University of Twente
The Netherlands

Development and evaluation of a questionnaire for daily measurements with chronic pain patients: A pilot study based on Acceptance and Commitment Therapy

Author:
Luisa Oevermann, University of Twente, Enschede (NL)

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Tutor:
Hester Trompetter, MSc.
Roessingh Research & Development and University of Twente, The Netherlands
(Department of Psychology, Health & Technology)

Dr. Karlein Schreurs
Faculty of Behavioral Sciences, University of Twente, The Netherlands
(Department of Psychology, Health & Technology)

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1. Abstracts

1.1. English

In the context of this paper, Acceptance and Commitment Therapy (ACT) was introduced. ACT is a new therapy that seeks to increase the psychological flexibility through processes like acceptance of negative experiences and the determination of personal values. A couple of studies show ACT to be effective for patients suffering from chronic pain. No studies are available about the suitability of ACT for daily measurements, so the paper at hand aims at the development and evaluation of a questionnaire for daily measurements with chronic pain patients. Items for the questionnaire were newly formulated and taken from existing questionnaires.

This paper contains two parts of research: In the first part, ten participants responded to a questionnaire by Three-Step Test Interview. The purpose was to find the most suitable items, especially for a new concept: ‘values-based living’. In the second part, three participants responded daily, for two weeks, to the chosen items from the first part. This part aimed at examining how the items function during daily measurements.

The researcher was successful in developing a questionnaire for daily measurements and was able to evaluate the quality of items for daily measurements. Recommendations were given to improve further research with the questionnaire.

1.2. Dutch

In de context van deze studie werd Acceptance and Commitment Therapy (ACT) geïntroduceerd. ACT is een nieuwe therapie en heeft het doel de psychologische flexibiliteit te verhogen door het accepteren van negative ervaringen en door onder andere het vastleggen van eigen waarden. Een aantal studies laten zien dat ACT geschikt is voor patiënten met chronische pain. Er zijn geen studies beschikbaar die onderzoek doen naar ACT en dagelijkse meetingen, dus de doelstelling van dit article is het ontwikkelen en evalueren van een vragenlijst voor dagelijkse meetingen bij patienten met chronische pijn. Items voor de vragenlijst werden nieuw geformuleerd en gebruikt uit al bestaande vragenlijsten.

Het artikel bestaat uit twee delen: In het eerste gedeelte gaven tien deelnemers antwoord op de vragenlijst met behulp van de Three-Step Test Interview. Het doel was het vinden van de meest geschikte items voor dagelijkse meetingen, met name voor een nieuw concept: ‘values-based living’. In het tweede deel van deze studie gaven drie deelnemers gedurende twee weken antwoord op de geselecteerde items, uit studie 1. Hier was het doel om te examineren hoe de items functioneerden tijdens de dagelijkse metingen.

De onderzoeker was succesvol in het ontwikkelen van een vragenlijst voor dagelijkse metingen. De kwaliteit van de items, gemeten gedurende twee weken, werd geanalyseerd. Aanbevelingen werden geven om verder onderzoek met de vragenlijst te verbeteren.

2. Introduction

Pain is one of the oldest symptoms people search treatment for. In the context of this paper an important difference must be made between acute and chronic pain. Acute pain can be diagnosed directly, treated causally and decreases after a restricted period. If this period is exceeded, the pain is called chronic pain. Chronic pain can, but does not necessarily need to, be elicited by an injury. Generally it lasts more than six month and becomes worse due to factors beyond the original cause. People living with chronic pain can experience constraints in the somatic, psychic, and social domain (Thorn, 2005). According to Bekkering et al. (2003), the annual incidence of the Dutch population experiencing low back pain, a type of chronic pain, is five percent. In Germany approximately five million people, which is eight percent of the population, suffer from chronic pain (Zimmermann, 2004). These high numbers show that the search for an effective treatment is highly relevant.

The aim of this study is to develop and evaluate a questionnaire for daily measurements with patients suffering from chronic pain. In this paper the author concentrates on the treatment of pain through psychotherapy, especially on 'Acceptance and Commitment Therapy' (ACT; spoken as 'act').

In the following, the origins of ACT are presented. Then the main concepts of ACT and its relation with chronic pain will be discussed. Subsequently the research questions are posed.

2.1. Origins of Acceptance and Commitment Therapy

When looking at the history of therapies with a behavioural approach there are two ancestors to this third and modern version of behaviour therapy.

The first wave is the traditional behaviour therapy, prevailing in the 1950th and 1960th (Harris, 2009). This traditional therapy focused primarily on behaviour change by two approaches. Within the classical conditioning, with its founder I.P. Pavlov, behaviour change was applied purely by stimulus and response. Within the operant conditioning, with its founder J.B. Watson, a basic human ability to learn was taken into account and thus behaviour change was realised by means of reinforcement and punishment. Within this wave of traditional behaviour, only direct observed behaviour was seen as crucial. Authors and clinicians of that time found the classical and operant learning principles not adequate enough to explain all human cognition (Hayes, 2006).

Thus the ignorance of complex cognitive processes led to the second wave of behaviour therapy in the 1970th, with 'Cognitive Behaviour therapy' (CBT) as the most dominant one (Harris, 2006). The major emphasis of CBT is the challenge of dysfunctional and negative thoughts and their replacement with positive and realistic ones. This '*cognitive intervention*' is the key strategy of CBT and is still applied in practice. However, according to Bach & Moran (2008), no "basic theoretical principles that are supposed to underlie the therapy" could be found and the effect sizes of CBT are rated modest (Hayes, 2006).

The third wave of cognitive and behavioural therapies became more popular, trying to take a more evidence- based approach. 'Acceptance and Commitment Therapy' (ACT) is a modern version of behaviour therapy and is the most representative one of this wave. As the term implies it has two interrelated intentions. On the one hand ACT tends to reach the acceptance that there might be things which are out of a persons' own control. On the other hand it tends to reach the commitment to take action to enrich a persons' life. These actions can be taken by means of helping to clarifying personal values and act according to them, and by learning 'mindfulness skills' (= psychological skills to handle painful thoughts and feelings effectively).

2.2. Acceptance and Commitment Therapy

Acceptance and Commitment Therapy is based upon 'Relational Frame Theory' (RFT). RFT is a quite technical theory and a detailed description is beyond the scope of this article. According to RFT human beings learn by interacting verbally with their environment (A-Tjak, De Groot, 2008). All private experiences, whether thoughts, memories, smell, touch or taste can be defined as events (Harris, 2006). People suffering from chronic pain generally try to avoid certain events and experiences that could cause pain in the future or did so in the past (Wicksell, Melin, Lekander & Olsson, 2008a). This phenomenon is generally called '**experiential avoidance**', 'emotional avoidance' or 'cognitive avoidance' (Hayes et al., 1994). Hayes (1994) defines it as

> a "putative pathological process [...] that occurs when a person is unwilling to remain in contact with particular private experiences (e.g., bodily sensations, emotions, thoughts, memories, behavioural predispositions) and takes steps to alter the form and frequency of these events and the contexts that occasion them".

Every day people are confronted with thoughts and situations they want to avoid. According to Harris (2006) the approach of avoidance works well in the material world, for instance building a shelter to avoid rain. But the more time and energy we spend on trying to get rid of unwanted experiences (thoughts, emotions, etc.) the more we could suffer psychologically in the long term. To clarify this argument an example of anxiety by Harris (2006) is presented: "The more importance we place on avoiding anxiety, the more we develop anxiety about our anxiety- thereby exacerbating it." In his book (2009) he gives an example of a man, who has unwanted thoughts and drinks a lot of beer whenever he wanted to get rid of these thoughts. Consequently, often applying such problem solving strategies makes people psychological inflexible in altering these strategies, mainly in relation to thoughts.

According to Ruiz (2010), 'experiential avoidance' is not problematic if the 'psychological flexibility' is maintained. It only becomes problematic if valued actions cannot be accomplished. To prevent situations of avoidance, a therapy has to operate against the inflexibility in thoughts. Thus the main goal of ACT is to develop 'psychological flexibility'.

Wicksell (2010) defines '**psychological flexibility**' as "the ability to act effectively in accordance with personal values in the presence of interfering thoughts, emotions, and bodily sensations".

Although ACT has several similarities with CBT, it differs crucial in its aim and underlying focus. The reduction of pain, the change of frequency or the content of thoughts is not relevant in the first place. Instead, the aim of ACT is the promotion of greater acceptance of negative private experiences in order to increase psychological flexibility. Psychological flexibility is increased through the implementation of six processes. A short description of these processes is given:

1. Acceptance
2. Cognitive Defusion
3. Contact with the Present Moment
4. Self as Context
5. Values
6. Committed Action

Through the '**Acceptance**' of uncontrollable events a person opens up and makes room for painful feelings, urges, etc. As Harris (2006) writes, Acceptance means "making room for unpleasant feelings [...] and allowing them to come and go without struggling with them". It implies the active and conscious embracement of negative experiences and thus 'Acceptance'

beholds the opposite of 'Experiential Avoidance'. Much research has been performed on acceptance in terms of chronic pain (see paragraph 2.2.1. 'The Effectiveness of ACT', page 9).

When thoughts are experienced as literally true and not just as words, this is called 'cognitive fusion'. A fusion can lead to the experience of pain if only reading the word 'pain' literally. This can lead to experiential avoidance described above, which could be a threat to the psychological flexibility. Thus the goal of the process '**Cognitive Defusion**' is to defuse one's thoughts so they have less impact and influence. It means to watch one's thinking and to change the interaction and relationship one has with own thoughts. A distance is created to decrease the attachment to private events, and to see the thoughts as what they are – words and (mental) pictures. Two examples of strategies to increase cognitive defusion are given to make this process more clear: A person learns to speak in terms like 'I think that I am suffering from pain' instead of 'I have pain', or speaking out loud a thought again and again until it is only a sound, instead of an emotional loaded thought.

People tend to shift their thoughts and daydream or operate on 'automatic pilot'. The process of '**Contact with the present moment**' or 'Being present' implies being conscious of one's own physical and psychological reality. By mindfulness exercises one learns to be present in the actual moment and pay attention to the here- and- now experience. This awareness of the world around oneself makes behaviour more flexible, thereby making actions more consistent with personal values.

'**Self as Context**' is a process in which a person learns to discriminate between the 'thinking self' and the 'observing self'. The process of 'thinking' contains the self- perception of a person, containing all thoughts that arise. During the process of 'observing', experiences are made through the awareness of the presence of these thoughts. Thus thoughts are seen in a broader context and not as essential of the self. Harris (2006) writes that the body, thoughts, and feelings change, but the 'I', which observes everything, never changes.

'**Values**' are chosen by a person to qualify his or her directions in life. They are essential in creating a meaningful life.

'**Committed action**' implies both the determination of personal goals, based on personal values, and an effective achievement of activities to reach these goals.

The processes described above can be represented in the 'ACT Hexaflex'(Hayes, 2006, p.8, Fig. 2). The author chose for an adapted illustration of the Hexaflex (Figure 1, by S. Bufink). The processes of 'Contact with the Present Moment', 'Acceptance', 'Cognitive Defusion' and 'Self as Context' can be assigned to the concept of 'Mindfulness and Acceptance'.

Mindfulness - Consciously bringing awareness to the 'here-and-now experience' with openness, interest and receptiveness - is a key aspect of psychological flexibility because it empowers valuing and committed action. 'Self as Context', 'Committed Action', 'Values' and 'Contact with the Present Moment' can be assigned to the concept of 'Commitment and Behaviour Change'. All processes are interrelated. Combined they increase psychological flexibility. Figure 1 shows that 'Contact with the Present Moment' and 'Self as Context' are overlapping. This is due to the fact that all psychological activity, of conscious human beings, involves the here-and-now as known (Hayes, 2006).

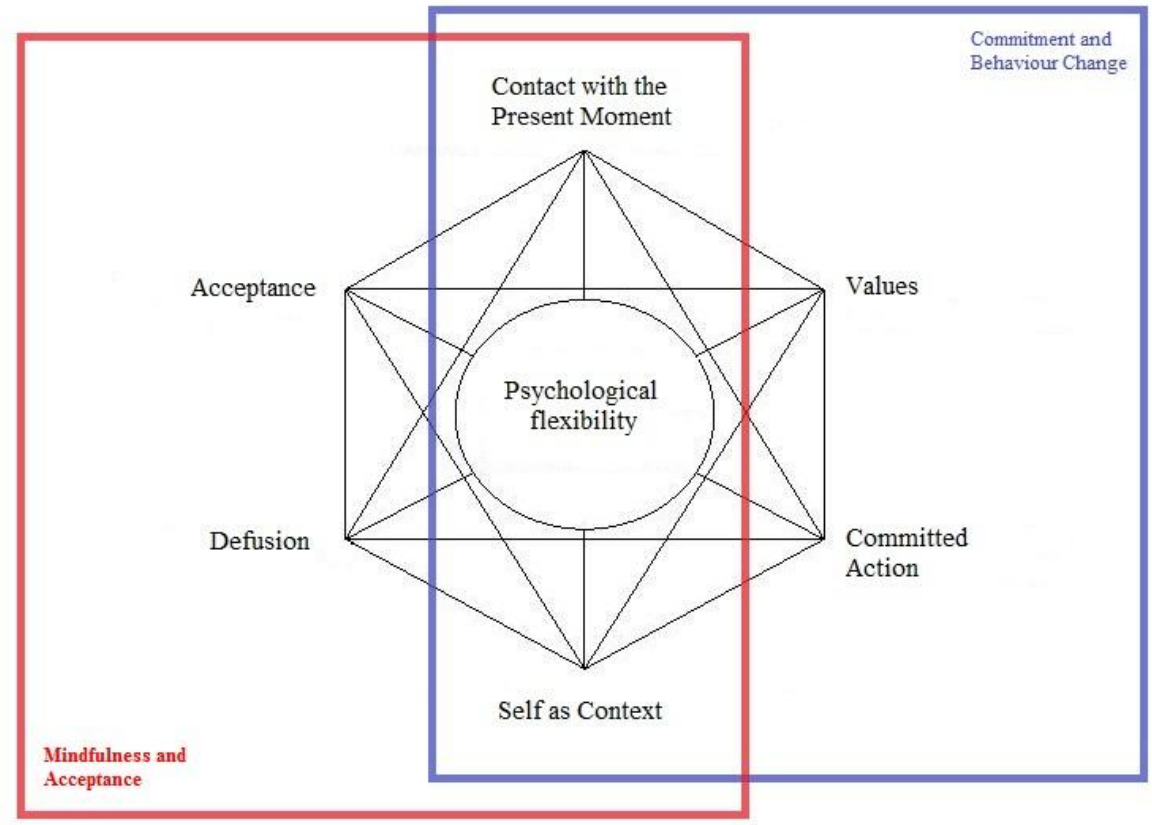

Figure 1: A model of the positive psychological processes ACT seeks to strengthen. (Hayes, 2006)

2.2.1. Effectiveness of ACT

Various studies with patients suffering from chronic pain have shown ACT to be effective. Here three studies will be presented.

In the study of Dahl, Wilson, & Nilsson (2004) the participants were workers, who present a certain amount of risk to develop disabilities due to pain and stress. The researchers showed that ACT can decrease the number of sick days and the use of medical treatment resources of these workers.

McCracken and Eccleston (2005) analyzed the acceptance of pain and patients' overall functioning (emotional, social, and physical functioning, medication consumption, and work status) at two different points of measurement. They found a relationship between the acceptance of pain at the first point of measurement and the functioning of the patient at the second point of measurement. According to McCracken, accepting pain, and thus engaging in activities regardless of pain, can lead to healthy functioning for patients with chronic pain.

Wicksell et al. (2008a) compared the effectiveness of ACT to a multidisciplinary treatment approach (MDT) on the functioning ability in relation to pediatric longstanding pain. They evaluated ACT to be more effective, performing better on the perceived functional ability in relation to this pain.

Although the studies mentioned above have shown the effectiveness of ACT in chronic pain, no research has been done on ACT using daily measurements so far. Thus especially for daily measurements more research is needed.

In a new study, the effectiveness and working mechanisms of ACT in patients with chronic pain will be analyzed. To assess the effectiveness and working mechanisms a single case design will be used. A Single-case study is a repeated measure design in which a single participant is observed over time. A number of observations are made at different times over the course of the treatment, for example daily (Hadert & Quinn, 2008). The items included in this new study have never been used before in daily measurements.

Therefore, a pilot-study of the (daily) items has to be performed. The pilot- study has to 1) give more information about the suitability of items (approached in part 1 of this study) and their functioning when assessed on a daily basis (approached in part 2). Further it has to 2) give general information about daily measurements (also approached in part 2). The ultimate goal of the pilot- study is to give specific recommendations for the larger study. For one of the concepts measured (in the large study), no suitable items were available, so the first part of this research focused on the selection of suitable items.

The following research questions can be conducted:

1) What items are most suitable for daily measurement of the concept 'values-based living'?
2) When performing daily measurements in pilot: How do the chosen items function when applied daily (for two weeks)?
3) What are the general outcomes of the pilot-study that can improve the large study?

3. Methods

Both research parts of this study are separated from one another in this and the next chapter, containing the results.

The first part of this study is based on the item selection process by means of 'Three-Step Test-Interview'. The second part is based on the analysis of the items' functioning during daily measurements.

Below relevant information about the participants and the applied procedure of each part are presented.

3.1. Part 1

3.1.1. Participants

In the first part of the research ten participants suffering from chronic pain participated. All participants were women, with huge age differences. They suffer from various forms of chronic pain. The participants of this study went through an eight- week pain rehabilitation program at the Roessingh Rehabilitation Centre (RRC). At the time of this research all participants were in their last week of treatment.

3.1.2. Procedure

The participants were contacted by the group leaders of the Roessingh Rehabilitation Centre to see whether anyone was interested to take part in this study. Participation was voluntary and did not have any financial or other reward. Interview appointments were made personally by the researcher at the Centre.

Each participant was interviewed separately in a quiet room. A voice recorder was used during all the interviews. Furthermore, notes were taken to ease the analysis of all statements afterwards. Before the interview started, the participants were instructed. The opportunity to read the instructions by themselves was given. After they agreed verbally, the paper questionnaire (Appendix A, I) was handed out to them. By means of an example ("Ik vermijd het doen van dingen wanneer er het risico bestaat dat het pijn zou doen of de dingen erger maken") the researcher wanted to assure that the participants got the intention of this part correctly. The applied technique will be presented in the following paragraph.

The length of the interviews varied between 5 and 23 minutes among the participants. Subsequent to the interviews, the participants were asked whether they were interested to participate in the second part of the study as well, the daily measurement of the questionnaire.

3.1.3. Three-Step Test-Interview

The author used the 'Three-Step Test-Interview' (TSTI) to collect the data. The TSTI comprises two main techniques, 'think aloud' and 'probing' (Hak et al. (2004)). 'Probing', where reports about thinking are elicited outside of the context of the questions, will not be used in this study. This technique is inconvenient in the context of this research.

In this paper the author applied the '**think aloud**' technique which aims at making the cognitive process of thinking visible. It contains three steps: The main step is 'concurrent think aloud', with the purpose to collect information about the participant's response behavior. The aim is a quiet observer and a participant who speaks out loud everything that comes into his/ her mind while reading an item. In general the process of thinking is hidden, but by verbalizing their thoughts and acts, like skipping items, the cognitions of participants become observable and therefore an analysis is feasible. Two additional steps are 'focused interview', which serves to complete the observational data from the first step, and 'semi-structured interview', which aims at eliciting experiences and opinions.

The questionnaire, containing 18 items, was discussed in two steps with each participant. In the first step the process of '*concurrent think aloud*' (described above) was applied. In the second step, so called 'problem-items' were given more attention and were discussed in greater detail. If a participant verbalized problems with items, skipped items or took a longer break in the 'concurrent think aloud' process, these items were discussed again. This discussion was realised by the steps of 'focused interview' and 'semi-structured interview'. The author chose a conjunction of these two steps because both illustrate and explore the observed data from the previous step ('concurrent think aloud') and because this research is a pilot and such an explicit distinction between them is not necessary.

3.2. Part 2

3.2.1. Participants

Five participants from the first part of the study had agreed to participate in the second part as well, but only three participants completed this study (see Table 1, page 13). They all have had an eight-week treatment at the RRC and already spend a couple of weeks at home, in their normal life circumstances.

Participant	Gender	Age	Education
1	female	42	HBO
2	female	32	HBO
3	female	21	SPH HBO

Table 1: Descriptive information about participants, part 2

3.2.2. Procedure

The item analysis of the first part had to be finished before the start of the second part and hence it took a couple of weeks before the daily measurements began.

Firstly, again contact was made with the participants as their daily therapy at the RRC had ended. The researcher received the mail address or phone number of the participants and contacted them to ask whether they were still interested to participate in the study. Of the five participants, four liked to be assessed via email and one via regular mail.

Secondly, a postal- package was sent to one participant. This package contained a letter of instruction, 14 questionnaires for daily completion and two retour-envelops to send the completed questionnaires (Appendix B, I) back to the researcher after two weeks. In the end the participant got a feedback paper (Appendix C, I) via mail, to evaluate the daily measurement. The participant had the opportunity to give her opinion about the suitability of the items for daily measurement and her personal impression and feelings while responding to the items. The other four participants received the instructions per email, including a link, which connects them with the online questionnaire tool 'Survey Monkey'. It is suitable for market survey, scheduling of events, feed-back from clients, planning of products, or education and training. This page is public for everyone who opens an account. On 'Survey Monkey' the same questionnaire like the postal one was created. Every participant received an anonymous code to ensure their privacy was protected. The participants were asked to fill in the questionnaire in the evening, between 6 pm and 9 pm. After they responded to the items, the results were immediately saved and could be analyzed by the researcher. This was advantageous because the researcher could take a daily look at whether the participants responded or not. A few days after the daily measurements, the participants received a new link per email, which presented them a feedback questionnaire on Survey Monkey. Like the feedback via mail, the participants had the opportunity to give their opinions about the suitability of the items for daily measurement and their personal impression and feelings during the two weeks of measurement.

In the following, results of the 'think aloud' interviews are presented (part 1). The second part below presents the outcomes of the daily measurements.

4. Results

This section, like the section where the methods were presented, contains two parts. In the first part, the participants evaluated the given questionnaire one-time. In the second part, the experiences of daily measurements were tested with a couple of the participants.

4.1. Part 1

The presented questionnaire consists of three different concepts. The most important concept in the context of this study is the one of 'values-based living'. The first research question "What items are most suitable for daily measurement of the concept 'values-based living'?" was approached by the analysis of the items 1 to 8, because they contain this concept. No questionnaire measuring this concept was available, thus items 1, 2 and 3 were chosen from the 'Life regard index' (Ballista & Almond, 1973) and items 4 and 5 were chosen from Hayes' Daily Diary Measure. Items 6, 7 and 8 are newly formulated items for this study.

The two remaining concepts of 'Psychological Inflexibility' and 'Pain' are important outcomes variables in the research context about the effectiveness of ACT in chronic pain patients. Items 9 to 13, chosen randomly from the PIPS (Psychological Inflexibility in Pain Scale) (Wicksell, 2008b), measure the concept of 'Psychological Inflexibility'. Items 14 to 18 were chosen randomly from the MPI-DLV (Multidimensional Pain Inventory, Dutch language version) (Lousberg et.al, 1999), measuring the concept of 'Pain'. The items of these two concepts (items 9 to 18) will be presented and discussed in less detail than the first eight items because they were not in the main focus of this study. The PIPS and the MPI-DLV were added to the questionnaire because this study provided the opportunity to gather responses to these concepts. The items of these scales already exist and the questionnaires are already validated, so they could be used without any further item analysis.

4.1.1. Outcomes

The main focus of attention is given to the concept 'values-based living'. The comments given by the participants concerning this concept, containing items 1 to 8, are presented below. Detailed evaluations of these items can be found in Appendix A, II.

Item 1 (*Als ik terugkijk op deze dag, vind ik dat ik volledig leefde;* English: *Looking back on this day I feel that I am living fully*) was considered difficult by five out of ten participants. Three participants found the expression 'volledig leefde' ('living complete and fulfilled') too

vague. One participant wished to have more response alternatives or an open item instead. The participants asked themselves what a fully life is. A participant noted that this item does not fit very well in the situation of the Rehabilitation Centre, because she does not have the feeling of a fully life there, but the feeling of 'being lived'.

Item 2 (*Als ik terugkijk op deze dag, vind ik dat ik me door niets heb laten tegen gehouden om te doen wat ik echt wilde doen*) implied a typing error in the word 'gehouden' (English: hold up). It had to be 'houden'. The remaining of this item was unobtrusive.

Item 3 (*Als ik terugkijk op deze dag, vind ik dat het lijkt of ik de dingen die echt belangrijk voor me zijn ook echt voor elkaar kon krijgen*) was commented by two participants. Both find 'het lijkt' problematic. One of them said either you handle something or not. 'Het lijkt' was seen as incorrect in this context. Further some participants got confused by the word 'echt' which was presented twice within this item.

Item 4 (*Als ik terugkijk op deze dag, vind ik dat ik succesvol was in het uitvoeren van acties die waardevol voor me zijn*) was considered difficult by two participants. For one participant the word 'succesvol' in combination with the word 'waardevol' was irritading. For the other participant the emphasis lies too much on 'succesvol' en 'acties'.

Item 5 (*Als ik terugkijk op deze dag, vind ik dat de dag van vandag onderdeel was van een vitaal leven*) can be compared with item 1 because the participants saw this item as difficult as the first item. 'Vitaal leven' was seen as a vague expression. According to one participant it is almost impossible to measure a concept like 'vitaal leven' based on a measurement of one day.

Item 6 (*Als ik terugkijk op deze dag, vind ik dat ik dingen heb kunnen doen die het leven de moeite waard maken*) was considerd a good item by the most participants. Only two found 'de moeite waard' too ample.

Item 7 (*Als ik terugkijk op deze dag, vind ik dat ik aan dingen toegekomen ben die belangrijk voor me zijn*) was considered a good item in general. One participant commended that 'dingen die belangrijk zijn' is a process and do not refer to one day.

Item 8 (*Als ik terugkijk op deze dag, vind ik dat ik heb geleefd, zoals ik altijd zou willen leven*) was evaluated very different by the participants. One half had no problems or comments on this item, whereas five participants got irritated by 'zou willen leven'. According to them, this item is too vague and unsuitable to ask.

A discussion of items 9 to 18, containing the concepts of 'Psychological Inflexibility' and 'Pain', will not be presented here, because these items lay beyond the main focus of this study. Evaluations and comments of them can be found in Appendix A, III.

Based on the outcomes of this first part of the study, items for the second part were selected.

4.1.2. Process of item selection

The aim of the item selection procedure was the creation of a questionnaire, suitable for daily measurement in the second part of this research. Taking all concepts into account items 3, 4, 6, 7, 9, 10, 11, 12, 13, 14, 16, 17 and 18 got the most positive responses and were rated as 'good'[1]. An overview is presented in Appendix A, IV.

As mentioned before, items 1 to 8 contain the main concept of 'values-based living'. Based on the participants responses, obtained by the think-aloud technique, items 1, 2, 5 and 8 were rated worst and thus were not taken into account any further in the selection process. The remaining items of this concept 3, 4, 6 and 7 were evaluated individually and independently by three researchers. According to the researchers, the phrasing 'het lijkt' of item 3 (*Als ik terugkijk op deze dag, vind ik dat het lijkt of ik de dingen die echt belangrijk voor me zijn ook echt voor elkaar kon krijgen)* was a too vague statement; item 4 (*Als ik terugkijk op deze dag, vind ik dat ik succesvol was in het uitvoeren van acties die waardevol voor me zijn)* contains the judgement 'succesvol' which was too objective in this context; item 6 (*Als ik terugkijk op deze dag, vind ik dat ik dingen heb kunnen doen die het leven de moeite waard maken)* presents the participant the opportuniy to decide what makes life worth living for him- or herself and item 7 (*Als ik terugkijk op deze dag, vind ik dat ik aan dingen toegekomen ben die belangrijk voor me zijn)* is easily and as subjectively formulated as neccesary. Based on these evaluations, items 6 and 7 were chosen to be most suitable for daily measurements of the concept 'values-based living'. The items can be found in the questionnaire of part 2 below.

The item selection of the remaining items (items 9 to 18) was made simple. All items from the second concept 'Psychological Inflexibility' were rated as 'good'[1] by the participants. So the researcher chose one item out of items 9 to 13 and three additional items from the original PIPS. From the third concept 'Pain' four items were selected out of items 14 to 18 and one additional item was chosen from the original MPI-DLV. Because the original PIPS and MPI-

[1] An item is rated as ‚good' if five or more participants evaluated the item as comprehensible and suitable for daily measurement.

DLV are valid tested scales and the items for these concepts were chosen at random in the first part, the author expected no problems when selecting other items from the original scales to use in the second part of this study.

4.1.3. General findings

To some participants the situation at the Rehabilitation Centre and the situation at home seemed to be very different. Especially the first participants commended that a lot of items would better fit into a situation at home. This is due to the fact that the participants can better respond to items containing values of life when they live in their familiar environment, engaging in habitual activities which are valuable for them, than following to the program of the RRC.

According to the participants, further difference should be made between pain and fatigue. Some of them got a little confused and could not response to the items as it was intended because the concept 'pain' did not perfectly fit to them. A few gave the suggestion of an extra questionnaire with items about fatigue or a combination of both, pain and fatigue. So the questionnaire should be adjusted in the second part of this study, however two different questionnaires are not necessary in this context.

Furthermore, several participants disliked the response alternatives 'wel-geen verandering' of the items because no change could be detected. This problem had been solved when the questionnaire was presented daily and not only once.

4.2. Part 2

This part corresponds to the second research question. The aim was to analyze how the selected items from part 1 function when applied in daily measurements, for two weeks.

Item 1 and 2 of the new questionnaire belonged to general information about the participants' personal code and the time of starting and finishing with each daily session and thus are not relevant in this context. As described above in the items selection process above (paragraph 4.1.2.), some items used in this second part were selected from the first part of the study (items 5, 7, 8, 9, 10, 11, 13) and others are chosen from the original scales of the concepts. Table 2 (page 19) clarifies the different numbering of the items in part 1 and part 2.

An overview of the items is given in Appendix B, I. For more detail see also paragraph 4.1.2 'Process of item selection'. The responses of three participants were analyzed. A detailed overview of each participant's answer can be found in Appendix B, II.

Concepts	values-based living'								PIPS					MPI-DLV				
Item number in part 1	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
rated as 'good' by participants			x	x		x	x		x	x	x	x	x	x			x	x
evaluated as suitable by researchers						x	x							random selection				
						↓	↓			↓				↓	↓			↓
Item number in part 2						7	8			5				10+11	13			9

Table 2: Numbering of items in part 1 and 2.

In the following paragraph the responses to each item will be presented separately. Subsequently the responses will be compared within each concept. Here the same like mentioned above is true for the items: Item 7 and 8 of the concept ‘values-based living’ are the most interesting. To keep track of the different concepts they are marked in different colours.

4.2.1. Outcomes

Items 3 to 6 are taken from the PIPS (coloured in red), representing the concept of ‘Psychological Inflexibility’. Higher scores on the items represent more psychological inflexibility and lower scores represent less psychological inflexibility, thus more flexibility.

Item 3

Participant 1 responded during the 14 days measurement to item 3 (*Als ik terugkijk op deze dag zou ik er bijna alles aan doen om van mijn pijn af te komen*.) with a mean score of 6.64 on the 10-point scale, ranging from 5 to 9 and a variance of 1.94. Participant 2 responded with a mean score of 5.21, a range from 3 to 7 and a variance of 1.57. Participant 3 responded with a mean score of 2.43, a range from 1 to 5 and a variance of 1.96. The participants responded with an overall mean of 4.76. The variance within the range was 4.0 for all participants.

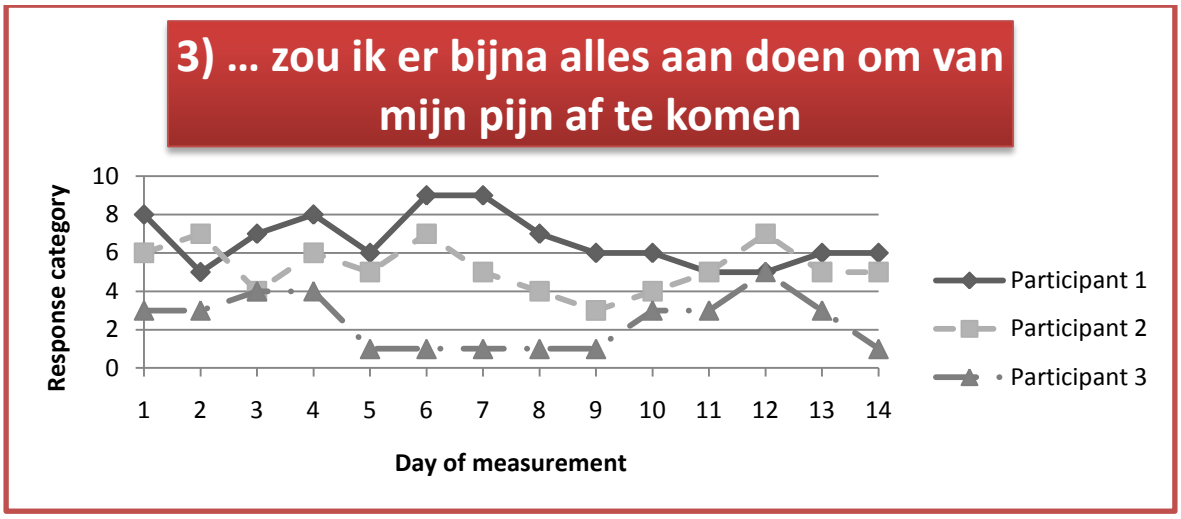

Figure 2: Responses of three participants to item 3 of the concept 'Psychological Inflexibility'.

Item 4

Participant 1 responded to item 4 (*Als ik terugkijk op deze dag is het belangrijk dat ik leer mijn pijn te controleren.*) with a mean score of 6.57, a range between 5 and 9 and a variance of 1.65. Participant 2 responded with a mean score of 4.14, a range between 3 and 6 and a variance of 1.06. Participant 3 responded with a mean score of 1.64, a range between 1 and 4 and a variance of 1.02. The overall mean of the measurements was 4.12. The variances within the range were 4.0, 3.0, and 3.0 respectively.

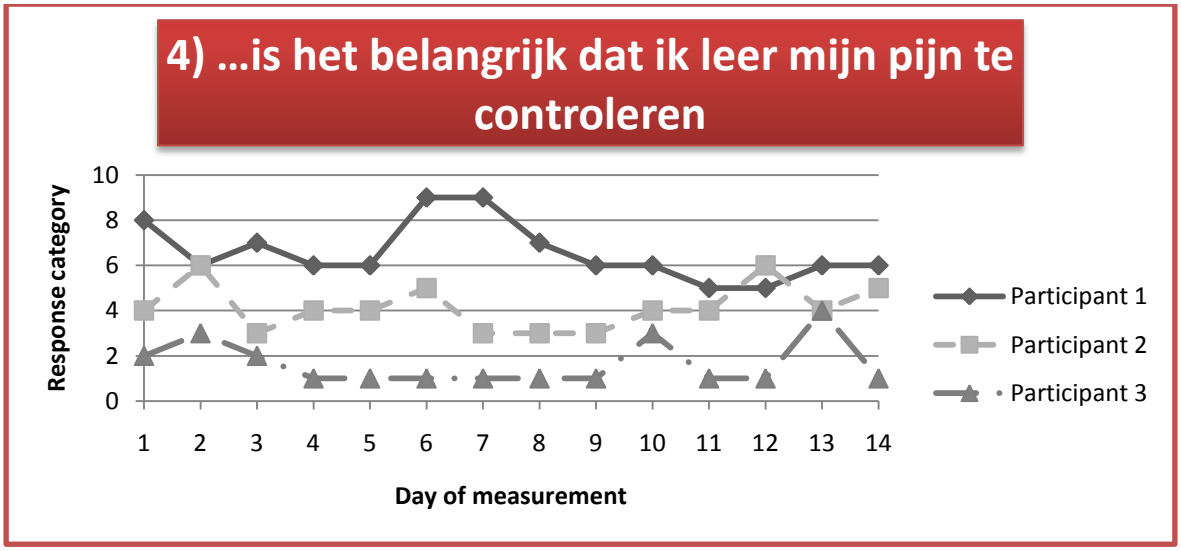

Figure 3: Responses of three participants to item 4 of the concept 'Psychological Inflexibility'.

Item 5

The overall mean of item 5 (*Als ik terugkijk op deze dag heb ik dingen uitgesteld vanwege mijn pijn.*) was 4.81. Participant 1 scored with a mean of 6.0, a range between 4 and 9 and a variance of 3.54. The mean score of participant 2 was 4.93. The range lay between 2 and 7,

and the variance was 2.53. Participant 3 responded with a mean score of 3.5, a range between 1 and 6 and a variance of 3.35. The variance within the range was 5.0 for all participants.

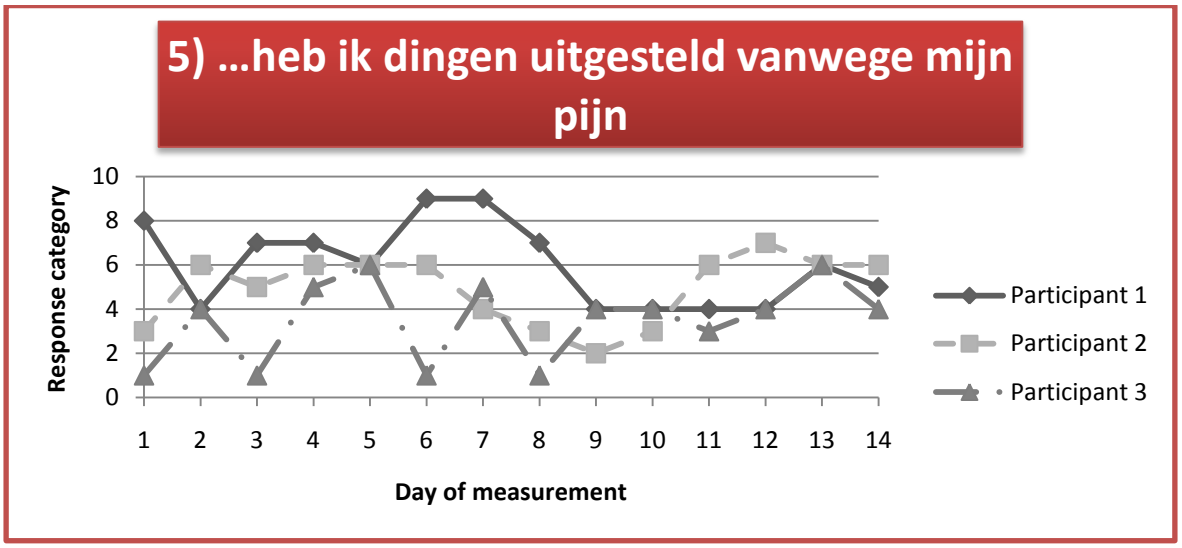

Figure 4: Responses of three participants to item 5 of the concept 'Psychological Inflexibility'.

Item 6

Item 6 (*Als ik terugkijk op deze dag heb ik het vermeden dingen te doen wanneer er het risico bestond dat het pijn zou doen of de dingen erger zou maken*.) was responded to by the participants with an overall mean of 4.64. Participant 1 responded to this item with a mean score of 6.79, a range between 4 and 9 and a variance of 2.03. Participant 2's mean score was 3.86, it ranged between 1 and 6 and had a variance of 2.59. Participant 3 responded with a mean score of 3.29, a range between 1 and 6 as well, and a variance of 2.84. The variance within the range was 5.0 for all participants.

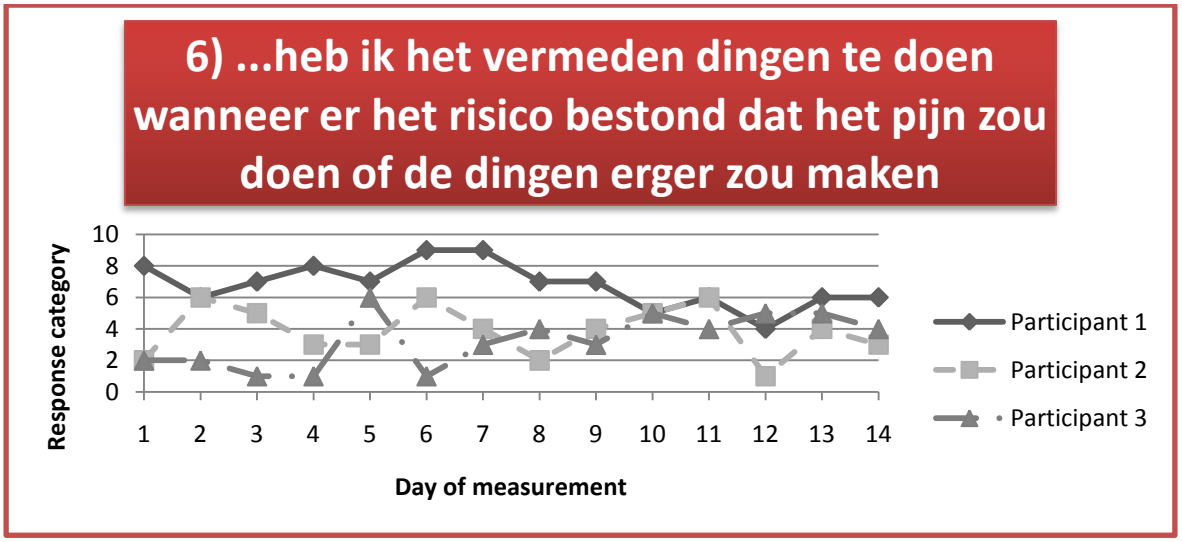

Figure 5: Responses of three participants to item 6 of the concept 'Psychological Inflexibility'.

Items 7 and 8 contain the concept of 'values-based living' (coloured in green). Scoring higher on these items means living more according to one's own values. Lower scores imply living less according to one's own values.

Item 7

Participant 1 responed to item 7 (*Als ik terugkijk op deze dag vind ik dat ik dingen heb kunnen doen die het leven de moeite waard maken*.) with a mean score of 6.21. Its range lay between 3 and 8 and the variance was 2.34. Participant 2 scored the mean 5.14 with a range between 2 and 7 and a variance of 2.13. Participant 3 responded with a mean score of 7.5, a range between 6 and 10 and a variance of 1.81. This item got an overall mean of 6.29. 5, 4, and 4 points were the variances within the range.

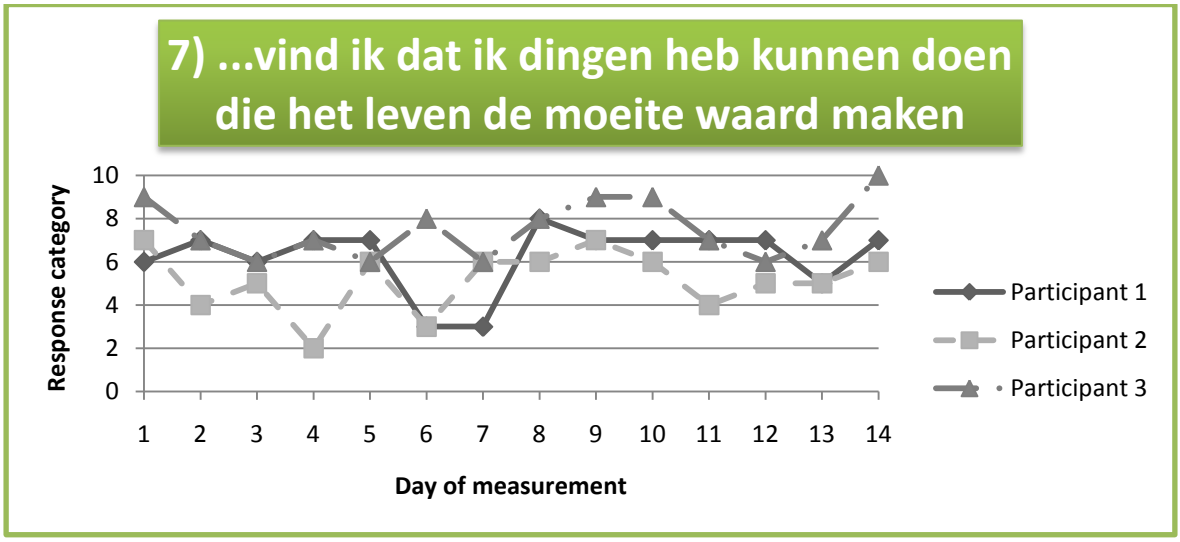

Figure 6: Responses of three participants to item 7 of the concept 'values-based living'.

Item 8

The overall mean of item 8 (*Als ik terugkijk op deze dag vind ik dat ik aan dingen toegekomen ben die belangrijk voor me zijn*.) was 6.0. The mean of participant 1 was 5.86 and a range between 2 and 7, participant 2 responded with a mean of 5.71 ranging between 3 and 8, and participant 3 with a mean of 6.43 and a range between 4 and 9. The variances were 3.36, 1.91, and 2.88, respectively. For all participants the variance within the range was 5 points.

Figure 7: Responses of three participants to item 8 of the concept 'values-based living'.

Items 9 to 13 were chosen from the MPI-DLV (coloured in blue), representing the concept of 'Pain'. Higher scores on these items imply more reduction of daily activity caused by pain. Lower scores imply less impact of pain in daily life.

Item 9

To item 9 (*Als ik terugkijk op deze dag heeft de pijn mijn mogelijkheden tot het uitvoeren van huishoudelijke werkzaamheden beinvloed*.) was responded with an overall mean of 5.48. Participant 1 scored a mean of 6.64, ranging between 4 and 9 and a variance of 2.56. Participant 2 scored a mean of 5.93, ranging between 2 and 8 and a variance of 2.53. Participant 3 scored a mean of 3.86, ranging between 1 and 6 and a variance of 2.9. The variances within the range were 5, 6 and 5 points respectively.

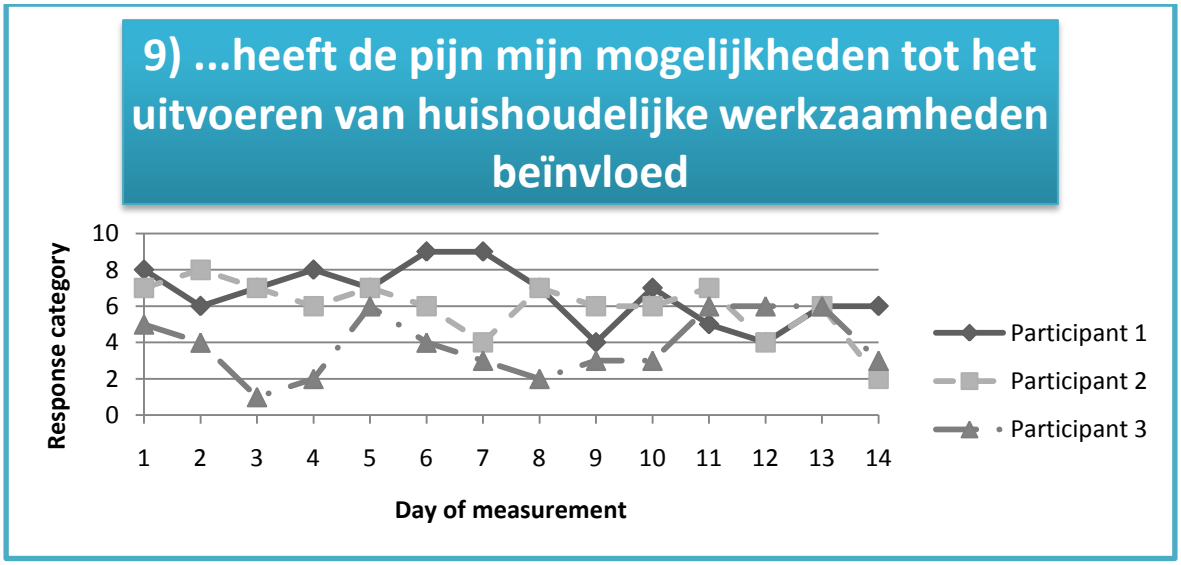

Figure 8: Responses of three participants to item 9 of the concept 'Pain'.

Item 10

The answers to item 10 (*Als ik terugkijk op deze dag ben ik door de pijn belemmerd bij deelname aan ontspanning.*) of both participant 1 and 2 ranged between 4 and 9, with a mean of 6.79 and 6.36 respectively. Participant 3 responded with a mean score of 3.86 and a range between 1 and 7. The variances were 2.03, 1.48, and 3.98, respectively. 5.67 was the overall mean of this item. The variances within the ranges were 5.0, 5.0, and 6.0 for participant 1, 2, and 3.

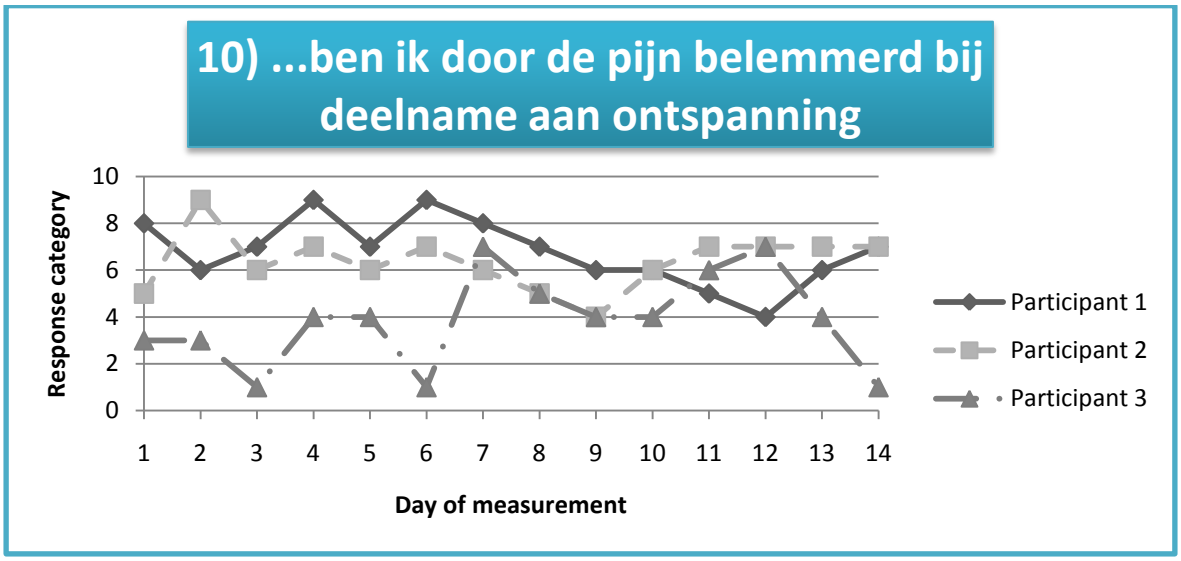

Figure 9: Responses of three participants to item 10 of the concept 'Pain'.

Item 11

6.43, 5.0, and 3.79 were the mean scores of participant 1, 2 and 3 to item 11 (*Als ik terugkijk op deze dag ben ik door de pijn belemmerd bij het uitvoeren van sociale activiteiten*.). The scores of participant 1 ranged between 4 and 9. The scores of participant 2 ranged between 2 and 7, and the scores of participant 3 ranged between 1 and 7. The variances were 3.03, 3.08, and 4.95, respectively. The mean of all measurements of all participants during the 14 days was 5.07. On this item the participants responded with a variance of 5, 5, and 6 points within their response range.

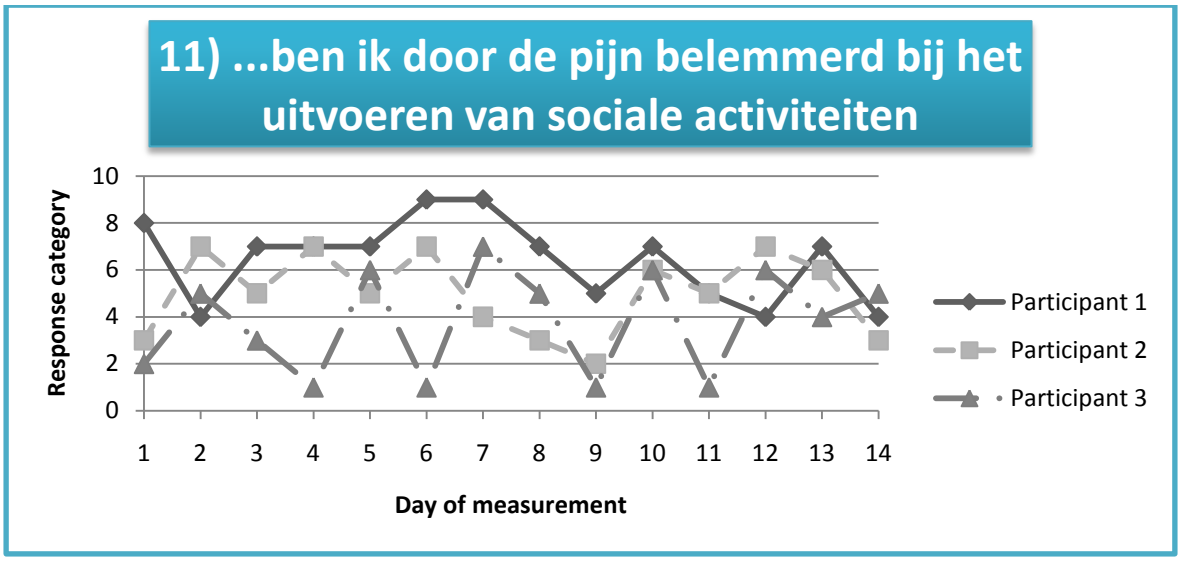

Figure 10: Responses of three participants to item 11 of the concept 'Pain'.

Item 12

Participant 1 responded with a mean score of 5.93 to item 12 (*Als ik terugkijk op deze dag heeft de pijn mijn vermogen om te werken (betaalde of onbetaalde werkzaamheden) beinvloed*.). The scores ranged between 3 and 9 with a variance of 3.92. Participant 2 responded with a mean score of 4.57, ranging between 0 and 8. The variance was 5.03. Participant 3 responded with a mean score of 3.9, a range between 1 and 7 and a variance of 6.38. The overall mean was 4.81. The variances within the ranges were 6.0, 8.0, and 6.0 respectively.

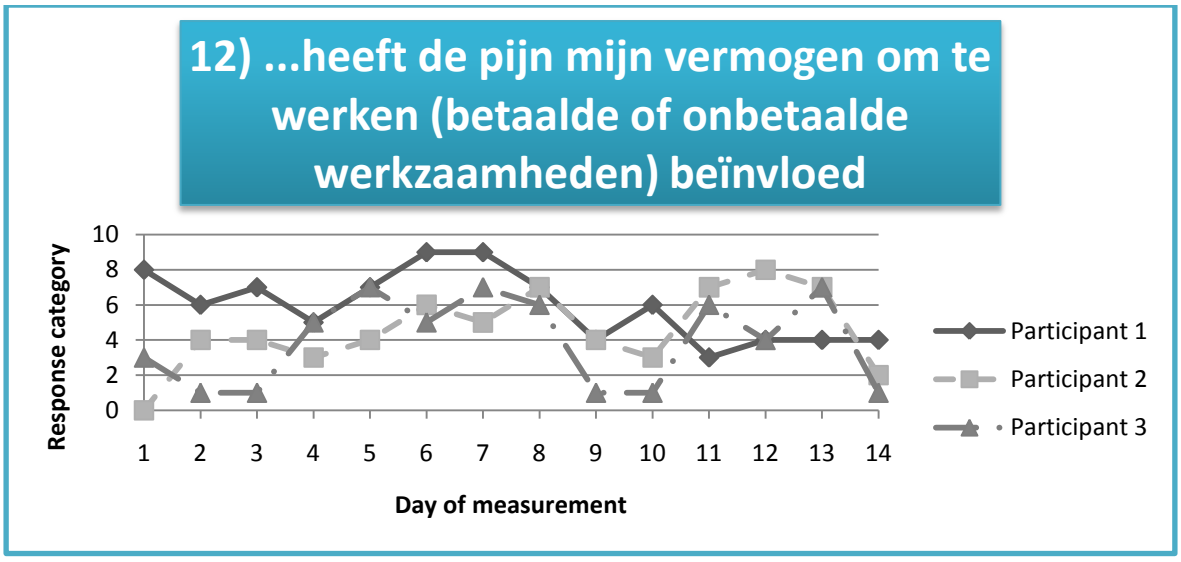

Figure 11: Responses of three participants to item 12 of the concept 'Pain'.

Item 13

Item 13 (*Als ik terugkijk op deze dag heeft de pijn het plezier dat ik ondervind van deelname aan gezin(sbezigheden) beinvloed*.) got an overall mean score of 4.45. Participant 1 responded to this item with a mean score of 6.5, participant 2 responded with a mean score of 4.86 and participant 3 responded with a mean score of 2.0. The ranges lay between 3 and 9, 2 and 8, and 1 and 6, and the variances were 2.73, 2.44, and 2.15, respectively. The variances within the ranges were 6, 6, and 5 points.

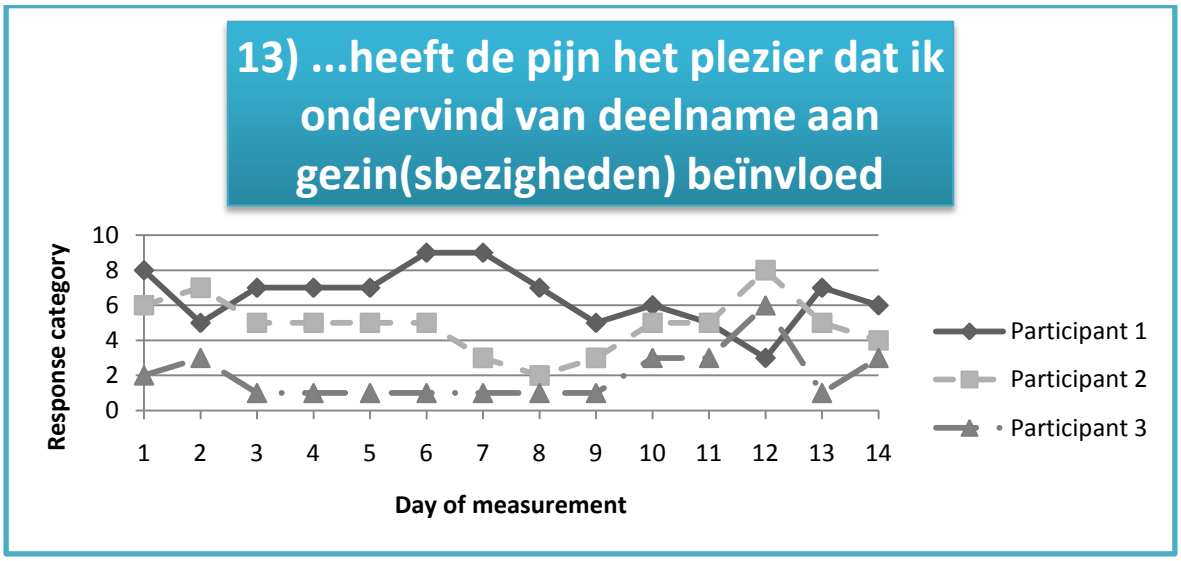

Figure 12: Responses of three participants to item 13 of the concept 'Pain'.

Below the items were clustered by the concepts 'Psychological Inflexibility', 'values-based living' and 'Pain'. Within each concept the items were compared separately between the participants.

The clustering intended to detect how the items function within one concept. Especially the concept 'values-based living' containing items 7 and 8 was important.

Concept of 'Psychological Inflexibility' (PIPS)

As mentioned before, higher scores on these items imply more psychological inflexibility. Lower scores on these items imply more psychological flexibility.

Participant 1 responded to the items of the concept containing Psychological Inflexibility with a mean of 6.5. The range was between 4 and 9. Participant 2 responded with a mean of 4.54. The range was between 1 and 7. Participant 3 responded with a mean of 2.71 and a range between 1 and 6. Thus the variances between the ranges was 5, 6, and 5 points.

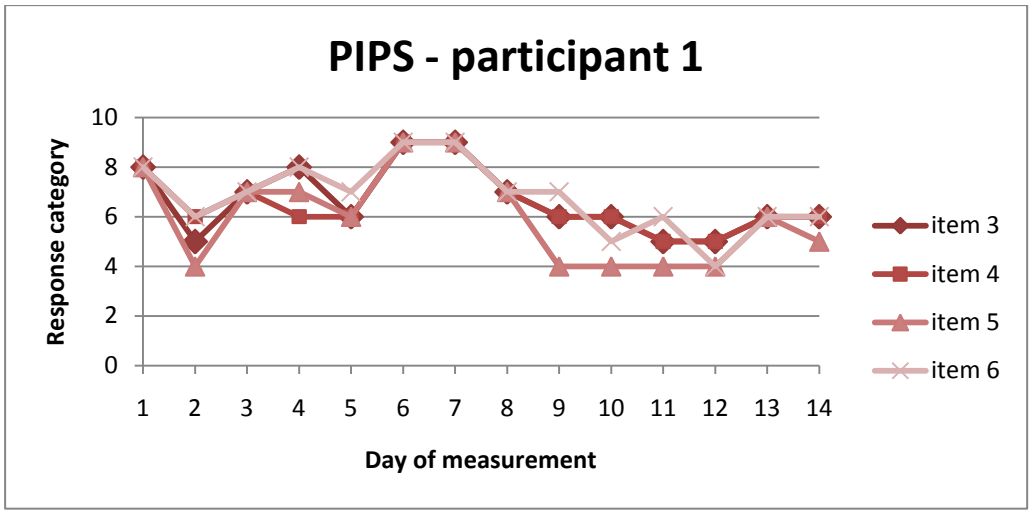

Figure 13: Responses of participant 1 to items of concept 'Psychological Inflexibility'.

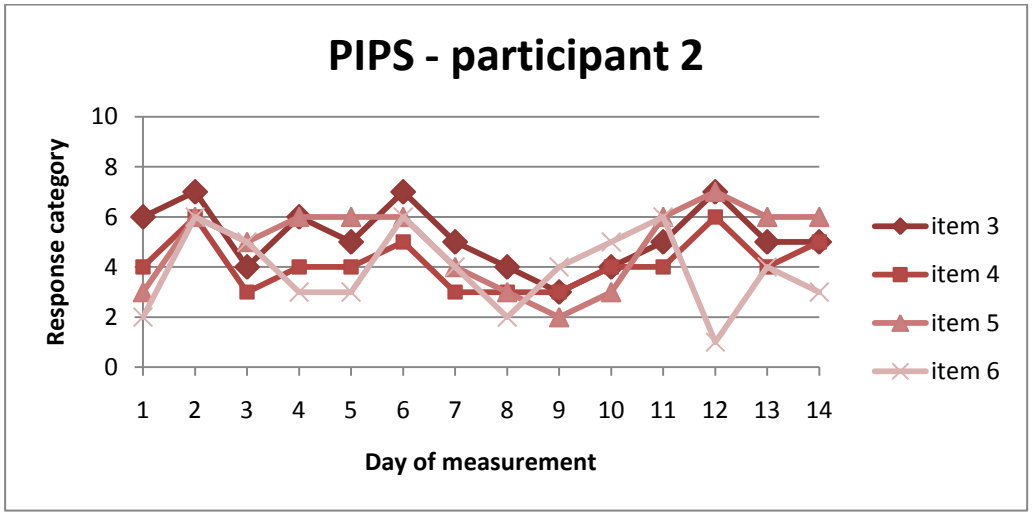

Figure 14: Responses of participant 2 to items of concept 'Psychological Inflexibility'.

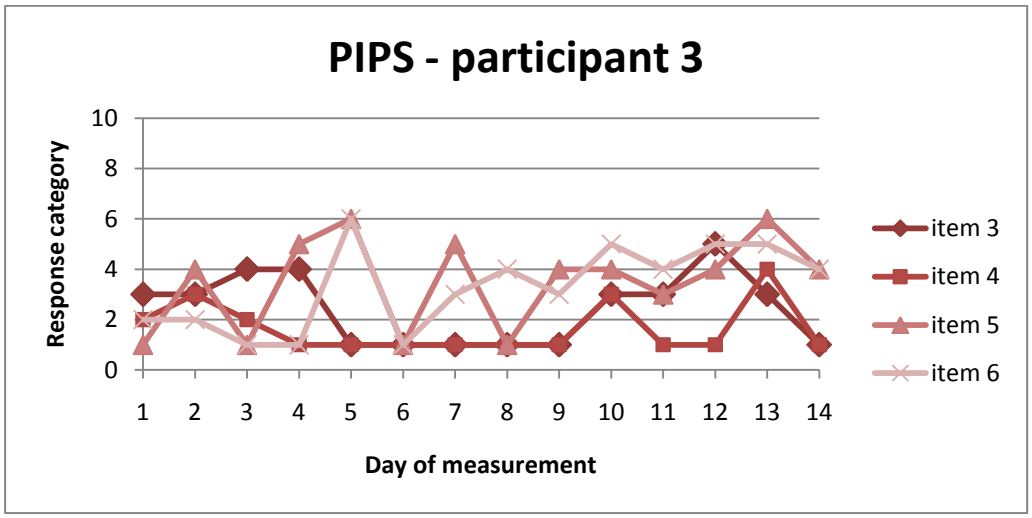

Figure 15: Responses of participant 3 to items of concept 'Psychological Inflexibility'.

Concept of ‘values-based living’

As mentioned before, higher scores on these items imply more ‘values-based living’. Lower scores imply living less according to one’s own values.

To items 7 and 8 of the ‘values-based living’ concepts was responded with a mean of 6.04 by participant 1, with a mean of 5.43 by participant 2 and 6.96 by participant 3. The ranges lay between 2 and 8 for participant 1 and 2 and between 4 and 10 for participant 3. The variance between the ranges was 6 points for all participants.

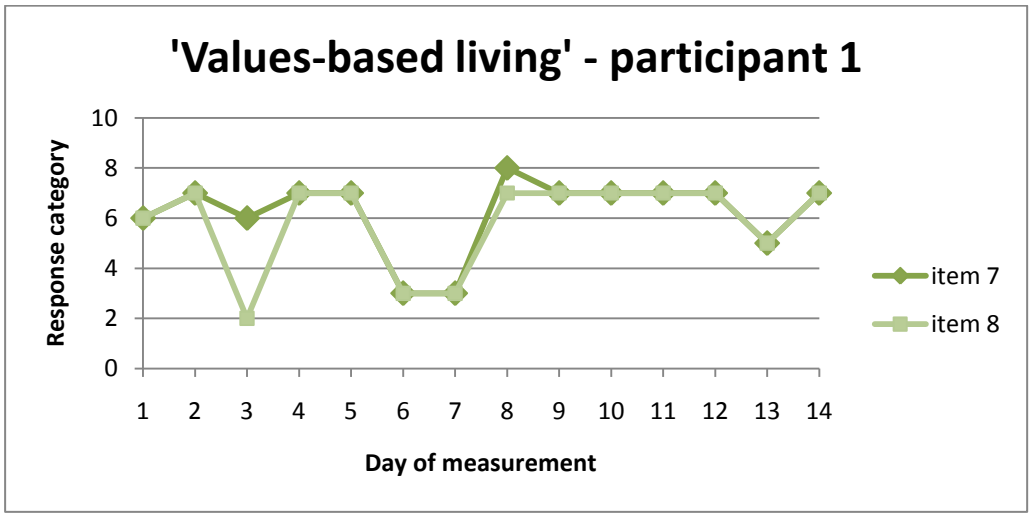

Figure 16: Responses of participant 1 to items of concept ‘values-based living’.

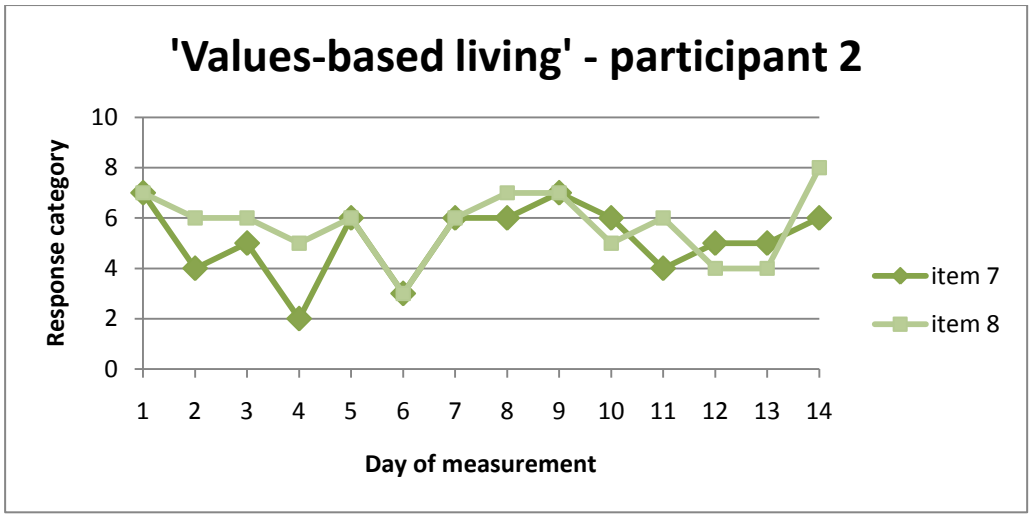

Figure 17: Responses of participant 2 to items of concept ‘values-based living’.

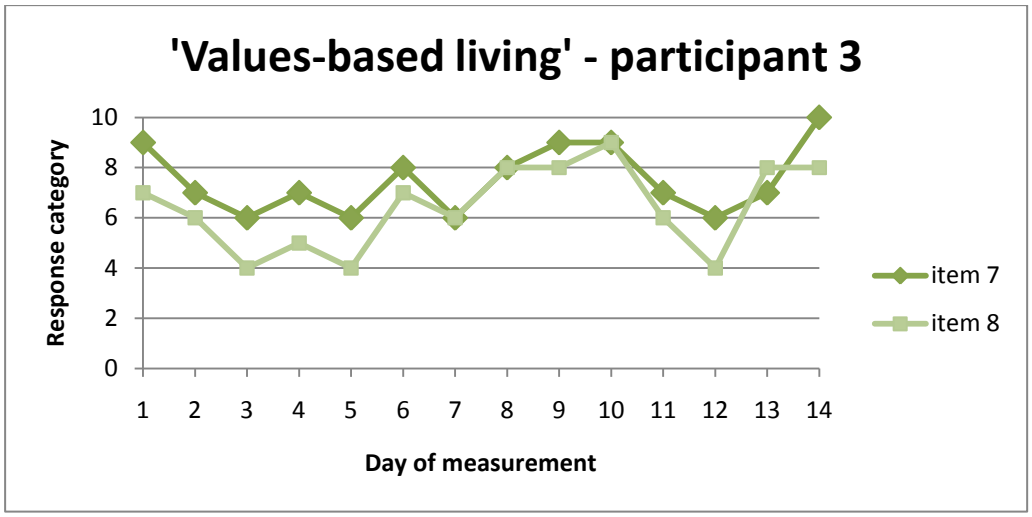

Figure 18: Responses of participant 3 to items of concept 'values-based living'.

Concept of 'Pain' (MPI-DLV)

As mentioned above, higher scores on this item imply more limitations of daily activity caused by pain. Lower scores imply less impact of pain in daily life.

Participant 1 responded to the concept of the Multidimensional Pain Inventory with a mean of 6.46, participant 2 with a mean of 5.34 and participant 3 with a mean of 3.49. The ranges varied between 3 and 9, 0 and 9, and 1 and 7, respectively. The variances between the ranges were 6 points for participants 1 and 3, and 9 points for participant 2.

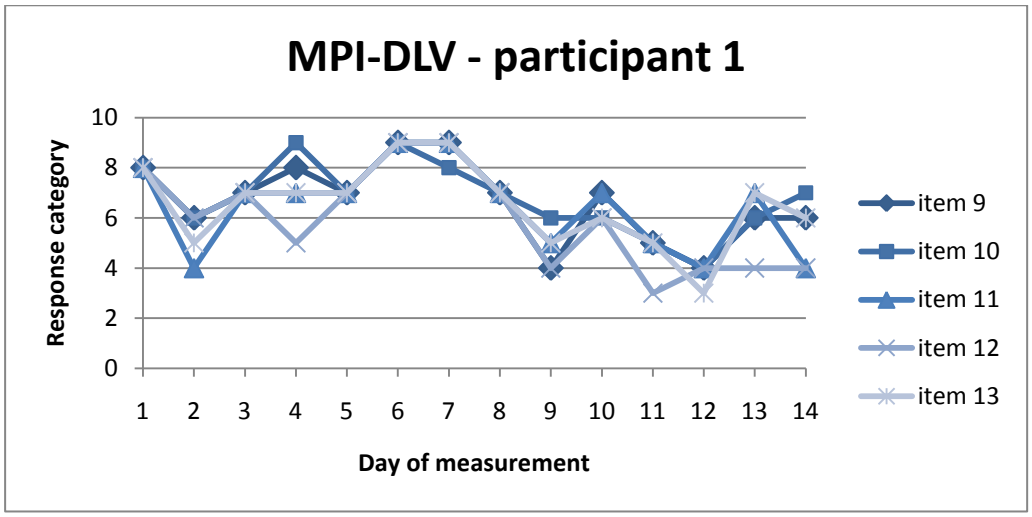

Figure 19: Responses of participant 1 to items of concept 'Pain'.

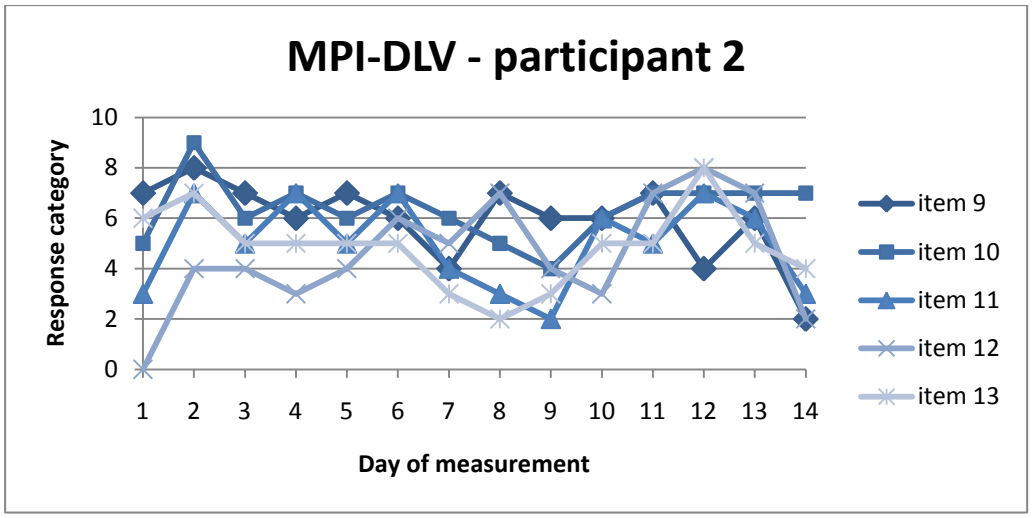

Figure 20: Responses of participant 2 to items of concept 'Pain'.

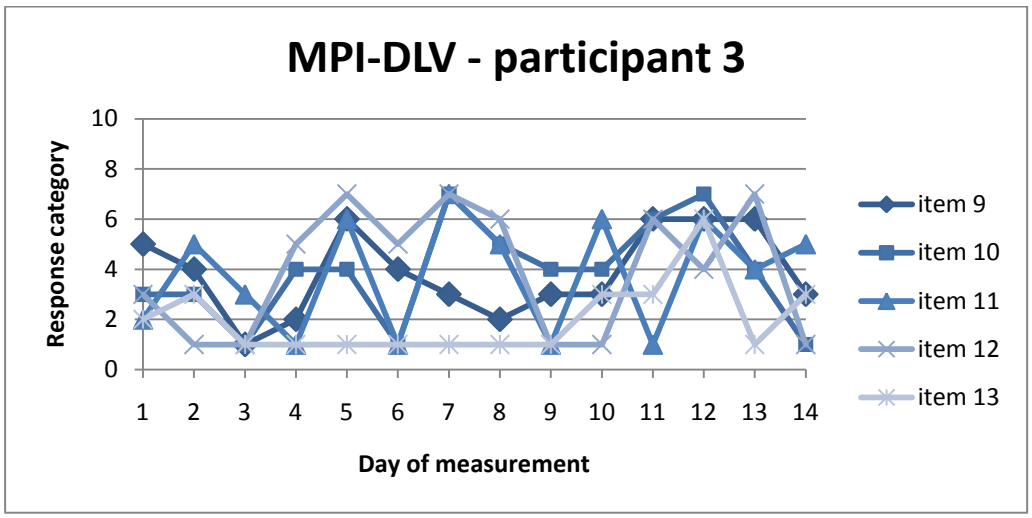

Figure 21: Responses of participant 3 to items of concept 'Pain'.

4.2.2. General findings

When looking at the individual items, the complete response range from 0 to 10 was used by the participants. Most of the responses lay between the categories 2 and 8. Furthermore, the range was almost the same for all items. For example a range of 4 points in item 3 and 5 points in items 5 and 6. A difference in the range was found only in item 12; on this item two participants responded with a range of 6 points and one participant responded with an 8-point range. Despite the overall comparable range, a variance between the responses of the participants could be found. Noticeable were the scores of participant 3 on items 3, 4 and 13. Here she responded with a very low score (category 1) on at least five days in a row. Concerning the other items, she responded with a greater variation than the other two participants and switched on some items (for example item 12) more extreme between the response categories from one day to another.

When the items were clustered into concepts of ‘Psychological Inflexibility’, ‘values based living’ and ‘Pain’ the range was almost always 6 points on a scale from 0 to 10, for all three participants. To the concept of ‘values-based living’ was responded with a range of 6 points by all participants. Within the concept of ‘Psychological Inflexibility’ the range of one participant was exactly 6 points. The range of the other two participants was 5 points. The concept ‘Pain’ presented a greater difference in the ranges. Here the range of two participants was exactly 6 points, but one participant responded with a range of 9 points.

Noticeable in the clustering was the inverted picture of the concepts. Representative for this picture were the responses of participant 3 on day 6 (Figures 15, 18, 21). She gave extreme low answers to the items measuring ‘Psychological Inflexibility’ (PIPS) and the items measuring ‘Pain’ (MPI-DLV), but high answers on the ‘values-based living’ scale, compared to the other two participants. This opposition in concepts can be explained by the fact that the responses between the three concepts are correlated: High scores on the PIPS and the MPI-DLV on one day go along with a low score on the ‘values based living’ scale on the same day and vice versa, low scores on the PIPS and MPI-DLV go along with a high score on the ‘values-based living'.

When comparing the mean values of the 14 days of measurement, a tendency among the responses could be found. Participant 1 scored almost always higher than participant 2 and 3 on the items. Participant 3 always scored lower than participant 1 and 2, with the exception of one day (day 12), where she scored higher than participant 1. The means of all items for all participants converge from day 9 on, and evened out at an average score.

4.2.3. Feedback of participants

After the daily measurements were finished and every participant had answered 14 times, a questionnaire, containing 8 items, was sent to them by e-mail. The participants were asked to give a feedback about their experiences with the daily measurements. In questions 1 and 2 the participants were asked if they managed to respond to the items daily and during the suggested time. All three of them answered this question negatively. Their reasons were that they had not enough time in the evening because of work, school, etc; they had no computer available a couple of days; or simply lost sight of it. One of the participants made the suggestion to respond to the items the next morning and thus think about the last day with a greater distance. The amount of time to answer the questions, about 5 minutes each day, was rated as acceptable. According to one participant, items 8 and 9 were comparable to item 11 because ‘ontspanning’ and ‘sociale activiteiten’ belong to ‘gezinsbezigheden. According to

another participant, items 3 and 4 were comparable and should be combined. She argued that if one wants to get rid of the pain (item 3), one wants to control the pain (item 4) as well, thus they were linked to each other.

All other items were not commented by the participants and thus can be seen as suitable for daily measurements.

A detailed overview of the feedback questionnaire can be found in Appendix C, I.

5. Discussion

5.1. Conclusion

The aim of this study was to answer the three research questions presented in the beginning.

The first research question 'What items are most suitable for daily measurement of the concept 'values-based living'?' was approached in the first part of this study. With regard to this concept, item 6 (*Als ik terugkijk op deze dag, vind ik dat ik dingen heb kunnen doen die het leven de moeite waard maken)* and item 7 (*Als ik terugkijk op deze dag, vind ik dat ik aan dingen toegekomen ben die belangrijk voor me zijn)* were chosen for the daily measurement by the ten participants and the three researchers. When including the other two concepts, totally seven out of 18 items (items 6, 7, 10, 14 split, 15, 18) were selected for daily measurement. These items were used in the second part of the study and can be used in the later, larger study as well. According to the participants, especially dealing with concepts like 'volledig leven' (item 1) and 'vitaal leven' (item 5) was challenging for them.
Generally, the researcher got the impression that the participants liked the possibility to influence the creation of a questionnaire, especially to give their opinions about the items.

The second research question: 'How do the chosen items function when applied daily (for two weeks)?' was approached in the second part of this study. The collected data was analysed in two different ways: Each item was (a) analysed separately to see how the participants responded daily, then (b) the items were clustered and compared based on the concepts of 'Psychological Inflexibility' (PIPS), 'values-based living', and 'Pain' (MPI-DLV).

Concerning the analysis of the individual items, an overall range of 6 points was found. This range provides the opportunity for improvements concerning the responses to the items. The variance of the response range within the items was small, with exception of item 12, although almost all response categories were used. This leads to the assumption that the items will work the same way with other participants or a different time period.

Concerning the analysis of the clustered items, an overall range of 6 points was found as well. Likewise, this range offers the opportunity for improvements. The variance of the range within the clusters was also small, with exception of the response of participant 2 on the concept 'Pain. Discrepancies between the items of the concept 'Pain' were not rated as exceptional because the MPI-DLV measures different activities. The items of the concept

‘values-based living’ were meant to measure the same. The discrepancy between the items roused the question whether they can be combined in one concept.

The third research question ‘What are the general outcomes of the pilot-study that can improve the large study?’ could be answered based on the general findings of the first and second part of the study and especially based on the feedback given by the participants after the daily measurements. Based on the outcomes of the first part, a distinction should be made whether a participant responded to the items at home or at the Rehabilitation Centre. The participants mentioned that some of the items, like item 9 (*Als ik terugkijk op deze dag, heb ik het vermeden activiteiten in te plannen vanwege mijn pijn*), do not fit in the context of living at the Rehabilitation Centre. This is important for the large study because therein, more measurements on a single participant will take place during a longer period. This implies that a participant will be in different treatment stages and will respond to the items at home and at the Rehabilitation Centre.

A couple of participants noted that all items contained the concept of ‘pain’ and ignored the concept of ‘fatigue’ which is important in the context of chronic pain as well. Because fatigue comes along with chronic pain, the author decided to state that the concept of ‘fatigue’ was combined to the concept of ‘pain’ at the beginning of the second part. Nevertheless, one participant criticized it as a missing concept. Thus the adjusted questionnaire began with the statement that fatigue is included in the items containing the concept of pain and not mentioned separately. This awareness is useful for the large study.

The online application for the daily measurements (questionnaire tool Survey Monkey) turned out to be beneficial for both sites. In case of a participant not responding, the researcher could easily contact her. The other way around, the participants could contact the researcher easily too, and it could be discussed how to continue. Furthermore, one participant did not send back the postal questionnaire. Keep in touch with this participant turned out be difficult. Thus it is recommended to use computers in the large study and possible later studies as well.

An important note should be made about the time of the day when a participant responds to the items. This time should be about the same each day, therefore it is important to discuss together with the participant when it suits the best.

5.2. Critical remarks

In general it turned out that the participants got the intention of the research in totally different ways. Some had no difficulties with the technique of ‘think aloud’ and gave their

opinion about the quality of the items. Others had the tendency to not only respond to the items but tried to arguing more and more about their answers. Justification of the answers was not the aim of the research, so the researcher had to intervene and stimulate the participants to talk about the quality or to go further with the items and not to go into a detailed explanation before the second step (discussion of 'problem items'). Thus the technique could not be applied in all cases.

The assumption arose that several participants had talked about the items among each other. This was disadvantageous in case a participant gave a comparable answer like a participant who was interviewed just before.

With regard to the second part of the research it was difficult to do more than descriptions of the results. Only a limited conclusion could be drawn about the suitability because no standardized group with 'healthy' persons (without chronic pain) was available.

5.3. Further research

With regard to the problem concerning the different situations at home and at the Rehabilitation Centre: Further research could concentrate on the question whether a foundation of an item pool could be created and be added by some variable items, depending on the particular measurement situation. It could be analyzed whether this approach is necessary and useful.

A couple of participants noted in the first part that a distinction between the concepts of 'pain' and 'fatigue' is important. Thus further research could work on the question whether a distinction between pain and fatigue is useful and necessary or should make the combination of the concepts more clearly.

Especially for the concept of 'values-based living' further items could be tested. This could be done by combining different questionnaire that have been tested already. The creation of new items for this concept is possible as well. If items are tested valid by statistical analysis, the concept of 'values-based living' could be used in other contexts than 'chronic pain'. However the author advises caution with the use of terms like 'vitaal leven' and 'volledig leven'.

With regard to the concept 'Pain' further research should concentrate on the question whether the items used in this study could be clustered into one concept.

Further research on ACT could examine whether other concepts, in addition to the one presented here ('Psychological Inflexibility', 'values-based living', 'Pain'), play a role in the research of 'chronic pain'.

Further research could concentrate on the establishing and testing of a standardized group, composing people that do not suffer from any kind of chronic pain. The comparison with a standardized group could help to give a better evaluation about the scores obtained in this study.

6. References

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7. Attachment

7.1. Appendix A

I) Questionnaire part 1

Pilot Single Case Design

Voorbeeldvraag

Ik vermijd het doen van dingen wanneer er het risico bestaat dat het pijn zou doen of de dingen erger maken.

Niet mee eens_____Mee eens

Vragen:

1) Als ik terugkijk op deze dag, vind ik dat ik volledig leefde.

   Niet mee eens_____Mee eens

2) Als ik terugkijk op deze dag, vind ik dat ik me door niets heb laten tegen gehouden om te doen wat ik echt wilde doen.

   Niet mee eens_____Mee eens

3) Als ik terugkijk op deze dag, vind ik dat het lijkt of ik de dingen die echt belangrijk voor me zijn ook echt voor elkaar kon krijgen.

   Niet mee eens_____Mee eens

4) Als ik terugkijk op deze dag, vind ik dat ik succesvol was in het uitvoeren van acties die waardevol voor me zijn.

   Niet mee eens_____Mee eens

5) Als ik terugkijk op deze dag, vind ik dat de dag van vandaag onderdeel was van een vitaal leven.

Niet mee eens _____ Mee eens

6) Als ik terugkijk op deze dag, vind ik dat ik dingen heb kunnen doen die het leven de moeite waard maken.

Niet mee eens _____ Mee eens

7) Als ik terugkijk op deze dag, vind ik dat ik aan dingen toegekomen ben die belangrijk voor me zijn.

Niet mee eens _____ Mee eens

8) Als ik terugkijk op deze dag, vind ik dat ik heb geleefd, zoals ik altijd zou willen leven.

Niet mee eens _____ Mee eens

9) Als ik terugkijk op deze dag, heb ik het vermeden activiteiten in te plannen vanwege mijn pijn.

Niet waar _____ Wel waar

10) Als ik terugkijk op deze dag, heb ik dingen uitgesteld vanwege mijn pijn.

Niet waar _____ Wel waar

11) Als ik terugkijk op deze dag, ben ik andere mensen uit de weg gegaan, toen ik pijn had.

Niet waar _____ Wel waar

12) Als ik terugkijk op deze dag, voelde ik me boos over mijn pijn.

Niet waar _____ Wel waar

13) Als ik terugkijk op deze dag, had de pijn de controle over mijn leven, niet ik.

Niet waar _____ Wel waar

14) Als ik terugkijk op deze dag, ben ik door de pijn belemmerd bij ontspanning en sociale activiteiten.

Geen verandering _____ Wel verandering

15) Als ik terugkijk op deze dag, heeft de pijn de mate van tevredenheid/het plezier dat ik ondervind van deelname aan mijn gezin(sbezigheden) veranderd.

Geen verandering _____ Wel verandering

16) Als ik terugkijk op deze dag, heeft de pijn mijn relatie met mijn partner en/of gezin veranderd.

Geen verandering _____ Wel verandering

17) Als ik terugkijk op deze dag, heb ik mijn bezigheden beperkt om de pijn zodoende niet erger te laten worden.

Geen verandering _____ Wel verandering

18) Als ik terugkijk op deze dag, heeft de pijn mijn mogelijkheden tot het uitvoeren van huishoudelijke werkzaamheden veranderd.

Geen verandering _____ Wel verandering

II) Evaluations of participants (part 1)

Participant 1:

Vraag:	Probleem?	Uitleg:
1	‚volledig leefde‘	Patiënte vraagt zich af wat ‚volledig leven‘ inhoud. Zij vindt het een heel omvattend begrip en moeilijk te beantwoorden. Zij geeft aan het gevoel te hebben geleefd te worden in het revalidatiecentrum.
2	woord	Het woord ‘gehouden’ moet veranderd worden in ‘houden’.
3	‘lijkt’	Het woord ‘lijkt’ is problematisch – iets voor elkaar krijgen of niet.
4		
5		
6		
7	‘belangrijk’	Patiënte vraagt zich af of het uitmaakt dat de dingen die belangrijk voor haar zijn niet goed voor haar zijn. Wel goed te beantwoorden.
8		
9	pijn	Zij vindt vraag goed voor mensen met alleen pijn (waar vermoedheid een minder belangrijke rol speelt).
10	pijn	Verschil met ‘vermoeidheid’. Goed voor alleen pijn.
11	pijn	Moeilijk door verschil tussen ‘pijn’ en ‘vermoeidheid’. Goed voor alleen pijn.
12		
13	pijn	Verschil met ‘vermoeidheid’. Goed voor alleen pijn.
14	pijn	Verschil met ‘vermoeidheid’. Goed voor alleen pijn.
15	pijn	Verschil met ‘vermoeidheid’. Goed voor alleen pijn.
16	pijn	Verschil met ‘vermoeidheid’. Goed voor alleen pijn.
17		
18		

Participant 2:

Vraag:	Probleem?	Uitleg:
1	‚volledig leefde‘	Patiënte wenst meer antwoordmogelijkheden of een open vraag; zij vindt ‘vitaal leven’ een veel omvattend begrip; Patiënte vindt dat ‘volledig’ zowel lichaamelijk als geestelijk inhoud, en dus moeilijk is om met ‘mee een’ ‘niet mee eens’ antwoord te geven
2		
3		
4		
5	‘vitaal leven’	Haar associatie met ‘vitaal’ is eerst lichaamlijk, en dan denkt patiënte dat het ook geestelijk kan zijn; vraagt zich af wat bedoelt word met de vraag
6		
7	‘dingen’	Patiënte stelt voor ‘activiteiten’ in plaats van ‘dingen’ te schrijven.

8	uitleg	Patiënte wil graag meer uitleg bij de vraag; vindt de antwoordmogelijkheden moeilijk
9	herhaling	Beoordeelt deze vraag slechter dan vraag 10
10		
11		
12	uitleg	Patiënte wenst meer uitleg bij de vraag.
13	'controle'	Patiënte vindt het woord 'controle' niet geschikt omdat zij tijdens de behandeling heeft geleerd om concepten als 'controle' of 'zelfcontrole' los te laten; zij denkt dat groote verschillen zichtbaar worden tussen de verschillende meetmomenten (voor of na de behandeling)
14	'belemmerd'	Zou voor 'belemmerd' een andere omschrijving kiezen.
15	uitdrukking	Patiënte zou de vraag anderes stellen; vindt 'gezinsbezigheden' geen goed woord
16		
17	'zodoende'	Zou een andere omschrijving voor kiezen.
18		

Participant 3:

Vraag:	Probleem?	Uitleg:
1		
2		
3		
4		
5	'vitaal leven'	Patiënte zou de vraag anders formuleren; Bv. 'goede dag gehad'
6		
7		
8		
9		
10		
11		
12		
13		
14		
15	Lengte	Patiënte vindt de vraag dubbelzinnig.
16		
17	Pijn	Patiënte geeft aan dat het concept 'pijn' een subjectieve ervaring voor iedereen is en dus niet voor iedereen hetzelfde geweegt worden kan.
18		

Participant 4:

Vraag:	Probleem?	Uitleg:
1	‚volledig leefde‘	Patiënte vindt ‘volledig leven’ te vaag, ruim. Bv. ‘goede/slechte dag’
2	te vaag	Zij vindt deze vraag al beter dan de 1e.
3		
4	‘succesvol’	Zij heeft moeite met het woord ‘succesvol’ in combinatie met ‘waardevol’.
5	‘vitaal leven’	Te vaag. Bv. ‘goede/slechte dag’
6	‘moeite waard’	Zij vindt het moeilijk aan te geven wat ‘de moeite waard’ is; vooral in het R. Bv. ‘nuttig’
7		
8	te vaag	Patiënte heeft probleem met het idee ‘zoals ik altijd zou willen leven’.
9	pijn; ‘vermeden’	Zij vindt dat ‘vermoeidheid’ erbij hoort, niet alleen ‘pijn’. Volgens haar is ‘vermeden’ een raar woord.
10	pijn	Niet alleen ‘pijn’, maar ook ‘vermoeidheid’.
11	pijn	Ook ‘vermoeidheid’.
12	pijn	Ook ‘vermoeidheid’.
13	pijn ‘controle’	Ook ‘vermoeidheid’. Bij 2e keer lezen: Patiënte denkt dat veel patiënten ‘controle’ ontkennen
14	pijn	Ook ‘vermoeidheid’.
15	Lengte	Zij vindt de vraag te lang.
16	‘relatie’	Vraag weegt voor haar te zwar om op 1 dag te antwoorden.
17	antwoord	Patiënte vindt de antwoordmogelijkheid niet goed.
18		

Participant 5:

Vraag:	Probleem?	Uitleg:
1		
2		
3		
4		
5		
6		
7	proces	Patiënte geeft aan dat ‘dingen die belangrijk voor mij zijn’ niet alleen betrekking op een dag hebben, maar een proces zijn.
8		
9		
10		
11		
12		
13		

14		
15		
16	proces	Zij geeft weer aan dat het om een proces gaat en dus op lange termijn te beoordelen is en niet op 1 dag.
17		
18		

Participant 6:

Vraag:	Probleem?	Uitleg:
1	‚volledig leefde‘	Patiënte vindt de vraag op zich wel goed, maar geeft aan dat in het R. andere termen gebruikt worden.
2	zinsopbouw	Zij vindt de zinsopbouw niet goed.
3	uitdrukking	‘voor elkaar kon krijgen’ zou patiënte anders schrijven.
4		
5	‘vitaal leven’	P. geeft aan dat het niet in het R. gebruikt wordt.
6		
7		
8		
9	‘vermeden’	Volgens haar is ‘vermeden’ geen goed woord.
10		
11		
12		
13	uitdrukking	Volgens de patiënte is ‘controle’ geen goede uitdrukking. Bv. ‘pijn overheerste’
14		
15	lang	Zij vindt het wel een lange zin, maar toch mooi.
16		
17	opbouw	Patiënte zou het anders schrijven/formuleren.
18	opbouw	Patiënte zou het anders schrijven/formuleren.

Participant 7:

Vraag:	Probleem?	Uitleg:
1		
2		
3		
4		
5		
6	vaag	Patiënte vindt de vraag te breed en algemeen; zij vindt het zwaar gezegd.
7		
8	vaag	Patiënte vindt de vraag te breed.

9		
10		
11		
12		
13		
14		
15		
16		
17		
18		

Participant 8:

Vraag:	Probleem?	Uitleg:
1	‚volledig leven‘	Patiënte vindt ‘volledig leven’ moeilijk te beanwoorden.
2	woord	Zij verbeterd het woord ‘gehouden’.
3		
4	‘succesvol’	Voor patiënte ligt de nadruk te zeer op ‘succesvol’ en actie. Bv. ‘tevreden’
5		
6		
7		
8	uitdrukking	De patiënte zou het concept ‘willen leven’ anders uitdrukken. Bv. ‘blij van’ of ‘...ik denk dat een waardevol leven is’
9		
10		
11		
12		
13		
14		
15	moeilijk	Volgens de patiënte is de vraag te moeilijk gesteld.
16		
17		
18	‘veranderd’	Vindt ‘belemmert’ een betere uitdrukking, omdat het een langzaam proces is.

Participant 9:

Vraag:	Probleem?	Uitleg:
1		
2		
3		
4	breed	De patiënte vindt de vraag el goed, maar een beetje te breed.

5	'vitaal leven'	Zij vindt vraag wel goed, maar door 'vitaal leven' wel breed en niet meetbaar.
6		
7		
8	breed	Volgens patiënte is 'willen leven' te breed.
9		
10		
11		
12		
13		
14		
15		
16		
17		
18		

Participant 10:

Vraag:	Probleem?	Uitleg:
1		
2		
3		
4		
5		
6		
7		
8		
9		
10		
11		
12		
13		
14		
15	moeilijk	Patiënte vindt de vraag na de 2e keer lezen moeilijker.
16		
17		
18		

III) Comments to items 9 to 18

Item 9 (*Als ik terugkijk op deze dag, heb ik het vermeden activiteiten in te plannen vanwege mijn pijn*) and item 10 (*Als ik terugkijk op deze dag, heb ik dingen uitgesteld vanwege mijn pijn*) were both evaluated positive and no changing was suggested. A small preference to item 10 was found. Some participants had the idea to combine both items.

All participants estimated Item 11 (*Als ik terugkijk op deze dag, ben ik andere mensen uit de weg gegaan, toen ik pijn had*) as a capable and clear item given that the researcher focuses only on pain. They noted that pain often comes along with exhaustion.

Item 12 (*Als ik terugkijk op deze dag, voelde ik me boos over mijn pijn*) was judged a clear and suitable item by all participants.

Item 13 (*Als ik terugkijk op deze dag, had de pijn de controle over mijn leven, niet ik*) displayed different responses. Some of the participants disliked the word 'controle' because in the Rehabilitation they have learned not to use concepts like 'control'. They learned to stop thinking and talking in term of trying to control their pain. For this research this item seems applicable because it can point up the differences between the diverse moments of measurements (whether someone stands at the beginning or end of the therapy).

Like item 11, item 14 (*Als ik terugkijk op deze dag, ben ik door de pijn belemmerd bij ontspanning en sociale activiteiten*) was seen as a useful item when related to pain only.

The most participants read item 15 (*Als ik terugkijk op deze dag, heeft de pijn de mate van tevredenheid/het plezier dat ik ondervind van deelname aan mijn gezin(sbezigheden) veranderd*) two times before they said aloud what they thought. They stated this item as a complex and difficult one.

Item 16 (*Als ik terugkijk op deze dag, heeft de pijn mijn relatie met mijn partner en/of gezin veranderd*) and item 17 (*Als ik terugkijk op deze dag, heb ik mijn bezigheden beperkt om de pijn zodoende niet erger te laten worden*) were considered as suitable even when heavyly weighted when based on one day. One participant mentioned to like this item more than item 9 and 10.

Item 18 (*Als ik terugkijk op deze dag, heeft de pijn mijn mogelijkheden tot het uitvoeren van huishoudelijke werkzaamheden veanderd*) was considered as a clear item, but not suitable for patients at the Roessingh Rehabilitation Center because they have no 'huishoudelijke werkzaamheden' there.

IV) Table of all items and participants

Pp. / Item	1	2	3	4	5	6	7	8	9	10	good's
1	d		g	b	(g)		g		g	g	4
2	(g)	(g)	(g)		(g)		g	g	g	g	4
3	(g)	(g)	g	g	(g)		g	g	g	g	6
4	g		(g)		g	g	g		(g)	g	5
5	g			b	(g)	(g)	g	g	(g)	g	4
6	g	(g)	(g)		(g)	g		g	g	g	5
7	(g)	g	(g)	g		g	g	g	g	g	7
8	g		(g)		(g)	g				g	3
9	(g)	(g)	(g)	g	(g)		g	g	g	g	5
10	(g)	(g)	g	g		g	g	g	g	g	7
11	(g)	g	g	g	(g)	g	g	g	g	g	8
12	g		g	g	(g)	g	g	g	g	g	8
13	(g)	d	g	(g)	(g)		g	g	g	g	5
14	(g)	g	g	g	g	g	g	g	g	g	9
15	(g)			b		(g)	g	d	g	d	2
16	(g)	g	(g)		(g)	g	g	g	g	g	6
17	g	g		(g)	(g)		g	g	g	g	6
18	g	g	(g)	g			g		g	g	6

7.2. Appendix B

I) Questionnaire part 2

Pilot2 – uiteindelijke items

(item 1 en 2 bevatten algemene informatie)

Als ik terugkijk op deze dag….

3. ….zou ik er bijna alles aan doen om van mijn pijn af te komen.

0: Niet waar	1	2	3	4	5	6	7	8	9	10: Wel waar
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

4. ….is het belangrijk dat ik leer mijn pijn te controleren.

0: Niet waar	1	2	3	4	5	6	7	8	9	10: Wel waar
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

5. ….heb ik dingen uitgesteld vanwege mijn pijn.

0: Niet waar	1	2	3	4	5	6	7	8	9	10: Wel waar
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

6. ….heb ik het vermeden dingen te doen wanneer er het risico bestond dat het pijn zou doen of de dingen erger zou maken.

0: Niet waar	1	2	3	4	5	6	7	8	9	10: Wel waar
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

7. ….vind ik dat ik dingen heb kunnen doen die het leven de moeite waard maken.

0: Niet mee eens	1	2	3	4	5	6	7	8	9	10: Mee eens
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

8. ….vind ik dat ik aan dingen toegekomen ben die belangrijk voor me zijn.

0: Niet mee eens	1	2	3	4	5	6	7	8	9	10: Mee eens
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

9. ….heeft de pijn mijn mogelijkheden tot het uitvoeren van huishoudelijke werkzaamheden beïnvloed.

0: Niet beinvloed	1	2	3	4	5	6	7	8	9	10: Wel beinvloed
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

10. ….ben ik door de pijn belemmerd bij deelname aan ontspanning.

0: Niet waar	1	2	3	4	5	6	7	8	9	10: Wel waar
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

11. ….ben ik door de pijn belemmerd bij het uitvoeren van sociale activiteiten.

0: Niet waar	1	2	3	4	5	6	7	8	9	10: Wel waar
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

12. ….heeft de pijn mijn vermogen om te werken (betaalde of onbetaalde werkzaamheden) beïnvloed.

0: Niet beinvloed	1	2	3	4	5	6	7	8	9	10: Wel beinvloed
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

13. ….heeft de pijn het plezier dat ik ondervind van deelname aan gezin(sbezigheden) beïnvloed.

0: Niet beinvloed	1	2	3	4	5	6	7	8	9	10: Wel beinvloed
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

II) Answers of participants (part 2)

item	participant	dag													
		1	2	3	4	5	6	7	8	9	10	11	12	13	14
3	**1**	8	5	7	8	6	9	9	7	6	6	5	5	6	6
	2	6	7	4	6	5	7	5	4	3	4	5	7	5	5
	3	3	3	4	4	1	1	1	1	1	3	3	5	3	1
4	**1**	8	6	7	6	6	9	9	7	6	6	5	5	6	6
	2	4	6	3	4	4	5	3	3	3	4	4	6	4	5
	3	2	3	2	1	1	1	1	1	1	3	1	1	4	1
5	**1**	8	4	7	7	6	9	9	7	4	4	4	4	6	5
	2	3	6	5	6	6	6	4	3	2	3	6	7	6	6
	3	1	4	1	5	6	1	5	1	4	4	3	4	6	4
6	**1**	8	6	7	8	7	9	9	7	7	5	6	4	6	6
	2	2	6	5	3	3	6	4	2	4	5	6	1	4	3
	3	2	2	1	1	6	1	3	4	3	5	4	5	5	4
7	**1**	6	7	6	7	7	3	3	8	7	7	7	7	5	7
	2	7	4	5	2	6	3	6	6	7	6	4	5	5	6
	3	9	7	6	7	6	8	6	8	9	9	7	6	7	10
8	**1**	6	7	2	7	7	3	3	7	7	7	7	7	5	7
	2	7	6	6	5	6	3	6	7	7	5	6	4	4	8
	3	7	6	4	5	4	7	6	8	8	9	6	4	8	8
9	**1**	8	6	7	8	7	9	9	7	4	7	5	4	6	6
	2	7	8	7	6	7	6	4	7	6	6	7	4	6	2
	3	5	4	1	2	6	4	3	2	3	3	6	6	6	3
10	**1**	8	6	7	9	7	9	8	7	6	6	5	4	6	7
	2	5	9	6	7	6	7	6	5	4	6	7	7	7	7
	3	3	3	1	4	4	1	7	5	4	4	6	7	4	1
11	**1**	8	4	7	7	7	9	9	7	5	7	5	4	7	4
	2	3	7	5	7	5	7	4	3	2	6	5	7	6	3
	3	2	5	3	1	6	1	7	5	1	6	1	6	4	5
12	**1**	8	6	7	5	7	9	9	7	4	6	3	4	4	4
	2	0	4	4	3	4	6	5	7	4	3	7	8	7	2
	3	3	1	1	5	7	5	7	6	1	1	6	4	7	1
13	**1**	8	5	7	7	7	9	9	7	5	6	5	3	7	6
	2	6	7	5	5	5	5	3	2	3	5	5	8	5	4
	3	2	3	1	1	1	1	1	1	1	3	3	6	1	3

7.3. Appendix C

I) Feedback Questionnaire

1. Lukte het om de vragenlijst elke dag in te vullen?

☐ ja
☐ nee

Vooral indien u 'nee' heeft aangegeven zijn we naar uw ervaring benieuwd. Kunt u misschien aangeven waarom het niet is gelukt?

2. Lukte het om de vragenlijst iedere dag in te vullen om de aangegeven tijd (tussen 18u en 21u 's avonds)?

☐ ja
☐ nee

Indien u 'nee' heeft geantwoord: kunt u misschien aangeven waarom het niet is gelukt? Ook indien u 'ja' hebt geantwoordt kunt u nadere toelichting geven (indien gewenst).

3. Zou u iets willen veranderen aan dit tijdstip van invullen? Zo ja, kunt u dan aangeven of u een ander tijstip prefereert, en welk tijdstip dan wel?

4. Kunt u aangeven hoeveel tijd u iedere dag besteed hebt aan het invullen?

5. Vond u deze tijdsinvestering acceptabel?

☐ ja
☐ nee

U kunt hier nadere toelichting geven over de tijdsinvestering: (optioneel)

6. Waren er volgens uw items <u>minder geschikt</u> voor een dagelijkse afname?

☐ 1. Als ik terugkijk op deze dag vind ik dat ik dingen heb kunnen doen die het leven de moeite waard maken.
☐ 2. ….vind ik dat ik aan dingen toegekomen ben die belangrijk voor me zijn.
☐ 3. ….zou ik er bijna alles aan doen om van de pijn af te komen.
☐ 4. ….is het belangrijk dat ik leer mijn pijn te controleren.
☐ 5. ….heb ik het vermeden dingen te doen wanneer er het risico bestond dat het pijn zou doen of de dingen erger zou maken.
☐ 6. ….heb ik dingen uitgesteld vanwege mijn pijn.
☐ 7. ….heeft de pijn mijn vermogen om te werken (betaalde of onbetaalde werkzaamheden) beïnvloed.
☐ 8. ….ben ik door de pijn belemmerd bij deelname aan ontspanning.
☐ 9. ….ben ik door de pijn belemmerd bij het uitvoeren van sociale activiteiten.
☐ 10. ….heeft de pijn mijn mogelijkheden tot het uitvoeren van huishoudelijke werkzaamheden beïnvloed.
☐ 11. ….heeft de pijn het plezier dat ik ondervind van deelname aan gezin(sbezigheden) beïnvloed.

7. Waarom waren deze item(s) minder geschikt?

8. Indien u verder commentaar heeft over het onderzoek kunt u het hier aangeven: (optioneel)