Internet-delivered relapse prevention after pain management: A qualitative pilot study

Nina Bendelin

Psykoterapeutprogrammet
magisteruppsats
vårterminen 2015
Handledare: Gerhard Andersson
Relapse prevention after pain management is a neglected area and Internet-based interventions have the potential to partly fill this gap. A challenge in designing effective relapse prevention program is how to motivate patients to persist throughout the full length of treatment. Following a regular pain management program, 29 participants underwent a 20 week long Internet–based relapse prevention program based on acceptance-oriented CBT. Qualitative analyses showed changes in attitudes towards their pain and body during the course of treatment. Degree of personal commitment in treatment goals seemed to affect gains relating to new perspective on self and future. Therapeutic strategies of defusion and mindfulness seemed to ease perspective changes and persistence to comply. Values interventions are hypothesized to be a plausible therapeutic strategy to engage participants in continuous behavior change. Further studies on non-compliers and drop-outs could enhance understanding of interventions necessary to maintaining motivation. When and how to give therapist support during Internet-based treatment for chronic pain is another area in need of further studies.

Acknowledgement

I wish to thank the following persons who have contributed to this report:

Gerhard Andersson for your encouraging and motivating guidance during the writing of this report.

Björn Gerdle and Department of Medical and Health Sciences for financing.

Colleagues at Pain and Rehabilitations Centre, University Hospital in Linköping for help while producing treatment content.

Jörgen Öberg for sharing your expertise while conducting the study.

Eva-Britt Lind for help with collecting and administering data.

Daniel Bånkestad Goine and Marie Blom for constructive remarks on the qualitative analysis.

Most of all; Participants in this treatment program who’ve generously shared their experiences of living with pain.
Abstract

Relapse prevention after pain management is a neglected area and Internet-based interventions have the potential to partly fill this gap. A challenge in designing effective relapse prevention program is how to motivate patients to persist throughout the full length of treatment. Following a regular pain management program, 29 participants underwent a 20 week long Internet–based relapse prevention program based on acceptance-oriented CBT. Qualitative analyses showed changes in attitudes towards their pain and body during the course of treatment. Degree of personal commitment in treatment goals seemed to affect gains relating to new perspective on self and future. Therapeutic strategies of defusion and mindfulness seemed to ease perspective changes and persistence to comply. Values interventions are hypothesized to be a plausible therapeutic strategy to engage participants in continuous behavior change. Further studies on non-compliers and drop-outs could enhance understanding of interventions necessary to maintaining motivation. When and how to give therapist support during Internet-based treatment for chronic pain is another area in need of further studies.
Table of content

Acknowledgement

Abstract

INTERNET-DELIVERED RELAPSE PREVENTION AFTER PAIN MANAGEMENT


Chronic pain

Pain is defined as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" [source](http://en.wikipedia.org/wiki/International_Association_for_the_Study_of_Pain#cite_note-IASPterms-4) (Merskey & Bogduk, 1994). Pain is most often considered chronic when lasting longer than three to six months (Debo, Hoeksema & Hobbs, 2013), although the transition from acute to chronic pain have also been suggested at 12 months (Main & Spanswick, 2001). In clinical practice pain is sometimes considered chronic when lasting longer time than what’s expected necessary to heal (Turk & Okifuji, 2011).

Pain is the most common reason for people in industrial countries to seek healthcare (Linton, 2005). In Sweden, 20 percent of the population is estimated to have severe or moderately severe pain (SBU, 2006). Living with chronic pain is likely to lead to substantial psychosocial consequences for the individual, as well as depression, tiredness and social isolation (Turk & Gatchel, 2002). Chronic pain is often associated with negative consequences for society as a whole, as in higher numbers of persons on sick-leave, loss of physical and social functions and decreased engagement in society (SBU, 2006; Robinson, Wicksell & Olsson, 2004). Chronic pain is internationally traditionally treated with behavior therapy (Turk & Gatchel, 2002), and treatment models based upon both operant psychology and the fear-avoidance model have been evidence-based (Stiles, Wright, 2008).

Pain rehabilitation and relapse prevention

Even though behavior therapy have been used in pain management for a long time and been proven to be successful, studies show that level of self-reported pain not by certainty is associated with return to work or improved quality of life (Linton, 2005). A relatively large proportion of patients undergoing a behavioral therapy based rehabilitation are not improved (McCracken, MacKichan, Eccleston, 2007). The amount of patients that relapse shortly after treatment is as well relatively large (Turk, Swanson & Tunks, 2008). Estimating the number of patients who relapse after pain management program is difficult, partly depending on limitations in follow-up time in trials (Morley, 2008). Turk and Rudy (1991) estimated that between 30-60 % of patients relapse in some form after completing pain management programs.

Skinner, Wilson and Turk (2012) stated that: “given what is known about treatment requiring lifestyle changes (…) it is naive to assume that brief rehabilitative treatments that require long-term lifestyle changes will be
maintained unless the benefits are not sufficiently (self-) reinforcing.” (p. 107). The same authors also claimed that patients’ cognition about pain, for example beliefs in medical care or visions of a satisfactory life with pain, may highlight their readiness to change, viewed from a “stage of change” model perspective. Since obstacles to travel to treatment as well as lack of trained therapists are likely to obstruct relapse prevention, they proposed Internet-based treatments as a possibility to enhance maintenance (Skinner, Wilson & Turk, 2012).

Furthermore, Vowles and McCracken (2008) concluded that even if cognitive behavioral therapy has documented effect, the working mechanisms behind the treatment are yet to be discovered. Hence, there is room for refining psychological treatments for chronic pain and a need to clarify underlying processes of change behind effective treatments of chronic pain.

**Internet-based treatments for chronic pain**

Internet-delivered treatments have with success been tried out in the purpose of extending the widths of treatment to other populations than those regularly seeking health care (Andersson, 2009). Several RCT:s on chronic pain (Buhrman, Fältenhag, Ström & Andersson, 2004; Thorsell, Finnes, Dahl, Lundgren, Gybrant, Gordh & Buhrman, 2011; Buhrman, Fredriksson, Edström, Shafiei, Tärnqvist, Ljótsson, Hursti, Gordh, & Andersson, 2013; Buhrman, Skoglund, Husell, Bergström, Gordh, Hursti, Bendelin, Furmark, Andersson, 2013; Buhrman, Syk, Burvall, Hartig, Gordh & Andersson, 2014) and two on headache (Ström, Pettersson & Andersson, 2000; Andersson, Lundström, Ström, 2003) have repeatedly indicated that internet-delivered interventions may be a successful format for providing treatment for pain. Internet-delivered cognitive behavioral therapy is a well-established form of health care, although not yet in somatic care for chronic pain. Guidance in how to adopt face-to-face interventions for chronic pain online have been asked for as well as more knowledge on level of therapist support needed (Keogh, 2010). Cavanagh (2014) found that people may develop acceptance skills with a minimum of therapist support and that these interventions might complement regular care. However, the same study asked for more knowledge on how to promote patients’ engagement in self-help interventions.

In their summary of future directions for understanding the mechanisms of psychological pain treatments, Jensen and Turk (2014), stated that self-management programs are of great value for chronic pain patients since residual symptoms are expected. Maintaining gains over time is an important issue, they stated, pointing at the internet as a way to deliver relapse prevention interventions for patients while they are in their homes. Lack of patient motivation and patient discipline to follow treatment assignments are two problems that need to be further addressed in research (Jensen & Turk, 2014).
**Patients’ experiences of Internet-based treatment**

Qualitative studies of patients’ experiences of Internet-based treatments are rare but needed to refine treatment, enhance compliance and ease facilitation. Skinner, Wilson, Hilary and Turk (2012) asked for research that develops strategies that effectively and efficiently deal with relapse problems and see Internet therapy as a plausible way.

An active approach to treatment during its course (Bendelin, Hesser, Dahl, Carlbring, Zetterqvist Nelson & Andersson, 2011) as well as after treatment has ended (Olsson Halmetoja, Malmquist, Carlbring & Andersson, 2014) seems to be associated with greater profits of treatment. Olsson Halmetoja et al. (2014) raised the question on wheatear Internet-based treatments are better suited for persons with an active approach to their well-being in general. If so, there’s a need to see in an early state which ones aren’t and learn what would motivate them to comply. Donkin and Glozier (2012) found that persistence in keeping to an Internet-based treatment program were enhanced through four processes; initial hope for benefits, enhancing personal engagement, reducing barriers to use and increasing ongoing motivation factors. They asked for further studies that determine how such processes effects outcome.

Olsson Halmetoja et al. (2014) also found that persons who made acceptance-oriented statements of themselves, their health and situation were the ones who used relapse prevention strategies and also reported a positive development after some time. They raised a question on whether an acceptance approach facilitates change.

Skinner, Wilson and Turk (2012) stated that in order to use Internet strategies for people with chronic pain in a more refined way, patients’ individual differences and mechanistic factors need to be considered. Since patients behave, feel and think differently in managing their chronic pain, treatment aiming at enhancing further change need to match patient characteristic in order to pinpoint witch areas of concern need to be focused during a relapse prevention intervention (Skinner et al., 2012). In doing so, the present study aim to serve as a second chance in helping patients overcome obstacles to maintain and generalize treatments gains.

**Research question**

In line with findings of Donkin and Glozier (2012), the treatment in the present study aimed to simplify and individualize tasks for participant to enhance persistence and compliance. Giving participants somewhat more free hands in working with the program as well as choosing treatment goals by their own means, hopes were that this would generate knowledge on what parts of treatment are relevant for them in terms of initiating change, keeping work
going over time and discovering key components or defining moments in their change work. Also in line with Donkin and Gloziers’ (2012) findings, hopes were that this would enhance personal commitment to engage in treatment and keep motivation high over time of treatment. Also, the current treatment program differs somewhat from previous similar programs, since it aims to reduce therapist support to a minimum.

This qualitative study aim to describe how chronic pain patients (from now on called participants) work with an internet-based relapse prevention program of acceptance-based cognitive behavioral therapy. Three research questions in focus are:

- how participants initiate behavior change,
- how they motivate themselves to maintain their change work over time and
- what they view as essential for their change when they look back.
Method

Pain Management program for Chronic Pain
Participants in the present study had before inclusion completed an 8 week long pain management program (PMP) at a Pain Rehabilitation Centre. The PMP contained group sessions with physiotherapist (PT), psychologist and occupational therapist (OT) and seminars on chronic pain and other aspects of health behavior. Individual sessions were available upon request, although the main part of rehabilitation is delivered in group, wherefore patients’ homework in between sessions and individual commitment to rehabilitation are emphasized. Psychological elements in the PMP consisted of 8 group sessions of acceptance-based cognitive behavior therapy (A-CBT) and two seminars.

Internet-based relapse prevention program after PMP
During a time span of 24 months, all patients completing the standard group-based PMP, were offered to participate in a 20 week long online self-help program with some therapist support, focusing on maintaining gains and behavior change. Selected parts of the A-CBT group sessions were the foundation in weekly chapters with work sheets presented on line. Additional chapters with repetition from PT- and OT-sessions were available. In these fixed work sheets it was yet open for the participants to state their own goals with treatment. Participants were given extensive online feedback from a psychologist during the first 4 chapters, where after they continued working independently during the latter four chapters, unless they asked for feedback. Beside the psychologist providing feedback, a consulting team consisting of a PT, an OT and a pain-specialist physician were available if necessary. Treatment chapters’ context is presented in Table 1.

Table 1  
Overview of content in treatment chapters

<table>
<thead>
<tr>
<th>Week</th>
<th>Treatment chapter</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Introduction to treatment program and it’s content</td>
</tr>
<tr>
<td>2</td>
<td>Values (goals)</td>
</tr>
<tr>
<td>3</td>
<td>Plan for change</td>
</tr>
<tr>
<td>4</td>
<td>Introduction to forth-coming work sheet focusing on values-based behavior change</td>
</tr>
<tr>
<td>5-10</td>
<td>Individual work</td>
</tr>
<tr>
<td></td>
<td>OT- and PT-worksheets available and delivered based upon individual needs by supporting psychologist</td>
</tr>
<tr>
<td>11</td>
<td>Summary and conclusions</td>
</tr>
<tr>
<td></td>
<td>Evaluation</td>
</tr>
<tr>
<td>12</td>
<td>Future plan for relapse prevention</td>
</tr>
</tbody>
</table>
One aim of the internet-based relapse prevention program was to establish rule-governed behavior in valued life-directions rather than focusing on getting rid of pain. Another aim was to give participants new experiences of acting in presence of pain to broaden their repertoire of pain behaviors and enable for them to act with psychological flexibility when performing pain related activities. Promoting readiness for future obstacles and overcoming boundaries aimed at enhancing self-efficacy. The final chapters aimed at helping participants take a courageous stance for the future from the position they were at. The treatment consisted of 8 chapters, which of most were done once a week. One chapter spanned over several weeks, depending on patients’ choice. The planned treatment time was 3 months. This time span was lengthened to 6 months. Since this was an open study performed in the main purpose of testing the applicability of a well proven treatment on an unknown group of responders, every eligible patient interested were included. Since it was a non-randomized trial, all participants were given the same intervention.

The provided treatment resembles a self-help book, based on cognitive behavioral therapy, focusing on values-based behavioral activation (McCracken & Yang, 2006), with treatment components also from Motivational Interviewing (Miller & Rollnick, 2012) and Acceptance and Commitment Therapy (Hayes, 2014). Treatment components were inspired from Acceptance and Commitment Therapy (values, willingness and committed actions), Motivational Interviewing (Decision making, Doing what’s important, Skills and Abilities, My choices) and Cognitive Behavioral Therapy (Problem-solving, Long-term consequences, Behavioral activation, Exposure to fears and losses in life).

Selection
Inclusion criteria for patients to be viewed as eligible were 1) completed pre measurement scores prior to start of PMP, 2) completing PMP 3) access to computer and internet. Out of 101 eligible participants who completed a PMP during inclusion time, 73 were proposed, see Figure 1. Of the 61 who were interested, 37 logged in and started working with the program. 26 participants completed at least 3 chapters and therefore completed the most important treatment parts in terms of relapse prevention. Another 3 participants completed only 2 chapters, however since their text had a highly informative value, they were still included in the qualitative analysis.
**Data collection**

The qualitative analysis is based upon contributions from 29 participants. Participants completed on average 5 chapters each (ranging from 2 to 8). 138 chapters of written text were all together included in the qualitative analysis. Since the aim of this qualitative study was to better understand what elements are important for participants in their change process, all written material that could have an informative value were included. An advantage of using participant’s own written text instead of interviews is that their experiences aren’t affected by memory loss as a consequence of time passed since treatment. The text they’ve written in the work-sheets could be viewed as a sort of diary notes which gives a detailed picture of their feelings, thought, fears and strains at the time. A disadvantage of not doing interviews is that participants can’t explain, frame or further develop their notes and no further questions can be proposed to them. However, the latter 3 work-sheets are written at the very end of treatment and have a slightly different focus then the previous. Participants evaluate their own work and they are encouraged to go back and read what they
have previously stated as goals in order to compare gains with goals. Reflections made by them in these evaluations to some extent compensate for the loss of own reflections that an interview could have provided. An important advantage of doing a qualitative analysis based upon already written text is that a rich material is available without having to disturb participants further.

**Participants**
Participants were mainly females (26 of 29). Mean age at inclusion time was 37 years old (spanning from 22 to 53). Duration of pain was at least 6 months prior to inclusion in the PMP. Mean time of pain duration was 6 years (spanning from 1 to 21). 34 % of participants were working to some extent, while 41 % had full time sick-leave compensation. The remaining was either in the process of applying for work, studying or had municipal support. 69 % of participants had a high school education, 17 % had college education.

**Measurements**
During and after the PMP, measures were collected as part of a clinical evaluation. Depression and anxiety were measured with Hospital Anxiety and Depression scale (Zigmond & Snaith, 1983). Psychological acceptance was measured with Chronic Pain Acceptance Questionnaire (Vowles, McCracken, McLeod & Eccleston, 2008). Psychological flexibility was measures with Psychological Inflexibility in Pain Scale (Wicksell, Lekander, Sorjonen & Olsson, 2010). Different aspects of pain were measured with The Multidimensional Pain Inventory (Kerns, Turk & Rudy, 1985), which is self-report instrument covering pain intensity, pain interference, ways of coping, social support and activity level. Pain level was measured using an analog scale (VAS) where participants mark pain level during last week. Life satisfaction was measure using Lisat-11 (Fugl-Meyer, Bränholm, & Fugl-Meyer, 1991). As this was a relapse prevention program, symptom changes were not expected, since the purpose was to maintain gains and prevent a decrease in symptoms. A positive outcome in terms of psychological acceptance towards pain and life satisfaction was however expected. An increase in pain acceptance was indeed seen 6 months after PMP ($p=.015$) which coincides with end of the relapse prevention program, and further improvement was seen at 1 year follow-up ($p=.008$). Life satisfaction was also improved 6 months after PMP ($p=.005$). Concerning symptom changes, no statistically significant changes in anxiety or depression were found. Pain level was however improved at 1 year follow up ($p=.036$) and improvements were also seen in psychological flexibility towards pain 1 year after completion of PMP ($p=.051$).
Qualitative method
A qualitative analysis of participants’ written text is a way to understand their own views and perspectives (Yin, 2011). Hence, this method was used in the current study, to learn about participants’ perspective on their relapse prevention work. Diary-like texts provide a description of an ongoing process (Peräkylä & Ruusuvuori, 2011) and this material suited the research questions well. As patients with chronic pain often have comorbid medical or psychiatric conditions, an advantage of a qualitative approach is that these contextual factors add further meaning to the material rather than being a hindrance for comparisons. Relapse prevention programs are a multifaceted treatment, as are PMP:s, since it’s difficult to state in an early stage which combination of interventions will help the particular patient. As this study aim to investigate participants experiences of how change was initiated and maintained over time, a qualitative approach is a plausible way to generate new ideas on how to construct a relapse prevention program, in line with what enhances motivation and evokes behaviour change.

Content analysis
The text material was coded using Open Code 3.1 (ICT Services and System Development and Division of Epidemiology and Global Health, 2013). Based upon the three research questions, the coding process was conducted with 3 broad questions in mind:

- How is behavior change initiated?
- What characterizes the process of behavior change over time?
- How did the change occur, when looking back?

Coded units containing content relevant to these initial questions were sorted into categories specific for each of the 29 individuals. All of these individual categories were then conceptualized in group categories based on similarity. For example, out of the question ”How is behavior change initiated”, the text from one participant resulted in coded units that were sorted into 5 individual categories (see Table 2). Together with individual categories from other participants, they were sorted into group categories.
Table 2

*Example of the coding process*

<table>
<thead>
<tr>
<th>Initial question</th>
<th>Coded units</th>
<th>Individual categories</th>
<th>Group categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>How is change initiated?</td>
<td>“react in a way that is my own”</td>
<td>Want to act as myself (with honesty)</td>
<td>My time now</td>
</tr>
<tr>
<td></td>
<td>“be involved in what I do”</td>
<td>Want to be involved</td>
<td>Longing for work and participation</td>
</tr>
<tr>
<td></td>
<td>“I want so much but my body can’t handle it”</td>
<td>Frustration and fear connected to dreams</td>
<td>Scepticism / Uncertainty</td>
</tr>
<tr>
<td></td>
<td>“I’m afraid of setting goals”</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>“manage myself”, “maximize my chances to succeed”</td>
<td>Enhance independence</td>
<td>Overcoming/Evolving</td>
</tr>
<tr>
<td></td>
<td>“Others can’t help me with this, it’s rather within me the change needs to occur”</td>
<td>Change needs to occur with me, take command of my situation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>“dare put myself in new and unknown situations”</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Up until now the 3 initial broad questions had served as a framework for the coding and conceptualization process. However, when all group categories were viewed together without the framework, ideas on new themes emerged from a time perspective rather than a content perspective. Six themes emerged from the group categories:

- Body
- Pain (or pain related symptoms)
- View of future
- Description of self
- Motivation
- Therapeutic strategies (used in the change process)
These aspects are central themes as they were described in written text by participants, in different ways in the beginning, during and at the end of program, spanning over several group categories.

Table 3

*Example of a number of group categories forming a theme based on a time-perspective*

<table>
<thead>
<tr>
<th>Group categories</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>My abilities/What I need</td>
<td>Body</td>
</tr>
<tr>
<td>A strong body/ Enjoy my body</td>
<td></td>
</tr>
<tr>
<td>Long term consequences/Choose with my health in mind/Spare myself</td>
<td></td>
</tr>
<tr>
<td>My health a necessity for goals</td>
<td></td>
</tr>
<tr>
<td>Try new ways/Create opportunities</td>
<td></td>
</tr>
<tr>
<td>Shift focus/Be reminded</td>
<td></td>
</tr>
<tr>
<td>Acknowledge/ Praise/Growth</td>
<td></td>
</tr>
</tbody>
</table>

There are similarities among participants in how they write about these themes and there are also differences in what aspects they emphasize, as presented in the Result section.

During the initial coding process, coded transcripts were evaluated by a colleague with experience from pain rehabilitation to ensure that the coding didn’t lead to a drift in focus and that a line could be seen from transcript to coded units to individual categories. As group categories started to emerge these were presented at a seminar with experienced pain rehabilitation researchers to be evaluated in terms of accuracy and informative value.
**Result**

Two aspects of motivation for change work were found in the material. At treatment start, motivation to change work is expressed either as what participants miss or as what they want to do differently. Treatment interventions used in this phase are values and for some also defusion. Four central themes changing throughout treatment were also found. Body (1), Pain (2), View of future (3) and Perspective of self (4) are described differently in the beginning, during and by the end of treatment. Therapeutic interventions used during the middle of treatment are willingness and for some also present moment. By end of treatment, some participants make decisions and plans for the future. Therapeutic intervention used in this phase is committed actions. Besides the three treatment interventions participants were expected to use (values, willingness and committed actions), another two (defusion and present moment) were described in participants’ written text. A summary of the result is presented in figure 2.

![Figure 2. Summary of result: Central themes, aspects of motivation and used therapeutic strategies.](image)

**Body and pain/pain-related symptoms**

Certain areas within the written content are described in different ways during the course of the program. One of those is participants’ view of their own body and another one is their perception of pain as well as pain-related symptoms (this may be tiredness, anxiety, depression as well as obesity and other health-related areas). When writing about their body in the earliest stages of the program, participants describe it as somewhat of a necessity for change in other areas, a limitation and something they need to deal with.

I want to exercise my body and become physically more and more active, so that I can manage work, family and have fun on my spare-time. (Participant 5)
Throughout the program a different view on their body emerges within the material. It’s described as a tool or a key for change, something usable, something worth investing in and worth nursing.

Tend to my body to get more energy. (…). I’m losing weight and I’m feeling that my body has more energy and strength. (…). I believe that if I become more physical and work my muscles, there might be more to take from when I get pain. (Participant 19)

By the end of the program a shift occurs in the way participants comment on their body. They are aware of it, notice its presence and see it as something that reminds them of using strategies.

Balance how much strength I put in and how much I manage. See my limitations. (…). I’ve felt good just being. I’ve managed my working postures without stiffness and pain… I’m pleased with my week, I’m especially happy for pulling through what I intended, that I’ve felt fresh in the morning and that I didn’t end up stiff and in pain. Things work out for me. I’m happy with my life. (…). I won’t neglect my abs practice, it made my pelvis hurt. (…). Slow down at work, take breaks, go for walks. Walk every day. Balance. Accept I don’t have energy for everything. (Participant 13)

As a shift in attitude towards their own body emerges during the program, participants also demonstrate a change of view in their perception of pain and pain-relates symptoms. In the earliest phase of the program, pain and related symptoms are described as something participants need to get pass, a problem they need to take on, something that must be focused upon, mentioning that now is the time for change.

Make sure I get out for walks a few times a week even though I’m working. (…) …. I must focus on exercising if I want to keep losing weight, so therefore I have to do it (…). I want to feel pretty and be comfortable with myself and like myself. I also hope that pain will be a liiitle less if I don’t put extra load on it. So I put my hopes into enduring all these weeks so that I can look the way I wish. (…). Don’t remember last time I did so now’s really the time to do something about it. (Participant 20)

During the course of the program, participants’ perception of pain as an obstacle is shifting towards pain being viewed upon as a part in their plan, i.e. a potential hindrance, but not their main focus. When it does occur participants hold on persistently to their plan and focus repeatedly on what they intent to do. Pain and the other related problems they initially struggled with, are not seen as a reason to stop, but rather as a call to fiercely maintain their commitments.

Do it anyway, do some or take a walk instead so that I at least move around some. (Participant 10)
When participants look back on what they’ve done during the program they tell of new experiences where they’ve encountered and gained progress by being persistent and not backing down when pain and other problems have emerged.

I haven’t succeeded in finding a solution for my sleep but rather accepted it the way it is. That made me let go of the frustration and anger with my sleep which is rather nice to lose. I keep looking for and trying out new solutions to the problem, but I’m feeling I’m not doing it as desperately as before. (Participant 28)

When pain keep increasing and fights with me, I will hold a positive attitude and try out new ways and ask for help. (Participant 9)

The quotations above illustrate a perspective shift, turning from viewing both body and pain as a constant hindrance for them to work on other problems in their life. Gradually they perceive their body as an aid for executing plans and pain as one of other potentially hindrances in their life. This leads up to a less strugglesome, a more flexible, curious and willing attitude to do what’s possible and let emotions of suffering as frustration, sadness and disappointment be there without acting upon it. Gains and experiences of overcoming obstacles seem to be consistent with acting persistent and not being broken down by a relapse.

**View of future and description/perception of self**

Most participants show a shift in how they view their body as well as pain/pain-related symptoms. Some also describe a growing new perspective on what the future might bring and their view of self. As for how they look upon the future, in the beginning participants write about longing, lacking and frustration. They question what suits them in terms of jobs, exercising and social relations.

To feel joy about my life, more faith in the future. (...). I don’t want to feel low which I do in bad days/times. I want to feel I can make plans without fearing I’ll get PAIN then. (Participant 8)

During the course of the program, participants’ concern about the future is visible in their planning and day to day work in reoccurring problem-solving where long-term consequences are taken under consideration. Meanwhile they to a large extent focus on taking small steps of change in their everyday life, they link what they do here and now to what they expect will come out of it eventually. This perspective seems to motivate them in their change process knowing that their pulled effort will reward itself later on.

Might start at my trainee position next week. Feels like an extremely tough and big step to take right now… Boss said to take things my own pace and only do as much as I know and can. She said I’m there for my sake, to see if working is possible. Feels exciting. As long as I don’t strive too high. (Participant 21)
What’s significant for participants attitude towards the future as they look forward by the end of program, is that they declare having made decisions about their lives, “heavy” decision that won’t be knocked over. One participant writes that she has raised the bar for what to expect out of life. Another person states that she’s not waiting anymore for her life to start.

I think I’m heading in the right direction… for sure, but I’m not yet all the way there, I’m thinking it will take time. Although I’m definitely on the go. I believe it shows since I’ve now raised the bar a millimeter since the Pain management program. I’m getting forward, I’m on the right track, I’m trying to live my life 😊 (Participant 2)

I’m pleased with my life even though I don’t have the slightest idea of what will happen next. (Participant 9)

Participants view of them self and descriptions of self are in the beginning characterized by expressions of loneliness, confusion regarding how to get a hold of their life and also a will to revenge oneself on life.

Work is such a great part of your life, but it can’t drain all your energy. Then life becomes ‘poor’. Can I do nothing but work, eat and sleep, I’ll turn into a bitch, no fun for anyone, least at all myself! (Participant 4)

During the course of program some participants start writing about improving their assertiveness skills. They take action for what’s in their interest, stating their needs and wants, declaring what’s their own responsibility and trying out new ways to hold their own opinion. They encourage themselves with statements as “carpe diem!” (Participant 5), “pull myself together” (Participant 12), “this is my race” (Participant 16). Honestly they declare truths about themselves as “… show some interest in my friends’ lives and problems. Frankly, become a better friend” (Participant 3).

I’ve learned to take it easy when I’m worse not to hurt myself in other ways. When I’m feeling worse, I need to inform those around me to avoid controversies. (…). I’ll keep a diary every day to monitor my activity level… (…). Make time for myself. (…). Decline if there’s something I can’t handle (…). Stay to it. It will calm down soon. Think it over and do something that gives you energy back. (…). Say yes when opportunities come along. (…). Seize opportunities and give suggestions. (…). Ask for help even with small things (Participant 29)

As participants look back on the effort they’ve made during the program, some describe changes and growth related to themselves. Also, some propose a different view on their situation as a whole, where unresolved problems don’t bother them in the same way. Some of them describe they’ve gained a larger perspective and a new focus in life. They praise themselves, they show pride and talk of self-confidence.
When I confronted what were ‘frightening’ and noticed I could deal with it, with my lower demands, I let go of many barriers. Trying all this, was an intense period and I was so tired I completely stopped bothering about what was happening or what people thought of me. I learned it’s all right to do/say wrongly sometimes. Now I’m getting closer to recognizing it’s okay to show how you really are/feel. I’m more comfortable with myself. (Participant 28)

Concerning the way participants write about themselves and the future, these two aspects seems to be imported for their readiness to move on after the program. When they describe a willingness to recognize their experiences of living with pain, amongst which experiences they previously repulsed, a shift in perspective of self emerges. Also, writing about a readiness for facing the uncertainty of the future seems to go hand in hand with making decisions about the future, longstanding commitments in their life.

**Motivation**

How participants go about when they declare their reasons to change is partly governed by the structure of the program and the treatment strategies within it. Still, there are differences amongst them when it comes to how they phrase their motives and what they expect to change in their lives. Initially, all of them describe things they miss, what they lack, what they long for and how they dream their lives would be like. They use expressions as being at the end of the road, enough is enough, turn a leaf.

I want to remember how it feels like to be tired in my muscles… and long for the next time. (Participant 26)

During the larger part of the program, when they strive week after week towards their goals, they use other ways to motivate themselves; some are encouraged by others and some acknowledge the progress they make and are therefore motivated. What distinguish some of the participants happens when setbacks occur, when they turn disappointed over knocked-over plans or when their plan is disrupted or mal-functioning. A group of them then encourage themselves in times of misfortune by using these experiences to clarify another round why they need to change. A relapse is not a failure in that perspective, merely a reminder of the importance of keeping up the steam and keeping focus in their work. Setbacks are also viewed as reminders of what they long for and their own responsibility to take action to move towards that.

Think about why I’m doing this, Write it down so I’ll see it every day. (…). Tell someone what I’ve done well by the end of the day. (Participant 29)
When looking upon those participants who find ways to meet misfortunes with an optimistic view, they distinguish themselves further when describing their motivation to keep up their change work after the program is ended. They are not only motivated by what they miss and want, they aim at changing how they go about to execute things and how they wish to live. This is visible already in the beginning when they not merely describe feelings they wish to achieve but also how they want their life to be and how they want thing to work. They use expressions as “hold on”, “even though” and “no matter what”.

Carrots in front of me – when one’s eaten I want to see the next a bit further. (Participant 9)

I can change everything at once as long as I want to!!! (Participant 20)

It’s worth being troublesome to get what I want! (Participant 28)

When life is back (Participant 13)

In conclusion, being able to see a setback as a useful experience may be important for their perception of their ability to handle relapses after on. Also, motivating yourself not only out of feelings you long for, but also from how you want to take on life, seems to be important for maintaining spirit even through times of misfortunes, as described by this participant:

I enjoy being the cheerful soul among people around me – I like to make people laugh and have a good time, it gives me a pleasant kick. I want to be happy and I am when I laugh joyful and have a good meal with my wife, my family and close friends. When I’m feeling well, I can be there for them and help them when they need me as they are there for me when I need them. I want to give back what they give me now, right now it feels as if I’m mostly the one who’s receiving. I want that balance back. (…). Life goes on right now and I want to enjoy it now, not later on. (Participant 2)

**Therapeutic strategies**

Concerning what therapeutic strategies participants rely on in their relapse prevention work, they write about values, willingness/acceptance and committed action. These are the three main components in the treatment. In the early phase of the program, participants write about what they value in life.

I want to be able to go to work and feel joy and anticipation for my day. Want to feel occupational pride and take pleasure in my work again. (Participant 4)

During the program they express willingness and describe movements towards what’s difficult in their lives.
Talk to my partner or someone else close to me about how I’m feeling (glad, sad angry, irritated – you name it). Won’t hold it to myself anymore or hide my feelings, rather show it and talk about it to make me feel better and get a perspective on life and my emotions which sometimes runs riot. (Participant 2)

By the end of the program they write about values-based commitment actions.

Think about what’s running that Duracell Bunny and chase it in the right direction. (Participant 29)

Besides these strategies, participants also use some others that aren’t prompted, although they are familiar to them from the pain management program they took part in prior to the relapse prevention program. One of these strategies is defusion, which some of them use meanwhile they declare their values, as a tool to take a step back and view things from a different angle before they go about to make changes.

I miss having patience to sit down and talk to my husband without simultaneously thinking about what to do next and worrying about things that have already happened. (Participant 18)

Present moment and mindfulness strategies are methods used in many ways in participants’ daily efforts to get closer to their suffering and make changes with willingness to feel, think and sense what’s painful. Experiences of being in the present moment seem to go hand in hand with approaching what’s difficult in life with willingness.

Start everything I do in a relaxed state. Take a few deep breaths. Think this is what I’m doing right now. (Participant 23)

As defusion seems to be helpful to participants when making their values directive, a similar process seems to occur when some of them are about to make longstanding commitments for the future, by the end of treatment. There are descriptions where participants describe a shift in perspective where they view themselves and their situation in a light where connections between their collected experiences are present. Participants seem to find this perspective helpful when making long-term decisions post treatment, and not only aiming at concrete changes but also making decisions about their attitude towards what’s difficult in life.

I won’t bother myself and I don’t want to be bothered by people’s opinion of what to do or what not to do because something’s better than the other etc etc. I will do what I want, what’s good for me and it’s up to them to handle that, they can have their own opinion and if this doesn’t suit them I can be without them. I want to live my life as I want to and in the way that’s best for me (and my partner). (Participant 2)
I want to be able to see the beauty of it. (Participant 17)

**Summary of conclusions**
Most participants describe changes in how they relate to their body and pain. Using their body in new ways gives new experiences of living with pain and discomfort. Allowing pain to take place in their lives brings on a larger perspective on their situation as well as a confidence. The foundation to their motivation seems to decide how persistent they keep up with their relapse prevention work. Some participants also show a change in attitude towards the future and a shift in perspective on themselves. An optimistic view on the future facilitates making commitments in their lives. Allowing pain to take place in their lives and acting with willingness to recognize their experiences, leads not only to concrete changes in their lives, but also to a change of attitude towards what’s difficult in life. The following quote is from a participant describing what motivates her to keep to her change work.

To truly deep inside believe that I’ve really done something well when someone tells me so or realize that others might appreciate something even though I’m not content. To admit to myself that I’ve done something well and not merely look at the row of mistakes and errors I could have avoided to get a better result. To dare be sad in front of others without acting as a clown at the circus. (Participant 29)
Discussion

Discussion of result
This study is an attempt to develop an Internet-based relapse prevention program for people with chronic pain. In doing so, several questions need to be asked, relating to structure and content of treatment. Three research questions were in focus in this study; (1) how behavior change is initiated, (2) what motivates patients to continue with their change work over time and (3) what patients retrospectively view as essential for change.

One dilemma in designing treatment programs for chronic pain patients is where to put the emphasis on what they value in life or dream about. In many treatments, goal-setting is placed in the beginning, to draw a direction for treatment and to be able to tell when goals are met and treatment is done. When chronic pain patients are about to state their goals, dreams or values, quite often they end up either with a blank sheet, goals that spring from what they ought to do or goals striving to regain what they’ve lost. Clarifying goals and values by end of treatment might seem odd but may be successful in the long term if these values are stated in a willing and present state of mind. The result in this study suggest that values not only focusing on what participants wish to achieve but also how they want to live, motivates them to get through the difficult phases of change and seem to facilitate a shift in perspective towards their pain and its effect on life. This in term seems to help participants when they are to make decisions about their future.

With this in mind one possible hypothesis relating to the first research question might be that initiating behavior change needs to be proceeded by a willingness to see that a realistic result of treatment is not a life filled with things they long for, but rather a life lived in a way that increases their chances to have what they long for.

Being able to motivate oneself during the course of treatment seems to help patients through relapses and facilitate making longstanding decisions. One reflection upon this is that relapse prevention programs for chronic pain patients might be structured so that it starts with the area where a patient is most motivated, even if this is not the most prioritized problem. This is in line with Skinner, Wilson and Turk’s suggestion (2012) that patient characteristics in terms of behaviors, feelings and beliefs need to be considered in pinpointing what to focus upon in relapse prevention. Acting with willingness in times of obstacles and relapses seems to ease the challenge of keeping to their new plan over time, for the present participants. Experiencing the effect of an acceptance attitude towards self and problems in life early in treatment, might encourage new attempts to take on obstacles rather than relapse when they occur. Present
moment is in some cases indicated to facilitate contact with such emotions that need to be met with willingness in order not to lead to a set-back. As described earlier, it has been claimed that patients’ vision of a satisfactory life with pain may highlight their readiness to change (Skinner, Wilson & Turk, 2012). Even this study suggests that the way participants state how they want their life to be, influences how persistent they keep to their change work. This study also suggests that patients’ view of their future may be affected by experiences of acting with willingness towards their pain during treatment. Also Olsson Halmeotoja, Malmquist, Carlbring & Andersson (2014) found that acceptance-oriented statements were associated with the use of relapse prevention strategies and possibly facilitating change. Cavanagh (2014) found that people can learn how to act with willingness with a minimum of therapist support, although he asks, as do others (Keogh, 2010; Skinner Wilson & Turk, 2012), on guidance on level of therapist support needed.

The present study differs somewhat from earlier Internet-based treatments for chronic pain when it comes to level of therapist support, partly since patients and therapist knew each other well before treatment and partly since therapist support during treatment was reduces to a minimum except for during the first two worksheets. Wheatar level of therapist support is a motivating factor for some might be investigated by giving therapist support either based upon participants’ request or based upon level of expressed motivation and engagement in participants’ work during treatment. Perhaps this could be one of such strategies that Wilson, Hilary & Turk (2012) asked for, in order to effectively and efficiently deal with relapse problems. Donkin and Glozier (2012) found that enhancing personal engagement and increasing ongoing motivation factors are processes that enhance persistence to an Internet-based treatment. The present study suggests the same although it is yet to explore how they affect outcome.

The second research question concerns how to motivate patients to continue change work over time. The effect of therapeutic support in this matter is yet to discover, although this study suggests that patients keep working even with a minimum of therapist support. If further support would have helped engage those who dropped-out is unknown. Results indicate two other aspects that might answer this research question. Long-term goals and values focusing on how patients want to live seem to ease the difficult phases of change and facilitate perspective shifts. Also, experiences of willingness early in treatment seem to encourage participants to handle obstacles in new ways. Possibly, these are two factors relevant to maintaining change work over time.

To simplify this treatment it was mainly built upon three treatment components; values, willingness and committed actions. Surprisingly, participants found use
of other treatment components they’d previously encountered; defusion and mindfulness/present moment. Defusion seems to be important when using values in a new attempt to reach change in life, rather than stating goals based upon what they lack in life. Present moment or mindfulness seems likewise go hand in hand with the ability to act with willingness towards emotions, setbacks and disappointments that always follow change work in treatment.

Chronic pain patients are a heterogenic group with diverse types of pain symptoms and diverse secondary social and psychological effects by pain. Hence it is valuable to enrich our understanding of what elements are important in their change work. Since social and psychological secondary problems contribute largely to their suffering it is as well essential to be aware of how pain is affecting their lives and the struggles they meet when applying skills learned in rehabilitation in their everyday life. When reflecting upon the result one remark that can be made is that the shift that occurs in participants’ writing during their work is a shift in attitude away from what can’t be changed or is difficult, demanding or unpredictable in terms of change. Taking a broad step away from the obstacles they’ve previously battled to diminish seems to bring them to a place where it’s easier to refocus on how they want to take on pain in life rather than how to get rid of it.

An answer on the third research question has not been found. One idea to why that is, is found in the quote from Skinner, Wilson and Turk (2002) on page 1, where they state that this is a long-term lifestyle-change. In that perspective there is not one singular change process that is done and can be viewed retrospectively. Rather behavior change when having chronic pain is a circular continuous process. What is essential for their life-style changes might rather be staying focused on their life-style.

**Discussion of method**

In this study a qualitative approach was chosen in an attempt to contribute with insights, new ideas or emerging concepts that may help to explain or broaden our understanding of what’s important for chronic pain patients in their struggle to maintain gains after a PMP. Such factors as initiating change, motivation over time, and the effect of key experiences were considered important by researcher beforehand and hence included in the initial broad questions when coding and categorizing the material. Focusing on content in text written beforehand has the advantage of capturing participants’ spontaneous reflections of their own actions. Hopefully such a material might conceive descriptions of change processes that a self-report measure wouldn’t show. Collecting data via interviews where participants are asked to describe their work retrospectively would generate a greater understanding of what participants remember and
possibly have generalized from treatment. It would however not give the rich material of patients’ day to day experiences of being in treatment.

This is a pilot study on the development of an Internet-based relapse prevention program, and as a consequence of the explorative design, it was open for all interested eligible patients. Almost all material available were included in the analyses, since every completed patient’s description were of interest. To enhance reliability, transparency has been sought through presenting quotes to illustrate the results. In terms of validity, certain aspects need to be highlighted. The qualitative analysis has been performed by the author alone and has been presented for colleagues throughout the process. Working side-be-side with another researcher would probably have led to further ideas raised and a higher validity. The author must also be viewed as biased in perception, due to prior involvement in design of treatment as well as psychology classes during the regular PMP. Knowing patients by person before treatment start is not the common way in Internet-based treatments.

When it comes to theoretical framework, the result has a strong influence of Acceptance Commitment Therapy (ACT) (Hayes, 2014). This is to a large extent due to the theoretical background of the author, but also an effect of trying to stay true to participants’ words in the content analysis. Participants’ writing is strongly influenced by an acceptance-oriented vocabulary since the worksheets they fill in are designed based on ACT. There are also influences from Motivational Interviewing (MI) (Miller & Rollnick, 2012) wherefore the Stages of change theory is applicable as well. Weather the writing itself has a therapeutic effect is yet another theoretical perspective. Analyzing the material with the Stages of change theory in mind might have generated more specific information about personal considerations and reflections relating to motivation to change and staying on track. However, viewing result from an ACT-perspective have the advantage of highlighting what behaviors participants write of and show in their writing. From a clinical point of view this is important information when trying to help participants broaden their repertoire of behaviors when acting in the presence of pain.

Concerning representativeness, two issues need to be raised since they are sometimes questioned concerning IT-based treatments. One is, whether patients at the chosen clinic are representative for chronic pain patients in general. The other question concerns drop-outs, and whether patients who did complete the internet-delivered intervention are representative for the group as a whole. Included patients had been referred to a specialist clinic which might indicate that they differ from the larger group of pain patients in primary care. Looking at their mean time of pain duration spanning from 1 to 21 years, (mean 6 years) it’s however not unlikely they resemble a primary care-population. Another
issue that indicates representativeness is the number of participants with a college education, 17 %, which is lower than normally in studies of internet based interventions where participants have been recruited via media. This indicates in part that participants are a clinical sample.

Some ethical considerations have been made during the study. Personal information has been changed in quotes, in order not to reveal private details. A consulting team consisting of a psychologist, an occupational therapist, a physical therapist and a pain-specialist physician were available during the program and were used on three occasions. An open process of analysis was sought for when asking experienced colleagues for feedback during the content analysis, to avoid drifting. A detailed description of the analysis process aimed to enhance openness about assumptions and consideration made. When illustrating result with quotes there is always a risk that some participants feel exposed. Trying to avoid that, quotes have been sought to be framed with a respectful explanation, especially when they contain emotional expressions of personal matters.

Of the 61 participants who showed interest in the study, 37 chose to engage. Why the remaining 24 did not is unknown but relevant to ask. It is reasonable to believe that everyone going through a PMP isn’t in need of a relapse prevention program. However, given the estimated number of patients relapsing, 30-60 % (Turk & Rudy, 1991) it is possible that those who chose not to engage need some other kind of intervention, an intervention at another time or guidance in how to engage. Since this exploratory pilot study indicates that internet delivered relapse prevention might be successfully given to pain patients, a next step would be to investigate what could be done to adjust the intervention to suit those who chose not to participate and also those who didn’t follow through the program to its end. The latter group might be found at an early state by looking at how they state their goals in beginning of treatment. To learn more of what generates sustained changes in pain patients relapse prevention work, interviews would be of great value, especially if done during treatment as well as after. However, analyzing participants’ written text is a proportionately easy way to use existing data to generate ideas of patterns in their change work. Being a pilot study on the development of a novel treatment form this attempt hopefully leads to more detailed studies on how the internet could be helpful in treating chronic pain patients.
References


Available from: http://www.phmed.umu.se/english/units/epidemiology/research/open-code/ [Accessed 15/03/06].


