The life adjustment process in chronic pain: Psychosocial assessment and clinical implications

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Previously, the subjective dimension of suffering from chronic pain has only infrequently been reported in the literature. However, in recent years qualitative psychosocial research has added new perspectives that describe how suffering from chronic pain affects life. The present paper refers to a qualitative study on the subjective experience of women diagnosed with chronic musculoskeletal pain. In a model for life adjustment, turning points and passages are described in three stages. In Stage I, there was increasing pain, disability, and physical and mental exhaustion. Alongside frustration and chaos there was a struggle to restore daily life; therefore, the picture of a healthy future was still intact. Acknowledging that pain may not be temporary marked the transition into Stage II, which was characterized by sorrow and loss, and the picture of the future faded. Once given an explanation of pain (a ‘pain diagnosis’), a new understanding developed, with gradual improvement of coping skills. Adjustment eventually progressed into Stage III with the constructive use of past experiences, and competence and control increased. A new picture of the future emerged that could be handled. However, living with pain still required regular maintenance work.

The outcome of qualitative investigations, including the one presented here, is discussed along with certain clinical implications. The following clinical implications are reviewed in the present study: distrust from health professionals may obstruct the adjustment process, prolong sick leave and hinder rehabilitation; providing the patient with a diagnosis (eg, an explanation of pain mechanisms) will facilitate life adjustment; acknowledging the individual experience of suffering from chronic pain will make concepts related to pain behaviour, secondary gain and sick role liable to question; and vocational rehabilitation measures should be harmonized with the actual stage of life adjustment.

Key Words: Chronic pain; Life adjustment; Pain rehabilitation; Psychosocial assessment; Qualitative studies

In recent decades, chronic pain has been studied intensely, and various disciplines of research have contributed to new knowledge. Biomedical research has increased our understanding of dysfunctional pain modulation mechanisms within the central nervous system (1-3), and psychological investigation has added information about how to cope with everyday life (4). The growing body of knowledge about the complexity of chronic pain has also included results from psychosocial research on treatment and rehabilitation (5,6).

Qualitative research and the subjective experience of chronic pain as a process

In psychosocial research, a growing interest has arisen in the subjective experience of chronic pain. Through a phenomenological approach based on narrative accounts, a defined psychosocial perspective has been developed that describes the experience of chronic pain as a process. Since the early 1980s, qualitative research has used the process perspective to describe how disability and illness affect life. In this context,
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the term 'biographical disruption' has been proposed by Bury (7) to focus on the discontinuity of the life adjustment process that may result from long-standing disability. Strauss and Corbin (8) have contributed to the understanding of the biographical illness process by describing its two dimensions, 'illness trajectory' and 'life trajectory', which continuously and mutually affect one another.

Previous qualitative studies

Previously, pain research has paid little attention to the lived experience of patients suffering from chronic pain (9). However, the value of qualitative research 'as windows into the meaning that pain holds for individuals' has recently been emphasised in an article published in Pain: Clinical Updates (10). In recent years, an increasing number of qualitative investigations have been reported in the literature (9,11-18).

The essentials of some of these studies will be described below.

In a pioneer study by Schaefer (13), in depth interviews were conducted over a period of one to two years with women diagnosed with fibromyalgia. A process of 'struggling to maintain balance' was described with the goal of finding an acceptable way to live with pain. That process involved a sequence of themes that were described as "Recalling perceived normality"; "Searching for a diagnosis"; "Finding out"; "Moving on"; and "Relinquishing the struggle". Burckhardt et al (16) described a similar course, also in a study of women with fibromyalgia. The subjects primarily reported "getting through a period of uncertainty, bearing about the illness and its treatment", and finally "coming to terms with having a chronic problem, and establishing new patterns of life".

The view of the future plays a significant role in qualitative research. Hellström et al (15) described the relationship between chronic pain patients' outlook on the future, their psychosocial features and coping on the multidimensional pain inventory scale (19). 'Dysfunctional' copers and 'interpersonally distressed' individuals exhibited a negative view of the future, whereas the 'adaptive coper' subgroup had a more positive view. The authors suggested that an adequate intervention might provide patients with a more constructive view of the future and initiate an increased motivation for health-seeking behaviour.

Walker et al (9) described the early lived experiences of patients suffering from chronic back pain. Similarly to Schaefer (13), some major themes were identified: "The pain takes over"; "Sense of loss"; "Being in the system"; "They (others) don't understand"; and "Coming to terms". The patients expressed great disappointment with the health care system, and felt misunderstood. They were frustrated because they were not provided with an explanation of pain and they were frequently told that the pain "was in their minds". The study described how the health care system encouraged powerlessness and contributed to the development of chronic pain. These experiences made it difficult for the patients to come to terms with their situation and, similarly to the description presented by Hellström et al (15), most could not see a future for themselves.

Finally, a study by Åsbring (17) illuminates the biographical work done by women with fibromyalgia and chronic fatigue syndrome, including a re-evaluation of their former identity and life. Åsbring described the following themes: "An earlier identity partly lost" and "Coming to terms with a new identity" (17). The main findings were that the illnesses involved a radical disruption of the women's biography, which had profound consequences for their identity, particularly in relation to work and social life. Furthermore, the biographical disruption was partial rather than total, calling for different degrees of identity transformation. Many of the women also experienced positive "illness gains", such as new insights, increased self-respect and greater personal integrity.

All the investigations referred to above describe adjustment processes to everyday life in a broader perspective. The similarity of the life adjustment processes, as reported in part or in whole in these previous studies, is striking.

BACKGROUND AND OBJECTIVES

In qualitative research into chronic pain, few studies describe the process of life adjustment as a whole model. There is still a lack of sufficient answers to questions such as 'which internal or external forces are active in the process of adjustment and how are they interrelated? How can one learn to live with chronic pain?' A previous sociopsychological qualitative investigation (20) was designed by one of the authors (ACG) of the present paper to contribute some answers to these questions. In that study, the specific objectives were as follows: to describe and identify significant aspects and themes in the course of life change because of chronic pain; and to propose a clinically useful model for that adjustment. A summary of the essential findings formed the basis for the present paper, and the methods, findings and discussion sections refer to that qualitative investigation.

The practical application of the proposed model for adjustment to chronic pain in our setting has focused on the need to modify the pain management program. Based on our experiences of the life adjustment model, a separate discussion relating to some clinical implications has been included. In that final section, certain issues that may be of importance for professional pain rehabilitation will be discussed.

METHODS

A qualitative method was used to collect data. As in other qualitative research, the ambition has been to present an intimate account of the 'experienced inside perspective' (21) by describing the thoughts and beliefs of the participants. A phenomenological framework was used to analyze the data (22-24).

Criteria for participation

The main criterion for participation was as follows: the interviewees were those who were referred to a tertiary pain rehabilitation setting (the pain management clinic) for participation in an outdoor pain management program during two weeks. The interviewees were informed that the investigation did not involve assessment of treatment. Further, they should have been diagnosed with common chronic musculoskeletal pain syndromes (for a duration of six months or more); specifically, the diagnosis was either myofascial pain syndrome (25), synonymous with 'trigger point syndrome' as described by the International Association for the Study of Pain (26), or fibromyalgia (27). Individuals with myofascial pain syndrome and fibromyalgia were included because these two disorders are among the few chronic musculoskeletal pain syndromes that have proposed diagnostic criteria (25-27) and were among the most frequently diagnosed pain syndromes in the setting (28).

The subjects

The sample investigated consisted of 18 subjects consecutively fulfilling the admission criteria.
Eleven subjects, all women, were diagnosed with myofascial pain syndrome and seven other women with fibromyalgia. The participants ranged in age from 23 years to 55 years (mean, 42 years), and reported having the illness between one and nine years (mean, three years). Their current sick leave ranged from 0.5 to three years (mean, one year), and the majority (60%) were blue-collar workers. The sociodemographic characteristics were representative of the general patient population referred to the clinic (28).

**Data collection methods**

The interviews were conducted in the women's homes by one of the authors (ACG) who at the time of the investigation did not belong to the staff of the pain management clinic. The first interview was done before the women took part in the rehabilitation program, and the second after the program had been completed and two months after the first interview. The interviews, which were taped, lasted 1 h to 2 h. The women were asked to describe their feelings and thoughts about pain from the time when trouble was first experienced until the present situation. The main theme of the interviews focused on how pain had entered their life, and how they coped with pain then and at the time of the interview. The interviews, which could be characterized as reflective dialogues (29), were intended to stimulate the women to give their life story from this particular period of life (30,31). This interview technique made it possible to describe the pain experience within a life context and from the person's biographical perspective.

**Data analysis**

The interviews were transcribed verbatim and were analyzed by using an inductive method (24,32). Themes that emerged in the first investigative step were used as sensitizing concepts (33) in the analysis of the material. Examples of such concepts were different means or strategies to conceal or acknowledge. Likewise, initial guides (34) were formed a synthesized structure, eg, the life adjustment model in three stages. All subjects gave informed consent to participate in the investigation, which was approved by the Ethics Committee of the Medical Faculty of Lund University, Sweden.

**RESULTS**

**A model for life adjustment**

The proposed model for life adjustment is to be considered the framework for a complex process of change. Various aspects of life adjustment can be followed in a longitudinal perspective from the retrospective accounts in the interviews. To emphasize turning points and passages along the course of the life adjustment, the process has been divided into three active stages of change, here denoted as Stages I, II and III (Table 1).

The concept 'life adjustment' and the expression 'learning to live with' chronic illness encompass changes in the relationships between the person's past, present and future life. This biographical perspective gives a natural link to life beyond illness and disability, eg, the healthy part of life that has been or will come in the future. In the following, some characteristics of the stages of the adjustment process and the work of maintaining adjustment will be described.

**STAGE I**

**Prelude**

Initially, this stage contains no direct signs of a life transition, but can still be regarded as the beginning of the adjustment process in patients with chronic pain. Stage I could cover several years, with periods of recovery and decline, gainful work and sick leave. What decided the length of it was how long it was possible to maintain the hope that pain was temporary and would disappear.

A slow beginning of the process of change was common among the interviewees, because the pain often appeared periodically, and was thus regarded as a temporary condition, eg, a natural interruption of a healthy life. Initially, such episodes did not influence the way of life or plans for the future. Being temporarily ill also allowed the afflicted person to receive help and support from others. Gradually, the healthy periods became shorter and fewer, and everyday life was increasingly influenced. It was no longer possible to maintain the idea that the pain was temporary. When the combination of increasing pain, disability, and physical and mental exhaustion reached a critical point, sick leave became the last resort for many of the interviewed women.

**Struggling to restore life**

In this initial process, an obvious phenomenon was a force of varying strength, a restoring force, aimed at retaining a previous life trajectory and holding on to one's familiar identity and social life. When the women became aware that this return to the normal life was not forthcoming, and when they were no longer able to cope with everyday life as before, their worries about their health increased. Sick leave, and perhaps physiotherapy, at first became a way out and gave rise to the hope of recovery.

The situation also led to an inability to fulfill previously natural and expected roles or tasks in life, such as being a mother or a breadwinner. Coping with the pain, while living an outwardly normal life, required physical as well as mental exertions that led to an immense everyday stress load. In the end, their strength

<table>
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my body well enough, and I am honest enough and capable of

understanding that this isn’t something in my head, this is some-

thing that has happened to my body,” one of the women

exclaimed during the interview. The situation was described not

only as insulting but also in its ultimate consequence, as a threat
to the person's own reason. The doubts of the surrounding world
made the situation even more difficult and became a drain on
their already weakened strength.

Acknowledgement

A crucial step in this early stage of the life adjustment process,

which we encountered in all accounts, was acknowledgement

that the pain was not temporary. This signified an emotional
and cognitive understanding. It was thus necessary to give up
the aspiration to return to life as it had been before. The

acknowledgement sometimes grew as an inner certainty, as the
coping strategies aimed at hiding the seriousness of pain no

longer sufficed. The interviewees said that they no longer had
the strength to explain away why the pains never lessened, no
matter what they did. The ambition to restore life to the way it
had been before was diminished.

Acknowledgement gave adjustment a new dimension,

which meant that their eyes were turned toward the future.

This gave rise to a new anxiety. What will happen, in the time
to come, with work, and other engagements and roles in life?

The significance of life adjustment in a wider perspective start-
ed to clarify. This turned the acknowledgement into a power-
ful force that, for some, initially led to a crisis in life with
feelings of loss and worry about the future. Later, this force
manifested itself as a striving for change and adjustment. It was
obvious that the women stopped actively searching for a mira-

cle treatment and instead began to trust their own resources.
The hope of recovery remained but was no longer an obstacle
to alternative possibilities in the life situation. Thus, change
and adaptation had begun.

STAGE II

Working through

The admission that the pain was there and would remain was
very prominent in all the accounts. This was a clear turning
point in the life adjustment process. We regard this as the
beginning of the second stage, which entails an active emo-
tional and cognitive adaptation, and an exploration of the new
conditions of life imposed by the pain.

Sorrow and loss

The admission was often succeeded by an emotional crisis for
the interviewees. Although some of them felt relieved to have
a medical explanation of their pain, the feeling of loss and sor-
row in life could be strong. One interviewee described it as, “A
gigantic mourning”. They missed the kind of life they were
used to. Some of them hid their sorrow by withdrawing, while
others gave voice to it.

Losing oneself

The women described how previously natural things like shop-

ping, sitting in the car, receiving guests at home, performing
tasks at work or running the household no longer could be
accomplished automatically. They surprisingly found that
activities demanded energy, thought and time. Uncertainty
about what the body was capable of in its present condition
disrupted self-esteem and self-confidence. This constituted a
major threat to the self-image. The interviewees described the
situation as confusing, and questions like: “What’s happening
to me? What have I become? What am I good for?” or rather:
“Can my body do what I want it to do?” scared them.

Leaving the role of being sick

As long as the pain was considered to be temporary, it was ade-
quate to receive support from significant others. As time went
by, however, the role of being sick, with its possibilities of rest,
withdrawal and being cared for by others became more and
more troublesome. The expectations of a return to active life
had not been fulfilled. This situation was described as confusing.

Confirmation

The great importance of professional support during the
prelude is made clear by the accounts of the interviewees. This
included getting a medical examination, an explanation and a
diagnosis, either at some other place or at our clinic. This
could provide the information they required to explain to others,
which in turn might generate increased understanding from the
surrounding world.

The medical investigation and the physician's attitude were
very important in facilitating personal adaptation in the life
adjustment process. Some women desperately tried to ‘prove’ to
people around them and to doctors and coworkers that their bod-
ies were in pain, with the result that others perceived them as
being too obsessed by their troubles. Many of the women had the
experience of being disbelieved when they sought medical treat-
ment, and that their troubles were neglected or regarded as a sign
of mental or social problems. They protested desperately: “I know
my body well enough, and I am honest enough and capable of
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Self-deception

Examples of coping strategies used by patients to maintain previ-
ous habits of life were a quick return to work regardless of
improvement, avoiding repeated sick leaves, various ways of
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have been wearing blinkers.”

The interviewees gave examples of how desperate they were to
use denial as a common solution, which also precluded support
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difficulties explaining the situation to others and felt isolated
with their worry and sense of inadequacy.
The sick role behaviour thus became less and less desirable, and the interviewees defended themselves against their dependence on others. They tried to re-establish their self-confidence by creating new patterns and routines in everyday life. This became an important part of their strive for independence and a normal life. Some described how those that were close to them found it difficult to accept that providing practical support could not always be allowed by the pain sufferer. Therefore, during the course of life adjustment, the importance of support from significant others were re-evaluated. The best support, according to many, was empathic understanding, such as emotional support with a confirming function.

Defining the problems
The understanding that the pain could have consequences for the entire life situation became an important driving force in the adjustment process during the second stage. It was clear from the accounts that the focus eventually and increasingly was moved from the pain and the body to important parts of life such as family life, social fellowship, working life and leisure time. How would these areas of life be influenced? Furthermore, it was clear that the medical explanation of pain played an important role in the problem-solving process of the second stage. The medical explanation of pain dispelled the mystery surrounding the situation, making it possible to establish control of the pain. Knowledge regarding the bodily condition played a decisive role in understanding the situation in the context of a new wholeness in life.

Finding solutions
In time, the attention of the women was directed towards changing, building up a new experience base and repairing their existence. They sought new ways of functioning with their bodies from everyday details, like running the home, to more complicated tasks in working life. Much had to be relearned. Certain roles, such as that of a friend among friends, might not have to be abandoned but could be performed in a new way. It is now that they are fully occupied with the task of ‘learning to live with’ the new conditions of their life, that they have acquired an insight into what these new roles are. For many of those interviewed, a period of sick leave became a ‘farewell to the past’, which we would consider the first stage of the adjustment of life from the second to the third stage was gradual, and in their accounts, the interviewees made it clear that they often oscillated between them (Table 2). Even if they had restored their accounts, the interviewees made it clear that they often relapsed or feel that their self-image was threatened again.

Picture of the future affects coping
The relation between the past, present and the future, i.e., the biographical course, was fundamental for the adjustment process in our study. The women’s acknowledgement at the end of Stage I led to the abandonment of the previous familiar biographical base line. At this stage, it was obvious that the picture of the future blurred and became threatening for some. Later, (Stage II), when a new trust in the body and a self-identity were forming, a new picture of the future developed. This stage was a ‘farewell to the past’, which we would consider the first step toward a ‘biographical reinforcement’ (7). Thus, an attuned, but somewhat positive, perspective on the future will have great importance for continuing life adjustment. The transition from the second to the third stage was gradual, and in their accounts, the interviewees made it clear that they often oscillated between them (Table 2). Even if they had restored meaning and security to their existence, they could relapse into despair or feel that their self-image was threatened again.

The study has also made it clear that after the three stages of this active period of life transition described here, the work of maintaining the adjustment reached is continuous. Living with pain becomes a natural part of life, and is thus not considered part of the adjustment process. The interviews revealed that a successful life change was important in order to live a good life in spite of the pain. In this section, we shall briefly focus on how the women described ‘the maintenance work’.

MAINTENANCE – LIVING WITH PAIN
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Competence of handling future changes
Those who had gone through the three stages of life adjustment described in detail how life had been normalized in spite
of the pain. They described skillful coping, which enabled them to re-establish their quality of life. This capability can be described as continuous maintenance work, ie, extra everyday labour to handle pain and disability. The accounts indicated that this labour was carried out on the private backstage, away from the outside world. In this way, the women learned and increasingly became aware of what the body was capable of. This led to increased self-knowledge.

A new attitude to life

The women were aware of the everyday changes with which they had learned to live and perceived them as a natural part of life. Their physical strength often had to be deliberately distributed and rationed to suffice for the things in life they wanted to prioritize. A specific kind of uncertainty had become a natural part of life. This was based on the fact that they had to take into account the possibility that the pain could suddenly and unexpectedly worsen and upset all planning. Adapting to such changes in the conditions of life required them to balance what the body was capable of against the desires of the mind. As an example of this, many of the women said that they often chose to accept a temporary worsening of the pain to be more socially active. One woman told of how she participated in a large family gathering, well aware of the fact that it would overtax her strength: “I had decided that I would damn well participate. No matter what the cost. I was ill for a fortnight afterwards. But, of course, the feeling of having been there was fine.”

Regular self-care

The women were aware of the importance of this maintenance work being done regularly. They had to regularly carry out their programs of exercise, relaxation and training. One of the women testified that this could not be done without self-discipline and sacrifice. She regarded this regularity as a straitjacket: “If I skip my training because I don’t have the time or the strength, my condition gets worse.” In spite of this, they gave voice to the security of knowing that there are measures they can take to handle pain. By having a choice of their own they were also able to control their situation. Many of the women expressed wonder at having learned to live with the pain: “When the pain started, I thought that was impossible.” Moreover, during the transition process and in our experience, there was often a reduction of drug use, resolving depression, and an overall enhanced quality of life (Table 3).

DISCUSSION

The interviews helped us reconstruct a life adjustment process that described different stages from a biographical perspective of the women’s lives. The investigation of adjustment focused on the importance of the individual’s biographical wholeness for understanding the adjustment to chronic pain and its consequences. It also demonstrated that the women had power of their own to change and create a new satisfying life role. Simultaneously, the power to adjust signified the ability to self-heal, a process that may take time and should be allowed to do so. However, before further discussion of the main findings and certain clinical implications, some methodological issues will be considered.

Methodological issues

Qualitative investigation does not involve objective comparison of measurements as in biomedical (quantitative) research. In qualitative research, with narrative accounts applied to a limited sample of interviewees, using inductive interpretation in a phenomenological framework, the findings are subjected to a reconstructive process (9,35). However, the validity of the results may be questioned due to the possibility of subjective bias in the process of interpretation. Nevertheless, the findings in qualitative investigation based on inductive analysis may have general validity (36). Referring to life adjustment processes in chronic pain, the similar findings of several previous and independent qualitative reports (9,13,15-17) add support to the validity of qualitative methodology.

However, a limitation for a more general application may be that only women were included in this study. Nevertheless, the Walker et al (9) investigation included a majority of males with chronic back pain, and the results were similar to those of our study. Recently, qualitative research on males diagnosed with fibromyalgia has demonstrated that males express a similar pattern of life change (18,37). However, additional future research will need to confirm whether the life adjustment model also applies to males suffering from chronic pain.

Another limitation was unintentional selection bias. It is well known that patients presenting with complex and refractory chronic pain, including certain individuals with fibromyalgia, are selected to tertiary care (38), including specialized pain clinics such as our setting. This patient category is more frequently characterized by dysfunctional coping and emotional chaos (38) and can be assumed to be at the early stage of the adjustment process (Stage I). Thus, we do not know whether all individuals diagnosed with fibromyalgia or myofascial pain syndromes develop features characteristic of Stage I or even pass through an adjustment process. We assume that there are individuals with chronic musculoskeletal pain that never become patients, perhaps due to constructive coping from the beginning.

Professional distrust obstructs the adjustment process

In the present study the interviewees stressed the importance of support provided by significant others throughout the adjustment process. During the early stage, vulnerability increased and professional support was of great importance. Information about the body and pain (being part of the cognitive/pedagogical treatment program) and increasing knowledge provided vital support for coping with chronic illness and its negative consequences.
However, patients suffering from complex pain disorders are frequently met with little sympathy in modern health care (17,39). In the qualitative study, many of the interviewees expressed their frustration about being misunderstood and distrusted early in the adjustment process. They felt rejected by the health care system, but sometimes also by relatives and employers, which added to their suffering and stigmatization (9,12,40). The early lack of support from the health care system and dealing with disbelief created powerlessness and anger (9,40). In the present study, it was evident that professional mistrust often obstructed the life adjustment process for a long time.

Previously, the stigmatization inflicted by health care on patients diagnosed with chronic pain has been infrequently and insufficiently reported in the literature (40). This may largely be because reports of the patient’s experience of suffering, such as ‘the insider perspective’ (41), have been neglected in pain research (9). In the Åsbring and Närävänen (40) report, women with fibromyalgia and chronic fatigue syndrome described that “questioning of their morality” (of not being ill, lying or being work-shy) was experienced as deeply violating. It constituted a threat to their identity and was sometimes a heavier burden than the illness itself.

**Pain behaviour a response to frustration and mistrust?**

Oversimplified conceptions about pain behaviour in patients with chronic pain are common among health care professionals, such as “there is little/no pain but exaggerated pain behaviour to obtain secondary gains”, and “inappropriate pain behaviour is part of a maladaptive and irreversible sick-role”. In the present sociopsychological study, some women in the early phase (Stage I) did report that they sometimes expressed their frustration in eye-catching behaviour. However, they often reported that their frustration was a consequence of not being understood or acknowledged. The women were also aware that others misjudged their pain behaviour, but they found no other strategy to attract attention to their suffering. Once acknowledgement was obtained (by getting an appropriate medical examination and an explanation of pain), frustration decreased, and there was little further need to express suffering in terms of deviant behaviour. Thus, according to the life adjustment model based on the present sample of pain sufferers, pain behaviour was rarely maladaptive or irreversible. On the contrary, it appeared to be a temporary and rational reaction.

**CLINICAL IMPLICATIONS**

Understanding chronic pain sufferers from their own perspective has important clinical implications relating to the modification of certain routines in their rehabilitation program. Essentially, this applies to: providing patients with an understandable diagnosis; focusing on cognitive intervention (rather than on behavioural deconditioning related to pain behaviour and sick-role), and in co-operation with the patient; and planning the adequate time for vocational rehabilitation and return to work. The adjustment of the rehabilitation program to the subjective perspective should lead to a better outcome (42,43).

**The diagnosis as an explanation**

As demonstrated in this qualitative study, it is important for chronic pain sufferers to be provided with a clinical diagnosis to progress in the adjustment process. However, there is still a widely held opinion among doctors that presenting the problematic pain patient with a diagnosis (such as fibromyalgia) will increase symptoms, pain behaviour and secondary gain, and promotes a chronic sick-role (44,45).

We consider this belief to be false. Because of the experience we gained from the life adjustment process we consider that providing the patient with an understandable diagnosis should be mandatory for initiating cognitive restructuring. Åsbring and Närävänen (40) reached the same conclusion, and there is much additional support for this standpoint in the literature: patients not receiving a pain diagnosis continue to regard pain as ‘mysterious’, are more frustrated, more likely to catastrophize (due to fear of inexplicable pain), conserve a pessimistic picture of the future, do not use constructive coping strategies and have a poor outcome (12,39,42,46-48). Significantly, Schafer (13) pointed out that individuals who were diagnosed found the explanation of pain to be a relief and found themselves at “the beginning of a whole new process and a long period of healing.”

In a biopsychosocial framework, it is essential to underline that providing a diagnosis does not imply ‘diagnostic labelling’, in a negative sense. In addition, the patient does not primarily want a diagnostic label, which implies disease. Instead, and based on the results of the present qualitative study, we concluded that there is a need for an explanation of pain and its mechanisms. Thus, from the subjective perspective, the understanding of pain is essential, not the ‘diagnostic label’. Previously, this important distinction appears to have received little attention.

Today, dysfunctional pain processing in the central nervous system (central sensitization and/or dysfunction of descending pain inhibition) is considered to be an essential mechanism in common chronic pain illnesses such as fibromyalgia and myofascial pain syndromes (2,49-51). Dysfunctional central pain processing can be explained within a suitable pedagogical model. Therefore, where we primarily use a neurobiological framework to explain chronic pain, it is our experience that most patients will accept information about the importance of emotional factors that may affect central pain processing as well (3). In the past, contributing psychological and social factors may have been rejected when presented as the main causes of pain.

**A new perspective confronts operant theory**

One finding from the study was that emotional support played an essential role during the adjustment process. However, there was no general tendency for the women to seek support from significant others for reasons due to secondary gain. When pain did not decrease, dependence on others became a burden (Stage II). Instead of developing a sick-role, it became necessary to resume the responsibilities at home that were essential for their self-confidence and female identity. Thus, there was little support for the concept of overprotective spouses enhancing secondary gain and pain behaviour originally relating to early operant conditioning theory (52,53). In contrast, many patients chose to conceal their suffering. Being dependent on others was experienced as a predicament and resulted in feelings of guilt and a threat to their self-esteem.

A similar observation was made by Hellström et al (15), who reported that support from significant others was a negative experience. This was most evident in situations when there was a desire to conceal disability or to manage by oneself.
TABLE 4
Qualitative psychosocial research findings confront common operant conditioning concepts relating to pain behaviour, secondary gain and sick-role

Common behavioural concepts – professional myths?

- They just keep on talking about their pain
- They are sometimes in pain but not all the time
- They become dependent on others
- They take advantage of the situation
- Their spouses and family get too much involved
- Presenting the patient with a pain diagnosis will only promote a sick-role
- Allowing sick leave will make her passive and more ill
- Vocational rehabilitation should be started without delay
- The subjective perspective as described by qualitative research
  - Living with pain is hard work. It is accomplished without insight from others
  - Pain behaviour can be a rational consequence of suffering and distrust
  - Persons suffering from chronic pain are aware that others misjudge their behaviour
  - Secondary losses* are of greater importance than secondary gains
  - Dependence on others is no option; independence is that which is desirable
  - The sick role is temporary. It will spontaneously be abandoned in due time
  - Mistrust shown by health care professionals hinders the life adjustment process, prolongs sick leave and delays return to work
  - The explanation of pain diagnosis (and pain mechanisms) will initiate constructive coping
  - Empathetic understanding is the best support
  - Within the patient there is a power to change and to create a new, satisfying quality of life
  - Vocational rehabilitation should be carefully planned and permitted to take the time required
  - Sick allowance may sometimes hasten the life adjustment process and return to work

*Secondary losses refer to issues such as loss of physical and mental health, function, social relations, confidence in health care, loss of job and finances, life control and quality of life.

Additionally, Morley et al (54) reported that chronic pain patients exercise caution about how and when they disclose their pain. According to their investigation, over 50% of the patients talked about pain only when asked, and a vast majority (90%) tried to hide their pain from others. Fear of being judged negatively and perceived as a burden influenced the decision not to talk about pain. Asbring and Närvinen (40) came to a similar conclusion. Not disclosing pain was a strategy for maintaining a positive relationship, and “suffering in silence was socially necessary”. In contrast, the patients felt it safe to communicate their distress (including pain behaviour) to doctors because of their professional roles. Therefore, assessment in the clinic may falsely diagnose ‘exaggerated pain behaviour’ which otherwise does not have a significant role.

The findings of a qualitative study by Newton-John and de C Williams (55) relating to pain communication have also questioned a simplified use of the operant conditioning model. It was found that spouses exhibited a wide variety of responses, such as “not responding-observe only”, “offering help but allowing the patient to reject the offer”, and “ignoring and distracting”. Others (42) have demonstrated that when significant others did provide support, it facilitated constructive coping as opposed to reinforcing pain behaviour and secondary gain. In a quite recent critical review of the operant behavioural literature, Newton-John (56) focused on several methodological weaknesses, and claimed that the interactions of chronic pain couples are more complex than a purely behavioural model can accommodate, and suggested that qualitative methods should be used to study the interactions of chronic pain couples over time.

Thus, as supported by the findings in modern qualitative research, common concepts relating sick-role, pain behaviour and secondary gain based on an operant conditioning model may have limited validity for subgroups of patients suffering from chronic pain (Table 4).

Vocational rehabilitation at appropriate time

Previously, we discussed the importance of having an image of the future in order to proceed in the adjustment process and the significance of initiating vocational rehabilitation at the appropriate time (55). Many of the women in the present study experienced that they had not taken part in decisions concerning their own vocational rehabilitation and return to work. One explanation is that the planning of rehabilitation had generally been done prematurely when the women still lacked a constructive picture of the future (Stage I). For example, different rehabilitation measures, such as occupational training, had often been undertaken too early in the adjustment process. Vocational rehabilitation that is too early and unplanned may have disastrous consequences, one being the disengagement of the rehabilitation program (57-60).

Accordingly, in professional pain rehabilitation it should be crucial to evaluate what extent the image of the future has been adapted to life with pain and its consequences. The planning of vocational rehabilitation should be harmonized with the actual stage of life adjustment that the patient is going through. A pain rehabilitation program that only answers questions such as why, what and how is not sufficient. Instead, the fundamental question should be when, e.g., at what time should certain measures be taken? Only the individual concerned owns the answer.

Finally, a common truism in this context is that extended sick leave should always be avoided since it may result in a permanent sick-role. In our experience, and based on the life adjustment model, we believe this assumption to be too simplistic. In fact, legitimate sick allowance might be necessary to provide the time required for certain individuals in the early chaos to proceed in the adjustment process, for cognitive restructuring, and to regain motivation for a return to work.

CONCLUSIONS

The life adjustment model has increased our understanding of women suffering from chronic pain. Its clinical implications have placed focus on the importance of the patient’s own perspective, the stigmatization inflicted by the health care system, the significance of providing the patient with an understandable pain diagnosis, and the need to adjust treatment and rehabilitation routines. It has also made us aware of the limitations of the traditional operant conditioning model and the need to plan vocational rehabilitation in harmony with the ongoing life adjustment process. We believe that the integration of routines based on psychosocial qualitative research into clinical practice should facilitate rehabilitation and return to work. We look forward to the reporting of other qualitative investigations, of which there is an urgent need.