by, for example, relative hypocortisolemia. These researchers contrasted this thypothalamic-pituitary-adrenal (HPA) response pattern with the hypercortisolemic responses observed in patients with depression (7). Van Denderen, Boersma, Zeinstra, Hollander and van Neerbos (8) reported decreased response to exercise of the sympathetic nervous system in patients with fibromyalgia when compared to healthy controls. Being medically unexplained, fibromyalgia is sometimes regarded as a psychosomatic disease or perhaps rather as a 'common distress disorder' together with chronic fatigue syndrome and irritable bowel syndrome (9). The importance of psychological factors in the course of fibromyalgia is put forward by for example Eich and Blumenstiel (10). Simultaneously, a growing body of results from research suggests abnormal biological processes involving, for example, the central nervous system present in patients with fibromyalgia (8).

In psychological research there has thus far been a dominance of quantitative research methods. One line of investigation has been of traumatic experiences, or levels of lifetime stress. Amir (11) found that 21% of a sample of patients with posttraumatic stress disorder (PTSD) fulfilled the criteria for fibromyalgia. Van Houdenhove et al. (12) used patients with multiple sclerosis (MS) or rheumatoid arthritis (RA) as controls and reported that patients with fibromyalgia show a significantly higher prevalence of emotional neglect, emotional and physical abuse and that a considerable subgroup of these patients also had experienced lifelong victimisation. The perpetrators were most frequently found in their families. Fibromyalgia has further been associated with the experience of high levels of daily stress when compared to other patients with pain (13). Psychometric research has further been used to predict good or bad outcome of rehabilitation measures or programs. Analysis of mood and coping strategies showed low correlations with fibromyalgia activity. In a study designed to compare group treatments of relaxation technique with group treatment combining relaxation technique with group therapy, the group receiving both kinds of treatment was found to have the best outcome results. The most successful patients had all participated in the group receiving group therapy and were also singled out as having suffered from pain for a shorter period of time, not having applied for disability pension and showing more initiative for conflict resolutions as measured by projective testing (14).

To date, theory generating qualitative research in the domain of psychological and social processes involved in psychosomatic disruptions or symptoms remission/recovery is scarce. Hallberg and Carlsson (15) however, used grounded theory and described women presently suffering from fibromyalgia. The women were found to have had a traumatic life history and were also described as being over active and preoccupied with their pain (15). Further Wentz, Lindberg and Hallberg (16) used grounded theory to generate a hypothesis on psychosocial processes involved in development and maintenance of fibromyalgia in women. In their study, adult psychological functioning was described in terms of lack of self-reference and self-protective ability. Intense activity or hypomanic helpfulness was often used as compensating self-regulation. Later in the process a marked increase in mental load was accompanied by generalised pain. The phase of persistence of fibromyalgia was characterised by still holding the qualities of an increased level of mental load due to for example crisis, somatic symptoms, cognitive difficulties or continued over activity. In addition, a subgroup of women having experienced total remission of symptoms lasting for many years, was identified. These women depicted their long-lasting pain gaps in a context of improved conditions of life and more successful self-regulation. A further

step in the research process was to invite women having recovered from fibromyalgia to relate their experiences.

The aim of this grounded theory study was, employing clinical psychological procedures, to elucidate psychological functioning and psychosocial processes in women originally diagnosed with fibromyalgia and presently recovered. In order to do this, women having recovered from the syndrome were interviewed semi-structured and invited to express their own views and experiences. The essential qualities found in the interviews were then to be picked up, labelled and categorised in order to illuminate the area under study – the course of fibromyalgia and the psychological resources, vulnerabilities and psychosocial conditions of the recovered women.

Methods

The sample consisted of 8 women aged 39-68 years (mean 56 years), who had earlier fulfilled The American College of Rheumatology (ACR) (1) criteria for fibromyalgia with the diagnosis also documented in their medical records. Further, the participants were to have considered themselves recovered from the state of fibromyalgia and no longer fulfil the ACR criteria for fibromyalgia.

The women were selected by the criteria of documented fibromyalgia and subjective and objective recovery. The selection did not aim at achieving a heterogeneous sample of participants due to obvious difficulties in finding participants fulfilling the above criteria. All women volunteering and fulfilling the criteria were included. The women's educational backgrounds were fairly long, ranging between 8 and 16 years of schooling (mean 13.7 years with onset at the age of 7 years). Five women were married, two were divorced and one was widowed (see table 1).

Procedure

The participants were recruited by an advertisement in a morning paper, asking for women that had recovered from fibromyalgia. Prospective participants were asked to call the first author (KW) at the Pain Clinic at Sahlgrenska University Hospital/Mölndal. They were then sent an informative letter about the study. If interested in participating they were asked to mail their written consent to the research group. After informed consent the participants underwent medical examination by the second author (CL) to confirm that they did not fulfil the ACR criteria for fibromyalgia. They also had to give their written consent for the second author to obtain their medical record of fulfilling the ACR criteria of fibromyalgia. The medical record was ordered and checked by CL. The women were interviewed by the first author, a clinical psychologist and doctoral candidate (KW), at the Pain Clinic at Sahlgrenska University Hospital/Mölndal. The interviewer has experience in psychiatry and pain rehabilitation.

In-depth interview

The interviews were semi-structured, in depth, and lasted 1.5 to 2 hours. They focused on the onset of symptoms, course of the illness, remission of symptoms, life-style, activity style, life history, object relations and views regarding reasons behind the development and remission of fibromyalgia symptoms.

The interviews were tape- recorded, transcribed verbatim and consecutively analysed according to Grounded Theory. The interview guide was adjusted alongside data gathering in order to further illuminate emerging data patterns.

Data analysis

The protocols were analysed in line with guidelines for Grounded Theory (e.g. 17) in order to explore a new area of which little is known. In this study the aim was conceptualisation of data patterns and formation of a hypothetical model on relationships between emerging concepts. Grounded Theory systematises induction and aims at explaining a phenomenon or as expressed by Charmaz (18, p 30) "grounded theory methods are designed to study processes, these methods enable the psychologist to

study the development, maintenance and change of individual and interpersonal processes".

Table 1. Background data on 8 informants

Age	35-45	46-55	56-65	66-
Number	2	1	3	2
Family				
Married/ cohabiting	1	1	2	1
Divorced	1		1	
Widowed				1
Number of children living at home	2	1	1	
Total number of children	4	3	6	4
Education				
Upper sec. education			1	
University	2	1	1	2
Employment/ Student				
Full time	1	1	1	
Part time	1			
Current level of working/ studying				
Fulltime	2	1	1	
Parttime				
None			2	2
Amount of years				
with F-pain	9 and 14	4	6, 10,17	15 and 24
recovered	1 and 7	2	4, 7, 10	2 and 6
Treated for psychiatric/ Psychological symptoms	1		2	

Table 2. Components of the core concept on parole –strengthened enough to be weak and the four higher order categories strong but not enough to be weak, increase in mental load -development of fibromyalgia, challenge of fibromyalgia, and decrease in mental load -symptoms remission

Strong but not enough to be weak	Increase in mental load - development of fibromyalgia
Dimension: Strained and benefited as a child	
Not being mothered	Load from external conditions
One parent loving	Localised pain
Overwhelming situation/unprotected child	Immobility
/used child	Existential threat
Stimulation/powerful role models	Loss of full health/disease
Traumatised mother	Health jeopardising behaviour
Helpless role models	/hypomanic response
Verbal/physical abuse	Sleepdeprivation/exhaustion
Premature strength	Invaded/difficulties regarding saying no
Lonely child	Loneliness
Spite/unrealisticness	Conflict
	Altered family situation
Dimension: Strong but not enough to be weak	Helpless/hopeless/captivity
	Invaded/verbal aggression
Alloplastic competence/educated	
/enjoying professional life	Challenge of fibromyalgia
Taking oneself seriously/able to enjoy	*Dimension: Maintained high level*
Capable of recieving help	*of load*
Weak self representation	
Self criticising/scared of criticism	Suppression of self
/easily invaded/overwhelmed	Helpless/hopeless/disaster
Inability to mourn/suffer	Stigmatised
Accumulated trauma	Cognitive difficulties
Always lived under stress	Load from somatic symptoms
Dissociative functioning/activity	Sleep deprivation
/incoherence	Increased level of activity/mental load
Redirection of perception	
Hypomanic strategies/omnipotence	
Denial/rigid annulment	
Psychosomatic reactivity	
Unresolved dependence	

Table 2. (Continued)

Challenge of fibromyalgia (continued)	Decrease in mental load-symptom remission
Dimension: Mastering strategies	
Seeking information about health	Being rescued
Talent/skills	Cease of overexertion
Skills/results from alternative treatment	Psychological conflict resolved
Actively seeking a better life	Improved management of negative affect
Economic resources	Improved family situation/happiness
Capacity of seeking/accepting help	Cease of localised pain
Sense of deserving a good life	
	On parole –strengthened enough to be weak
Dimension: Support counteracting	
helplessness/loneliness/despair*:*	Health depending on careful management
Protecting fellow human or spouse	Not being overactive
Acceptable life-solution offered	Personally relevant low level of strain
A good relationship with a good doctor	Efficacious defences
	Personal growth
Decrease in mental load-symptom remission	
Life situation improved	
Control/magic control	
Platform of diagnosis	
Relief from social pressure/ humiliation	

The quality of an inductively derived qualitative theory could be estimated by its ability to explain the phenomenon or the area under study and its ability to interpret and predict actions connected to it.

Induction is founded by the creation of concepts later forming a theory or hypotheses. The first step of induction in this study was reading through an interview. The next step was line by line coding. Coding was performed by the first author, supervised by a senior researcher (LH). The codes reflected both 'identification' and an 'objectivist standpoint'. The voices of the participants were therefore anticipated through identification with the participant's point of view and simultaneously anticipated from a standpoint of finding out what was 'out there' not necessarily sharing the perspective of the participants. Both so called in vivo and in vitro codes came to use, meaning conceptualising the content of the interviews, using concepts not related to theoretical frameworks on psychological functioning combining them with concepts stemming from theoretical frameworks. This was a conscious decision that aimed

at capturing as much as possible of qualities in the dimension of experiences, conditions and psychological functioning present in the interviews. Most codes belonged to the in vivo species. The coding procedures resulted in between 500 and 700 codes in each interview. The line-by-line coding was also performed twice 'not looking back' at the first version. The versions were compared and a third version of coding was created. The codes were then listed 'separately' from the interview and the list of codes was used in the creation of preliminary categories. The categories created were then compared with the interview. Each interview resulted in a preliminary model through an axial coding procedure where relationships between categories, other categories and subcategories were tested in data. The categories and preliminary models stemming from each interview were compared. New categories were created expressing a higher level of abstraction. This means that categories with similar 'meaning' as existential threat, localised pain and sleep deprivation were clustered into the higher order category increase in mental load - development of fibromyalgia. This higher order category described strain having been added or having escalated at the time of onset of symptoms.

Theory was further built through the next step of identifying a core concept to which the other categories were related. In all stages of the inductive process relationships between codes, categories and the core concept were hypothesised and tested in data to secure that the emerging result was grounded in the data. Selective sampling of literature completed the inductive process. For example, the phenomenon of incoherence in psychological functioning resulted in comparison to defence and self-structures described in child abuse literature and articles on dissociation.

Ethics

The study affected healthy participants volunteering to share their experiences of recovering from a presumed chronic disease. Some of the questions asked during the interviews were potentially upsetting, however, the participants were informed about the content of the semi-structured interview in advance in a letter. The participants were also offered the possibility to turn to the first author for counselling or assistance if they became upset after the interview. The Ethical Committee at the Medical Faculty, Gothenburg University, accepted the study design.

Results

The analysis resulted in the identification of five higher order categories/concepts describing psychological functioning in women who have recovered from fibromyalgia. These concepts were labelled strong but not enough to be weak, increase in mental load – development of fibromyalgia, challenge of fibromyalgia, decrease in mental load –symptoms remission and on parole –strengthened enough to be weak. A core concept on parole –strengthened enough to be weak was identified among them. The core concept was central in the process appearing in data and relates to the other higher-order categories. The core concept and the higher order categories are briefly described below. The subcategories and codes that pertain to the higher order categories clarify their content and variation in expression.

Strong but not enough to be weak

This concept illuminates a lack of psychological integration of vulnerable, weak, insecure, hurt, unprotected or overstrained parts of the self with skilful and creative parts. This pattern of incoherent functioning holds the dimensions of developmental conditions, strained and benefited as a child, and adult functioning, strong but not enough to be weak.

Strained and benefited as a child: The pattern of strained and benefited as a child, was in the interviews 'incoherent' in the sense that the child was exposed to malfunctioning of parenthood simultaneously as she could benefit from love from at least one adult or that she might have had an opportunity to identify with a parent experienced as happy, skilful or powerful. When signs of not having been mothered were identified in the narrations, this was paired with that the father was experienced as having been loving. This could be illustrated by the following excerpt from the interviews:

'…when I was little, before I almost could walk, I crept away to the neighbours and my mother says...[that]I have never liked it at home and I would want to say that have you never thought of why…I moved away from home when I was 14 years old…she was always negative, bitter, cold. Cried easily…I have never sat in the lap of my mother…[she has? never read a story to me…I loved to be with ?my father while he was working close to home]. We had a very good relationship…'

The pattern of strain related to incapacity of parenthood appeared in the interviews as verbal or physical abuse. The child might also have been exposed to an overwhelming situation of having had a parent in a chronic condition of emotional crisis. In relation to this parent the child was unprotected regarding emotional pain, anger or demands expressed by this parent. Simultaneously, one or both parents might have been professionally successful, well educated or gifted supplying the daughter with both stimulation and powerful role models. A little girl that, partly due to her father seldom being home, was left to her mother's depression and aggression, exemplifies this pattern:

'she was a very depressive woman… she told me at early age...that –if abortion had been free you had not existed [Name]…she turned to me when she was sad, so it was my mission to get her in a good mood…when I was thirteen I was allowed to go to the country –house alone…I have managed on my own since…they were very busy with their lives…daddy worked all the time and my mother was very active in politics… '

Data indicated that the women as children might have had to show premature strength and thereby dissociated vulnerable aspects of the psyche. Another expression of strained and benefited as a child, found in the interviews, was that of having been a lonely child not having benefited from the company of peers exemplified by one informant, besides describing her own loneliness as a child, simultaneously depicted her mother as light-hearted and autonomous. Data further show signs of strain due to a traumatised mother being the caregiver, which also constituted a helpless role model for the child to identify with.

In the narrations a quality of spite/stubbornness and unrealisticness also appeared. The child, in a life situation marked by strain, sought security in notions of high levels of self-control. One informant, wilfully failed tests at school that would have created possibilities for her to get a good education due to ' I didn't want to do it…don't know if it was because I was forced to…'.

Being strong but not enough to be weak mirrors that in the adult women, capable parts of the psyche were intensely used to desert, encapsulate or cover the vulnerable, weak, insecure, unprotected or overstrained parts. This incoherence in psychological functioning simultaneously meant that the women gained pleasures and security from their competence, condensed into the subcategories alloplastic competence, being educated, and enjoying professional life. The label alloplastic, in this context, aims at an appearing ability to influence and/or change the surrounding world or otherwise conditions of life. The strengths of the women also showed itself as an ability to take themselves seriously and being able to enjoy life. In certain segments of life, longings or wishes were taken seriously. Examples of this were wishes for, and satisfaction from, a good private or professional life. Another example of the resourcefulness of the informants, present in the interviews, was that the women showed a capacity to receive help.

Besides obvious resourcefulness evident as well were signs of a weak self-representation in terms of problems in the area of a lack of sense of separateness and experience of identity sufficient to endure interpersonal conflicts. Moreover the same weak self-representation appeared to have played a role in setting standards, contemplating and understanding health needs. This pattern could be exemplified with one informant that for the first time got aware of bodily signals and limitations after having acquired marked bodily pathology due to working to an extreme extent.

In the narration were signs of that the weak self-representation of the women was paired with that they were self-criticising, scared of criticism, easily invaded or easily overwhelmed. The informants easily had felt that they deserved criticism. In relation to ongoing criticisms there were indications that the informants had difficulties protecting themselves which seemed to result in that they got invaded or overwhelmed. Qualities of unsolved dependencies, mainly in relation to a parent, also appear in data:

'…I will never get any confirmation that I am good enough…but it is immensely difficult…a psychologist ?said that I should learn? not to take all that my mother throws out [at me]…'

The interviews also contained clear elements of an inability to mourn or suffer emotionally. A state of being dammed up with negative affect or having an experience of that one has always lived under stress could accompany this inability to mourn or suffer. 'The stress' did not appear as a response to ongoing threats or demands from the outside world but rather as a pressure 'from the inside'. When an interview contained signs of inability to mourn and the informant had faced repeated challenges, there was a case of an accumulated trauma.

In order for the women to desert, encapsulate or cover the weak parts of the self the data held evidence of dissociative functioning. Facts of life and wishes could have been kept apart. Intense activity and 'tuning in' into this activity also served as dissociation. One informant described how she could not just give way to just being, thinking and feeling:

'…since I was a child I have been like voluntary work and in that sense I always sat doing things at home…[also] sewing and gardening…[reading?] Yes, books…[somebody said to me][it can't be good keeping on like that all the time but I experienced it… not like stressful but it was relaxation to me reading a good book…embroidering, having to concentrate just on that and leaving the other…'

Besides dissociative functioning this excerption also exemplifies signs of that the informants used redirection of perception in order to divert attention into the outer world away from unmanageable mental content. The interviews further gave evidence of emotional reactions as fear or mourning in crisis were counteracted by hypomanic strategies. This meant that painful affective reactions could be avoided by fantasies of that the woman herself was a person able to 'take it right'. The avoidance of 'take it right' could be also be complemented with industriousness, an interesting life content or exercise. Frightening or sad revelations might, in the narrations, also be handled through denial, isolation or rigid annulment meaning that mounting health problems or lack of sleep were met with decisiveness regarding not being influenced by these events. The frightening possibility of not being healthy was instead met by perseverance regarding exhausting activity as continuing to work full time in spite of substantial strain from deprivation of sleep and somatic symptoms.

Increase in mental load – development of fibromyalgia

This concept describes mental load that was added or had escalated at the time of onset of fibromyalgia-symptoms. In the narrations data patterns showed a combination of many stressors contributing to an increase in mental load that preceded and paralleled the onset of fibromyalgia symptoms. Localised pain might have been introduced or got more pronounced at the time of onset of symptoms. One informant related to this combination of stressors and narrated that she had faced a new and very psychologically and ergonomically demanding employment. Due to a breakdown in public transport she had to travel a prolonged time to work:

'…at the time [the pain] was mostly …in the neck and shoulders and the headache got worse…and gradually it was very difficult to sleep and so I got pain…it ached. Sometimes I could not keep my legs still…I could not sit still at all…it turned over…to fibromyalgia.'

A very ambitious informant developed localised pain in her thirties and fibromyalgia in her forties in a situation of increase of mental load, being forced into immobility at work due to static work-tasks moreover she faced longer and exhausting journeys to work:

'[…this travelling was a bit tough…?]…a bit tough...but fun also...I found gradually it was hard for the body…I sat very much in the car…if I was in excellent shape it worked out much better but the shape just poured away from me…driving that much…I didn't have the energy for daily exercise… when I came home…I slept a few hours instead…it somewhat cracked me…'

In the narratives an increase in mental load was also evident as crisis in the form of an existential threat as to admit the loss of full health/disease. This in turn might give rise to even further strain by triggering health jeopardising behaviour or a hypo-manic response in the form of an enormous effort to

maintain the same high level of activity as before bodily symptoms and sleep-deprivation. This in turn had as a consequence physical and mental exhaustion:

'it must not be a disease I still want to be a [profession]…I was afraid to become a fibromyalgia-old woman, you know, someone who can't do anything, doesn't want to do anything, not having the strength to do anything…I could not sleep because I had pain… I could be awake once an hour…[…for 5 years you worked full time and got worse and worse?]…Yes from the beginning it was only the joints …I was tired but…my life was like trying to make it work…'

Signs of mental load in the form of being psychologically invaded or difficulties regarding saying no were present in data. An informant, for example, told about a situation in which she had worked overtime and had also developed localised pain. Her situation also included sleep-deprivation due to working day and night shifts. She ignored her exhaustion. In this situation, she developed fibromyalgia:

'I got pains in the arm… tendonitis…I should really have slowed down then and not kept working that much…and got even more pain…[?] There was a shortness of staff and I had difficulty saying no…it was used...[it was known that I] usually work extra time…I was very much alone, my husband travels a lot…I might as well work…'

According to the interviews, the development of symptoms could also coincide with mental load as helplessness, hopelessness or feelings of captivity. Also a socio-economic life situation could be experienced as inescapable.

Challenge of fibromyalgia

The interviews reflected also the pattern of response given by the informants and their networks, to the onset of symptoms. Three separable dimensions of challenge of fibromyalgia were identified: maintained high level of load, mastering strategies, and support counteracting helplessness and despair.

Data patterns indicated a maintained high level of load after the phase of increase in mental load accompanied by the onset of generalised pain. The category helpless/hopeless/heading for disaster illustrates that the women could get terrified by symptoms and their consequences; fear of getting worse and anxiety and self-doubt. The sense of self might have been suppressed in order to avoid thinking of oneself and the future, not thereby having to experience helplessness/hopelessness or that one was heading for a disaster. One means of avoidance was to concentrate solely on daily routines. Signs of that the women also might face the frightening state and stage, of being undiagnosed, were also present in data:

'…I was afraid it was cancer…I liked to [hike]…my…son…14 years old said I want to go with you rambling…I had to tell him, what will happen if I die while we are out ?in the wilds?…'

Some women experienced themselves stigmatised or ashamed of not being able to give an explanation to friends, employers or to themselves of their symptoms. Further, load from somatic symptoms, together with sleep-deprivation, is a consistent finding in the interviews. Cognitive difficulties, regarding remembering, controlling affects, finding the right words, being able to concentrate and to plan created problems while working '… leads also to having to stay over at work' as expressed in one interview. There were further signs in the interviews of both getting good effect from alternative treatment as Eastern medicine and methods such as relaxation and that these effects were counteracted by an increased level of activity and/or mental load.

The dimension mastering strategies mirrors the resourcefulness of the informants, such as creativity and problem-solving capacity at work during the state of fibromyalgia. Seeking information about health was a consistent pattern throughout data. Further the obvious talent and skills of the informants often meant that they had an interesting life through an interesting job that partly compensated for the setback of somatic symptoms. Parts of the quality of life could be regarded as not at risk of being lost and also meant an identity of professional success and of being attractive on the labour market to fall back upon. The women could, according to patterns in data, also be said to actively have sought a better life, or having improved their life-situation as a whole, the women thereby also exhibiting a sense of deserving a good life, at least partially. In spite of having been

confronted with the diagnosis of a presumed chronic disease, one woman narrates:

'I decided to leave my husband….I had decided [two years prior] but I didn't go through with it until ?the children were older?…but a part of the recovery, I believe, is about my taking control over my life and not letting anyone else handle me… '

In the year of the original decision to get a divorce this informant hunted down alternative treatment in the form of Eastern medicine and regained a great deal of energy. Her narration also illustrates another consistent quality in the interviews, namely that the women developed skills or experiences of good results from alternative treatment. The informants might have benefited from this treatment in the form of substantial gaps in pain ascribed to treatments like massage, acupuncture, techniques of relaxation, chi-gong or zone-therapy to relieve pain. Parallel to this, data-patterns showed that the women often had sufficient economic resources that meant possibilities to ease their symptoms or experience pain-gaps through training and/or services from private providers. Descriptions of how the women kept up their spirit or managed to work through this kind of relief were present in the interviews. To these problem-solving patterns, the capacity to seek and accept help was somewhat a parallel. One informant with a very modest income accepted help from her father and brother to be able to travel abroad, seeking the benefit of a warmer climate, living there at a very low cost. The interviews also contained examples of that the informants sought counselling for a period of time to deal with psychosocial stressors

The interviews contained patterns of that the women got different kinds of support that counteracted their helplessness, loneliness and despair. A fruitful empathic and problem-solving atmosphere in the marriage, at work or in friendships was depicted. Another example of support was that realistic and acceptable life-solutions were offered to the woman. A well-educated informant developed incapacity to handle stress as well as pronounced hand-motor difficulties. At the stage of gradual remission of symptoms, she was offered work in line with her interest in which stress-tolerance and hand-motor skills were of less importance. A good relationship with a good doctor, that showed empathy, was also highly valued.

Decrease in mental load – symptom remission

In all interviews, a decrease in mental strain proceeded and paralleled the remission of fibromyalgia symptoms. Active strategies from the women to improve their lives or manage their symptoms did not in themselves seem to result in vanishing of symptoms. It was rather in a situation of actual decrease in the level of mental load that the symptoms gradually or instantly vanished. Based on the interviews, the degree of mental load seemed to decrease or the life situation was considerably improved either as a result from the women having taken active measures themselves or as 'a gift from above'.

The interviews showed signs of the importance of getting the platform of diagnosis of fibromyalgia. The diagnosis might have driven away fears of other diseases and constituted prerequisites for control or action. In data there were also signs of that a sense of control or magic control was important to decrease mental load. The magic part of the sense of control could be expressed as a notion of being absolutely sure to be able to achieve what you have decided to achieve.

A relief from social pressure or humiliation through retirement could also exemplify the stage of decrease in mental load –symptom remission. Early retirement, offered by a doctor without the woman herself having thought of the possibility, exemplifies 'a gift from above' or 'being rescued pattern' present in the data. Cease of overexertion of body and mind was also a turning point in the narratives exemplified by a very ambitious and strained teacher who struggled, for about 15 years, to increase her work hours with one lesson a week every year, in spite of pain and severe cognitive difficulties including sensitivity to noise. Her doctor, a specialist, advised her not to work as a teacher whatsoever. She acquired relaxing skills to achieve moments of relief from her fibromyalgia symptoms, and used these gains to manage to work and to increase her work hours.'…didn't realise that I ran over my energy, that I worked over my strength…?the doctor said?…I

can't see you going back as a teacher, and he was right but I did it anyway…I realise now that I made it worse….the healing-process would have been faster if I had not at any cost …I should be doughty.'

The informant cited above gradually but rather quickly recovered from fibromyalgia after old age pension.

To a decrease in mental load might contribute a quality of that a psychological conflict was resolved. A new way of handling personally important issues meant an end to painful psychological tensions. An extreme fear of being sick-listed or retired and thereby no longer belonging to the world of the healthy and active could be expressed.

One woman martyred by pain, cognitive difficulties and sleep deprivation, regained her good sleep, had a stepwise full remission of symptoms and was able to return to work full time after having accepted and found something meaningful in her current sick-listing 50%:

'[...about being sick-listed ….?] …then it felt like I just give in to this… let it take over…I have had a terrible fright of this must not take over like…it must not be a disease, I want to be [a professional] still, it was important…tired, in pain and sad. And at the same time I didn't want to be at home…when I was sick-listed 50%…I just lay down and stared into the ceiling. [Two years after starting to take antidepressants to manage the reaction to sick-listing half time she starts to find being at home half time an acceptable alternative to working full time]… important to accept that one can be at home…at first…it was a stigma…but at last I might enjoy...[a school-child] comes home and says it's nice that you're at home…'

In addition the data showed signs of that women marked by intense tension from unresolved existential threats or unresolved relational hardships in life could experience symptom remission either accompanying personal growth or antidepressants.

One woman experienced immediate symptom remission from this kind of medication. A further expression of decrease in mental load was an improved family situation including subsequent happiness at the time of remission of symptoms. Recovery could also be ascribed to cease of localised pain as ceasing of recurring migraines due partly to menopause.

On parole –strengthened enough to be weak

The state and stage of being on parole from symptoms of fibromyalgia, including improved coherent functioning, mirrors a dominating data pattern and the explicit statement from the women that health was conditional, depended on careful management and was maintained by ways of living. Symptoms were held off by management or by a health-promoting work style. The women named sobriety while exercising, pacing of activity, avoiding heavy lifting or taking a short rest after work in order to enjoy the evening. The interviews also contained signs of that the women were not overactive any more. During the phase of parole, health could also be cared for the through the women having found a personally relevant low level of strain. For example, one interviewee handled her difficulty to stand interpersonal frustrations through organising her life very much on her own conditions emphasising her need for a great deal of time on her own and an interesting work life marked by high levels of self control (being able to self decide her work hours etc). The stage of parole was also marked by that the women developed or employed efficacious defences or an increase in defence operations, also in the sense that they used coping strategies and chose a life –style congruent with their self-image. This phenomenon could be exemplified with a need for industriousness, hypo-manic repair or dissociation:

'[…fulltime?] I like my job. I think it depends on that. Yes, it means a lot to me.'

Efficacious defences could also mean a need of 'filling up' with meeting people or enjoying cultural events. The interviews also held qualities of some degree of personal growth, which meant that needs were no longer ignored at the original level. Besides that obvious continuous care for physical well-being were proofs of being less rigid and of less incoherent self-regulation, the data also contained signs of other processes of 'changing one-self', exemplified by learning to say no:

'Yes, the first time was, I dare say, so that I almost started to cry that I didn't [do what was asked for] it was hard to say no, but I don't know, I just started to say no and I said No, …and that is how it is…´

Discussion

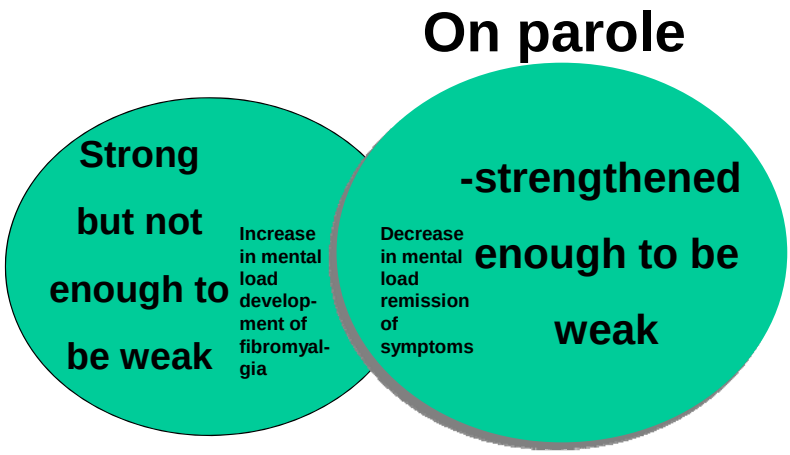
The aim of this study was to elucidate the course of fibromyalgia in relation to the psychological resources, vulnerabilities and psychosocial conditions of the recovered women. Simultaneously grounded theory methodology aims at generating emergent conceptual categories and their properties integrated into hypotheses resulting in theory (17). One tentative interpretation of our result is identification of change or growth regarding psychological functioning thereby securing parole from fibromyalgia symptoms (see figure 1).

Change or growth regarding psychological functioning was also benefited by the preceding experience of a decrease in mental load accompanied by remission of symptoms. This hypothesis includes a temporal process of the four higher order categories resulting in the core concept on parole –strengthened enough to be weak. This means, concerning an adult, to have the self-structure -strong but not enough to be weak that is effective in a response, to exposure to a sufficient amount of increase in mental load, of development of fibromyalgia. The next phase of the process – challenge of fibromyalgia means that a high level of mental load is maintained but also counteracted by the woman's supportive network.

At a later stage, characterised by a decrease in mental load, symptom remission occurs. The stage of on parole –strengthened enough to be weak represents the present and underlines that a change in the direction of more coherent psychological functioning has taken place. This change allows and includes careful management of corporeal and mental health needs in order to preserve recovery.

This interpretation implies a process of disintegrated capable and vulnerable parts of the psyche, including an inflexible defence structure, responding to variations in mental load. Childhood conditions of strain and insufficient support in combination with possibilities of developing alloplastic skills resulted in the 'separation' of strong parts of the psyche from weaker parts. In adult life, management of negative affect was impaired and not handled, or self-inflicted exposure to different kinds of strain largely contributed to overexertion of mind and body. Simultaneously the women often enjoyed professional success. In a situation of increase in mental load, fibromyalgia symptoms developed.

The challenge of the disease resulted in both a vicious circle of strain and helplessness and the use of mastering skills. The network of support often supplied useful aid and recognition. To gain remission of symptoms, a substantial decrease in mental load needed to be achieved. The decrease in load was a result from either or both efforts stemming from the women themselves or from some kind of external intervention. The stage of conditional recovery was actively maintained relying on an increased coherence of psychological functioning including a more flexible understanding of health needs such as pacing of activity and efficacious or coherent psychological defence measures.



Model 1. A process of conditional recovery from fibromyalgia grounded in data from eight females.

In the present result the women were characterised by marked alloplastic competence. Simultaneously this competence had no immediate relationship to recovery from fibromyalgia. The women did, in other words, not lift themselves by the hair in order to recover. A hypothesised relationship between competence in the area of affecting your conditions of life and recovery might instead be discussed in terms of, a more direct access to feelings of hope and relief when opportunity knocks in the form of a pronounced decrease in mental load. From a more theoretical perspective on self-regulation (19), the capacity to plan and the notion of being able to affect the conditions of your life, could work in the opposite direction of psychosomatic outburst due to competence in the area of cognitive processing of affects. Improved and/or more integrated mental functioning might have been promoted by the decrease in mental load in the women recovered.

Patterns compared

Maintenance of fibromyalgia in women was found, by Wentz, Lindberg and Hallberg (16), to corresponded to high levels of mental load. This event might be interpreted in term of the prerequisites of neutralising interactions between vulnerable psychological functioning, mental load and reduced cognitive functioning not being at hand. In the present results both some deeds of the participants and/or external factors worked in the opposite direction of the qualities of a maintained high level of mental load. One aspect of vulnerability connected to maintenance of fibromyalgia was the deterioration of conditions of life, preceding onset of fibromyalgia and resulting from fibromyalgia (16).

In the present study signs in data indicate the deterioration was annulled or neutralised as through significant positive change in the conditions of life and/or through other kinds of ‘decreasers’ regarding mental load as through talent and skills meaning a decent life situation or cease of overexertion of body and mind. Further mental load might also have been neutralised through the difficulties related to incoherent functioning being handled through personal growth, or compensated for through the creation of advantageous living conditions.

Data patterns related by Wentz, Lindberg and Hallberg (16) display conditions of life as less advantageous when compared to the present results. Bearing in mind alloplastic competence identified in the present results being one of the most obvious difference in personality structure when compared to women maintaining fibromyalgia (24), alloplastic difficulties and helplessness accounted for, also could specifically be looked upon as contributing to the described difficulties during the state of fibromyalgia.

This interpretation also finds some support in studies comparing levels of psychological capability and psychological well being with levels of fibromyalgia symptoms. Walker, Keegan, Gardner, Sullivan, Bernstein and Katon (20) found that the severity of a psychosocial trauma significantly correlated with measures of physical disability and psychological difficulties in patients with fibromyalgia but not in patients with rheumatoid arthritis. Psychosocial strain was hypothesized as frequently being an important factor in development, maintenance and levels of disability in fibromyalgia. Buckelew, Murray, Hewett, Johnson and Huyser (21) reported that higher self-efficacy was related to less pain and less physical impairment in fibromyalgia patients.

Another interesting data pattern mirroring alloplastic competence and levels of mental load in the present interviews was that many of the participants conducted their journey to recovery through a stage of gaps in pain due to help from acquired skills or results in relation to alternative treatment.

The pattern of symptom remission being preceded by a phase of pain gaps due to symptom management might mean that decrease in mental strain is partly a continuum of more or less constant mental relief, or increased management of health needs, showing itself as gaps in pain or ongoing remission of pain. A parallel to this might be that ‘pain behaviours’, aiming at easing pain (taking medication, walking, relaxing, taking hot showers or baths and using electric pads), has been found to be related to less frequent pain in a group of 81 women with pain from fibromyalgia but not in a group experiencing other kinds of pain (22).

Transformation as remedy?

The present results describe a process of development of psychological functioning, from covering up and deserting weakness to instead taking care of weakness. Comparison being a key technique using grounded theory means that this process might be further understood by being re-contextualised into the area of research on adaptation to chronic disease. Charmaz (18) describes a process of personal growth in relation to chronic disease. The process takes off from a kind of mild dissociation, trying to ignore the somatic condition. Closely resembling data patterns identified in the present results, the depicted process could be summarised as change in the direction of improved coherent functioning of the psyche. According to Charmaz (18) chronically ill individuals extend control over their lives, from instead of dissociating, identifying with and listening to their bodies, and thereby learning to take better care of corresponding needs. The dynamics of 'transformation' into acceptance of the altered life situation improved coherence and gave rise to 'a new wholeness of self' and an access to 'a voice from within', according to Charmaz (18). The conceptualisation of the process of 'transformation' in relation to chronic disease has also been used or applied in relation to the chronic condition of fibromyalgia by Scammell (24) focusing solely on successful 'transformation'. An unexpected finding was that after being successful regarding 'transformation' most out of eight participants, no longer considered themselves as suffering from fibromyalgia. Confirming the findings of the present study Scammell (24), employing a grounded theory design, relates qualities of increased coherence as 'transformed to a more authentic self' and 'healthier life choices'. Further, identified patterns of psychological resourcefulness as a capacity of seeking and accepting help, also in the present results, finds support in the results of Scammell (24) describing that all 'transformed' participants had had psychotherapy and had sought help from alternative practitioners. The finding of the present study on economic resources on behalf of the participants also finds its parallel in the results of Scammell (24) reporting that all participants belonged to middle or upper middle class. In addition Scammell (36) described that the recovery process reached a stage where the participants experienced increased trust in themselves and thereby gradually recovered. The present results together with the results of Scammell (24) highlights the possibility of 'transformation', into a more coherent psychological functioning, triggered by a challenging somatic condition, being a key remedy in relation to fibromyalgia. Such a hypothesis might find some support by the results of Keel, Bodoky, Urs and Müller (14) showing increased rehabilitation outcome in relation to fibromyalgia, when relaxation techniques were supplemented with psychological intervention (group psychotherapy). In addition the most successful participants were described in terms of being 'able to decrease their excess work-activity and extreme helpful nature (learning to say no)' Keel, Bodoky, Urs and Müller (14:237).

Implications for treatment and prevention

- Assessment of the subjective situation
- Decrease in mental load aiming at stabilisation of psychological functioning
- A good relationship with a good doctor
- Treatment modalities tried out in order to decrease symptoms
- Increase awareness of the context of experiences of relief in pain or 'pain-gaps'
- Personal growth through group therapy or individual therapy

A decrease in mental load, aiming at stabilisation of psychological functioning of the individual comes forward as a measure, needing to be considered, in treatment of fibromyalgia. Hence, the subjective situation of the individual (not forgetting the latent level) needs, through clinical psychological exploration, to be thoroughly assessed. Personally relevant stressors of the individual influencing health, including exhausting hyperactivity, need to be accounted for in both prevention and rehabilitation. These kinds of measures parallel the basic prerequisites of recovery outlined in relation to trauma (as child abuse) by Herman (25). The first stage of recovery according to Herman (25) is the establishment of conditions of safety as a sense of power or control. In the case of sufferers from

fibromyalgia, issues of diagnosis, sleep deprivation, workload, over activity or the need for support from the family and significant others should be dealt with. In order to do so a good relationship to a good doctor also needs to be established. Thereafter, different treatment modalities such as relaxation need to be offered and tried in order for the individual to experience some control, relief and hope. Personal growth could be facilitated through group therapy and/or individual psychotherapy. This need for verbalising the issues of life might find its parallel in the view of Herman (25) that unmanageable experiences are dealt with through the action of 'telling a story'. Increased awareness of the context of experiences of relief in pain or gaps in pain could be an integrated part in the insight guiding individualised rehabilitation, in the direction of decrease in symptoms. Outcome of treatment should be assessed both long term and short term. Quoting one of the participants' answers to an interview question on rehabilitation measures:'…different things work for different people…'

Methodological considerations

The sample was, due to limited accessibility, small and also not strategically selected. At the same time, the sample held some qualities of heterogeneity according to age, education and professional background. The sample was also reasonably homogeneous according to patterns of being or having been well established on the labour market and having had reasonably stable family conditions during adult age. The sample also must be characterised by qualities of an active stance, the women on their own initiative having contacted the research group. These characteristics of the sample should be taken into account when considering transference of the results. If women marked by pronounced lesser ability to receive help and less of an alloplastic stance, recovers from fibromyalgia, nothing is known about them from this study. Further if the size of an accessible sample is limited, from the start of the study, this might mean that further work is needed to more fully test and develop variation and content of the identified categories.

The choice of grounded theory was guided by the research question aiming at individual and interpersonal processes in relation to a third process - the development and recovery from fibromyalgia. Further grounded theory was chosen based on preparedness to form a theory or a model from the emerging concepts. The interview guide was inspired by clinical psychological procedures aiming at mapping, for example, the onset and course of symptoms, activity-style, symptoms management and interpersonal relationships. In the service of abstraction in this study a procedure of studying codes separated from the interview they belonged to, was employed. Categories formed from the scrutiny of codes were then tested against the source (the interview) in the service of 'grounding the abstraction'.

Data was further anticipated from a constructivist angle acknowledging the role of samplings decisions and development of the interview guide alongside the emergence of categories and hypothetical theory. Through strategies of construction, hypotheses on patterns and events can be tested alongside data gathering using the strategy of constant comparison. In order to evaluate emerging results different possible effects of the researchers need also to be assessed and shared. It is indisputable that the researcher will affect the research process and to deny the human touch might instead contributes to 'subjectivity'. Instead the effect of the positioned researcher should be accounted for in the service of assessment of subjectivity. The women were interviewed by the first author prior knowledgeable of women with fibromyalgia through clinical work and through having interviewed several women suffering from fibromyalgia for research purpose (16). The educational and theoretical background of the interviewer could be summarised as developmental psychology based on psychodynamic theory with special interest in maturational processes in somatically healthy women and health psychology especially psychophysiology /neuropsychology related to musculoskeletal pain. The preconceptions of the interviewer in relation to development of fibromyalgia could be summarised as ideas about strainful childhood conditions and difficulties regarding self-regulation.

A ‘sensitizing concept’ (18) used as a starting point in the present study, was also that women recovered from fibromyalgia, when compared to women with fibromyalgia, might be a different group altogether showing dissimilar patterns.

The grounded theory method contrasts with traditional quantitative research designs and assumes openness and flexibility of approach. The generated hypotheses, or ideas, may later be verified through traditional logico-deductive methods (18).

Conclusions

The result from the present grounded theory study concerns a hypothesis including a core concept, on parole –strengthened enough to be weak constituting a final step of a temporal relationship of five higher-order categories forming a process over time. This means further research is needed to explore possible causal links as psychosomatic mechanisms. Briefly, we suggest that recovery from fibromyalgia is conditional, relies on increased coherence in psychological functioning and appears as to be allowed and maintained by favourable conditions of life and ways of living.

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