

Scientific Research in  
Horizontal Support  
Correction for Paratonia

**Training**

Physiotherapy

**Researchers**

S. van Binsbergen (463345)

M. van Dieten (466813)

**Client**

Andrew Thijssen

**Supervisor**

Nol Bernards

Irene Vonck

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## Summary

In this scientific investigation, research has been done into the effect of Innocare horizontal support. What effect does this have on Paratonia and the care of dementia patients? Nowadays people live longer, partly as a result of the improved healthcare system in the Netherlands. Due to this increasing age, Dementia has become more commonplace in older people.

Paratonia significantly impedes the care of Dementia patients. With this practical research we hope to discover an alternative to help reduce Paratonia, which in turn will benefit the care of the patient.

This practical research will take place at the Brabantzorg organization in Schaijk. The Paratonia Assessment Instrument (PAI) compiled the population research. Initially seven people were selected to potentially take part in this research. Of these seven people, three suitable patients were finally selected who met the criteria of Paratonia, as set out by the PAI. The three patients were screened every other week using reliable measuring instruments: Modified Ashworth Scale (MAS), Clinical Global Impression Scale (CGI) en de PACSLAC-D.

The results can be found in chapter 4 “Results”. Patient number one had a variable experience using the horizontal support. The results depended heavily on the patient’s own physical state. The second patient needed time to adjust to the Innocare support system, however after the third measurement the results improved considerably. According to the patient’s close family, the patient was more relaxed and the health assistant confirmed that the patient was more comfortable using the horizontal support. Signs of Dementia in the third patient increased during the research. This was detrimental for the initial research results, however once it stabilized, the results improved and the patient seemed more relaxed. The time taken to care for the patients remained the same as at the start of the research, however the care burden became lighter. This means that it became easier for the health assistant to care for the patient. However the care assistants were unsure how to implement the Innocare horizontal support. The support was implemented incorrectly a number of times. Suggestions addressing this problem are discussed in Chapter 6 “Discussions and Suggestions”.

The conclusion of this research is that more scientific research is needed. Never the less a clear picture has emerged showing the effect of the Innocare horizontal support. However because of the minimal number of research patients, it is difficult to determine what effect the horizontal support has had on Paratonia and patient care. This is a pilot study. Is this problem significant enough for a national research? Is this worth following up? Since only three patients took part in the study, we can only make a general assumption based on these test results.

## PREFACE

We started with practical research in the main phase of the Physiotherapy training at the Arnhem and Nijmegen College. During this practical research, an individual research was made including a literature report. The starting point of the practical research is that the student takes on the role of researcher. Scientific research is undertaken and supported by a research report. Regular communication will be needed between the student, the guiding mentor and with the client, to achieve a desirable result. In this practical research we will supply Dementia patients with a horizontal support correction. With the use of measuring instruments we will research if the use of horizontal support correction has an impact on Paratonia (see preface for more information). A Bibliography will accompany the research into corrective horizontal support. This includes reviewing articles concerning the reliability and validity of the measuring instruments used during this research. The duration of this research is 20 weeks. The following statistics will be included in the final report:

1. Inception report
2. Research design
3. Research report
4. Final presentation
5. Portfolio

We would like to express our gratitude to the care and occupational therapy department. It is thanks to their involvement and help with the project that we were able to reach our results. Lastly we would like to thank our mentor Nol Bernards and also our client Andrew Thijssen for helping us to realize our project.

S. van Binsbergen & M.v. Dieten  
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## Introduction

### 1.1 Motivation for Research

Paratonia is a phenomenon characterised by rigid muscles in a certain position. This can be observed in a later stage of dementia. Paratonia is a patient's unconscious co-operation or obstruction in any form of passive movement. In the last phase of dementia this symptom occurs frequently.

Paratonia significantly hampers the care of patients with dementia due to the unconscious resistance of the muscles during passive motion (for example while being washed or dressed). The unconscious resistance is possibly caused by pain during motion, but this is only a presumption. The caretaker experiences a great deal of trouble as it makes the daily care physically demanding. Through increasing dementia and Paratonia the patient will lose his ability to walk and will ultimately become and remain bedridden. This means a decrease of mobility in which the patient can contribute less and less to his own care. By running a practical research we hope to discover an alternative that reduces Paratonia and makes care easier. As yet there are no alternative interventions which have been proven to be suitable for patients with Paratonia and which actually work.

Recent research has shown that passive motion of the muscles has no effect on Paratonia.

Corrective support is a new approach in treatment of dementia care. We will research if this new treatment method actually has effect.

At the research location we decided to implement the Innocare horizontal support. A reason for this choice amongst others was that that this support could be used in any bed because both the support and the beds have the same measurements. When a patient is deceased the support can be re-used and the support is reimbursed by the health care insurance. Finally the caretaker can easily implement the support when he has been well – instructed.

We will also take a closer look at the pain experienced by patients with Paratonia. The PACSLAC-D measuring instrument maps pain experienced by the patient with Paratonia. We will also judge the different possibilities of care with regard to the horizontal support. Does corrective support during morning care have any effect on the pain experienced by the patient with Paratonia?

### 1.2 Questions (& PICO-questions)

Question from the practice: does a corrective horizontal support have an effect in either positive or negative sense when taking care of patients.? To clarify what is being researched several PICO- questions have been drafted:

- Does a corrective support have an effect on the burden during morning care (helping out of bed, dressing, use of toilet) of a patient with Paratonia?

P = Paratonia

I = corrective horizontal support

C =

O = effect on care burden during morning care (helping out of bed, dressing, use of toilet)

On the basis of this PICO – question we want to visualize the problems a caretaker experiences while treating a patient with Paratonia. These patients make care difficult due to the unconscious resistance of muscles during passive motions (for example while being washed or dressed). This causes a great deal of trouble for the caretakers. It makes daily care difficult and physically demanding. By increasing dementia and Paratonia the patient will lose his ability to walk and become and remain bedridden. This means a decrease of mobility, which results in the effect that the patient will not be able to contribute to his care. Also the quality of care will stagnate as regards to the average patient.

The second PICO-question is based on the pain experienced by the Paratonia patient.

- Does a corrective horizontal support have effect on the pain experienced by the patient with Paratonia during morning care?

P= Paratonia patient

I = corrective horizontal support

C =-

O = effect on pain during morning care

The third and last question is based on muscle tone of the Paratonia patient.

- Does a corrective horizontal support have effect on muscle tone during passive motion?

P = Paratonia patient

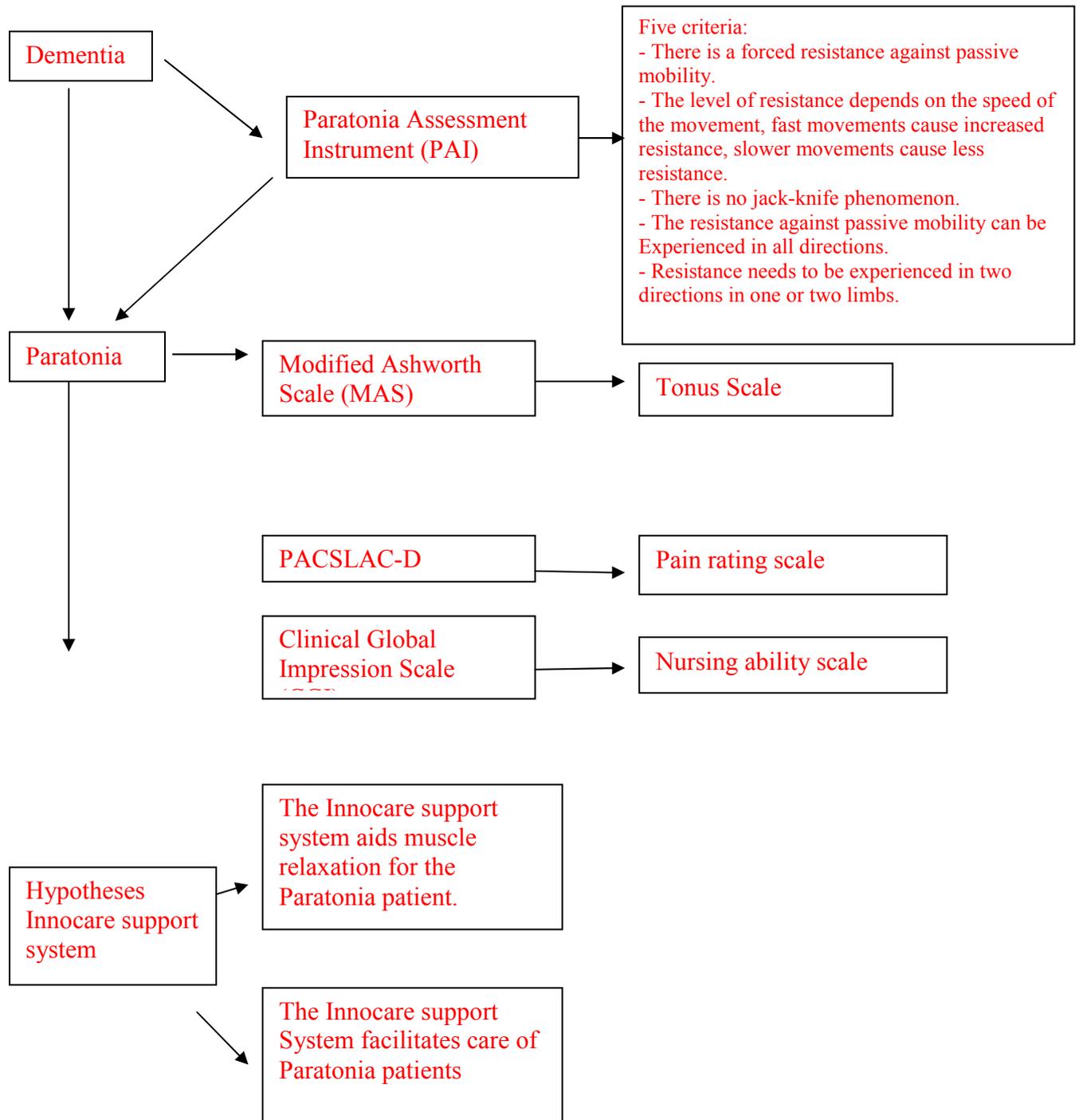
I =corrective support

C =-

O =effect on muscle tone during passive motion

### 1.3: Conceptual Model

In the diagram below, you will find a conceptual presentation of the theoretical framework with further options for treatment and the pros and cons of these options. The relationships between the various links are connected with the arrows.



## 2 : Theoretical Framework

The aim of the theoretical framework is to show the relevant literature. Below we will indicate the relevant literature and write a short summary of the relevant literature. We will also explain specific definitions.

### 2.1 : Dementia

“ Dementia is a generic term for a clinical syndrome caused by various mental illnesses, all of which are characterized by various combinations of numerous cognitive, mood and behaviour disorders. The criteria of the Diagnostic and Statistical Manual of Mental Disorders IV Text Revision (DSM-IV-TR) are used most frequently. Dementia is diagnosed when the memory is impaired in combination with one or more of the following: aphasia (speech and oral impediments), apraxia, agnosia or an performance impediment.”

This description is sourced from the concept guidelines of Dementia. This source also describes the various forms of Dementia. The estimate of the number of patients with one form or another of Dementia in the Netherlands, is between 200,000 and 300,000. Alzheimer is the type of Dementia which occurs most frequently (50%-60% of Dementia patients); Vascular Dementia 10%-15%; Lewy-Body 10%; and a combination of Alzheimer and Vascular Dementia 15%. The remaining groups are comprised of the more rare forms of Dementia such as FTD , Parkinson and Creutzfeldt-Jacob (CJD).

## 2.2: Paratonia

Hypertonia can be regarded as a separate form of Paratonia in combination with another symptoms such as “gegenhalten” (retaining), arteriosclerotic rigidity, motor negativism and Paratonic rigidity. The Jack-knife phenomenon does not occur in Hypertonia in combination with Paratonia. This specific form of Hypertonia, which occurs exclusively in patients with Dementia, creates an extra burden on patient care. Hypertonia in combination with rigid joints can prevent basic patient hygiene, prevents the patient from getting dressed and increases the risk of decubitus and skin lesions.

“ Paratonia is a form of Hypertonia with an involuntary resistance against passive motion. Increasing Dementia can have an accumulative effect on Paratonia: actively moving along (with passive motion) in the beginning of the illness, then developing into active resistance at a later stage. The degree of resistance depends on the speed of (passive) movement (the slower the movements, the less resistance). More pressure also results in more resistance. Resistance can be experienced in any direction, there is no Jack-knife reaction.

Very little is known about the progress of Paratonia. However what has become clear, is that as the Dementia progresses, so does the Paratonia. Both the seated position in a wheel chair and the horizontal position in bed become very difficult to correct, due to high muscle spasticity. Paratonia is especially prevalent during the last phases of Dementia, during the period that a patient is unable to walk and has become totally dependant on carers. Approximately 80% (Hans Hobbelen, Denkbeeld 2007) of the residents of psychogeriatric departments are affected by Paratonia.

### **2.3: Possible causes for Paratonia**

“Increased muscle tone in Paratonia patients can be compared with the increased muscle tone experienced when a patient is frightened or uncomfortable. This can be a result of a sudden touch or when the patient notices that something is happening. An increase of muscle tone can also be a result of the patient feeling insecure or worried. Insecurity is also exacerbated by the feeling of uncertainty. The use of a corrective horizontal support gives the patient much needed support and this in turn reduces the stress of insecurity. This in turn results in a reduction of muscle tone (SPIRONTUS)”

### **2.4: Innocare Comfort Horizontal Support System**

This care system can be used both by adults and children. It can be used for patients with Spastic Tetraplegic muscle diseases, Dementia and also when there are signs of pain due to Rheumatism or MS. The support system is particularly useful for patients with Psychogeriatric or somatic symptoms, aiding stiffness and helping to prevent contractures. Unfortunately, the Innocare horizontal care system has not yet been scientifically tested.

In the first appendix you will find a guide with diagrams, instructing the carer how to help the patient use the Innocare Support System. The two positions are either seated or horizontal. These two positions need to be alternated. The support system will offer stability and a correct posture in both these positions.

## 2.5: Modified Ashworth Scale (MAS)

This equipment measures the severity of Hypertonia when moving a shoulder, elbow, wrist, hip, knee and ankle. The scale is from 0-4, the lowest score of 0= no visible muscle tone and 4= a heightened muscle tone, preventing all movement. (See appendix 2)

The muscle tonus is assessed measuring the patient's limit of painfree movement.

## 2.6: Paratonia Assessment Instrument (PAI)

This equipment makes it possible to verify if the Dementia patient has signs of Paratonia. The following criteria are used to determine Paratonia:

- There is an involuntary resistance against passive movement.
- Resistance increases depending on the speed of movement: more speed = more resistance, slower movement = less/no resistance.
- There is no Jack-knife phenomenon
- Resistance to passive movement can be felt in all directions.

Resistance should be felt in two directions in one limb or in two different limbs  
(See appendix 3)

## 2.7 PACSLAC-D

This is a measuring instrument that is used to measure pain in people with dementia who have problems communicating. This scale exists of 24 parts in 3 sub scales: face, resistance and socio-emotional mood. Scores of 4 or higher means there is pain involved. (appendix 4)

## 2.8 Clinical Global Impression Scale (CGI)

This measuring instrument compares the global change as regards the previous treatment. The caretaker marks the global gravity of the illness. A selection can be made out of:

1. normal, not ill
2. minimal ill
3. slightly ill
4. moderately ill
5. very ill
6. gravely ill
7. critically ill

At the following treatment a form is filled in to mark any improvement . This then is compared to the previous treatment. Filling in the CGI is a simple way to note any improvement, or stagnation. The caretaker fills in the measuring instrument during or after care. (appendix 5)

## 2.9 Neurologie & Paratonia

Research into how neurology plays a role in Paratonia lead us to Jan van der Rakt. Van der Rakt has done a lot of research in this area. We have read his articles and they are the source of our ideas. According to his (Van de Rakt) concept it is conceivable that (er neurologisch gezien bij paratonie statische reacties of tonische reflexen actief zijn) The question van der Rakt posed himself: why does the body make such an effort to remain in this pose which is costing so much energy. Our central nerve system needs to be continuously fed with stimulants. When these stimulants diminish then the projection of that area in the cerebral cortex disappears. The Paratonia patient would do anything to pass on information. If he is not able to move he uses pressure to give that information. For example legs are the pressed together. As the nerve system's abilities decrease the body will try to gain information via tangible functions resulting in less movement. For these people it is very important to be stable, stability is the basis of movement. When basic stability is disturbed the dementia patient will huddle together to stabilize himself. The body is in a foetal position. Through horizontal support, which gives the body the stability it needs the muscles will be able to relax.

## 2.10 Pain and dementia

At first sight it is very difficult to know whether elderly dementia patients. The doctor, caretaker or the fysiotherapist have to verify what is going on and if there is any pain involved. It is a challenge for all the disciplines in the nursing home to identify their problems and their fysical or emotional needs. Pain is a major discomfort for people with dementia.

Between 45% up to 80% of the psycho geriatric patients experiences pain. Often the patient feels pain but is not able to recognize or convey this . This results in expressions of emotions as fear, anger and restless behavior.

Patients with dementia experience pain in a different way which has to do with the different kinds of dementia and the parts of the brain affected. With Alzheimers the patient feels the pain but not the emotional experience that comes with it. The patient feels the pain but does not experience it. Possibly there is less pain. In Alzheimers therefore we can speak of a decrease of pain while on the contrary in Vascular dementia there is an increase in pain experience. This can be caused by Neuropathological changes in the central nerve system. According to various sources it appears that patients with dementia are not treated sufficiently with painkillers .

*Nowadays dementing elderly receive fewer prescriptions for painkillers than elderly without dementia. This can be explained by the fact that diagnostics of the dementia patient is very complex. Next to ' self report pain rating scales' which are suitable for communicative patients there are observational scales which can be used for the non-communicative patient. Autonomous reactions to pain in patients of dementia do not contribute to the reliability of pain diagnostics. The choice of instruments to diagnose pain is mostly determined by the characteristics of the patient and not by the properties of pain as an emotional experience. Patients who cannot actively contribute to the pain measuring instruments are observed for the external symptoms of pain . Such as used in our measuring instrument PACSLAC-D. Observational scales are suitable to indicate the emotional aspects of pain.*

## 2.11 Hypothesis 1

Our assumption about the functioning of the horizontal support is; people with Paratonia have very little support from themselves. Because of neurological problems they get minimal information from their body and thus feel insecure. Insecureness causes increased muscle tone. The horizontal support provides the patient with security and ensures that the patient knows where his body is located. We think this may reduce the muscle tone.

## 2.12 Hypthesis 2

The use of the Innocare horizontal support decreases the muscle tone and this will facilitate the nursing of the patient. Patients with Paratonia make care considerably difficult by the unconscious opposing muscles (for example during washing or dressing) It makes care physically demanding. By using Innocare horizontal support the nursing of these patients will become easier.

### 2.13 Hypothesis 3

By using the corrective horizontal support the pain will diminish . This is because the muscle tone declines by support and security which means that it will be easier for the patient to move and he will experience less pain. Facilitating care is equivalent to having less pain during the care.

### 3.Method

In this chapter we discuss how we executed the research and which method we used. We will also discuss the procedure, the measuring instruments, the population of the group that has been researched and the analysis.

#### 3.1 Short research summary

We initially had an exploratory conversation with our principal at the ‘Nieuwe Hoeven’, the location of the research. Together with the principal we constructed the PICO-question and discussed it with the supervisor. Once the assignment was clear we started searching for suitable measuring instruments while considering their validity and reliability. We have made a selection by studying the scientific articles with relation to the measuring instruments. Our principal suggested seven possibly suitable patients for our research.

By using the first measuring instrument; the Paratonia Assessment Instrument (PAI) we reduced our research population to three suitable patients. We used the Modified Ashworth Scale (MAS), the Clinical Global Impression Scale (CGI) and the PAKSLAC-D to realize a reliable benchmark. In total we have executed six measurements including the benchmark. On the basis of these six measurements we have been able to realize the results of the research. By presenting the results in an accessible chart we can draw a clear conclusion as is described in this research report.

#### 3.2 Preliminary investigation

Before we could start our research it was necessary to do a preliminary investigation of the validity and reliability of several measuring instruments:

- Paratonia Assessment Instrument (PAI)
- Modified Ashworth Scale (MAS)
- Clinical Global Impression Scale (CGI)
- PACSLAC-D

In the theoretical framework these instruments are further clarified.

The following chart describes our search strategy. The sources, the search terms and the number of results are displayed below. The explanation of why certain articles were excluded for use and so for rating is listed in the table below. Per article it is explained why it is not appropriate for this research.

\*\*\*\*\*green chart!!\*\*\*\*\*

1. Three articles surfaced through this search strategy. The first article concerns: Prevalence, incidence and risk factors of Paratonia in patients with dementia: a one-year follow-up study. This article was not applicable for this research because it gave no useful information about the validity and reliability of the measuring instrument PAI. This text concerned information about the presence of Paratonia in patients with dementia.

The third article was: Classification of resistance to passive motion using minimum probability of error criterion. This article was not of use because passive motion was the main subject.

2. First article: Assessing the reliability of the Modified Ashworth Scale between two physiotherapists in adult patients with Hemiplegia. In this article with patients with Hemiplegia were examined. This concerns a unilateral paralysis of the body. This does not match Paratonia and therefore was not of use for the research.

Second article: Reliability of the Modified Ashworth Scale in the assessment of plantar flexor muscle spasticity in patients with traumatic brain injury. This article concerns patients with traumatic brain damage. This article was not of use for this research, as it does not concern Paratonia.

3. First article: pain and dementia: a diagnostic challenge. This article does not concern measuring instruments but pain with dementia in general. For this research it is necessary to know if PACSLAC-D is a valid and reliable measuring instrument to assess pain with the dementing patient.

4. Second article: Yearbook Fysiotherapie Kinesitherapy 2010. This article does not concern the Modified Ashworth Scale measuring instrument.

5. Second article: Development and preliminary validation of the pain assessment checklist for seniors with limited ability to communicate (PACSLAC). This article concerns the development of the PACSLAC-D .It is important for the research question to investigate the reliability and validity of PACSLAC\_D. In the article that is reviewed the reliability and the validity is more pronounced than in this article.

### **Article 1: Diagnosing Paratonia in the demented elderly: reliability and validity of the Parotonia Assessment Instrument (PAI)**

This article describes the 3 fases in which the PAI were researched .The measuring instrument was examined on validity reliability and feasibility. In the first fase the PAI was developed according to the definition of Paratonia. In the second fase investigation was done into the feasibility of the PAI. In the third and last fase the reliability of the PAI was investigated. There were several different research groups whose size and gender did not

match. There were 4 assessors who assessed the patients separately. They were not aware of each other's results.

**For the assessment forms please refer to Appendix 6**

### *Conclusion*

It transpired that the PAI is a reliable valid and feasible instrument to diagnose Paratonia in with dementia. The measuring instrument is easy to use in daily practice. In the future the PAI may provide different treatment strategies for Paratonia'. Research proved the reliability of PAI to be sufficient to good to even near perfect.(0,625 to 1)

- $K < 0$  = bad
- $K 0 - 0,20$  = low
- $K 0,20 - 0,40$  = moderate
- $K 0,41 - 0,60$  = reasonable
- $K 0,61 - 0,80$  = sufficient to good
- $K 0,81 - 1,00$  = Near perfect

All assessors (4) were positive about the use of the PAI in daily practice. Approximately 10 minutes per patient is needed for the assessment.

### **Article 2: Interrater Reliability of a Modified Ashworth Scale of Muscle Spasticity**

This research aims to investigate the Modified Ashworth Scale in spasticity of the flexion and extension of the elbow. In this investigation there is one research population of 30 patients. This population consists of 17 men and 13 women. The age varies between 17.6 and 59.3 years. All patients had lesions in the central nerve system. One of the patients had MS, 5 patients had closed brain injury and the remaining 24 patients had CVA. Both assessors have tested the population by conducting the MAS.

**For the assessment form please refer to Appendix 7**

### *Conclusion*

The assessors who conducted the test manually with 30 patients had an similarity of 87% of their measurements on the level of spasticity.

Their assessments are based on the Modified Ashworth Scale (MAS). They were significantly correlated. The value  $p < 0,01$  indicates that the results are not based on co-incidence. The reliability of the MAS refers to further clinical investigation.

### **Article 3: Pain in elderly people with severe dementia: a systematic review of behavioural pain assessment tools.**

The aim of this research is to investigate different pain measuring instruments. These need to be applicable to elderly people with severe dementia. The evaluation of the psychometrical quality of the measuring instruments stood central to this research.

In this research 12 pain-measuring instruments have been selected. One of them is the PACSLAC-D. These 12 pain-measuring instruments were investigated concerning validity, feasibility, homogeneity and reliability.

**For the assessment forms of this article please refer to Appendix 8**

#### *Conclusion*

The PAINAD, PACSLAC, DOLOPLUS2 and the ECPA are the measuring instruments with the best psychometrical qualities. We however only investigated the PACSLAC.

The PACSLAC is the only measuring instrument that focuses on the subtle changes in behaviour. The PACSLAC is one of the few measuring instruments in which the items are based on pain in the patient with dementia. On the basis of the Cronbach's alpha the PACSLAC is not well composed as concerns the parts. It is favorable when a grade is higher than 0.7 however the results were between 0.55 and 0.73.

### **Article 4: Clinical Global Impressions in Alzheimer's clinical Trials.**

This article describes that the CGI is designed to accompany the assessor in evaluating a clinical change. The core of the measuring instrument is to look at the aspects of the behavior of the patient. In this article multiple scientific studies have been consulted on the creation and the development of the CGI. In these scientific studies medicine has been given to patients with dementia. By means of using the CGI clinical changes could be scored.

**For the assessment form of this article please refer to Appendix 9**

#### *Conclusion*

New investigations into the CGI are recommended as there are several problems concerning the reliability and the validity of the measuring instrument. The first being that the structure of the reliability of the scale and sensitivity to changes can be improved. Another problem is that there is a general lack of agreement at the global scale design.

### 3.3 population survey

The population survey is the total mass of monitoring results, which the investigation focuses on. We have a population survey of 3 people. We started the research with seven people. By taking the test with the Paratonia Assessment Instrument (PAI) 4 people dropped out, they were not suitable to participate in our research. In the inclusion criteria was included that the patients should have a form of dementia (Alzheimers Vascular dementia and Lewy-body dementia) and must meet the criteria of the DSM-IV. On the basis of this scale can be determined if there is any dementia and in which fase the patient finds himself. There are 3 stadia including the last, which the participants must meet.

First stadium (light dementia): periods of apathy interspersed with periods of irritability. Work and social activities are frustrated. Personal hygiene and judgment are sufficient to live independently. Second stage (moderate dementia): disorder of different functions (memory, sense of time and place, practical and intellectual abilities, language and behaviour) Independent living becomes a risk. Supervision is necessary, possibly to a limited extent. Third stadium (severe dementia) the patient cannot perform daily activities (such as minimal personal hygiene). The patient is completely dependent and often does not recognize family and surroundings.

Additionally the patients need to meet the definition of Paratonia according to the Paratonia Assessment Instrument.

Men and women are included in this research. The age should vary between 60 and 90. The three patients who participated are 75, 80 and 83 years old.

At the exclusion criteria it is important that no medication should be used for its negative impact on Paratonia.

Patient 1 is born in the year 1932. This means the woman is 80 years old. Indicated below are the co-morbidities.

- Recurrent Tia's
- Combination dementia: vascular and Alzheimer
- 2010: severe dementia
- Arthritis in neck and back
- Varices and ulcus cruris

Patient 2 is born in 1929. The patient is 83 years old

- Diabetes mellitus type 2
- Hypertension
- Cholecysetomy ODS
- Prebyacusic (KNO) (1998)

- Entracaps (2003) Lensextraction OD with placement of intraocular lens, idem OS in 2002
- Suspected vascular dementia, suspected of self-neglect .
- Superimposed Dawson
- Vitamine B12 and folic acid deficiency
- Word-find-disorders, desorientation, memory disorders
- MRI: major atrophy and major vascular white matter anomalies throughout the brain
- Trigger-thumb left, split
- Non-Proliferative Diabetic Retinopathy (2008)
- Depression (2009)
- Wrist fracture
- Recurrent UTIS

Patient 3 is born in 1937. Which means that she is 75 years old.

- Abdominal uterus removal 1983
- Athrodesis ankel ri (1985)
- Athrodedis ankel le(1988)
- Athroscopically removed loose fragments from the right knee (1996)
- Small avulsion fracture based ground phalanx thumb
- GGZ: depression: medication Cipramil (2001)
- GGZ: SDAT (2006)
- Medial collum fracture left (KHP)(2011)

These patients received a corrective horizontal support by Innocare during the research. The caretakers are offered a training in which the application of this support is explained on the basis of theoretical knowledge. In addition, skills are practiced and explained. When the patient lies in bed the corrective support will be implemented. During the day the patient uses the wheelchair. During the night the patient will lie on his back and will be turned on his side by the caretaker to prevent decubitis.

Measuring is done with the measuring instruments: the Modified Ashworth scale for muscle spasticity, the PACSLAC-D for pain and the Clinical Global Impression Scale for the care burden. The measuring was done once every other week during morning care. The caretaker fills in the form of the CGI so that the care burden can be analyzed. All measurements are then merged in graphs so that a clear image is formed in terms of the results of the research.

### 3.4 Procedure

The research is done at the Nieuwe Hoeven in Schaijk and Vierhoven in Schaijk. Two of the patients live in the Nieuwe Hoeven and one patient lives in Vierhoven. The measurements

have been done every other week, and have been executed with the help of MAS, the CGIS and the PACSLAC-D.

For the patient from Vierhoven we have done the measurements ourselves. Our client has measured the other two patients from the Nieuwe Hoeven. Different caretakers have executed the CGIS. This depended on their working hours; however, we tried to have the CGI done by only one caretaker.

The measurements took place on the dates below:

- 8th October 2012
- 23rd October 2012
- 6th November 2012
- 19th November 2012
- 4th December 2012
- 17th December 2012

Per measurement we have described the results and displayed them in a chart. These charts and descriptions can be found in chapter 4 (results).

### 3.5 Obtaining measuring instruments

To form a suitable group of our designated patients for the investigation of the Innocare Support we needed a measuring instrument to diagnose Paratonia. Our client offered this to us. The instrument is called the Paratonia Assessment Instrument which we found of use to compose our patient group. We excluded patients without Paratonia and so remained with patients needed for our research. After that we needed measuring instruments to measure pain in patients with Paratonia, the measures of muscle tone and the burden of care. The following instruments were designated by our client and the ergo therapists in Brabantzorg; CGI, MAS and the PACSLAC-D. It was our assignment to investigate the usability and validity of these measuring instruments.

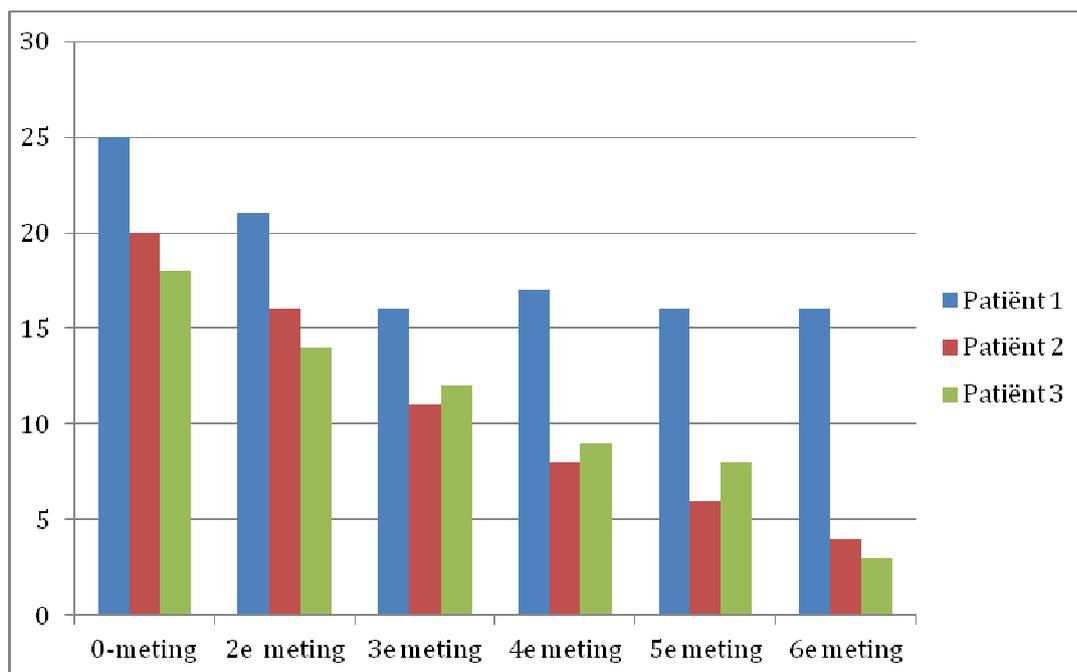
## 4 Results

In this chapter we describe the results of the research. In the charts below the results are displayed per measuring and per measuring instrument. For the MAS we have two charts; one for the left and one for the right side of the body. The instruments are outlined above the charts.

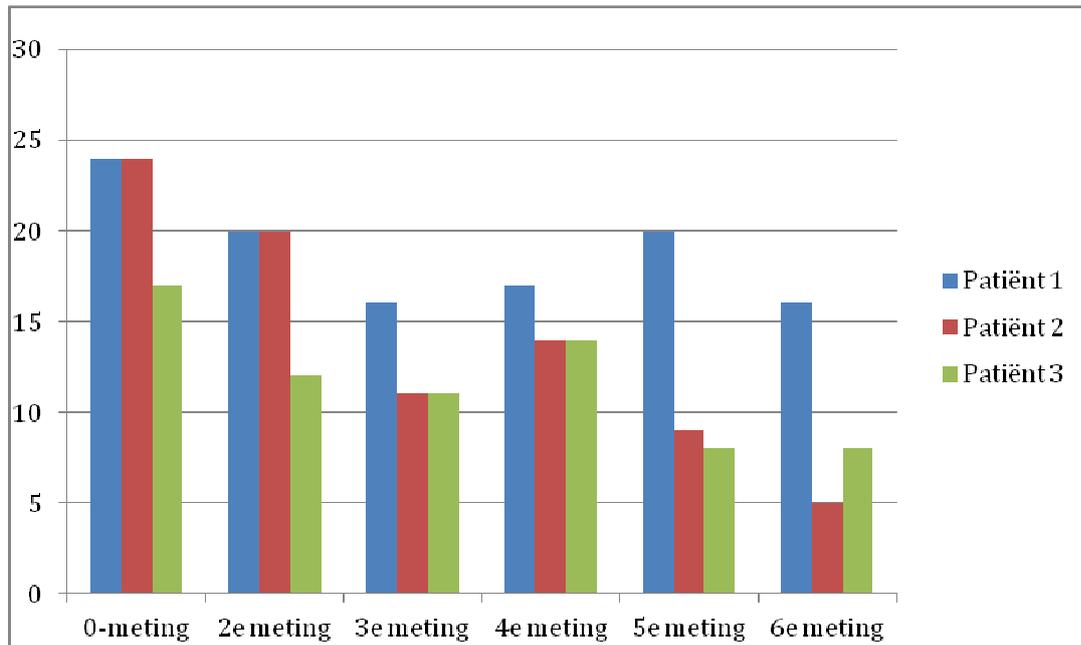
### 4.1 Results MAS

Below are the MAS results. The higher the results of the MAS are the more negative they are. The results of the wrist, elbow, shoulder, ankle, knee and hip have been added and displayed in the chart.

Tabel 1 Resultaten Linkerzijde



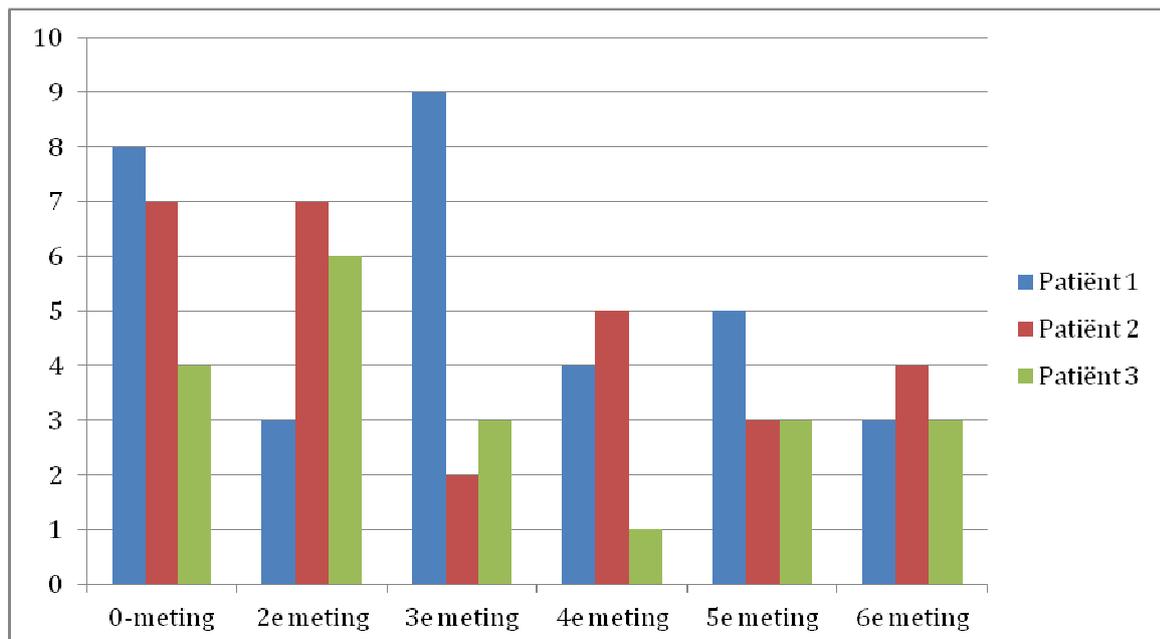
Tabel 2 Resultaten Rechterzijde



#### 4.2 results PACSLAC-D

Below are the results of the pain-measuring instrument the PACSLAC. The lower the score at this instrument all the more positive it is for the patient.

Tabel 3 Resultaten PACSLAC-D

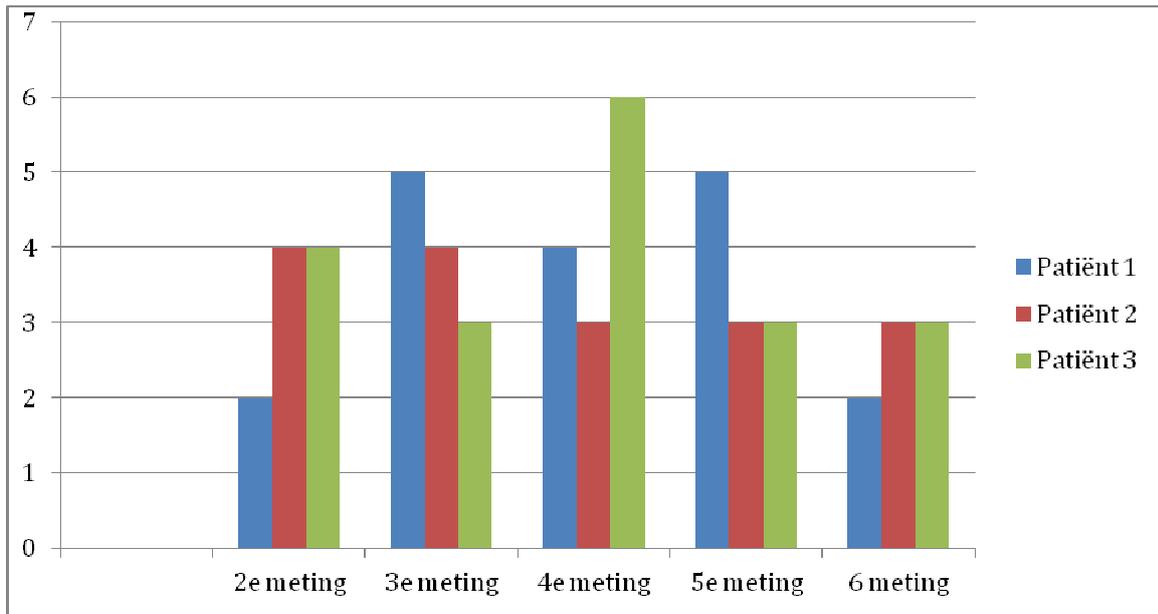


### 4.3 Results CGIS

In the chart below are the results of the CGIS. With the legenda below it you can see precisely what the axis on the left means.

The benchmark is not included in this chart as no comparison can be made yet. At the benchmark the global severity of the condition over the past week has been noted.

Chart 4 Results CGIS



- 1= marked improvement
- 2= much improved
- 3= minimal improvement
- 4= no change
- 5= slightly worse
- 6=much worse
- 7=very much worse

### 4.4 Survey of measurements

In this section we discuss the patients and the measurements.

#### Patient 1

At the first measuring the lady had a bladder infection. This is included in the research as it can affect the result negatively.

<u>Meetinstrument</u>	<u>Score</u>	
<u>MAS</u>	<u>Links 25</u>	<u>Rechts 24</u>
<u>PACSLAC-D</u>	<u>8</u>	
<u>CGI</u>	<u>Matig ziek</u>	

At the second measuring the corrective support during the night was not correctly applied as a pillow between the knees was missing. The CGIS indicates that there was a lot of improvement compared to the beginning of the treatment.

<u>Meetinstrument</u>	<u>Score</u>	
<u>MAS</u>	<u>Links 21</u>	<u>Rechts 20</u>
<u>PACSLAC-D</u>	<u>3</u>	
<u>CGI</u>	<u>Veel verbeterd</u>	

At the third measuring the patient was suffering from her right arm and was again not properly supported. She had pressure ulcers on the rump and it was doubtful if her position had been changed during the night. The CGI indicated that she had deteriorated a little.

<u>Meetinstrument</u>	<u>Score</u>	
<u>MAS</u>	<u>Links 16</u>	<u>Rechts 16</u>
<u>PACSLAC-D</u>	<u>9</u>	
<u>CGI</u>	<u>Minimaal slechter</u>	

At the fourth measuring we noticed that the patient reacted more alert as compared to the previous measurement. For the 3rd time the support was not correctly applied. As at the second measuring a pillow was missing between her knees. On the CGI there was no change to be seen.

<u>Meetinstrument</u>	<u>Score</u>	
<u>MAS</u>	<u>Links 17</u>	<u>Rechts 17</u>
<u>PACSLAC-D</u>	<u>4</u>	
<u>CGI</u>	<u>Geen verandering</u>	

At the 5th measuring the caretaker told us that the last couple of nights the patient was turning a lot in her sleep. And she had a bladder infection just like at the benchmark. We

saw this back in our measurements, as they were less positive compared to the previous time.

<u>Meetinstrument</u>	<u>Score</u>	
<u>MAS</u>	<u>Links 16</u>	<u>Rechts 20</u>
<u>PACSLAC-D</u>	<u>5</u>	
<u>CGI</u>	<u>Minimaal slechter</u>	

At the sixth measuring the patient seemed very quiet. The previous evening the caretakers were not able to undress her due to aggressive behaviour. She did sleep well. After the sixth measuring she had to stay in bed because the doctor came visiting. So after care she was put to bed again.

<u>Meetinstrument</u>	<u>Score</u>	
<u>MAS</u>	<u>Links 16</u>	<u>Rechts 16</u>
<u>PACSLAC-D</u>	<u>3</u>	
<u>CGI</u>	<u>Veel verbeterd</u>	

## Patient 2

During the first measuring (benchmark) the patient did not like to be washed, especially her face. Apart from that there were no remarks.

<u>Meetinstrument</u>	<u>Score</u>	
<u>MAS</u>	<u>Links 20</u>	<u>Rechts 24</u>
<u>PACSLAC-D</u>	<u>7</u>	
<u>CGI</u>	<u>Matig ziek</u>	

At the second measuring the patient did not want any care and the caretaker put her back to bed. The CGI indicates that there has been no change since the beginning of the treatment.

<u>Meetinstrument</u>	<u>Score</u>	
<u>MAS</u>	<u>Links 16</u>	<u>Rechts 20</u>
<u>PACSLAC-D</u>	<u>7</u>	

At the third measuring the patient was inclined to ignore the caretaker. She is more comfortable in the support but the training falls short as not all carers have the knowledge to install the support properly.

<u>Meetinstrument</u>	<u>Score</u>	
<u>MAS</u>	<u>Links 11</u>	<u>Rechts 11</u>
<u>PACSLAC-D</u>	<u>2</u>	
<u>CGI</u>	<u>Geen verandering</u>	

At the fourth measuring the patient showed less resistance and showed more social interaction. During the test (MAS) the patient showed resistance during movement. Unfortunately the support is not accepted by all of the carers, which means that not everyone implements the support correctly.

<u>Meetinstrument</u>	<u>Score</u>	
<u>MAS</u>	<u>Links 8</u>	<u>Rechts 14</u>
<u>PACSLAC-D</u>	<u>5</u>	
<u>CGI</u>	<u>Minimaal verbeterd</u>	

At the fifth measuring the patient was much quieter compared to the previous measuring. She seemed to be more relaxed and was also correctly supported.

<u>Meetinstrument</u>	<u>Score</u>	
<u>MAS</u>	<u>Links 6</u>	<u>Rechts 9</u>
<u>PACSLAC-D</u>	<u>3</u>	
<u>CGI</u>	<u>Minimaal verbeterd</u>	

During the sixth measuring the patient was very co-operative. The carer mentioned that it differs per day how she responds. The previous day the patient was not co-operative. The support was implemented correctly and she was relaxed.

<u>Meetinstrument</u>	<u>Score</u>	
<u>MAS</u>	<u>Links 4</u>	<u>Rechts 5</u>
<u>PACSLAC-D</u>	<u>4</u>	
<u>CGI</u>	<u>Minimaal verbeterd</u>	

### Patient nr3

At the first measuring (benchmark) the patient resisted somewhat using her hands; there were few comments for the first measuring.

<u>Meetinstrument</u>	<u>Score</u>	
<u>MAS</u>	<u>Links 18</u>	<u>Rechts 17</u>
<u>PACSLAC-D</u>	<u>4</u>	
<u>CGI</u>	<u>Licht ziek</u>	

At the second measuring there was very little change to be noted on the CGI.

<u>Meetinstrument</u>	<u>Score</u>	
<u>MAS</u>	<u>Links 14</u>	<u>Rechts 12</u>
<u>PACSLAC-D</u>	<u>6</u>	
<u>CGI</u>	<u>Geen verandering</u>	

During the third measuring the patient was very co-operative. She showed no resistance on the PACSLAC-D. She was quiet and comfortable in the support.

<u>Meetinstrument</u>	<u>Score</u>	
<u>MAS</u>	<u>Links 12</u>	<u>Rechts 11</u>

<a href="#">PACSLAC-D</a>	<a href="#">3</a>	
<a href="#">CGI</a>	<a href="#">Minimaal verbeterd</a>	

At the 4th measuring the patient was co-operative. It did transpire that there was an increase of dementia. However this is not reflected in the PACSLAC-D and the MAS.

<a href="#">Meetinstrument</a>	<a href="#">Score</a>	
<a href="#">MAS</a>	<a href="#">Links 9</a>	<a href="#">Rechts 14</a>
<a href="#">PACSLAC-D</a>	<a href="#">1</a>	
<a href="#">CGI</a>	<a href="#">Veel slechter</a>	

At the fifth measuring there were no changes. There was a slight improvement on the MAS in comparison to the previous measuring, however the score on the PACSLAC-D was higher. The CGI indicated a minimal improvement.

<a href="#">Meetinstrument</a>	<a href="#">Score</a>	
<a href="#">MAS</a>	<a href="#">Links 8</a>	<a href="#">Rechts 8</a>
<a href="#">PACSLAC-D</a>	<a href="#">3</a>	
<a href="#">CGI</a>	<a href="#">Minimaal verbeterd</a>	

At the sixth measuring there were few remarks except that the patient was relaxed and that the support was well implemented

<a href="#">Meetinstrument</a>	<a href="#">Score</a>	
<a href="#">MAS</a>	<a href="#">Links 3</a>	<a href="#">Rechts 8</a>
<a href="#">PACSLAC-D</a>	<a href="#">3</a>	
<a href="#">CGI</a>	<a href="#">Minimaal verbeterd</a>	

## 5: Conclusion

In this chapter we will discuss the results per patient. We concluded that each patient reacted differently to the corrective support system. This makes it difficult to make a conclusion. Each person also reacts differently to his or her particular environment.

### 5.1: Conclusion patient 1

The results of this test depend strongly on the physical state of the patient. This patient twice had a urinary tract infection during this research. This happened between the first and the fifth test. The MAS results were quite high in comparison with the other results. The PACSLC-D also had the highest score in comparison to the third test. At the fifth test the MAS was higher in comparison with the previous two tests. As a result of these tests we are able to make a hypothesis. Our hypothesis is that the results of the test equipment depend strongly on the physical ability of the patient. We also noticed that the patient was more alert during her urinary tract illness. She was more aware of her immediate surroundings. During the testing of PACSLAC-D we noticed that the patient experienced pain in her face. We noticed that the patient showed little social-emotional contact or movement. Her family reported that the patient seemed calmer and more relaxed. We noticed a large improvement between the first and last tests. We noticed that her muscle spasticity reduced and she seemed more relaxed.

### 5.2: Conclusion patient 2

We noticed that patient 2 needed to get used to the support system and we noticed no change on the CGI during the first couple of tests. After the fourth test there was a marked improvement on the CGI, MAS and PACSLAC-D. Moreover the carers noticed that the patient became calmer and she did not resist as much during the tests and care. The patient was more comfortable due to the horizontal care support and appeared more relaxed. The patient is very capable of showing her dissatisfaction in a non-verbal manner. This was apparent during the whole test period. Initially there was a physical resistance, which became less during the testing period.

### 5.3 Conclusion Patient 3

There was an overall improvement in the health of this patient as can be seen in the results of the MAS and PACSLAC-D. An increase of Dementia was determined discovered during the fourth survey. This can clearly be seen on the CGI. The results were an increase in deterioration as the period progressed. We think this was because of the progression of Dementia. Due to this deterioration the patient seemed to react less to the care. This became apparent during the testing. Because of the fact that the patient did not resist the

care and was comfortable in the support system, our hypothesis is it had a positive effect on both the care and the patient. Similarly to the first patient, family members told us that the patient appeared more relaxed and rested.

#### 5.4: What practical effect does this have?

Two of the three patients reacted positively to the support system. The second patient needed to get used to the support system, however as the test period evolved we saw a marked improvement in the results of the tests. There were also improvements in patient 3, however the results were affected of the increasing dementia on her physical condition. The results of the tests on patient #1 depended on her physical state. Empirical perception played a large part in determining the test results for both patient #1 and #3. Family members of both these patients told us that the patients appeared calmer and more relaxed. This is not a reliable fact, just an observation. The corrective support system had a different result on the Paratonia in each patient. It is important to consider each patient's physical condition. This can have a large influence on the results of the tests. We obtained a clear impression of the Innocare support system.

However the tests were done on a small group of patients and more extensive research would need to be done. This could be done on a national scale, thereby increasing the test population.

#### 5.5 PICO questions

As you could read in the introduction there are several PICO questions. The first PICO question is as follows and concerns the care burden:

- Does a corrective horizontal support have an effect on the care burden during morning care ( getting out of bed, dressing etc) on patients with Paratonia

P=patient with Paratonia

I=corrective horizontal support

C=-

O=effect on care burden during morning care

The time needed to take care of the three patients has remained the same compared to the period previous to the treatment. This is the result of a final conversation with the caretakers. However the burden of care had become less. The caretakers indicated that they were unsure about the implementation of the Innocare horizontal support. Due to a lack of training (especially for the evening and night shift) the support had not been entirely well

placed. By improving the frequency on training this can be taken care of (see recommendations)

The second PICO question is based on pain in the patient with Paratonia.

- Does a corrective horizontal support during morning care have an effect on pain in a patient with Paratonia?

P= patient with Paratonia

I= correctieve horizontal support

C=-

O=effect on pain during morning care

For this question we looked at the results of the PACSLAC-D. In the graph placed under the chapter Results you can see that the outcome per patient varies enormously. In the graph it can be observed that there is a marked improvement of the patients during the sixth measurement in comparison with the benchmark. There were Interim fluctuations. Analysing the measurements it can be concluded that the Innocare horizontal support has a positive effect on pain as is observed on the PACSLAC-D.

The third and last PICO question is based on muscle tone in the patient with Paratonia.

- Does a corrective horizontal support have an effect on the muscle tone in the patient with Paratonia during passive movement.
- 

P=patient with Paratonia

I=corrective horizontal support

C=-

O= effect on muscle tone during passive movement.

In the graphs concerning the Modified Ashworth Scale there is marked decrease of muscle-tone in the patients. There is a clear decending line, which means that the Innocare horizontal support also has a positive effect on muscle tone on both sides of the body.

## 6. Discussion & recommendations

In this chapter we will show the recommendations on the basis of the results and the conclusion which are addressed to the client and Hans Hobbelen.

Hans Hobbelen who is a senior scientific researcher, would like to set up a national study of the Innocare horizontal support. What we now have examined on a small scale, Hans Hobbelen wants to investigate further at national level

The most important item we came across is that knowledge about Innocare falls short at the care. We noticed that the support was not correctly applied. This can have a negative influence on the results. There was a one-time training offered by Innocare at the research location during which the support was discussed and where the caretakers practiced in applying the support. Unfortunately not everyone was present whereby the knowledge was not well spread. However in every room there was an instruction present to support the application of the horizontal support. This did not appear to be sufficient for the caretakers who were not present at the training. We strongly recommend that this training should be given several times so that as many as possible caretakers get a chance to attend. In addition we believe the training should be mandatory. Our last recommendation would be to offer instruction films to refresh memories when necessary.

The second thing we noticed was that the horizontal support was not accepted by the whole group of caretakers. This may be because some caretakers were not present during the training but the reason could also be that there is no scientific proof yet that the horizontal support has any effect. We noticed that the caretakers doubted the effect of the horizontal support and regard the application as extra work of which they do not see the benefit yet.

By presenting this research report we hope to convince the caretakers of the beneficial effects of the support. Information and knowledge offered in trainings as described above are of utmost importance.

Our third recommendation would be to have the same caretaker present during morning care when measuring take place. This way you can get a more realistic view of the progress of the patients. Each caretaker has a different approach to provide care. Some patients will score higher on the PACSLAC-D when handled a little too roughly. Probably the opposite happens when care is gentle.

In short, getting a realistic view of the progress of the patients is important when the same caretakers are present. To give any recommendations is difficult as it all has to do with working hours and timetables of the caretakers as well as taking into account illness and replacements. We hope that these recommendations can be implemented during further research. Apart from these pitfalls we completed our research well with all disciplines (occupational therapists and caretakers).

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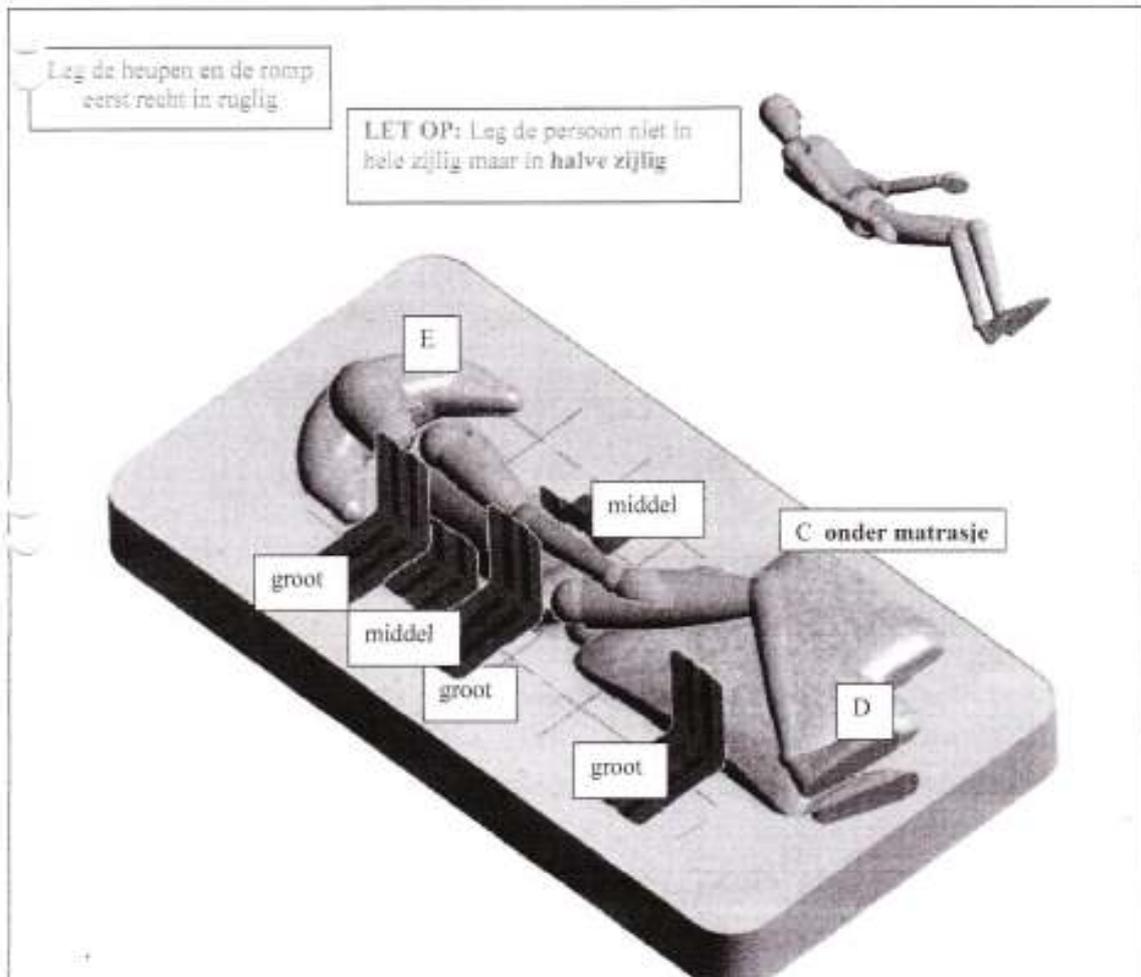
## Appendix 1: innocare ligondersteuning

Naam:

Datum:

### Linker zijligging (halve zijlig)

- Leg allereerst als hoofdkussen een Hoefijzer kussen neer.
- Leg onder het matrasje ter hoogte van de knieën een klein rechthoekig kussen (C), zodat de onderste knie op het kussentje komt te liggen.
- Leg onder het rechterbeen een D kussen en trek aan het matrasje zo dat het been al naar rechts ligt.
- Zet dan een steun achter dit D kussen, zodat het been er niet af kan schuiven.
- Trek dan aan het matrasje ter hoogte van het bekken zo dat de persoon in een **gedeeltelijke** zijlig komt te liggen en plaats tegen de achterzijde van de heup een grote steun (zwart).
- Plaats daarna een grote steun (zwart) aan de achterzijde van het lichaam tegen de schouderbladen.
- Plaats in het midden van de rug een middel steun (geel).
- Zet tegen de onderbuik een middel steun (geel).





## MODIFIED ASHWORTH SCALE

### Scoreformulier

Naam patiënt

Naam behandelaar

datum						
Lichaamshelft	L / R	L / R	L / R	L / R	L / R	L / R
Schouder						
Elleboog						
Pols						
<b>Totaal BE</b>						
Heup						
Knie						
Voet						
<b>Totaal OE</b>						
<b>Totaal OE+BE</b>						

Score	Omschrijving
0	<i>Geen verhoogde spiertonus</i>
1	<i>Geen verhoogde spiertonus</i> Manifesteert zich als een plotseling optredende spanning gevolgd door een ontspanning of treddst op als een minimale weerstand aan het eind van de bewegingsuitslag wanneer het aangedane lichaamsdeel wordt bewogen in flexie- of extensierichting
1+	<i>Gering verhoogde spiertonus</i> Manifesteert zich als een plotseling optredende spanning en blijft daarna als geringe weerstand voelbaar tijdens het resterende bewegingstraject

2	<i>Meer uitgesproken verhoogde spiertonus</i> Het betreffende lichaamsdeel beweegt echter vrij gemakkelijk
3	<i>Aanzienlijk verhoogde spiertonus</i> Passief bewegen is moeilijk
4	<i>Niet te bewegen</i> Aangedane lichaamsdeel is niet te bewegen in flexie- of extensierichting

## Appendix 3: Paratonia Assessment instrument

### The Paratonia Assessment Instrument (PAI)

The PAI is a dichotomous assessment instrument with which an examiner can establish the presence (or absence) of Paratonia by successively moving all four limbs passively in flexion and extension while the participant is in a sitting position (see Figure 2) or supine in bed (Hobbelen *et al.*, 2008). The examiner starts with a slow movement of the limb, after which the movement is accelerated. The PAI is a construct of five criteria that allow for a categorical diagnosis of Paratonia, i.e., Paratonia can only be diagnosed when all five criteria are present: 1) an involuntary variable resistance; 2) a degree of resistance that varies depending on the speed of the movement (e.g., a low resistance to slow movements and a high resistance to fast movement); 3) resistance to passive movement can be felt in any direction (no distinct pattern); 4) no clasp-knife phenomenon; and 5) resistance is present in 2 movement directions in 1 limb or in 2 different limbs.



**Figure 2**

with permission from Cambridge University Press reprinted from; Hobbelen et al. Diagnosing Paratonia in the demented elderly: reliability and validity of the Paratonia Assessment Instrument (PAI). *International Psychogeriatrics* 2008, 20 (4); 840-852 The PAI actually differentiate between Paratonia, spasticity after stroke and parkinson's rigidity. In spasticity after stroke there is often a distinct pattern visible, a resistance in 1 movement direction or in one side of the body (hemiplegia) and is sometimes accompanied with a claspknife phenomenon. Parkinson's rigidity is not dependent on the speed of the movement (lead-pipe phenomenon). In absence of a clasp-knife phenomenon and a clear pattern one can rule out spasticity and in the presence of speed dependency one can rule out parkinson's rigidity. The PAI is derived from the new consensus definition of Paratonia and has only expert and face validity. In a three stage study in which respectively 87, 97 and 24 participants with an established form of dementia were included interobserver reliability weighted Cohen's Kappa ranged from 0.63 to 1.

## Appendix 4: PACSLAC-D

### Nederlandse versie van de Pain Assessment Checklist for Seniors with Severe Dementia (Pacslac-D)\*

Datum: \_\_\_\_\_ Tijdstip beoordeling: \_\_\_\_\_

Naam patiënt/ bewoner: \_\_\_\_\_

#### Doel:

Deze checklist wordt gebruikt om pijn te beoordelen bij patiënten met dementie die geen of slechts beperkte mogelijkheden hebben te communiceren

#### Instructies:

Kruis aan welke items van de PACSLAC voorkomen tijdens de periode waarin u geïnteresseerd bent

De score per subschaal kan worden berekend door de het aantal kruisjes per subschaal op te tellen

Door alle subschaal scores op te tellen berekend u de totale schaal score

#### Opmerkingen:

\_\_\_\_\_

Gelaat	Aanwezig
Uitdrukking van pijn	
Een specifiek geluid of uiting van pijn 'm' of 'oef'	
Wenkbrauwen fronsen	
Gezins:	
Rimpels in het voorhoofd	
Krommen en krommen	
Verandering in de ogen (scheel kijken, mat, helder, meer bewegingen)	
Pijnlijke plek aanraken en vasthouden	
Pijnlijke plek berispen	
Tengetrokken	
<b>Verzet/ afweer</b>	
Verbale agressie	
Fysieke agressie (bijv. mensen en/ of voorwerpen wegduwen, anderen krabben, anderen slaan, stompen, schoppen)	
Gezigend (gezigteend)	
Achternuitdeinzen	
Niet aangeraakt willen worden	
Niet-coöperatief/ weerstand tegen zorgverlening	
<b>Sociaal emotioneel/stemming</b>	
Nom./pukkebaas	
Schreeuwen/ knippen	
Donkere blik	
Verdrietige blik	
Geen mensen in de buurt laten komen	
Ontsteld (outdaze)	
Elozend, rood gelaat	
Rusteloos	

#### Subschaal scores:

Gelaat \_\_\_\_\_

Verzet / Afweer \_\_\_\_\_

## APPENDIX 5: Clinical global impression scale

**GLOBALE KLINISCHE BEOORDELING  
(CLINICAL GLOBAL IMPRESSION: CGI)**  
(in te vullen door behandelaar/onderzoeker)

Naam: .....

Datum: .....

Ingevuld door: .....

**Instructie:**

*Vul deze schaal in nadat u een gesprek met de patiënt hebt gehad.  
Beoordeel op basis van al uw ervaring met dit soort patiënten.*

**1. Globale ernst van de aandoening (gemiddeld gedurende de laatste week)**

- 1 Normaal, niet ziek
- 2 Minimaal ziek
- 3 Licht ziek
- 4 Matig ziek
- 5 Matig ernstig ziek
- 6 Ernstig ziek
- 7 Zeer ernstig ziek

**2. Globale verandering (ten opzichte van het begin van behandeling)**

- 1 Zeer veel verbeterd
- 2 Veel verbeterd
- 3 Minimaal verbeterd
- 4 Geen verandering
- 5 Minimaal slechter
- 6 Veel slechter
- 7 Zeer veel slechter