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The use of behavioral observation tools in nursing care for patients with disorders of consciousness

Through The Eyes Of Neuroscience Nurses

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Through the Eyes of Neuroscience Nurses

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CHAPTER 1

Introduction and outline of the thesis

Miss. C. was a 53 year old woman who had been in an accident where a car hit her moped with nearly 80 kilometres per hour. With no helmet for protection, the damage to her brain was severe. After a few weeks in the intensive care unit she woke up from a coma, which merely meant that she opened her eyes. Once medically stable she was transferred to the neurosurgery nursing ward. She laid in bed with her eyes open and sometimes appeared to be clearly looking directly at people around her or following them across the room with her eyes. She never spoke though, nor ever moved her limbs and the nursing team had to take over all normal functions, such as feeding, bathing and even alternating her position in bed to avoid pressure ulcers. She was not able to communicate or express any kind of discomfort.

During one of my shifts I felt a change in miss. C's behaviour. Her eyes were slightly wider than normal when I approached her to turn her on her side. She looked at me with heavy breathing and slight perspiration on her forehead. As my colleague lifted her head to remove the pillow, I saw a clear grimace and we heard a faint groan. There isn't a single way to objectively report this, but in this moment I was convinced that she was in pain. The behaviour repeated itself every time we put the slightest strain on her neck. My colleague and I checked her vital signs, detected a fever and we commenced a diagnostic routine with the physician. The following day a serious meningitis was confirmed, of which we know it can cause severe pain when straining the neck. Though I managed to adequately detect this in Miss. C.'s behaviour, I feel unease at the fact that I am not able to objectify my clinical observations and confirm or report on the presence or absence of her pain...

Pain measurement as essential part of nursing care

One of the most vital parts of the nursing profession is detecting, observing or measuring clinical signs in patients. By developing a 'clinical eye' and performing adequate assessments we are able to prevent complications, treat discomfort and safe lives. (Rothman, Solinger, Rothman, & Finlay, 2012) In order to do so, it is important that we develop both observational and communication skills, so we are able to distil critical information from each patient. We ask the right questions at the right time and combine these patient-reported data with objective data such as vital signs and laboratory results. All of this information is used to prioritize, plan and initiate both nursing and medical care.

A clear example of this process, and essential part of nursing care, is pain assessment. (Feo, Kitson, & Conroy, 2018) Changes in the severity of pain can be an indicator of potential tissue damage due to complications, infections or new diseases and nurses must therefore frequently ask patients about their pain experience. (van Boekel, et al., 2019) Though simple as it sounds, this assessment requires adequate and frequent questioning about the intensity, location and frequency of pain, in order to initiate the proper treatment. (Boekel, et al., 2017) (Dequeker, Lancker, Hecke, & Hecke, 2018) This assessment has proven difficult to implement in acute care settings, even when patients are

able to adequately communicate. (Shugarman, et al., 2010) (van Boekel, et al., 2016)

In the field of acute neurology and neurosurgery, but also in subsequent long-term care and rehabilitation, pain assessment has proven even more complex in patients with acquired brain injury (ABI) and accompanying disabilities. Neuroscience nurses often care for patients with severe aphasia, confusion, delirium and even disorders of consciousness (DOC), all of which limit the ability to self-report pain. (Chatelle C. , et al., Pain issues in disorders of consciousness., 2014)

Disorders Of Consciousness and other limitations to self-report pain

With the advancement of modern medicine, patients with ABI survive their injury more often than ever before. (Wilkins, et al., 2017) ABI is generally defined as any damage to the brain that occurs after birth and is not related to a congenital or a degenerative disease. (World Health Organization, 1996) This definition therefore includes a wide variety of diseases such as Traumatic Brain Injury and Stroke.

When surviving ABI a patient can at some point develop DOC, causing them to be less awake and aware of their surroundings. During the acute phase of ABI, the level of consciousness may fluctuate and is often measured by nurses with the Glasgow Coma Scale (GCS). (Vink, et al., 2018) Neurological deterioration of two or more points on the GCS occurs in about 12% of all stroke patients before reaching the hospital. (Slavin, et al., 2018) Absence of functional communication or functional object use despite behavioural evidence of wakefulness (i.e. spontaneous eye opening, indicating the end of the comatose phase) is considered a prolonged disorder of consciousness (PDOC). Two clinical entities are distinguished: the Minimally Conscious State (MCS) and the Unresponsive Wakefulness Syndrome (UWS), both diagnosed with the Coma Recovery Scale - Revised. (Kalmar & Giacino, 2005) It is estimated that 0.1 to 0.2 hospitalized and institutionalized UWS patients per 100.000 members of the general population in the Netherlands exist, some with continued life-prolonging treatment up to 25 years. (Erp, et al., 2015) Though acute DOC, MCS and UWS diagnoses differ in the severity of consciousness impairment, any form of DOC usually results in extensive, if not complete, dependency on health care professionals.

These patients are fragile and unable to self-report pain or pain intensity. Patients who are unable to communicate their pain are at risk of under recognition and under-treatment of their discomforts. (Herr K. , Coyne, McCaffery, Manworren, & Merkel, 2011) Moreover, patients with DOC are at risk of developing spasticity or other conditions that require physiotherapy, which is often considered painful by patients' family. (Latchem, Kitzinger, & Kitzinger, 2016)

Due to the abstract and complex concept of consciousness, health professionals often wonder whether patients with DOC can experience any pain at all. Several recent studies indicate that even in the most severe cases of DOC, functional magnetic resonance imaging (f-MRI) scans show neurological activity indicative of some form of pain experience, albeit on a non-cognitive level. (Chatelle C. , et al., 2014) In the absence of hard evidence for the presence or absence of conscious perception, health care professionals must always assume their patients are able to experience pain. Nurses and physicians must therefore rely on pain behaviour observation tools. (Chatelle C. , et al., Pain issues in disorders of consciousness., 2014)

From patient care to clinical research to implementation science to patient care

The clinical scenario of miss. C. is just one of numerous that the author of this thesis experienced as a neuroscience nurse and it reflects the importance of clinical observation by nurses for patients unable to adequately communicate themselves. Behavioural observation is a complex process though, as the behaviour associated with pain experience may differ among patient groups, depending on age, brain function and physical limitations such as paralysis. Also, the presence of behaviour is never a guarantee for the presence of pain experience, as the behaviour might be caused by other discomforts such as hunger, fear or a full bladder. But what if there was a way to objectively identify the right behavioural signs associated with pain in different patient groups with neurological disorders? In order to obtain this clinically desirable goal, we must rely on the principals of Evidence Based Practice (EBP) and Quality Improvement (QI).

EBP is the integration of scientific research, clinical expertise and the patient's wishes or needs.[Sacket] This process is used to determine the "right thing to do" in different clinical scenario's, which in this case means finding the right behavioural signs associated with pain in patients with DOC due to ABI. Finding the right tools to observe and measure this behaviour is not enough though. In order to truly improve the care for these patients we must implement them in clinical practice. How we should accomplish this can be investigated with QI, were we study ways to "do things right". Only when these two research approaches are combined as Evidence Based Quality Improvement, we can determine ways to "do the right things right", which is precisely what we've aimed to do in this thesis. (Shojania & Grimshaw, 2005) (Glasziou, Ogrinc, & Goodman, 2011)

Aim of the thesis

The aim of the research in this thesis is to explore which instruments could aid neuroscience nurses in behavioural observation and how they could be implemented in daily practice.

Outline of the thesis

Although the chapters in this thesis are presented in (more or less) chronological order, it can be divided into three parts reflecting different stages that lead to quality of care:

1. **Stating the current state of practice and the desired situation**
2. **Choosing and validating the appropriate instrument**
3. **Implementation of pain behaviour observation scales**

Part I - Current state of practice and the desired situation.

The first part of this thesis will focus on the state of practice of two important behavioural observations of neuroscience nurses: pain behaviour observation and consciousness assessment. In **CHAPTER 2** we illustrate how pain behaviour observation is of critical value in patients with communications disorders and will present the current state of use in both acute and long-term care settings in the Netherlands. In **CHAPTER 5** we focus on a well-established behavioural observation tool: the Glasgow Coma Scale (GCS).

This well-known instrument, developed in 1974, appears to be widely introduced among neuroscience nurses in Europe, though training, application and use varies immensely.

Part II - Choosing and validating the appropriate instrument.
In the second part we define our desired situation for future practice. In a preliminary literature study we identified potentially relevant pain behaviour observation tools and described their current state of research. At this point we found ourselves torn between two options. The Rotterdam Elderly Pain Observation Scale (REPOS) is not specifically designed or validated for patients with disorders of consciousness, but is readily available in Dutch and might be of use in patients with severe aphasia or confusion. (Boerlage, et al., 2019) A more suitable instrument appears to be the Nociception Coma Scale (NCS), but this instrument requires further validation. (Schnakers, et al., 2010) To ensure evidence based quality improvement, we choose to further validate the NCS and present the results of inter-rater agreements among nurses in **CHAPTER 3**. Whilst doing so, other validation studies were published and we summarize these findings in the systematic review of clinical properties in **CHAPTER 4**.

Part III - Implementation of pain behaviour observation scales.
In the last part we crossed the bridge from evidence based practice to evidence based quality improvement. As the REPOS and NCS are validated for different patient groups, both scales will need to be implemented. In **CHAPTER 6** we illustrate how the generally accepted strategy for implementation mainly focusses on education. By gradually training nurses in the applications of the REPOS we hoped to see an increase in the use of this scale among patients with severe aphasia, confusion or language barriers. Unfortunately, a mere educational strategy proves insufficient when patient populations fluctuate. In the last **CHAPTER 7** we combine the knowledge of previous chapters towards implementation of the NCS in three hospitals in the Netherlands and Belgium.

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CHAPTER 2

A survey on pain assessment in patients with disorders of consciousness in Dutch hospitals and nursing homes

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Abstract

BACKGROUND

The current variation in the use of behavioural pain observation tools, documentation and pain protocols in patients with Acquired Brain Injury (ABI) patients with Disorders Of Consciousness (DOC) is unwanted and unknown.

METHODS

A national survey in Dutch hospitals with neurology and neurosurgery nursing wards and nursing home professionals.

RESULTS

From 43 facilities (35 hospital wards, 8 nursing homes) 106 surveys were analysed, completion/participation rate 88% and 40% respectively. 16% of the facilities used a behavioural pain observation tool. This was more often in general hospitals (24%) than in university hospitals (10%) or nursing homes (0%). Variation in measuring/observing pain could be assumed in 72% and variation in documentation in 88%. A specific pain protocol was used in 14% of the facilities.

CONCLUSION

This study shows an undesirable variation in pain management in ABI patients with DOC, which should be addressed in the future to enhance quality of care.

Introduction

Acquired brain injury (ABI), meaning any kind of brain damage occurring after birth, poses a grave threat all around the globe in modern day society. In the United Kingdom there were over 350.000 hospital admissions with ABI between 2011 and 2012. (Headway 2012) In the Netherlands the amount of hospital admissions with ABI is estimated on 160.000 per year. (Hersenstichting 2014) Amongst the worst possible outcomes of ABI are prolonged disorders of consciousness (DOC), characterized by the complete absence, or only inconsistent presence, of signs of awareness despite wakefulness (i.e. spontaneous eye opening).

DOC can occur as a vegetative state, also known as Unresponsive Wakefulness Syndrome (VS/UWS), and Minimally Conscious State (MCS). (Laureys et al. 2010) Both VS/UWS and MCS patients show spontaneous eye opening and at least partial preservation of vegetative functions, allowing them in general to breathe on their own. VS/UWS patients show no signs of awareness of the self or the environment; only reflexive behaviour is seen. (Jennett and Plum 1972;Monti et al. 2010) MCS patients show minimal and fluctuating signs of consciousness, but no functional communication or object use. (Giacino et al. 2002)

There are 35.623 VS/UWS-patients estimated in Europe (Ashwal 2004). However impressive, as van Erp et al. stated in a systematic review on the prevalence of VS/UWS patients, differences in methodology render it impossible to draw conclusions on the true scale of the problem (van Erp et al. 2014). Despite the lack of proper numbers, the need for excellent healthcare for these vulnerable patients is undeniable.

By definition, communication with DOC patients is not or barely possible. Healthcare professionals and specifically nurses know that this hinders adequate pain enquiry and assessment, i.e. observing and measuring. Therefore, these patients fully rely on their caretakers' abilities to assess and interpret behaviour that is associated to pain. In MCS patients, unlike VS/UWS patients, noxious stimulation can produce a brain activation profile similar to healthy controls. (Boly et al. 2008;Laureys et al. 2002) Though brain activity during painful stimuli might not be entirely equal to healthy controls, it can never be said with absolute certainty that DOC patients do not experience pain. Even more, the very nature of their state imposes risks of pain (mobilization, contractures, pressure ulcers) unlike any other patient population. Body movement, verbal response and facial expression are behavioural signs that might indicate pain. An objective behavioural pain observation tool that records and measures these signs could aid in the assessment and documentation of pain for ABI patients with DOC.

In the Netherlands there are known variations in the current practice to assess, interpret, report and treat pain in ABI patients with DOC, however the extent is unknown. To enable future quality improvement and uniformity of care it is important to get insight is this variation. Therefore the aim of this study was to explore the current practice in the Netherlands in pain assessment, documentation and use of protocols for ABI patients with DOC admitted to hospitals and nursing homes.

Methods

In order to obtain insight in current practice in the Netherlands, the facilities where the target patient population was admitted were mapped and their current procedures for pain assessment and report were investigated as well as the availability of pain protocols.

Participants

The website *www.ziekenhuis.nl* was used to identify hospitals in the Netherlands with a neurological or neurosurgical nursing ward. Neurosurgical nursing wards were only selected if intracranial surgery was performed. Nursing homes that had been identified as providing care for DOC patients in a previous study were addressed as well.
Eligible hospital wards were contacted by e-mail and asked to assign one to five nurses to participate in an online survey. Long-term care facilities received five printed copies of the same survey, with a stamped return envelope enclosed.

The assigned nurses from participating hospital nursing wards received the survey by an e-mail through the SurveyMonkey® web service. The provided link was restricted to one participation and linked to the e-mail address of the receiver. Though the nurses were assigned by their superiors in office, participation to the survey was not mandatory. One facility requested to receive a web link, which they passed on to the requested amount of nurses. The web link was open for participation to anyone who had the link and had no restrictions on IP-address.
Lastly one of the authors (PV) attended the annual Neuro & Rehabilitation Congress for nurses, where the survey was promoted among some of the attending professionals. Considering the factual questioning of the survey the authors determined this would not affect the results with any kind of participation bias.
There were no incentives offered to participating nurses.

Survey Design

The online survey was developed in SurveyMonkey® and pre-tested among five nurses for usability, technical functionality and clarity of the questions. The results were acquired between February 24th and April 30th of 2014. It made use of adaptive questioning to reduce the number and complexity of the questions, resulting in 10 to 17 questions, spread across six to 13 pages (or screens). There were three questions on participant characteristics, five on measuring/observing pain, six on reporting observations, one on the availability of a protocol and two statements (see **APPENDIX I** for the survey questions). Participants were able to review their answer with a Back button and e-mail participants were able to access their answers with the provided link until March 31st.

Three reminder e-mails were send once a week to ensure an optimum participation rate. All e-mails were send on Monday morning at six am for optimum response. (Jill Zheng 2011) Long-term care facilities that did not return the printed survey were contacted by telephone or with a personal visit and in agreement with team managers a new method of the survey was provided (paper or web link).
Submitted surveys were checked for completeness within the SurveyMonkey® web service. Participants with incomplete surveys were contacted by mail to complete the survey, unless full responses from other participants from the same facility were available.

Analysis

Descriptive analysis was applied to the survey results and percentages were calculated. The authors refrained from statistical testing between groups, because participation subgroups are too small and by their very nature heterogeneous.

Results

Results are reported according to the Cherries Checklist (Eysenbach 2004). Results of participation are reported as completion rates, the ratio of facilities/nurses who agreed to participate and the number of actual completed surveys or participation rates.
Of the 95 eligible hospital nursing wards 40 agreed to participate. After three reminder e-mails a completion rate of 88% of these facilities was obtained. This resulted in data on 37% of all neurology/neurosurgery hospital nursing wards in the Netherlands. Out of 20 contacted eligible nursing homes, only four responded on first request. After telephone calls and two personal visits another four nursing homes participated, resulting in a participation rate of 40%. This resulted in data on 35% of all nursing homes in the Netherlands the target patient population. The full acquisition of response can be seen in **FIGURE 1**.
There were no incomplete surveys: 106 completed surveys were

analysed. See **TABLE 1** for participant characteristics. In nearly all facilities the nurses indicated that they measured or observed pain in patients with Disorders Of Consciousness (DOC) due to Acquired Brain Injury (ABI). In only 16% of the participating facilities a behavioural pain observation tool was used and this seemed more common in general hospitals (24%) than in university hospitals (10%) or nursing homes (0%). In a majority of 72% of the facilities a variation in the way of measuring/observing between nurses could be assumed. Even though in nearly all facilities (95%) all nurses document their measurements or observations in patient files, in 88% of the facilities way of documentation varies between nurses. In 14% of the participating wards a pain protocol was used for these patients. A pain protocol was only found in wards where a behavioural pain observation tool was used and as such the protocol included instructions on the use of the instrument and in some cases a decision tree to assess a patient's ability to communicate. It is unclear if the professionals using a pain protocol were specifically trained in the use of these instruments or merely followed instructions in the manual provided. In none of the participating nursing homes a pain protocol was available. See **TABLE 2**.

Variation in way of measuring/observing is less among the group using a behavioural pain observation tool (28% vs 81%). Variation in way of documenting measurements/observations of pain was high in both groups (71% vs 92%).
The most commonly used behavioural pain observation tool was the Rotterdam Elderly Pain Observation Scale (REPOS)(Herk et al. 2009), followed by the Pain Assessment in Advanced Dementia (PAINAD) (Warden et al. 2003) and the Pain Assessment Checklist for Seniors with Severe Dementia (PACSLAC-D)(Cheung and Choi 2008). See **FIGURE 2**.

At the end of the survey participants were asked to respond to two statements, see **FIGURES 3 & 4**. Nurses working on a ward that used a behavioural pain observation tool and/or pain protocol tended to agree more (54% vs 20%) to the statement that their facility showed sufficient attention for pain in patients with DOC due to ABI. They also tended to agree more (69% vs 56%) to the statement that they are able to express their observations on pain in patients with DOC due to ABI sufficiently to colleagues or other disciplines. Nurses working in nursing homes tended to agree more to both statements, compared to nurses from hospitals.

Discussion

The aim of this study was to get insight into the current variation of pain assessment, documentation and protocols for patients with Acquired Brain Injury (ABI) and Disorders Of Consciousness (DOC) admitted to Dutch health care facilities. The results show that substantial variation exists in both assessment of pain behaviour and documentation of such behaviour by nurses within facilities and between (different kinds of) facilities. Nurses observe different sets of behaviours or vital signs and lack a consistent structure of documenting their observations. The use of a behavioural pain observation tool appeared to reduce this variation in measurement, but didn't necessarily seem to reduce variation in documentation between nurses. Out of the few facilities that indicated to use a behavioural pain observation tool, none used an instrument that has been either developed or validated for this specific patient group. Some facilities indicated that their choice of instrument was based on the availability of an instrument in the digital patient file software, resulting in a 'convenience choice' of instrument instead of an evidence based choice. The instruments that are used are all developed or validated for a different group of non-communicative patients: elderly or patients with severe dementia. One of these instruments, the Rotterdam Elderly Pain Observation Scale (REPOS), is a Dutch behavioural pain observation tool using 10 behavioural signs and a decision tree to assess pain in elderly non-communicative patients. (Herk, van Dijk, Tibboel, Baar, de Wit, & Duivenvoorden 2009)
It has been advised in the Dutch journal 'Nursing' as (at that time) the best available and most practical choice (based on language and usability) for the assessment of pain in patients with DOC due to ABI. (Vink and van Overbeeke 2012)
Based on the response to the statements it seems that hospital nurses are more likely to experience the need of a behavioural pain observation tool, than nursing home professionals. This last group tended to agree more with the two statements given. They indicate that there

is sufficient attention for pain in this patient group and are, to their opinion, able to objectify and express their observations adequately. Some of the participating nursing homes indicated to work with 'focus points' for nursing plans. Pain/comfort is one of these focus points, which could explain why there was more attention for this nursing care aspect in these facilities. It should be noted however, that despite the fact that pain management in long-term care has been recognized as a serious problem worldwide, numerous studies have shown it is still a highly untreated aspect of care. (Kaasalainen et al. 2013) It could therefore also be considered that the found difference in agreement to the statements is caused by the differences in level of education. The majority (78%) of the participants from hospitals had a Baccalaureate in Nursing degree or higher, while the majority (74%) participants from nursing homes had a Diploma or Associate in Nursing degree.

All facilities indicated that pain was measured or observed in some way. However, the variation between nurses in facilities and between facilities poses a great problem, as pain assessment in a consistent manner and on a regular basis is especially crucial in non-communicative patients. (Wells et al. 2008) Just like other pain assessment tools, a behavioural pain observation tool must be chosen for the appropriate target patient population. (Herr et al. 2011;Puggina et al. 2012) Even with ample pain assessment instruments at hand, such as for patients with severe dementia, validation of the instrument for the target population and the utility in clinical settings is required. (Achterberg et al. 2013)
The lack of national guidelines for pain management in DOC patients in the Netherlands and unfamiliarity with (partially) validated pain observation tools may contribute to the clinical practice variation at hand. The use of a national pain standard and collaboration of the interdisciplinary team is critical for any successful pain management program. (McLean Whitehurst and Gorden 2012) Empowering nurses and medical staff with knowledge about the possibility of pain perception in these patients and skills to observe pain adequately seems crucial to ensure proper beliefs and attitudes towards pain management. (Achterberg, Pieper, van Dalen-Kok, de Waal, Husebo, Lautenbacher, Kunz, Scherder, & Corbett 2013;Puggina, Paes da Silva, Schnakers, & Laureys 2012)

The low prevalence of Unresponsive Wakefulness Syndrome (VS/UWS) and Minimally Conscious State (MCS) in Europe can be considered as a limitation to the generalizability of this study. (van Erp, Lavrijsen, van de Laar, Vos, Laureys, & Koopmans 2014) The incidence in DOC patients is dependent on the complexity of the neurology/neurosurgery patients presented to each facility. Taking in hand the variety in both mortality and persistent disability in ABI patients, both research and clinical care guidelines remain scarce. This includes the availability of literature for pain assessment in these patients, which is limited though growing. The authors believe that other countries with a well-developed nursing care system might encounter the same need for objective observation tools and pain protocols to guide daily nursing care. Response bias was limited in this study, because the research group was not affiliated with most of the participating facilities and none of the responses were forwarded to team managers of colleagues. The survey was not anonymous, which may have influenced the response to the statements at the end of the survey. As a final limitation, the survey did not fully enquire nurses on the reasons why there was practice variation in observing/measuring pain and documenting pain.

This is the first study investigating the procedures and methods of pain assessment within the nursing care in the Netherlands for patients with DOC due to ABI. An extensive acquisition has been performed using multiple methods of communication (phone, e-mail, personal visit). Average response rates to online surveys normally lie around 30% and this average seems to drop since online surveys became more common. (Sheehan 2001) Therefore the authors considered an e-mail response rate of 60% to be highly representative and due to the multi-method approach a response rate of 68% of participating facilities was acquired. Though the authors believe the conclusions on nursing homes are in line with general practice in all nursing homes in the Netherlands, the response rate of these facilities is limited. The authors are convinced that the participating hospitals are representative for all neurology/neurosurgery wards in the Netherlands, as the sample shows a wide spread across the country and has a representative ratio of university and general hospitals. See **FIGURE 5**.

This study shows that there is considerable variation in the assessment and documentation of pain in ABI patients with DOC. Practice variation is undesirable and a threat to the quality of care, especially in pain management. The behavioural pain observation tools that are currently used in facilities are all developed or validated for a different group of non-communicative patients. To assess pain in ABI patients with DOC in a valid and uniform way, one should use an instrument that has been developed specifically for these patients, such as the Nociception Coma Scale (NCS) developed by the Coma Science Group in Belgium. (Schnakers et al. 2010) Though research on the psychometric properties is slowly accumulating, this instrument has not yet found its way into daily nursing care yet.

Conclusion

This study shows an undesirable variation in pain management in ABI patients with DOC in the Netherlands and provides clinically important data for future research and quality improvement. Our results shows that there is need for education to enhance awareness, local training in pain observation and documentation skills as well as clinical research in nursing care and eventually large-scale implementation research. Alongside it is required to develop a uniform multi-disciplinary protocol on the early detection, prevention and treatment of pain in patients with DOC due to ABI. Both clinical and implementation research should not only focus on the observation and measurement of pain, but also pay extra attention to documentation to support intra- and inter-disciplinary communication and as such ensure future improvements on all aspects of pain management. The development and use of national guidelines as a basis for the validation and implementation of instruments is mandatory to support uniformity in the assessment of pain. It also gives the opportunity to develop evidence based quality indicators to support internal and external quality improvement and provide performance transparency. In all accounts, the study shows that there is need to understand, measure, document and manage pain in this fragile patient population.

Acknowledgements
Research Group 'Niemand tussen Wal en Schip'.
Participating hospitals and nursing homes.

Figure 1

Flowchart of survey response acquisition (total completed surveys and total unique nursing wards) and chosen interventions for acquisition in chronological order from top to bottom.

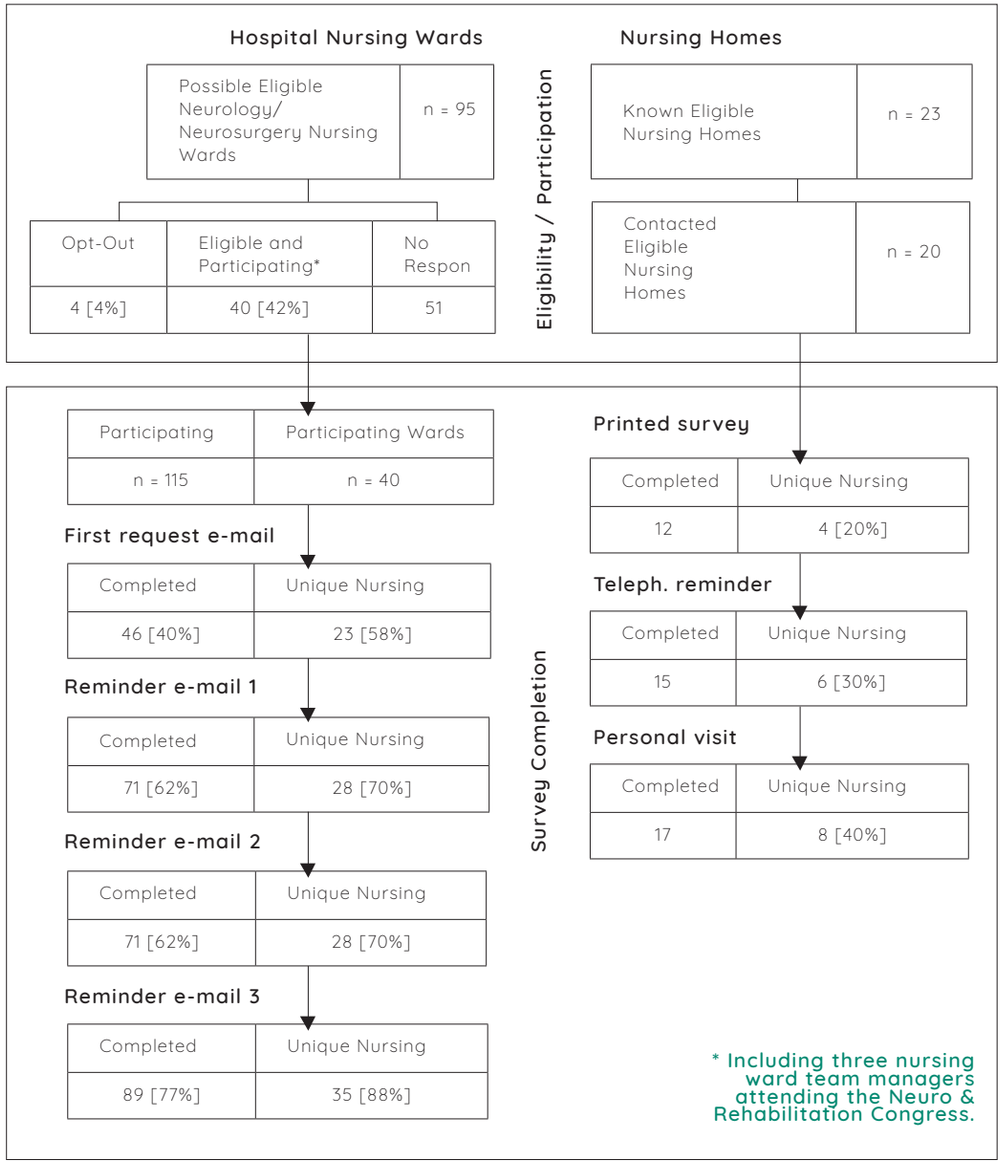

Table 1

Participant characteristics and participants per ward (average and range).

	Total (N=106)		University Hospital Nursing Wards (n=30)		General Hospital Nursing Wards (n=59)		Nursing Home (n=17)	
Percentage of total participants	NA		29%		57%		16%	
Head nurse or Team manager	13	(12%)	2	(7%)	8	(14%)	3	(20%)
Senior nurse	21	(20%)	11	(37%)	10	(17%)	0	(0%)
Specialized Neuroscience Nurse	23	(22%)	7	(23%)	16	(27%)	0	(0%)
Baccalaureate of Science in Nursing	17	(16%)	4	(13%)	12	(20%)	1	(7%)
Associate of Science in Nursing	26	(25%)	6	(20%)	13	(22%)	7	(41%)
Diploma in Nursing	6	(6%)	0	(0%)	0	(0%)	6	(35%)
Participants per ward, mean	2		3		2		2	
Participants per ward, range	1-5		1-5		1-5		1-5	

Table 2

Conclusions based on the information provided by the survey.
Q = question

	Total (n=43)		University Hospital Nursing Wards (n=10)		General Hospital Nursing Wards (n=25)		Nursing Home (n=8)	
Using a behavioral pain observation tool. Based on Q5.	7	16%	1	10%	6	24%	0	0%
All nurses measure/observe pain in patients with DOC. Based on Q4 and Q7.	41	95%	10	100%	24	96%	7	88%
Variation in way of measuring/observing pain. Based on Q4 and Q8.	31	72%	9	90%	17	68%	5	63%
All nurses document on their measurement/ observation of pain. Based on Q9 and Q13.	41	95%	10	100%	24	96%	7	88%
Variation in way of documenting measurements/observations of pain. Based on Q10 to Q14.	38	88%	10	100%	21	84%	7	88%
Use a pain protocol for patients with DOC due to ABI. Based on Q15.	6	14%	1	10%	5	20%	0	0%

Figure 2

Most commonly used behavioral pain observation tools.

REPOS = Rotterdam Elderly Pain Observation Scale (Herk et al., 2009),
PAINAD = Pain Assessment in Advanced Dementia (Warden et al., 2003)
PASLAC-D = Pain Assessment Checklist for Seniors with Severe Dementia (Cheung and Choi, 2008).

Pain Observation Tool Used

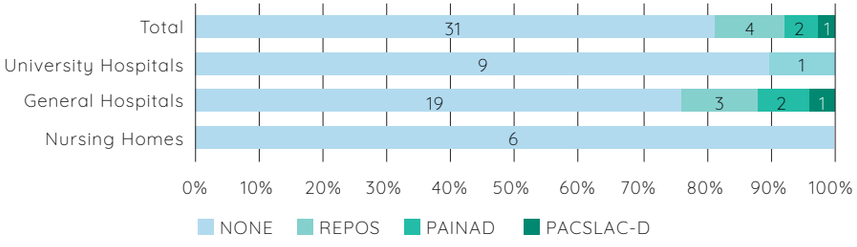

Figure 3

Agreement to statement 1, divided to workplace and the presence or absence of a pain observation tool and/or protocol.

DOC = Disorders Of Consciousness
ABI = Acquired Brain Injury

"In my facility there is sufficient attention for pain in patients with DOC due to ABI."

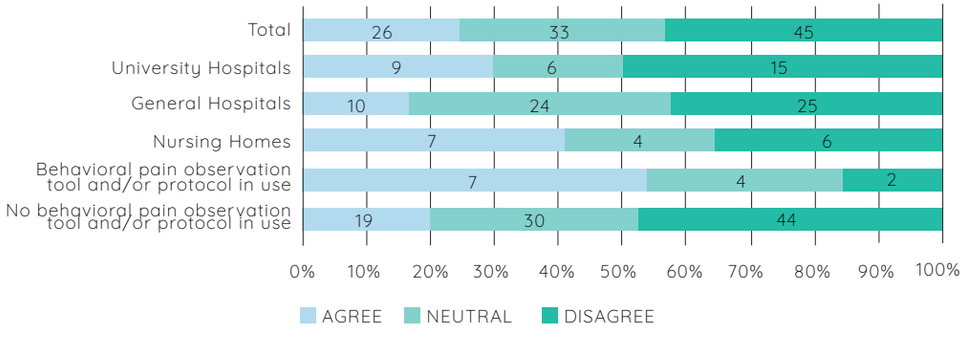

Figure 4

Agreement to statement 2, divided to workplace and the presence or absence of a pain observation tool and/or protocol.

DOC = Disorders Of Consciousness
ABI = Acquired Brain Injury

"I can express my observations on pain in patients with DOC due to ABI sufficiently to colleagues or other disciplines."

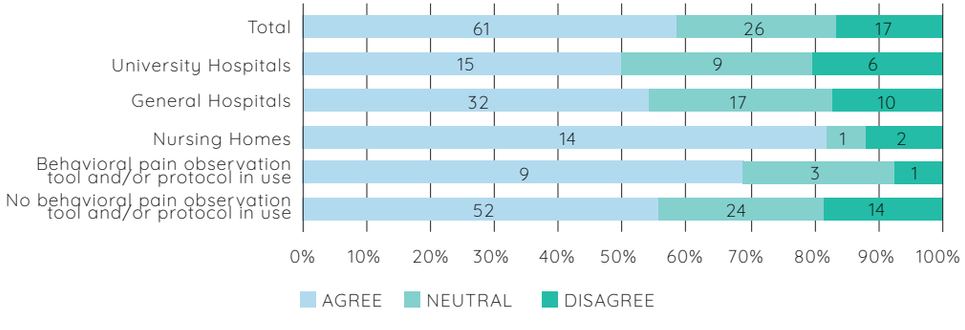

Figure 5

Geographical spread of the participating facilities in the Netherlands.

Appendix I

Survey Questions

Q1. General Participant Information

Q2. What kind of facility do you work at?

Q3. What is your job description in your facility?

Q4. Do you measure or observe pain in patients with disorders of consciousness (DOC)?
- Yes; continue to Q5.
- No; continue to Q7.

Q5. Do you use a behavioural pain observation tool for measuring or observing pain? (in patients with DOC)
- Yes; continue to Q6.
- No; continue to Q7.

Q6. Which behavioural pain observation tool do you use for measuring/ observing pain? (in patients with DOC)

Q7. Do your colleagues measure or observe pain? (in patients with DOC)
- Yes; continue to Q8.
- No; continue to Q9.
- I don't know; continue to Q9.

Q8. Do all your colleagues measure or observe pain in the same way? (in patients with DOC)
- Yes; continue to Q9.
- No; continue to Q9.
- I don't know; continue to Q9.

Q9. Do you document your observations on pain in a report or patient file? (in patients with DOC)
- Yes; continue to Q10.
- No; continue to Q13.
- I don't know; continue to Q13.

Q10. Do you always document your observations on pain in the same way/ structure? (in patients with DOC)
- Yes; continue to Q11.
- No; continue to Q13.

Q11. Is this way or structure embedded in the nurse patient file?
- Yes; continue to Q12.
- No; continue to Q12.
- I don't know; continue to Q12.

Q12. What is the way or structure you use to document your observations on pain? (in patients with DOC)

Q13. Do your colleagues document their observations on pain in patients with DOC?
- Yes; continue to Q14.
- No; continue to Q15.
- I don't know; continue to Q15.

Q14. Do your colleagues document their observations on pain in the same way? (in patients with DOC)
- Yes; continue to Q15.
- No; continue to Q15.
- I don't know; continue to Q15.

Q15. Does your facility have a pain protocol for patients with DOC?

Q16. Agree/Neutral/Disagree: "In my facility there is sufficient attention for pain in patients with DOC due to ABI."

Q17. Agree/Neutral/Disagree: "I can express my observations on pain in patients with DOC due to ABI sufficiently to colleagues or other disciplines."

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CHAPTER 3

Nurses Assessing Pain with the Nociception Coma Scale: Interrater Reliability and Validity

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Abstract

BACKGROUND

The Nociception Coma Scale (NCS) is a pain observation tool, developed for patients with disorders of consciousness (DOC) due to Acquired Brain Injury (ABI).

AIM

To assess the inter-rater reliability of the NCS and NCS-R among nurses for the assessment of pain in ABI patients with DOC. A secondary aim was further validation of both scales by assessing its discriminating abilities for the presence or absence of pain.

METHODS

Hospitalized ABI patients (n=10) were recorded on film during three conditions: (1) baseline, (2) following tactile stimulation and (3) following noxious stimulation. All stimulations were part of daily treatment for these patients. The 30 recordings were assessed with the NCS and NCS-R by 27 nurses from three university hospitals in the Netherlands. Each nurse viewed nine to twelve recordings, totaling 270 assessments.

RESULTS

Inter-rater reliability of the NCS/NCS-R items and total scores was estimated by intraclass correlations (ICC), which showed excellent and equal average measures reliability for the NCS and NCR-R total scores (ICC 0.95), and item scores (range 0.87-0.95). Secondary analysis was performed to assess differences in ICCs among nurses' education and experience and to assess the scales discriminating properties for the presence of pain.

CONCLUSION

The NCS and NCS-R are valid and reproducible scales that can be used by nurses with an Associate (of Science) in Nursing degree or Baccalaureate (of Science) in Nursing degree. It seems that more experience with ABI patients is not a predictor for good agreement in the assessment of the NCS(-R).

Background

The assessment and early diagnosis of pain is of great importance for proper diagnosis and adequate pain management. However, self-assessment tools are inapplicable to patients with disorders of consciousness (DOC) by acquired brain injury (ABI), causing them to fully rely on the clinical expertise and judgment of nurses and physicians. This may cause great variation in pain assessment and possibly inadequate pain management.

ABI is defined as any brain damage that occurs after birth from a traumatic or non-traumatic event (Ontario Brain Injury Association, 2013) and can result in cognitive, communicative, physical, emotional, or behavioral impairments such as DOC (i.e. vegetative state/ unresponsive wakefulness syndrome or minimally conscious state). Previous research has shown that, despite their sometimes fluctuant behavioral patterns, patients with DOC could experience pain (Schnakers et al., 2010a). Pain observation tools have been developed to assess pain in different non-communicative patient categories, such as intubated/sedated patients, children and patients with severe dementia (Schnakers et al., 2010a; Roulin & Ramelet, 2012). However, for non-communicative ABI patients (due to DOC) only one instrument is available; the Nociception Coma Scale (NCS). It rates four behavioral responses to pain on a four-point-scale: motor response, verbal response, visual response and facial expression (Roulin & Ramelet, 2012), see **BOX 1**. The validity of the NCS has been studied by Schnakers et al., showing promising clinimetric properties (Schnakers et al., 2010a; Schnakers et al., 2010b; Chatelle, Majerus, Whyte, Laureys, & Schnakers, 2012; Schnakers, Chatelle, Demertzi, Majerus, & Laureys, 2012). In 2012, they showed that exclusion of the visual response item significantly increased the cut-off sensitivity of the scale, and therefore proposed to revise the NCS (NCS-R) (Chatelle et al., 2012).

In the work of Schnakers et al., the inter-rater reliability of the NCS and NCS-R was assessed by two experienced neuropsychologists. However, the NCR scales are particularly relevant for everyday nursing practice in (university) hospitals, rehabilitation centers and nursing homes. If empirical research would conclude that the NCS/NCS-R can be used by nurses in a reproducible manner, improvement of pain management could be initiated by implementing these scales in daily care. Primary aim of this study was to assess the inter-rater reliability among nurses for the assessment of pain in non-communicative ABI patients with the NCS and NCS-R. The authors also assessed the internal consistency and examined whether the nurses education level and years of experience with ABI patients affected the reliability. Secondary aim was to assess discriminating abilities for the presence of pain.

Methods

Design

In order to obtain insight in current practice in the Netherlands, the This prospective reliability study was designed and reported according to the COSMIN-checklist (Mokkink et al., 2012), Box B (reliability), and the Guidelines for Reporting Reliability and Agreement Studies (GRRAS) (Kottner et al., 2011).

A forward translation of the NCS's items (English to Dutch) was performed by one of the authors (PV), with Dutch as mother tongue and a Cambridge Proficiency Level C2 (World Health Organization, 2013). A backward translation was performed by a nurse with UK English as mother tongue and proficient knowledge of Dutch. Any discrepancies were quickly resolved by consensus. Because the NCS consists of observational items based on visual ratings of behavior that are reported with common terminology in neurological care,

the authors decided that further research on Box G (cross-cultural validation) of the COSMIN-checklist was not necessary in this study (Beaton, Bombardier, Guillemin, & Ferraz, 2000; Mokkink et al., 2012).

Ethics

The study design was presented to the medical ethics committee of the Academic Medical Center (AMC) and University of Amsterdam, the Netherlands and a waiver of authorization was granted.

Patients

Patients were recruited on the Neurology/Neurosurgery ward of the AMC, a ward with 44 beds. Eligibility was assessed by the study researcher (PV) and the patients' treating physicians. Patients were found eligible if they were 18 years or older, were diagnosed with ABI, had no administration of neuromuscular relaxants or sedation in the past 24 hours, were not intubated and had a stable Glasgow Coma Scale (GCS) for the past 24 hours. In order to ensure responsiveness to the different items of the NCS/NCS-R, the minimum GCS was five (E2M2V1). Besides these medical characteristics the patients needed to be unable to respond adequately to the question "Are you in pain? /Do you have pain?". If patients were found eligible for the study, the patients' legal representative was contacted to acquire written consent for the acquirement of video material, after which the patient was given a random study number consisting of three digits.

Observers

Observers were registered nurses recruited on the Neurology/ Neurosurgery ward of the AMC, the Neurosurgery ward of the Free University Medical Center (VUmc) in Amsterdam and the Neurology ward of the Erasmus University Medical Center in Rotterdam, the Netherlands.

Video acquirement

Following written consent of the eligible patient's legal representative, three videos were recorded for each patient with a Logitech® HD Webcam C525. One video was recorded for baseline reference, with face and upper limbs visible without interaction with nurses or physicians.

A second video was recorded during tactile stimulation during daily nursing care, for example the combing of the hair or the application of bandages. A third video was recorded during noxious stimulation that was part of daily nursing care, for example the application of pressure to the nail bed performed for the assessment of the GCS. All videos were recorded on the same day or in a period of time where the patient had the same GCS as the baseline video.

Videos were encoded with the patients' study number and a letter to signify the stimulation: (B) baseline, (T) tactile and (N) noxious. Videos were stored in a save directory of the hospitals internal network and were handled with the same privacy policy as other medical records.

Video acquirement

The 30 video recordings (three per patient, n=10) were divided over three Microsoft® PowerPoint® 2013 presentations. Each nurse assessed a presentation containing the baseline, tactile and noxious stimulation videos of three or four patients in a random order (decided by use of a random generator). Each video was assessed independently by a possibly different set of nine nurses. This random observer approach was used to mimic daily practice, during which different nurses in different shifts are involved in the care for ABI patients. Nurses were placed alone in a room with a laptop showing one of the PowerPoint presentations. A short introduction to the NCS was given in the presentation with explanation by one of the authors (PV). After the instruction, the nurse was asked to review the videos one by one and assess the patient's behavior with the NCS on a structured form. One of the authors (PV) would remain present for technical support and to ensure no other nurses were consulted. No clinical information about the patient's conditions was provided. Observers were given unlimited time to complete a session and were allowed to review each video as often as they liked. This corresponds with a similar situation in daily practice, since nurses would review a patient's behavior when in doubt. After completing a session the observer was asked to fill out a form about their experience with the video material and the NCS.

Statistical Analysis

Sample size analysis was based on an expected average inter-rater

reliability (intraclass correlation) coefficient (ICC) of 0.61 as reported in the original article of Schnakers et al.(Schnakers et al., 2010b) With 10 patients in a baseline, noxious and tactile situation, totaling 30 NCS video observations and nine repeated observations per video, the 95% CI would extend about 0.14 from the observed intraclass correlation when the expected intraclass correlation is 0.61. Calculations were made with nQuery Advisor 7.0®.

Weighted kappas were calculated to examine the reproducibility of the NCS items. The weighted kappa statistic can be calculated between pairs of nurse observers. However, the calculation of an overall weighted kappa value for each set of nine nurse observers is not possible using this method. Therefore, an overall weighted kappa value was estimated using ICCs, one way random effects model (Fleiss JL & Cohen J, 1973). The same ICC model was used to examine the reliability of the NCS and NCS-R total scores. For all calculations the single measure ICCs and average measure ICCs are reported. Strength of agreement (0.00-0.20), fair (0.21-0.40), moderate (0.41-0.60), substantial (0.61-0.80) or excellent (0.81-1.00).(Landis & Koch, 1977) Differences in reliability estimates for the NCS and NCS-R between the two main nursing education levels in The Netherlands, i.e. Associate of Science in Nursing (ASN) and Baccalaureate of Science in Nursing (BSN) were compared and a Mann-Whitney U test was used to assess differences in mean NCS and NCS-R scores between these two groups. The same analysis was performed for nurses below and above the median years of experience with ABI patients. Internal consistency reliability (Cronbach's α) and item rest correlations were calculated to assess the homogeneity of the NCS versions and the relative contribution of each NCS item to the reliability of the total score (α if item deleted).

Validity analysis were done with mixed model (multi-level) regression, accounting for the dependency between observations was performed to test for differences in NCS and NCS-R total and item-scores of patients in baseline, tactile and noxious stimulations. In addition, Receiver Operating Characteristics (ROC) curve analysis was used to determine a cut-off value to discriminate between absence of pain (baseline), possible presence of pain (tactile and noxious) and probable presence of pain (noxious). From the ROC curves the sensitivity (presence of noxious stimulation and NCS/NCS-R total score ≥ cut-off value) and specificity (absence of noxious stimulation and NCS/NCS-R total score ≤ cut-off value) were derived. Cut-offs were obtained using the method of Youden that minimizes false positive and false negative classifications. The Area under the ROC curve (AUC) was used to assess the overall validity of both NCS versions in detecting the presence of pain.

Continuous data are reported with median and interquartile range unless otherwise indicated, categorical data is reported with frequencies and percentage. P-values below 0.05 were considered statistically significant, unless otherwise indicated. All analysis were performed with IBM® SPSS® v. 21.0 software.

Results

Between November 2012 and May 2013, 10 patients were included in the study. For one patient no noxious stimulation occurred in daily practice, but the missing recording was compensated by two noxious stimulations in another patient. Baseline characteristics of the patients are shown in **TABLE 1**, along with the characteristics of the observers. A total of 27 nurse observers, nine per center, participated in the assessment of the videos. All nurses indicated that they had never used a pain observation tool and seven (25.9%) considered themselves very inexperienced on this matter (no knowledge), seven (25.9%) inexperienced (some knowledge) and three (37.0%) neutral. Ten (37.0%) nurses considered themselves experienced users of pain observation tools, mainly because they expected the items of the scales to be part of their acquired skills as a nurse. Each video was assessed by nine nurses (three per center), resulting in 270 observations per NCS item. All nurses indicated that they were not disturbed during their assessment of the videos and that their assessment was not influenced in any way. Three assessment forms were incomplete, resulting in 0.4% missing data; one observation in verbal response, one in visual response and two in facial expressions. Missing data were not imputed.

Reliability

Single measure ICC for the NCS and NCS-R total scores was 0.67 and 0.69 respectively. Average measures ICC was 0.95 for both versions

(**TABLE 2**). Average measure ICCs for all individual items on the scale exceeded 0.81, with the visual response item showing the lowest single measures (0.42) and average measures (0.87) ICC.
Single measures ICC for ASN degree nurses was 0.65 (95% CI; 0.35-0.89) for the NCS and 0.74 (95% CI; 0.48-0.92) for the NCS-R. Single measures ICC for BSN degree nurses was 0.76 (95% CI; 0.56-0.91) for the NCS scores and 0.82 (95% CI; 0.65-0.94) for the NCS-R. All average measure ICCs exceeded 0.80. There were no statistically significant differences between the NCS scores and NCS-R scores of ASN degree and BSN degree nurses (Mann-Whitney U test p= 0.80 and p=0.75, respectively). Single measures ICC for nurses with less than seven years of experience with ABI patients was 0.73 (95% CI; 0.37-0.88) for the NCS scores and 0.62 (95% CI; 0.35-0.88) for the NCS-R. For nurses with more than seven years of experience these were 0.57 (95% CI; 0.30-0.85) for the NCS and 0.55 (95% CI; 0.28-0.84) for the NCS-R. All average measure ICCs exceeded 0.80. There was also no statistically significant difference between the scores of experience groups on both the NCS and NCS-R (Mann-Whitney U test p=0.77 and p=0.45, respectively). Cronbach's α for internal consistency reliability was 0.68. Removal of the visual response item (creating the NCS-R) decreased the Cronbach's α to 0.61.

Validity

Multi-level Mixed Model analysis showed an overall statistically significant difference in NCS and NCS-R mean total scores of the Baseline, Tactile and Noxious Stimulations, ($p<0.001$). For the individual items, there were highly significant differences, especially between Baseline and Noxious stimulations for the Motor, Verbal and Facial response items. An overview of the results is presented in **TABLE 3.**

Two ROC curve analysis were performed, the first combining tactile and noxious stimulation as "possible presence of pain" and the second with noxious stimulation defined as "probable presence of pain". This showed the following cut-off values for the NCS: <2 no pain, 2-3 possible presence of pain, ≥3 probable presence of pain. The cut-off values for the NCS-R were: <1 no pain, 1-2 possible presence of pain, ≥2 probable presence of pain. The complete overview of cut-off values and associated accuracy values (sensitivity, specificity and area under the ROC curve) is shown in **TABLE 4**.

Evaluation of the NCS scale by nurse observers

On the evaluation form 16 (59.2%) of the nurses agreed with the statement "I found the NCS difficult to assess". A majority of 21 (77.8%) agreed with the statement "I would use the NCS in my daily care for non-communicative ABI patients". Another 16 (59.2%) agreed with the statement "The NCS would improve my judgment about the presence or absence of pain in non-communicative ABI patients".

Discussion

The NCS and NCS-R appear to be valid and reliable scales to assess pain in hospitalized patients who are unable to communicate due to ABI. The current study shows that these scales can be used in a reproducible manner by nurses in different university hospitals with an ASN or BSN degree. Comparison between the two main educational groups in nurses (ASN and BSN degree) showed a slightly better agreement among nurses with a BSN degree. Notably, the nurses with less than seven years of experience with ABI patients showed a better agreement than nurses with more years of experience. This could suggest that confounding by education is at play and that more experienced nurses less often had BSN degrees, but in fact the opposite was true. The evaluation forms learned that less experienced nurses found the NCS/NCS-R harder to assess and were more likely to agree that the NCS would aid them in their judgment for the presence of pain. More experienced nurses are possibly more likely to use their own set of skills for the assessment of pain. This could suggest a longer adaption time for the use of the NCS among more experienced nurses, though overall agreement coefficients were still more than acceptable. Apart from excellent reliability among nurses, the NCS showed, considering the limited number of items, acceptable internal consistency and remained as such with the removal of the visual response item (NCS-R). The observed inter-rater agreement was higher than previous findings by Schnakers et al (κ 0.61) (Schnakers et al., 2010b). This difference can be explained due to the difference in agreement statistics. This study estimated weighted kappa statistics by calculation of ICCs, whereas

Schnakers et al. calculated the Cohen's kappa for two observers. The current study also used a greater pool of observers (n=27 vs. n=2 in Schnakers study), with more variety reflecting daily practice. On the aspect of validity, this study supports previous findings by Chatelle et al. (Chatelle et al., 2012), although some differences were noted. Chatelle et al. reported statistically significant differences between tactile and noxious stimulation for all items, whereas the verbal and visual response items in this study showed no such difference. This study also supports previous findings on the notion that the visual response item is the weakest link in the NCS. The item showed the lowest inter-rater agreement and omitting it from the scale, i.e. applying the NCS-R, improved the accuracy in discriminating the presence or absence of pain. In daily nursing practice, fixation of the eyes to a painful stimulant could however aid nurses in their judgment of the presence of pain and omitting it from the scale could make nurses less aware of this behavior. Also, the visual response item contributed to the internal consistency reliability of the NCS.

Limitations of this study were the restrictions of video assessment, which may have made it more difficult to assess the patient's behavioral response. Nurses indicated that it especially influenced their assessment of the visual response item, since the patient's eyes were the most difficult to see on the videos. Also, three patients (33.3%) had a tracheostomy tube, which may have influenced the assessment of the verbal response item. This may explain why there was no statistically significant difference in mean verbal score between the different stimulations. These patients do however represent an important part of the ABI population, at least in the acute period of hospital admission, and should therefore not be excluded from pain assessment with the NCS. Nurses working with ABI patients will often encounter tracheostomy tubes and should still be able to assess the NCS at their best approach. Lastly, this study's assessment was based on the skills of acute care nurses in academic hospitals and may not easily be generalized to nursing homes, due to differences in skill and education. Long-term care facilities for these patients with persistent disorders of consciousness should therefore be included in future aims for research and use of the NCS.

The current study shows that the NCS can be implemented through limited training to nurses with some experience with ABI patients. The NCS could therefore be used as a tool to aid in the judgment of pain during the daily care of hospitalized non-communicative ABI patients. However, due to the thus far contradicting results with other studies on optimal cut-off values for the presence of pain, it cannot serve as an absolute measure for the presence of pain. Further prospective research on the NCS should focus on optimal cut-off values for the presence of pain and the clinical implementation of the scale in hospitals and nursing homes.

Conclusion

In conclusion, the NCS and NCS-R can be used in a reproducible manner by acute care nurses with an ASN or BSN degree. Limited instruction and no experience with pain observation scales already provided more than sufficient agreement for the assessment of pain in non-communicative ABI patients. Though apparently the weakest link on the scale, the visual response item contributed to the scale's internal consistency and its agreement is likely to have been underestimated due to limitations in video assessments. With these study results, the implementation of the NCS among acute care nurses seems justified and pain assessment and management during daily care of ABI patients can greatly be improved.

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Box 1

Nociception Coma Scale (NCS).

The original NCS as developed by Schnakers et al.(Schnakers et al., 2010) The NCS-R omits the visual response item.(Chatelle, Majerus, Whyte, Laureys, & Schnakers, 2012)

Motor response	
3	Localisation to painful stimulation
2	Flexion / withdrawal
1	Abnormal posturing
0	None/flaccid
Verbal response	
3	Verbalisation (intelligible)
2	Vocalisation
1	Groaning
0	None

Visual response	
3	Fixation
2	Eye movements
1	Startle
0	None
Facial expression	
3	Cry
2	Grimace
1	Oral reflexive movement/startle response
0	None

Table 1

Baseline characteristics of participants and observers.

Participants (n=10)	
Male/Female (%)	2/8 (20/80%)
Median age in years [range]	55.8 [26.4-75.4]
Diagnosis	
Cerebrovascular Accident (%)	7 (70%)
Traumatic (%)	1 (10%)
Brain abscess (%)	2 (20%)
Glasgow coma scale, median score [range]	
Eyes, maximum score is 4	4 [4]
Movement, maximum score is 6	5 [2-6]
Verbal, maximum score is 5	1 [0-3]
Total [range]	10 [6-12]
Observers (n=27)	
Male/Female (%)	8/19 (30/70%)
Median age in years [range]	32 [22-57]
Education	
Diploma in nursing (%)	1 (3,7%)
Associate of science in nursing (%)	10 (37.0%)
Baccalaureate of science in nursing (%)	15 (55.6%)
Master of science (%)	1 (3.7%)
Years of experience	
Median years in healthcare [range]	13 [1-39]
Median years with ABI patients [range]	7 [1-28]

ABI; acquired brain injury.

Table 2

Inter-rater agreement en internal consistency of the NCS and NCS-R (N=30).

Item	Single measures ICC (95% CI)	Average measures ICC (95% CI)	Item rest correlation*	Cronbach's α if item deleted*
Motor response	0.68 (0.56-0.80)	0.95 (0.92-0.97)	0.39	0.69
Verbal response	0.62 (0.49-0.76)	0.94 (0.89-0.97)	0.49	0.63
Visual response	0.42 (0.29-0.59)	0.87 (0.78-0.93)	0.48	0.61
Facial expression	0.61 (0.47-0.75)	0.93 (0.89-0.97)	0.58	0.54
Total NCS	0.67 (0.53-0.80)	0.95 (0.91-0.97)	--	0.68
Total NCS-R	0.69 (0.56-0.81)	0.95 (0.92-0.98)	--	0.61

* Cronbach's α if item deleted values from NCS with 4 items. Values for Total NCS and Total NCS-R denote total scale internal consistency. Abbreviations: NCS; Nociception Coma Scale, NCS-R; Nociception Coma Scale Revised, ICC; Intraclass correlations, CI; confidence interval.

Table 3

Mixed model (multi-level) regression results (N=30).

						p- values		
	Baseline	Tactile	Noxious	F	p-value	B vs T	B vs N	T vs N
Motor	0.10 ±0.11	0.52 ±0.98	1.38 ±0.75	8.27	0.002[a]	0.198	0.000[a]	0.013[a]
Verbal	0.11 ±0.21	0.39 ±0.51	0.59 ±0.67	2.51	0.108	0.211	0.038[a]	0.361
Visual	0.79 ±0.67	1.04 ±0.78	1.30 ±1.01	1.96	0.169	0.288	0.063	0.381
Facial	0.32 ±0.34	1.03 ±0.71	1.30 ±0.78	12.07	0.000[a]	0.002[a]	0.000[a]	0.234
NCS	1.32 ±0.93	2.99 ±1.80	4.49 ±2.28	14.99	0.000[a]	0.008[a]	0.000[a]	0.021[a]
NCS-R	0.53 ±0.44	1.94 ±1.49	3.19 ±1.44	15.73	0.000[a]	0.007[a]	0.000[a]	0.018[a]

Mean scores per item and both scales and comparison of means by Multi-level Mixed Model regression analysis, assuming constant correlation between pairs. Figures are means ± standard deviation. P-values per model and in comparisons per stimulation, [a] statistically significant if p <0.05. Abbreviations: NCS; Nociception Coma Scale, NCS-R; Nociception Coma Scale Revised, F; F-statistic, B; 'baseline', T; 'tactile stimulation', N; 'noxious stimulation'.

Table 4

Accuracy of the NCS versions and cut-off points for (possible) presence of pain.

	NCS				NCS-R			
	Cut-off	Sens	Spec	AUC	Cut-off	Sens	Spec	AUC
Possible presence of pain[a]	≥2	73.6%	68.0%	78%	≥1	76.7%	74.7%	82.2%
Probable presence of pain [b]	≥3	72.2%	67.3%	76.4%	≥2	74.4%	74.7%	79.6%

[a] 'Baseline' vs. 'Tactile + Noxious', where 'Tactile + Noxious' is possible presence of pain.
[b] 'Baseline + Tactile' vs. 'Noxious', where 'Noxious' is near certain presence of pain.

NCS; Nociception Coma Scale, NCS-R; Nociception Coma Scale Revised, Sens; sensitivity, Spec; specificity, AUC; Area under the ROC curve.

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CHAPTER 4

Clinimetric properties of the Nociception Coma Scale (-Revised): a systematic review

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Abstract

BACKGROUND AND OBJECTIVE

The Nociception Coma Scale is a nociception behaviour observation tool, developed specifically for patients with disorders of consciousness (DOC) due to (acquired) brain injury. Over the years the clinimetric properties of the NCS and its revised version (NCS-R) have been assessed, but no formal summary of these properties has been made. Therefore, we performed a systematic review on the clinimetric properties (i.e. reliability, validity, responsiveness and interpretability) of the NCS(-R).

DATABASES AND DATA TREATMENT

We systematically searched CENTRAL, CINAHL, Embase, PsycInfo and Web of Science until August 2015. Two reviewers independently selected the clinimetric studies and extracted data with a structured form. Included studies were appraised on quality with the COSMIN checklist.

RESULTS

Eight studies were found eligible and were appraised with the COSMIN checklist. Though nearly all studies lacked sample size calculation, and were executed by the same group of authors, the methodological quality ranged from fair to excellent.

CONCLUSION

Important aspects of reliability, construct validity and responsiveness have been studied in depth and with sufficient methodological quality. The overview of clinimetric properties in this study shows that the NCS and NCS-R are both valid and useful instruments to assess nociceptive behaviour in DOC patients. The studies provide guidance for the choice in NCS-R cut-off value for possible pain treatment and cautions awareness of inter-professional differences in NCS-R measurements.

Introduction

The assessment and treatment of pain is one of the most important areas in both medical and nursing care. Patients who are unable to communicate their pain are at risk of under recognition and under-treatment of their discomforts. (Herr et al., 2011) Among these patients exists a particularly fragile group with disorders of consciousness (DOC), such as unresponsive wakefulness syndrome (UWS) and minimally conscious state (MCS), due to acquired brain injury (ABI). Both patient groups show behavioural sleep-wake cycles, but only MCS patients might interact with objects or people and even give (adequate or inadequate) verbal responses. Both diagnoses are by definition incompatible with a reliable and consistent ability to communicate about pain experiences, while the nature of these conditions is characterised by various factors that can give rise to pain (e.g. spasticity, contractures, etc). (Thibaut et al., 2015)

It has been a subject of discussion whether these patients are capable of experiencing pain in a similar way as conscious patients. These discussions may complicate communication among healthcare professionals and between medical staff and the patient's family. The general consensus tells us however, to assess pain behaviour in all of these patients regardless of neurological capacity of nociceptive awareness. (Chatelle et al., 2014) (Schnakers et al., 2012)

For the assessment of nociceptive behaviour among these patients, the Nociception Coma Scale (NCS) has been developed in 2009. (Schnakers et al., 2009) It is a nociception behaviour observation scale, consisting of four items (motor response, verbal response, facial expression, visual response) with each a range score of 1 to 3. Over the years the scale has been further validated, revised to the Nociception Coma Scale – Revised (NCS-R), which omits the visual response item, and its practical implications have been discussed. Despite this research, the NCS(-R) has not been implemented in the field of neuroscience nursing, possibly due to the lack of a definitive conclusion on its clinimetric properties and practical implications. (Vink et al., 2015)

This systematic review therefore aims to evaluate the clinimetric properties, in terms of reliability and validity, of the NCS and NCS-R as an instrument to assess nociceptive behaviour in patients with DOC. To ensure a systematic approach we used the Consensus-based Standards for the selection of health status Measurement Instruments (COSMIN) checklist. (Mokkink et al., 2010a) (Mokkink et al., 2010c) Such an in-depth overview would reveal gaps in validity and reliability and provide guidance for future research. It would also provide conclusions for clinical implementation of the scale(s) and ensure confidence for clinicians and nurses to use the NCS(-R) for the measurement of pain in DOC patients. This is an important prerequisite to determine a solid evidence-based pain assessment and -treatment policy for these patients.

Methods

The study was entered in the International prospective register of systematic reviews (PROSPERO) on May 26th 2015.
The recommendations of the Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) was used for the reporting of this study. (Prisma Statement, 2009)

Identification of studies

In August 2015 one of the authors (PV) performed a literature search in CENTRAL, CINAHL, Embase, PsycInfo and Web of Science. The search

was repeated in August 2016. The search strategy consisted of the terms “nociception coma scale” without limitations on language or publication date. To ensure a sensitive search the strategy consisted of free text and did not use any Medical Subject Headings. A clinical librarian was consulted to investigate the sensitivity of the search strategy and no other feasible strategy was found.
To identify eligible studies, the search results were screened on titles and abstracts by two authors (PV and HV) independently. Disagreements were resolved by discussion. Articles were included if they met the inclusion criteria. Full-text of the article was reviewed when title/abstract did not provide sufficient information. Reference lists of the potentially eligible studies were manually searched to identify additional articles. We also contacted experts in the field to detect possible studies. Again, no limitations were imposed on language, publication date or publication status.

Studies were eligible for inclusion if:

1. **The aim of the study was to evaluate one or more clinimetric properties of the NCS or NCS-R as a tool to measure nociceptive behaviour.**
2. **The study population consisted of adult patients (>18 years) with DOC due to acquired brain injury.**
3. **The study was published as original article.**

In the absence of a golden standard reference for the measurement of pain in non-communicative patients with DOC, studies comparing the NCS or NCS-R to instruments measuring the same construct were considered eligible. For the same reasons the authors carefully considered the inclusion of studies aimed to evaluate the correlation between the NCS or NCS-R to a physiologic phenomenon known to be present during nociception. Reviews, guidelines, descriptive studies, editorials or poster publications were excluded. Publications of which full-texts were unavailable to university libraries were also excluded. Disagreements were solved by discussion.

Data Extraction
A structured form was used to extract data from original studies on in- and exclusion criteria, number of patients, number of observations, patient characteristics (age, diagnoses), methods of painful stimuli, the researched scale (NCS/NCS-R) and context (interventions, setting). Context data on clinical setting, observation technique and observers was extracted by one of the authors (PV). Age was extracted as provided by the article or, when all data was available, calculated into a median with range. Data on clinimetric properties included internal consistency, interrater reliability, intra-rater reliability, measurement error, content, construct, criterion validity and responsiveness. The definitions used are presented in **TABLE 1**. Data on clinimetric properties was extracted by two authors (PV and CL) independently, whereas disagreements were resolved by discussion. If no consensus could be reached, a third author (JM) was consulted. As one researcher (PV) was the author of one of the publications (Vink et al., 2014), a third, independent researcher (JM) carried out quality assessment in this case.

Quality Assessment
The COSMIN checklist was used to assess methodological quality of the studies. (Mokkink et al., 2010a) (Mokkink et al., 2010b) (Mokkink et al., 2010c) Two authors (PV and CL) independently assessed the methodological quality of the eligible studies. Disagreements were resolved by discussion and consultation of the COSMIN checklist manual (Mokkink et al., 2013) or a third author (JM). The reviewers provided each clinimetric property with an overall quality score, based on the 4-point scale (excellent, good, fair or poor) of the corresponding quality criteria of the COSMIN checklist. An overall rating was obtained by consensus of all involved reviewers. The reviewers were not blinded for authors, research environments and journals.

Outcome Measurements
For reliability outcomes the authors maintained magnitude criteria as described by Terwee et al. Reported Cronbach’s alpha were considered adequate if above 0.70 and further classified as unacceptable (> 0.5), poor (0.5-0.59), questionable (0.6-0.69), acceptable (0.7-0.79),

good (0.8-0.89) or excellent (≥ 0.9). (Terwee et al., 2007)We classified strength of agreement by means of Intra Class Correlation (ICC) or (weighted) kappa as slight (0.00-0.20), fair (0.21-0.40), moderate (0.41-0.60), substantial (0.61-0.80) or excellent (0.81-1.00). (Landis and Koch, 1977)

Results

Identification of Studies

The results of the literature searches are summarized in the flow diagram in **FIGURE 1**. Among the five searches a total of 95 references were assessed for eligibility on title and abstract. On the basis of title or abstract 26 found references were excluded on type of publication: conference publication (n=15), meeting/editorial (n=8), book (n=3). Among the remaining 69 references the reviewers identified 29 unique studies, among which eight were found eligible for review by both reviewers independently. (Chatelle et al., 2015) (Chatelle et al., 2014) (Chatelle et al., 2012) (Riganello et al., 2015) (Sattin et al., 2013) (Schnakers et al., 2009) (de Tomasso et al., 2015) (Vink et al., 2014) The eligibility of one other study (Thibaut et al., 2015) was questioned by both reviewers and eventually excluded based on the full-text. One study (Suraseranivongse et al., 2015) was excluded because it couldn't be obtained by online databases, university libraries or by contacting the authors. A complete list of the in- and excluded studies is provided in Appendix S1 (available online).

Description of Included Studies

One study (Vink et al., 2014) reported on internal consistency, three on reliability (Schnakers et al., 2009) (Vink et al., 2014) (Riganello et al., 2015), one on content validity (Schnakers et al., 2009), two on cross-cultural validity (Sattin et al., 2013) (Vink et al., 2014), three on construct validity (Schnakers et al., 2009) (Vink et al., 2014) (de Tomasso et al., 2015) and three on responsiveness (Schnakers et al., 2009) (Chatelle et al., 2012) (Vink et al., 2014) (Chatelle et al., 2015).

The included studies were published between 2009 and 2015 and originated from Belgium (n=5), Italy (n=2) and The Netherlands (n=1). From the eight included studies, three investigated clinimetric properties of the NCS (Schnakers et al., 2009) (Sattin et al., 2013) (Riganello et al., 2015), three of the NCS-R (Chatelle et al., 2014) (Chatelle et al., 2015) (de Tomasso et al., 2015) and two of both NCS and NCS-R (Chatelle et al., 2012) (Vink et al., 2015). The developer of the original NCS was involved in six of the included studies. All studies used the NCS(-R) as an instrument to assess nociceptive behaviour. The study details are summarized in **TABLE 2**.

The patient samples from seven of the included studies are a good representation of ABI patients with DOC, which are prevalent in both (semi)acute and long-term settings. Two studies included patients from acute or semi-acute settings such as Intensive Care Units (ICU), neurology and neurosurgery hospital wards. (Vink et al., 2014) (Chatelle et al., 2015) Three studies included patients from both (semi-)acute settings and long-term care facilities. (Schnakers et al., 2009) (Chatelle et al., 2012) (Riganello et al., 2015) All studies with the exception of Vink et al (2014) included patients with confirmed diagnosis of UWS, also known as vegetative state (VS), or MCS by means of the Coma Recovery Scale – Revised. (Kalmar and Giacino, 2005) None of the studies included intubated patients. The patients of the included studies show a variation in age, reasons for admission, diagnosis and time since onset. A summary of these characteristics are presented in **TABLE 2**. Five studies used observations after standardized administration of a painful stimulus to the nailbed during at least five seconds until a behavioural response was observed. (Schnakers et al., 2009) (Chatelle et al., 2012) (Chatelle et al., 2014) (Vink et al., 2014) (Riganello et al., 2015) The observers consisted of neuropsychologists, physiotherapists and (neuroscience) nurses. The assessment of methodological quality by means of the COSMIN checklist is rated as poor, fair, good or excellent. The ratings are summarized in **TABLE 3** and further explained in the following paragraphs.

Reliability

A total of three studies reported on reliability of the NCS and/or NCS-R. (Schnakers et al., 2009) (Vink et al., 2014) (Riganello et al., 2015) A summary of the psychometric values on internal consistency (Cronbach's α) and Interrater Agreement (kappa or ICC) is presented in **TABLE 4 & 5**.

Internal Consistency

Only the study of Vink et al (2014) investigated the internal consistency of the NCS and NCS-R. The methodological quality for this item of reliability was rated as good, because more thorough testing of the item response theory might have been desirable. Although a limited number of patients (n = 10) were included, the number of observations (n = 270) was increased by using video observations and a large pool of observers (n=27). Three video observations (during rest, tactile and noxious stimuli) per patients were shown to nurses from different hospitals with different levels of education (minimum of Associate in Nursing Degree) and experience with ABI patients (median seven years, range 1-28). The found Cronbach's α was questionable for both NCS (α=0.68) total scores and NCS-R (α=0.61) total scores. To test internal consistency Cronbach's α was recalculated when removing each sub score item from the scale. The result remained questionable, with the exception of facial expression. Cronbach's α when removing this item was poor with α 0.54.

Reliability

In the study of Schnakers et al. (2009) neuropsychologists, with experience in patients with DOC, assessed the NCS during noxious stimulus of 15 patients. The methodological quality for this item was rated as fair, due to a moderate sample (n=48) and an unclear indication of observer independency (e.g. blinding and adequate time interval). The found interrater agreement was substantial (k = 0.61) for total scores, substantial for facial expression and visual response (k = 0.73) and excellent for motor response and verbal response (k = 0.93).
Vink et al (2014) investigated the interrater agreement between hospital (neuroscience) nurses. The methodological quality for this item was rated as good. The sample size was moderate, but the number of observations was increased as described in the above section 'internal consistency'. The found single measure intra-class coefficient (ICC) was substantial for both NCS (ICC = 0.67) and NCS-R (ICC = 0.69). An average measure ICC of 0.95 (excellent) was found for both scales. No statistically significant differences were found in ICC estimates when comparing groups of nurses based on educational level or years of experience.

Riganello et al (2015) tested interrater agreement between two observers. One observer had a background in neuropsychology and had used the NCS for six months. The other observer had a background in physiotherapy and had used the NCS for two months. Both observers had experience working with severely brain-injured patients. The methodological quality for this item was rated as good, because a moderate sample size was included (n=44). The assessments were performed by two observers independently and repeated after one week. The interrater agreement during the first measurement occasion was *fair*, k=0.40 (0.21–0.47 sub scores) and *moderate*, k=0.57 (0.33–0.62 sub scores) at the second measurement occasion. This study also reported intra-rater reliability, which ranged from *substantial* (k=0.66) to *moderate* (k=0.57) among their two raters. Observations were obtained with one-week interval.

Validity

Content Validity

The content validity was only assessed by the developers of the NCS in the original article of Schnakers et al. (2009). The methodological quality for this item was rated as excellent. The sub score items were selected from earlier scientific publications on pain assessment in non-communicative patients. Vital signs, such as breathing, respiration and heart rate, were not incorporated in the NCS on the basis of a pilot study and previous scientific research. Social behaviours, such as interpersonal interaction, were excluded from the NCS, due to the behavioural limitations of UWS/MCS patients.

Cross-Cultural Validity

Two studies investigated part of the cross-cultural validity. Sattin et al (2013) described the translation of the NCS to Italian. The methodological quality for this item was rated as poor. The scale was translated according to international standards with multiple forward and backward translations, but after translation no further group analysis was performed. Vink et al (2014) translated the NCS to Dutch, also according to international standards but again without further group analysis. The methodological quality for this item was therefore also rated as poor. The authors state that the behavioural descriptions

of the NCS are such common terminology in neurological care, that further testing of cross-cultural validity was not necessary.

Construct Validity

One study investigated construct validity of the NCS and two of the NCS-R. In the 2009 study of Schakers et al. the NCS was correlated with other pain behaviour measurement instruments. The methodological quality for this item was rated as good, mainly due to a moderate sample size (n = 48). Convergent validity was established between the NCS and the Neonatal Infant Pain Scale (NIPS) (Lawrence et al., 1993), the Faces Legs Activity Cry Consolability pain assessment tool (FLACC) (Merkel et al., 1997), the Pain Assessment In Advanced Dementia Scale (PAINAD) (Warden et al., 2003) and the Checklist of Non-verbal Pain Indicators (CNPI) (Feldt, 2000). The Spearman rank correlations were all above 0.71 on total scores and ranged from 0.26 to 0.79 on individual items. All total score correlations were statistically significant ($p < 0.05$). From the sub score items (motor, verbal, face, visual) only the motor response had no statistically significant correlation with the NIPS, FLACC and CNPI.

The study of Chatelle et al. (2014) correlated the NCS-R to metabolism in the anterior cingulate cortex (ACC), which is known to be involved in pain processing. The methodological quality for this item was rated as good. Though the study was of excellent design, the sample size was moderate (n=49) and there was insufficient information to determine the appropriateness of the statistical analysis. The NCS-R was recorded during a standardized painful stimulus on the nailbed, after which a PET-scan was performed. A relation was found between the NCS-R total scores and the posterior part of the ACC (Z=2.76; corrected p-value=0.18). A statistically significant relation was found between the ACC metabolism and the level of consciousness, as measured by the Coma Recovery Scale - Revised, suggesting that the NCS-R only reflects the construct nociception (convergent validity).

One study by De Tommasso et al. (2015) compared electroencephalography (EEG) and electro-oculography (EOG) results during visual, auditory, non-noxious and noxious laser stimulation between UWS/MCS patients and healthy controls. The methodological quality for this item was rated as fair, because the study population was small (n = 20; 9 patients, 11 controls). Also, though statistical analysis for comparing EEG/EOG results of UWS patients with the control group was sufficiently described, no correlation coefficients, distributions or p-values were provided. It is therefore not possible to assess the strength of the correlations with the NCS-R. The cortical response to noxious laser stimuli was reported to be uncorrelated to NCS-R scores.

Responsiveness

A total of four studies reported on responsiveness of the NCS and/or NCS-R for an increase of nociception. An overview of the resulting cut-off values is presented in **TABLE 6**.

Schnakers et al. (2009) compared the NCS total scores with nociception thresholds as provided by the Checklist of Non-verbal Pain Indicators (CNPI). The methodological quality for this item was rated as *good*, mainly due to a moderate sample size (n = 48) and lack of a priori hypotheses descriptions. A significant difference ($p < 0.05$) was found between mean NCS total scores, grouped according to the CNPI threshold for no nociception (NCS 2.5 ± 1.5), light nociception (NCS 5.1 ± 1.7) and moderate nociception (NCS 8.0 ± 1.0). No individual t-values or p-values were provided.

The study of Chatelle et al. (2012) investigated the changes of the NCS total and sub scores between resting observation (baseline), tactile/non-noxious stimulus and noxious stimulus. Though the sample size(n=64) could have been bigger, the methodological quality for this item was rated as *excellent* because observation techniques and analyses were well executed. The total score and motor, verbal and facial sub scores all increased significantly between these conditions. The visual response item was not significantly different between non-noxious and noxious stimulus. An ROC analysis of the NCS revealed an optimal sensitivity of 46% and specificity of 97%, at a cut-off value of 4. Because of the lack of discriminative abilities of the visual response item, the authors decided to remove it from the scale and thereby created the NCS-R. ROC analysis for the NCS-R resulted in a sensitivity of 96% and specificity of 89%, also with a cut-off value of 4. Separate

analysis for MCS and UWS patients revealed a NCS-R cut-off value of 4 for MCS patients (sensitivity 83%, specificity 95%) and 3 for UWS patients (sensitivity 96%, specificity 89%).

Vink et al (2014) investigated the cut-off values for the NCS and NCS-R to differentiate between absence of pain (no stimulus), possible presence of pain (none versus tactile stimulus) and probable presence of pain (tactile versus noxious stimulus). The methodological quality for this item was rated as *excellent*, because methodological flaws were limited by the use of video recordings. An ROC analysis revealed a cut-off value of NCS ≥3 for the probable presence of pain (sensitivity 72%, specificity 67%). For the NCS-R the ROC analysis revealed a cut-off value of ≥2 for the probable presence of pain (sensitivity 74%, specificity 74%).

Chatelle et al (2015) investigated responsiveness of the NCS-R in an acute care setting. Patients with an NCS-R score of 4 or higher, measured by trained nurses, during potentially painful nursing care interventions were and found eligible for the study. After analgesic treatment, the NCS-R was reassessed during similar conditions. The methodological quality for this item was rated as *fair*, because of a moderate sample (n = 39), the lack of blinding, comparison to a control and a vague description of the time interval ('within 24 hours'). The NCS-R total scores decreased significantly after analgesic treatment (5.2±1.3 vs 3.7±1.9; z=4.37; p<0.0001) and so did the sub scores of motor response (2±0.7 vs 1.5±0.9; z=3.09; p=.002), verbal response (1.2±1.1 vs 1±1; z=2.22; p=0.027) and facial expression (2±0.5 vs 1.2±0.9; z=3.92; p<.0001). This did not differ according to etiology or the level of consciousness, suggesting the NCS-R only measures nociception.

Discussion

The results of our systematic review show that all clinimetric properties of the NCS and most of the NCS-R have been studied and tested. This systematic review shows that the aspects of reliability, construct validity and responsiveness have been studied sufficiently for the NCS/NCS-R. The methodological quality of the studies investigating these aspects ranged from fair to excellent. In comparison to similar systematic reviews on pain observation scales, such as the COMFORT pain scale, the quality of the studies is rather high. (Maaskant et al., 2016) For clinical implications and future research some comments must be made.

The reliability of the scale(s) is one of the best studied aspects of validity. Three studies, all on the NCS, used observers from different professions and different methods of observation and analyses. (Schnakers et al., 2009) (Vink et al., 2014) (Riganello et al., 2015) The results of these studies tend towards *substantial* to *excellent* interrater agreement, though Riganello et al (2015) reports a range from *fair* to *moderate*. The different results in this last study might be due to the limited number of observers (n=2) and a difference in background (physiotherapy) of one of the observers. Though we believe that the NCS produces consistent and reproducible results, further research on inter- and in particular intra-rater agreement between different disciplines could strengthen this statement. In clinical practice the possible difference in measurement between professions should be kept in mind and if possible eliminated by interdisciplinary training/ education.

Construct validity proves to be one of the most difficult aspects of validity to investigate for these scale(s). Because there is no golden standard for pain measurement to compare the NCS(-R) with, the researchers had to correlate the NCS(-R) scores to other pain behaviour measurement tools for the same construct or a physiologic phenomenon known or suspected to be present during nociception. This resulted in the support of convergent validity by Schnakers et al (2009) and divergent validity by Chatelle et al (2014), both showing good methodological quality. We believe that there is sufficient evidence to use either NCS or NCS-R to assess nociceptive behaviour in UWS/MCS patients. New knowledge and technologies to measure (neuro)physiological structures involved in nociception and nociceptive awareness could strengthen this statement in future research.

The responsiveness of the NCS and NCS-R are of great importance to

daily practice for both nurses and physicians to evaluate the adequacy of pain management. The results of four studies show that the NCS and NCS-R increase during nociception, thus detecting change over time in nociceptive behaviour. (Schnakers et al., 2009) (Chatelle et al., 2012) (Vink et al., 2014) (Chatelle et al., 2015) For clinical practice we suggest a pain protocol that combines a cut-off value with the clinical judgement of the healthcare professional to initiate diagnostic and/or pain reducing interventions, pharmaceutical or non-pharmaceutical.

Three studies, varying from *fair* to *excellent* methodological quality, have tried to find an overall cut-off value for the presence of nociception. (Schnakers et al., 2009) (Chatelle et al., 2012) (Vink et al., 2014) However, the choice for a cut-off value might prove difficult for clinical practice as cut-off values differ among the studies and may even differ between MCS and UWS patients. (Schnakers et al., 2012). Firstly, Chatelle et al. found no statistically significant difference in visual subscores between non-noxious and noxious stimulation conditions. They did find a statistically significant difference between baseline vs. non-noxious and baseline vs. noxious stimulation. In the NCS-revised (NCS-R) the visual item was omitted, though the item could prove of importance when the patient shows nociception behaviour without non-noxious stimulation. Secondly, in the treatment of severely affected and hypocommunicative patients, it is generally accepted to 'err on the safe side' when it comes to pain treatment, i.e. to regard the possibility of treating non-existing pain acceptable in order to prevent under-treatment of pain.
Following this, we suggest to assess nociception behaviour with the NCS, but maintain the lowest found cut-off value of ≥2 for the NCS-R. (Vink et al., 2014)This study did not differentiate between MCS and UWS patients, therefore the cut-off values of NCS-R ≥4 (MCS) and ≥3 (UWS) as found by Chatelle et al. (2012) might prove more valuable for settings with fully diagnosed patients. Whichever cut-off value is chosen, it can only be used as a general guideline since each individual patient can have different neurological or motor limitations to show nociceptive behaviour. For example, the use of neuro-muscular function blockers or the presence of a tracheostomy will limit the patient's ability to reach a score on NCS motor or verbal item respectively. A score below any given cut-off value is thereby no guarantee for the absence of nociception and in patients with low baseline scores, any increase in NCS should give rise to assessment of possible discomfort, rather than waiting for a general threshold score to be reached. When a pain reducing intervention is administered, either pharmaceutical or non-pharmaceutical, intra-patient changes in NCS scores should be used to assess the effectiveness of the chosen treatment and determine a future treatment plan.

The quality of cross-cultural validation was poor in both studies investigating this aspect. (Sattin et al., 2013) (Vink et al., 2014) We believe that this item of validity might require further research, considering all included studies have been conducted in West-European countries. Though nociceptive behaviour does not differ among cultures, the observation and assessment of such pain-related behaviour might be subject to the observers (cultural) perception on pain.

Overall, the studies are of sufficient quality for an evaluation of the clinimetric properties of the NCS and NCS-R. A recurring limitation of these studies is the lack of sample size calculation, except for one (Vink et al., 2014). This may be due to the low incidence and prevalence of DOC (van Erp et al., 2014) or insufficient knowledge of the COSMIN guidelines. The low prevalence of prolonged DOC might also be the reason why the group of authors on the subject is relatively small. Many of the articles are written by the same group of authors and samples in the studies might partially even consist of the same patients. Further research in different countries and settings by different authors is recommended. Another possible limitation is the lack of blinding, though it can be discussed if blinding the observer of the painful stimuli is possible or even necessary. We believe that the NCS or NCS-R will be used in situations where the healthcare professional will either notice or suspect a painful stimulus. By not blinding the observers in the studies they have therefore closely joined and simulated daily practice.

In conclusion, we believe that the overview of clinimetric properties in this study shows that the NCS and NCS-R are both valid and useful instruments to assess nociceptive behaviour in DOC patients. Future

research on cross-cultural validity and intra-rater agreement will further strengthen this statement. Until a gold standard is available to determine the actual conscious perception of pain in DOC patients, healthcare professionals can use the NCS/NCS-R scores to determine a treatment strategy.

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Figure 1 PRISMA flow diagram of search.

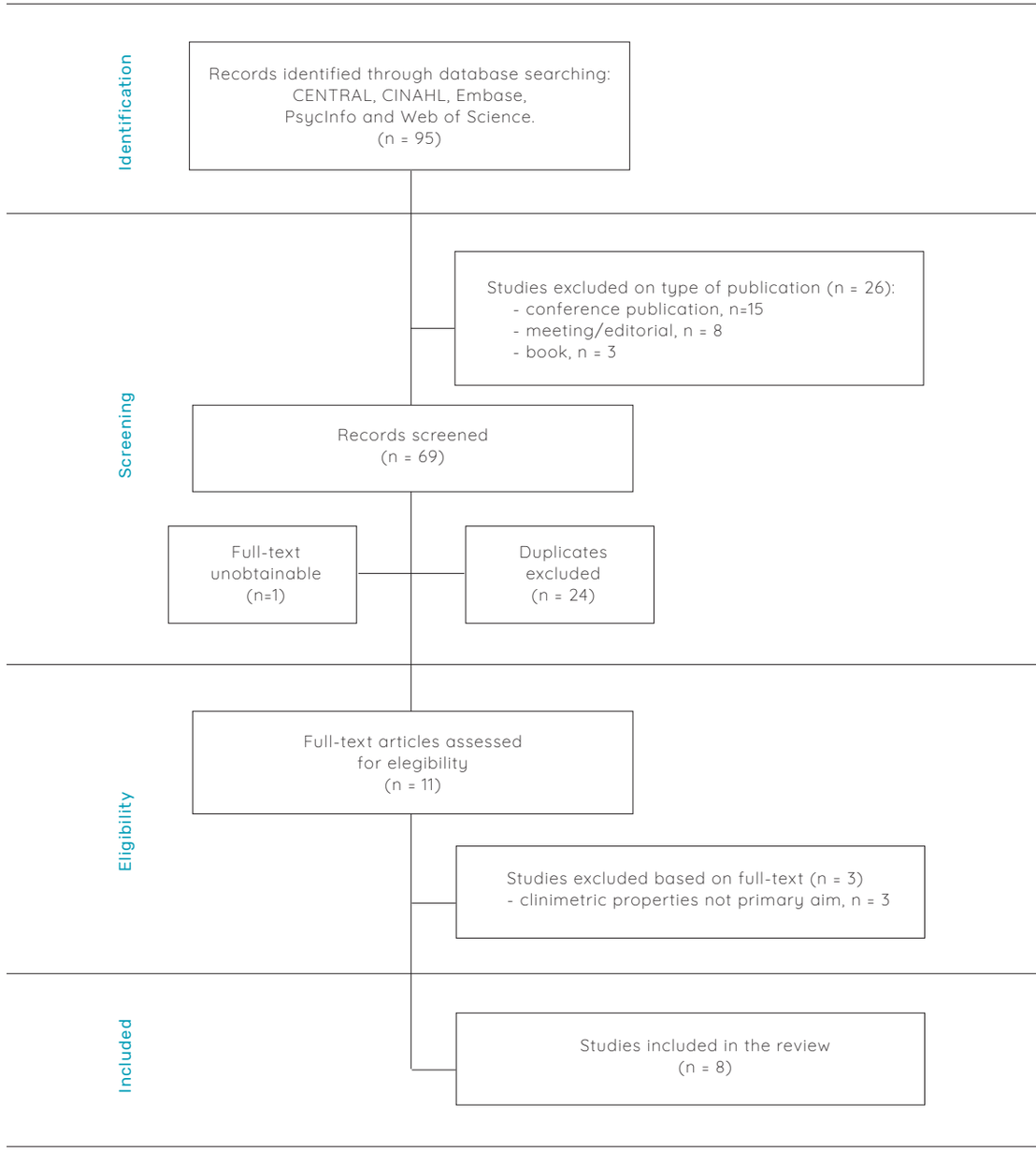

Table 1

Definitions of Clinimetric Properties.

Reliability	
Internal consistency	The extent to which the different items of a (sub)scale are correlated, thus are measuring the same construct.
Reliability	The extent to which the measurement tool produces consistent and reproducible results.
Measurement error	Systematic and random error in the scores, that is not attributed to the true changes in the construct.
Validity	
Content validity (including face validity)	The extent to which the domain of interest is comprehensively reflected by the items of the measurement tool.
Construct validity: structural validity	The extent to which the scores of the measurement tool are an adequate reflection of the dimensionality of the construct to be measured.
Construct validity: hypothesis testing	Comparing the scores of the measurement tool to scores of another measurement tool that is considered to measure the same construct (convergent validity) or a different construct (divergent validity).
Criterion validity	The extent to which the scores of the measurement tool relate with a reference standard ("gold standard").
Other	
Responsiveness	The ability of a measurement tool to detect change over time in the construct to be measured.

Definitions of clinimetric properties. (Mokkink et al., 2013)

Table 3

Methodological quality of primary studies.

Author, year	Internal Consistency	Reliability	Content Validity	Cross-Cultural	Construct Validity	Responsiveness
Schnakers et al, 2009	-	fair	excellent	-	good	good
Chatelle et al, 2012	-	-	-	-	-	excellent
Sattin, 2013	-	-	-	poor	-	-
Chatelle, 2014	-	-	-	-	good	-
Vink et al, 2014	good	good	-	poor	-	excellent
Chatelle et al, 2015	-	-	-	-	-	fair
De Tomasso et al, 2015	-	-	-	-	fair	-
Riganello et al, 2015	-	good	-	-	-	-

Table 2

Summary of Included Clinical Trials

Author, year Country	Scale	Inclusion / Exclusion criteria	No. of patients / controls	Reason for admission (patients)	Diagnose of DOC (patients)	Age in years[a]	No. of observations	Observation technique	Context: time since onset	Context: setting
Schnakers et al, 2009 Belgium	NCS	A, B, C, D, / F, G, H	Patients: 48	TBI: 17 AN: 10 IS: 7 HS: 7 Other: 7	VS: 28 MCS: 20	[20-82]	2 per patient, total 96	Observation during: baseline, non-noxious stimulus, standardized noxious stimulus to nailbed	< 1 month (n=31) 1 month to 6 years (n=17)	ICU, Neurology Wards, Neuro-rehabilitation and nursing homes.
Chatelle et al, 2012 Belgium	NCS, NCS-R	A, B, C, D, / F, G, H,	Patients: 64	TBI: 22 AN: 20 HS: 8 IS: 3 Other: 11	VS: 27 MCS: 37	[20-82]	3 per patient, total 192	standardized noxious stimulus to nailbed	< 1 month (n=21) 1 month to 6 years (n=43)	ICU, Neurology Wards, Neuro-rehabilitation and nursing homes.
Chatelle et al, 2014 Belgium	NCS-R	None described	Patients: 49	TBI: 21 AN: 17 SAH: 3 HS/IS: 4 Other: 4	VS: 18 MCS: 31	40 [21-83]	1 per patient, total 49	Observation during: standardized noxious stimulus to nail bed + PET-scan same day	< 1 year (n=26) > 1 year (n=23)	Not specified.
Vink et al, 2014 The Netherlands	NCS NCS-R	A, B, C / I	Patients: 10	TBI: 1 HS/IS: 7 Other: 2	GCS*: 10 [6-12]	56 [26-75]	total 270	Video recordings during: baseline, non-noxious stimulus, noxious stimulus (varies)	Not specified	Neurology / Neurosurgery Ward
Chatelle et al, 2015 Belgium	NCS-R	A, B, D, E, / G, H, I	Patients: 39	TBI: 15 HS: 13 AN: 6 IS: 3 Other: 2	VS: 12 MCS: 27	61 [21-93]	2 per patient, total 78	Observation: During/before potentially painful nursing cares, + Before and after analgesic treatment	< 1 month (n=36) 1 month to 6 years (n=3)	Acute Care: ICU and Neurology Ward
De Tomasso et al, 2015 Italy	NCS-R	D	Patients: 9 Controls: 11	TBI: 4 HS: 2 AN: 2 IS: 1	VS: 5 MCS: 4	Patients: 60.6 [44-76] Controls: 60.2 [50-68]	2 series of 25 laser, electrical, auditory and visual stimuli per patient/control	EEG and EOG	< 1 month (n=0) 1m to 6y (n=9) [3m-4y]	Long-term Care
Riganello et al, 2015 Italy	NCS	A, B, C, D, / F, G, H	Patients: 44	TBI: 19 HS: 9 IS: 16	VS: 26 MCS: 18	53.6 (19.3)	total 176	Observation during: standardized noxious stimulus to nailbed	< 1 month (n=0) 1 month to 6 years (n=44)	Semi ICU hospital (n=16) and Long-term Care (n = 28)

Inclusion Criteria
A. Age over 18 years;
B. No administration of neuro-muscular blockers or sedative agents within 24 hours prior to assessment;
C. Documented periods of eye-opening;
D. Diagnosis of UWS or MCS based on the Coma Recovery Scale - Revised;
E. Presence of potential pain during care interventions.

Exclusion Criteria
F. Fractures or flaccid paralysis of the upper limbs;
G. History of premorbid brain injuries;
H. Developmental, psychiatric or neurological disorders prior to admission;
I. Intubation.

NCS Nociception Coma Scale; NCS-R = Nociception Coma Scale Revised; TBI = traumatic brain injury; HS = Haemorrhagic Stroke, including subarachnoid haemorrhage and intracranial haemorrhage; AN = anoxia; IS = ischemic stroke; GCS = Glasgow Coma Scale. VS = Vegetative State; UWS = unresponsive wakefulness syndrome; MCS = minimally conscious state; EEG = electroencephalographic; EOG =electro-oculogram; ICU = Intensive Care Unit; a: numbers are presented as [range], median [range] or mean (SD).

Table 4

Summary of internal consistency coefficients.

	Item Rest Correlation	Cronbach's α (if item deleted)[a]
Motor response	0.39	0.69
Verbal response	0.49	0.63
Visual response	0.48	0.61
Facial expression	0.58	0.54
Total NCS score	-	0.68
Total NCS-R score	-	0.61

Internal consistency from Vink et al (2014). [a]: Cronbach's α if item deleted values from NCS with four items. Values for total NCS and NCS-R scores denote total scale internal consistency.

Table 5

Summary of interrater agreement coefficients.

	Unweighted Cohen's Kappa Schnakers et al, 2009	Single-measure ICC Vink et al, 2014	Unweighted Cohen's Kappa (week 1 & 2) Riganello et al, 2015
Motor response	0.93	0.68	0.21 & 0.33
Verbal response	0.93	0.62	0.47 & 0.62
Visual response	0.73	0.42	0.37 & 0.41
Facial expression	0.73	0.61	0.34 & 0.38
Total NCS	0.61	0.67	0.40 & 0.57
Total NCS-R	-	0.69	-

Interrater agreement coefficients from Schnakers et al (2009), Vink et al (2014) and Riganello et al (2015).

Table 6

Summary of discriminative values.

Study	Patient Groups	Group Mean ± SD/ Cut-Off Value	Sensitivity	Specificity	Definition
Schnakers et al, 2009	All	NCS 2.5 ± 1.5	NA	NA	No nociception
	All	NCS 5.1 ± 1.7	NA	NA	Light nociception
	All	NCS 8.0 ± 1.0	NA	NA	Moderate nociception
Chatelle et al, 2012	All	NCS ≥4	46%	97%	Noxious stimulation present
	MCS	NCS-R ≥4	83%	95%	Noxious stimulation present
	UWS	NCS-R ≥3	96%	89%	Noxious stimulation present
Vink et al, 2014	All	NCS ≥2	74%	68%	Possible presence of pain
	All	NCS ≥3	72%	67%	Probable presence of pain
	All	NCS-R ≥1	77%	75%	Possible presence of pain
	All	NCS-R ≥2	74%	73%	Probable presence of pain

Group mean values from Schnakers et al (2009) and cut-off values vrom Chatelle et al (2012) and Vink et al (2014). MCS = minimally conscious state, UWS = unresponsive wakefulness syndrome.

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CHAPTER 5

Consciousness assessment: A qurrent neuroscience questionnaire of nursing practice in Europe

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Abstract

AIMS AND OBJECTIVES

To study practice in consciousness assessment among neuroscience nurses in Europe.

BACKGROUND

Over the years, several instruments have been developed to assess the level of consciousness for patients with brain injury. It is unclear which instrument is being used by nurses in Europe and how they are trained to use these tools adequately.

DESIGN/METHODS

A cross-sectional questionnaire, created by the European Association of Neuroscience Nurses Research Committee, was sent to neuroscience nurses in 13 European countries. The countries participated in 2016 with a response period of 3 months for each country.

RESULTS

A total of 331 questionnaires were completed by nurses in 11 different countries. Assessment of consciousness was part of the daily routine for a majority of bedside nurses (95%), with an estimated median frequency of six times per shift. The majority uses a standardised instrument, and the Glasgow Coma Scale is the most common. Most participants assess consciousness primarily for clinical decision-making and report both total scores and subscores. The majority was formally trained or educated in use of the instrument, but methods of training were divers. Besides the estimated frequency of assessments and training, no significant difference was found between bedside nurses and other nurse positions, educational level or kind of institution.

CONCLUSION

Our study shows that consciousness assessment is part of the daily routine for most nurses working in neurology/neurosurgery/neurorehabilitation wards in Europe. The greatest variation existed in training methods for the use of the instruments, and we recommend standardised practice in the use of assessment scales.

RELEVANCE TO CLINICAL PRACTICE

In clinical practice, both managers and staff nurses should focus on formalised training in the use of assessment tools, to ensure reliability and reproducibility. This may also increase the professionalism in the neuro-science nurses' role and performance.

Background

Neurological conditions affect people of all ages and are consequences of damage to the brain, spinal cord and nerves as a result of illness or injury. Several diseases that affect the brain result in diminished or altered levels of consciousness. In Europe, stroke is one of the leading causes of death and disability and the burden of stroke is expected to increase. (Béjot, Bailly, Durier, & Giroud, 2016) Also Traumatic Brain Injury (TBI) is an important cause of hospital admissions in Europe. From a European survey in 2012; 1.375.974 hospital discharges (data from 24 countries) and 33.415 deaths (25 countries) related to TBI were identified. (Majdan, et al., 2016) During the acute phase of TBI or diseases causing brain injury, an accurate assessment of a patient's consciousness is paramount for the early diagnosis and management of deterioration. This requires a scoring tool that offers a (visual) trend of observations and establishes a baseline from which nurses and other health care professionals can perform, compare and repeat evaluations of a patient's level of consciousness, and thus adjust treatment accordingly.

Over the years, several tools have been designed to address this need, of which the Glasgow Coma Scale (GCS) has been regarded as the gold standard for over forty years. (Teasdale & Jennett, 1974) (Teasdale, Allen, Brennan, McElhinney, & Mackinnon, 2014) Other tools are for instance 'Alert Voice Pain Unresponsive Scale' (AVPU), 'Full Outline of Unresponsiveness' (FOUR), or the 'Coma Recovery Scale – Revised' (CRS-R). Each tool has its own strengths and weaknesses and may be more applicable to conditions or patient groups, e.g. stroke, unresponsive wakefulness syndrome and minimally conscious states. (Kelly, Upex, & Bateman, 2004) (Holdgate, Ching, & Angonese, 2006) (Brunker, 2006) (Baker, 2008) (Waterhouse, 2008) (Kornbluth & Bhardwaj, 2011)

It is essential that nurses and other healthcare professionals have the skills and knowledge to perform an accurate assessment of consciousness. One of the aims of the European Association of Neuroscience Nurses (EANN) is to contribute to development of these skills and knowledge, but variations in both choice and use of consciousness assessment tools have been discussed at scientific meetings and discussions. The aim of this study is therefore to identify practice variation in assessing the level of consciousness among neuroscience nurses in Europe. It is not our intention to determine or dictate the best instrument to be used, but to examine the neuroscience nurses' understanding of the rationale underpinning the particular tool in use and explore the knowledge base in performing a neurological assessment of consciousness.

Methods

Participants

The study was proposed by the EANN Research Committee to the representatives of the member countries at the 2015 annual EANN board meeting and the questionnaire (in English) was distributed to the board members. Recruitment of participants included members from the following countries: Austria, Belgium, Croatia, Denmark, Finland, Iceland, Italy, Malta, the Netherlands, Norway, Poland, Serbia, Sweden, Switzerland, Turkey and the United Kingdom.

Questionnaire Design

The study was conducted by distributing a descriptive cross-sectional questionnaire. An online questionnaire was created by the first author

(PV). An expert panel consisting of the EANN Research Committee members reviewed the questionnaire for content and face validity. After revisions, the questionnaire was translated by the representatives of the participating countries. It was translated from English to Danish, Dutch, German, Greek, Italian, Macedonian, Swedish and Turkish. Due to logistic challenges only a forward translation (English to native) was possible for Greek and Italian. For the remaining languages, a backward translation ensured the quality of translation according to World Health Organization (WHO) standards. (WHO Research Tools) The questionnaire was developed and administered using the online survey provider SurveyMonkey®, and each language was pre-tested by the countries' representatives and/or colleagues.
If a list of eligible participants was provided by each country's representative, a direct invitation to participation was sent by email through SurveyMonkey®. If such a list was not available, a direct weblink was spread through social networks and email contacts by each country's representative.

A description of the background and purpose of the questionnaire was included in the invitation. The questionnaire consisted of 45 questions, 1 for language selection, 19 for participant characteristics (educational level, years of experience, level of specialization and work setting) and 5 for evaluation of the questionnaire. The remaining 20 questions (**APPENDIX A**) related to consciousness assessment where conditional logic ensured that participants would only receive the questions that would apply to them. For example, if the participant replied that he/she did not receive training, all questions about the training methods would be omitted. Participants could review their replies with a back button. After submission, a participant could not change his/her answer.
Countries participated at different intervals between February and August 2016, with a response period of 3 months per country. To increase participation and completion rate, participants would receive a reminder by email every week, until they had completed the questionnaire or the study period ended. All emails were sent on Monday morning at 6am. Submitted questionnaires were checked for completeness within the SuveryMonkey® web service, so reminders for completion could be sent every week.

Data Saturation
For saturation of data in each country the authors required completed questionnaires from at least one university hospital and/or two general hospitals. Exceptions were made for Macedonia and Malta, due to the small number of hospitals in those countries.
For generalizability on a European level the authors required data saturation from at least one country in Northern Europe, one country in Western Europe, one country in Southern Europe and one country in Eastern Europe.

Ethical issues
Participation in the study was voluntary and responses were anonymous. Countries with only one participant were excluded from analysis, to maintain the participant's anonymity. No ethical committee was consulted for this study, because this is not a requirement in the initiating countries of this study (The Netherlands and Denmark).

Analysis
The results of the questionnaire are presented by descriptive analysis. All data were tested for normality by a Kolmogorov-Smirnov test, a Q-Q plot and Levene's test. Categorical variables were expressed as n (%). Normally distributed variables were expressed by their mean and standard deviation, not normally distributed data by their median and range. Normally distributed data were tested with the independent samples Student's t-test for 2 groups and one-way ANOVA for >2 groups. In case of skewed data, we used the independent samples Mann-Whitney U-test for 2 groups and Kruskal-Wallis test for >2 groups. If possible, differences were compared between countries, between positions (bedside nurses vs. other nurse positions), educational level and kind of institution. Statistical analysis was performed using SPSS Statistical software for Windows (version 24.0, IBM SPSS Inc., Armonk, NY). All countries with less than previously stated data saturation were excluded in the analysis. Analysis was performed for participants who replied that consciousness assessment was part of their daily routine (**FIGURE 1**).

Results

Participant Demographics

In total 331 nurses returned the questionnaire of which 2 were excluded from analysis because they were the only respondents for their country (Croatia and Norway). Data saturation was accomplished for Austria, Belgium, Denmark, Finland, Italy, Macedonia, Malta, the Netherlands, Sweden, Turkey and the United Kingdom. Based on the response, groups used for analysis changed per question or set of question, as shown in **FIGURE 1**.

For 279 (85%) out of 329 nurses the assessment of consciousness is part of their daily routine. The majority were bedside nurses (n=199, 71%), other characteristics are presented for each country in **TABLE 1**. Countries where some bedside nurses do not perform consciousness assessment as part of their daily routine were Austria, Denmark, Sweden and Turkey. In the description of the results, the 20 questions regarding the consciousness assessment are gathered in six themes as described below.

How often do neuroscience nurses in Europe assess consciousness?

The median frequency of consciousness assessment was estimated at 6 [0-100] times per shift for the overall sample. There was a statistically significant difference in the estimated frequency per country. The results for each country are shown in **TABLE 2**. There was no statistically significant difference between bedside nurses and other nurse professionals or educational level. Consciousness assessment was less frequent in Rehabilitation Centres (median 2, range 1-10), compared to General and University Hospitals.

How do nurses in Europe assess consciousness?

Out of the participants that assess consciousness, most (n=254, 91%) use a standardized instrument to assess consciousness. Countries where not all nurses use a standardized instrument were Austria (n=1, 25%), Belgium (n=4, 9%), Finland (n=5, 31%), Italy (n=5, 20%), Macedonia (n=3, 60%), Sweden (n=2, 11%), Turkey (n=1, 7%), United Kingdom (n=4, 6%). There was no statistically significant difference between bedside nurses and other nurse professionals, educational level or kind of institution (**TABLE 3**).

The GCS was the most commonly used instrument in each country and in 85% (n=237) of the total sample. There was more variation in instruments used among bedside nurses than other nurse professionals. Other known instruments besides the GCS were (among others) the Coma Recovery Scale – Revised (n=37, 13%), Full Outline of Unresponsiveness (n=27, 10%) and the Moscow Coma Scale (n=14, 5%). Frequency of use and knowledge of the existence of instruments are shown in **TABLE 3**.

How do nurses in Europe report their consciousness assessment?

Out of the 254 participants who use a standardized instrument, 56% (n=142) reported both total scores and subscores of the consciousness assessment. This was also the main method of reporting in each individual country, except for Malta where most participants (n=4, 57%) reported clinical signs of decline in consciousness (not part of a scale). This answer was also given by a large group (n=11, 37%) in Italy and 17% (n=44) of all participants. The second largest group of the total sample, 18% (n=46), only reported the total score. There was no statistically significant difference between bedside nurses and other nurse professionals, educational level or kind of institution.

With what purpose do nurses in Europe assess consciousness?

Most of the participating nurses (49%, n=125) answered ‘clinical decision making’ as their primary purpose of consciousness assessment. There was, however, statistically significant variation between countries. In Belgium the primary purpose of consciousness assessment was ‘reporting’ according to 39% (n=16). In Finland 45% (n=5) replied ‘reporting’ and the same proportion ‘clinical decision making’. In Malta the main purpose was divided among participants between ‘clinical decision making’ (28%, n=2), ‘reporting’ (28%, n=2) and ‘communication with medical staff’ (28%, n=2). There was no statistically significant difference between bedside nurses and other nurse professionals, educational level or kind of institution.

Are nurses in Europe trained to assess consciousness?

Out of 254 participants who use a standardized instrument, 68% (n=174) stated that they had been formally trained or educated in

the use of the assessment scale. In all participating countries, the majority confirmed being trained or educated, except for Belgium where 59% (n=24) indicated not to have received formal training or education. This difference was statistically significant. There was no statistically significant difference between bedside nurses and other nurse professionals, educational level or kind of institution.

If yes, how are they trained?

The way nurses were trained was very diverse among the participants. Among the nurses that were trained 22% (n=39) had been trained by teachers/trainers, 20% (n=35) by colleagues and 21% (n=36) by both colleagues and teachers/trainers. Bedside nurses were less often trained by teachers/trainers (19%, n=23) than nurses in other positions (29%, n=16) and were mostly trained by colleagues. In all countries, at least some participants were trained by physicians. Belgium was the only country where physicians were primary teachers /trainers.

Most participants trained practically in the clinical setting (73%, n=127), the second largest group (25%, n=43) had been educated by classroom teaching. In this questionnaire only Denmark, the Netherlands and Sweden seemed to have an online training for consciousness assessment.

Most of the participants who replied to this question (58%, n=52) claimed that they were trained in the same way as their colleagues. The rest was trained differently (12%, n=21) or did not know (30%, n=52). Only 17% (n=30) were trained in the same way as physicians, but the majority (72%, n=125) was unsure of this. For those participants who had received training/education this was usually not repeated (39%, n=62) or less than once a year (36%, n=58). Only in Italy, Sweden and Turkey most of the participants stated that they trained at least once a year.

Discussion

Our study confirms that consciousness assessment is part of the daily routine for most nurses working in neurology/neurosurgery/ neurorehabilitation wards/units in Europe. It has been well known that nurses with specialist education and/or training in neuroscience nursing have higher competence in consciousness assessment than nurses who only have basic education. (Heron, Davie, Gillies, & Courtney, 2001) (Mattar, Liaw, & Chan, 2013) (Reith, Brennan, Maas, & Teasdale, 2016) However, our study also demonstrates that there is a great variability of practice in our group of neuroscience nurses.

Even though frequencies varied widely among the participants, consciousness assessment is performed about 6 times per shift in hospital settings and 2 times per shift in rehabilitation centres. This is not surprising, as patients in rehabilitation clinic are generally more stable than in the acute hospital care and thus not in need of having frequent assessments. The highest number of assessment per shift was 100 (**TABLE 2**). This can be explained by variation in how many hours a shift lasts. We did not ask for that in the questionnaire. Besides the estimated frequency and training of participants, no statistically significant difference was found between bedside nurses and nurses in other positions, levels of education or kind of institution. This suggests that consciousness assessment has been implemented to the same extent across Europe.

In general, a standardized instrument is used and, as expected, the GCS is the most commonly used instrument in Europe. However, there was a small group of participants (9%) who replied that they did not use a standardized instrument. Considering the fact that even the use of GCS does not warrant standardization in assessment, this finding indicates serious practice variations and potential lack in quality of care and safety for patients with disorders of consciousness. (Braine & Cook, 2017) (Reith, Brennan, Maas, & Teasdale, 2016) From an extensive review of scientific studies, Braine and Cook (2016) concluded that there are at least eight different ways to apply noxious stimuli in the two subscales of GCS (motor and eye-opening) to assess reaction. This variation may besides other challenges result in a limited interrater reliability of the GCS. Thus, standardization not only in education and training, but also guidelines in how to use an assessment tool is crucial. In our study, we found it satisfactory to learn that most participants

using a standardized instrument report the outcome of the assessment with both total and subscores. To effectively monitor consciousness levels and individual patient's functional limitations, it is essential to report the subscores. This allows other succeeding nurses and other healthcare professionals to repeat the assessment and previous measurements and pinpoint the change in different neurological functions such as arousal, motor function and verbal response. The results also show that there are a large number of participants who do not report the subscores at all, which suggests that the above mentioned statements are not commonly known or implemented. In an international study covering 48 countries including neurological physicians and nurses from different disciplines it was reported that strategies for reporting the GCS varied greatly, and 35% of the participants limited the reporting to a summary score. (Reith, Brennan, Maas, & Teasdale, 2016)

It is also interesting to learn that the primary purpose of consciousness assessment is not always clinical decision making, even though this is most often what the instruments are intended for. Some of the participants only perform the assessment, simply to report it to nurse colleagues and/or physicians. One of the major conclusions is that this study shows a difference in autonomy among neuroscience nurses across Europe. In some countries, clinical decision making may only be limited to physicians, instead of based on interdisciplinary collaboration. Further education and positioning of neuroscience nurses may change this in the future.

Our results confirm that consciousness assessment by nurses may be considerably improved with formal and uniform training. Even though most participants using standardized instruments were formally trained to do so, teaching methods were very diverse and possibly difficult to implement in the same way across Europe. Bedside teaching may be feasible in well-organized and well-staffed clinical settings, but it is reliant on several factors such as the prevalence of patients with disorders of consciousness, workload, colleagues' teaching skills, etc. From the findings in this study it is also concluded that a more systematic approach is needed, such as classroom teaching or e-learning, which may be beneficial in addition to bedside training.

Limitations

Limitations in this study are related to the logistics of an international questionnaire. The study was dependent on the network of the EANN board members, quality of translations and purely digital communication, and it was found difficult to obtain equal groups in the different participating countries. Selection bias cannot be completely avoided in online surveys, as the participants might be more (technologically) skilled or educated than those not to participate. Another limitation is the lack of qualitative input from the participants, besides the multiple-choice questions. Because of several languages involved, it was not possible to insert open-ended questions for further analysis.

Conclusion

In conclusion, our study shows that consciousness assessment is part of the daily routine for most nurses working in neurology/neurosurgery/neurorehabilitation wards in Europe. The majority uses a standardized instrument, in particular the Glasgow Coma Scale. The greatest variation existed in training methods for the use of the instruments and we recommend standardized practice in the use of assessment scales.

Future research

Future research should focus on developing new, or implementing existing instructions or training material and recognition of neuroscience nurses across Europe as specialists in assessment of consciousness.

Relevance to clinical practice

This study shows that a frequent and clinically relevant task for nurses has been implemented across Europe, but in different ways and to different extents. Consciousness assessment is an important step in diagnoses and treatment of patients with brain injury. As the mortality rate of these patients drop, adequate diagnosis of consciousness level will prove to be more and more important in the future of neuroscience care. Therefore, both managers and staff nurses should focus on

formalized training in the use of assessment tools, to ensure reliability and reproducibility. This may also increase the professionalism in the neuroscience nurses' role and performance.

What does this paper contribute to the wider global clinical community?

• Insight on how well-known and internationally implemented nursing tasks may vary across countries.

• An example for the need of international standards in education or training for clinically relevant nursing assessment tasks.

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Figure 1 Flowchart of analysis, based on the participants' responses

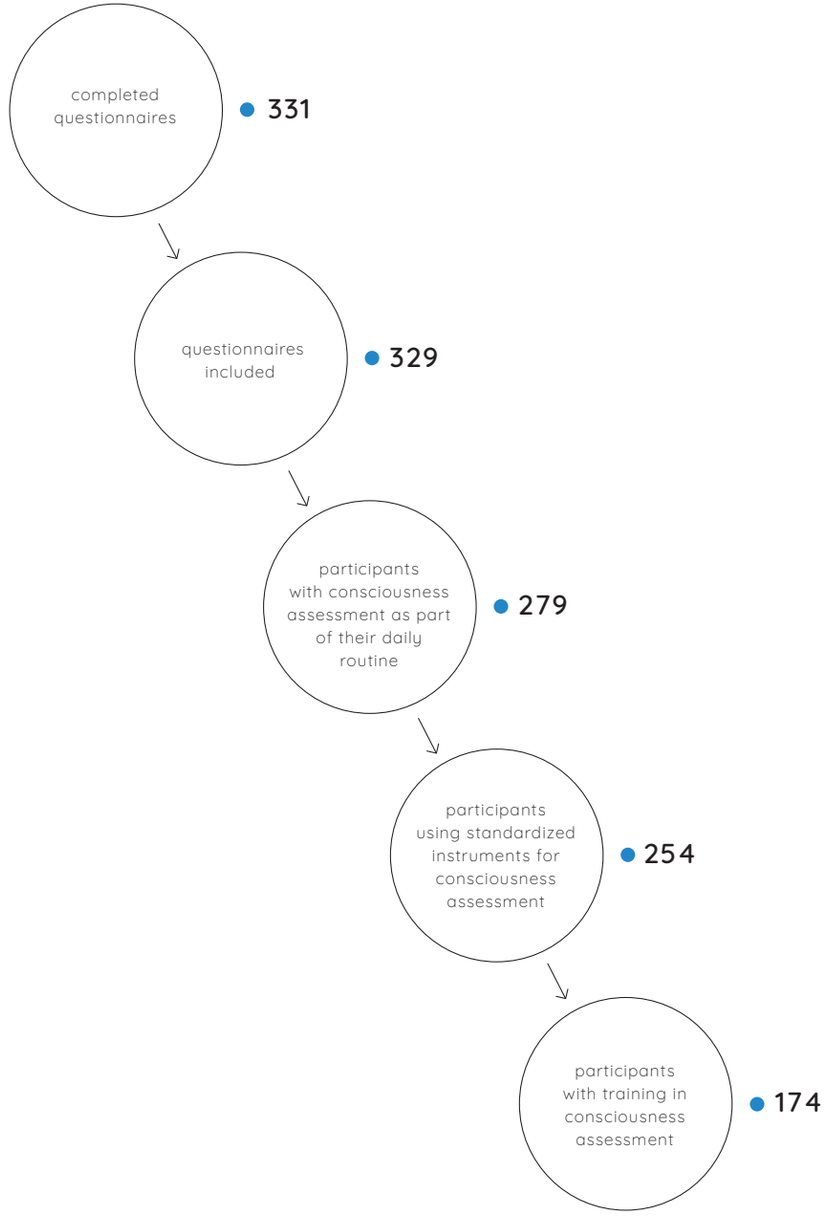

Table 1

Participant characteristics

	N	Age in years *mean (SD)* or *median [range]*	Educational Level *n (%)*				Female / Male *n*	Years of experience as a nurse *mean (SD)* or *median [range]*	Specialized neuroscience nurse *n (%)*	Work Setting *n (%)*		
			Bachelor Degree	Master Degree	Doctoral Degree	Other				University Hospittal	General Hospital	Rehabilitation Centre
Austria	4	30.8 (3.8)	0 (0%)	1 (25%)	**3 (75%)**	0 (0%)	3 / 1	9.8 (3.7)	2 (33%)	**4 (100%)**	0 (0%)	0 (0%)
Belgium	45	49 [25-58]	**30 (67%)**	2 (4%)	8 (18%)	5 (11%)	37 / 8	18 [1-37]	30 (64%)	10 (22%)	**35 (78%)**	0 (0%)
Denmark	26	42.1 (1.9)	**14 (54%)**	1 (4%)	9 (35%)	2 (8%)	25 / 1	13.5 (1.8)	22 (47%)	**18 (69%)**	3 (12%)	5 (19%)
Finland	16	39.1 (2.3)	**9 (56%)**	1 (6%)	4 (25%)	2 (13%)	16 / 0	11.4 (2.1)	2 (11%)	**16 (100%)**	0 (0%)	0 (0%)
Italy	35	37.2 (1.6)	3 (9%)	**21 (60%)**	8 (23%)	3 (9%)	27 / 8	13.9 (1.7)	0 (0%)	15 (43%)	**20 (57%)**	0 (0%)
Macedonia	5	45.6 (1.5)	**5 (100%)**	0 (0%)	0 (0%)	0 (0%)	5 / 0	19.2 (3.4)	4 (80%)	**4 (80%)**	1 (20%)	0 (0%)
Malta	7	34.3 (2.4)	1 (14%)	0 (0%)	2 (29%)	**4 (57%)**	6 / 1	11.3 (3.0)	0 (0%)	0 (0%)	**7 (100%)**	0 (0%)
Netherlands	42	38.7 (1.7)	**19 (45%)**	2 (5%)	7 (17%)	14 (33%)	34 / 8	14.6 (1.6)	32 (73%)	11 (26%)	**31 (74%)**	0 (0%)
Sweden	18	41.3 (2.7)	**13 (72%)**	1 (6%)	2 (11%)	2 (11%)	16 / 2	10 [1-39]	2 (10%)	**12 (67%)**	6 (33%)	0 (0%)
Turkey	14	33.2 (2.0)	**9 (64%)**	2 (14%)	3 (21%)	0 (0%)	13 / 1	11.8 (2.3)	5 (31%)	**11 (79%)**	3 (21%)	0 (0%)
United Kingdom	67	41.1 (1.2)	**29 (43%)**	10 (15%)	11 (16%)	17 (25%)	59 / 8	15 [1-40]	66 (80%)	30 (45%)	**36 (54%)**	1 (1%)
Total	279	40 [21-67]	132 (47%)	41 (15%)	57 (20%)	49 (18%)	241 / 38	15 [2-29]	167 (50%)	131 (47%)	142 (51%)	6 (2%)

Note: Numbers in **bold** are the largest group (modus)

Table 2

Estimated frequency of consciousness assessment per shift.

Country	Consciousness assessment per shift. Median [range]
Austria	6.5 [6-15]
Belgium	4 [1-25]
Denmark	4 [1-20]
Finland	4 [1-20]
Italy	10 [2-100]
Macedonia	6 [1-10]
Malta	10 [5-20]
Netherlands	8 [0-60]
Sweden	2.5 [1-20]
Turkey	6 [1-24]
United Kingdom	12 [1-60]
Total	**6 [1-100]**

Table 2

Use and knowledge of consciousness assessment tools.

Instrument	Used by (n, %)	Known of its existence (n, %)
Glasgow Coma Scale	237 (84.9%)	243 (87.1%)
Reaction Level Scale 85	4 (1.4%)	7 (2.5%)
Coma Recovery Scale - Revised	3 (1.1%)	37 (13.3%)
Modified Glasgow Coma Scale	2 (0.7%)	2 (0.7%)
Moscow Coma Scale	2 (0.7%)	14 (5.0%)
NIH Stroke Scale	1 (0.4%)	1 (0.4%)
Alert Voice Pain Unresponsive (AVPU)	1 (0.4%)	9 (3.2%)
Scandinavian Stroke Scale	1 (0.4%)	2 (0.7%)
Full Outline of Unresponsiveness (FOUR)	0 (0.0%)	27 (9.7%)
Jouvet Coma Scale	0 (0.0%)	6 (2.2%)
Bozza-Murribini Scale	0 (0.0%)	3 (1.1%)
Don't know the name	3 (1.1%)	NA
No Instrument used	25 (9.0%)	NA
Total	**279 (100%)**	

NA = not applicable

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CHAPTER 6

How incremental video-training did not guarantee implementation due to fluctuating population prevalence

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Author contribution

PV planned the study, provided the training, collected the data and submitted the study. PV and BT planned and performed the analysis. CL, MWH, INS and HV contributed to the planning and analysis of the study. All authors contributed to the paper.

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Abstract

Stroke patients admitted at the Neurology/ Neurosurgery ward of the Academic Medical Centre in Amsterdam, The Netherlands, may experience problems in communication, such as aphasia, severe confusion/delirium or severe language barriers. This may prevent self-reported pain assessment, therefore pain behaviour observation scales are needed. In this project we therefore aimed to implement the Rotterdam Elderly Pain Observation Scale (REPOS) by video training.

We used a stepped-wedge cluster design with clusters of four to five nurses with intervals of two weeks, for a total study duration of 34 weeks. Primary endpoint was the proportion of shifts in which nurses used the REPOS when caring for an eligible patient. A questionnaire was sent biweekly to assess self-perceived competence and attitude on pain measurement in patients able or unable to self-report pain-intensity. No other strategies were used to promote the use of the REPOS.

Though the proportion of shifts in which trained nurses cared for eligible patients increased from 0% at baseline to 83% at the end of the study, the proportion of cumulative shifts where the REPOS was used decreased from 14% to 6% respectively. Process evaluation suggests that this decrease can (in part) be attributed to low and varying prevalence of eligible patients and opportunities for practice. In total 24 (45.3%) nurses had used the REPOS at least once after 34 weeks, with a median of two times (1-33). Nurses perceived themselves 'competent' to 'very competent' in pain behaviour observation. There was no negative attitude towards pain measurement.

This study shows that education alone may not be effective when implementing a pain behaviour observation scale for non-communicative patients with Acquired Brain Injury. Individual motivation of health professionals and individual patient factors may be of influence for the use of the REPOS.

Introduction

Problem

Even in modern medicine, stroke has a severe impact on patients all over the world. While mortality rate is dropping and both primary prevention and acute treatment have improved, it is estimated that from 2025, Europe will count 1.5 million new stroke patients per year due to the aging population. (Bejot, Bailly, Durier, & Giroud, 2016; Wilkins E, 2017) Among the many different effects and complications of stroke, there are some that prevent adequate communication, such as severe aphasia, confusion and delirium.

Aphasia is present in about one third of all acute stroke patients in varying forms and severity. (Kauhanen et al., 2000; Laska, Hellblom, Murray, Kahan, & Von Arbin, 2001; Pedersen, Jorgensen, Nakayama, Raaschou, & Olsen, 1995) Though evidence on the prevalence of severe confusion is not available, the prevalence of a formally diagnosed delirium lies around 10%. (Dahl, Ronning, & Thommessen, 2010; Nydahl et al., 2017) With about 41,300 stroke patients per year in the Netherlands, this would annually mean 13,800 patients with aphasia and 4,130 patients with delirium during the acute phase of stroke. (Buddeke J, 2016)

Besides these effects originated by the stroke itself, the Academic Medical Centre (AMC) in Amsterdam, The Netherlands, often comes across patients unable to speak Dutch. Amsterdam hosts many multi-lingual people of different backgrounds. There are about 180 different ethnicities in the city and at least 35% of the population has a non-Western migration background. (Amsterdam, 2017) It is therefore not uncommon that patients are admitted with severe language barriers for nurses who are mainly Dutch native speaking.

At the neurology/neurosurgery nursing ward of the AMC, the 'AMC Neurocentre', patients are often admitted with one or more of the above-mentioned communication disorders. This may interfere with common nursing practices or communication, in particular the measurement of pain-intensity. Addressing pain is considered as being fundamental or basic nursing care and essential for delivering high care quality. (Feo, Kitson, & Conroy, 2018) The nurses of the 'AMC Neurocentre' therefore asked for (video) training to provide the skills and knowledge that is needed for pain behaviour observation. The team consists of approximately 55 nurses with different levels of education (Associate and Bachelor degree) and experience in neuroscience nursing.

Available Knowledge

According to international guidelines, self-reported pain instruments are considered the best possible method. Commonly used instruments are the Numerical Rating Scale (NRS), Visual Analogue Scale (VAS), Wong-Baker Faces Pain Scale-Revised (FPS-R) and the Verbal Rating Scale (VRS). (Schug, Palmer, Scott, Halliwell, & Trinca, 2016; Wells, Pasero, & McCaffery, 2008) In some cases of stroke patients with one or more of above-mentioned communication problems, none of these instruments work sufficiently well and nurses must rely on pain behaviour observation scales to adequately assess (potential) pain.

The Rotterdam Elderly Pain Observation Scale (REPOS) has been developed in 2009 for older patients incapable of reporting pain themselves. It is a Dutch scale with ten behaviours that may indicate the presence of pain. (van Herk, 2009) As stroke patients and specifically patients with aphasia or delirium tend to be older, this scale seems appropriate for the use in acute stroke care. (Ellis & Urban, 2016; Nydahl et al., 2017; Vink, 2012)

Rationale

Though single-component (educational) implementation strategies are generally considered less effective, there is also no compelling evidence that multi-faceted strategies are more effective in changing health-care professionals behaviour. (Harvey & Kitson, 2015; Lynch, Cadilhac, Luker, & Hillier, 2016; Squires, Sullivan, Eccles, Worswick, & Grimshaw, 2014) Training with patient videos (focussed both on knowledge and skills) has proven to be effective for implementation of pain behaviour observation scales. (Gelinas, Arbour, Michaud, Vaillant, & Desjardins, 2011)

Training the entire Neurocentre nursing team at once is costly, logistically complicated and may not provide a sustainable solution that withstands regular changes within the team. We therefore chose a more gradual educational strategy by using a stepped-wedge cluster design with parts of the nursing team as clusters. We hypothesize that the risk of contamination from this design will cause the number of nurses using the REPOS to increase faster than the number of nurses receiving training and may be used as a potential method of implementation itself. (Mdege, Man, Taylor Nee Brown, & Torgerson, 2011)

Aims

In this evidence based quality improvement study we aim to evaluate (a) if an educational strategy can increase the use of the REPOS in patients with severe aphasia, confusion or language barriers, and (b) if the risk of contamination from a stepped-wedge cluster design within a nursing team has an effect on the speed of implementation.

We consider the implementation successful if at the end of the study...

- ....the REPOS is used in ≥85% of the shifts in which nurses care for eligible patients
- ...pain assessment is compliant (≥1 REPOS measurement per 12 hours) in ≥85% of patient days.

Methods

Context

The 'AMC Neurocentre' is part of a tertiary care setting with regional responsibilities. It provides specialized care in cerebrovascular diseases such as intra-arterial trombectomy and coiling of intracranial aneurysms. It operates 20 regular nursing beds and nine beds on the Brain Care Unit, a Stroke Unit for acute cerebrovascular care. A multidisciplinary team is available, consisting of neurologists, neurosurgeons, nurses, nursing aids, physiotherapists, occupational therapists and speech therapists. In 2017 the unit had 129 admissions per month on average, of which 108 (83%) had a length of stay longer than 24 hours. The average length of stay was 7.2 days.

Participants

The participants of this study were registered nurses working at the 'AMC Neurocentre', with either an Associate (or similar) or Bachelor degree in nursing. Nurses who were not involved in nursing care activities, for example due to illness, or who had a temporary contract (<two months) were not included in the study.

Target(s)

Recommendation

The instrument to be implemented is the Rotterdam Elderly Pain Observation Scale (REPOS), a pain behaviour observation tool developed for elderly patients unable to use self-reported pain instruments. (van Herk, 2009) As of February 2017, pain behaviour observation is part of the local hospital protocol and the REPOS is indicated for patients admitted to general nursing wards who are unable to self-report pain intensity, though still able to make verbal or non-verbal contact with health professionals. A flowchart is part of the local hospital protocol to help nurses decide on the use of pain behaviour observation tools.

The REPOS consists of ten behavioural items that are associated with the presence of pain, each worth one point. The nurse observes the patient for a minimum of two minutes, at least twice a day, once during ambulation or nursing care activities and once during rest. If the REPOS shows a score of two or higher the nurse will assess possible causes for the observed behaviour and provide a second pain-score that reflects their clinical judgement. This is a NRS score where zero indicates that the nurse assumes there is no pain present that causes the behaviour

and ten indicates that the nurse assumes the worst imaginable pain is present. A list of other possible causes of the observed behaviour (hunger, full bladder, fear) aids the nurse in choosing an appropriate NRS. The REPOS is documented in the electronic patient file and evaluated daily during rounds with the physicians.
The aim of pain behaviour observation with the REPOS is to provide insight in pain intensity for non-communicative patients and eventually more adequate pain treatment. As the treatment of pain is dependent on adequate pain assessment, this study focusses on the implementation of the REPOS and not the treatment of pain itself.

Intervention

Educational Strategy

The initiative for video-training was based on desires of the nursing team to be classically trained and approved by the staff advisor on Education prior to the start of the study. Every two weeks clusters of four to five nurses received a standardized training for 45 minutes at two consecutive days, with a total of 14 clusters. Nurses were allocated to a cluster based on the planned working schedule for each time period. Cluster were therefore random at first, but as the study progressed the untrained nurses would deliberately be scheduled to work on days of the video training.
The video training started with a short introductory presentation, explaining the aim of pain behaviour observation, the content of the local hospital protocol and how to use and document the REPOS. An online training module with 12 practice videos of real patients, developed by the designers of the REPOS, was then used to familiarise the nurses with the scale. (Centre) During training, each of the four to five nurses observed each video and assessed pain behaviour with the REPOS individually, after which an inter-rater agreement (Fleiss' kappa, fixed marginal) was calculated for the cluster. (Randolph, 2008) If there was less then substantial agreement ($\kappa \leq 0.60$), observation differences were discussed and the video was repeated until agreement was substantial or higher. Videos were always alternated with a video of a different patient before repeating, to avoid repetition learning. Training was provided by the same trainer (PV), who used a checklist to ensure each cluster received the same tips on the use and documentation of the REPOS. For more information about the training and responses, see the process evaluation in the results section.

Motivational Strategy

No motivational strategy was used to promote the use of the REPOS. Every two weeks however, alternating the training periods, a questionnaire was send as part of the study. This may be considered as a repeated reminder.

Measures

Data were obtained from patient data files by the first author as part of a regular quality evaluation (PV). Besides the indication for pain behaviour observation no patient characteristics were collected.

Primary Outcomes

The primary outcomes reflect behaviour of nurses, as this best reflects actual implementation.

- Proportion of shifts in which nurses used the REPOS when caring for an eligible patient.
- Proportion of patient days at which pain assessment was compliant to local hospital protocol (≥1 REPOS measurement per 12 hours)

Secondary Outcomes

Secondary outcomes were (a) the self-perceived competence in pain behaviour observation of patients able and unable to self-report pain and (b) the attitude towards pain measurement. The self-perceived competence was measured with a 4-point Likert scale, where a higher score meant the nurse felt more competent (very incompetent, incompetent, competent, very competent).

- Recognizing pain in patients that can communicate well.
- Measuring pain intensity in patients that can communicate well.
- Recognizing pain in patients that can't communicate well or are (severely) confused.
- Measuring pain intensity in patients that can't communicate well are (severely) confused.

Attitude was measured with an adaption of the Negative Pain Belief Scale (NPBS) by Shugarman et. al (2010), consisting of four questions

with a 5-point Likert scale. (Shugarman et al., 2010)
A higher cumulative score meant a more negative attitude towards pain measurement. See **APPENDIX 1** for more information.

Data for secondary outcomes were collected with a questionnaire that was send every two weeks by email. To promote completion of the survey a reward, in form of a gift card worth five to 25 euro, was allotted among every 10 completed questionnaires and reminders were send out daily for one week.

Process Evaluation

To assess mechanism(s) through which the implementation strategy (gradual video-training) may or may not work, the following data were collected for process evaluation.

- Percentage of trained nurses (absolute numbers and full-time equivalent).
- Proportion of shifts during which trained nurses cared for eligible patients.
- Number of trainings completed, including video's shown and repeated.
- Experienced workload as a barrier in pain assessment.
- Nursing views on their influence on pain treatment.
- Process data are used for a side by side analysis of the primary outcome.

Verbal responses of the participants were gathered by the trainer (PV) both during and after training to provide qualitative insights to abovementioned data. At the end of the second day of training, nurses were asked in open-ended question how they experienced the video training.

Statistical Analysis

For analyses we used descriptive statistics and inferential statistics. All data were first tested for normality by a Kolmogorov-Smirnov test, a Q-Q plot and Levene's test.
Categorical variables were expressed as n (%). Continuous normally distributed variables were expressed by their mean and standard deviation, not normally distributed data by their median and minimum and maximum range for skewed distributions. To test groups, categorical variables were tested using the Pearson's Chi-square test or Fisher's exact test, when appropriate. Normally distributed continuous data were tested with the independent samples Students t-test and in case of skewed data, with the independent samples Mann-Whitney U-test. Data were analysed with R Statistics (Version 1.0.153) and SPSS (version 24.0, SPSS inc., Chicago, USA).

Sample Size Calculation

Methods of Hussey and Hughes (2007) were used for power calculation for the main outcomes, with 16 time periods and 13 clusters with at least one observation per time period. With an alpha of 0.05, a power of ≥0.8 can be obtained for increase in proportions from 0% to ≥15% or 15% to ≥42%. (Hussey & Hughes, 2007)

Ethical Considerations

The research protocol was approved by the medical ethical committee of the AMC Hospital on January 6, 2017. Data were collected for routine quality control by PV in the role of staff advisor on quality and patient safety. Other than the indication for pain behaviour observation and the duration of communication disorders, no individual patient data was collected.

Results

The study was conducted in 2017 from February 27th to September 29th. A total of 835 individual patient files were evaluated for patients eligible for pain measurement with the REPOS. This resulted in the inclusion of 88 patient files (639 patient days) for analysis of our primary endpoint. The frequencies of indications for the use of the REPOS, are shown in **TABLE 1**. For reporting the Standards for Quality Improvement Reporting Excellence (SQUIRE) 2.0 was used. (Ogrinc et al., 2016)

During the study period 68 nurses were employed at the Neurocentre, of which 62 were included in the study. Most nurses (51,4%) had an

Associate degree (or similar) and 52.9% had less than 5 years of experience in neuroscience nursing. Further characteristics are shown in **TABLE 2**. A total of 50 nurses received the training, resulting in 90% of the employed nurses being trained at the end of the study.

Nurse Behaviour

The proportion of shifts in which trained nurses cared for eligible patients increased significantly from 0% at start of the study to 83% at the end of the study (p-value <0.001). The REPOS was documented 138 times for 36 (41%) eligible patients, of which 48 (35%) were measured by trained nurses. The proportion of nurses that at some point during the study period used the REPOS at least once for eligible patients increased gradually from four (7,4%) to 24 (45.3%) at the end of the study (p-value <0.001), with a median of two times (1-33). Four nurses were responsible for 62% of all REPOS measurements and 51% of all REPOS measurements were performed in 8% (n=7) of all eligible patients.

In total, there were 96 nursing shifts (5,8%) with at least one REPOS measurement. Overall, the proportion of cumulative shifts in which the REPOS was used (when required) decreased from 14% at baseline to 6% at the end of the study (p-value <0.01). The OR of cumulative shifts with versus without a REPOS measurement compared to baseline increased during time period 1 through 6, but declined again after that. (**TABLE 3**) These changes in OR were statistically significant different from baseline for each time period,, with the exception of T6 (10-12 weeks). Further analysis of these results are shown in the process evaluation.

Secondary Outcomes

On average, the questionnaire was completed by 55% of the employed nurses per time period of two weeks. The completion rate decreased over the duration of the study from 76% to 39% (p-value <0.001).

Self-perceived competence

At the start of the study 97% of the nurses that completed the questionnaire considered themselves 'competent' to 'very competent' in recognizing and measuring pain in patients who are able to communicate adequately. This increased to 100% at the end of our study. For patients that require pain behaviour observation, 86% of the nurses considered themselves 'competent' to 'very competent' at the start of the study, which increased to 93%.

Attitude

During the study there was one measurement of one nurse (0.3%) with a negative attitude towards pain measurement (NPBS > 12). All other time periods there was no negative attitude among nurses. The NPBS did not change significantly during the study.

Process Evaluation

Training

All trainings were held at the end of the day shift and were held on two consecutive days, except for cluster 10 in which training days were one day apart. Nurses were interested in the training and eager to learn about the REPOS, often asking the trainer when they would be scheduled for training. Some clearly stated they were waiting for the training before they would use the REPOS. Reactions to the training were generally positive. Frequently mentioned quotes during the debriefing of the video training were:

- 'The REPOS is not complicated, but it requires some practice.'
- 'I am able to use the REPOS right away.'
- 'The videos are good for practice, because we can rewind and pause the behaviour.'
- 'It is difficult to rely on something (i.e. pain behaviour observation) that is so subjective.'
- 'I find it hard to determine when I should use the REPOS'

Participants found the nuances in word choice (i.e. pain behaviour) the most difficult and much of the discussions during training were on the interpretation of the pain behaviours as described by the original designers of the scale. This was an important aspect of the training though, as it contributed to good inter-rater agreement.

Planning of biweekly training based on existing working schedules proved logistically complex. As more nurses were trained it became more difficult to find two days were untrained nurses would be present.

It also proved difficult to start the training on time, as it was planned at the end of the day shift. The training had a median duration of 85 minutes (85-90) per training, during which a median of 14 videos (10-15) were observed. Videos were played one to three times (median 1) before a substantial interrater agreement (kappa ≥0.67) was achieved.

Exposure to eligible patients

During the study all nurses cared at least one shift for eligible patients, with a median of 27 shifts (1-57). The chance of exposure to an eligible patient fluctuated due to varying prevalence and started to decrease drastically after T7. In the first three time periods an average of 166 REPOS measurements were required, while in the last three time periods an average of 33 REPOS measurements were required. In time period 14 (18-22 weeks) only 8 REPOS measurements were required. This decrease in chance for practical application of acquired skills and knowledge may (in part) have attributed to decline of the use of the REPOS. The number of required and performed REPOS measurements, both cumulative and per time period, are shown in **FIGURE 1**.

Other

From the 361 responses to the questionnaire the participants agreed or strongly agreed 300 (83.1%) times with the statement 'my colleagues find pain assessment an important part of the nursing profession'. In 94 responses (17.7%) the participants agreed or strongly agreed with the statement 'I am unable to measure pain in patients who can't communicate well or are severely confused due to lack of time or increased workload'. In 87 (24.1%) of the responses they were neutral on this statement and in 180 (49.9%) they disagreed or strongly disagreed. For the statement 'nurses have no influence on the treatment of pain', nurses disagreed in 349 (96.7%) of their responses.

Discussion

In this evidence based quality improvement study we aimed to evaluate an educational implementation strategy to implement a pain behaviour observation scale. For this purpose we used a stepped-wedge cluster design within one nursing team, expecting the risk of contamination to be of positive influence on the speed of implementation. Despite a consistently executed video training, where interrater agreement was obtained within clusters, our aims for implementation were not achieved. Though there was a significant increase in the proportion of trained nurses that cared for patients that required pain behaviour observation with the REPOS, the actual use, which is equivalent to behaviour in our view, decreased during the study period.

We chose this single-component implementation strategy because our nurses explicitly asked for education, which is quite common among healthcare professionals when there is a need to change practice or implement scientific innovations. Though we are aware of the positive impact of motivational strategies, we deliberately wanted to evaluate the effect of education alone and to determine whether we should acknowledge healthcare professionals' wishes for educational strategies in future implementation projects.

The process data in this study provides insight in mechanisms that may have prevented nurses from using the REPOS more frequently. The results of the NPBS show for example that there wasn't a negative attitude towards pain measurement in general and pain behaviour observation in particular. The questionnaire results show that lack of time or increased workload was not a barrier for pain measurement or behavioural pain observation. This is in accordance with studies on 'care left undone' during nursing shifts, which show that pain management and treatment are least likely to be reported as missed. (Ausserhofer et al., 2014; Ball, Murrells, Rafferty, Morrow, & Griffiths, 2014)

Data on the provided training show that limited repetition of videos (max 3 times) was needed to acquire a substantial agreement among the nurses. This indicates that the videos were suited for acquiring basic skills to use the REPOS for pain behaviour observation. In order to maintain and improve these skills, it seems that practicing with actual patients is important. In at least six time periods, both the number of individual patients and the number of required REPOS measurements was very low, down to 4 required REPOS measurements per week in time period 14. During the study, the chance for nurses to be exposed to eligible patients decreased and as such the chance of nurses practicing their acquired skills decreased as well. After video training

the nurses were eager to practice, but for some nurses several weeks passed before they got the first opportunity to use the REPOS.

It is noticeable that most REPOS measurements were performed by the same group of nurses. These nurses used the REPOS before training and continued to do so after training. This may indicate that individual motivation is more important than mere training.
The qualitative insights gathered during and after training also indicates that nurses find it hard to indicate when a patient requires a REPOS measurement instead of other instruments. This is also reflected by the fact that more than half of the REPOS measurements were performed in only 8% of the eligible patients. This suggests that once a nurse starts using the REPOS others may follow, but if nobody starts using it the patient receives no form of pain assessment.

Limitations of the study

The choice for a stepped-wedge cluster design within a single nursing team, whereby multiple measurements were done by the same nurses, has shown some limitations in this study. Due to the decrease in the actual use of the REPOS, formal analysis using a generalized mixed model or generalized estimation equation was not possible. Therefore, we analysed between and within baseline and every time point towards an allowable statistical procedure. Another limitation of this study was that actual knowledge and skills, obtained at the end of training, was not consistently measured. We are therefore unable to prove that the training itself guaranteed the skills and knowledge needed in daily nursing care. In future studies a standardized test reflecting learning points of the training should be incorporated in the measurements. The feedback at the end of the training was generally positive, but this may have been due to interviewer bias as the evaluation was done by the trainer himself. In future similar quality improvement studies we suggest to perform a barrier and facilitator analysis to determine both required training forms and skills measurement.

Conclusion

This study shows that education alone may not be effective when implementing an evidence based quality improvement. Pain behaviour observation for non-communicative patients with Acquired Brain Injury may be more complicated than merely providing knowledge and (simulated) practice. Future implementation projects or research should include an extensive assessment of potential barriers (prevalence, chance of exposure) and facilitators in order to adequately select a motivational strategy alongside education.

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Appendix 1

The adaption of the Negative Pain Belief Score (NPBS, including typographical emphasis (**bold** and *italic*), as used in the questionnaire.

Patients **don't** report their pain accurately.

1. Strongly disagree
2. Disagree
3. Neutral
4. Agree
5. Strongly agree

Pain **can't** be measured by observing a patients behaviour.

1. Strongly disagree
2. Disagree
3. Neutral
4. Agree
5. Strongly agree

Patients who **don't** report pain *themselves* have no pain.

1. Strongly disagree
2. Disagree
3. Neutral
4. Agree
5. Strongly agree

Patients who **can't** report pain themselves have **no** pain.

1. Strongly disagree
2. Disagree
3. Neutral
4. Agree
5. Strongly agree

Table 1

Frequencies of indications for the use of the REPOS.

Patients unable to self-report pain intensity (total)	**88 (100%)**
due to aphasia	41 (46.6%)
due to confusion/delirium	15 (17.0%)
due to language barrier	14 (15.9%)
due to a combination	18 (20.5%)
aphasia and confusion	*6 (6.8%)*
aphasia and language barrier	*6 (6.8%)*
confusion and language barrier	*5 (5.7%)*
aphasia, confusion and language barrier	*1 (1.1%)*
Duration of communication disorder (days)	**3.5 (1.0-35.0)**
REPOS measurements required (per patient)	**4 (1-35)**

Table 2

Nurse characteristics.

Nurses employed (per day, median, min-max)	55 (52-58)
Working contract (median hours per week, min-max)	32 (20-36)
Full time equivalent (median, min-max)	32.0 (31.4-32.2)
Number of shifts worked in care (median, min-max)	79 (4-129)
Years of experience in neuroscience nursing	
<1 year	16 (23.5%)
1-5 years	20 (29.4%)
5-10 years	10 (14.7%)
>10 years	22 (32.4%)
Level of education	
Associate degree (or similar)	35 (51.4%)
Bachelor degree	32 (45.6%)
Master degree	1 (1,4%)

Table 3

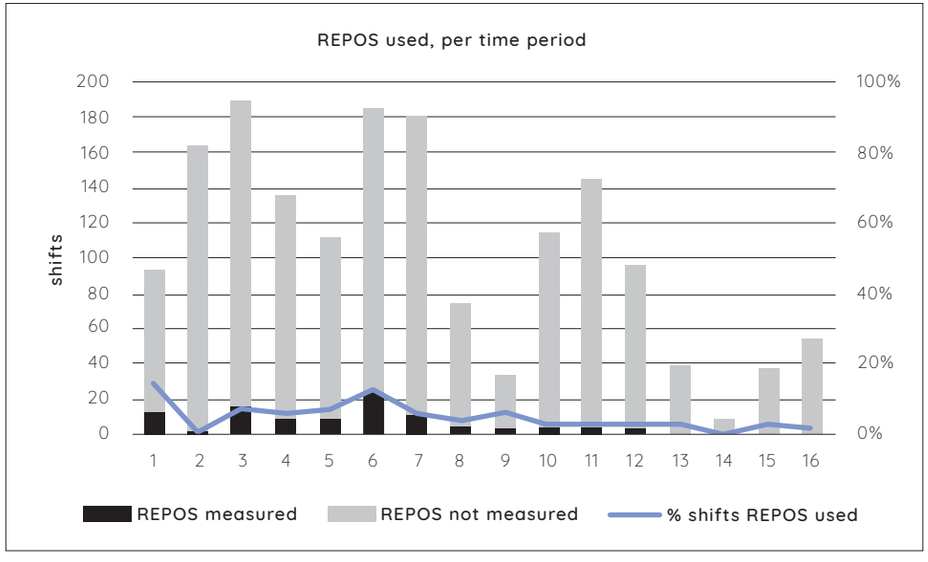
Proportion of shifts with and without REPOS measurements and Odds Ratio (OR) when compared to baseline.

Time period	Cumulative shifts with REPOS	Cumulative s hifts without REPOS	OR (95% CI) when compared to baseline	p-value
1	13	80	-	-
2	14	243	0.36 (0.15-0.86)	0.012*
3	28	419	0.41 (0.19-0.90)	0.017*
4	36	547	0.41 (0.20-0.87)	0.015*
5	44	651	0.41 (0.21-0.88)	0.016*
6	67	814	0.51 (0.26-1.04)	0.044*
7	78	984	0.49 (0.25-1.00)	0.041*
8	81	1056	0.47 (0.24-0.97)	0.024*
9	83	1087	0.47 (0.24-0.96)	0.024*
10	86	1199	0.44 (0.23-0.90)	0.019*
11	90	1340	0.41 (0.21-0.84)	0.009**
12	93	1433	0.40 (0.21-0.81)	0.007**
13	94	1471	0.39 (0.20-0.80)	0.007**
14	94	1479	0.39 (0.21-0.80)	0.007**
15	95	1516	0.39 (0.20-0.78)	0.006**
16	96	1569	0.38 (0.20-0.76)	0.006**

* = p-value <0.05, ** = p-value <0.01

Figure 1

Required number of REPOS measurements per time period.



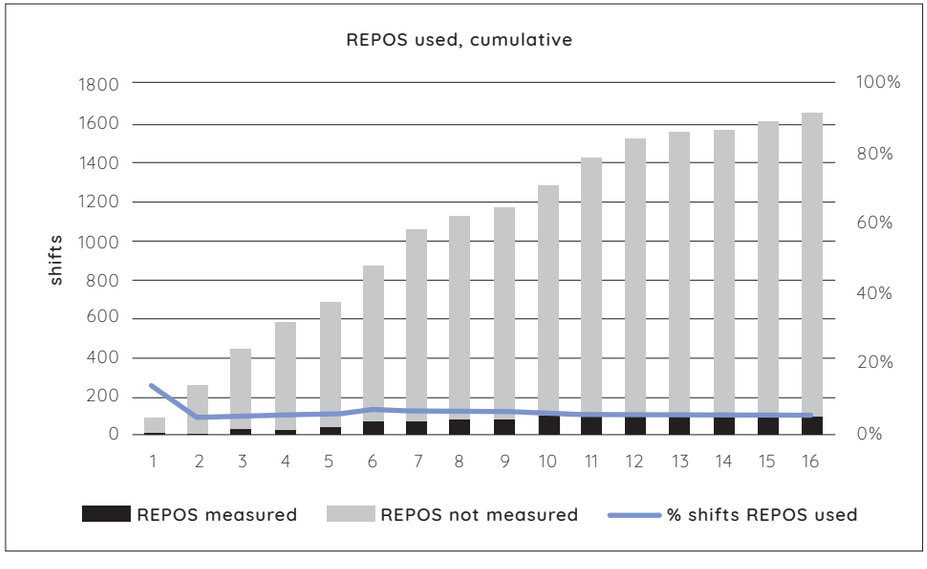


Figure 1 Legends:
Black (part of) column: REPOS measured
Grey (part of) column: REPOS not measured
Line: percentage of shifts where REPOS was used (when required)

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CHAPTER 7

Implementation of the Nociception Coma Scale for hospital patients with disorders of consciousness

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Abstract

AIM

Testing the effectiveness of multifaceted strategies to implement the Nociception Coma Scale (NCS) for patients with Disorders of Consciousness (DOC) in three hospitals (The Netherlands and Belgium).

DESIGN

A before-after-after study design was used. Primary outcomes were adherence, knowledge and (self-perceived) competence.

METHODS

The NCS and guidelines were integrated in patient files and local hospital protocols of all settings. Educational strategies were video training (e-learning and group lessons) and bedside teaching. Performance feedback was used in one hospital.

RESULTS

The proportion of patient days with ≥1 NCS documentations increased from 4% at baseline to 65% three months after implementation (T1). This remained relatively stable (60%) at nine months after implementation (T2). The proportion of patient days with ≥2 NCS documentations (full adherence) increased from 0% at baseline to 31% at T2. A statistically significant increase was found in knowledge and self-perceived competence in measuring pain in DOC patients.

Introduction

Problem description

Acquired Brain Injury (ABI) may result in disorders of consciousness (DOC), either briefly (coma) or prolonged (minimally conscious state or unresponsive wakefulness syndrome). In the acute hospital phase about 12% of all stroke patients have a neurological deterioration of two or more points on the Glasgow Coma Scale. (Slavin, et al., 2018) By definition, a patient with DOS is unable to self-report any discomfort and pain and must therefore rely on health care professionals observing behaviour that may be indicative of such experiences.

Ensuring comfort, including pain management, is one of the essential and fundamental care activities nurses provide on a daily basis to ensure person-centred care. (Feo, Kitson, & Conroy, 2018) For DOC patients in particular, early recognition and monitoring of behaviour possibly indicative of pain or discomfort is challenging but also a vital aspect of nursing. To implement validated pain behaviour observation tools as daily practice acute settings, where prevalence of these patients varies, single-component implementation strategies have proven unsuccessful. (Vink, et al., 2019)

Available Knowledge

The Nociception Coma Scale (NCS) is a pain behaviour observation tool that has been developed for patients with DOC and has been tested in acute and long-term care settings. (Schnakers, et al., 2010) It consists of four items (motor response, verbal response, facial expression, visual response), each with four sub-items of behaviour, resulting in a score from zero to 12. Since the development in 2009 the validity of the scale has been assessed in several studies. A revised version (NCS-R) has been published in 2010, omitting the 'visual response' item that proved to be less reliable, and further validated. (Chatelle, Majerus, Whyte, Laureys, & Schnakers, 2012) (Vink, et al., 2017) A minimal instruction proved sufficient to ensure excellent average measures reliability among nurses, regardless of experience and educational levels. (Vink, Eskes, Lindeboom, Munckhof, & Vermeulen, 2014) Lastly, the NCS has proven responsive to pain treatment and appears relevant to clinical practice for early recognition and monitoring. (Chatelle, et al., 2016)

An extensive literature search for the NCS has been performed in a previous study by our group, resulting in both an overview of clinimetric properties as well as recommendations for clinical practice. (Vink, et al., 2017) These recommendations have been translated into a local hospital protocol and reviewed on clarity, feasibility, compatibility and effort by both policy-makers and change champions (nurses). The resulting recommendation has also been reviewed by WSvE as a DOC-expert.

Implementation of these recommendations requires the bridging of evidence-based medicine and clinical quality improvement (QI), so called Evidence Based Quality Improvement. (Glasziou, Ogrinc, & Goodman, 2011) For adequate dissemination, an analysis of potential barriers is required and a multi-faceted implementation strategy should be considered to promote change in daily clinical practice of health care professionals. (Shojania & Grimshaw, 2005) The 'Checklist for identifying determinants of practice' by Flottorp et al. (2013) was used to structure and prioritise barriers using different techniques of qualitative research, which is further explained in **APPENDIX A**. (Flottorp, et al., 2013) As the success or failure of implementation may be caused by circumstances and background factors, a process evaluation should be conducted to provide additional insight. (Grol, Eccles, & Davis, 2013) (Grimshaw, et al., 2006) (Shojania & Grimshaw, 2005)

Methods

Study Design

We used a before-after-after study design for an evidence-based quality improvement project, with one measurement period before implementation and two measurements after implementation. The total study duration was thirteen months, lasting from September 2017 through October 2018. The intervention took place from December 2017 through February 2018, resulting in a measurement period of three months before (T0), three months directly after the intervention (T1) and three months at the end of the study (T2).

Context

The study was conducted at the neurology and/or neurosurgery wards of the Academic Medical Center (AMC) in the Netherlands and the Antwerp University Hospital (UZA) and General Hospital Nikolaas (AZN) in Belgium. Researchers PV and KG both had prior working relations in the AMC and UZA/AZN respectively and were thereby familiar with settings, patients and teams. Setting characteristics are shown in **TABLE 1**.

Targets

Recommendation

Guidelines

The NCS is indicated for patients who are unable to self-report pain (intensity) due to DOC, as defined as a period where the GCS is equal to or less than:

- E4: eyes open spontaneously,
- M5: localization painful stimulus,
- V4: confused verbal response.

The NCS is *not* indicated for patients…

- … younger than 18 years,
- …admitted on an Intensive Care Unit,
- …who are sedated or intubated, or
- …showing signs of aphasia or severe confusion.

Recommended Clinical Intervention

1. Use the NCS at least twice a day, once when the patient is in rest (no tactile stimulus) and once when the patient is active (tactile stimulus), during or after potentially painful interventions (physiotherapy, wound care) or when a patient shows any signs of nociception.
2. Omit the visual response item if the patient is unable to show visual responses or visual responses are unclear or uncertain, thus using the NCS-R.
3. Add a Numerical Rating Scale to the NCS(-R) score which indicates whether you believe the observed behaviour reflects no pain (0) or the worst imaginable pain (10).

Recommended Behaviour

Contact the physician if:

- NCS(-R) score is higher than 1 and/or
- NCS(-R) score has increased with 2 or more points and/or ‘Pain score according to nurse’ is higher than 3.

Population

Nurses

Target population of this study consists of ±60 registered nurses working at the AMC NeuroCentre, ±16 at the neurosurgery ward of AZN and ±25 of the neurosurgery ward of UZA. Participant characteristics were obtained during baseline measurement and are presented in **TABLE 2**. All participating nursing wards offer internships to bachelor student nurses. Though they are not the primary target group, they will not be excluded from implementation strategies.

Aim(s)

In this study we set out to investigate the effectiveness of a tailored multi-faceted implementation strategy, based on a formal problem analysis, and provide insight in this process for evidence-based quality improvement. We hypothesize that nurses need more than just general knowledge and skills in order to use the NCS at least once a day in patients with DOC.

In this evidence based quality improvement project satisfactory implementation is defined with (primary) structure and process outcomes as follows:

1. In December 2018 the NCS(-R) is part of local hospital protocol and the (electronic) patient file.
2. In March 2018, >80% of the nurses has sufficient knowledge (test score ≥55%) of DOC and the NCS(-R).
3. The proportion of patient days with partial or full adherence (≥1 documented NCS) versus no adherence to the recommendation has significantly increased three months after the implementation compared to baseline and remains stable or increases further eight months after implementation.
4. The proportion of patient days with adherence (≥2 documented NCS documentations) versus no or partial adherence to the recommendation has significantly increased six months after the implementation period, compared to baseline.

Multi-faceted Intervention

A formal problem analysis was used to identify potential barriers and plan a mix of implementation strategies accordingly. For more information, see **APPENDIX A**: Problem Analysis and Determinants. An overview of the implementation strategies per participating nursing ward are presented in **TABLE 3**.

Educational Strategy

Online Learning Material

An online learning module of approximately one hour was developed, consisting of a theoretical video (8.5 minutes), also available as plain text, and two patient stories with a total of twelve short video's for NCS observation (30 seconds – 3 minutes). Videos were recorded with actors specialized in patient behaviours. The theoretical part and a knowledge test, which corresponded to the questionnaire measurements (see Measures), were mandatory to all nurses. They were provided an account and access to the module from December 1st 2017 and reminded on their progress until March 2018.

Group Learning Activities

Group lessons (approximately 45 minutes) were organized in December 2017 and January 2018. The videos were used, alongside demonstration of the NCS documentation in the electronic patient file. Participants were given the opportunity to ask in-depth questions on DOC, pain behaviour observation, the NCS and the use of the electronic patient file. Experiences and patient stories were exchanged and the trainer (PV) emphasized the benefits of the NCS.

Bedside Teaching

In January 2018 bedside teaching was offered for one month during the daily morning activities at the AMC Neurocenter. AM visited the AZN and KG visited UZA during weekends to offer bedside teaching. Nurses were asked to observe a patient unable to self-report pain with the NCS, after which the authors discussed the observations and aid with the documentation of the outcome in patient files. If there were no eligible patients present, AM and KV simulated this and encouraged the nurses to discuss the NCS.

Informational Strategy

Via e-mail all physicians and allied health care professionals at the AMC NeuroCentre and the neurosurgeons at UZA gained access to a short video (2.5 minutes), informing them on the NCS(-R), it's application and what they can/should expect from nurses. Allied health care professionals of the AMC NeuroCentre were invited to join the group learning activities and physicians were also informed personally during one of the regulatory staff meetings.

Motivational Strategy

Marketing

In December 2017 two posters were put up around the nursing wards to motivate the use of the NCS. The posters were changed after 2 weeks and conveyed a different message:

1. The use NCS is the first step towards adequate pain management for patients with DOC.
2. The NCS is not complete without the expertise of a nurse, therefor document the 'pain score according to nurse'.

Pocket cards with instructions on the NCS were distributed among nurses and nurse students.

Feedback & Reminders

In January performance feedback was provided to the team at the AMC NeuroCentre about NCS use and documentation. An overview of adherence was placed on locations of the unit each morning and the weekly (digital) newsletter provided a summary of the implementation progress. The performance feedback showed per patient if the appropriate instrument used in each shift and whether the patient had any pain.

Measures

Primary Outcomes

The primary outcomes are (a) adherence to the recommendation and (b) knowledge and (c) (self-perceived) competence. Adherence to the recommendation (i.e. behaviour) was measured as the proportion of patient days with at no adherence, partial adherence (1 NCS documentation) or full adherence (≥2 NCS documentations). Patient days are defined as (part of) a calendar day of admittance per patient.

Knowledge is measured with a standardized test, consisting of eight multiple-choice questions regarding DOC and the NCS(-R). A score of 55% and higher was needed to pass the test. The self-perceived competence was measured with a 4-point Likert scale, where a higher score meant the nurse felt more competent (very incompetent, incompetent, competent, very competent). The following questions were addressed: 'recognizing pain behaviour in patients with DOC' and 'measuring pain intensity in patients with DOC'. For comparison the same questions were asked about patients able to communicate adequately.

Secondary Outcomes

The secondary outcomes were (a) attitude towards pain measurement, (b) the total number of documentations regarding pain, (c) the proportion of interdisciplinary consult documented with and without NCS(-R) scores and (d) documentation of non-pharmaceutical interventions for the relief of pain. Attitude was measured with an adaption of the Negative Pain Belief Scale (NPBS) by Shugarman et. al (2010), consisting of four questions with a 5-point Likert scale. (Shugarman, et al., 2010)

Data Collection

Adherence to the recommendation (i.e. behaviour of health professionals) was measured three times per time period. Patients were identified during the measurement week by reviewing the Glasgow Coma Scales and clinical behaviour. After receiving informed consent by the patients' legal representatives, data were obtained from patient data files with a standardized data collection form for at least three consecutive days of admission during the week of measurement. Data on patient characteristics involved diagnosis, Glasgow Coma Scale, presence of tracheostomy and administered medication with analgesic (side) effects. If informed consent was not provided only process data (i.e. nurse behaviour) were recorded.

The health care professionals' knowledge, self-perceived competence and attitude were measured in the time periods before and after implementation with an online questionnaire, which was sent via SurveyMonkey® during the week of measurement. Daily reminders were sent for one week, after which the questionnaire was closed.

Analysis

For the analysis we used descriptive statistics and inferential statistics. All outcome variables were tested for normality with the Kolmogorov-Smirnov test, a Q-Q plot and Levene's test. Categorical variables are expressed as n (%). Continuous variables are expressed by their mean and standard deviation when normally distributed and by their median and interquartile range (IQR) when not-normally distributed.

Differences in proportions in categorical variables and outcomes before and after the intervention were tested with Pearson's Chi-square test or Fisher's exact test when appropriate. (Bland & Butland) For the proportion of 'no', 'partial' and 'full adherence' odds ratios were calculated for the comparison of time periods.

Data from the questionnaire measures (knowledge, self-perceived competence and attitude) were analysed for overlapping of samples.

For paired data the dependent samples Students t-test is used for normally distributed continuous data and the Wilcoxon signed rank test in case of skewed data. Data were analysed with R Statistics (Version 1.0.153) and SPSS (version 24.0, SPSS inc. Chicaco, USA).

Sample Size Calculation

Nquery Advisor version 7.0 is used for Sample size calculation for the primary outcomes adherence and knowledge, with an alpha of 0.05 and beta at ≥ 0.8. To find an increase in full adherence from 1% to 25% we will need 34 observed patient days per time period. When assuming not-normally distributed test scores (knowledge) we would need 15 nurses per time period to detect a probability of 0.8 that the mean test scores are lower before than after intervention. To find an increase in proportion of nurses passing the test from 50% to 85% we would need 27 nurses per group.

Ethics

The research protocol was approved by the medical ethical committees of the AMC in June 2017 and UZA , in consultation with AZN, in August 2017. Patients' legal representatives were informed of the study by the researchers and asked written Informed Consent for the collection and use of patient data. If written consent could not be obtained only data un-relatable to the patient was obtained by PV in the role of staff advisor on quality and patient safety (AMC) and by nurse students of AZN and UZA as part of the patients care team.

Process Evaluation

The process evaluation aims to describe the strategy as planned, as delivered and the actual exposure of the target population to the intervention. Results are presented in **APPENDIX B**: Measurements and Results of the Process Evaluation.

Results

In total 152 patient days were observed in 42 unique patients. The number of patients and observed patient days per setting are presented in **TABLE 4**. Patient-related data could be obtained with informed consent for 28 patients, of which characteristics are presented in **TABLE 5**.

Adherence to Recommendation

The proportions of adherence per time period are described in **FIGURE 1**. The proportion of patient days with partial or full adherence (≥1 NCS documentations) increased from 4% at baseline (T0) to 65% one to three months after implementation (T1), resulting in an odds ratio of 40.82 (95% CI 10.35-241.95, p <0.0001). At six to nine months after implementation (T2) partial or full adherence remained relatively stable at 60%, with a statistically non-significant odds ratio of 0.80 (95% CI 0.29-2.18, p 0.65). The proportion of patient days with full adherence (≥2 NCS documentations) increased from 0% at baseline to 31% at T2, resulting in an odds ratio of 31.78 (95% CI 4.41-1398.43, p <0.0001) versus no or partial adherence.

Knowledge

A total of 117 nurses completed the standardized test at least once during the study and 50 completed the test both before and after implementation. Paired analysis among these nurses showed a statistically significant increase of 19.3 percentage point in average test scores before and after the intervention, t(49) = 4.755, p < 0.0005. The proportion of nurses that had an average test score ≥55% changed from 57% to 91% after the intervention, X2(1) = 24.224, p = <0.001).

Self-perceived Competence

Nurses perceived themselves competent or very competent in 'recognizing pain behaviour in patients with DOC' for 93% of their responses before the intervention and 91% after the intervention. This decrease was not statistically significant (X2 3.626, p 0.276). For 'measuring pain intensity in patients with DOC' nurses perceived themselves competent or very competent in 69% of their responses before and 76% after the intervention, which is a statistically significant increase (X2 8.385, p 0.035). Paired analysis among 44 nurses showed no statistically significant change in these two competencies (z=0.378, p=0.705 and z=0.280, p=0.780 respectively).

Secondary Outcomes

Attitude

During the study there were no nurses or with a negative attitude towards pain measurement (NPBS > 12). Paired analysis showed a slight decrease of 2 points in average NPBS scores before or after the intervention, $t(49) = -4.750$, $p < 0.0005$.

Documentations

There was a documentation of interdisciplinary consult in 118 (78%) of the patient days. In 49 (42%) there was a mention of pain and in 12 (10%) the NCS(-R) was mentioned. There was no statistical difference before or after the intervention in the number of documentations about pain per patient day or the proportion of interdisciplinary documentations that mention pain.

Besides the NCS the use of other pain behaviour observation scales such as POS and REPOS also increased. At six to nine months after implementation of the NCS 87% of all patient days had at least one documentation of a pain behaviour observation scale, compared to 37% at baseline.

Discussion

With the study of this evidence-based quality improvement project we showed that a multi-faceted intervention can be used to increase the use of a pain behaviour observation tool such as the NCS(-R) for patients with Disorders of Consciousness from 4% to 65% of patient days.

Though a statistically significant increase in both partial and full adherence was found, the clinical impact remains slightly unsatisfying with full adherence in 31% of the patient days and partial adherence in 29% of the patient days after nine months. One explanation for this may be that the indication to use the NCS(-R) is not always clear to nurses, as patients may vary in consciousness level during the day and can sometimes even obey small commands. This is reflected in the use of other pain behaviour observation instruments, such as the Rotterdam Elderly Pain Observation Scale (REPOS). We believe, however, that any pain behaviour observation is better than none, and the choice of instrument may indeed be arbitrary in patients balancing on the edges of consciousness.

Besides the choice of the instrument, pain behaviour observation may remain a task not all nurses are comfortable with. Perhaps more than other instruments in healthcare, the NCS requires not only observation and documentation, but also a (subjective) interpretation. As stated in previous research a low score on the NCS(-R) is no guarantee for the absence of pain and a high score on the NCS(-R) is no guarantee for the presence of pain. (P. Vink et al., 2017) By adding the 'pain score according to nurse' to the NCS(-R) nurses were given the option to quantify their clinical expertise. However, expressing this subjective interpretation of patient behaviour may require a level of clinical leadership that has not been addressed in this study. Determinants that could have further improved the adherence, were 'communication and influence' and 'team processes'. Analysis of interdisciplinary consults showed that pain assessment is not integrated well in existing team processes.

Limitations

As patients with DOC are unable to communicate, the role of their family and support network is of extreme value to daily nursing care. At the AMC NeuroCentre and UZA they are able to participate in as informal caregivers in daily care activities of their beloved one, such as feeding, ambulation and washing. In QI projects however, currently the nursing wards do not have a structure in place to involve patients or their representatives. This can be perceived as a missed opportunity as we were unable to identify the needs and wishes regarding their role in pain behaviour observation as a potential determinant for change. (van, Mclerney, & Cooke, 2015)

A limitation of this project is the method of identifying eligible patients, both for inclusion in the study and for providing feedback and bedside teaching. As DOC may occur only briefly during the acute phase, it is difficult to capture the moment in time and approach patients' family for inclusion and investigation of needs and wishes. The lack of in-depth insight in the needs and wishes of the patients' family probably hasn't prevented more frequent use of the NCS, but the role of patients'

family in pain behaviour observation should be explored further.

A limitation in the study of this project is the method of analysis, as an interrupted time series analysis would have provided a better understanding of the effect of the implementation strategies.(Shojania & Grimshaw, 2005) With only three measurement points before and after the intervention and a low incidence rate in DOC patients, this analysis was not possible in this study. Also the results may have been influenced by the fact that DOC patients were more consistently present in the AMC hospital then in the other hospitals. Future studies should consider a longer period of measurement, more data points or a continuous measurement approach to increase the number of available observations.

Recommendations

Based on our experience in this project we can recommend to use the checklist by Flottorp et al. (2013) to design tailored implementation strategies in future evidence based quality improvement projects. For the determinants in the domain 'Patient Factors', patients or their informal care givers should be included in the project. However, the goal and feasibility of this participation should be considered expressively beforehand. (van, Mclerney, & Cooke, 2015) Especially for patients in an acute phase or with potentially life-changing severity of diseases, such as DOC, it can be expected that informal care givers are not able or willing to participate at the most desirable level.

The largest part of the intervention consisted of a broad educational strategy, offering multiple means of learning to adhere to the varying needs of nurses. This approach has proven effective as the knowledge of nurses increased significantly. The development of innovative training material in the form of practice videos that reflect recognizable situations of clinical nursing practice is needed to ensure the trialability of the recommendation, as the prevalence of non-communicative patients may vary over time. (Vink, et al., 2019) Using the videos both in group and online learning material ensured that the resources (money, time) contributed to the learning style of each nurse.

Group lessons appear the cheapest but are potentially difficult to organize when workload is high or personnel is scarce. Organizing and planning the lessons to address the large nursing team at the AMC within two months proved nearly impossible, whereas the smaller nursing teams at AZN and UZA were more easily brought together. The use of online learning material created the opportunity for nurses to learn in their own pace and at a moment that was convenient to them. Based on our experience during this project, however, we recommend to determine the order in which online and group teachings should occur beforehand. Nurses were less motivated to practice with the online video training if they hadn't received theoretical explanation in group lessons yet. We also advice the online video training to consist of different material so nurses feel it provides an additional learning opportunity besides the group lessons.

The freedom for nurses to choose a suitable moment to complete the e-learning comes with the risk of the task being forgotten in daily work routines. A large amount of time has been spent on the motivation and reminding of nurses to complete the obligatory part of the module.

Lastly, individual bedside teaching proved the most plannable when the prevalence of DOC patients was constant, but also costly compared to group learning when provided for a longer period of time. As shown in previous research, this method of teaching may be of greater potential for nurses and should be further investigated in future research. (Gordon, Melillo, Nannini, & Lakatos, 2013)
Due to the large amount of time and effort spent on the educational strategy, it is easily interpreted as the most relevant. We believe, however, that the increase in knowledge alone was not enough for an increase in adherence, as is concurrent with previous research. (Vink, et al., 2019) The monitoring of team performance was generally well accepted at the AMC and could have been of a longer duration and with more actual reflection as a team. (Giesbers, et al., 2016) However, in the absence of a continuous monitoring system for pain assessment in specific patient groups, gathering the required data for feedback on team performance was a tedious and time-consuming task. Future quality improvement projects and research regarding this subject

should aim on having an easy identifying and monitor system as part of the facilitating strategy.

Ensuring comfort and alleviating pain is associated with compassionate care and is one of fundamental aspects of nursing care along with nutrition, medication management and infection prevention. (Feo, Kitson, & Conroy, 2018) Pain behaviour observation requires not only the use of an appropriate scale but possibly also interdisciplinary collaboration, clinical leadership and adequate decision-making of nurses. Future attention must be given to team interventions and structural empowerment of nurses on quality outcomes such as pain assessment and treatment. (Goedhart, Goedhart, Oostveen, Vermeulen, & Vermeulen, 2017) Taking these aspects into account in clinical practice and future scientific research will increasing the scientific knowledge on basic nursing care and thereby aid in the design of tailored implementation strategies. (Zwakhalen, et al., 2018)

Conclusion

This evidence-based quality improvement project provides an example of successful implementation of a potentially complex change in nursing behaviour, of which strategies and ideas can be drawn for clinical practice about daily essential care activities of nurses in similar contexts. It has shown that a broad educational strategy, combined with facilitating and motivational strategies can increase the use of the Nociception Coma Scale (-Revised) and overall pain behaviour observation in patients with Disorders of Consciousness. Further implementation of the NCS(-R) will provide opportunities in research with focus on the actual presence and treatment of pain, including non-pharmaceutical interventions. By doing so we have gotten one step closer to giving voice one of the most fragile patient groups, those who are unable to express their pain or discomfort themselves.

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Figure 1

Distribution of adherence rates per time period.

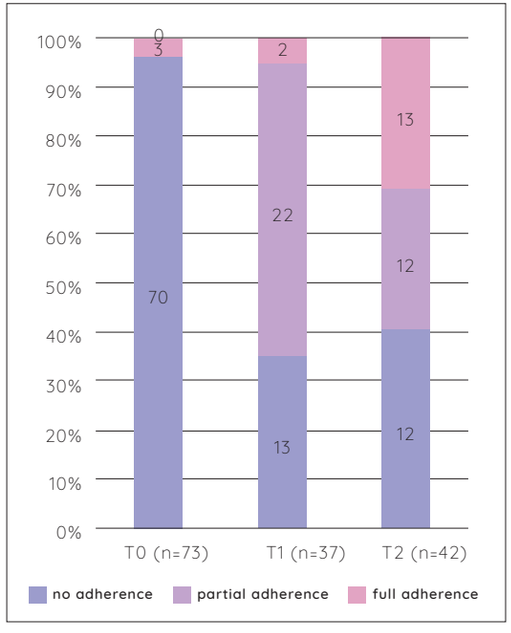

Table 1

Characteristics of participating hospitals.

	AMC	AZN	UZA
Type of Hospital	University Hospital	General Hospital	University Hospital
Accreditation	JCI	NIAZ	JCI
Nursing Ward	Neurology/ neurosurgery	Neurosurgery/ pain treatment	Neurosurgery/ thoracic & vascular surgery
Specialization	*Neurovascular disease*	*Brain- and spinal surgery*	*Brain surgery*
Unit Size	29	32	26
Regular nursing beds	*20*	*25-29*	*16*
Specialized beds	*9 brain care unit*	*3-7 brain surgery*	*5 medium care 5 camera supervised*
Pain Behaviour Observation Tools at start of study	REPOS	POS PAINAD	REPOS
Patient File	electronic	paper	paper

JCI: Joint Commission International, NIAZ: Dutch Institute for Accreditation in Healthcare, REPOS: Rotterdam Elderly Pain Observation Scale, PAINAD: Pain Assessment in Advanced Dementia Scale.

Table 2

Participant characteristics before implementation.

	AMC	AZN	UZA	Total
Nurses contracted	62	16	25	103
Respondents to baseline measurement	36 (50%)	12 (75%)	18 (72%)	75 (73%)
Female	30 (83%)	12 (100%)	17 (94%)	59 (89%)
Age				
<25 years	**12 (33%)**	1 (8%)	3 (17%)	**16 (24%)**
25-35 years	8 (22%)	**4 (33%)**	4 (22%)	**16 (24%)**
36-45 years	6 (17%)	3 (25%)	2 (11%)	11 (17%)
46-55 years	4 (11%)	3 (25%)	2 (11%)	9 (14%)
56-65 years	6 (17%)	1 (8%)	**7 (39%)**	14 (21%)
Years in current position				
<1 year	11 (31%)	1 (8%)	3 (17%)	15 (23%)
1-5 years	8 (22%)	2 (17%)	3 (17%)	13 (20%)
5-10 years	4 (11%)	3 (25%)	1 (6%)	8 (12%)
>10 years	**13 (36%)**	**6 (50%)**	**11 (61%)**	**30 (45%)**
Years at current work place				
<1 year	10 (28%)	2 (17%)	3 (17%)	15 (23%)
1-5 years	8 (22%)	2 (17%)	3 (17%)	13 (20%)
5-10 years	5 (14%)	2 (17%)	1 (6%)	8 (12%)
>10 years	**13 (36%)**	**6 (50%)**	**11 (61%)**	**30 (45%)**
Knowledge of the NCS (test score)	35% (±31%)	47% (± 26%)	49% (± 22%)	41% (±29%)

Bold text represents modus.

Table 3

Planned implementation strategies per setting.

Intervention	AMC	AZN	UZA
Facilitating strategies			
NCS(-R) incorporated in patient file	electronic	paper	paper
Recommendation in local hospital protocol	electronic	paper	paper
Pocket card distributed among nurses	yes	no	no
Educational strategies			
Group lessons	several	1	1
E-learning	yes	yes	yes
Bedside teaching	yes	yes	yes
Informational strategies			
Video send to other healthcare professionals	yes	no	yes
Motivational strategies			
Posters	2	2	2
Performance feedback	yes	no	no
Patient focused strategies			
Brochure about NCS(-R) and the study	yes	yes	yes

Table 4

Number of patients included and patient days observed per measurement and time period.

	patients included				patient days observed			
Month	AMC	AZN	UZA	Total	AMC	AZN	UZA	Total
T0: before implementation								
Sept. '17	3	2	3	**8**	12	5	9	**26**
Oct. '17	4	1	5	**10**	15	2	11	**28**
Nov. '17	2	2	2	**6**	7	6	6	**19**
Total	*6**	*4**	*8**	**18***	*34*	*13*	*26*	**73**
T1: 1-3 months after implementation								
Mar. '18	3	1	1	**5**	12	3	3	**18**
Apr. '18	3	0	0	**3**	11	0	0	**11**
May '18	2	0	0	**2**	8	0	0	**8**
Total	*8**	*1**	*1**	**10***	*31*	*3*	*3*	**37**
T2: 6-9 months after implementation								
Aug. '18	2	3	0	**5**	8	12	0	**20**
Sept. '18	2	0	0	**2**	8	0	0	**8**
Oct. '18	2	1	1	**4**	8	3	3	**14**
Total	*2**	*4**	*1**	**11***	*24*	*15*	*3*	**42**

*unique patients

Table 5

Patient characteristics.

	N = 42
Observed Patient Days (median, range)	
Total	152
Median, range	4 (2-12)
Informed Consent Obtained	28 (67%)
Glasgow Coma Scale (per patient day)	
Eyes (median, range)	3 (1-4)
Motor (median, range)	5 (1-6)
Verbal (median, range)	1 (1-4)
Tracheostomy (n)	2
Receiving Anticonvulsants (n)	14 (50%)
Receiving Antidepressants (n)	0 (0%)
Pain Medication Received (per day, median, range)	
Paracetamol (mg)	3000 (0-4000)
Metamizol (mg)	0 (0-4000)
Tramadol (mg)	0 (0-0)
Morphine (mg)	0 (0-84)

Appendix A

Problem Analysis and Determinants

To identify relevant determinants as barriers for implementation, a qualitative study was conducted. The design of this study developed over time, incorporating new insights in subsequent methods. We used known techniques for quality improvement projects such as brain writing and Ishikawa model alongside qualitative research to gather in-depth understanding of the barriers and facilitators for implementation.(Grol, 2013; Thompson, 2003) The process of data collection was iterative so that determinants could be further investigated or validated over the course of the study.

Sample

Structured interviews were conducted among four participants that were chosen as a purposeful sample to represent the interdisciplinary teams working at the nursing wards: a nurse, a physician, a nurse manager and a member of the allied health professionals. For subsequent focus groups nurses were selected by the nurse manager, mainly based on the availability and opportunities in existing working schedule. The researcher and nurse manager aimed to create groups that represented the overall nursing team in age, education and experience.

Data Collection

Semi-structured interviews

Semi-structured interviews were used to form a list of potential barriers and facilitators for the implementation of the Nociception Coma Scale. The interviews combined techniques used to create new ideas (Brain Writing) and to structure them (Ishikawa Model).

Interviews were conducted by researcher PV at the AMC and student-nurses BL, YW and AM at UZA and AZN. The location of the interview was chosen by the interviewee, such as an office or meeting room within the hospital. Relationships were established before the interview and the participants of the AMC had knowledge of PV's previous involvements in quality improvement and research. During the interview the interviewers refrained from suggestions of personal experience or ideas on potential barriers and facilitators.

Interviewees were presented eight Ishikawa Models reflecting four undesirable situations and their four counterpart desirable situations. Categories that were presented in the models were human, management, equipment, knowledge and process.(Grol, 2013) Each model was presented with the open-ended question: 'Which factors could contribute to the following situation?' Situations were presented in the following order:

Undesirable Situation	Desirable Situation
1. The NCS will not be used by healthcare professionals.	2. The NCS will be used by healthcare professionals.
3. The NCS will not be used according to local hospital protocol.	4.The NCS will be used according to local hospital protocol.
5. The NCS will not be used in inter-professional communication.	6. The NCS will be used in inter-professional communication.
7. Pain treatment will not be adjusted according to intra-patient changes in NCS scores.	8. Pain treatment will be adjusted according to intra-patient changes in NCS scores.

The interviews were conducted in the following order: nurse, physician, nurse manager, allied health professional. The interviewer used the models as an interview guide and wrote down the responses immediately, ensuring a direct member check. Each subsequent interviewee continued to build on the responses of previous interviewees, thereby mimicking the process of Brain Writing. The interviews lasted approximately 30 minutes each and audio was recorded and transcribed verbatim.

Focus Groups

Health Professionals

Focus groups were used to further investigate and validate potential determinants that were identified in the interviews. Each focus group consisted of at least six participants, resulting in a sample of 17 nurses (28%) and one physician (5%) and lasted 45 to 60 minutes. A structured

protocol and procedure was developed in advance and adjusted for each focus group, altering the focus based on the data saturation.

Each focus group started with a short introduction on the Nociception Coma Scale, the local hospital protocol (i.e. recommendation) and a demonstration how the NCS(-R) can be documented in the electronic patient file. During the first focus group, statements were presented that reflected potential barriers that were mentioned during the interviews. Participants were asked to respond freely to each statement. When needed the moderator would ask for clarification. All focus groups then discussed the following questions:

1. How would you like to be educated in the use of the NCS?
2. How can we increase adherence to the hospital protocol?
3. What role do you think patient's family can play in pain behaviour observation?

The focus groups were moderated by PV and assisted by FH who wrote down participants' responses on post-its and placed them upon A3 posters representing each question. This ensured a direct member-check and visualization of the conversation.
Data saturation was achieved after three focus groups, when all relevant determinants from the 'Checklist for identifying determinants of practice' by Flottorp et al. (2013) were identified or could be excluded from the project. Audio was recorded and transcribed (verbatim) by FH for analysis between each focus group.

Patient Family / Support Network

When approached for informed consent of inclusion in the study, patients' legal representatives were also offered a questionnaire on their experience regarding pain assessment and treatment. The questionnaire consisted of 14 questions that were adapted from the Consumer Quality Index 'Pain Module'.(Krol, 2013) They were also asked if they were willing to participate in a focus group to further explore their needs regarding the subject, but none were willing to do so. The questionnaire did not result in the identification of new relevant determinants regarding patient needs, beliefs or preferences.

Data analysis

With the Ishakawa Models, the interviews resulted directly in a visualisation of potential barriers and facilitators. Each audio recording was replayed between interviews to identify any data that wasn't written down during the interview. After all four interviews were finished, the models were summarized in a lists of potential barriers in the appropriate items of the Flottorp checklist.

Worksheet 2 of the Flottorp checklist was used to identify determinants that required further investigation.(Flottorp et al., 2013) Data from the transcribed focus groups validated previously identified determinants or added new determinants to the list. Each potential barrier was triangulated with existing internal quality data, literature review and baseline questionnaire results (see Measures).

Determinants

Worksheet 4 of the Flottorp checklist was used to prioritize determinants that were identified in the Problem Analysis. For each determinant the evidence was reviewed and impact scores determined by the researcher and senior- or head-nurses of the participating nursing ward.

Impact Scores	
- 3 = major reduction in adherence,	+ 1 = minor increase in adherence,
- 2 = moderate reduction in adherence,	+ 2 = moderate increase in adherence,
- 1 = minor reduction in adherence	+ 3 = major increase in adherence

The potentially most influential barriers for all settings were:

- Learning style
- Information System
- Skills needed to adhere
- Awareness and familiarity with the recommendation
- Trialability of behaviour
- Accessibility of the recommendation

For the AMC specifically the following determinants were also identified as potential barriers:

- Self-monitoring or feedback
- Monitoring and feedback

Potential Barriers

All Settings

Determinant (Impact Score), Evidence	Potential Implementation Strategy
Guideline Factors	
Accessibility of the recommendation (-1) *Focus Groups*	*Facilitating Strategy:* Make the recommendation (protocol) readily available in paper (AZN/UZA) or existing digital document systems (AMC).
Trialability of behaviour (-2), *Literature, Prevalence*	*Educational Strategy:* Provide an alternative practice method to cope with varying prevalence of DOC patients, such as (online) video training.
Clarity of recommendation (-1), *Expert opinion, Interviews*	*Facilitating Strategy:* Provide and pre-test a clear recommendation.
Compatibility of recommended behaviour (-1) *Focus Groups*	*Informational Strategy:* Emphasis in the theoretical explanation of the NCS how the use of the instrument can benefit patient care and clinical decision making by nurses.
Individual Health Professional Factors	
Learning style (-3), *Interviews, Focus Groups*	*Educational Strategy:* Offer multiple methods of education, including group lessons, e-learning and bed-side teaching. Minimize the obligatory part of e-learning, allowing nurses to choose their own method of learning. Minimize the educational strategy for healthcare professionals other than nurses (physicians and allied health professionals).
Awareness and familiarity with the recommendation (-2), *Questionnaire*	*Educational Strategy:* Provide knowledge on the NCS and marketing for the new recommendation (posters/newsletters).
Skills needed to adhere (-2), *Focus Groups*	*Educational Strategy:* Practice skills of pain behaviour observation in clinical practice.
Nature of the behaviour (-2), *Literature, Focus Groups*	*Educational Strategy* Emphasize on the documentation of the NCS (not only the observation) during bedside teaching.
Domain knowledge (-1), *Standardized Tests*	*Educational Strategy:* Provide knowledge on DOC and pain assessment.
Patient Factors	
Patient beliefs and knowledge (-1), *Questionnaire*	*Patient-focused Strategy* Provide written information about pain behaviour observation in patients unable to communicate pain (intensity).
Incentives and Resources	
Information System (-3), *Interviews, Focus Groups*	*Facilitating Strategy:* Ensure the availability of documentation forms in (electronic) patient files.
Continuing education system* (-2), *Focus Groups*	*Educational Strategy:* Embed the education in existing training/education programmes.

* out of scope of this project

AMC

Determinant (Impact Score), Evidence	Potential Implementation Strategy
Guideline Factors	
Accessibility of the intervention (-1), *Expert opinion, Interviews*	*Facilitating Strategy:* Provide a pocket card to aid in bedside NCS observation and decision making and incorporate the NCS (with instructions) in the electronic patient file.
Individual Health Professional Factors	
Knowledge about own practice (-1), *Focus Groups*	*Motivational Strategy:* Provide feedback on team performance .
Self-monitoring or feedback (-3), *Interviews, Focus Groups*	*Motivational Strategy:* Provide feedback on team performance.
Professional Interactions	
Team processes (-1), *Interviews, Focus Groups*	*Organizational Strategy:* Formalize the use of the NCS in multidisciplinary consultation or daily rounds.
Capacity for Organisational Change	
Monitoring and feedback (-3), *Interviews, Focus Groups*	*Motivational Strategy:* Provide feedback on team performance.

Potential Facilitators

All Settings

Determinant (Impact Score), Evidence	Potential Implementation Strategy
Guideline Factors	
Feasibility of recommended clinical intervention (+2), *Interviews, Focus Groups*	-

Appendix B

Measurements and Results of the Process Evaluation

Process Evaluation

Facilitating Strategy

The local hospital protocols were published electronically on September 17th 2017 at the AMC and paper versions were made available in November 2017 for AZN and UZA. We were unable to determine whether nurses had read the protocol, as the document management system can be used anonymously. Electronic and paper documentation forms became available in the (electronic) patient files between September and November 2017.

Educational Strategy

The development of the video material, to be used during both group and online learning activities, took about 28 hours including one day of filming. The development of the online module took approximately 36 hours, including creating the online environment, creating accounts and developing the online quiz features. A large part (27%) of the time spent on the online learning module was spend on motivating and reminding nurses to follow the online learning module.

Seven group learning activities were planned at the AMC and five were eventually realized. One was cancelled because the nurses were required on the unit and one was cancelled because the present nurses had already attended the class before. As AZN and UZA had smaller teams, one group learning activity was sufficient. In total 28 nurses (41%) and 11 (61%) of nurses students at AMC had attended the group learning activity, compared to 14 (88%) and 16 (64%) at AZN and UZA respectively.

By the end of February 2018, 80 nurses (78%) of the nurses had started the online learning module. The median completion rate was 21% (11%-74%) and all completed the obligatory theory and test.

Informational Strategy

The informational video has been send out to all residents, attending physicians and allied health professionals. Three attending neurosurgeons and two residents were personally informed of the NCS during a staff meeting.

Motivational Strategy

Posters were placed according to plan in December. Performance feedback to the AMC team was provided in January for 15 days, spread out over the month. A total of 18 hours was needed to provide feedback, including the reviewing of all patients present, retrieving documentations on pain assessment and spreading the results across the unit. A total of 64 nurses (94%) were exposed at least once to the performance feedback with a median of 13 shifts (IQR 10-15) of exposure.

Patient-Focused Strategy

During interviews and focus groups with health professionals it became clear that there were different opinions on the participation of patients' family or support network. According to health professionals the extent to which information about pain and pain behaviour observation is provided could vary per patient, based on the estimation of their needs and abilities by the nurse. If family is very involved and participates in daily nursing care, nurses said to be more likely to involve them in observations of skin, facial expressions, et cetera. When approached for informed consent, many family members were hesitant to participate and only five out of 17 (29%) questionnaires were completed. For this reason the brochure was not published during the implementation phase and therefore not distributed by nurses during the study. The aim to conduct focus groups may have been too ambitious as patients' family, as they are overwhelmed by the dire situation of their loved one.

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General discussion

CHAPTER 8

Introduction

The research in this thesis originated from the practical needs of nurses to obtain a list of behavioural signs that might indicate pain in patients unable to self-report pain experience. We therefore aimed to explore which instruments could aid neuroscience nurses in behavioural observation and how they could be implemented in daily practice. Though simple as this may sound, the studies in this thesis have shown its complexity in both the validation and implementation of pain behaviour observation scales. Such instruments may be viewed as clinical checklists or aids for clinical decision making, but its value remains depended on the context in which it is used and interpreted. In the absence of a golden standard to measure pain experience, there is no checklist that can ever guarantee the actual presence or absence of pain in patients with disorders of consciousness (DOC). In this thesis we have been able to identify appropriate instruments that can aid nurses and other healthcare professionals in their clinical decision making and provide insights in how to implement such instruments in clinical practice. With this discussion we would like to emphasize that the use of the instrument is not the only determinant for good clinical practice and we hope to inspire future researchers and quality improvers to look beyond the checklists and towards the various professionals that could use it.

The use of instruments and measurement in general is typical for the era in which this thesis started. The documentation of healthcare professionals has become a standard for data aggregation to indicate the quality of care provided. Adequate documentation provides continuation of care among professionals and services and helps to evaluate the provided treatments.

Though it may be clear that writing something down is not the same as delivering care, the documentation was the only way for governments and clinical auditors to obtain any objective data on the quality of care. Percentages of documentation has thereby become the standard indication of accountability: if it is not written down, how do we know if the care is delivered? This data driven culture in healthcare is fuelled even more by the digitalization of patient files, increasing both the potential for documentation but also the delivery of data about the documentation. It is therefore no surprise that the primary outcome of some studies in this thesis are documentations of pain assessment and not the performance or quality of the assessment itself.

Within the field of quality improvement however, we notice (and applaud) a paradigm shift where accountability and quantification in numbers, indicators or incidents, is now accompanied by a trust in healthcare professionals and the desire to learn from what goes well instead of what is missing or goes wrong. The Safe-II movement is a clear example of this new approach, where emphasis is shifted from adverse events towards the complexity of care process that results in both desired and adverse events. (Hollnagel, Wears, & Braithwaite, 2015) This approach exudes a trust in healthcare professionals are resilient to complex changes and have an intrinsic desire to deliver the best possible care which is not only seen in data, but especially

in professional behaviour . In this discussion we therefore summarize the findings of the studies, compare them with the current movements in the field of Quality and Safety and formulate recommendations to improve clinical practice, quality measurement and future research.

Summary

In our first study we have enquired Dutch healthcare institutions about the use of pain behaviour observation scales for patients unable to self-report pain. (Vink, Verweij, van Erp, Lucas, & Vermeulen, 2015) Only 16% out of 43 institutions used such an instrument, mostly in general and university hospitals. Unfortunately, these instruments were not always validated for DOC patients due to Acquired Brain Injury (ABI). Interestingly enough, 59% of the participants agreed with the statement 'I can express my observations on pain in patients with DOC due to ABI sufficiently to colleagues or other disciplines'. This study shows that there was a great gap between the world of research and clinical practice. Though the first publications of the Nociception Coma Scale (NCS) were already available, this had not reached healthcare professionals caring for these patients. Similarly, the need for such an instrument to standardize interprofessional communication on pain behaviour was not clear among nurses. We believe this may be due to the unfamiliarity with this concept at the time.

In the multi-centre reliability study of the inter-rater agreement of the NCS, 78% (n=21) of participating nurses indicated they would use the NCS in daily care and 59% (n=16) agreed it would improve their judgement about the presence or absence of pain in noncommunicative ABI patients. (Vink, Eskes, Lindeboom, Munckhof, & Vermeulen, 2014) This may indicate that once a nurse has seen and used the NCS, he or she may come to realisation of its usability for clinical practice. In the same study we have shown that nurses require very little instruction to obtain an excellent interrater agreement, regardless of educational level. An interesting finding was the lower intra-class correlation coefficient (ICC) for nurses with more experience (≥7 years) than those with less experience. The experienced nurses were less likely to agree with the statement "I found the NCS difficult to assess", but showed

more variation in their observations than less experienced nurses.

In our third study we've combined all relevant articles on the clinimetric properties of the NCS(-R) and conducted a systematic review to determine if the instrument was sufficiently validated for the use in clinical practice. (Vink, et al., 2017) In eight individual papers we identified data on internal consistency, content validity, cross-cultural validity, reliability, construct validity and responsiveness. These last three aspects of validity may very well be the most vital for clinical practice and have been investigated in methodologically fair to excellent studies, appraised with the COSMIN checklist. We did find discrepancies in the cut-off value in two studies. (Vink, et al., 2018) (Chatelle, Majerus, Whyte, Laureys, & Schnakers, 2012) The use of a cut-off value has become a best practice in self-reported pain assessment, where a pain score above four is considered intolerable. It is therefore logical that a similar approach was used for behavioural pain assessment, but this proved to be more complicated. The cut-off value for the presence of pain can only be determined by the interpretation of the stimuli that is given during measurement. For example, when administering pressure on the nail bed we assume that at some point this will cause pain. However, as we can not confirm that this is true, without a fMRI determination a cut-off value relies merely on the assumption. Combined with the fluctuating and varying states of consciousness of the relatively small pool of patients, we chose to advise on the safest cut-off value possible. We also argue that the cut-off value should not be used as the primary source for clinical decision making, but intra-patient changes over time and the clinical expertise of health professionals should always be included. And as such, in this study we did not only conclude the NCS(-r) to be ready for clinical practice, we also provided a guideline for interpretation and set the first steps towards a movement where the clinical measurement tool is not deemed all-knowing.

As we have established the validity of the NCS(-r), we were interested in ways to implement this in neuroscience nursing. In this field it is common practice to use a behaviour observation tool to assess the level of consciousness. In an international survey in Europe we aimed

to identify how these instruments were used and if any training was provided to nurses. This could aid in forming a implementation strategy for the NCS(-r) and similar instruments. With 331 questionnaires completed by nurses in 11 different countries, we concluded that the Glasgow Coma Scale (GCS) was the most common instrument (85%) for consciousness assessment. The development of the GCS dates back to 1974 by Teasdale et al., which means there was ample time to implement the instrument among neuroscience nurses across Europe. However, we did find a variation on the use of the instrument such as score calculation and purpose of the measurement. We also found a great variation in the way nurses were trained to use the instrument. Some (22%) were trained by teachers/trainers, while others were trained by colleagues (20%). This study provided both recommendations for improvement in current practices of consciousness assessment as well as interesting points to consider when implementing new behaviour observation tools, such as the method of teaching and the purpose of the behaviour observation. As we try to determine the presence of pain with a pain behaviour observation tool, we must also state why this is relevant. Is it merely because we wish our patients to be comfortable or do we wish to use the signal of pain as a diagnostic variable for complications?

At this point in the thesis we had sufficient information to come up with an approach for implementation. There were two possible paths to take: a single-component method that focusses on education and training or an extensive exploration of barriers and facilitators that would result in a custom multi-component implementation strategy. In our first implementation study we chose the single-component strategy, as this is the most common approach to implementation. (Vink, et al., 2019) The instrument to be implemented first was the Rotterdam Elderly Pain Observation Scale (REPOS), for patients unable to communicate a self-reported pain score due to severe aphasia, confusion or language barriers. We chose a gradual educational strategy by using a stepped-wedge cluster design with parts of the nursing team as clusters. We hypothesised that the risk of contamination from this design would cause the number of nurses using the REPOS to increase faster than the number of nurses receiving training and may be used as a potential

method of implementation itself. Unfortunately, this was not the case, as the proportion of cumulative shifts where the REPOS was used decreased from 14% to 6%, respectively. Process evaluation thought us an important lesson because it was clear that we provided a sufficient educational strategy but were unable to provide direct application in daily practice due to fluctuation in patient prevalence.

In the second implementation study, a before-after study with two measurements periods after implementation, we chose a more thorough approach to select appropriate implementation strategies. We conducted a formal problem analysis with the 'Checklist for identifying determinants of practice' by Flottorp et al. (2013) to identify potential barriers and plan implementation strategies accordingly. We used known techniques for quality improvement projects such as brain writing and Ishikawa models alongside qualitative research to gather in-depth understanding of the barriers and facilitators for implementation.(Grol, 2013; Thompson, 2003) The result were three custom implementation strategies for three hospitals: the Academic Medical Center (AMC) in the Netherlands and the Antwerp University Hospital (UZA) and General Hospital Nikolaas (AZN) in Belgium. The potentially most influential barriers for all settings were: (1) information system, (2) learning style, (3) skills needed to adhere, (4) trialability of behaviour, (5) awareness and familiarity with the recommendation, (6) accessibility of the recommendation. To address barriers one to four a varied educational strategy was developed. Online video training was provided to ensure consistency in delivery of the theory and trialability of the NCS observations, as we had learned in the previous study that variation in patient prevalence could prevent learning opportunities. During group lessons the same material was used and supplemented with explanation on the documentation of the observation in the (electronic/paper) patient file. Lastly, bedside teaching was provided to provide extra learning opportunities with actual patients and a more direct insurance of skill development. Other implementation strategies were motivational strategies, to address barrier five, consisting of posters, pocket cards and (in the AMC) team performance feedback. Though far more time-consuming than our previous implementation study, the results were also more satisfying. The proportion of patient days with ≥1 NCS documentations (partial to full adherence) increased from 4% at baseline to 65% three months after implementation (T1). This remained relatively stable (60%) at nine months after implementation (T2). The proportion of patient days with ≥2 NCS documentations (full adherence) increased from 0% at baseline to 31% at T2. A statistically significant increase was found in knowledge and self-perceived competence in measuring pain in DOC patients. Besides the NCS, the use of other pain behaviour observation scales such as POS and REPOS also increased. At six to nine months after implementation of the NCS 87% of all patient days had at least one documentation of a pain behaviour observation scale, compared to 37% at baseline. With the completion of this study we have been able to provide in-depth information on common potential barriers across different settings and strategies how to overcome them.

Recommendations for the future

During this thesis we have learned that the fluctuation of patient prevalence can be of significant impact on both clinical research and potential for implementation. As we have concluded in our implementation study of the REPOS we recommend a viable way to identify patients with disorders of consciousness in an early stage. This will benefit future researchers for the eligibility-assessment and inclusion in trials, as well as clinical educators that wish to provide bedside teaching as part of (ongoing) implementation processes. For facilities with an electronic patient file a report combining consciousness assessment, data on communication disorders and pain assessment is advised. This will also aid in the development of quality indicators and team performance feedback.

A second recommendation for future research and practice is to address how nurses experience using a pain behaviour observation tool and how the result of the measurement is used. Research has now shown that the use of the NCS is of benefit to clinical practice and can be used to quantify the efficacy of pain medication administration. (Chatelle, et al., 2016) In a qualitative study Poulsen et al. (2019) also showed that nurses agree with the relevance of the NCS, but provides

an important side note that the NCS-r score is and remains merely an indication and should never replace the clinical experience of nurses. (Poulsen, Poulsen, Balle, & Givard, 2019) National guidelines should state the importance of clinical judgement and provide potential implementation and application strategies for different settings and contexts. This would allow local protocols to state which of the two (the score or clinical judgement) will determine the appropriate treatment.

As a recommendation to future implementation (studies) we wish to emphasize the importance of appropriate learning strategies, along side other motivational strategies. Learning how to observe and interpret patient's behaviour is a practical skill that is not easily addressed in formal education. Learning in the workplace is more 'contextual', 'focussed on tool use' and delivers 'practical wisdom'. Combining formal education focussed on conceptual/theoretical knowledge with bedside teaching focussed on the practical knowledge may be the fastest and most lasting methods to increase professional expertise. (Tynjälä, 2008) (Jantzen, 2019) More research is needed on bedside teaching, but also on how to deliver performance feedback to nursing teams effectively on patients' outcomes that nurses influence the most. Both research topics are closely related to research on workplace learning, continuous professional development of nurses and evidence-based quality improvement. (Pool, Poell, Berings, & ten Cate, 2015) This enables nurses and their nursing leaders to understand and utilize the clinical scholarship continuum to its full potential. (Carter, Mastro, Vose, Rivera, & Larson, 2017)

The last recommendation is a complicated one and is a direct result of the movements in the world of quality improvement: decide if a standardized instrument is always needed or only in certain situations. As described above, the use of an instrument or checklist can be of great value for those who are not (yet) familiar with the appropriate pain behaviours for a given patient population. A validated instrument helps to structure clinical observations, quantify them, and provide a common language to describe those observations. However, you may wonder if a nurse truly needs to use this instrument each day

or that he or she may gain enough experience to omit the instrument completely. This would result in a decrease in documentation burden and increase the autonomy of neuroscience nurses. Rather then seeing a pain behaviour tool as a routinely performed task, we would use it as a steppingstone to gain clinical experience and afterwards trust on our nurses to use this experience for the best possible care. To further study this we are left with what one might call a measurement paradox. To determine whether routine measurement in daily practice can at some point be omitted, we will need to measure it. This means that during such a study the measurement will at some point need to shift from the nurse caring for the patient to the researcher observing. Besides this potentially complex study design it will, above all, require a shift in culture. We are not yet (or no longer) used to place complete trust in the clinical experience of nurses and omitting 'objective' data and documentation might be out of healthcare, quality improvement and assurance professionals' comfort zone.

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Nederlandse samenvatting

In onze eerste studie hebben we Nederlandse gezondheidsinstellingen ondervraagd naar het gebruik van pijngedrag observatieschalen bij patiënten die niet in staat zijn tot zelfrapportage. (Vink, Verweij, van Erp, Lucas, & Vermeulen, 2015) Slechts 16% van de 43 instellingen maakte gebruik van een dergelijk instrument, meestal in algemene en universitaire ziekenhuizen. Helaas zijn deze instrumenten niet altijd gevalideerd voor DOC-patiënten vanwege Acquired Brain Injury (ABI). Opvallend genoeg was 59% van de deelnemers het eens met de stelling 'Ik kan mijn observaties over pijn duidelijk verwoorden naar collega's of andere disciplines (bijvoorbeeld artsen)'. Uit dit onderzoek blijkt dat er een grote kloof bestaat tussen de wereld van het onderzoek en de klinische praktijk. Hoewel de eerste publicaties van de Nociception Coma Scale (NCS) al beschikbaar waren, had dit de zorgprofessionals die voor deze patiënten zorgen nog niet bereikt. Ook de noodzaak van een dergelijk instrument om de interprofessionele communicatie over pijngedrag te standaardiseren was niet duidelijk bij de verpleegkundigen. Wij denken dat dit misschien te wijten is aan de onbekendheid met dit concept op dat moment.

In de multi-center betrouwbaarheidsstudie van de inter-rater agreement van de NCS gaf 78% (n=21) van de deelnemende verpleegkundigen aan de NCS te gebruiken in de dagelijkse zorg en 59% (n=16) was het erover eens dat het hun oordeel over de aan- of afwezigheid van pijn bij niet-communicatieve ABI-patiënten zou verbeteren. (Vink, Eskes, Lindeboom, Munckhof, & Vermeulen, 2014) Dit kan erop wijzen dat als een verpleegkundige de NCS eenmaal heeft gezien en gebruikt, hij of zij zich bewust wordt van de bruikbaarheid ervan voor de klinische praktijk. In hetzelfde onderzoek hebben we aangetoond dat verpleegkundigen zeer weinig instructie nodig hebben om een uitstekende inter-rater agreement te verkrijgen, ongeacht het opleidingsniveau. Een interessante bevinding was de lagere intra-class correlation coefficient (ICC) voor verpleegkundigen met meer ervaring (≥7 jaar) dan voor verpleegkundigen met minder

ervaring. De ervaren verpleegkundigen waren het minder vaak eens met de stelling "Ik vond de NCS moeilijk in te schatten", maar lieten meer variatie zien in hun waarnemingen dan minder ervaren verpleegkundigen.

In onze derde studie hebben we alle relevante artikelen over de clinimetrische eigenschappen van het NCS(-R) gecombineerd en hebben we een systematische review uitgevoerd om te bepalen of het instrument voldoende gevalideerd is voor het gebruik in de klinische praktijk. (Vink, et al., 2017) In acht individuele artikelen hebben we gegevens geïdentificeerd over interne consistentie, inhoudsvaliditeit, cross-culturele validiteit, betrouwbaarheid, construct-validiteit en responsiviteit. Deze laatste drie aspecten van validiteit zijn misschien wel het meest essentieel voor de klinische praktijk en zijn onderzocht in methodologisch verantwoorde tot uitstekende studies, beoordeeld met de COSMIN-checklist. In twee studies hebben we wel discrepanties gevonden in de afkapwaarde. (Vink, et al., 2018) (Chatelle, Majerus, Whyte, Laureys, & Schnakers, 2012) Het gebruik van een afkapwaarde is een best practice geworden in zelfrapportage pijnmeting, waarbij een pijnscore van vier of hoger als onacceptabel wordt beschouwd. Het is dan ook logisch dat een vergelijkbare benadering werd gebruikt voor pijnmeting met pijngedrag observatieschalen, maar dit bleek ingewikkelder te zijn. De afkapwaarde voor de aanwezigheid van pijn kan alleen worden bepaald door de interpretatie van de stimuli die tijdens de meting worden gegeven. Bij het toedienen van druk op het nagelbed gaan we er bijvoorbeeld van uit dat dit op een gegeven moment pijn zal veroorzaken. Maar omdat we niet kunnen bevestigen dat dit waar is, is zonder een fMRI-bepaling een afkapwaarde alleen gebaseerd op deze aanname. In combinatie met de fluctuerende en wisselende bewustzijnstoestanden van de relatief kleine groep patiënten, hebben we ervoor gekozen om te adviseren over de veiligste afkapwaarde die mogelijk is. We stellen ook dat de afkapwaarde niet moet worden gebruikt als de primaire bron voor klinische besluitvorming, maar dat intra-patiënt veranderingen in de tijd en de klinische expertise van de zorgprofessionals altijd moeten worden meegenomen. Hierdoor hebben we in deze studie niet alleen de NCS(-r) klaargestoomd voor de klinische praktijk, maar ook een richtlijn voor interpretatie gegeven en de eerste stappen gezet naar

een visie waarin het klinisch meetinstrument niet als alwetend wordt beschouwd.

Omdat we de validiteit van de NCS(-r) hebben vastgesteld, waren we geïnteresseerd in manieren om dit in te implementeren binnen de wereld van neurologische verpleegkunde. Binnen dit werkveld is het gebruikelijk om een instrument voor gedragsobservatie te gebruiken om het niveau van het bewustzijn te beoordelen. In een internationaal onderzoek in Europa hebben we getracht in kaart te brengen hoe deze instrumenten werden gebruikt en of er een training werd gegeven aan verpleegkundigen. (Vink, et al., 2018) Dit zou kunnen helpen bij het vormen van een implementatiestrategie voor de NCS(-r) en soortgelijke instrumenten. Met 331 vragenlijsten die door verpleegkundigen in 11 verschillende landen zijn ingevuld, concludeerden we dat de Glasgow Coma Scale (GCS) het meest gebruikte instrument was (85%) voor de beoordeling van het bewustzijnsniveau. De ontwikkeling van de GCS gaat terug tot 1974 door Teasdale et al., wat betekent dat er voldoende tijd was om het instrument te implementeren onder neurowetenschappelijke verpleegkundigen in heel Europa. We vonden echter wel een variatie op het gebruik van het instrument, zoals de scoreberekening en doel van het instrument.

We vonden ook een grote variatie in de manier waarop verpleegkundigen werden opgeleid om het instrument te gebruiken. Sommigen (22%) werden getraind door leerkrachten/opleiders, terwijl andere werden getraind door collega's (20%). Dit onderzoek gaf zowel aanbevelingen voor verbetering in de huidige praktijk van bewustzijnsbeoordeling als interessante punten om in overweging te nemen bij het implementeren van nieuwe gedragsobservatie-instrumenten, zoals de manier van lesgeven en het doel van de gedragsobservatie. Omdat we proberen de aanwezigheid van pijn te bepalen met een instrument voor gedragsobservatie, moeten we ook aangeven waarom dit relevant is. Is het alleen omdat we willen dat onze patiënten zich prettig voelen of willen we het signaal van pijn gebruiken als diagnostische variabele voor complicaties?

Op dit punt in het proefschrift hadden we voldoende informatie om met een aanpak te komen voor de implementatie. Er waren twee mogelijke paden te bewandelen: een één-componentmethode die zich richt op educatie en training of een uitgebreide verkenning van

barrières en kansen die zou resulteren in een op maat gemaakte multi-component implementatiestrategie. In onze eerste implementatiestudie kozen we voor de één-componentstrategie, omdat dit de meest gangbare implementatieaanpak is. (Vink, et al., 2019) Het instrument dat als eerste werd geïmplementeerd was de Rotterdamse Ouderen Pijnobservatieschaal (REPOS), voor patiënten die door ernstige afasie, verwarring of taalbarrières niet in staat zijn om een pijnscore te communiceren. We kozen voor een stapsgewijze onderwijsstrategie door gebruik te maken van een getrapt clusterontwerp met delen van het verpleegkundig team als clusters. We veronderstelden dat het risico op kruisbestuiving door dit ontwerp het aantal verpleegkundigen dat het REPOS gebruikt sneller zou doen toenemen dan het aantal verpleegkundigen dat een opleiding krijgt en dat dit als een mogelijke methode voor de implementatie zelf kan worden gebruikt. Helaas was dit niet het geval, aangezien het aandeel van de cumulatieve diensten waarbij het REPOS werd gebruikt daalde van respectievelijk 14% tot 6%. In de procesevaluatie werd duidelijk dat we een voldoende educatieve strategie boden, maar niet in staat waren om een directe toepassing in de dagelijkse praktijk te bieden vanwege de fluctuatie in de prevalentie van patiënten.

In de tweede implementatiestudie, een voor-na-studie met twee meetperiodes na de implementatie, hebben we gekozen voor een meer diepgaande aanpak om geschikte implementatiestrategieën te selecteren. We hebben een formele probleemanalyse uitgevoerd met de Checklist for identifying determinants of practice' van Flottorp et al. (2013) om potentiële barrières te identificeren en implementatiestrategieën dienovereenkomstig te plannen. (Flottorp, et al., 2013) We gebruikten bekende technieken voor kwaliteitsverbeteringsprojecten zoals brain writing en Ishikawa-modellen naast kwalitatief onderzoek om diepgaand inzicht te krijgen in de barrières en kansen voor implementatie. Het resultaat waren drie implementatiestrategieën op maat voor drie ziekenhuizen: het Academisch Medisch Centrum (AMC) in Nederland en het Universitair Ziekenhuis Antwerpen (UZA) en het Algemeen Ziekenhuis Nikolaas (AZN) in België. De (in potentie) meest invloedrijke barrières voor alle instellingen waren: (1) informatiesysteem, (2) leerstijl, (3) vaardigheden die nodig zijn om de aanbeveling te volgen, (4) testbaarheid van gedrag, (5) bewustzijn en bekendheid met de aanbeveling, (6) toegankelijkheid van de aanbeveling. Voor de barrières één tot vier werd een gevarieerde educatieve strategie ontwikkeld. Er werd online videotraining gegeven om te zorgen voor consistentie in het aanleren van de theorie en het oefenen van observeren met de NCS op praktijksituaties. Dankzij de videotraining konden verpleegkundigen altijd oefenen, ongeacht mogelijk fluctuerende prevalentie van de patiëntenpopulatie. Tijdens de groepslessen werd hetzelfde materiaal gebruikt en aangevuld met uitleg over de documentatie van de observatie in het (elektronische/papieren) patiëntendossier. Tot slot werd er 'aan bed' onderwijs gegeven om extra leermogelijkheden te bieden met echte casuïstiek en zodoende een meer zekerheid te geven van de ontwikkeling van vaardigheden. Andere implementatiestrategieën waren motiverende strategieën, voor barrière vijf, bestaande uit posters, zakkaartjes en (in het AMC) teamprestatie feedback. Hoewel dit veel tijdrovender was dan onze vorige implementatiestudie, waren de resultaten ook bevredigender. Het aandeel van de patiëntdagen met ≥1 NCS-documenten (gedeeltelijke tot volledige naleving) steeg van 4% naar 65% drie maanden na de implementatie (T1). Dit bleef relatief stabiel (60%) op negen maanden na de implementatie (T2). Het percentage patiëntdagen met ≥2 NCS-documentaties (volledige naleving) steeg van 0% op de basislijn naar 31% op T2. Er werd een statistisch significante toename gevonden in kennis en zelfkennis in het meten van pijn bij DOC-patiënten. Naast de NCS nam ook het gebruik van andere observatieschalen voor pijngedrag zoals POS en REPOS toe. Op zes tot negen maanden na de implementatie van de NCS had 87% van alle patiëntdagen ten minste één documentatie van een pijngedrag observatieschaal, vergeleken met 37% bij start van de studie. Met de voltooiing van deze studie zijn we in staat geweest om diepgaande informatie te verstrekken over gemeenschappelijke potentiële barrières in verschillende settings en strategieën om deze te overwinnen.

Dankwoord

Lang heb ik nagedacht over een passend metafoor om mijn promotietraject te omschrijven. In de proefschriften van mijn collega-verpleegkundigen lees ik vergelijkingen als een toeristische route of een bergbeklimming, maar het lukt mij niet om tot een dergelijke beeldspraak te komen. Dit proefschrift is precies wat het is: mijn werk, mijn keuzes en mijn professionele passie. Het is een weergave van mijn eigen transitie van praktisch georiënteerde zorgverlener naar wetenschapper naar kwaliteitsverbeteraar. Van doen naar meten naar implementeren. Veel van wat ik heb meegemaakt staat niet in dit proefschrift. Zoals de studies die ik niet heb uitgevoerd, de fouten die ik heb gemaakt, de soms maanden (jaren) lang durende writersblock omdat ik me liet afleiden door alle andere prachtige aspecten van de verpleegkundige zorg. Maar het belangrijkste van wat er nog ontbreekt aan dit proefschrift zijn al die mensen waar ik mee heb mogen werken, die mij hebben gesteund en gemotiveerd of me juist hebben tegengesproken wanneer het nodig was. Voor al deze mensen dit hoofdstuk, mijn dank aan jullie is groot!

Om bij het begin te beginnen: Cees, bedankt! Dankzij jouw aanmoedigende woorden is dit hele traject gestart. Ik weet nog goed hoe ik in jouw kantoor stond en je me vroeg of ik wilde promoveren. Een betaalde plaats had je niet voor me, hoe graag je me die ook wilde geven. Maar begeleiding en ondersteuning, dat kon ik krijgen en heb je me ook zeker gebracht. Je hebt me veel vrijheid gegeven in mijn keuzes in het traject, nooit aan me getwijfeld en me bovendien een platform gegeven om mijn vers opgedane kennis en ervaring te delen met nieuwe wetenschappers in de master Evidence Based Practice in Healthcare. En enorm bedankt dat je, toen de tijd daar rijp voor was, de plaats van eerste promotor hebt overgedragen aan Hester. Dit vond je geheel vanzelfsprekend en dat waardeer ik enorm.

Want Hester, jij was al mijn mentor voordat er überhaupt sprake was van een promotietraject. Toen ik moest nadenken over mijn scriptie galmde door het AMC aan alle kanten: je moet bij Hester Vermeulen zijn. Jouw mentorschap is veel verder gegaan dan alleen de begeleiding rondom de studies. In jou vond ik een sparringpartner over ons prachtige vak, de positie van wetenschap, leiderschap, kennis, vaardigheden en alles wat er maar op mijn pad kwam. Je bent altijd bereikbaar geweest, gaf me altijd het zetje waar ik het nodig had en gaf me de ruimte om tussendoor te pauzeren, reflecteren, dromen en weer terug te keren. Ik kan niet in woorden omschrijven hoeveel ik van je geleerd heb, het is te veel en te gevarieerd. Voor het mentorschap, de kennis, het leiderschap, de visie en bovenal voor de persoon die je bent: bedankt!

En aan mijn derde promotor, Markus, eveneens enorm bedankt. Ik heb je pas laat in het traject benaderd, maar ik waardeer enorm hoe je vanuit de anesthesiologie hebt meegedacht en meegeschreven aan dit proefschrift. Dank voor je expertise, bereikbaarheid en kritische blik!

Gedurende mijn hele traject heb ik me verplaatst van de werkvloer, naar het ondernemerschap, naar onderwijs en naar de rol van stafadviseur. Onderweg ben ik ontzettend veel mensen tegengekomen in het AMC, en later VUmc en zelfs in België. Katrin, dank voor de kansen die je mij hebt gegeven bij Odisee en voor alle samenwerking die daaruit volgde. Dank aan al die lieve collega's van het AMC voor hun steun, kritische blik en natuurlijk de gezelligheid. Speciale dank aan alle verpleegkundigen en artsen van het Neurocentrum, die jaar in jaar uit mijn stunts en plannen weer tolereerden. Jullie zijn allen meer dan bereid geweest om de studies vorm te geven, uit te voeren en zo samen te bouwen aan een nieuw hoekje kennis van het neuroverpleegkundig vak. Jullie toonden begrip voor de keuzes die ik maakte om het vak met wetenschap te combineren, zelfs als jullie de passie voor data en analyses niet met mij deelden. Voor dit alles, bedankt!

Als laatste dankwoord in de professionele sfeer wil ik het AMC als organisatie bedanken. Welke stap ik ook zette, welke richting ik ook uitging, ik mocht mij binnen het AMC bewegen en ontwikkelen. Hoewel er nog een hoop werk te doen is voor de positionering van verpleegkundigen met een ambitie in de wetenschap, ben ik ervan overtuigd dat we hier samen aan kunnen bouwen.

Gelukkig heb ik naast een wereld van drukte, werken, leren, onderzoeken een tweede wereld waar ik tot rust kan komen. Dank aan al mijn lieve vrienden die mij blijven aanmoedigen. Hoe ver mijn professionele wereld ook van jullie af staat, jullie zijn altijd geïnteresseerd en benieuwd naar de stappen die ik onderneem. Dank voor al die keren dat ik mij kon verliezen in onze ongein, in het lachen, huilen, dansen, feesten. En dank voor het begrip als ik duidelijk even te veel aan mijn hoofd had om écht gezellig te zijn. Dank dat ik altijd mijn eigenwijze zelf kan zijn, dat geen hersenspinsel te raar is en ik altijd bij jullie terug kan komen om in onze bubbel te bivakkeren tot ik weer klaar ben om de buitenwereld te trotseren.

Dan de alinea's die ik met een brok ik mijn keel moet schrijven. Want mijn dank aan de volgende personen is niet in woorden uit te drukken. Pap, mam, ik had geen betere ouders kunnen wensen. De steun en liefde die jullie mij mijn hele leven hebben gegeven is enorm en heeft mij gemaakt tot de persoon die ik nu ben. Mam, zoals je weet ben jij mijn inspiratie geweest om het vak in te gaan. Onze gedeelde passie heeft onze band enorm versterkt en hoewel ik na 9 jaar afscheid nam van de directe patiëntenzorg begrijp je als geen ander wat mijn werk inhoudt, welke keuzes ik maak en waarom. Pa, excuses voor alle gesprekken over de zorg, het AMC en Epic die je hebt moeten aanhoren. Maar vooral dank voor al je adviezen, voor het uiten van je zorgen waar het nodig was, voor het meedenken in elke stap. Want zowel in mijn persoonlijke als professionele ontwikkelingen, jullie staan altijd voor me klaar, denken altijd mee, kijken altijd over mijn schouder. Zodra er iets nieuws op mijn pad komt kan ik bij jullie terecht. Dan wegen we de voors en tegens, maar zijn jullie vooral de spiegel die mij steeds weer zegt "blijf bij jezelf en doe wat je leuk vindt."

Dank ook aan mijn lieve zus, met wie ik kan lachen, sparren en huilen. Onze vakanties met zijn zessen zijn me ontzettend dierbaar en zijn een welkome onderbreking geweest in de hectiek van afgelopen jaren. Dank en ik hou van jullie!

Tot slot, de man waar ik oprecht niet zonder kan leven. David, wat had ik zonder jouw geduld, liefde, support toch gemoeten. Dan was er van dit alles (en van mij) niets terecht gekomen. Mijn dank, mijn liefde voor jou, het is groter dan hier op papier kan worden neergezet.

Data management sheet

This thesis is based on the results of surveys among healthcare professionals, observation of healthcare professionals behaviour and patient-related data. All studies were approved by the Medical Ethical Committee of the Academic Medical Center (AMC) in Amsterdam and deemed to concern usual care, meaning they did not need to adhere to the 'Wet medisch-wetenschappelijk onderzoek met mensen'. Nonetheless, all data is handled with care in compliance with applicant privacy laws.

The surveys in chapter 2, 5, 6 and 7 are conducted with SurveyMonkey, a cloud-based survey development tool, for the duration of the survey only. After completion of a survey, all data were downloaded and stored locally in a secure folder at the AMC. Data was visible only to members of the research group working at the AMC. For the international survey in chapter 4, data was anonymized before it was shared among co-authors for verification of the analysis.

Observations of healthcare professionals were obtained using standardized data sheets in chapter 3 and extracted from patient data files in chapter 6 and 7. Patient-related data was obtained in chapter 2, 6 and 7 with standardized data sheets. All digitalized data was digitally stored at a secure folder at the AMC, paper datasheets were anonymized if necessary (with an identification key stored at the secure folder) and stored in a locked file cabinet at the AMC.

Data will be stored with a maximum of 15 years, in accordance to patient/participation informed consent forms.

Portfolio

NAAM PROMOVENDUS

Peter Vink

PHD PERIODE

01-04-2019 t/m 19-11-2020

PROMOTOR(EN)

prof. dr. H. Vermeulen
prof. dr. C. Lucas
prof. dr. Dr. M.W. Hollmann

GRADUATE SCHOOL

Radboud Institute for Health Sciences

COPROMOTOR(EN)

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Cursussen	Jaar afgerond	ECTS
Post Initiële Masteropleiding Kwaliteit en Veiligheid in de Patiëntenzorg (Radboud UMC, Nijmegen)	2019	60
Master Evidence Based Practice in Healthcare (Universiteit van Amsterdam)	2013	97

Onderwijs	Jaar afgerond	ECTS
Presentatie: In het Web van Onderwijs en Onderzoek - Symposium 'Professionals In The Lead' (Academisch Medisch Centrum, Amsterdam, The Netherlands)	2013	0,2
Lezing: 'Pijn Meten bij Non-Communicatieve Patiënt met NAH' (Opleiding tot Verpleegkundig Specialist Pijn, Rotterdam, The Netherlands)	2013	0,2
Lezing: 'Pijn Meten bij Non-Communicatieve Patiënt met NAH' (Hogeschool Odisee, Opleiding Verpleegkunde, Sint-Niklaas, Belgium)	2013	0,2
Lezing: 'Evidence Based Practice op de Verpleegafdeling' (Hogeschool Odisee, Opleiding Verpleegkunde, Sint-Niklaas, Belgium)	2013	0,2
Lezing: 'Pijn Meten bij Non-Communicatieve Patiënt met NAH' (II) (Hogeschool Odisee, Opleiding Verpleegkunde, Sint-Niklaas, Belgium)	2014	0,2
Lezing: 'Evidence Based Practice op de Verpleegafdeling' (Hogeschool Odisee, Opleiding Verpleegkunde, Sint-Niklaas, Belgium)	2014	0,2
Lezing: 'Measuring pain in (sub)comatose patients. The Holy Grail in Neuroscience.' (University of Amsterdam, Master Evidence Based Practice in Healthcare, Amsterdam, The Netherlands)	2015	0,2
Workshop: 'Schrijven van een CAT' (Nursing Experience 2012, Ede, The Netherlands)	2012	0,2
Workshop: 'Evidence Based Practice' (Nursing Experience 2013, Ede, The Netherlands)	2013	0,2
Lezing: 'Evidence Based Practice voor artsen en verpleegkundigen jeugdgezondheidszorg' (Inspiratiedagen Consortium Rivas-Careyn, Papendrecht, The Netherlands)	2014	0,2
Journal Club: 'Aan tafel met wetenschappelijke kost?' (Nutricia, Eindhoven, The Netherlands)	2014	1
Lezing: 'Lezen, lekker belangrijk' (Algemene Ledenvergadering Artsen(vereniging) Jeugdgezondheidszorg, Utrecht, The Netherlands)	2015	0,2
Journal Club: AJN (Stichting GGD Jeugdgezondheidszorg, Goes, the Netherlands)	2015	1
Lezing: Diner Discutant PAAM Congres (Nutricia, Berlijn, Germany)	2015	0,5
Lesdag: EBP (4 uur lesgeven) (Jeroen Bos Ziekenhuis , Den Bosch, the Netherlands)	2015	0,8
Workshop: Inspiratiedagen Ryvas-Careyn (2x) (Consortium Ryvas-Careyn, Papendrecht, the Netherlands)	2015	1
Workshop: Nursing Experience (2x) (Nursing, Ede Wageningen, the Netherlands)	2015	1
Lesdag: Introductie in EBP (3 uur) (Alfa College, locatie Kluiverboom, Groningen, the Netherlands)	2016	0,6
Workshop: Evidence Based Practice (Westfries Gasthuis, Hoorn, the Netherlands)	2016	0,5
Workshop: Nursing Science (2x) (Nursing Science Congres 2016, Groningen, the Netherlands)	2016	1
Workshop: Evidence Based Practice (3x) (Nurse Academy Congres, Ede, the Netherlands)	2016	0,5
Cursus: 'Evidence Based Practice Nursing' voor docenten verpleegkunde (6 x 4 uur) '14/'15 (Odisee Campus Waas, Sint-Niklaas, Belgium)	2015	4,8
Cursus: 'Evidence Based Practice Nursing' voor docenten verpleegkunde (6 x 4 uur) '15/'16 (Odisee Campus Waas, Sint-Niklaas, Belgium)	2016	4,8
Congres: 'EBP Summer Course' (8 uur) (Nursing, Ede, the Netherlands)	2015	1,6
Congres: 'EBP in één dag' 2016 (8 uur) (Nursing, Ede, the Netherlands)	2016	1,6
Congres: 'EBP in één dag' 2017 (8 uur) (Nursing, Ede, the Netherlands)	2017	1,6
Workshop: Nursing Experience (2 x 1 uur) (Nursing, Ede, the Netherlands)	2017	0,4
Lezing: Evidence Based Practice (1 uur) (Tergooi Ziekenhuis, Hilversum, the Netherlands)	2018	0,2
Lezing: Evidence Based Practice (2 uur) (UMC Utrecht, Utrecht, the Netherlands)	2018	0,4
Congres: Blended Training EBP (8 uur) (Nursing, Ede, the Netherlands)	2018	1,6
Lezing: Evidence Based Practice (0.5 uur) (Leerhuis Westfriesgasthuis, Hoorn, the Netherlands)	2018	0,1
Workshop: Zoeken naar literatuur (1,5 uur) (Leerhuis Westfriesgasthuis, Hoorn, the Netherlands)	2018	0,3
Congres: 'EBP in één dag' 2019 (8 uur) (Nursing, Ede, the Netherlands)	2019	1,6
Lezing: Implementation of pain behaviour measurement tools for patients with consciousness disorders (capita selecta) (Universiteit van Amsterdam, master EBP in Healthcare, Amsterdam, the Netherlands)	2019	0,2
Lezing: Measuring pain in (sub)comatose patients: the holy grail in neuroscience (capita selecta) (Universiteit van Amsterdam, master EBP in Healthcare, Amsterdam, the Netherlands)	2018	0,2

Congressen, seminars en lezingen	Jaar afgerond	ECTS
Posterpresentatie: Pijn Meten bij Non-Communicatieve Patiënt met NAH (Neuro- en Revalidatiecongres 2013, Ede)	2013	0,25
Posterpresentatie: Nurses Assessing Pain with the Nociception Coma Scale: an inter-rater reliability assessment (World Federation of Neuroscience Nurses Congress 2013, Gifu, Japan)	2013	0,5
Posterpresentatie: Nurses Assessing Pain with the Nociception Coma Scale: an inter-rater reliability assessment (II) (7th World Congress World Institute of Pain, Maastricht, The Netherlands)	2014	0,5
Posterpresentatie: Pijn bij NAH-patiënten met verlaagd bewustzijn. De huidige staat van wetenschap en praktijk. (Neuro- en Revalidatiecongres 2014, Ede, The Netherlands)	2014	0,25
Presentatie: Pijn Meten bij Non-Communicatieve Patiënt met NAH (Neuro- en Revalidatiecongress 2013, Ede, The Netherlands)	2013	0,25
Pijn, als woorden tekort schieten... (Nursing Pijn Congres, Bunnik, The Netherlands)	2013	0,25
Presentatie: Pijn Meten bij Non-Communicatieve Patiënt met NAH (II) (Nursing Revalidatiezorg Congres, Ede, The Netherlands)	2015	0,25
Presentatie: Pijn Meten bij Non-Communicatieve Patiënt met NAH (III) (2-daags Neurologisch-Neurochirurgisch Congres 2015, Blankenberge, Belgium)	2015	0,5
World Federation of Neuroscience Nurses Congress 2013 (World Federation of Neuroscience Nurses, Gifu, Japan)	2013	1
7th World Congress World Institute of Pain (World Institute of Pain, Maastricht, The Netherlands)	2014	1
The 10th Quadrennial Congress of the European Association of Neuroscience Nurses (European Association of Neuroscience Nurses, Belgrade, Serbia)	2015	1
2-daags Neurologisch-Neurochirurgisch Congres 2015 (Belgische Vereniging Neuroverpleekgundigen & Belgische Vereniging Neurochirurgn, Blankenberge, Belgium)	2015	0,5
Presentatie: Assessing pain in patients with disorders of consciousness: the current state of practice and evidence. (The 10th Quadrennial Congress of the European Association of Neuroscience Nurses, Belgrade, Serbia)	2015	0,5

Totaal EC punten: 193,3 waarvan 193,3 afgerond

Curriculum Vitae

Peter Vink is born August 24th 1988 in Amsterdam, the Netherlands. In primary school he was barely noticed by his teacher and was advised to go to a NLQF level 2 (VMBO) secondary school. To everyone's surprise however, including his own, he obtained the maximum score on his final tests (CITO). Since the teacher's advice in the Netherlands is decisive for admission to secondary school levels, he could not enter a NLQF 4+ (Athenaeum/Gymnasium) class like his sister. Therefore, for two years he had to prove himself in a mixed NLQF4 (havo-VWO) class, after which he reached the threshold by the skin of his teeth to take place in the NLQF4+ (Atheneum) class from the third year onwards. The clumsiness and the (major) variation of his grades during this school period were not a reflection of Peter's ability, but rather a matter of interest (or lack of). An average of 5.5 was necessary, but not every subject gave him enough interest and energy to go for higher grades. After 6 years he was clearly done with all this theoretical learning, he wanted to get to work and knew exactly in which field: as a nurse, just like his mother. The secondary school teachers asked several times why he did not want to become a doctor, "after all, you did VWO". But leave it up to Peter to know exactly what he wants, why he wants it and how anyone who contradicts him will only enforce his desire to accomplish it.

His mother taught him how beautiful nursing could be and he couldn't wait to be at a patient's bedside. He therefore opted for the HBO-V dual program, in which, from the end of his first year, he spent more time at bedside than in a classroom. Because of this form of training with the hospital as his formal employer, the propaedeutic year had to be passed in one go, so this time there was no room for weak grades. As this was a field of his choosing and definitely interested him, learning proved to be less of a problem then in secondary school. These 4 years were the absolute formative years for Peter. In this field he could develop as a professional, but also as a person and

define his view on life. The HBO-V was followed by a short sabbatical in Barcelona, followed by an induction period to become a paediatric nurse. Due to working and learning conditions, this turned out not to be the right path for him and he opted for plan B: a master's degree in Evidence Based Healthcare. Working as a certified nurse in the Neurosurgery department, he would spend his Thursday evenings in class and manage to pass all but one class in a single attempt, all the while working day-, evening- and nightshifts, specializing in neuroscience nursing and trying to have the social life.

After the Master's program, Peter wasn't finished with scientific research, as Cees Lucas asked him to continue his research as a PhD student (in his free-time). In order to achieve this, he reduced his working hours at the Neurosurgery ward and founded his own company Omni Cura, with which he shared his freshly acquired knowledge about science with anyone who would listen: teachers of nursing students (in the Netherlands and Belgium), doctors and, of course, nurses. Supported and promoted by his mentor Hester Vermeulen, he spoke at conferences about the importance of Evidence Based Practice and thus expanded his company as an online knowledge platform. For three years he experienced first-hand the importance of the trias académica: education, research and nursing practice.

Captured by the power of data, his focus shifted from daily nursing practice to quality of care and in 2016 he was hired as Quality & Safety staff advisor for his department. A second master's degree in 'Quality & Safety in Patient Care' from the NFU followed, with which the story of his thesis slowly but surely unfolded. With knowledge and experience from nursing practice, the analytical mind of a researcher and a passion for quality improvement and implementation, Peter keeps working on the wonderful nursing profession, and is far from finished obtaining new knowledge and skills...