Pain and its consequences in dementia: Observing the complex relationship between pain, behaviour and ADL in nursing home residents

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CHAPTER 8

Summary and General discussion
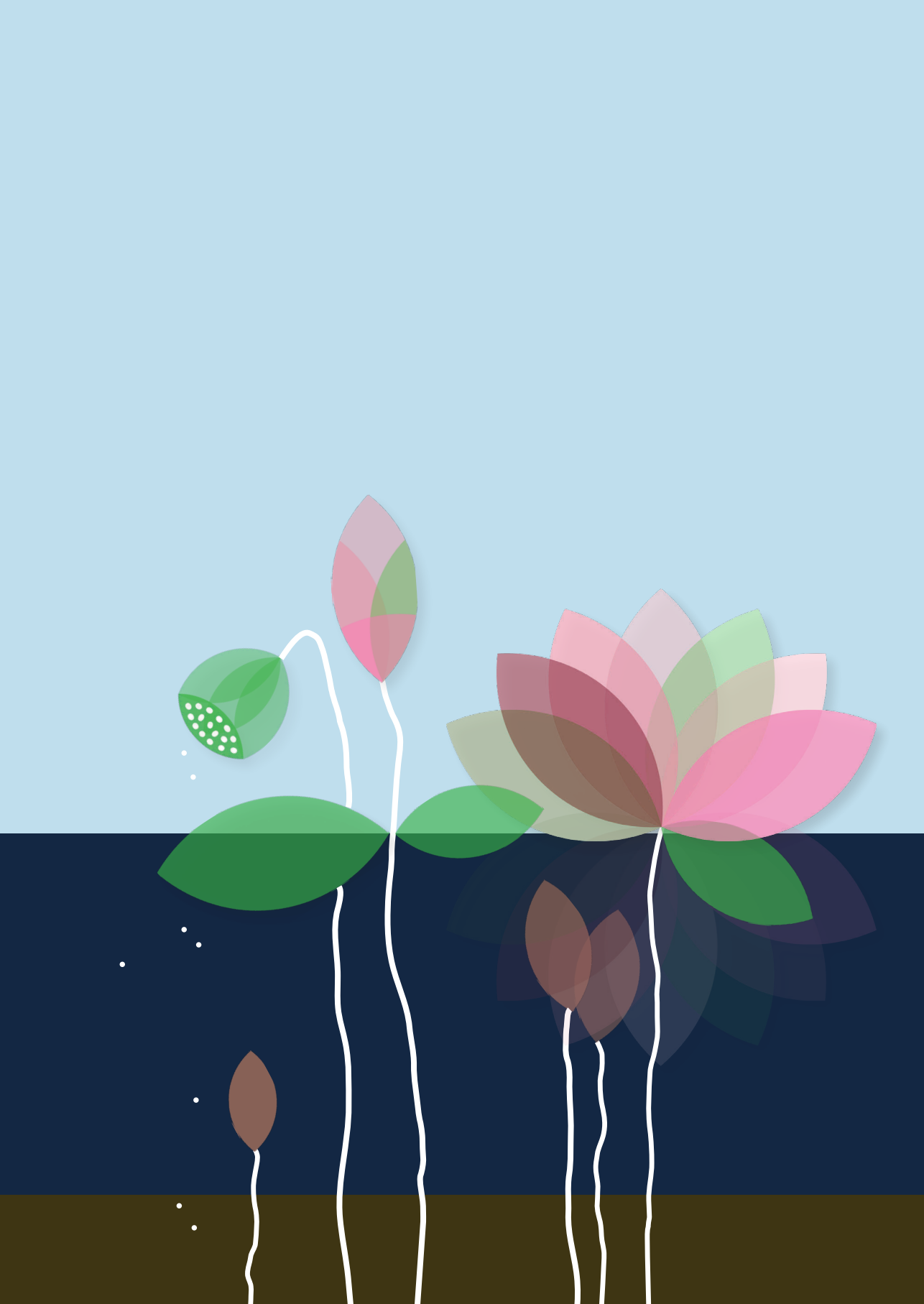
The primary aim of this thesis was to investigate the complex relationship between pain, neuropsychiatric symptoms, and ADL functioning in dementia. In part II, we aimed to study the psychometric properties of the PAIC observational pain assessment instrument. In this final chapter, the main findings are summarized and critically discussed. In addition, methodological considerations are discussed. Finally, implications for clinical practice are presented and recommendations are made for further research.

Summary of main findings

Part I. Relationship between pain, neuropsychiatric symptoms, and ADL functioning

Chapter 2 | The current state of evidence regarding the challenges of pain management in persons with dementia

This narrative review explores evidence from relevant and recent literature regarding four key perspectives of pain management. First, from a biological perspective the impact of neuropathological changes of the brain in dementia leads to a change in the nociception of pain: the intensity of pain and affective response is different. Furthermore, loss of communicative skills hampers the self-report of pain, and therefore the detection of pain. Consequently, pain assessment (second perspective) should focus on behavioural expressions of pain such as agitation and aggression, for example by using observational measurement instruments with good psychometric properties. Additionally, there is ample evidence of undertreatment and inadequate treatment of pain in persons with dementia (third perspective). The fourth key perspective debates the lack of interdisciplinary education and training of healthcare professionals (fourth perspective). There is an urgent need for evidence-based guidelines.

Chapter 3 | The strength of associations between pain, neuropsychiatric symptoms, and physical functioning in persons with dementia

Despite the increased attention for pain in dementia, this systematic review shows that only few studies have explored the association between pain, neuropsychiatric symptoms (NPS) and physical functioning. Most evidence was found for a positive association between pain and depression, followed by a positive association between pain and agitation/aggression. Physical functioning was often not the main topic of the included studies. There was little evidence for the association between pain, transfers, and bathing. All associations found in this review were relatively weak. This may be the result of inadequate assessment; use of valid measurement instruments was often lacking.

Chapter 4 | The relationship between the course of pain and change in ADL functioning, both in general and regarding specific ADL functions

This longitudinal study showed that pain is associated with ADL functioning cross-sectionally. Residents with pain (PACSLAC-D score ≥4) were more ADL dependent than residents without pain.

Moreover, a change in pain within the first 3 months of follow-up predicted a decline in ADL functioning over the 6-month follow-up period, independent of dementia severity. Specifically, a decline was found in the ADL-activities 'transferring' and 'feeding'.

Part II. Pain assessment in impaired cognition: PAIC

Chapter 5 | Content validity of the Dutch version of the Pain Assessment in Impaired Cognition scale

First, the PAIC (36 items) was translated into Dutch and content validity was examined. Overall, the study showed good content validity and it suggests that especially the items of the body movement domain correspond well with the clinical experience of the Elderly Care Physicians (ECP) and nurses in Dutch nursing homes. Compared to the body movement domain, lower content validity was found for a number of items of the facial expression domain and, to a lesser extent, for items of the vocalizations domain. Interestingly, the think-aloud test performed in this study revealed differences between physicians and nurses in the notions of pain characteristics. For example, unlike ECPs, nurses found the item 'freezing' specific for pain.

Chapter 6 | Observer agreement on the individual 36 items of the Dutch version of the PAIC in a real-life nursing home setting

This observational study in five Dutch nursing homes showed that the 36 items of the Dutch version of the PAIC have promising intra- and interobserver agreement. The items of the domains of body movements and vocalizations in particular showed good observer agreement. In the facial expression domain, there were fewer items with good observer agreement.

Chapter 7 | Observer agreement and factor structure of each of the 36 items of the Pain Assessment in Impaired Cognition scale

Finally, in a multicentre observational study, which took place in four European countries, the inter- and intraobserver agreement, and factor structure of the PAIC (36 items) was analyzed. Results showed that reliability of especially the items of the body movement and vocalizations domains was generally good. For five items of the facial expression domain ('looking sad', 'tightened lips', 'empty gaze', 'seeming disinterested', and 'looking tense'), the agreement between observers was below 70%. This was true for observations during rest and during movement. Poor agreement was found especially in the Netherlands, where education and training in the use of observational measurement instruments was low. Furthermore, factor analysis showed individual items could be clustered into six underlying components: 1) vocal pain expression; 2) face anatomical descriptors; 3) protective body movements; 4) vocal defence; 5) tension; and 6) lack of effect.

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Interpretation and critical discussion of findings and methodology

The evidence presented in this thesis builds on the existing evidence that the management of pain in persons with dementia is challenging. However, it narrows it down by dividing the challenges into four areas of interest: neuropathology, pain assessment, analgesic treatment, training and education. This thesis focusses especially on the relationship between pain and ADL functioning, and on pain assessment by examining the psychometric properties of the PAIC observational pain instrument.

The following section addresses the methodological strengths and limitations that should be considered when interpretating the results presented in this thesis. First, the design of the study investigating the relationship between pain and ADL functioning, including follow-up and statistical analyses, will be discussed. In the second part, we will elaborate on issues related to the development of the PAIC, including psychometric testing and item overlap.

Part I. Pain and ADL functioning

The systematic review on the complex relationship between pain, NPS and ADL functioning does not provide satisfactory results in terms of causality (Ch. 3). Especially the relationship between pain and ADL functioning was underexposed and we found no longitudinal study investigating this relationship. In order to examine if, and how, a change in pain influences ADL functioning in dementia we performed a longitudinal study with linear regression analyses. We investigated the effect of pain on ADL functioning in general, but also on specific ADL activities. This provides more in-depth information on which ADL activity is affected most by pain.

A key finding in Chapter 4 of this thesis is that pain has an impact on ADL functioning in dementia, irrespective of dementia severity.[1] This is an important finding, because a decline in ADL functioning is often interpreted as a sign of increasing dementia severity, whereas it can also be caused by pain.[2-4] However, due to the fluctuation of pain and ADL functioning over time, there is a need to reflect on choices regarding statistical analyses.

As there is a partially reciprocal relationship between dementia, pain, NPS and ADL functioning (see introduction Figure 1) unravelling single pathways is difficult. Besides linear regression analyses, other statistical approaches were explored, such as multilevel modelling for longitudinal data. This would account for dependency in data, e.g., residents within organizations, but also for dependency in repeated measures on the individual level. However, correlations at the unit of organization level (different wards) were negligible. Furthermore, multilevel modelling would enable the use of all available data, including those lost to follow-up at three months. Even so, the inclusion of pain as a time varying covariate did not provide a clearer view on the relationship, as we aimed to stay close to daily clinical practice.

Therefore, we chose a more simplified statistical approach of linear regression analyses with the change in pain score during the first three months of follow-up as a predictor for ADL functioning at six months follow-up.

Furthermore, to examine the relationship between pain and ADL functioning, data from the STA-OP! trial was used (Ch. 4). ADL functioning was not a primary subject of interest and data collection was at 3 and 6 months follow-up. A longer follow-up period might have captured more changes. In a Norwegian study, for example, the course of ADL functioning in persons with dementia was examined over a follow-up period of 36 months with biannual measurements.[2] The study showed that ADL impairment increased with the progression of dementia, and the association between dementia severity and ADL impairment was stable over time. This stability of the relationship of ADL and dementia severity over time might suggest that a longer follow-up period, compared to the follow-up period used in the STA-OP! trial (6 months), or frequent measurements of ADL functioning is not necessary. However, this could be different for the relationship between pain and ADL, because pain can be acute or chronic and may fluctuate over time. Also, in the Norwegian study the assessment started immediately after admission to the nursing home. The onset of a decline in ADL functioning can be pinpointed more precisely when multiple measurements in follow-up studies start at admission. The downside of a longer follow-up period is a larger number of dropouts due to, for example, death, transfer to other facilities, but also an increasing number of refusals to be tested due to worsening of cognitive status.[5][6] To accommodate the loss to follow-up, one could shorten the time period needed by including an intervention that potentially forces a change in pain and ADL functioning, e.g., an analgesic trial. This shorter follow-up period, for example a period of 8-10 weeks[7] may be more feasible in clinical practice. A shorter follow-up period could also eliminate possible barriers which hamper successful implementation of research in long-term care, such as understaffing/high workload, high staff turnover, lack of time, and lack of financial resources.[8][9]

Part II. Pain Assessment in Impaired Cognition: PAIC

The PAIC was developed in a European group of experimental and clinical researchers. The goal was to develop an internationally agreed upon observational measurement instrument, with thoroughly investigated psychometric properties, an ultimately valid and reliable tool, which is sensitive to change. The tool should be suitable for use in a research and clinical setting, and facilitate international research on pain management in dementia. The results presented in this thesis regarding the initial development of the PAIC (hereinafter referred to as PAIC36) were used in refining the final version of the PAIC (hereinafter referred to as PAIC15).

In the process of examining the research version of the PAIC36, a total of 36 promising items were studied. These items were selected from 12 existing pain observation instruments, which makes this instrument a meta-tool. Across Europe, several studies have been conducted in the road map for an optimal instrument for research and practice.[10] Three of these studies are described in this thesis.

For the validity of the PAIC36, the think-aloud test among nurses and elderly care physicians (ECPs) was an important step.[11] This think-aloud test is not often used in the development of instruments, but it is very appropriate for research in our setting. Performing this test with potential users provided insight into the thought processes that determine the user's response to an item and whether the items are understood as they were intended.

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However, we did not take full advantage of all available expert input. Other potential users, such as physiotherapists, psychologists, and occupational therapists, were not part of the study. Their clinical opinion, but also their cultural beliefs and experience in pain management, is missing. As these healthcare professionals play a significant role in guiding and treating residents with pain, this might have an adverse effect on the instrument's reliability and validity.[12] This is especially important considering the results of the content validity study (Ch. 5), in which we found that nurses and ECPs do not speak the same language when it comes to pain. A valid and reliable measurement instrument could close this 'linguistic' gap.

By contrast, one of the strengths of the multicentre observational study (Ch. 7) is that it took place in four countries (Italy, Serbia, Spain and the Netherlands). This means that the PAIC36 was studied in culturally different clinical settings which facilitates cross-cultural research on pain in persons with dementia. Due to globalization and migration, many countries have very diverse populations. In order to provide patient-centred care, understanding the cultural and ethnic background of residents as well as healthcare professionals is important.[13] Especially considering that many cultural aspects influence different domains of pain: physical, psychological, spiritual, and social. In other words, people with different cultural backgrounds respond differently to pain.[14]

In the Dutch study described in Chapters 5 and 6, these cultural patterns were not addressed during, for example, the think-aloud test. Healthcare professionals' attitudes and beliefs about pain are associated with the content of the health advice given to the resident or their relative.[15] For example, when a nurse believes that it is important to avoid certain tasks and rest when having low back pain, this will be the advice given to the resident. In order to provide adequate pain management, healthcare professionals need to be aware not only of their own attitudes and beliefs about pain, but also of the cultural background of the resident and how this may influence their experience of pain, and their personal needs regarding pain management.

During the psychometric testing of the PAIC36, a short training was given to the nurses, about different aspects of observing a resident. This included, for example, not performing other tasks while observing and not giving a personal interpretation of the different items, but also practicing filling out the PAIC36 using a videoclip. Despite these efforts, observer agreement of the facial items of the Dutch version of the PAIC36 (Ch. 6) was low compared to the domains of body movement and vocalizations.[16] This is remarkable, as we know that facial expressions are the most valid expressions, certainly in laboratory settings.[17][18] A possible explanation could be that observing 36 items during a relatively short period of time is challenging. Also, nurses may not have followed the instructions provided during the training. Perhaps a more plausible explanation is that nurses are unaware of the fleeting and variable nature of facial expressions. We know that nurses and other healthcare professionals find facial expressions most difficult to interpret.[19][20] Healthcare professionals seem to recognize changes in behaviour or a decline in ADL functioning more quickly than they recognize changes in facial expressions.[21][22]

It could be worthwhile to investigate the correct use of the PAIC15 and how *well* the observation is executed, both in studies and in everyday practice. This could provide valuable information for future educational training and implementation programmes.

Item overlap and development of the PAIC15

As previously mentioned, the interplay between pain, NPS, ADL functioning in dementia is complex. This is also reflected by the overlap of items between measurement instruments, such as the Katz-ADL scale and the Reisberg Global Deterioration Scale (GDS), but also items of the PACSLAC-D and CMAI that measure pain and agitation respectively. This does not aid the unravelling of the relationship. For example, the items concerning assisted bathing, eating and toileting are incorporated in both the Katz-ADL scale and the Reisberg GDS. Physical aggression items, such as hitting and kicking, are both incorporated in the PACSLAC-D and CMAI. Overlapping items weaken the discriminant validity of a measurement instrument and this may have led to an overestimation of the relationship between pain and ADL functioning in dementia presented in this thesis (Ch. 3, 4). [23] During the development of the PAIC36, steps were taken to minimize overlap of items between the different constructs of pain, NPS and ADL functioning in dementia. The PAIC36 'research version' consisted of 36 items and item reduction was completed through 7 steps: 1) gathering empirical evidence on individual items (Ch. 5, 6, 7); 2) item difficulty (Ch. 5); 3) inter-rater reliability (Ch. 6, 7); 4) construct validity; 5) content validity (Ch. 5); 6) feedback external reviewers; and 7) consensus meeting with expert panel.[24] For example, the items 'crying', 'looking sad', and 'seeming disinterested', which might also indicate a depression, were excluded. The item reduction process resulted in the exclusion of 21 items, leading to the final version of the PAIC: PAIC15.

A very important and unique part in developing the PAIC15, was the use of experimental pain.[24] In this way it became clearer which item/behaviour truly was a result of pain, reducing possible overlap with items of behavioural observation tools even further. In clinical studies mimicking experimental pain by including guided movement is advised, since pain is more likely to occur during movement.[24]

Not having a 'gold standard' for pain in persons who cannot communicate remains a problem in the validation of observational pain instruments. Recently a study in the field of biomedics showed interesting results on the positive correlation between pain biomarkers in saliva and the score of the PAINAD scale, one of the oldest pain observation scales.[25] Pain biomarkers, tumour necrosis factor receptor type II (sTNF-RII) and secretory IgA (sIgA), were determined in the saliva of persons with moderate to severe cognitive impairment. This technique is rather simple, safe, non-invasive, and therefore a promising strategy to reinforce the validity of pain measurement instruments, such as PAIC15.

Although the final version of the PAIC15 warrants further refinement in terms of sensitivity to change/responsiveness, first results on cut-off scores are underway[26] and COSMIN recommendations have been followed, resulting in the most promising observational measurement instrument available so far.

In summary, the psychometric evaluation of the PAIC presented in this thesis not only results in a promising measurement instrument, but also provides useful information for the development and improvement of educational programmes that contribute to the utilization of the PAIC15.

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Implications for clinical practice and organizational aspects

Several implications for future clinical practice and organizational aspects result from this thesis.

Despite the growing body of evidence, including this thesis, concerning the relationship between pain in dementia and its consequences and the quest for the optimal observational measurement instrument, regular assessment and guidelines are poorly implemented in clinical practice (Ch. 2 and 3). Moreover, research has shown that implementing an observational measurement instrument is not enough to reduce pain in persons with dementia.[27] In order to facilitate successful pain management, we need to think beyond measurement instruments and focus on a systematic approach of pain.[28]

In the Netherlands, the Dutch association for elderly care physicians, Verenso, developed a national guideline for the multidisciplinary recognition and treatment of pain in vulnerable elderly.[29]

There are several points of concern, some resulting directly from this thesis, and some suggestions.

Organizational aspects

1. Implementation of a multidisciplinary pain team

A pain team can formulate a pain protocol adjusted to the healthcare organization, for example the nursing home.[30] Preferred participants in pain teams are a nurse, occupational therapist, psychologist, physiotherapist and an elderly care physician. This team can facilitate training and feedback, consultation, the availability of assessment instruments (and their implementation in electronic patient file systems) and availability of information materials and different types of interventions.

2. Individualized patient care and treatment plan

Next to organizational tasks, the pain team can support an interdisciplinary approach in the team that treats the patient, which allows for developing such an individualized care and treatment plan. This plan should incorporate non-pharmacological as well as pharmacological interventions.

3. Collaboration between physicians and nurses (Ch. 5.)

For a proposed care and treatment plan to be successful, it is important that physicians collaborate closely with the nursing staff. Nurses are the eyes and ears of the team, making them the patients' advocates. By involving the nursing staff, treating pain becomes a team responsibility.

4. Use a stepwise approach (Ch. 2.)

Using a stepwise or systematic approach incorporating an observational pain measurement instrument is important. The STA-OP! programme is an example of such a stepwise approach. STA-OP! has proven to be successful in reducing pain as well as challenging behaviour.[31-33]

5. Improve implementation

However, implementing (new) evidence-based guidelines or measurement instruments is a challenging endeavour. It requires commitment from healthcare organizations and policymakers. Over the years, some important findings emerged which may help to improve implementation strategies.[34] For example, barriers to effective pain management can be grouped into three themes: patient related (sensory and cognitive impairment, fear of addiction), caregiver related (lack of knowledge, difficulty communicating with family or physician), and system related (lack of funding, lack of standardized approaches, lack of education, high workload and staff turnover).[35 36]

Whilst the patient- and caregiver-related barriers can be incorporated in educational programmes, the system-related barriers are the most challenging. This should be the focus during implementation of evidence-based pain guidelines. In this light, Verenso developed an implementation protocol for the multidisciplinary guideline on pain; recognition and treatment of pain in frail elderly.[37] Special attention was paid to the organizational aspects of the implementation process, combined with evident and reproducible policy reports. Also, the University Network of Eldery Care of the University Medical Center in Groningen (UNO-UMCG) is currently investigating the implementation of the PAIC15 in two Dutch nursing homes (https://huisartsgeneeskunde-umcg.nl/effectiviteit-van-pijninterventies).

6. Use pain champions

A cornerstone of successful adherence to a newly implemented guideline and practice change, is the use of motivational leaders, or so-called pain champions.[8 34] They can be the go-to person for all nursing staff, the connector between nursing staff and physician, and the driving force behind integrating the observation of pain in routine care.[22 34]

Education and interdisciplinary learning and training

1. Interdisciplinary training (Ch. 2, 4 and 5)

A prerequisite for adequate pain management is integrating and facilitating continuous education and training of healthcare professionals in elderly care.[32 38 39]
As previously mentioned, this thesis showed a mismatch concerning the notion of pain between nurses and physicians working in nursing homes (Ch. 5). This reflects the gap in the knowledge of both nurses and physicians. Pain is subjective and difficult to recognize in persons with dementia. However, the consequences of pain, as presented in this thesis, are more easily recognized by nursing staff.[31 39 40] For instance, nurses observe changes in behaviour, but are often unable to distinguish whether changes in behaviour are caused as part of NPS in dementia, or by pain. Misinterpretation is also likely to occur in case of a change in ADL functioning: decline in ADL functioning is ascribed to an increase in dementia severity (Ch. 4). Therefore, it is important to develop an educational training programme with a special focus on interdisciplinary training and a multidimensional approach to pain.
Key components of an educational training programme should cover important patient- and care-related topics such as the perception, expression, recognition, and assessment of

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pain, with special attention for a change in ADL functioning. Also, the pharmacological and non-pharmacological treatment of pain should be addressed as well as cultural aspects of pain.[22] Furthermore, it is important to raise awareness about 'red flag-conditions' which are known to cause pain, such as co-morbidities (e.g., osteoporosis, cardiovascular disease, cancer), performing certain activities (e.g., getting dressed, transferring), but also pain as an occupational disease resulting from previous profession such a being a hairdresser or a construction worker. The individual's biography is an important element in the assessment of pain.[41 42] Admission to the nursing home should be the starting point for documenting a resident's pain history, including coping strategies.[43-45]

2. What type of education?

Besides the topics of a pain education training programme, it is equally important to look into how such programmes are operationalized. In the course of the development of PAIC, an e-learning course was created (https://www.free-learning.nl/modules/paic15/start. html). This e-learning course includes background information on the different domains and items of the PAIC15, but predominately includes training videos on how to use the PAIC15 correctly. However, training videos alone may not change nurses' behaviour.[46 47] It is therefore necessary to combine several educational interventions. Few studies have been conducted on educational interventions in pain management in nursing homes. As a result, a combination of interactive training workshops, interdisciplinary discussions of case reports, training videos and e-learning seems most promising to enhance knowledge and improve skills in pain management.[7 34 48 49]

Recommendations for future research

Based on the results of this thesis, several recommendations can be made for future research.
As discussed earlier, more longitudinal research is needed on all aspects of pain management, for example, a more in-depth examination of the relationship between pain and ADL functioning using different statistical approaches. However, intervention studies on educational training programmes and large-scale pain management testing programmes are also important subjects of interest.

Investigating the relationship between pain and ADL functioning

Although not widely accepted in medical research, case studies, or n-of-1 trials, could be an alternative way to investigate the relationship between pain, NPS and ADL functioning.[50] A lot of research involves interventions tailored to a group of individuals. N-of-1 trials are considered to be the most ideal study design to investigate causality on an individual level.[51] As stated throughout this thesis, the relationship between pain, ADL, NPS and dementia is reciprocal and therefore difficult to investigate in large clinical trials where the heterogeneity of the study sample is substantial. N-of-1 trials use key elements of clinical trials (i.e., randomization, blinding) but have a more flexible approach in which participants serve as their own control. Furthermore, series of n-of-1 trials can highlight individual differences and reveal characteristics related to responders and non-responders. A meta-

analysis of multiple n-of-1 trials can reveal evidence which can be applied to a whole group of individuals[52]. More importantly, participants benefit directly from the intervention.

Pursuing n-of-1 trials, especially in dementia care, could be a key factor in closing the gap between evidence-based medicine, derived from large clinical trials (often with high heterogeneity), and real clinical practice where individualized patient care is the core business.

Furthermore, applying different statistical approaches, such as multilevel modelling, allows for studying the dynamic interplay between pain, NPS and ADL functioning in dementia. Multilevel modelling can be used to examine different trajectories of pain, NPS, and ADL functioning, as well as how these trajectories are interrelated over time.

Also, another statistical approach, such as mediation analysis, could be used to explain the mechanisms that underlie the relationship between pain (independent variable), NPS, ADL functioning, and dementia severity (dependent variables). In this way, the main mechanisms by which pain affects NPS and ADL functioning in persons with dementia could be revealed, providing, among other things, important information for the development of more effective interventions.[53]

Pain assessment with PAIC15

To contribute to the usage and implementation of PAIC15 in clinical practice, several additional studies are needed (Ch. 5, 6, 7). It is important to collect evidence on cut-off scores for different pain intensities. As mentioned, first results on cut-off scores for possible and probable pain are underway.[26] Future research on cut-off scores should also include severe pain. Perhaps it is possible to examine whether a specific score would be suggestive of a specific treatment or drug. Furthermore, investigating the sensitivity to change, for example by initiating analgesic trials, is an important part of future research. Especially since a recent double-blinded randomized placebo-controlled trial investigating the validity of the German PAINAD showed insufficient sensitivity to change/responsiveness.[54]

Additionally, the feasibility of PAIC15 must be examined in persons with other neuro-degenerative diseases, such as Parkinson's disease, Huntington's disease, and persons with cerebrovascular accidents that have aphasia and facial paralyses.[55] [56] Studies on the use of PAIC15 in patients with aphasia are underway (Carolien de Vries, LUMC), and studies in Huntington's disease are in the design phase (Gregory Sprenger, LUMC). All of these groups, including Parkinson's, face many challenges regarding the usability of pain observation scales such as PAIC15. These include evaluation of motor symptoms and facial expressions, because these may be affected heavily by the primary disease, and thus the expression of pain may be hampered.[57]

Further, it might also be worthwhile to investigate the feasibility of the PAIC15 in persons with young onset dementia. It is conceivable that, for example, ageism does not play a significant role in pain behaviour in young onset dementia and that pain behaviour in this group might therefore be different.

Lastly, testing PAIC15 in different clinical settings, such as hospitals, rehabilitation centres, but also in primary care. In the Netherlands, an increasing number of persons with dementia live at home. It might be interesting to test whether PAIC15 can also be used

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by informal caregivers or family. A recent study by Bentur et al., showed promising results about the use of pain assessment tools by family members.[58]

Non-pharmacological and pharmacological treatment of pain

The evidence for efficient treatment with analgesics, such as paracetamol and opioids, is scarce (Ch. 2), resulting in both over- and undertreatment of pain.[59] Little is known about medication dosage, titrating analgesics, and optimal duration of analgesic use. This is one of the reasons physicians are reluctant to prescribe opioids, also known as opiophobia.[60] A much safer way to treat pain are non-pharmacological interventions, such as massage and music therapy, exercise and movement therapies (e.g., rocking chair), but also using the robotic seal PARO.[61-65]

However, strong study designs on non-pharmacological treatment options in dementia patients are lacking. To achieve adequate pain management, large-scale analgesic trials combined with non-pharmacological interventions are necessary.

Novel technologies

Despite the development of PAIC15, pain assessment in persons with dementia still faces many challenges. These often originate from the barriers mentioned before, such as lack of time and difficulty differentiating pain from other forms of discomfort.

An interesting focus of research could therefore be the application of modern technology, such as automatic pain assessment systems.[66 67] In the past 5 years interest in this complementary diagnostic is increasing, and the results are very promising.[66 67] However, most systems have been developed for young or middle-aged individuals and are not yet suitable for older individuals.

For example, wrinkles which could lead to false positives. Therefore, research is needed in the field of geriatric medicine, and in the future automatic pain assessment systems may lead to better pain management and a reduction in the workload of nursing staff.

Overall conclusion

Recommendations from this thesis may lead to further improvement of pain management in persons with dementia. The most important recommendation is that besides challenging behaviour, a decline in ADL functioning should also serve as a red flag for the presence of pain. Therefore, the clinical message is: if there is a decline in ADL functioning, do not automatically attribute it to the progression of dementia but check for other causes. Pain is definitely a cause to be considered.

The development of PAIC was the starting point for creating a robust valid, reliable, and international meta-tool which can be used in clinical as well as research practice. At present, research on psychometrics, clinical utility and feasibility of PAIC15 is ongoing. Throughout this thesis, important suggestions are made for much-needed educational training programmes and implementation strategies.

Follow-up on Hans

Hans, who suffers from Lewy body dementia and Parkinson's disease, suddenly expressed challenging behaviour such as agitation, and verbally and even physically aggressive behaviour towards other residents and nursing staff. There was also a change in his ADL functioning: his wife noticed that there were more OFF moments and that he was limping with his right foot. The nursing staff elaborated on possible causes for his sudden change in behaviour and mobility. They consulted with the elderly care physician (ECP), psychologist, and physiotherapist. Together with the nursing staff, the psychologist evaluated the agitated and aggressive behaviour, among other things by measuring the agitated behaviour with the Cohen Mansfield Agitation Inventory (CMAI). His score of 86 (range 29-203) indicated significant agitated behaviour. Furthermore, a physical examination by the ECP and physiotherapist resulted in the identification of increased muscle stiffness, postural instability, and difficulty walking. During walking, Hans frequently moaned and sometimes had a pained expression on his face. In addition, the nursing staff filled out the PAIC15 for three consecutive days, during rest and during movement. The PAIC15-scores were especially high during movement: 31 (range 0-45). This led to a follow-up physical examination by the ECP, with special focus on locomotion. An ingrown toenail of the great toe of the left foot was found. After a partial avulsion of the lateral edge of the nail plate and matrixectomy, the pain was alleviated. Within the next week, Hans' walking pattern improved and the frequent OFF moments decreased. Moreover, the agitated and aggressive behaviour disappeared.

A multidisciplinary approach of a change in behaviour and ADL functioning, use of observational measurement instruments, with special attention for the presence of pain, can significantly contribute to the quality of life.

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