



Contents lists available at ScienceDirect

# Pain Management Nursing

journal homepage: [www.painmanagementnursing.org](http://www.painmanagementnursing.org)

## Nociception Coma Scale—Revised: Nurses' Experience in Clinical Practice



Ingrid Poulsen, RN, PhD<sup>\*,†</sup>, Maria Balle, RN<sup>‡</sup>, Kirsten Lavi Givard, RN, MSc<sup>\*</sup>

<sup>\*</sup> RUBRIC (Research Unit on Brain Injury Rehabilitation Copenhagen), Department of Neurorehabilitation, Traumatic Brain Injury, Copenhagen University Hospital, Rigshospitalet, Hvidovre, Denmark

<sup>†</sup> Section of Nursing Science, Health, Aarhus University, Aarhus C, Denmark

<sup>‡</sup> Department of Neurology, Copenhagen University Hospital, Herlev, Denmark

### ARTICLE INFO

#### Article history:

Received 2 June 2018

Received in revised form

2 February 2019

Accepted 2 February 2019

### ABSTRACT

**Background:** The Nociception Coma Scale—Revised (NCS-R) is a rating scale developed and validated for measurement of nociception and pain among patients with brain injuries in unresponsive wakefulness syndrome or minimally conscious state. However, little is known about its use in daily clinical practice. **Aims:** The aim of this study was to explore clinical experience with the NCS-R by means of focus group interviews with nurses and nurse assistants in a subacute rehabilitation ward for patients with severe brain injuries.

**Design:** Qualitative focus group interview study.

**Settings:** Department for highly specialized neurorehabilitation for patients with severe brain injuries.

**Participants/Subjects:** Nurses and nurse assistants.

**Methods:** In total, 12 experienced registered nurses and nurse assistants participated in two recorded focus group interviews. The participants were selected from the subacute neurorehabilitation ward on the following criteria: Employed at the ward for at least 11 months and being introduced to and having experience with using the NCS-R in own patients for a minimum period of 6 months. An inductive qualitative analysis was conducted by reading the interview text through several times, and meaning units were defined first separately and later jointly between the authors. Then meaning units were coded and categorized into subthemes and themes.

**Results:** We found three themes, general relevance of the NCS-R, NCS-R versus level of consciousness, and overall assessment of pain in patients with disorders of consciousness, with a total of eight subthemes.

**Conclusions:** The content and subscales of the NCS-R are relevant for pain assessment in patients with severe brain injury in subacute rehabilitation. However, with the present cutoff value at 4 points, challenges are associated with using NCS-R, especially in patients with unresponsive wakefulness syndrome because they are at risk of not being assessed with respect to pain.

© 2019 American Society for Pain Management Nursing. Published by Elsevier Inc. All rights reserved.

It is a great clinical challenge to assess pain in patients with severe brain injuries because patients are unable to express themselves in a reliable manner when they are unconscious. This applies both to the early phase after injury and to patients who remain unconscious in the chronic phase. After the comatose state,

patients who survive severe brain injuries will often go through the following phases in their awakening process: the unresponsive wakefulness syndrome (UWS, preserved arousal but no signs of consciousness [Laureys et al., 2010]); and the minimally conscious state (MCS, preserved arousal and reproducible but fluctuating behavioral signs of consciousness [Giacino et al., 2002]). In combination, these states are called disorders of consciousness (DOC).

Studies using neuroimaging methodology indicate that some patients in DOC would be able to perceive pain, although they cannot express themselves (Schnakers et al., 2010a). There is, however, a difference in brain activation between patients in UWS and MCS after noxious stimulation, where the stimulation of

Address correspondence to Ingrid Poulsen, RN, PhD, RUBRIC (Research Unit on Brain Injury Rehabilitation Copenhagen), Department of Neurorehabilitation, Traumatic Brain Injury, Copenhagen University Hospital, Rigshospitalet, Kettegaard allé 30, DK-2650 Hvidovre, Denmark.

E-mail address: [Ingrid.poulsen@regionh.dk](mailto:Ingrid.poulsen@regionh.dk) (I. Poulsen).

patients in UWS activates areas in the brain isolated from higher-order associative cortical activity, whereas patients in MCS have been found to be very similar to healthy controls (Schnakers et al., 2010a). A review by Schnakers and Zasler (2015) found that some patients in UWS have brain activation in response to cognitive tasks and that approximately 40% of patients in UWS are misdiagnosed and are, in fact, conscious. Therefore, patients in DOC should always be considered as having the potential to perceive pain (Schnakers & Zasler, 2015).

Treating pain is essential to avoid an unpleasant and immediately frightening experience and to impede the development of chronic pain (Herr, Bjoro, & Decker, 2006). In the treatment of pain, validated and reliable assessment tools are needed to detect and monitor pain treatment. Several attempts have been made to develop scales that assess pain in patients who are unable to reliably express themselves, such as infants and young children (Merkel, Voepel-Lewis, & Malviya, 2002), people with dementia (Ersek, Herr, Neradilek, Buck, & Black, 2010), and patients who are undergoing brain surgery (Echegaray-Benites, Kapoustina, & Gelinias, 2014). However, only two assessment tools exist that were have been developed for non-sedated patients with severe brain injuries: The Nociception Coma Scale (NCS), consisting of behavioral signs of nociception, which was developed by Schnakers et al. (2010b); and the Pain Assessment Scale (PAS), which was developed by Poulsen et al. (Poulsen, Brix, Andersen, Westergaard, & Guldager 2016). The term *nociception* rather than *pain* is used when describing pain in patients with DOC (Schnakers et al., 2010b). The PAS by Poulsen et al. (2016) consists of behavioral and physiologic/autonomic signs of nociception. This scale has been tested only for interrater reliability, and further validation studies are ongoing (Poulsen et al., 2016). Because several studies have examined the validity and reliability of the NCS, it is currently the most common pain assessment scale recommended for clinical use (Vink et al., 2017).

The NCS consists of four subscales: motor response, verbal response, visual response, and facial expression. Each of the subscales is scored from 0 to 3 points, where 3 points equals the greatest possible sign of pain for each individual item. NCS registers response from noxious stimuli, and the scale was proven to discriminate between patients in UWS and MCS, indicating an overlap with the Glasgow Coma Scale (GCS) (Schnakers et al., 2010b). The NCS was further examined for psychometric properties to distinguish between noxious and non-noxious stimuli in patients in DOC (Chatelle, Majerus, Whyte, Laureys, & Schnakers, 2012). In that study, NCS total scores and subscores (motor, verbal, and facial) were higher for the noxious than for the non-noxious stimulation conditions, but not for the visual subscale (Chatelle et al., 2012). Furthermore, a cutoff value of 4 points for differentiation of patients receiving a noxious stimulation versus a non-noxious stimulation was found. Exclusion of the visual subscale increased the cutoff sensitivity to 73% and at a specificity of 97%, and the authors therefore proposed a revision of the scale excluding the visual subscale: Nociception Coma Scale–Revised (NCS-R) (Chatelle et al., 2012) (Table 1).

In a review from 2017 based on eight studies aiming to synthesize the clinimetric properties of the NCS and NCS-R representing reliability (interrater reliability and internal consistency), validity (content validity, cross-cultural validity, and construct validity), and responsiveness (Vink et al., 2017), the authors concluded that both the NCS and the NCS-R are valid and useful instruments for assessment of nociceptive behavior in patients in DOC. Furthermore, the authors concluded that the cutoff value of the NCS-R can be used as guidance for clinical use. However, Vink et al. (2017) caution that there can be interprofessional differences in NCS-R measurements. In 2016 the clinical usefulness of the

**Table 1**  
Nociception Coma Scale-revised

Motor responses
3-Localization to painful stimulation
2-Flexion withdrawal
1-Abnormal posturing
0-None/flacid
Verbal responses
3-Verbalization (intelligible)
2-Vocalization
1-Groaning
0-None
Fascial responses
3-Cry
2-Grimace
1-Oral reflexive movements/startle response
0-None

NCS-R was examined (Chatelle et al., 2016). Patients with severe brain injuries in UWS and MCS in the subacute and chronic phases were included and the scale's sensitivity to change was tested. Most patients had potential pain (e.g., fractures, thoracic drain, spasticity). Patients who scored 4 points or more on the NCS-R were treated with appropriate analgesics after consultation between the treating nurse and physician. It was found that the NCS-R scores were significantly lower during treatment than before treatment; thus it was concluded that the NCS-R is a useful clinical tool for assessing and monitoring treatment of potential pain in patients with DOC. There could, however, be up to 24 hours between when the two pain measurements were made, which may lead to questions about what the difference measured is an expression of considering that many painkillers have an effect time of about 4–6 hours. More studies are therefore needed to build up evidence of the NCS-R's clinical usefulness. To our knowledge, no studies have previously used a qualitative approach to illuminate nurses' experience using NCS-R in patients with severe brain injuries.

## Aim

The aim of this study was to explore the clinical experience with the NCS-R through focus group interviews with nurses and nurse assistants (NAs) in a subacute rehabilitation ward for patients with severe brain injuries.

## Methods

We conducted two focus group interviews. A total of 12 nursing personnel participated (9 registered nurses [RNs] and 3 NAs) out of approximately 60 possible employed at the ward (Table 2). The inclusion criteria for the interview were a minimum of 11 months of clinical experience, having been introduced to the NCS-R either by group education or individually by the department's clinical nurse specialist, and experience using the NCS-R. Two ward nurses recruited the nurses, considering inclusion of both RNs and NAs, limited or ample seniority, and experience in the specialty of brain injury rehabilitation.

The focus group interviews were conducted by an experienced researcher and a clinical nurse specialist. The focus group interview format was chosen because we wanted to achieve an insight into nurses' interpretations, interactions, and norms (Halkier, 2016) in relation to their experience with NCS-R in patients who are unable to communicate pain. An interview guide was developed to cover the following areas: content of the NCS-R, division of items of the NCS-R, interdisciplinary use, and directions for use. The following questions guided the interviews: Does the content of the NCS-R correspond to your experience of what the signs of pain are? Is

**Table 2**  
Participants' Time of Employment at the Ward

RN 1	2 years
RN 2	1 year
RN 3	11 years
RN 4	1½ years
RN 5	15 years
RN 6	2 years
RN 7	4 years
RN 8	11 months
RN 9	5 years
NA 1	1½ years
NA 2	1½ years
NA 3	10 years

RN = registered nurse; NA = nurse assistant.

the way the scale is divided in items meaningful in clinical practice? Is the scale used among colleagues within the interdisciplinary team? How do you perceive the directions for use? Interviews were recorded digitally and transcribed verbatim. The interview text consisted of 38 written pages corresponding to a total of 2 hours of interviews.

#### Translation and Implementation of the NCS-R

After the NCS-R scale had been translated into Danish by Danish colleagues (Lena Aadal, Ph.D., Tove Kilde, M.Sc., and psychologist Lars Evald, Ph.D, from the Hammel Neurorehabilitation and Research Center) and approved by the original author (C. Schnakers), it was introduced to all nurses in the department 6 months before the interview to be used in patients unable to reliably communicate pain. The nurses were introduced to the scoring system, the cutoff value of 4 points, and the manual description of the scoring procedure.

According to the manual, to observe spontaneous behavior it is recommended to begin by scoring the patient at rest for at least 1 minute while the patients has open eyes. The score to observe pain is conducted during a (potentially) painful treatment or stimulation of a part of the body.

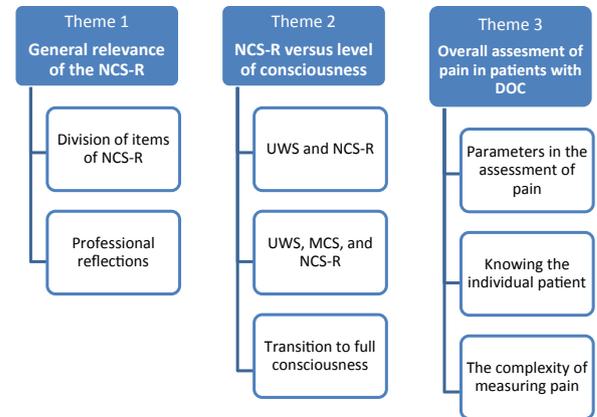
In the department, it was already mandatory for the nurses to screen patients for pain by means of either the PAS scale (Poulsen et al., 2016) or a visual analog scale (VAS) (Haefeli & Elfering, 2006) corresponding within the first 24 hours of admission as part of quality monitoring. Furthermore, it was mandatory to assess pain before and after pain-relieving treatment (both medication and other actions, e.g., repositioning).

#### Analysis

The analysis was inspired by Kvale (1996). The qualitative analysis was done as an inductive process between the three authors. First they read the interview text solely several times to get an overview of the content and meaning units were found and decided. After this the authors met and discussed the meaning units until agreement was achieved. Next the authors initially coded the texts separately, after which the codes were compared and discussed until agreement was reached. At last codes were categorized into subthemes and themes by the three authors (Fig. 1).

#### Preconception

The authors of this study were all employed in the department where the study was conducted. The last author was the clinical nurse specialist responsible for implementing the NCS-R in the



**Figure 1.** Themes and subthemes arose from the two focus group interviews. NCS-R = Nociception Coma Scale–Revised; DOC = disorders of consciousness; UWS = unresponsive wakefulness syndrome; MCS = minimally conscious state.

department. The second author was a bachelor nurse student, and the first author was the head of research at the department. The authors represented both the inside and outside perspective because they were all familiar with the department but also had a distance to the setting in that they were not part of the clinical nursing staff. After reading the literature and before the focus group interviews were conducted, the authors had the impression that the NCS-R would be suitable in this specific clinical practice. To increase trustworthiness, the authors discussed and reflected together during the analysis of the interviews.

#### Setting

The study was performed in a specialized subacute rehabilitation department for patients with severe brain injuries in Copenhagen, Denmark. The department receives patients from the eastern part of Denmark and has a catchment area of approximately 2.6 million inhabitants. Highest priority is given to patients who, after initial treatment in a neurosurgical or other clinic, have a GCS score in the 3- to 12-point range 1 day after cessation of sedation. Patients with a higher GCS scores are admitted if they have severe focal neurologic deficits or are severely agitated. Patients are transferred from the intensive care unit as soon they ventilate spontaneously, even if their prognosis for recovery might appear extremely poor. Around-the-clock treatment and rehabilitation are started at day 1 by interprofessional teams comprising a neurologist/psychiatrist, neuropsychologist, physiotherapist, occupational therapist, nurse, social worker, and, if needed, speech therapist. Rehabilitation is based on principles that give emphasis to sensory stimulation and direct functional training (Engberg, Liebach, & Nordenbo, 2006).

#### Ethical Issues

The Helsinki Declaration was respected. The participating RNs and NAs were informed orally and in writing about the purpose of the interview and were informed that their participation was voluntary and that they could withdraw their consent at any time without providing reasons why and without suffering any consequences. Furthermore, the participants were assured that data would be handled confidentially and that for the publication of the results, their identity would not be revealed. All invited participants gave their informed written consent and none subsequently withdrew their consent.

## Results

Three themes and eight subthemes arose from the two focus group interviews (Fig. 1).

### *Theme 1: General Relevance of the NCS-R*

In general, the nurses agreed on the relevance of the content of the NCS-R scale related to patients in UWS and MCS. The nurses expressed that the three subscales (verbal response, motor response, and facial expression) made sense and all comprised areas that were included in the general observation of pain in patients with DOC.

#### *Division of Items of the Scale*

The nurses found that the principle of the division of the items of the NCS-R represents a clear logic; the higher the points, the more pain. To work with a concrete measure makes an evaluation easier (e.g., assessment 1 hour after treatment with analgesics or after repositioning the patient). At the same time, the nurses occasionally found that the score might not correlate with their professional clinical judgment:

I find it hard to “measure and weigh” the patient, because they are so different, they react so differently if in pain. I mean to fit them into a scale: Now [with the NCS-R] you have to score 4 to indicate pain. We have talked about patients who score 0 (points), but clinically show signs of pain and the other way around—patients who have a high score, but whose symptoms might be explained by other things than pain. You just have doubts if it's about pain, regardless of the NCS-R score. (RN 2)

This nurse seemed to lack confidence in the division of the NCS-R scale and the picture it provided about the patients being in pain and to what degree. She found that too much bias was present when interpreting the score. She also related critically to the cutoff value of 4 points used to indicate pain. She found that the clinical evaluation of the patient with DOC who is in pain was more complicated and unpredictable than assumed when using the NCS-R.

Furthermore, the nurses questioned the understanding of, for example, the single area “oral reflexive movements/startle response” (the behavior that gives 1 point in the item facial expression). They suggested that the score on this particular area might not be used if not properly understood.

#### *Professional Reflections*

The nurses naturally made general observations of the patient at rest for comparison with situations in which the patient was active, but they found it hard to identify the resting situation for use as a baseline with the NCS-R score. Nevertheless, the nurses thought that it encouraged professional reflection to use an assessment scale resulting in a score. The results of the score invite intervention, and using the score promotes a systematic approach and continuity in the evaluation of the patient who is suspected of being in pain. Without a score, assessment becomes more random and subjective. Furthermore, the nurses questioned the situations in which the NCS-R was used.

How do we know when a situation is potentially painful? According to the NCS-R, you should score in situations during potentially painful treatment. Do we agree on the potentially painful situations, so that we can obtain a basis for comparison? (RN 5)

The nurses would have preferred a clearer definition of the situations in which the NCS-R should be used. They also pointed out that they found it unethical to stimulate the patient in a probably painful way to provoke a reaction “just” to get a score for the NCS-R. They also questioned when exactly to use the NCS-R.

Do I score during a specific situation, or do I gather the overall impression from a whole shift? If so, do I score from the poorest situation with the highest possible score or do I provide an average score? (RN 6)

### *Theme 2: NCS-R versus Level of Consciousness*

The target group for the use of NCS-R represents a broad spectrum of patients with DOC, meaning patients in either UWS or MCS. The nurses found several issues related to this.

#### *Patients in UWS and NCS-R*

The nurses expressed that most patients with DOC are unable to express themselves verbally or nonverbally in a reliable way, especially patients in UWS. The nurses expressed that in relation to the verbal subscale, it would be impossible for patients in UWS to obtain the score 3 for verbal response. To get the score 3, patients would have to be able to express “at least one clearly intelligible negative verbalization.” The nurses contested that this demands linguistic ability and consciousness, which patients with severe brain injury do not have. The nurses also stressed that patients who are unable to express pain verbally are not necessarily free of pain. Thus they found it “unfair” that those patients would seldom or never be able to achieve the highest score of 3, and they agreed on the following:

The scale does not really account for the level of consciousness. (RN 2)

In fact, one of the nurses suggested a change or even the exclusion of the verbal response in grade 3 to achieve a more realistic picture of the pain experience related to the level of consciousness.

Furthermore, the nurses argued that patients with severe brain injury often suffer from motoric limitations because of paralysis and sensory disturbances. This means that they would probably never be scored in the high end (3 points) on the NCS-R in the subscale for motor response. To get the score 3 in the motor subscale, the patient must be able to “locate and make contact with the (potentially) painful area and/or push away the caregiver's hand.” Nurses stated:

Sometimes the motoric responses are difficult [to assess], especially in patients in UWS. They often don't move at all and not in a way that you can see that they are in pain. They don't have the physical ability to react on the specific subjects on the NCS-R scale due to contractures and paresis. This means that they don't fit into the categories of the motor response and therefore may not get a fair score. They are lost... they sort of “slip through” (RN 1)

The nurses identified problems with the use of the NCS-R in this respect and therefore believed that it prevented a secure interpretation of the patient in pain.

#### *NCS-R for Patients in UWS and MCS*

The nurses pointed out that patients with tracheostomies are excluded from a valid score because of their inability to produce

sound and speak regardless of their level of consciousness. This makes the score unreliable regarding the presence of pain for a large part of the target group.

The nurses found that the subscale of facial expression was highly relevant. It represented issues that made the nurse aware of the suspicion of pain. However, some of the subjects were considered rather ambiguous. The patient will get the score 3 if they display crying and tears during potentially painful care. The nurses agreed that crying with tears was very rare in patients with UWS. If crying with tears occurred, it would likely be due to other things, such as autonomic reactions, infection, or lability. The nurses did not consider this a common and definitive sign of pain, and they did not believe that it should be placed as the highest score on the subscale.

#### *Transition to Full Consciousness*

When patients are regaining full consciousness after brain injury and during the recovery period after posttraumatic amnesia or confusion, the nurses were very much aware of patients' capacity in being able to give a more subjective secure response about being in pain. Thus, if patients were able to express themselves verbally or had regained more motor skills, the nurses would choose to turn away from the NCS-R and use, for example, the VAS to achieve a more reliable subjective response from the patient.

If the patient is able to communicate clearly and point out where the pain is, I would rather use a VAS or NRS [Numeric Rating Scale]. (RN 6)

#### *Theme 3: The Overall Assessment of Pain in Patients with DOC*

The nurses experienced a need for autonomic/physiologic parameters in the overall assessment of pain.

#### *Parameters in the Evaluation of Pain in patients with DOC*

The nurses included observations of physical vital indicators such as pulse, respiratory rate, skin color, and sweating in their total evaluation of the patient being in pain.

You have to use the parameters of the EWS [Early Warning Score] as a supplement to the NCS-R and document with notes what makes you assume that the patient is in pain. That is why our patients are under surveillance...we get indicators on pain from observing their pulse and respiratory frequencies. (NA 3)

A nurse provided an example:

I performed a score by the NCS-R today, but the patient scored zero. However, the patient had a very high pulse and respiratory rate—so the patient was treated with analgesics. He did not achieve any grade on the NCS-R scale. (RN 2)

Together with the physician, the nurse evaluated when and how to intervene on this observation and in this particular case they did not include the result of NCS-R in the treatment decision. The nurses agreed that the NCS-R cannot stand alone as a tool for evaluation of the patient who may be in pain; it can only form part of the overall assessment.

#### *The Necessity of Knowing the Individual Patient*

The nurses pointed out the need to know each patient's reactions, conditions, and capacities as an essential element in the overall assessment besides the NCS-R and in some cases replacing it. They highlighted the diversity in patients, in brain injuries, the

process of "awakening" after brain injury, and especially the individual patient's unique rehabilitation progress and the importance of taking these factors into consideration. The nurses found that professional clinical judgment is crucial to the interpretation of patients' pain status. They stated that sometimes the patient does not react to the specific point in the NCS-R (e.g., moaning), but because the nurse has knowledge about the individual patient's way of reacting in certain situations and commonly compare this to, for example, the level of pulse and sweating, the interpretation becomes more nuanced.

Sometimes the patient gets a high score [on the NCS-R] during an activity, but if I use my knowledge about the patient and my experience with him, I can conclude that it's not necessarily about pain, but could be about a need for emptying the bladder or being re-positioned. (RN 5)

Thus the nurses questioned the accuracy of an NCS-R score in giving information about the patient experiencing pain.

#### *The Complexity in the Measurement of Pain in Patients with DOC*

The complexity in measuring and assessing pain in patients with DOC is increased by the fact that there might be other explanations for the signs and symptoms of pain. The nurses mentioned disorders of perception as an example. In the following quote a nurse evaluated whether the NCS-R was able to help differentiate disorders of perception from the pain experience:

When one of our patients is sitting on a bathing chair, she reacts very violently. In that case, my colleague used the NCS-R because it might be about pain. She experienced that it was difficult to interpret the result. The patient reached a total score on the subscales of more than 4, but several questions arose: Was it fear or pain? Was it actually painful for her? Did she react due to the situation—the bath—or due to the chair? Did the patient just feel uncomfortable or unsafe and yet reacted in this way because of DOC? After the activity, the patient calmed down completely and was positioned comfortably in bed and everything was OK. So, should we have given her an analgesic based on the NCS-R score? (RN 9)

In this case the nurse expressed that the NCS-R did not succeed in differentiating pain from disrupted perception and pointed out that knowledge of the patient was essential to a nuanced interpretation of the patient's reactions. The nurses found a similar issue related to difficulty differentiating dysautonomia from pain.

## **Discussion**

The findings of our study indicate that the NCS-R has a potential for use in clinical practice in patients with DOC. However, it seems that there is a need for adjustment of the scale and its recommended cutoff level. As a main finding, the nurses perceived that the subscales of the NCS-R were intuitively true based on their experience, and they were positive about the point scoring used by the scale. They suggested, however, that the scale should be supplemented by assessment of physiologic/autonomic signs of pain. This is in concordance with the PAS scale (Poulsen et al., 2016), which consists of both behavioral and physiologic signs of pain like, for example, pulse, blood pressure, and sweating. Also Arbour et al. (2014) found that flushing as well as respiratory rate could be considered physiologic indicators of the presence of pain in patients with DOC. Evidence on the use of physiologic signs of pain remains very limited, and there is a need for more studies to clarify if adding physiologic signs of pain will add valuable information for

patients in DOC. Though the nurses in our study did not mention specific observations of visual issues, it may be discussed if the visual subscale of the original NCS scale is missing as an important clinical aid in the nurses' assessment of pain, as stated by Vink et al. (Vink, Eskes, Lindeboom, van den Munckhof, & Vermeulen, 2014).

Another important finding was that the nurses were critical of the functionality of the NCS-R in patients with UWS. They argued that the scale was unable to assess these patients fairly because they very rarely would reach the set cutoff level at 4 points as a sign of pain. This is a clear disadvantage of the scale because those patients are the most difficult ones to assess. It is criticized that the high end of the scale is rarely or never reached, which was exemplified by the single area "crying with tears" in the facial subscale giving the score of 3. This is seen by the nurses as an ambiguous behavior more than a definitive facial expression about being in pain, and they thus probably would not score this as pain. Furthermore, in the acute and the subacute phase of rehabilitation, patients are at risk of many complications, such as disturbed sense of perception or dysautonomia (Whyte et al., 2013), which in fact makes it difficult to distinguish between these complications on the one hand and signs of pain on the other.

The only study in which the clinical relevance of NCS-R has been evaluated is Chatelle et al.'s study (2016). The authors found that the scale was capable of capturing a difference between before and after analgesic treatment, which was found to be a significant reduction in NCS-R scores in patients with UWS and MCS. Patients were included based on a score of at least 4 on the NCS-R. However, interpretation of the result of the study was challenged in several ways. First, diagnosis of UWS and MCS was made based on GCS scores, which is against the recommendations for the use of the Coma Recovery Scale—Revised (Giacino et al., 2002), and thus the diagnosis may be insecure. Second, the time between the two assessments was up to 24 hours, and thus the change over time may not necessarily reflect that the scale is sensitive to changes. Third, the authors did not discuss the issue that patients in UWS may have difficulties reaching the cutoff of 4 points, and that was a considerable concern among the nurses in our study. The cutoff value set at 4 points was also discussed by Vink et al. (2014, 2017), who point out that intubated patients constitute a large part of the patient group with UWS and MCS and that they should not be excluded from the use of NCS-R but nevertheless can hardly reach the cutoff as a result of physical conditions. A similar issue may be raised for patients with paresis and aphasia concerning the subscores in the motor and verbal response categories, respectively. A score less than a cutoff value therefore is not a guarantee of the absence of pain, and any increase in the NCS-R should therefore make the nurses consider a pain-relieving intervention (Vink et al., 2017). Furthermore, Vink suggests lowering the cutoff value to, for example, 2 points or, as an alternative, narrowing down the target group for the NCS-R to patients with a minimum GCS score of 5 points, as used in the inclusion criteria in the reliability study by Vink et al. (2014).

The cutoff value at 4 points also produced problems in another manner in our study, as expressed by the nurse who had doubts about the high score reached by the patient on a bathing chair. By using her knowledge of the individual patient, considering whether the reaction was due to anxiety or pain, they concluded that if she had perceived this as pain (indicated by the NCS-R), the patient would have received an incorrect intervention.

In our study the nurses expressed discomfort relating to the fact that NCS-R is to be assessed in situations that are potentially painful. The original NCS was developed by neuropsychologists who exposed patients to noxious and non-noxious stimulation to observe their reaction (Schnakers et al., 2010b). This is very different from the practices of nurses. Nurses are educated not to

harm patients because this runs counter to the international ethical code of nursing (ICN, 2012). Thus nurses would prefer that stimulations and scoring formed part of daily treatment and already planned care. This is also the case in other studies aimed at testing the NCS-R (e.g., Vink et al., 2014). Moreover, the need for an overall assessment by nurses to determine if patients are in pain or not is often advocated by both relatives and physicians at rounds. For this purpose, the NCS-R, which is scored in a specific situation, seems insufficient. We argue, therefore, that elements such as level of activity, the actual context, and the impression of anxiety or disrupted perception assessed by the nurse, together with physiological signs of pain, should supplement the NCS-R score (Vink et al., 2014). As stated by Vuille et al. 2017, scales developed for nursing practice must match the practice and professional judgments of nurses in a meaningful way to be accepted and implemented (Vuille, Foerster, Foucault, & Hugli, 2017). We agree on this important concern in preparation of such instructions and will ourselves take this into consideration in our continuous work with the NCS-R.

### Strengths and Limitations

Taking a qualitative approach, the present study is the first to describe nurses' experience with the NCS-R. A qualitative approach is important when evaluating scale functionality; a quantitative approach alone is inadequate. This study addresses the importance of studying the users' perspective because nurses are the professional group that assesses and treats pain in patients around the clock. The validity of our study could have been enhanced if we had included focus group interviews from other departments. We had planned to do so, but we are the only department in Denmark that uses the NCS-R. We included both RNs and NAs in the study and intended to mirror the departments nursing staff in experience, seniority, and professions.

### Conclusions

Our study points out that the content and subscales of the NCS-R are relevant for pain assessment in patients with severe brain injury in subacute rehabilitation. However, the scale cannot serve as an absolute single measure for determining the presence of pain. The cutoff value of 4 points should be reconsidered because a large number of patients with UWS cannot reach a high score on the NCS-R. In the experience of the nurses, NCS-R needs to be supplemented by both physiologic/autonomic signs of pain and by the nurses' knowledge of the individual patient's reactions. The nurses' clinical judgment is crucial in the use of NCS-R to achieve an overall pain assessment in patients with DOC to identify patients in pain and evaluate any pain-relieving interventions.

### Acknowledgments

The authors acknowledge the nurses sharing their clinical experience with us and making the focus groups study possible. Also thank you to the management of our departments for support our clinical research.

### References

- Arbour, C., Choiniere, M., Topolovec-Vranic, J., Loiselle, C. G., Puntillo, K., & Gelinas, C. (2014). Detecting pain in traumatic brain-injured patients with different levels of consciousness during common procedures in the ICU: Typical or atypical behaviors? *Clinical Journal of Pain*, 30(11), 960–969.
- Chatelle, C., De Val, M. D., Catano, A., Chaskis, C., Seeldrayers, P., Laureys, S., Biston, P., & Schnakers, C. (2016). Is the Nociception Coma Scale—Revised a

- useful clinical tool for managing pain in patients with disorders of consciousness? *Clinical Journal of Pain*, 32(4), 321–326.
- Chatelle, C., Majerus, S., Whyte, J., Laureys, S., & Schnakers, C. (2012). A sensitive scale to assess nociceptive pain in patients with disorders of consciousness. *Journal of Neurology, Neurosurgery, and Psychiatry*, 83(12), 1233–1237.
- Echegaray-Benites, C., Kapoustina, O., & Gelinas, C. (2014). Validation of the use of the Critical-Care Pain Observation Tool (CPOT) with brain surgery patients in the neurosurgical intensive care unit. *Intensive Critical Care Nursing*, 30(5), 257–265.
- Engberg, A. W., Liebach, A., & Nordenbo, A. (2006). Centralized rehabilitation after severe traumatic brain injury—a population-based study. *Acta Neurologica Scandinavica*, 113(3), 178–184.
- Ersek, M., Herr, K., Neradilek, M. B., Buck, H. G., & Black, B. (2010). Comparing the psychometric properties of the Checklist of Nonverbal Pain Behaviors (CNPI) and the Pain Assessment in Advanced Dementia (PAIN-AD) instruments. *Pain Medicine*, 11(3), 395–404.
- Giacino, J. T., Ashwal, S., Childs, N., Cranford, R., Jennett, B., Katz, D. I., Kelly, J. P., Rosenberg, J. H., Whyte, J., Zafonte, R. D., & Zasler, N. D. (2002). The minimally conscious state: Definition and diagnostic criteria. *Neurology*, 58(3), 349–353.
- Haefeli, M., & Elfering, A. (2006). Pain Assessment. *European Spine Journal*, 15(Suppl 1), S17–S24.
- Halkier, B. (2016). *Fokusgrupper (Focusgroups)*, 3. Copenhagen, Denmark: Samfundslitteratur.
- Herr, K., Bjoro, K., & Decker, S. (2006). Tools for assessment of pain in nonverbal older adults with dementia: A state-of-the-science review. *Journal of Pain and Symptom Management*, 31(2), 170–192.
- ICN. (2012). *The ICN Code of Ethics for Nurses*. Geneva, Switzerland: International Council of Nurses.
- Kvale, S. (1996). *InterViews. An introduction to Qualitative Research Interviewing*. London: Sage.
- Laureys, S., Celesia, G. G., Cohadon, F., Lavrijsen, J., Leon-Carrion, J., Sannita, W. G., Szabon, L., Schmutzhard, E., von Wild, K. R., Zeman, A., Dolce, G., & European Task Force on Disorders of Consciousness. (2010). Unresponsive wakefulness syndrome: a new name for the vegetative state or apallic syndrome. *BMC Medicine*, 8, 68.
- Merkel, S., Voepel-Lewis, T., & Malviya, S. (2002). Pain assessment in infants and young children: The FLACC Scale: A behavioral tool to measure pain in young children. *AJN The American Journal of Nursing*, 102(10), 55–58.
- Poulsen, I., Brix, P., Andersen, S., Westergaard, L., & Guldager, R. (2016). Pain Assessment Scale for Patients With Disorders of Consciousness: A preliminary validation study. *The Journal of Neuroscience Nursing*, 48(3), 124–131.
- Schnakers, C., Chatelle, C., Majerus, S., Gosseries, O., De Val, M., & Laureys, S. (2010a). Assessment and detection of pain in noncommunicative severely brain-injured patients. *Expert Rev Neurother*, 10(11), 1725–1731.
- Schnakers, C., Chatelle, C., Vanhaudenhuyse, A., Majerus, S., Ledoux, D., Boly, M., & Laureys, S. (2010b). The Nociception Coma Scale: A new tool to assess nociception in disorders of consciousness. *Pain*, 148(2), 215–219.
- Schnakers, C., & Zasler, N. (2015). Assessment and management of pain in patients with disorders of consciousness. *PM & R: The Journal of Injury, Function, and Rehabilitation*, 7(11 Suppl), S270–S277.
- Vink, P., Eskes, A. M., Lindeboom, R., van den Munckhof, P., & Vermeulen, H. (2014). Nurses assessing pain with the Nociception Coma Scale: Interrater reliability and validity. *Pain Management Nursing*, 15(4), 881–887.
- Vink, P., Lucas, C., Maaskant, J. M., van Erp, W. S., Lindeboom, R., & Vermeulen, H. (2017). Clinimetric properties of the Nociception Coma Scale (Revised): A systematic review. *European Journal of Pain*, 9, 1463–1474.
- Vuille, M., Foerster, M., Foucault, E., & Hugli, O. (2017). Pain assessment by emergency nurses at triage in the emergency department: A qualitative study. *Journal of Clinical Nursing*, 27(3-3), 669–676.
- Whyte, J., Nordenbo, A. M., Kalmar, K., Merges, B., Bagiella, E., Chang, H., Yablon, S., Cho, S., Hammond, F., Khademi, A., & Giacino, J. (2013). Medical complications during inpatient rehabilitation among patients with traumatic disorders of consciousness. *Archives of Physical Medicine and Rehabilitation*, 94(10), 1877–1883.