

How do chronic pain patients assess the on  
Acceptance and Commitment Therapy  
based online intervention “Living with  
pain”?

**MASTERTHESIS**

Nora van Maklenburg s0210986

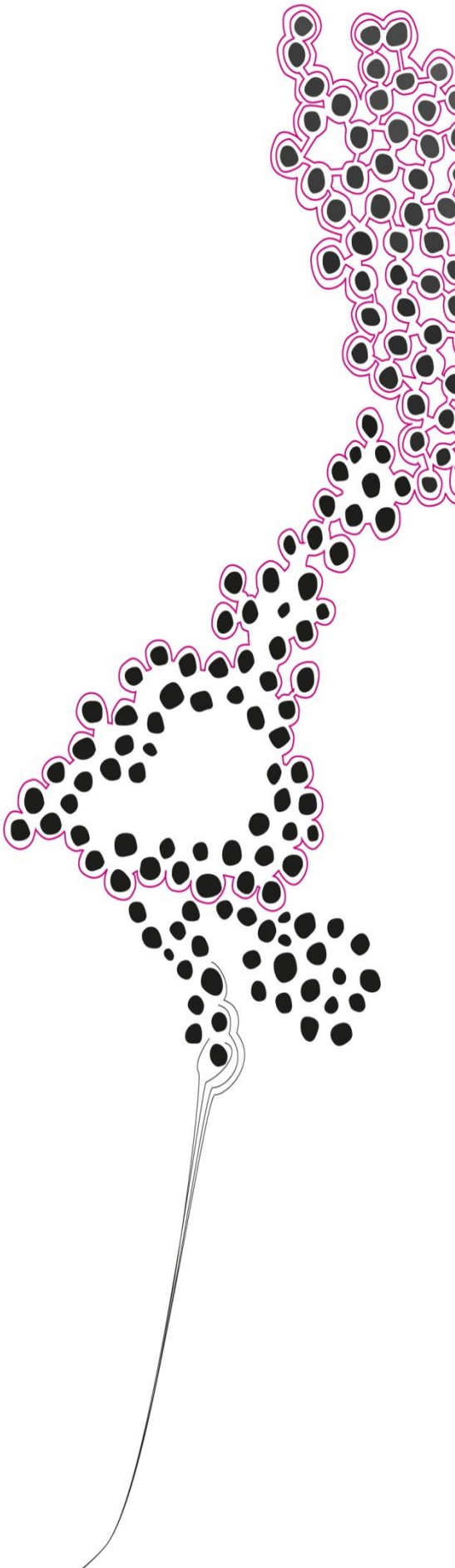
Supervisors:

1<sup>st</sup> Dr. Hester Trompetter

2<sup>st</sup> Prof. Dr. Karlein Schreurs

*Department:*

PPT- GW



## **Table of Contents**

|  |    |
|--|----|
| <b>Abstract</b>                                      | 2  |
| <b>Introduction</b>                                  |    |
| Chronic pain   | 3  |
| Acceptance and Commitment Therapy                    | 4  |
| Web-based treatments                                 | 6  |
| Development and usability of web-based interventions | 8  |
| <b>Method</b>  |    |
| Procedure and Participants                           | 10 |
| Intervention “ <i>Living with pain</i> ”             | 12 |
| Measuring instruments and analyses                   | 15 |
| <b>Results</b>                                       |    |
| Mindfulness exercises                                | 18 |
| Exercises  | 20 |
| Feedback/ Counseling                                 | 21 |
| Text   | 22 |
| Experiences of others                                | 23 |
| Videos, Metaphors, Diary                             | 24 |
| Acceptance   | 25 |
| Software   | 26 |
| Course in general                                    | 27 |
| Participants satisfaction                            | 28 |
| <b>Discussion</b>                                    |    |
| Recommendations and implications                     | 29 |
| Limitations  | 34 |
| Implications and future research                     | 35 |
| <b>References</b>                                    | 36 |
| <b>Appendix A</b>                                    | 40 |
| <b>Appendix B</b>                                    | 42 |

## Abstract

**Background:** Acceptance- and commitment-based psychological interventions are a promising alternative for the treatment of chronic pain and indicate significant clinical improvement. Adherence plays a major role in the effectiveness of these interventions. To increase adherence, it is important to increase an intervention's suitability for users, so they are motivated to use it.

**Objective:** This study aimed at evaluating the experiences and satisfaction of chronic pain patients using an on Acceptance and Commitment Therapy (ACT) web- based intervention. The experiences and satisfaction formed the grounds to improve the functionality and quality of the intervention and implement ACT in web- based interventions.

**Methods:** In the main study 238 persons with chronic pain were randomly assigned to one of the three conditions: the experimental group ( $n= 82$ ), a minimal intervention group ( $n= 79$ ) and a waiting list control group ( $n= 77$ ). This study focuses on the data of the participants of the experimental group that received the web- based intervention. Out of these 82 participants, 57 participants filled in the questionnaire about their experience with the online intervention properly. The qualitative and supporting quantitative data were analyzed.

**Results:** In general the intervention was rated positive. Mainly the mindfulness- exercises, the experienced acceptance through the intervention and the exercises in general were highly valued. Conversely the feedback received in the intervention and the software were rated less favorably and received the most suggestions of improvement.

**Conclusions:** The intervention is a promising treatment modality and is rated well. To increase adherence, more persuasive systems should be used and the way of giving feedback should be improved.

**Achtergrond:** Psychologische interventies als Acceptance Commitment Therapy zijn een veelbelovend alternatief voor de behandeling van chronische pijn en laten significante klinische verbetering zien. Adherentie speelt een belangrijke rol voor de effectiviteit van een interventie. Om adherentie te verhogen, is het belangrijk om de geschiktheid van een interventie te verhogen voor de gebruikers, zodat ze gemotiveerd zijn deze te gebruiken.

**Doelstelling:** Deze studie is gericht op de evaluatie van gebruikerservaringen van patiënten met chronische pijn die de op Acceptance and Commitment Therapy gebaseerde interventie hebben gebruikt. De doelen zijn de verbetering van de functionaliteit en de kwaliteit van de interventie en de implementatie van ACT in web-gebaseerde interventies.

**Methode:** In het hoofdonderzoek worden 238 personen met chronische pijn random verdeeld aan een van de drie condities: de experimentele groep ( $n = 82$ ), een minimale interventie groep ( $n = 79$ ) en een wachtlijst controlegroep ( $n = 77$ ). Deze studie richt zich op de gegevens van de deelnemers van de experimentele groep die de web-gebaseerde interventie hebben ontvangen. Van de 82 deelnemers hebben 57 deelnemers de vragenlijst ingevuld over hun ervaring met de online interventie. De kwalitatieve en ondersteunende kwantitatieve gegevens werden geanalyseerd.

**Resultaten:** In het algemeen is de interventie positief beoordeeld. Voornamelijk de mindfulness- oefeningen, de ervaren acceptatie door de interventie en de oefeningen in het algemeen werden zeer gewaardeerd. Omgekeerd worden het feedback en de software minder gunstig beoordeeld en kregen de meeste suggesties voor verbetering.

**Conclusies:** De interventie is veelbelovend en wordt in het algemeen goed beoordeeld. Om therapietrouw te verhogen, moeten persuasieve systemen worden gebruikt en de manier van feedback moet worden verbeterd.

Chronic pain is a substantial public health issue. It can affect different life domains, has a high comorbidity with mental disorders and gives rise to high economic, social, and medical costs. Appropriate treatment for all chronic pain patients is difficult and alternative, effective ways on enhancing positive physical and emotional functioning need to be explored. Therefore, this study aims at evaluating the experiences of chronic pain patients using the internet- based and guided self-help intervention “Living with pain” which is based on Acceptance and Commitment Therapy (ACT). The intervention showed improvements on different physical and emotional aspects, which will be presented later in this paper (Trompetter, Bohlmeijer, Veehof & Schreurs, 2014). By analysing qualitative and supporting quantitative data, users’ experiences and evaluations are taken into account to adjust and improve the intervention. User- based usability adjustments can potentially influence users’ adherence which affects the effectiveness of an intervention. This can also help to implement ACT in web- based interventions and lead to a standardization of those, which could have impact on a reduction of social, economic and medical costs.

### **Chronic pain**

A person who suffers from pain for up-to three month or longer or when the recovery takes longer than expected, receives the diagnosis chronic pain (DSM-IV, 2000). The International Association for the Study of Pain (IASP) defines pain as “*an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage.*” This definition covers physical as well as psychological aspects of pain. In the Netherlands 18% of the population are affected by chronic pain which affects different life domains of the concerned person (Breivik, Collet, Ventafridda, Cohen & Gallacher, 2006). Chronic pain not only impairs physical quality of life, it also affects emotion and social life domains (Lamé, Peters, Vlaeyen, Kleef and Patijn, 2005). In the Netherlands, 41% of the chronic pain patients experience impairments in physical functioning, and more

than 20% in their mental health. Furthermore, chronic pain has a high comorbidity with depression, anxiety and other psychological problems (Miller and Cano, 2009; Katz, Pagé, Fashler, Rosenbloom, & Asmundson, 2014). In addition to chronic pain affecting different life domains and being a strain for affected individuals and family, it also negatively impacts the economy and society due to work absenteeism and healthcare expenditure (Breivik et al., 2006). In the Netherlands healthcare expenditure for pain amounts to around €289 million a year (IASP, 2010).

Treatment options for chronic pain include surgical, somatic, psychological, physiotherapeutic and pharmaceutical and alternative therapies. Most of these treatment options persist to be hardly effective (Turk, Wilson & Cahana, 2011). Even when traditional treatments were effective in reducing pain, impairments in emotional functioning remained (Martin, Deyo, Mirza, et al., 2008). Only modest effects were found for pain removal and pain control, despite grown knowledge about chronic pain during the last decades (Turk et al., 2011). A meta- analysis identified psychological treatments as modestly effective in improving coping with pain, as well as in increasing emotional functioning (Hoffman, Papas, Chatkoff & Kerns, 2007). Cognitive- behavioral therapy (CBT) is a common psychological treatment for chronic pain. CBT consists of behavioral and cognitive technics. Even though CBT works for some chronic pain patients, it is not effective for all patients (Vlaeyen & Morley, 2005). More research for alternative therapies of chronic pain is necessary. ACT is an alternative form of CBT which aims at accepting pain, rather than expending energy by treating and reducing symptoms of pain.

### **Acceptance and Commitment Therapy**

ACT aims to improve the daily functioning and effective pain management, rather to control or change pain symptoms (Hayes, Strosahl & Wilson, 2012). ACT is a third generation cognitive behavioral therapy based on the Relational Frame Theory (RFT) (Hayes, 2004). The

goal of ACT is to increase psychological flexibility, which is defined as “*the ability to be open, present-focused, and aware, and to change or persist in behavior when doing so serves ones values and goals*” (McCracken, Gutiérrez- Martínez & Smyth, 2012, p. 820).

Psychological flexibility is promoted by the six core processes of ACT: *acceptance* (the awareness of aversive internal experiences and active embracement of those), *cognitive defusion* (the power to create a context to let undesirable functions of thoughts change or disappear), *contact with the present moment* (the awareness of occurring internal and external experiences without controlling them), *self as context* (the experience of a person to be more than the own feelings, thoughts or the experiences which occur), *values* (the discovery of the own important beliefs and options of life) and *committed action* (the creation of goals according to values) (Hayes et al., 2012). To create more flexibility, mindfulness techniques are used. Kabat- Zinn (1990) described mindfulness as a process of bringing a certain quality of attention to moment-by-moment experience and “*paying attention in a particular way: on purpose, in the present moment, and nonjudgmental*” (Kabat-Zinn, 1994, p.4).

Evidence for positive outcomes of treatment with ACT is growing rapidly. A brief course of an acceptance based treatment can have positive long lasting impact on chronic pain patients, even among those with an extensive history of pain (Wetherell, Afari, Rutledge, Sorrel, Stoddard, Petkus & Hampton Atkinson, 2011). According to a systematic review and meta-analysis of acceptance-based interventions for the treatment of chronic pain, medium effect sizes were found for the effects of ACT compared to a control condition in improving depression, pain intensity, physical well-being, anxiety and quality of life (Veehof, Oskam, Schreurs & Bohmeijer, 2011). The findings of this study suggest that ACT is not superior to CBT but can be used as an alternative for treating chronic pain. Another randomized controlled trial found significant differences in pain-related functioning, mental health-related quality of life, self-efficacy, depression, anxiety and psychological flexibility (Wicksell,

Kemani, Jensen, Kosek, Kadetoff, Sorjonen, Ingvar & Olsson, 2013). Furthermore, this study found changes in psychological flexibility not only during the treatment, but also at follow up. Previously most treatments and therapies were delivered face-to- face, however web- based treatment is a fast growing method in healthcare.

### **Web- based treatments**

Web- based treatments belong to eHealth, which is defined as “... *the use, in health sector, of digital data- transmitted, stored and retrieved electronically- in support of healthcare, both at the local site at a distance*” (WHO, 2013). E (mental) Health could develop to be an important factor in our society, not only for the reason that the technology is vastly available, but most of all because of the growing proportion of older people in society. The number of older people will explode in contrast to neonatal, which will lead to a pressure on the market for health care providers (Van Gemert-Pijnen et al., 2013). EHealth can have a positive influence on the individual, on society and maybe cost- effectiveness. Barriers for the implementation of eHealth are e.g. a lack of financial incentives, a lack of standardization and a lack of motivation and ability by users to use technology (Nijland, 2011; Van Gemert-Pijnen et al., 2012). A web- based intervention is a primarily self- guided intervention program, with the aim to provoke changes in health and to enhance awareness and knowledge of the issue (Barak, Klein & Priudfoot, 2009). Web- based self- help interventions were developed in recent years for the treatment of among others chronic pain, with the aim to increase time- and cost- effectiveness of psychological interventions (Bender, Radhakrishnan, Diorio, Englesakis & Jadad, 2011). Additional advantages are among others the availability for a greater number of patients, patients are able to work independently and the reduction of the therapist’s waiting list (Cuijpers, Straten & Andersson, 2008).

According to different systematic reviews and randomized controlled trials web- based CBT self- help interventions show promising results in the improvement of living with pain,

lowering activity limitation and reduction of pain (Bender et al., 2011; Macea, Gajos, Daglia Calil, & Fregni, 2010). Despite the positive effects of internet- based psychological interventions based on CBT, more research is needed to evaluate the effectiveness of an internet- based psychological intervention based on ACT for chronic pain (Trompetter et al., 2014).

A randomized controlled trial of a guided internet-delivered ACT showed promising results in reductions of measures of pain-related distress, anxiety and depressive symptoms, also at a follow-up after six month (Buhrman, Skoglund, Husell, Bergstöm, Gordh et al., 2013). Another randomized controlled trial by Trompetter et al. (2014) evaluated an internet-delivered, guided self- help intervention based on ACT, “Living with pain”. Participants who followed the intervention showed improvements on pain interference, reductions in psychological distress, pain intensity, psychological inflexibility and pain catastrophizing. More detailed information concerning the intervention “*Living with pain*” is available in the method section of this paper. Research shows that evidence exists to support the effectiveness of web- based interventions like *Living with pain*. However, effectiveness can be undermined due to a lack of adherence to web- based interventions (Kelders, van Gemert-Pijnen, Werkman, Nijland, Seydel, 2011 & Christensen, Griffiths & Farrer, 2009).

Adherence is a major issue for efficacy of web based interventions, because the more adherent a person is, the better the outcomes. This correlation is the so called dose response relation (Donkin, Christensen, Naismith, Neal, Hickie & Glozier, 2011; Manwaring, Bryson, Goldschmidt, Winzelberg, Luce, Cuning et al., 2008). Kelders, Kok, Ossebaard & van Gemert-Pijnen (2012) introduced for the term adherence the concept of “intended usage”: “*the extent to which individuals should experience the content (of the intervention) to derive maximum benefit from the intervention, as defined or implied by the creators*”. In a systematic review Kelders et al. (2012) investigated whether intervention characteristics and persuasive



design affect adherence to a web-based intervention. Persuasive design comprises of primary task support, dialogue support, social support and credibility support (Oinas- Kukkonen & Harjumaa, 2009, see appendix B). Results show that increased interaction with a counselor, more frequent intended usage, more frequent updates and more extensive employment of dialogue support improved predicted adherence. Also telephone consultations may have positive impact on adherence (Buhrman, Fäلتenhaga, Ströma & Andersson, 2004). Main reasons for non-adherence are no time, the intervention is not working for the participant or the technology is not working well (Kelders et al., 2012). The condition to reach a high adherence, is a good usability and a sophisticated development of a web- based intervention.

**Usability and development of web- based interventions.** In human- computer interaction (HCI) usability is a core term. Usability is defined as “*the capability to be used by humans easily and effectively; quality in use and the effectiveness, efficacy, and satisfaction with which specified users can achieve goals in particular environments*” (Hornbaek, 2005). According to the study of Hornbaek (2005) challenges can occur in measures of usability. Among those challenges Hornbaek states that questionnaires about satisfaction are often administered to users after participating in an interface. The disadvantage of this usability measure is that the answers are hard to link to specific parts of the interaction or interface. Testing effectiveness, efficiency or satisfaction can help to explore usability of a system. It is important to evaluate participants’ experience with an online intervention, to provide a continued or improved quality. The quality of usability of a website is important to guarantee users’ usage. A high quality enhances satisfaction and usage, this improves and stabilizes learned techniques and thus can support people with chronic pain. A good usability can lead to more adherence which can influence the effectiveness of web- based interventions.

For the development of web-based applications there is no scientifically underpinned agreement on how to best develop web- based interventions (Kelders, Pots, Oskam,

Bohlmeijer, Van Gemert-Pijnen, 2013). One way to develop a web-based intervention is the CeHRes (Center for eHealth Research and Disease Management) roadmap for the development of eHealth technologies (see Appendix B). Principles of the roadmap are among others the participatory development process (including different target groups), intertwinement with implementation (development of an intervention involves implementation) and continuous intervention cycle (constant measuring of process and impact) (van Gemert-Pijnen, Peters, Ossebaard, 2013).

In sum, development and usability of web- based interventions is of high importance and a long evaluative cycle. This study focuses on the two last steps of the CeHRes roadmap, namely the formative evaluation between the operationalization and overall evaluation of the intervention “Living with pain”. This study makes use of the qualitative and supporting quantitative data of the three- armed randomized controlled trial concerning the experiences of the experimental group, with the aim to find out how participants experienced the web-based intervention. The development of a program like *Living with pain* remains to be an iterative process. This means, by testing, analyzing and evaluating the process changes and refinements are made with the goal to (1) improve the functionality and quality of the web-based intervention (2) implement ACT in web- based interventions and (3) come closer to a standardization of web- based interventions. The research question of this paper is: How do chronic pain patients assess the on Acceptance Commitment Therapy based online intervention “Living with pain”? The supporting sub questions of this research are:

- Which parts of the online intervention were valued positive by the participants?
- Which parts of the online intervention were valued less by participants?
- What are the suggestions of participants?
- Which improvements could increase the usability and adherence of the intervention?

## Method

### Procedure and participants

This study examined the data of the randomized controlled trial main study of the intervention “Living with pain” (Trompetter et al., 2014). In the main study 238 persons with chronic pain were randomly assigned to one of the three conditions: the experimental group ( $n = 82$ ) receiving the web- based intervention “Living with pain”, based on ACT. A minimal intervention group ( $n = 79$ ) receiving a web- based intervention based on expressive writing (Pennebaker, 1997) and a waiting list control group ( $n = 77$ ). In the main study of the intervention “Living with pain” participants with chronic pain were recruited through advertisements in Dutch newspapers and online patient platforms. Chronic pain patients could register for the study on the website [www.haalmeeeruitjelevenmetpijn.nl](http://www.haalmeeeruitjelevenmetpijn.nl) (for detailed information see Trompetter et al., 2014).

This study focused on participants’ data of the experimental group of the intervention period, which contained  $N = 82$  people with chronic pain. Out of these 82 (100%) participants,  $n = 57$  (69.5%) participants filled in the questionnaire properly about their experience with the online intervention afterwards.

The average age of the original experimental group ( $N = 82$ ) was 53.00 years ( $SD = 13.31$ ) with 63 (76.8%) women and 19 (23.2%) men participating. Sixteen participants (19.5%) were low educated, 29 participants (35.4%) were middle educated and 37 participants (45.1%) high educated. Forty-nine (60%) of the participants suffered from pain longer than five years. Twelve (14.6%) participants received no diagnosis, also 12 (14.6%) participants received the diagnosis fibromyalgia and 41 (50 %) participants received other diagnosis.

In the group of the participants who filled in the questionnaires properly ( $n = 57$ ) the average age was  $M = 54.42$  years ( $SD = 12.28$ ) with 45 (78.9%) women and 12 (21.1%) men participating. The participants in this group were higher educated, with 27 (47.4%) high

educated participants, 21 (36.8%) participants middle educated and nine (15.8%) participants low educated.

Out of all participants of the experimental group ( $n= 82$ ), 59 (72%) participants finished all nine modules of the intervention and 39 participants (47.6%) were adherent (completing intervention and working with it >3 hours per week). From participants who filled in the qualitative questionnaires ( $n= 57$ ), 53 (93%) participants finished all nine modules of the intervention and 35 participants (61.4%) were adherent (see Table 1).

**Table 1.** Characteristics of participants

| <b>Characteristics of participants (%)</b> | <b>ACT<br/>(<math>n= 82</math>)</b> | <b>ACT<br/>(<math>n= 57</math>)</b> |
|--|-------------------------------------|-------------------------------------|
| <b>Gender</b>                              |                                     |                                     |
| Female                                     | 76.8                                | 78.9                                |
| Male                                       | 23.2                                | 21.1                                |
| <b>Age (M/SD)</b>                          | 53.00/13.31                         | 54.42/12.28                         |
| <b>Education</b>                           |                                     |                                     |
| High                                       | 45.1                                | 47.4                                |
| Middle                                     | 35.4                                | 36.8                                |
| Low  | 19.5                                | 15.8                                |
| <b>Duration of complaints (in years)</b>   |                                     |                                     |
| 0.0-0.5                                    | 0.0                                 | 0.0                                 |
| 0.5-1                                      | 8.5                                 | 5.3                                 |
| 1-2  | 14.6                                | 15.8                                |
| 2-5  | 18.3                                | 19.3                                |
| >5   | 58.5                                | 59.6                                |
| <b>Diagnosis</b>                           |                                     |                                     |
| No diagnosis                               | 14.6                                | 12.3                                |
| Lower back pain                            | 3.7                                 | 3.5                                 |
| Whiplash                                   | 2.4                                 | 3.5                                 |
| Fibromyalgia                               | 14.6                                | 12.3                                |
| Joint pain                                 | 8.5                                 | 12.3                                |
| CVS  | 4.9                                 | 5.3                                 |
| Back pain (...)                            | 1.2                                 | 1.8                                 |
| Other diagnosis                            | 50.0                                | 49.1                                |
| <b>Course</b>                              |                                     |                                     |
| Adherent                                   | 47.6                                | 61.4                                |
| Non- adherent                              | 52.4                                | 38.6                                |
| Completers                                 | 72.0                                | 93.0                                |

ACT ( $n= 82$ ), all participants of the ACT- based intervention; ACT ( $n= 57$ ), participants of the ACT- based intervention who filled in the qualitative questionnaire and are assimilated in analysis.

## **Intervention “Living with pain”**

The web- based intervention “Living with pain” is based on the self- help book by Veehof, Hulsbergen, Bohlmeijer & Schreurs (2010) and the online self- help intervention “Living to the full” (Bohlmeijer & Hulsbergen, 2008). The online intervention uses the six core processes of ACT which are defined in the introduction. The intervention *Living with pain* is almost a “typical” web- based intervention, as it is meant to be used and updated once a week, includes interaction with the system and a counselor, uses some aspects of persuasive technology, and about 50% of the participants are adherent (Kelders et al., 2012). The content of the modules consisted of information/text, exercises, mindfulness exercises, diaries, metaphors, frequently ask questions, videos and experiences of others (see Appendix B). The participants could work through the nine modules in nine to twelve weeks, the time investment was higher than three hours per week. After finishing a module, the participants got feedback every week by a student counsellor (Trompetter et al., 2014).

The first module (*Week 1 Pain and therapy*) contained psycho- education for chronic pain and participants were acquainted with mindfulness. In the second module (*Week 2 Keeping out of the pains way*) participants learned about aversive effects of experiential avoidance. During the module the participants were shown how to accept negative events. The third module (*Week 3 Pain and still happy*) contained the process of ACT “values and actions”. Participants were prepared to be open focusing their personal values. Through exercises participants got insight of their own values. Furthermore, they learned how to apply these values in life. The fourth module (*Week 4 Flourishing of the rose*) contained similar to the third module the process of ACT “values and actions” and can be seen as a continuation of week 3. The fifth module (*Week 5 Stopping resistance*) contained the process of “acceptance”. In this module participants learned about possibilities how to accept pain complaints. The context of the sixth (*Week 6 “Yes, but I have pain”*) and seventh module (*Week 7 “I am...who*

am I?) contained the processes of “cognitive defusion” and “self as context”. Participants learned to recognize problematic and unhelpful thoughts about pain. The eighth module (*Week 8 I don't have pain alone*) focused on the social aspects of chronic pain and included the social environment in the intervention. In the last module (*Week 9 Living with pain, a new story*) the participants could formulate new values and goals, learned about how to recognize and cope with possible relapse.

**Information/ text.** All modules contained detailed information of the respective content of the week. Information was given in the beginning of each module, as well as during the module.

**Exercises.** Exercises were part of every module. Exercises ranged from making lists (e.g. writing down values or favorite ways of avoidance) to writing down problematic thoughts or feelings (e.g. writing down thoughts about pain and speaking them out loud with the sentence “I have the thought that”. Afterwards participants should write down what happens then).

**Mindfulness exercises.** Eight modules contained mindfulness exercises for example body scan or breathe to your pain. Participants were introduced to this method by text and participants could download mp3-files with mindfulness exercises, which contained 10-15 minute exercises.

**Diary.** Participants had opportunity to keep a personal diary. For example, in one module participants were asked to keep a diary for a few days about personally distressing moments, for clarification examples were available.

**Metaphor.** Metaphors were given in seven modules. A metaphor compares two unlike things, so a subject can be understood easily for example “*Je zou het observerende zelf kunnen vergelijken met de hemel. De wolken (je lichamelijke sensaties, gedachten en gevoelens) veranderen continu. Soms is er regen of onweer. En soms is het stralend blauw. 's*

*Nachts verschijnt de maan en verandert de stand van de sterren. Maar de hemel blijft altijd hetzelfde, zichzelf. Laat deze metafoor eens op je inwerken. Wat ervaar je dan?"* Metaphors were available in (interactive) text and videos.

**Frequently ask questions (FAQ).** Answers of FAQ's were given in two modules of the intervention. In week three FAQ's related to mindfulness were given (e.g. how to cope with problems during mindfulness exercises). Answers about FAQ's concerning cognitive defusion and thoughts were given in week six.

**Videos.** Six videos were available in module two, three, five and seven. Depending on the module, they contained information (e.g. cognitive defusion or mindfulness). Instructors were researchers and therapists of the University of Twente with specialization in ACT and chronic pain.

**Experiences of others.** During the intervention the participants had the option to read experiences of previous ACT- participants every week. Previous ACT- participants who participated in the intervention answered following questions: What meant the course to you? What did you like about the course? What were challenging or difficult moments during the course? What advises you can give to people who are following the course?

**Counselling/ feedback.** The counselling was provided once a week to support the participants. The counsellors were five recently graduated psychology students. They were supervised and were trained by a registered cognitive behavioral therapist with ample experience in working with ACT and Expressive Writing (Trompetter et al., 2014). Among others the counsellors were trained in writing emails as counsellor and received information about chronic pain. The participants were randomly allocated to the counsellors. Each counsellor supported approximately 30 participants via e-mail. The participants were asked to send a weekly message with the experienced progress they made, after they completed a

module. Participants could also ask questions about the exercises and texts (Trompetter et al., 2014).

### **Measuring instruments and analyses**

All qualitative analyses were performed using ATLAS.ti, all quantitative data was analyzed using SPSS 22 (IBM SPSS Statistics). The data of the main research was available as SPSS- document. The master file covered all qualitative and quantitative data which were collected during the main research (Trompetter et al., 2014). The questionnaire about the three most valued parts, three least valued parts and suggestions for improvement of the intervention was filled in by 59 of the 82 participants of the experimental group. Two were not valid and were neglected in analyses. With the drop-out of 25 participants, 57 are remaining for major analysis.

**Qualitative evaluation.** The questionnaire about the experiences of the online intervention was administered online (Appendix A). Evaluation was available after the participants finished the online intervention “Living with pain”. The participants could write down the three most valued parts, the three least valued parts and suggestions to improve the online intervention.

#### **Steps in qualitative analyses**

- First the data was coded by open coding and the open codes were patterned in categories. Second selective coding was used on the basis of developed categories.
- The coding was firstly performed by one rater. To increase the reliability, a second rater was involved. The second rater controlled the open codes and categories. Discords were discussed and levelled.
- Answers like “xxx” or “no” or statements in a wrong section (e.g. something positive in least valued) were negated.



- Participants had the option to rate three most valued and three least valued of the intervention (see Appendix A). No hierarchy was used, the three options of most valued was pooled in one, the same was done with the three points of least valued.
- Only statements that were mentioned > two times were assimilated in results.

**Completion, adherence and treatment satisfaction.** In this paper particular quantitative questionnaires were selected from the main research to support qualitative data. The main research covered more quantitative questionnaires, which were administered online (Trompetter et al., 2014). Selected questionnaires for this study covered questions about:

- Satisfaction (CSQ-8): The Dutch version of the Client Questionnaire (CSQ-8) was used to evaluate the overall satisfaction with the services of the intervention after the participants ( $n=57$ ) completed the intervention (Attkinson & Zwick, 1982). The scores ranged from 8-32 with higher scores indicating more satisfaction, internal consistency was excellent ( $\alpha = .93$ ).
- Assistance: To evaluate the satisfaction with the assistance through feedback, participants ( $n=57$ ) could answer on different aspects of assistance. The three different aspects were pooled in one, internal consistency was excellent ( $\alpha = .93$ ).
- Adherence: The adherence was measured in both groups (ACT  $n= 81$  and ACT  $n= 57$ ) by self- assessed average hours spent on the intervention over four and eight weeks from baseline. Adherence was defined as (1) working with the intervention > three hours per week and (2) completing the intervention (six to nine modules) (Trompetter et al., 2014).
- Completers: The completion (participants who completed six to nine modules) was analyzed in both groups (ACT  $n= 81$  and ACT  $n= 57$ ).
- Grade of course: participants ( $n=57$ ) could rate the intervention on a scale from 1 (very poor) to 10 (very good).

## Results

In total 99 codes were established based on the qualitative data to analyze the experiences and suggestions of the 57 participants. These codes were aggregated into 11 categories that were distributed over two main aspects of the intervention: Module content (info/text, (mindfulness-) exercises, metaphors, videos, experiences of others, feedback/counseling, diary)) and other frequently upcoming statements (acceptance, software and course in general). In total 117 statements were made by 55 participants about most valued parts of the intervention, 55 statements by 43 participants about least valued parts and 35 suggestions were made out of the 57 participants (see table 2).

**Table 2.** General overview

| <b>Upcoming contents<br/>of modules</b> | <b>Most valued<br/>Number of<br/>statements</b> | <b>Least valued<br/>Number of<br/>statements</b> | <b>Suggestions</b> | <b>Total</b> |
|---|---|--|--------------------|--------------|
| Mindfulness exercises                   | 35  | 9  | -                  | 44           |
| Exercises                               | 21  | 10   | -                  | 31           |
| Feedback/Counselling                    | 6   | 17   | 15                 | 38           |
| Text                                    | 5   | 1  | 6                  | 12           |
| Experiences of others                   | 5   | 1  | -                  | 6            |
| Videos                                  | 2   | 2  | -                  | 4            |
| Metaphor                                | 1   | 3  | -                  | 4            |
| Diary                                   | -   | 2  | -                  | 2            |
| <b>Other upcoming<br/>statements</b>    |   |  |                    |              |
| Acceptance                              | 39  | -  | -                  | 39           |
| Software                                | -   | 4  | 7                  | 11           |
| Course in general                       | 3   | 3  | 9                  | 15           |
| Total                                   | 117   | 55   | 35                 | 206          |

### **Mindfulness exercises**

In Table 3 the mentioned mindfulness- exercises are listed. Mostly rated positive, mindfulness- exercises were rated by 35 (61.4%) participants with 40 statements. Participants valued mindfulness exercises to cope with their pain in an alternative way (*“mindfulness om te leren op een andere manier met pijnklachten omgaan; mindfulness om erbij stil te staan”*). There were some difficulties to learn the alternative approach, but it was worth the effort for the participants (*“Mindfulness heel zwaar maar het helpt wel”*). Two respondents valued the

mindfulness exercises less for the reason of personal taste (*“mindfulness is mij te soft heb ik niets mee; de oefeningen vond ik wat minder heb van internet andere mindfulness oefeningen gehaald en ben daar mee aan de slag”*) and difficulties learning it on their own (*“en het mediteren heb ik moeite mee”*). The mindfulness exercises concerning breathing was named by ten participants and valued positive by eight participants. The relaxation participants experienced through the breathing exercise, especially in conjunction with the body scan was valued (*“de ademhalings oefeningen vind ik ook prettig. Als ik moe ben, dan ga ik mijn hele lichaam langs heerlijk met de ogen dicht. Nog even rusten en ben weer opgeknapt”*). Two participants valued these exercise less, when it was asked just to focus on breathing and had difficulties to perform it (*“de ademhalingsoefeningen met alleen maar je aandacht richten vond ik minder prettig; ik snap het principe voor mij voelde het alleen minder prettig”*). The specific mindfulness exercise “body scan” was valued positive by six respondents and less valued by three participants for the reason of inexperience with this sort of exercise (*Body analyse. Dat heb ik ook nooit gedaan”*).

**Table 3.** Ratings on mindfulness- exercises

| Mindfulness-<br>exercises | Most valued<br><br>Number of<br>statements | Least valued<br><br>Number of<br>statements | Suggestions<br><br>Number of<br>statements |
|---------------------------|--|---|--|
| Mindfulness               | 21   | 4   | -  |
| Breathing                 | 8  | 2   | -  |
| Body scan                 | 6  | 3   | -  |
| Total                     | 35   | 9   | -  |

## Exercises

Table 4 lists the mentioned exercises, which in general were rated 21 times positive for reasons of experienced space and confidence (*“Het meeste heb ik gehad aan de oefeningen; de oefeningen hebben mij ruimte gegeven”*). The exercise to communicate about pain in week 8 was rated ten times. Five times it was rated positive for the reason to communicate about the pain with family members or other close people. Five times it was less valued, because the exercise had no positive outcome or due to personal taste (*“Ik ben geen prater mijn echtgenoot ook niet; Deze les heb ik gedaan maar alleen. Het invullen samen met een ander was in mijn geval niet zo ’n succes”*). The exercise “working on condition” was brought up four times. One participant valued the enforcement of the condition as a positive motivator (*“De nadruk op conditie”*). Three times it was rated negatively, because the exercise was superfluous for the reason of already good endurance of participants (*“Ik zit bij een loopgroep en mijn conditie is redelijk goed”*).

The exercises “I have the thought that” was valued by two participants due to the fact of becoming aware that thoughts are not actually facts (*“Het beoefenen van de zin ik heb de gedachte dat ik pijn heb”*). The exercise “recognition of values” were also valued two times to get aware of own values (*“over waarden in het leven om die eens duidelijk op een rijtje te zetten”*). The exercises “carry your pain with you” and “the flower” were valued two times positive (*“Ik heb veel gehad aan de oefening met het briefje bij je dragen”*) and two times less (*“er moest een keer met kruisjes gewerkt worden en die vond ik heel lastig om in te vullen”*). Furthermore, it was stated by two participants, that they are using the (mindfulness-) exercises apart from the intervention, because it helps them in daily life (*“Oefeningen met name de scan/ ademhalingsoefening gebruik ik regelmatig”*).

**Table 4.** Ratings on exercises

| Exercises                              | Most valued<br>Number of<br>statements | Least valued<br>Number of<br>statements | Suggestions<br>Number of statements |
|--|--|---|-------------------------------------|
| Communication<br>about pain            | 5                                      | 5                                       | -                                   |
| Exercises                              | 7                                      | -                                       | -                                   |
| Condition                              | 1                                      | 3                                       | -                                   |
| Carry your pain<br>with you            | 1                                      | 1                                       | -                                   |
| Flower                                 | 1                                      | 1                                       | -                                   |
| I have the<br>thought that             | 2                                      | -                                       | -                                   |
| Recognize<br>values                    | 2                                      | -                                       | -                                   |
| Exercises used<br>apart from<br>course | 2                                      | -                                       | -                                   |
| <b>Total</b>                           | <b>21</b>                              | <b>10</b>                               | <b>-</b>                            |

### Feedback/ Counseling

The feedback was mentioned 38 times by 21 (36.8%) participants. As listed in Table 5 it is the category with most suggestions for improvement (15 times). Six participants valued the feedback as positive support during the intervention (*"de feedback van mijn begeleider was goed en duidelijk; Feedback, gaf me stof tot nadenken"*). Seventeen participants valued the feedback negative, because they experienced it as impersonal and superficial (*"Feedback was echt onder de maat; De feedback kon beter. Ik miste gerichte adviezen die echt op mij gericht waren"*). Suggestions for improvement were for example to change the way of feedback, by

making the feedback more personal, improve quality and more appropriate (“*persoonlijk contact uitbreiden bv per telefoon; Misschien 1 bijeenkomst plannen om te weten met welke persoon je contact hebt via de mail; iets meer inhoudelijke feedback*”). Two participants missed adequate feedback on the exercises (“*Begeleiding aangezien je geen feedback kreeg op de gemaakte opdrachten*”). Four participants would like to have more support (“*Iets meer stok achter de deur*”) and five suggested more interaction or help during the intervention. Quantitative analyses showed that participants in general were moderately satisfied with the assistance, but not overly enthusiastic (scale range from 1-5,  $M=3.53$ ,  $SD=.684$ ,  $n=57$ ).

**Table 5.** Ratings on feedback

| Feedback                                | Most valued<br>Number of<br>statements | Least valued<br>Number of<br>statements | Suggestions Number of<br>statements |
|---|--|---|-------------------------------------|
| Feedback                                | 4                                      | 4                                       | 1                                   |
| change way of<br>communicating feedback | -                                      | 4                                       | 8                                   |
| More personal                           | -                                      | 3                                       | 1                                   |
| No feedback on exercises                | -                                      | 2                                       | -                                   |
| Impulse to reflect                      | 2                                      | -                                       | -                                   |
| Support                                 | -                                      | 4                                       | 5                                   |
| Total                                   | 6                                      | 17                                      | 15                                  |

## Text

Eleven (8.7%) participants valued the text with six suggestions in total (see Table 6). Five participants valued the good explained theory positively for better understanding and reflection (“*stuk theorie waardoor ik kritisch ging nadenken*”), one participants rated the theory less, because of the quantity. Three participants suggest to concise the text so it is not

tedious reading repetitive sentences (*“Niet teveel herhalen in de teksten (teveel copy/paste). Kan wat bondiger; Betere tekststijl steviger korter directer”*). Three participants suggest to adjust the language closer to the target group and making it more suitable for beginners of the sector mindfulness (*“ik ben niet zo thuis in de taal die hierbij gebruikt wordt; misschien de vraagstelling in iets eenvoudiger NL stelling”*).

**Table 6.** Ratings on text

| Text                               | Most valued<br>Number of<br>statements | Least valued<br>Number of<br>statements | Suggestions |
|------------------------------------|--|---|-------------|
| Theory                             | 5                                      | 1                                       | -           |
| language closer to<br>target group | -                                      | -                                       | 3           |
| More cohesive                      | -                                      | -                                       | 3           |
| Total                              | 5                                      | 1                                       | 6           |

### Experiences of others

Six participants valued the experiences of others (see Table 7). Five valued these experiences as helpful, because they felt less alone with their situation (*“Het lezen van de ervaringen van andere mensen; Ervaring verhalen hielpen”*) one participant valued it less due to personal taste (*“de ervaringsverhalen waren soms te somber voor mij”*).



## Videos

The videos in the intervention were mentioned four times by four respondents. Two times it was valued positive because they experienced it as a supporting part of the intervention (*“De video's die vertoond werden gaven me een duidelijk beeld van de bedoeling van de cursus”*). Two respondents valued the movies less (*“filmpjes waren wel heel saai en voegden niet veel toe aan”*) (see Table 7).

## Metaphors

The metaphors were mentioned by four participants and valued positive one time for easier understanding of the subject (*“De metaforen in de lessen”*) and less valued three times because of difficult understanding (*“Sommige anekdotes begreep ik moeilijk”*) (see Table 7).

## Diary

Two statements were done about the diary (Table 7), both were not valued due to the reason of disuse (*“Dagboek heb ik niet gebruikt”*).

**Table 7.**

|                          | Most valued             | Least valued            | Suggestions |
|--------------------------|-------------------------|-------------------------|-------------|
|                          | Number of<br>statements | Number of<br>statements |             |
| Experiences of<br>others | 5                       | 1                       | -           |
| Videos                   | 2                       | 2                       | -           |
| Metaphors                | 1                       | 3                       | -           |
| Diary                    | -                       | 2                       | -           |
| Total                    | 8                       | 8                       | -           |

### **Acceptance, awareness and coping with pain**

The participants' experienced acceptance, awareness, coping with pain and relaxation through the intervention was rated very well, with in total 39 statements by 33 participants. As listed in Table 8, participants valued the experienced acceptance in general, because of the awareness of occurring internal and external experiences without controlling them and accepting their pain (*"Aanvaarden dat het is zoals het is"*), the acceptance of limitation caused by pain (*"Enige bevestiging dat accepteren van beperkingen belangrijk is"*) and the acceptance of pain by achieving their values (*"Gerichte doelen nastreven zonder aan pijn te denken"*). The awareness participants experienced were rated positive, because they gave more attention to other important things in life (*"Waarnemen van wat ik belangrijk vind in het leven; Meer zorg voor de dingen die ik doe"*) and recognizing their values (*"Over mezelf nadenken wat ik nog zou willen"*). Nine participants valued positively how they learned how to cope with their pain (*"Op een andere manier met pijnklachten omgaan"*). Furthermore, the experienced relaxation was valued positively by five participants (*"door vooral me beter te ontspannen een prettiger leven op te bouwen"*).

**Table 8.** Ratings on acceptance, awareness and coping

|                             | Most valued<br>Number of<br>statements | Least valued<br>Number of<br>statements | Suggestions |
|-----------------------------|--|---|-------------|
| Acceptance                  | 4                                      | -                                       | -           |
| Acceptance of<br>limitation | 2                                      | -                                       | -           |
| Acceptance of<br>pain       | 10                                     | -                                       | -           |
| Awareness                   | 12                                     | -                                       | -           |
| Coping with<br>pain         | 9                                      | -                                       | -           |
| Relaxation                  | 5                                      | -                                       | -           |
| Total                       | 39                                     | -                                       | -           |

### Software

Software were mentioned eleven times by seven (12.3%) participants as listed in Table 9.

Main suggestions were to improve the software (*“Verbeteringen van ICT nu teveel (systeem?) fouten waardoor je bepaalde oefeningen niet kon doen of in het ingevulde niet werd opgeslagen; Ik ben voortijdig gestopt omdat de techniek niet goed werkte oefeningen bleven niet ingevuld en dit was zeer frustrerend hopelijk is dit inmiddels in orde”*). Software was less valued by three respondents (*“Teveel software tekortkomingen”*). Following the course on the iPad did not work by two participants and capability was suggested (*“Cursus geschikt maken voor gebruik op I - pad : niet alle functionaliteiten werken erop”*). Two participants had problems to save a file (*“Kon vaak niets opslaan laptop loopt iedere keer bij opstarten van dit programma vast!”*).

**Table 9.** Ratings on software

| Software        | Most valued<br>Number of<br>statements | Least valued<br>Number of<br>statements | Suggestions |
|-----------------|--|---|-------------|
| Improve         | -                                      | -                                       | 4           |
| shortcomings    | -                                      | 2                                       | 1           |
| Capability iPad | -                                      | 1                                       | 1           |
| File not saved  | -                                      | 1                                       | 1           |
| Total           | -                                      | 4                                       | 7           |

### Course in general

Statements about the course in general were done by 15 participants (Table 10). Eight participants would like to have more time for the course, because time- management was difficult sometimes (*“ik zou als suggestie voor de toekomst bieden om er wat meer tijd voor te nemen. Ik merkte zelf dat met een drukke baan en sociaal leven het moeilijk was om soms maar een week te hebben voor de cursus en de oefeningen... zelf zou ik twee weken per onderdeel prettiger hebben gevonden zeker meer naar het einde toe”*). Three participants valued the course in general positively, because they had the feeling that the intervention gave them more quality in live (*“cursus erg goed geholpen”*). Two participants suggested an option to download the intervention to look it up sometimes (*“Ik vindt het jammer dat de cursus na afloop niet in zijn geheel te downloaden is eventueel tegen betaling”*). Two participants suggested to give more support or interaction during the course, (*“ik vond het uiteindelijk erg afstandelijk en meer een soort LOI cursus; Nu is er te veel gelegenheid om de cursus te ‘vergeten’. Bijvoorbeeld even bellen om de 14 dagen”*).

**Table 10.** Ratings on course in general

| Course                 | Most valued<br>Number of<br>statements | Least valued<br>Number of<br>statements | Suggestions |
|------------------------|--|---|-------------|
| More time<br>necessary | -                                      | 3                                       | 5           |
| Valued                 | 3                                      | -                                       | -           |
| Option to<br>download  | -                                      | -                                       | 2           |
| Support                | -                                      | -                                       | 2           |
| Total                  | 3                                      | 3                                       | 9           |

**Participants' satisfaction**

The average grade (1-10) of the course was rated with  $M = 7,39$  ( $SD=1.19$ ). Five participants (8.8%) gave the course a five, seven participants (12.3%) a six, 14 (24.6%) participants a seven, 26 participants (45.6%) an eight, two participants (3.6%) a nine and three (5.3%) a ten. In total, participants evaluated the intervention positive on the CSQ-8 (scale range from 8-32,  $M=24.79$ ,  $SD=4.03$ ,  $n= 57$ ).

## Discussion

This study aimed at evaluating the experiences of chronic pain patients using the internet- based and guided self-help intervention “Living with pain” which is based on Acceptance and Commitment Therapy (ACT). By analysing qualitative and supporting quantitative data, experiences and assessments were estimated to adjust and improve the intervention. This study showed that the usability of the intervention is rated quite highly by the participants who properly finished in the questions about three most valued, three least valued parts and suggestions of the intervention ( $n= 57$ ). Mainly the mindfulness- exercises, the experienced acceptance through the intervention and the exercises in general were valued positive by participants. Conversely the feedback and software were rated less and had the most suggestions. Adherence (completing intervention and working with it >3 hours per week) was moderate under all participants ( $n=82$ ) and good under participants who completed the intervention and questionnaires ( $n=57$ ) (Kelders et al., 2012). Based on the findings, recommendations were established. By implementing these recommendations, a more suitable intervention for chronic pain patients could be developed, approximating the user’s needs and personal taste. In the next section, recommendations are discussed and listed.

### **Recommendations and implications for the intervention “Living with pain”**

**(Mindfulness) exercises.** Most (mindfulness-) exercises were rated well by participants. The (mindfulness-) exercises helped participants by improving their daily functioning. These findings correspond with the quantitative findings of RCT, identifying improvements on pain interference, reductions on psychological and pain-related distress and improvements in psychological flexibility (Trompetter et al., 2014; Buhrman et al., 2013; Wicksell et al., 2013). Still the exercise to work on endurance is not deemed necessary for all chronic pain patients. Not all participants experienced the need to improve their physical condition, as suggested by the results. A solution could be a questionnaire in advance to

personalize the intervention (Kelders, 2012). Questions about physical condition could be asked in advance, so that exercise about condition is integrated or not during the intervention. Some participants had difficulties with the (mindfulness-) exercises (e.g. body scan, breathing exercise, talk about pain). Participants had the opportunity to ask their counsellor questions on the exercises and it is not clear if they took the chance. If they did and the provided response did not help further, it could be a solution to offer an additional course, were chronic pain patients are introduced to (mindfulness-) exercises, which should be investigated further.

**Feedback.** The way of communicated feedback was rated negatively and had the most suggestions for changes from participants. Participants valued the feedback as a good reminder, but wished the feedback would be more empathic and personal, because participants experienced the feedback as superficial. The feedback was provided for guidance, support and encouragement (Trompetter, 2014). However, only six participants experienced it this way. Fifteen participants desired more interaction, support and adequate feedback during the intervention. It is debatable whether a weekly personal feedback is necessary or economical, because experimental research reveals that feedback by persuasive technology can have positive effects on behavior (Midden & Ham, 2008). In another study, it was demonstrated that there are no significant differences on effectiveness and adherence providing a virtual counselor or personal feedback by a counselor (Kelders et al., 2012). This could have influence on cost- effectiveness, which should be investigated further. If it is still decided to use personal feedback, it should be considered to train counselors better.

Counselors have been five recently graduated psychology students and each provided feedback to approximately 30 participants in the main study (Trompetter et al., 2014). Even though the counselors received training in writing e-mails and information of chronic pain, intensity of the training should be improved for a better quality in feedback. It should be taken into account that one counsellor supported approximately 30 participants via e-mail, which

could have had influence on the quality of the e-mails. Supporting less users (e.g. 20) per week could be a solution, although this solution would attend to higher costs. Furthermore, to ensure anonymity, the statements that were made about the feedback were not linked to the individual counselors. It is possible, that not all counselors provided feedback that were experienced as insufficient by the participants, but only one.

Another solution could be to give the participant the option to call the counsellor, which indicates to be promising as an effective approach (Buhrman et al., 2004). These solutions could have some advantages as the intervention does feel more personal for users and difficulties with exercises could helped out. To avoid a high frequency of calls, these could be limited to a maximum of, for example four calls per user during the intervention. It could be a consideration to make no use of weekly personal feedback, but a virtual counsellor and integrate the call option. Recent research is limited concerning the impact of phone calls during a web- based intervention for chronic pain. More research is necessary if this option also works as effective approach with ACT and would be profitable.

The most desirable option for future interventions is to make further use of personal feedback during the intervention and to add dialogue support as reminders and praise. As mentioned before, the counselling was provided to give guidance, support and encouragement. The personal feedback could cover the guidance and support, the dialogue support could cover the encouragement. This option would create a more personal environment, which was desired by participants.

**Text.** The results indicated that some participants would like the texts to be more cohesive, closer to the language of a certain target group and less repeating. On the other hand the text helped participants to understand the theory of ACT, pain and other aspects like cognitive defusion. It could be a solution to make the text shorter, but to give participants the option to read more information through a folding up menu. The advantage could be, that



intervention users would read the necessary information, but are also able to read more if interested. By this, it could be avoided that people are losing the motivation to follow the intervention due to too much informational content. Groups who would benefit from this option are people who already know a lot about mindfulness, have a lower educational background or are not interested in too much theory.

**Experiences of others.** Experiences of others were valued by four participants, two participants suggested more interaction during the course. It is recommended to make more use of persuasive technology as social (e.g. cooperation) and dialogue support (e.g. reminders). The intervention *Living with pain* makes already use of persuasive technology, which predicts better adherence of users (Kelders et al., 2012). Some parts of Persuasive System Design (Appendix B) are used in the intervention *Living with pain* e.g. primary task support (e.g. tunneling) and social support (e.g. cooperation and recognition). Dialogue support (e.g. reminders) seems to be important for adherence, therefore it is recommended also to integrate more dialogue support (Kelders et al., 2012).

**Videos, Diaries and Metaphors.** Participants did not mention these categories very often and reactions on these parts of the intervention were varied. The metaphors were rated negatively by three participants, because they were experienced as being difficult to understand. It could be an option to use easier phrasing for better understanding. It is doubtful if not mentioning the diary and videos can be interpreted as enrichment for participants during the intervention. Personally it is advised to make further use of the diary and videos as supporting element, still it should be investigated further.

**Acceptance, awareness and coping with pain.** The experienced acceptance in general through the intervention, has positive effects on how the participants cope with their pain and disabilities. 39 positive statements about acceptance, awareness, relaxation and coping with pain were made by 33 participants. The subjective assessments by participants

support the aim of ACT, namely to improve the daily functioning, effective pain management and psychological flexibility through the six core processes (Hayes et al., 2012).

**Software.** As evaluated in the results, one person stopped with the course because of software problems and improvements are urgently advised by eight participants. Therefore all software problems should become better in quality and the intervention should also be working on iPad. It should be mentioned that eight participants complained about the software and 49 participants did not mention software per se. Still it is important always to pursue of good software functionality, because reasons not to adhere to a web-based intervention are often software problems (Kelders et al., 2012).

**Course in general.** It was mentioned that more time is necessary for the course. It could be a solution to cut the intervention into shorter segments or extend the content of one week over two weeks. One advantage could be, that chronic pain patients do not feel stressed using the intervention. Extending the intervention or cutting it in shorter segments, could also contain disadvantages as the intervention would take longer. This could have negative influence on the motivation of the users. Alternatively a course could be given in advance, so users of the intervention learn how to manage working with the intervention. Advantages or disadvantages of this item should be investigated in further research.

To increase usability and adherence of the intervention, in summary it is advised to:

- Use more persuasive technology (dialog-, primary task-, and social support)
- Personalize/tailor intervention (questionnaire in advance about physical condition)
- Improve feedback
- Offer option for phone call
- Make intervention qualified for iPad (tablets and smartphones)
- Improve software problems

## **Limitations**

Even though this study was realized with best purposes some limitations exist. First, the study was performed by one person which reduces the reliability of the study. Qualitative data was coded and categorized by one rater. To increase reliability a second rater was introduced and rating disagreements were discussed and levelled, still the second rater just controlled the already existing codes and categories. Interpretation was tried to be avoided, but like in most qualitative research studies analyzing objectively implicates some difficulties as subjectivity. Second, the qualitative questionnaire about satisfaction was administered after the intervention. This is a problem, because participants could not log in anymore and they provided general information that is hard to link to specific parts of the intervention (Hornbaek, 2006). Third, not all statements are assimilated in this study, just statements that were mentioned > two times, which means not all statements were analyzed. In addition consideration should be given that participants did not refer to all aspects of the intervention. It is indefinite if aspects that were not mentioned means participants valued or did not valued these aspects (e.g. feedback, software). This could be a disadvantage because interesting valued, non-valued parts or suggestions were neglected. Fourth, the web-based intervention is evaluated in a study. Therefore, the moderate adherence and completion of the participants could have been influenced. Fifth, the drop- out rate amounts to 25 (30.5%) participants. This high percentage could have implications on the research, namely missing not randomized data which leads to distortions of research data. The number of participants who completed the intervention or were adherent to the intervention was higher in the group who made completed the questionnaire compared to those who did not. In other words, the information about valuable or not valuable parts of the information is obtained from participants who were highly motivated to follow and complete the intervention. Thus, data of people who stopped earlier with the intervention for unknown reasons is missing and cannot be examined.

## **Implications and future research**

In the main research positive evidence for the effectiveness on chronic pain is established (Trompetter et al., 2014). In this study, usability was evaluated and contingent influence on adherence was elaborated. Further research could examine which parts of the intervention improved positive outcomes. Therefore a full or fractional factorial design is recommended to establish the working mechanisms (e.g. counseling, multimedia, personalization) of the intervention (Kelders, 2012). Furthermore, it could be achieved to tailor the web- based self- help intervention to the profile of the patient (Andersson, Estling, Jakobsson, Cuijpers & Carlbring, 2011), to reduce drop-out and increase adherence. Until now, few research is done about the relationship between adherence and outcome of web-based interventions. Also a large variety of measuring and reporting adherence makes research difficult (Donkin, Christensen, Naismith, Neal, Hickie & Glozier, 2011).

This research indicated that implementing interventions in the E (mental) Health sector should involve experts as well as users, like in the CEHRES- roadmap. An iterative process helps improving the quality, functionality and effective use of an intervention like “Living with pain”. The E (mental) Health sector is getting more important in supporting people and enhance cost- effectiveness. Therefore, more research of the whole E (mental) Health sector is not only important but necessary.

## References

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). doi:10.1176/appi.books.9780890423349
- Andersson, G., Estling, F., Jakobsson, E., Cuijpers, P., & Carlbring, P. (2011). Can the patient decide which modules to endorse? An open trial of tailored internet treatment of anxiety disorders. *Cognitive behaviour therapy*, 40(1), 57-64. doi: 10.1080/16506073.2010.529457.
- Bender, J. L., Radhakrishnan, A., Diorio, C., Englesakis, M., & Jadad, A. R. (2011). Can pain be managed through the Internet? A systematic review of randomized controlled trials. *Pain*, 152(8), 1740–50. doi:10.1016/j.pain.2011.02.012
- Bohlmeijer, E.T., & Hulsbergen, M. (2008). *Voluit leven. Mindfulness of de kunst van het aanvaarden, nu als praktisch hulpboek* [Living to the Full. Mindfulness or the Art of Acceptance, now as a Practical Help Book]. Boom: Amsterdam.
- Breivik, H., Collett, B., Ventafridda, V., Cohen, R., & Gallacher, D. (2006). Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment. *European Journal of Pain*, 10(4), 287-333. doi: 10.1016/j.ejpain.2005.06.009
- Buhrman, M., Fålténhag, S., Ström, L., & Andersson, G. (2004). Controlled trial of Internet-based treatment with telephone support for chronic back pain. *Pain*, 111(3), 368-377. doi: 10.1016/j.pain.2004.07.021
- Buhrman, A., Skoglund, A., Husell, H., Bergström, K., Gordh, T., Hursti, T., Bendelin, N., Furmark, T., Andersson, G. (2013). Guided internet-delivered acceptance and commitment therapy for chronic pain patients: A randomized controlled trial. *Behavior Research and Therapy*, 51(6), 307-315. doi:10.1016/j.brat.2013.02.010

- Christensen, H., Griffiths, K. M., & Farrer, L. (2009). Adherence in Internet interventions for anxiety and depression: Systematic review. *Journal of medical Internet research*, 11(2). doi:10.2196/jmir.1194
- Cuijpers, P., van Straten, A., & Andersson, G. (2008). Internet-administered cognitive behavior therapy for health problems: a systematic review. *Journal of behavioral medicine*, 31(2), 169–77. doi:10.1007/s10865-007-9144-1
- Donkin L., Christensen H., Naismith S.L., Neal B., Hickie I.B, Glozier, N. (2011). A Systematic Review of the Impact of Adherence on the Effectiveness of e-Therapies. *Journal of Medical Internet Research*, 11(3), e19. doi:10.2196/jmir.1134
- Gemert-Pijnen van, J.E., Peters, O., Ossebaard, H.C. (2013). Improving eHealth. Den Haag: Boom/Lemma.
- Hayes, S. C. (2004). Acceptance and commitment therapy, relational frame theory, and the third wave of behavioral and cognitive therapies. *Behavior Therapy*, 35, 639-665.
- Hayes, S. C., Strosahl, K., & Wilson, K. G. (2012). *Acceptance & Commitment Therapy: The process and practice of mindful change* (2nd. ed.). New York: Guilford Press.
- Hornbæk, K. (2006). Current practice in measuring usability: Challenges to usability studies and research. *International journal of human-computer studies*, 64(2), 79-102.
- International Association for the Study of Pain (IASP) (2013). *IAPS Taxonomy*. Retrieved on February 26, 2013 via <<[http://www.iasp-pain.org/AM/Template.cfm?Section=Pain\\_Definitions](http://www.iasp-pain.org/AM/Template.cfm?Section=Pain_Definitions)>>
- Kabat-Zinn, J. (1990). *Full catastrophe living: Using the wisdom of your body and mind to face stress, pain and illness*. New York: Delacorte.
- Kabat-Zinn, J. (1994). *Wherever you go, there you are: mindfulness in everyday life*. New York: Hyperion.

- Katz, J., Pagé, M. G., Fashler, S., Rosenbloom, B. N., & Asmundson, G. J. (2014). Chronic Pain and the Anxiety Disorders: Epidemiology, Mechanisms and Models of Comorbidity, and Treatment. In *Mental Health and Pain* (pp. 119-155). Springer Paris.
- Kelders, S. M. (2012). *Understanding adherence to web-based interventions*. Universiteit Twente. doi:10.3990/1.9789036534178
- Kelders S.M., Kok R.N., Ossebaard H.C., Van Gemert-Pijnen J.E.W.C. (2012). Persuasive system design does matter: A systematic review of adherence to web-based interventions. *Journal of Medical Internet Research*, 14, e152
- Kelders, S.M., Pots, W.T.M., Oskam, M.J., Bohlmeijer, E.T., Gemert-Pijnen, J.E.W.C. van (2013) *Development of a web-based intervention for the indicated prevention of depression*. BMC medical informatics and decision making, 13 (26). 1 - 11.  
doi:10.1186/1472-6947-13-26
- Kelders, S. M., Van Gemert-Pijnen, J. E., Werkman, A., Nijland, N., & Seydel, E. R. (2011). *Effectiveness of a Web-based intervention aimed at healthy dietary and physical activity behavior: a randomized controlled trial about users and usage*. Journal of medical internet research, 13(2). doi: 10.2196/jmir.1624
- Lamé, I. E., Peters, M. L., Vlaeyen, J. W., Kleef, M. V., & Patijn, J. (2005). Quality of life in chronic pain is more associated with beliefs about pain, than with pain intensity. *European Journal of Pain*, 9(1), 15-24. doi:10.1016/j.ejpain.2004.02.006
- Macea, D. D., Gajos, K., Daglia Calil, Y. A., & Fregni, F. (2010). The efficacy of Web-based cognitive behavioral interventions for chronic pain: a systematic review and meta-analysis. *The Journal of Pain*, 11(10), 917-929. doi:10.1016/j.pain.2010.06.005
- Martin B.I., Deyo R.A., Mirza S.K., et al. (2008). Expenditures and health status among adults with back and neck problems. *JAMA*, 299(6), 656–64.  
doi:10.1001/jama.299.6.656

- McCracken, L.M. Gutiérrez- Martínez O. & Smyth, C. (2012). “Decentering” reflects of psychological flexibility in people with chronic pain and correlates with their quality of functioning. *Health Psychology*, 32(7), 820-823. doi:10.1037/a0028093
- Midden, C., & Ham, J. (2008). The persuasive effects of positive and negative social feedback from an embodied agent on energy conservation behavior. In *AISB 2008 Convention Communication, Interaction and Social Intelligence* (Vol. 1, p. 9).
- Miller, L. R., & Cano, A. (2009). Comorbid chronic pain and depression: who is at risk? *The Journal of Pain*, 10(6), 619-627. doi:10.1016/j.jpain.2008.12.007
- Trompetter, H. R., Bohlmeijer, E. T., Veehof, M. M., & Schreurs, K. M. (2014). Internet-based guided self-help intervention for chronic pain based on Acceptance and Commitment Therapy: A randomized controlled trial. *Journal of behavioral medicine*, 1-15.
- Turk, D. C., Wilson, H. D., & Cahana, A. (2011). Treatment of chronic non-cancer pain. *Lancet*, 377(9784), 2226–2235. doi:10.1016/S0140-6736(11)60402-9
- Veehof, M. M., Oskam, M. J., Schreurs, K. M., & Bohlmeijer, E. T. (2011). Acceptance-based interventions for the treatment of chronic pain: a systematic review and meta-analysis. *Pain*, 152(3), 533-542. doi:10.1016/j.pain.2010.11.002
- Veehof, M.M., Hulsbergen, M., Bohlmeijer, E.T., & Schreurs, K.M.G. (2010). *Leven met pijn. De kunst van het aanvaarden [Living with pain. The Art of Acceptance]*. Amsterdam: Boom.
- Vlaeyen JWS, Morley S. (2005). Cognitive-behavioral treatments for chronic pain: what works for whom? *Clinical Journal of Pain*, 21 (1), 1–8.
- Wetherell, J.L., Afari, N., Rutledge, T., Sorrel, J.T., Stoddard, J.A., Petkus, A.J & Hampton Atkinson, J. (2011). A randomized, controlled trial of acceptanceand commitment therapy and cognitive- behavioral therapy for chronic pain. *Pain*, 152(9), 2098-2107. doi:10.1016/j.pain.2011.05.016



Wicksell, R. K., Kemani, M., Jensen, K., Kosek, E., Kadetoff, D., Sorjonen, K., ... & Olsson, G. L. (2013). Acceptance and commitment therapy for fibromyalgia: a randomized controlled trial. *European Journal of Pain*, 17(4), 771.e1-14.  
doi:10.1016/j.epain.2009.11.015

## Appendix A

### Qualitative questionnaire experiencing the intervention (after intervention)

1. Wanneer u terugkijkt op de cursus: Kunt u drie dingen noemen uit de cursus waar u het meeste aan heeft gehad? Meest gehad 1; meest gehad 2; meest gehad 3 (benoemen van minder dan drie dingen is ook mogelijk)
2. Wanneer u terugkijkt op de cursus: Kunt u drie dingen noemen uit de cursus waar u het minste aan heeft gehad? Minst gehad 1; minst gehad 2; minst gehad 3 (benoemen van minder dan drie dingen is ook mogelijk)
3. Heeft u nog algemene suggesties ter verbetering van de zelfhulpcursus?

### Quantitative questionnaires

#### *Quantitative questionnaires about satisfaction (CSQ-8) Dutch version (after intervention)*

1. Wat vindt u van de kwaliteit van de zelfhulpcursus die u heeft ontvangen? (schaal: slecht- uitstekend)
2. Heeft u het soort hulp ontvangen dat u hoopte te krijgen? (schaal: Nee, beslist niet- Ja, zeker wel)
3. Hoeverre heeft de zelfhulpcursus aan uw wensen voldaan? (schaal: Aan geen van mijn wensen is voldaan- Aan al mijn wensen is voldaan)
4. Stel dat een van uw kennissen dezelfde hulp nodig heeft, zou u dan de zelfhulpcursus aanbevelen? (schaal: Nee, beslist niet- Ja, zeker)
5. Hoe tevreden bent u met de hoeveelheid hulp die u heeft ontvangen? (Schaal: Zeer ontevreden- Zeer tevreden)
6. Heeft de zelfhulpcursus u geholpen beter om te gaan met uw problemen? (Schaal: Nee, het heeft de zaak alleen maar verergerd- Ja, het heeft aanzienlijk geholpen)
7. Hoe tevreden bent u over het geheel genomen met de zelfhulpcursus die u heeft ontvangen? (Schaal: Zeer ontevreden- Zeer tevreden)

8. Zou u de zelfhulpcursus nog een keer doen, als u dat nodig zou hebben? (Schaal: Nee, beslist niet- Ja zeker)

*Assistance (after intervention)*

1. Ik vond mijn begeleider deskundig (schaal helemaal met oneens- helemaal met eens)
2. Ik voelde me begrepen door mijn begeleider (schaal helemaal met oneens- helemaal met eens)
3. Ik vind dat mijn begeleider goed inhoudelijk feedback gaaf (schaal helemaal met oneens- helemaal met eens)

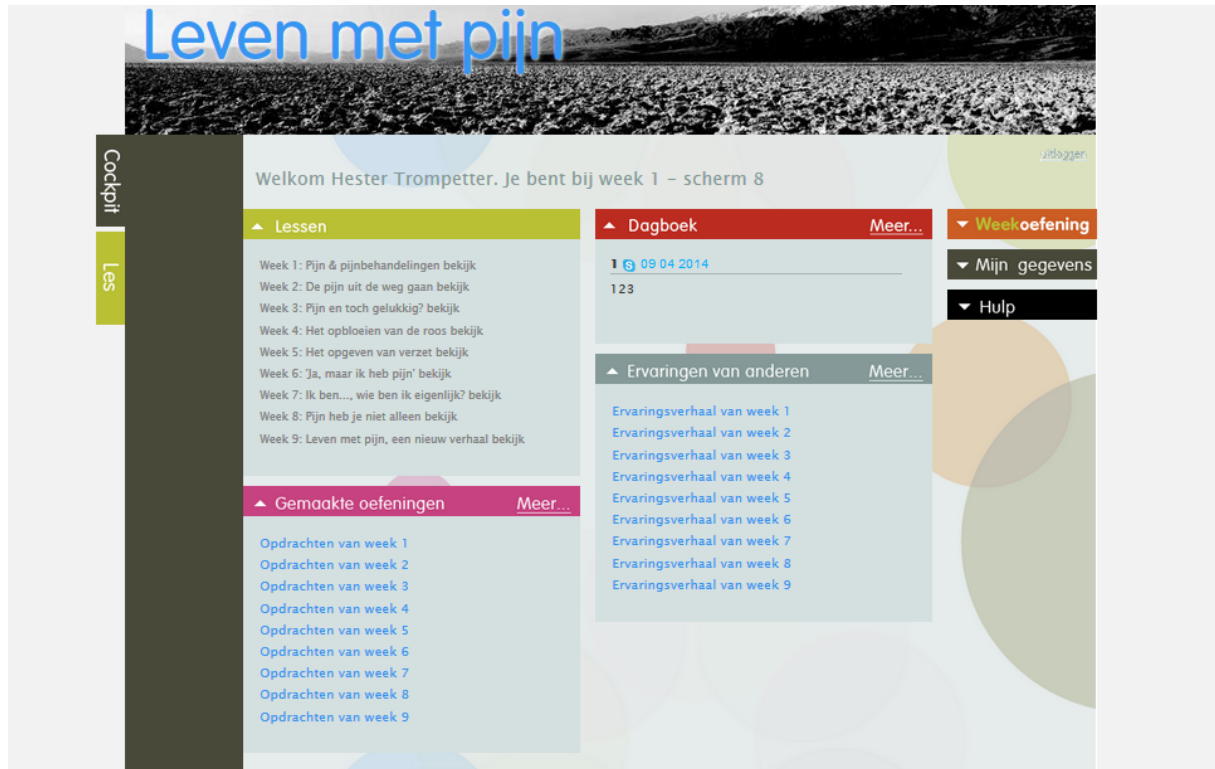
*Self- assessed adherence (four and eight weeks from baseline)*

*Grade of course (after intervention)*

Welke cijfer zou u de zelfhulpcursus geven? (schaal 1-10; heel slecht- heel goed)

## Appendix B

### Screenshot of the online intervention “Living with pain”



### Week 1-9

#### *Week 1 Pain and therapy*

1. Introduction
2. What is pain?
3. The value of (acute) pain
4. What is chronic pain?
5. Chronic pain explained specified
6. Pain treatment
7. Exercise: your experience with pain treatments
8. Mindfulness exercise: body scan

## *Week 2 Keeping out of the pains way*

1. Control does not work (obviously)
2. Avoidance, a good alternative
3. Strategies to avoid unwished experiences
4. Exercise: my favorite ways of avoidance
5. Exercise: what does my avoidance imply?
6. Why avoidance is not the solution
7. Exercise: the wonder question
8. Exercise: what does my avoidance imply? (continuation)
9. Why avoidance is not the solution (continuation)
10. Diary: distressing moments
11. Mindfulness exercise: attention for breathing
12. Metaphor: tug of war
  - a. Continuation tug of war

## *Week 3 Pain and still happy*

1. Introduction
2. Handholds for a lucky life
3. What are values (not)?
4. What do you want from life?
5. Exercise: what kind of person you want to be?
6. Exercise: recognize your values
7. Exercise: wat levert het je op?
8. Metaphor
9. Mindfulness exercise: rotatory body scan and attention for breathing
10. Mindfulness: FAQ and answers

## *Week 4 Flourishing of the rose*

1. Introduction
2. Exercise: the rose
3. Metaphor: the rose

4. Oefening: doelen stellen en acties bepalen
5. Exercise: recognize your bars
6. And now?
7. Mindfulness exercise: breathe to your pain

#### *Week 5 Stopping resistance*

1. Introduction
2. Quitting resistance
3. What is acceptance?
4. What acceptance is not
5. Metaphor: the unwished guest
6. Are you ready?
7. Exercise: carry your pain with you
8. Acceptance you can learn
9. Mindfulness exercise: ruimte maken en toestaan wat er is
10. Exercise: acceptance in action
11. Exercise: carry your pain with you (continuation)
12. Pain and care about you well
13. Exercise: improve condition
14. The key question

#### *Week 6 “Yes, but I have pain”*

1. Introduction
2. Thoughts are just interpretations of reality
3. 3a. Pain thoughts
- 3b. Painthoughts (continuation)
- 4a. Words in our head, so powerful as reality
- 4b. Words in our head, so powerful as reality (continuation)
5. Cognitieve defusion
- 6a. Exercise: ‘I have the thought that...’
- 6b. Exercise: ‘I have the thought that...’(continuation)

7. Exercise: take leave BUT
8. Exercise: alternative ways expressing thoughts
  4. Metaphor: The Muppet show and our mind
  5. Mindfulness exercise: observing thoughts
  6. FAQ's en valkuilen

*Week 7 "I am, ... who am I?"*

1. Introduction
2. The self (image)
3. Exercise: Who am I
4. Our self-image dictates our Handeln
5. Exercise: Who am I (continuation)
6. Observing self
7. Metaphor: the sky
8. Exercise: 'Who am I?' (continuation)
9. Exercise: judging
10. Exercise: compare
11. 'I always compare!'
12. 'Ik ben altijd evenveel waard'
13. Mindfulness exercise: 3 minutes ademruimte

*Week 8 I don't have pain alone*

1. Introduction
2. Lack of understanding
3. Patronen in communicatie
4. Exercise: communication about pain
5. Exercise: automatic reactiepatronen
6. Influence of the environment on pain

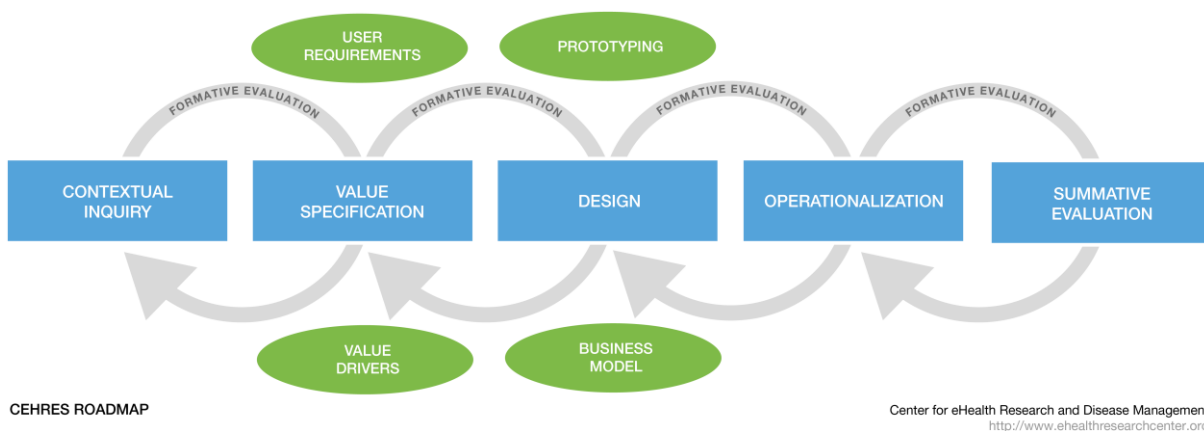
7. The environment suffers as well
8. Hoe verder?
9. The function of behavior
10. Exercise: welke meester dien je?

### *Week 9 Living with pain, a new story*

1. Introduction
2. Exercise: the flower, five modules further
3. Commitment
4. Exercise: performing actions
5. Metaphor: the bus
6. Exercise: old stories
7. Motto of new stories
8. Mindfulness exercise: alles in één
9. Tot slot: coping with relapse
10. Exercise: recognize signals of relapse

Exercise: What to do by relapse?

### CEHRES Roadmap





## Persuasive System Model (Oinas- Kukkonen)

|  | PERSUASIVE DESIGN FEATURES  |   |   |  |
|--|---|---|---|--|
| PERSUASION CONTEXT   | PRIMARY TASK SUPPORT  | DIALOGUE SUPPORT  | CREDIBILITY SUPPORT   | SOCIAL SUPPORT   |
| <b>The Intent</b><br><div>Persuader</div> <div>Change type</div>   | <i>Reduction</i><br><i>Tunneling</i><br><i>Tailoring</i>                                  | <i>Praise</i><br><i>Rewards</i><br><i>Reminders</i>                           | <i>Trustworthiness</i><br><i>Expertise</i><br><i>Surface credibility</i>                              | <i>Social learning</i><br><i>Social comparison</i><br><i>Normative influence</i>             |
| <b>The Event</b><br><div>Use context<sup>a</sup></div> <div>User context<sup>b</sup></div> <div>Technology context<sup>c</sup></div> | <i>Personalization</i><br><i>Self-monitoring</i><br><i>Simulation</i><br><i>Rehearsal</i> | <i>Suggestion</i><br><i>Similarity</i><br><i>Liking</i><br><i>Social role</i> | <i>Real world feel</i><br><i>Authority</i><br><i>Third party endorsements</i><br><i>Verifiability</i> | <i>Social facilitation</i><br><i>Cooperation</i><br><i>Competition</i><br><i>Recognition</i> |
| <b>The Strategy</b><br><div>Message</div> <div>Route</div>   |   |   |   |  |

<sup>a</sup> Problem domain dependent features

<sup>b</sup> User dependent features e.g. goals, motivation, lifestyles, and others

<sup>c</sup> Technology dependent features