Mindful rehabilitation: A pilot project with pain patients

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ABSTRACT

The pain rehabilitation clinic discussed here is a multicultural environment, with patients from Sweden as well as several other nations. Some are war refugees who have had severe traumatic experiences, and most are not able to work at all. They have been remitted to a five-month multimodal rehabilitation program, and often do not have a deeper awareness regarding their life situation. Mindfulness, *awareness and attention in the present moment*, has been found to reduce pain and increase physical and psychological health. The project aims to increase patients’ awareness and acceptance of their life situation, and thereby increase their compliancy with the rehabilitation program. Almost 80 patients used the Mindfulness chart and recorded activities performed, thoughts, emotions, body sensations, levels of perceived stress and energy for three days. Working with the Mindfulness chart may increase one’s awareness of one’s life situation and of where one’s pain may originate from, and can thereby support the rehabilitation strategy. After five months of rehabilitation, when returning to work, the Mindfulness chart and the new awareness of the life situation (“What is possible to work with”) can be used together by the patient, the medical team, the regional social insurance office, and the employer to find the best way back for the patient. All patients were not able to fill in the Mindfulness chart and could only fill in minor parts. Reasons for this included: too traumatic, no interpreter, illiterate, too demanding, etc. But even an incompletely filled in chart gave the medical team a good idea of where to start the rehabilitation. The Mindfulness chart may be useful in rehabilitating pain patients.

Key words: energy, mindfulness, pain, rehabilitation, stress
INTRODUCTION

The pain rehabilitation clinic discussed here is a multicultural environment, with patients from Sweden as well as several other nations and cultures. Some are war refugees who have had severe traumatic experiences, and most are not able to work full time. They have been remitted to a five-month multimodal rehabilitation program, and often do not have a deeper awareness regarding their life situation but simply know that they feel pain. In the first seven weeks of the rehabilitation, different techniques and methods are introduced in order to develop a good and functional rehabilitation strategy for the patient. Patients with long-term pain symptoms like high stress, exhaustion and low energy are in great need of support to mobilize the willpower to change their habits, their life situation. The rehabilitation program aims to support them so that they can handle their pain and mobilize the willpower to change and develop their lifestyle, and thereby be able to work again.

People need strong motivation and a strong intention to change their life habits, to change their behavior (e.g. Jouper, 2009). An increased awareness and acceptance of their life situation is necessary before they can mobilize their power and develop a strategy to work with behavioral changes, and awareness in the present can be improved through the practice of mindfulness (cf. Kabat-Zinn, 2009). When people in daily life describe their life situation, they often do so in terms of how much stress and energy they feel (Thayer, 2001). An increased level of stress reduces one’s motivation and intention to adapt to new activities as well as to perform the new activities (Stetson et al., 1997); therefore, behavior-changing programs need to include stress-reducing activities (Nigg, Borelli, Maddock, & Dishman, 2008). It is possible to self-estimate one’s level of stress and energy hour for hour during the day (Kjellberg & Iwanowski, 1989; Kjellberg & Wadman, 202) to see (to be more aware of) how stress and energy fluctuate with different thoughts, emotions and activities.

The tense-energy model (inspired by Thayer, 2001) describes four levels of living conditions and four squares of stress and energy (see Figure 1). Low stress and high energy give a state of calm energy whereby the individual has good health, time to do what they want, and good concentration capacity. High stress and high energy give a state of tense energy, with the individual living at the top of their capacity, being productive and having relatively good health. High stress and low energy give a state of tense tiredness whereby the individual is exhausted,
experiences anxiety and may be depressed. Low stress and low energy give a state of *calm tiredness*, which could be an apathetic situation or a state of relaxation and recovery. Patients who have been remitted to the pain clinic are mainly in the tense tiredness state (high stress and low energy), and the rehabilitation hopefully brings them to calm energy state (low stress and high energy) according to Figure 1.

![The four-square tense-energy model (Thayer, 2001).](image)

There is a positive correlation between concentration ability and self-estimated health and energy, and a negative correlation with stress (Jouper, Hassmén & Johansson, 2006), meaning that it is easier to concentrate when one’s energy is high and more difficult when one’s stress is high. It is best to change one’s behavior and learn new cognitive methods like meditation, relaxation and mindfulness (needs high concentration) at the time of day when one’s during the day energy level is high. When the energy level is low and the stress level is high, it is more effective to take a quick walk to reduce the stress level than to perform concentration activities (Thayer, 2001). The ability to stay concentrated when performing cognitive methods seems to be a key function (Jouper, Hassmén & Johansson, 2006).
Mindfulness-based stress reduction – awareness and attention in the present without judging (Kabat-Zinn, 2009) – has been shown to reduce stress-related symptoms like pain, anxiety and depression (McCracken & Yang, 2008). Present awareness in one’s life situation means to be in contact with and sensitive to one’s emotions, thoughts and body manifestations. Not judging upcoming thoughts and emotions means to accept the manifestations and not react negatively to the thoughts or emotions; if one does not react, there will be no stress response or increased body tension. It can be assumed that pain patients’ work with awareness and attention in the present with their activities, thoughts, emotions, body manifestations, and levels of stress and energy may help them in their rehabilitation.

The aim of this pilot project is to investigate whether multicultural pain patients can increase their awareness and attention in the present, accept their life situation, and thereby receive support in the rehabilitation process. A second aim is to follow medical staff’s experiences in working with introducing a new rehabilitation tool.

METHOD

The pilot project is more a test and implementation of a new rehabilitation tool in the multimodal rehabilitation program than a longitudinal experimental rehabilitation trial. The purpose is to record experiences of medical staff and patients’ reactions to the new tools, and learn how to develop new rehabilitation routines.

Participants

All members of the medical staff at the pain clinic were shown how to use and fill in the mindfulness chart, and tried it themselves.

Almost 80 multicultural pain patients were offered the opportunity to use and fill in the mindfulness chart during their first seven weeks in the rehabilitation program. It was tested on patients who understood Swedish and who did not need interpretation.

Ethics

When patients were remitted to the rehabilitation program they were informed about the program, that the clinic was associated with the National Register for Pain, and that all
questionnaires and tests would be collected in the register and might be used for research. They have given their written consent that their information can be used for research.

Mindfulness chart

Participants filled in the Mindfulness chart (Figure 2) on three separate days and put the information together into one “mean life situation picture”. The chart was filled in from waking in the morning and every hour until bedtime with main activities, thoughts, emotions, body sensations, and levels of stress and energy. Stress and energy were estimated on a vertical Likert scale from Min (1) to Max (7). The self-estimated scores were connected a solid line and a dotted line to illustrate how stress and energy fluctuated during the day and how emotions and thoughts changed when stress and energy levels changed.

Figure 2. Mindfulness chart: noting thoughts, emotions, body, activities, stress and energy.

Procedure

The staff was introduced to the Mindfulness chart in summer 2009, and tried using it and made plans for how to use it during the autumn. In the first part of 2010 some patients tried to use the chart, and based on their experiences the plans, instructions and chart were revised. After
the revision, most of the patients used the chart during 2010 and 2011. The pilot project was finished in January 2012.

RESULTS

Introducing Mindfulness chart to staff

Most of the staff felt it was strenuous to use the Mindfulness chart or to be aware of their own behavior, thoughts and emotions during the day; it can create an uncomfortable feeling. Those who were aware of their stress and energy levels felt it more clearly when using the chart. Some started filling in the chart but did not finish: “This is nothing for me, I already know how it is, I don’t need to have it on paper”. Most of the staff saw a potential in using the chart, and it was decided to try it on patients.

Patients

Most of the patients felt that working with the Mindfulness chart went well, and could see their own behavior more clearly and get an idea of what to do to improve their health. For example, those who recognized that they did not eat breakfast “worked at eating breakfast”, those who had no regular schedule at all during the day “worked with structures and routines”, and those who felt more pain “worked with relaxation”. Some patients could not fill in the chart. Reasons for this included: too traumatic, no interpreter, illiterate, too demanding.

Some patients wanted to continue using the chart during the five months of rehabilitation to see how their new behavior, methods for handling pain and strategies worked out. Some used the chart as a starting point when discussing “how much I can work and what I can work with” with the medical team, the regional social insurance office and employers. Below are three examples of patients’ Mindfulness charts.
Mindfulness chart, patient 1

<table>
<thead>
<tr>
<th>Thought</th>
<th>get up, I will not survive</th>
<th>I don’t care</th>
<th>I have to</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotion</td>
<td>worry, anxiety</td>
<td>depressed, emptiness</td>
<td>worry</td>
</tr>
<tr>
<td>Body</td>
<td>pain, stiffness</td>
<td>PAIN</td>
<td>restless tiredness</td>
</tr>
<tr>
<td>Activity</td>
<td>breakfast</td>
<td>bus</td>
<td>mindfulness &amp; coffee, lunch, reflection, bus, shopping</td>
</tr>
</tbody>
</table>

7 Max

6

5

4 Mean

3

2

1 Min

Wake up  5 6 7 8 9 10 11 12 1 2 3 4 5 6 7 8 9 10 11 going to sleep

From when you wake up in the morning until you go to bed, mark every hour your level of Energy, ____, and Tension, ---, on the scale from Min (1) to Max (7). Make notes of your Thoughts, Emotional feelings, Body awareness and main Activity.
Mindfulness chart, patient 2

<table>
<thead>
<tr>
<th>Thought</th>
<th>husband emptiness, emptiness, myself</th>
<th>love, gratefulness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotion</td>
<td>grief, harmony, calm, grief/pain/grief,</td>
<td>happiness, calm, peace</td>
</tr>
<tr>
<td>Body</td>
<td>pain, headache, heaviness, lightness, pain, headache,</td>
<td>warm, easiness</td>
</tr>
<tr>
<td>Activity</td>
<td>shower, breakfast, mindfulness, walking, dinner,</td>
<td>play with pet, rest, TV, went to bed</td>
</tr>
</tbody>
</table>

![Graph](Mindful.rehabilitation.9)

From when you wake up in the morning until you go to bed, mark every hour your level of Energy, ____, and Tension, ---, on the scale from Min (1) to Max (7). Make notes of your Thoughts, Emotional feelings, Body awareness and main Activity.
### Mindfulness chart, patient 3

<table>
<thead>
<tr>
<th>Thought</th>
<th>stay in bed, I don’t want to, I should, maybe better later, nice just being, need to sleep, lovely, hope I sleep better tonight</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotion</td>
<td>tired, depressed, tired, depressed, relaxed, happy, satisfied, happy</td>
</tr>
<tr>
<td>Body</td>
<td>stiffness, pain, pain, pain, pain, pain, pain, less pain, less pain, okay pain, okay pain</td>
</tr>
<tr>
<td>Activity</td>
<td>get up, bicycle, gardening, exercise, lunch, qigong, bicycle, coffee, cleaning, dinner, shower, TV</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>7 Max</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td></td>
</tr>
<tr>
<td>4 Mean</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
</tr>
<tr>
<td>1 Min</td>
<td></td>
</tr>
</tbody>
</table>

| Wake up | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | Going to sleep |

From when you wake up in the morning until you go to bed, mark every hour your level of Energy, ——, and Tension, ---, on the scale from Min (1) to Max (7). Make notes of your Thoughts, Emotional feelings, Body awareness and main Activity.
Rehabilitation staff

With the Mindfulness chart patients’ behaviors and needs became clearer to rehabilitation staff, and the chart was able to be used in discussions with the patient and during medical staff team meetings. Together with the patient, the staff discussed what their main problem could be and which strategies should be used to change the situation. During the medical teams’ discussions the chart could be used to discuss special difficulties, the most effective strategy and which profession should go in first. Within the medical team there was no consensus on how to use the chart; some professions found it very useful and some felt they did not need any new tools.

Working capacity discussions

The problem here is that all parties involved need to have the same perspective and agree on what the reasonable, possible level of gainful employment (occupation) is. The remitted doctor, the responsible rehabilitation doctor, the rehabilitation staff, the patient, the employer and the regional social insurance office all take part in the discussion. In some cases in this study, the Mindfulness chart could be used to reach a “common-sense” agreement on the patient’s “life situation and working capacity”, and help him/her find the way back to gainful employment.

DISCUSSION

The project purpose was to investigate whether the Mindfulness chart could support the rehabilitation of multicultural pain patients.

The Mindfulness chart can give a concrete, current view of the situation: how the patient’s life situation is, whether it is stressful and exhausting or energetic and healthy, and how thoughts, emotions and body sensations change with changing levels of stress and energy. The individual patient can use this concrete view, this increased awareness, in the rehabilitation process as well as in the process back to gainful employment. The use of and the ability to adhere to “the new insights” into life differ among patients and probably depend on how well an individual accepts the situation (cf. Kabat-Zinn, 2009).
The three examples of the Mindfulness chart above illustrate how the patients’ thoughts and emotions changed with changing levels of stress and energy. These changes can also be analyzed using Thayer’s (2001) tense-energy model (Figure 1). *Patient 1* wakes up with high tension and low energy and the stress level (feeling anxiety, worry and pain) increases when the patient prepares to take the bus. The patient practices mindfulness, eats lunch and has a coffee break and the energy level increases and the stress level decreases. When the patient takes the bus again the energy decreases (feeling worried and frightened). The patient moves around in the tense-energy model during the day, from *tense tiredness* to *calm energy* and back to *tense tiredness*, and then falls asleep exhausted (*calm tiredness*) according to Figure 1. *Patient 2* wakes up exhausted (feeling grief, emptiness and pain), practices mindfulness, takes a walk and has lunch and the levels of stress and energy decrease. The patient returns home, plays with pets (feeling love, warm and happiness) and falls asleep with more energy than stress. The patient moves from *tense tiredness* (exhausted) to *calm tiredness*, and further to a state of *calm energy* according to Figure 1. *Patient 3* wakes up in a state of exhaustion. Through strategies of health care, physical exercise, gardening, qigong, the level of stress declines slightly and the energy increases. The stress level decreases when the patient comes home to family (feeling calm and satisfied). The patient moves from *tense energy* (living on the edge) and ends the day in *calm tiredness* according to Figure 1. These three examples are relatively similar but illustrate how thoughts, emotions and body manifestations change depending on activities, like in the example of the stress level increasing when taking the bus and decreasing when performing mindfulness exercise. The examples also illustrate how patients can independently use the Mindfulness chart and be aware in the present, noting their feelings (which indicates acceptance of the situation) without “getting lost in catastrophe” (cf. Kabat-Zinn, 2009).

Introduction to staff

The clinic management showed great interest in the project and stimulated the process, thereby influencing the curiosity to find new rehabilitation tools and possibilities for patients. The staff’s introduction to the Mindfulness chart continued for several months, which probably increased their acceptance of the project. The staff showed the same reaction patterns that patients did when using the chart: some did not fill it in, citing the reason “I already know how my life is”, and some filled it in halfway and said “This might work”. Most of them worked hard
with the chart, however, saw great potential in it, and integrated it into the rehabilitation process. During change and developing processes, it is important to show respect for others’ experiences and let the processes take time.

Patients’ increased awareness

Most pain patients are tense, feel stress with declining energy, and have poor memory, reduced concentration ability, reading and writing deficiency, as well as difficulty reading schedules, especially if they suffer from ADHD. This makes it difficult for them to stay concentrated for longer periods, and they can be less successful in using cognitive methods (meditation, mindfulness, etc.) or may have more problems filling in the Mindfulness chart (Jouper et al., 2006; Thayer, 2001). Filling in the Mindfulness chart or adhering to different activities may increase stress (“one more thing to do”) and thereby reduce a person’s will to perform new activities (Stetson et al., 1997). The new awareness of one’s life situation is probably demanding and increases stress, and a natural reaction to this is to avoid the situation (Kabat-Zinn, 2009), which could also be a common behavior among these patients. The patients have to accept the new “life-situation awareness” before they can develop new recovery strategies and life habits. For some patients this may take a longer time than the first seven introductory weeks; they might need to work with this during the entire five months of rehabilitation.

Rehabilitation staff

A natural desire among the rehabilitation staff was to get a “perfectly filled out Mindfulness chart” so they could make a “perfect” rehabilitation plan for their patient. This likely only happens in a small number of cases, and when the patient has fully accepted the situation. A calm, healthy and well recovered individual may experience working with the Mindfulness chart as mildly stressful, and it may feel good and comfortable to confirm that “I’m healthy and feel good”. In meetings with the patient, from when he/she does not want to write anything in the chart until he/she is completely filling it in and has accepted the situation, it is probably equally valuable to respond to the patient on the same level where he/she is at the moment. A chart that is filled on only 10% probably gives the same valuable information about the patient’s situation as a chart that is completely filled in.
Working capacity discussions

A successful discussion about working capacity in which all parties are in agreement about the situation is probably a utopian idea. The discussion situation – a patient with a long-term diagnosis, used to being exhausted and with low self-esteem, discussing his/her future with the remitted doctor, the responsible rehabilitation doctor, rehabilitation staff, employers and the regional social insurance office – must be very stressful and important to the patient. In some cases the Mindfulness chart has offered great support in discussions, enabling good consensus about the situation. The great benefit may be that the patient finds a way to describe the situation, to accept it, to take responsibility for it, making it possible to argue for his/her working ability, which probably improves the patient’s empowerment.

Continuing process

The pain clinic has expanded the assignment to cover patients who have more illness and have a longer path back to work than those who have already tried the Mindfulness chart. This group has increased degrees of resignation, exhaustion, pain and need for support. They are not able to fill in the Mindfulness chart themselves; some need an interpreter or supervision. It is of interest whether they can be supervised as a group or whether this must be done individually. Can the use of the Mindfulness chart enhance their awareness of their life situation, and is it possible to discuss their situation according to the chart? How will this affect supervision instructions, etc? This project will continue during 2012.

Conclusions

The Mindfulness chart and self-estimated thoughts, emotions, body sensations, activities, and stress and energy levels may be a useful tool in the rehabilitation of multicultural pain patients.
REFERENCES


