

The experienced barriers and facilitators of healthcare professionals regarding the current use of the Pain Assessment Checklist for Seniors with Limited Ability to Communicate-Dutch (PACSLAC-D): a qualitative study

Name: A.M. Prins
Student number: 3612007
Course: Research Internship 2: Master Thesis
Status: Final
Reference style: Vancouver

Lecturer: Dr. S.W.M. Weldam
Supervisor: Dr. W.H. Oldenmenger
Internship: Erasmus MC, Rotterdam
Date: June 19, 2020
Master program: Clinical Health Sciences, Nursing Science
Utrecht University

Journal: Journal of Pain and Symptom Management

Word count: 3640
Word count abstract: 300
Word count abstract Dutch: 300

English Abstract

Title: The experienced barriers and facilitators regarding the Pain Assessment Checklist for Seniors with Limited Ability to Communicate-Dutch (PACSLAC-D): a qualitative study

Background: Approximately 50% of people with dementia also have a painful condition. Symptoms associated with dementia may lead to difficulties expressing pain experiences. To objectively measure the pain of patients with dementia, the Pain Assessment Checklist for Seniors with Limited Ability to Communicate–Dutch (PACSLAC-D) was developed. Clinical practice shows that the PACSLAC-D is not used effectively in daily practice on the geriatric ward of a general hospital due to improper implementation. To re-implement the PACSLAC-D on the geriatric ward, it is necessary to assess the experienced barriers and facilitators of healthcare professionals (HCPs) regarding the current use of the PACSLAC-D.

Aim: To describe HCPs' experienced barriers and facilitators regarding the current use of the PACSLAC-D on the geriatric ward of a general hospital.

Method: A generic descriptive qualitative research design was used, with focus groups and individual interviews. Data analysis was conducted through thematic analysis.

Results: Eighteen HCPs participated in the focus groups or interviews. The themes “barriers,” “facilitators,” and “implementation” were identified. The main barrier was nurses' resistance of use. This resistance can be explained by the nurses' preference to rely on clinical judgment and the multi-interpretability that nurses experienced. Most important facilitators were the insight that the PACSLAC-D gave into the degree of experienced pain in patients and the course of pain over multiple days.

Conclusion: Various barriers and facilitators concerning use of the PACSLAC-D in daily practice were described. The main barrier, nurses' resistance of use, was explained by nurses' preference to rely on their clinical judgement and the poor interrater reliability of the PACSLAC-D. To overcome this barrier, HCPs should be engaged in formulating the re-implementation strategy.

Recommendations: A tailored re-implementation strategy must be developed in consultation with the HCPs. Future research should evaluate the effects of the re-implementation.

Keywords: Pain, dementia, PACSLAC-D, barriers, facilitators

Nederlandse samenvatting

Titel: De ervaren belemmerende en bevorderende factoren tijdens het gebruik van de PACSLAC-D: een kwalitatief onderzoek

Achtergrond: Ongeveer 50% van de mensen met dementie heeft een pijnlijke aandoening. Patiënten met dementie kunnen pijn moeilijk uiten. Om de pijn van patiënten met dementie te objectiveren is de Pain Assessment Checklist for Seniors with Limited Ability to Communicate Dutch (PACSLAC-D) ontwikkeld. Uit de klinische praktijk blijkt dat de PACSLAC-D niet goed gebruikt wordt op de geriatrische afdeling van een algemeen ziekenhuis door een onjuiste implementatie. Om de PACSLAC-D op de geriatrische afdeling opnieuw te implementeren, moeten de ervaren belemmerende en bevorderende factoren van zorgverleners bij het huidige gebruik van de PACSLAC-D worden geïnventariseerd.

Doelstelling: Het beschrijven van de belemmerende en bevorderende factoren die zorgprofessionals ervaren tijdens het gebruik van de PACSLAC-D op de geriatrische afdeling van een algemeen ziekenhuis.

Methode: Gebruik werd gemaakt van generiek beschrijvend kwalitatief onderzoek met focusgroepen en individuele interviews. De resultaten werden thematisch geanalyseerd.

Resultaten: Achttien zorgprofessionals namen deel aan de focusgroepen en interviews. De thema's "belemmerende factoren", "bevorderende factoren" en "implementatie" werden geïdentificeerd. De belangrijkste belemmerende factor was de weerstand van gebruik van verpleegkundigen. Deze weerstand kan worden verklaard door de voorkeur van gebruik voor de klinische blik van verpleegkundigen en de multi-interpreteerbaarheid die verpleegkundigen ervaren. De belangrijkste bevorderende factoren waren het inzicht dat de PACSLAC-D gaf in de mate van pijn en het verloop van pijn over een aantal dagen.

Conclusie: Zorgprofessionals beschreven verschillende belemmerende en bevorderende factoren voor het gebruik van de PACSLAC-D in de dagelijkse praktijk. De belangrijkste belemmerende factor, weerstand van verpleegkundigen, werd verklaard door de voorkeur voor de klinische blik van verpleegkundigen en de slechte interbeoordelaarsbetrouwbaarheid van de PACSLAC-D. Om deze belemmering te overwinnen zouden zorgverleners betrokken moeten worden bij de her-implementatiestrategie.

Aanbevelingen: Zorgverleners moeten betrokken worden bij het ontwikkelen van een her-implementatiestrategie. Toekomstig onderzoek moet de effecten van de herimplementatie evalueren.

Trefwoorden: Pijn, dementie, PACSLAC-D, implementatie, verpleegkundigen

Introduction

The world's population is aging. The global population of people aged 65 years and older is expected to increase from 901 million in 2015 to almost 2.1 billion by 2050 (1,2). Due to this population growth, there will be an increase in the prevalence of dementia. Approximately 47 million people worldwide were living with dementia in 2015. This number is expected to increase to 131 million by 2050 (3,4).

Generally, 50% of people with dementia also have a painful condition (5). To assess pain, self-reports are the gold standard (6–9). However, self-report often becomes compromised in patients with dementia (10–12). Symptoms associated with dementia (e.g., memory impairment, behavioral symptoms, and decline of language capacity) may lead to difficulties expressing pain experiences (9,11–18). Behavior associated with pain may be absent, making it difficult to interpret pain in patients with dementia. Furthermore, symptoms attributed to dementia may actually be indications of pain. Aggressive behavior, for example, may be a protective response by patients unable to articulate their pain. Pain can therefore go unrecognized, which leads to inadequate pain management. Inadequate pain management for people with dementia can cause adverse outcomes, such as neuropsychiatric symptoms, decreased quality of life, increased caregiver burden, nursing care burden, increase in healthcare costs, and avoidable institutionalization (19–22). It may also result in adverse drug side effects such as confusion, falls, and opioid overdose (19–27). Consequently, healthcare professionals (HCPs) may incorrectly recognize or interpret expressions of pain and thus inadequately assess and treat pain (9,13,28–35). To objectively measure the pain of patients with dementia, several observational pain assessment scales have been developed (28,35). Fuchs-Lacelle (36) developed and validated the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC) (37,38). The items of the PACSLAC are based on a list of pain indicators for seniors with cognitive impairments. This list consists of six items: nonverbal vocalizations, facial grimacing and wincing, bracing, rubbing, restlessness, and vocal complaints (36). As a refinement, Zwakhalen et al. (39) developed a reliable, valid, and useful 24-item Dutch version of this scale called the PACSLAC – Dutch (PACSLAC-D) (8,37). The 24-items are clustered in three categories: facial and vocal expression, resistance/defense, and social-emotional aspects/mood (8,40,41).

To assess pain, an HCP must use the PACSLAC-D any time a change of behavior is reported that might be related to pain. The PACSLAC-D must be used to reassess the pain after every pain intervention (36,39). An HCP will score an item if the behavior is present during the five minute observation period (42). A score of four or higher indicates that the patient has pain (28,37,38).

In 2012, the PACSLAC-D was implemented on the geriatric nursing ward of a general hospital by informing the HCPs of the pain assessment measurement. However, the PACSLAC-D is not used properly in daily clinical practice, and it is unclear what causes this misuse.

To optimize the implementation strategy – and thereby improve care for patients with dementia – a tailored implementation approach is needed (43,44). To re-implement the PACSLAC-D on the geriatric ward, it is necessary to first assess the experienced barriers and facilitators of HCPs in the current use of the PACSLAC-D. Once these specific factors are known, tailored re-implementation strategies can be developed.

Aim

The aim of this study was to describe the experienced barriers and facilitators of HCPs regarding the current use of the PACSLAC-D on the geriatric ward of a general hospital.

Method

Design

A generic descriptive qualitative research design was used (45–48). Three focus groups were conducted with HCPs working on the geriatric ward. Focus groups stimulate the exchange of views through discussion, allow mutual differences or similarities to drive the conversation, and enable themes to emerge (49–51). HCPs from the neurology ward of the same hospital were approached for additional interviews to enrich and confirm the initial data. The neurology ward was chosen because it had attempted to re-implement the PACSLAC-D in early 2019. This article follows the COnsolidated criteria for REporting Qualitative (COREQ) research guidelines (52).

Participants

The population of interest consisted of HCPs working on a geriatric or neurology ward at a general hospital. The participants were selected through purposeful sampling to establish variation among them (53). The study inclusion criteria were as follows: currently working at the geriatric or neurology ward as a nurse or nurse practitioner, physician, or geriatric physiotherapist; experienced with the use of the PACSLAC-D; fluent in Dutch; and aged eighteen years or older.

Data Collection

Participants were invited by email, by WhatsApp, or face to face. All focus groups and individual interviews were held between February and March 2020. The focus groups and interviews were audio-recorded and video-recorded and then transcribed verbatim. The interview guide was developed based on the results of a pilot implementation in Dutch nursing homes in 2011 (40). The interview guide was reviewed in a pilot interview and included the following key topics: pain measurement, use of the PACSLAC-D in daily practice, barriers and facilitators of the PACSLAC-D, and ways to improve the use of the PACSLAC-D. Demographic characteristics that were collected consisted of age, level of education, work experience, and profession.

Ethical Considerations

The protocol for this study was submitted for approval to the Commission of Medical Ethics of the Erasmus MC (MEC-2019-0820). Approval was granted on February 3, 2020. All participants were given written information concerning the study, including the aim and the contact details of the researchers. In addition, the participants were informed that they could withdraw at any time without any penalty. Prior to the data collection, signed consent forms were collected from the participants. Confidentiality was maintained through all steps of data

collection and analysis through the allocation of a code for each participant. During the study, the researcher worked as a nurse on the geriatric ward where this study was conducted.

Data Analysis

A thematic analysis approach was used to analyze the data by two student researchers (A.P. and A.K.). Thematic analysis is a useful and flexible method for qualitative research that searches for themes or patterns (54,55). This method is an analytical approach that leads to organizing and analyzing the data through examining its rich details. In this study, the procedure proposed by Braun and Clarke (54,55) was used. The verbatim transcribed data was read several times, and initial ideas were noted in order to become familiar with the data. Then, interesting features of the data were coded manually by A.P. After that, the two researchers (A.P. and A.K.) reviewed the codes and clustered them according to potential themes. During the next stage, the researchers A.P. and A.K. identified themes and subthemes, made comparisons between the data, and created a thematic map. Differences were resolved through discussion between the two researchers until agreement was reached. Finally, an ongoing analysis was conducted to refine the specifics of each theme and to identify the overall narrative of the analysis (54,55). After the analysis, quotes were selected and translated by A.P. To enhance the study's validity and reliability, investigator triangulation was used (56). The researchers' thoughts and mindsets during the analyses were documented through theoretical memos. These memos provide insight about how the themes were deduced from the data (57).

Results

A total of 35 HCPs were approached for participation. Twenty-eight agreed to participate, and ultimately eighteen HCPs were able to participate in three focus groups and two individual interviews. The participants' mean age was 30 years (standard deviation [SD] = 11.1), and the mean work experience was 7.6 years ($SD = 9.9$). The participants' characteristics are listed in Table 1. Reasons for not attending the interviews were also collected and are listed in Figure 1.

Table 1

Figure 1

The data analysis resulted in the identification of three themes: 1) barriers, 2) facilitators, and 3) implementation. The themes "barriers" and "implementation" have subthemes.

Barriers

Participants mentioned lack of knowledge concerning the use of the PACSLAC-D as a barrier. Moreover, the nurses cited resistance to using the PACSLAC-D and a preference for relying solely on their clinical judgment.

Lack of knowledge

Participants frequently commented that they did not know how to interpret the items of the PACSLAC-D and how to interpret the score of the PACSLAC-D. In addition, most participants were unaware that a PACSLAC-D protocol could be found in the Electronic Patient Dossier (EPD).

When I see a Numeric Rating Scale [NRS] of three in the chart, I know what interventions are required. But with a PACSLAC score of seven, I don't know what to do. (Participant 7)

All participants implied that no training on the PACSLAC-D was provided during their introduction period at the ward. A majority of the nurses stated that they learned to use the PACSLAC-D on the job.

Nurses' resistance of use

Nurses spoke about their resistance towards the PACSLAC-D. They experienced the

PACSLAC-D as lengthy and requiring substantial effort to complete. For those reasons, most nurses refused to use the PACSLAC-D.

All participants mentioned the multi-interpretability and subjectivity of the PACSLAC-D. The participants indicated they did not consider the PACSLAC-D reliable due to this multi-interpretability and subjectivity:

But I must say that I find some items of the PACSLAC-D difficult to interpret. Like a dark look, for instance. I find this quite difficult to judge because “What is a dark look?” Just like “restless”; when is someone restless.... I always find that difficult and subjective. You may measure a dark look differently than me. (Participant 8)

The majority of the nurses declared that they could observe and acknowledge pain themselves and that they did not need the PACSLAC-D to do that for them. The nurses also indicated that they did not need the PACSLAC-D to act on observed pain or to inform the physician that a patient was in pain. This attitude was expressed most strongly by nurses with more than four years of work experience.

I personally feel that clinical judgment is more important than all those instruments – let that be clear. (Participant 3)

I feel I can observe and acknowledge pain myself. I do not need the PACSLAC-D to do that. I will inform the physician of my observations. It may be courageous but... this is what I observe; it is not necessary to fill out the PACSLAC-D to inform the physician. (Participant 4)

Facilitators

In contrast to the nurses with more work experience, nurses with less than four years of work experience indicated that the PACSLAC-D reinforced their clinical judgment. They stated that the PACSLAC-D confirmed the interventions employed to treat the pain. When asked about the advantages of the PACSLAC-D, all participants unanimously said the PACSLAC-D can provide insight into the degree of pain and the course of pain over several days.

Yes, then they can see what I have observed in the days that I took care of the patient. They can compare the items of the PACSLAC-D with their observed items of the PACSLAC-D to see if the pain symptoms decrease. (Participant 5)

Furthermore, all participants agreed that the PACSLAC-D was universally usable for patients in their last stages of life. The PACSLAC-D was also found useful for patients with a

language barrier. When asked about the usability of the PACSLAC-D on their own wards, the participants of the geriatric and neurology contradicted each other. Nurses from the neurology ward indicated that the PACSLAC-D is usable for patients with dementia and less convenient for patients with aphasia. However, the nurses from the geriatric ward declared that the PACSLAC-D is less convenient for patients with dementia, due to possible underlying delirium, and that it is more suitable for patients with aphasia.

Implementation

When asked how to improve the use of the PACSLAC-D on the wards, the participants offered diverse responses. A low number of participants replied that the current use of the PACSLAC-D was sufficient, whereas others thought that lessons should be learned from the current use. The majority of the nurses expressed several recommendations to improve or adjust the PACSLAC-D.

Current use

To improve the use and re-implementation of the PACSLAC-D, one must have insight into the current use of the PACSLAC-D. The data demonstrated that the nurses with more work experience did not use the PACSLAC-D and instead relied on their clinical judgment. Furthermore, HCPs acknowledged that use of the PACSLAC-D was not part of their daily routine. They also admitted that when a patient with dementia was verbally capable of expressing pain in one way or another, the PACSLAC-D was not used.

It is just that the use of the NRS is habit. You fill out the NRS for 80% of your patients with pain, and for the other 20%, you must deviate from your routine. You must realize that you should use the PACSLAC-D. (Participant 12)

Recommendations

When asked how to improve the current use of the PACSLAC-D, the nurses made several recommendations. The HCPs pled for a shorter version of the PACSLAC-D and a logical placement of the PACSLAC-D in the EPD. They would prefer that PACSLAC-D was placed next to the NRS. Furthermore, weighting of the items of the PACSLAC-D was indicated as preferable. HCPs indicated that they thought that a higher score on the PACSLAC-D implies more pain similar to the NRS.

The score is the PACSLAC-D is similar to the score of the NRS. Right?! (Participant 7)

It is absurd that the weighing of the items is the same because in daily practice, this is not the case. (Participant 8)

One participant mentioned the use of the Rotterdam Elderly Pain Observation Scale (REPOS) in a former hospital. The participants of that focus group found the REPOS a shorter and more specific list that removes the items that can also be attributed to anxiety or delirium. The participants were enthusiastic about the decision tree in this scale and the need to provide a description of the current situation of the patient.

Awareness

All participants agreed that awareness should be raised about the existence and use of the PACSLAC-D among nurses and physicians throughout the entire hospital. Most participants thought this could be accomplished through a mandatory e-learning. Several nurses argued that training on the use of the PACSLAC-D could increase the interrater reliability among nurses, and improve the willingness for usage.

Just so we are all on the same page. With a course or video images, you would be much more on the same page. The score would be more accurate in use. (Participant 5)

The participants also pleaded for a “user manual” containing usage agreements. Participants suggested adding cut-off values when dealing with pain symptoms that could also be attributed to anxiety or delirium. Furthermore, the participants would appreciate a description of what the items of the PACSLAC-D contain.

When you follow the list, you need to score the item of aggression. Even when the patient has a history of aggressive behavior. Your PACSLAC-D score will be higher even though you don't feel you have to act on it. (Participant 10)

When someone has a history of aggression, you should be able to score “not applicable”. We should make agreements about when you score an item or not. (Participant 16)

Yeah, exactly. Just the possibility to fill out “yes”, “no”, or “not applicable”. (Participant 13)

Discussion

The results of this study indicate that HCPs experience more barriers towards use of the PACSLAC-D than facilitators. The main barrier in this study was the nurses' resistance of use. This resistance can be explained by the experienced multi-interpretability of the PACSLAC-D and nurses' preference to rely on their clinical judgment. According to the interviewed nurses, the PACSLAC-D is considered unreliable and subjective due to its multi-interpretability. In addition, nurses turned to their clinical judgement because they found themselves capable of assessing pain in patients with dementia without needing a pain observation scale.

The nurses in this study indicated they prefer to use their clinical judgment to determine whether a patient is in pain rather than using the PACSLAC-D. This finding is in line with earlier research demonstrating that nurses believed that they could observe whether a patient was in pain (40,58–62). Furthermore, nurses experienced the use of observation scales as simplistic, often inaccurate, and disrespectful of clinical expertise and judgement (58). However, research has shown that nurses who rely exclusively on their clinical judgement underestimate pain (63), which can lead to delayed diagnosis of serious conditions and insufficient treatment (63,64). Clinical judgement can therefore not replace pain observation scales (63).

Another explanation of the nurses' resistance is that the nurses found the PACSLAC-D to be multi-interpretable and subjective. Research has demonstrated that the multi-interpretability of the PACSLAC-D can derive from poor interrater reliability among HCPs (40), which is remarkable because the PACSLAC-D is a valid and reliable instrument to observe pain in patients with dementia (36). Previous research has reported good interrater reliability among HCPs when using the PACSLAC-D (65,66). The interrater reliability was not evaluated in this study and is therefore unknown. Nevertheless, good interrater reliability cannot be expected when there is no attention to interrater reliability during implementation. In the current situation, the PACSLAC-D was implemented by only informing the HCPs in one instructional meeting. An example of implementation research with attention to interrater reliability is the study by Masman et al. (67). The REPOS, a comparable pain observation scale for patients with dementia, was implemented through in-service training. The training included ten paired observations with an experienced REPOS observer to ascertain sufficient interrater reliability (40,65,67,68). The interrater reliability of the REPOS resulted in a Cohen's kappa of 0.73 and was considered good (67).

Implementing new knowledge adhering to the standard of care among HCPs is difficult and commonly met with reluctance (43,69–71). Additionally, innovations in nursing care often require a change in nurses' behavior. Attempts to change behavior are likely to

depend on the functioning of the team (72). To improve the willingness of change within teams, staff should be engaged in the change initiatives to improve implementation. This way, the sustainability of innovations improves the daily practice (73). A possible strategy for improving staff engagement is the appointment of a nurse champion (74). A nurse champion can create a positive relationship with staff in order to implement practice changes, educate staff about pain management and pain protocol implementation, and organize and facilitate interdisciplinary practice initiatives (74). A nurse champion at ward level could also act as an experienced PACSLAC-D observer to maintain good interrater reliability. Based on the reluctance of HCPs and the difficulty of implementing new knowledge, it is important to use tailored implementation strategies (70,71,75).

Strengths and Limitations

The findings of this study should be considered within the context of several limitations. Firstly, due to restrictions imposed related to the COVID-19 pandemic at the time of data collection, additional interviews with HCPs on other wards could not take place. It is therefore unclear if the implementation of the PACSLAC-D is considered successful on the other wards of the general hospital. Secondly, the sample population was limited. Only 18 of the 35 approached candidates participated. The researcher worked on the geriatric ward as a nurse and was therefore familiar with all the participants, which could lead to information bias. The researcher could as a result failed to ask follow-up questions. It is unclear as to whether data saturation was fully achieved. The results should, therefore, be considered with caution.

A strength of this study was the use of focus groups, which allowed participants to discuss the topic with each other, rather than with just one interviewer. Individual interviews on other wards were used to enrich the data from the focus groups. Additionally, several methods enhancing the rigorous design were used, such as conducting a pilot interview, analyzing interviews based on consensus within the research team, and transparently describing the study in accordance with COREQ principles. Peer reviews and reflections during data analysis were used to reduce the risk of bias. Furthermore, this study offers insight into the experienced barriers and facilitators of PACSLAC-D use. These insights can contribute to the design of re-implementation strategies for general hospitals with the same initial implementation approach. Finally, regarding the level of participation: 28 of the approached 35 candidates took part in the study, five candidates had other commitments and only two candidates were unwilling to participate. Therefore, disinterest among the main population was not deemed as a barrier in this study.

Conclusion

Various barriers and facilitators regarding the use of the PACSLAC-D in daily practice were described. The main barrier, nurses' resistance of use, was explained by the clinical judgement of nurses and poor interrater reliability for the PACSLAC-D. To overcome this barrier, HCPs should be engaged in formulating the re-implementation strategy. With this approach, changes to their daily practice are more likely to be accepted and therefore maintained.

Recommendations

First, a choice must be made by the staff on whether to continue with the PACSLAC-D or implement another pain observation scale for patients with dementia. Regardless of which pain observation scale is chosen, a tailored re-implementation strategy is needed. The re-implementation strategy should take the recommendations of this study's participants into account. The re-implementation must be driven by the HCPs themselves. As recommended by the participants, a hospital-wide e-learning program with an additional in-service training program to enhance interrater reliability should be developed. The in-service training could be based on the training provided in the study by Masman et al. (67). The in-service training program must be led by an experienced HCP encouraging a combination of clinical judgement and consistent use of pain assessment (76). The e-learning and training program must be completed every three years to guarantee the standard of care. To promote the nurses' continued and effective usage of the PACSLAC-D, a nurse champion should be appointed. Subsequently, an evaluation study should be initiated to determine whether the PACSLAC-D is used in daily practice and the interrater reliability among HCPs.

Reference list

1. United Nations. World Population Ageing [Internet]. New York; 2015 [cited 2019 Oct 13]. Available from:
https://www.un.org/en/development/desa/population/publications/pdf/ageing/WPA2015_Report.pdf
2. He W, Goodkind D, Kowal P. An Aging World: 2015 [Internet]. Washington, DC; 2016 [cited 2019 Oct 13]. Available from:
<https://www.census.gov/content/dam/Census/library/publications/2016/demo/p95-16-1.pdf>
3. Livingston G, Sommerlad A, Orgeta V, Costafreda SG, Huntley J, Ames D, et al. Dementia prevention, intervention, and care. *Lancet*. 2017 Dec 16;390(10113):2673–734.
4. Prince M, Anders W, Maëlenn G, Ali G-C, Yu-Tzu W, Prina M, et al. World Alzheimer Report 2015 The Global Impact of Dementia An Analysis of prevalence, Incidence, cost and trends [Internet]. 2015 [cited 2019 Oct 13]. Available from:
<https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf>
5. Tan ECK, Jokanovic N, Koponen MPH, Thomas D, Hilmer SN, Simon Bell J. Prevalence of Analgesic Use and Pain in People with and without Dementia or Cognitive Impairment in Aged Care Facilities: A Systematic Review and Meta-Analysis. *Curr Clin Pharmacol*. 2015;10:194–203.
6. AGS Panel on Persistent Pain in Older Persons. The Management of Persistent Pain in Older Persons. *J Am Geriatr Soc*. 2002 Jun;50(S6):205–24.
7. von Baeyer CL. What's the score in pain assessment? *Med J Aust*. 2012 Apr 2;196(6):379.
8. Zwakhalen SMG, Koopmans RTCM, Geels PJEM, Berger MPF, Hamers JPH. The prevalence of pain in nursing home residents with dementia measured using an observational pain scale. *Eur J Pain*. 2009 Jan 1;13(1):89–93.
9. Malara A, De Biase GA, Bettarini F, Ceravolo F, Di Cello S, Garo M, et al. Pain Assessment in Elderly with Behavioral and Psychological Symptoms of Dementia. *J Alzheimer's Dis*. 2016 Feb 22;50(4):1217–25.
10. Hadjistavropoulos T, Herr K, Turk DC, Fine PG, Dworkin RH, Helme R, et al. An Interdisciplinary Expert Consensus Statement on Assessment of Pain in Older Persons. *Clin J Pain*. 2007 Jan;23(Supplement 1):S1–43.
11. Hadjistavropoulos T, Herr K, Prkachin KM, Craig KD, Gibson SJ, Lukas A, et al. Pain

- assessment in elderly adults with dementia. *Lancet Neurol.* 2014 Dec;13(12):1216–27.
12. Achterberg WP, Pot AM, Scherder EJ, Ribbe MW. Pain in the Nursing Home: Assessment and Treatment on Different Types of Care Wards. *J Pain Symptom Manage.* 2007 Nov;34(5):480–7.
 13. Achterberg WP, Pieper MJC, van Dalen-Kok AH, de Waal MWM, Husebo BS, Lautenbacher S, et al. Pain management in patients with dementia. *Clin Interv Aging.* 2013;8:1471–82.
 14. Fuchs-Lacelle S, Hadjistavropoulos T, Lix L. Pain assessment as intervention: a study of older adults with severe dementia. *Clin J Pain.* 2008 Oct;24(8):697–707.
 15. Kaasalainen S, Akhtar-Danesh N, Hadjistavropoulos T, Zwakhalen S, Verreault R. A Comparison Between Behavioral and Verbal Report Pain Assessment Tools for Use with Residents in Long Term Care. *Pain Manag Nurs.* 2013 Dec;14(4):e106–14.
 16. Markey G, Rabbani W, Kelly P. Association of dementia with delayed analgesia in patients over 70 with acute musculoskeletal injury. *Emerg Med J.* 2013 Oct 7;30(10):875.1-875.
 17. McDermott JH, Nichols DR, Lovell ME. A case-control study examining inconsistencies in pain management following fractured neck of femur: an inferior analgesia for the cognitively impaired. *Emerg Med J.* 2014 Oct;31(e1):e2–8.
 18. Zwakhalen S, Docking RE, Gnass I, Sirsch E, Stewart C, Allcock N, et al. Pain in older adults with dementia : A survey across Europe on current practices, use of assessment tools, guidelines and policies. *Der Schmerz.* 2018 Oct 21;32(5):364–73.
 19. Black W, Almeida OP. A systematic review of the association between the Behavioral and Psychological Symptoms of Dementia and burden of care. *Int Psychogeriatrics.* 2004 Sep 24;16(3):295–315.
 20. Barber JB, Gibson SJ. Treatment of Chronic Non-Malignant Pain in the Elderly. *Drug Saf.* 2009 May;32(6):457–74.
 21. Schoenmakers B, Buntinx F, Devroey D, Van Casteren V, DeLepeleire J. The process of definitive institutionalization of community dwelling demented vs non demented elderly: data obtained from a network of sentinel general practitioners. *Int J Geriatr Psychiatry.* 2009 May;24(5):523–31.
 22. Parmar J, Coe MB, Dobbs B, McKay R, Kirwan MC, Cooper T, et al. Diagnosis and management of dementia in primary care Exploratory study. *Can Fam Physician.* 2014;60:457–65.
 23. Van Kooten J, Delwel S, Binnekade TT, Smalbrugge M, Van Der Wouden JC, Sgm

- Perez R, et al. The impact of early emergency department allied health intervention on admission rates in older people: a non-randomized clinical study. *BMC Geriatr*. 2012;15(29).
24. Van Kooten J, Binnekade TT, Van Der Wouden JC, Stek ML, Scherder EJA, Husebø BS, et al. A Review of Pain Prevalence in Alzheimer's, Vascular, Frontotemporal and Lewy Body Dementias. *Dement Geriatr Cogn Disord*. 2016;41:220–32.
 25. Warden V, Hurley AC, Volicer L. Development and Psychometric Evaluation of the Pain Assessment in Advanced Dementia (PAINAD) Scale. *J Am Med Dir Assoc*. 2003 Jan;4(1):9–15.
 26. Aasmul I, Husebo BS, Flo E. Staff Distress Improves by Treating Pain in Nursing Home Patients With Dementia: Results From a Cluster-Randomized Controlled Trial. *J Pain Symptom Manage*. 2016 Dec;52(6):795–805.
 27. Herrmann N, Lanctôt KL, Sambrook R, Lesnikova N, Hébert R, McCracken P, et al. The contribution of neuropsychiatric symptoms to the cost of dementia care. *Int J Geriatr Psychiatry*. 2006 Oct;21(10):972–6.
 28. Zwakhalen SM, Hamers JP, Abu-Saad HH, Berger MP. Pain in elderly people with severe dementia: A systematic review of behavioural pain assessment tools. *BMC Geriatr*. 2006 Dec 27;6(1):3.
 29. Scherder E, Herr K, Pickering G, Gibson S, Benedetti F, Lautenbacher S. Pain in dementia. *Pain*. 2009 Oct;145(3):276–8.
 30. Scherder E, Oosterman J, Swaab D, Herr K, Ooms M, Ribbe M, et al. Recent developments in pain in dementia. *BMJ*. 2005 Feb 26;330(7489):461–4.
 31. Herman AD, Johnson TM, Ritchie CS, Parmelee PA. Pain Management Interventions in the Nursing Home: A Structured Review of the Literature. *J Am Geriatr Soc*. 2009 Jul;57(7):1258–67.
 32. Horgas AL, Elliott AF, Marsiske M. Pain Assessment in Persons with Dementia: Relationship Between Self-Report and Behavioral Observation. *J Am Geriatr Soc*. 2009 Jan;57(1):126–32.
 33. Marzinski LR. The Tragedy of Dementia: Clinically Assessing Pain in the Confused, Nonverbal Elderly. *J Gerontol Nurs*. 1991 Jun 1;17(6):25–8.
 34. World Health Organization. Dementia [Internet]. 2019 [cited 2019 Sep 12]. Available from: <https://www.who.int/news-room/fact-sheets/detail/dementia>
 35. Machiels M, Metzelthin SF, Hamers JPH, Zwakhalen SMG. Interventions to improve communication between people with dementia and nursing staff during daily nursing

- care: A systematic review. *Int J Nurs Stud*. 2017 Jan;66:37–46.
36. Fuchs-Lacelle S, Hadjistavropoulos T. Development and preliminary validation of the pain assessment checklist for seniors with limited ability to communicate (PACSLAC). *Pain Manag Nurs*. 2004 Mar 1;5(1):37–49.
 37. Chan S, Hadjistavropoulos T, Williams J, Lints-Martindale A. Evidence-based Development and Initial Validation of the Pain Assessment Checklist for Seniors With Limited Ability to Communicate-II (PACSLAC-II). *Clin J Pain*. 2014 Sep;30(9):816–24.
 38. Zwakhalen SMG, Hamers JPH, Berger MPF. The psychometric quality and clinical usefulness of three pain assessment tools for elderly people with dementia. *Pain*. 2006 Dec 15;126(1–3):210–20.
 39. Zwakhalen SMG, Hamers JPH, Berger MPF. Improving the clinical usefulness of a behavioural pain scale for older people with dementia. *J Adv Nurs*. 2007 Jun;58(5):493–502.
 40. van 't Hof CE, Zwakhalen SM., Hamers JPH. Interventies bij het signaleren van pijn bij verpleeghuisbewoners met dementie: de pilot implementatie van een pijnbeoordelingsinstrument (PACSLAC-D). *Tijdschr Gerontol Geriatr*. 2011 Apr 6;42(2):67–78.
 41. Kunz M, Scharmann S, Hemmeter U, Schepelmann K, Lautenbacher S. The facial expression of pain in patients with dementia. *Pain*. 2007 Dec;133(1):221–8.
 42. Nederlandse Vereniging voor Klinische Geriatrie. Richtlijn Diagnostiek en Behandeling van Dementie. Utrecht; 2015.
 43. Wensing M, Grol R. Implementatie: effectieve verbetering van de patiëntenzorg. 7th ed. Houten: Bohn Stafleu van Loghum; 2017. 410 p.
 44. Ista E, van Dijk M, van Achterberg T. Do implementation strategies increase adherence to pain assessment in hospitals? A systematic review. *Int J Nurs Stud*. 2013 Apr;50(4):552–68.
 45. Cooper S, Endacott R. Generic qualitative research: a design for qualitative research in emergency care? *Emerg Med J*. 2007 Dec 1;24(12):816–9.
 46. Caelli K, Ray L, Mill J. 'Clear as Mud': Toward Greater Clarity in Generic Qualitative Research. *Int J Qual Methods*. 2003 Jun 29;2(2):1–13.
 47. Percy WH, Kostere K, Kostere S. Generic qualitative research in psychology. Vol. 20, *The Qualitative Report*. Nova Southeastern University, Inc.; 2015. 76–86 p.
 48. Kahlke RM. Generic Qualitative Approaches: Pitfalls and Benefits of Methodological

- Mixology. *Int J Qual Methods*. 2014 Feb;13(1):37–52.
49. Gerrish K, Lacey A. *The research process in nursing*. Oxford: Wiley-Blackwell; 2010.
 50. Krueger RA. *Focus Groups: A Practical Guide for Applied Research*. Los Angeles: SAGE Publications Sage CA: Los Angeles, CA; 2015.
 51. Polit DF, Beck CT. *Nursing Research: Principles and Methods*. 9th ed. Philadelphia: Lippincott Williams & Wilkins; 2012.
 52. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Heal Care*. 2007 Sep 16;19(6):349–57.
 53. Holloway I, Galvin K. *Qualitative Research in Nursing and Healthcare*. 4th ed. Oxford: Wiley-Blackwell; 2016.
 54. Braun V, Clarke V. What can “thematic analysis” offer health and wellbeing researchers? *Int J Qual Stud Health Well-being*. 2014 Jan 15;9(1):26152.
 55. Maguire M, Maguire M, Delahunt B. Doing a thematic analysis: A practical, step-by-step guide for learning and teaching scholars. *All Irel J High Educ*. 2017 Oct 31;9(3).
 56. Carter N, Bryant-Lukosius D, DiCenso A, Blythe J, Neville AJ. The Use of Triangulation in Qualitative Research. *Oncol Nurs Forum*. 2014 Sep 1;41(5):545–7.
 57. Boeije H. *Analysis in qualitative research*. 1st ed. London: SAGE; 2010.
 58. Zisk-Rony RY, Lev J, Haviv H. Nurses’ Report of In-hospital Pediatric Pain Assessment: Examining Challenges and Perspectives. *Pain Manag Nurs*. 2015 Apr;16(2):112–20.
 59. Lawton R, Parker D. Barriers to incident reporting in a healthcare system. *Qual Saf Heal Care*. 2002;11(1):15–8.
 60. Walker N, Gillen P. Investigating nurses’ perceptions of their role in managing sedation in intensive care: An exploratory study. *Intensive Crit Care Nurs*. 2006 Dec 1;22(6):338–45.
 61. Beurskens S, van Engelen E, Lemmens J, Wolters P, Swinkels R. Het gebruiken van meetinstrumenten. *Onderwijs en gezondheidszorg*. 2010 Jun;34(4):22–6.
 62. Schiavenato M, Craig KD. Pain Assessment as a Social Transaction. *Clin J Pain*. 2010 Jul;1.
 63. Boerlage AA, Valkenburg AJ, Scherder EJA, Steenhof G, Effing P, Tibboel D, et al. Prevalence of pain in institutionalized adults with intellectual disabilities: A cross-sectional approach. *Res Dev Disabil*. 2013 Aug 1;34(8):2399–406.

64. Rothschild AW, Ricciardi JN, Luiselli JK. Assessing Pain in Adults with Intellectual Disability: a Descriptive and Qualitative Evaluation of Ratings and Impressions Among Care-Providers. *J Dev Phys Disabil.* 2019 Apr 15;31(2):219–30.
65. Cheung G, Choi P. The use of the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC) by caregivers in dementia care facilities. Vol. 121, *Journal of the New Zealand Medical Association NZMJ.* 2008.
66. Chow S, Chow R, Lam M, Rowbottom L, Hollenberg D, Friesen E, et al. Pain assessment tools for older adults with dementia in long-term care facilities: a systematic review. *Neurodegener Dis Manag.* 2016 Dec 18;6(6):525–38.
67. Masman AD, van Dijk M, van Rosmalen J, Baar FPM, Tibboel D, Boerlage AA. The Rotterdam Elderly Pain Observation Scale (REPOS) is reliable and valid for non-communicative end-of-life patients. *BMC Palliat Care.* 2018 Dec 21;17(1):34.
68. Herk R van. A Closer Look at Pain in Nursing Home Residents [Internet]. Rotterdam; 2008 [cited 2020 May 3]. Available from: https://repub.eur.nl/pub/13962/proefschrift_R.van_Herk.pdf
69. van Achterberg T, Schoonhoven L, Grol R. Nursing Implementation Science: How Evidence-Based Nursing Requires Evidence-Based Implementation. *J Nurs Scholarsh.* 2008 Dec 1;40(4):302–10.
70. Kajermo KN, Boström A-M, Thompson DS, Hutchinson AM, Estabrooks CA, Wallin L. The BARRIERS scale -- the barriers to research utilization scale: A systematic review. *Implement Sci.* 2010 Dec 26;5(1):32.
71. Vermeulen H, Tiemens B. Implementatie van evidence based practice. Houten: Bohn Stafleu van Loghum; 2015.
72. Holleman G, Poot E, Mintjes-de Groot J, van Achterberg T. The relevance of team characteristics and team directed strategies in the implementation of nursing innovations: A literature review. Vol. 46, *International Journal of Nursing Studies.* Pergamon; 2009. p. 1256–64.
73. Parkerton PH, Needleman J, Pearson ML, Upenieks V V., Soban LM, Yee T. Lessons from nursing leaders on implementing TCAB. *Am J Nurs.* 2009 Nov;109(11 SUPPL. TCAB):71–6.
74. Kaasalainen S, Ploeg J, Donald F, Coker E, Brazil K, Martin-Misener R, et al. Positioning Clinical Nurse Specialists and Nurse Practitioners as Change Champions to Implement a Pain Protocol in Long-Term Care. *Pain Manag Nurs.* 2015 Apr 1;16(2):78–88.

75. Knowledge-to-Action (KTA) Framework [Internet]. WHO. World Health Organization; 2020 [cited 2020 May 3]. Available from:
https://www.who.int/reproductivehealth/topics/best_practices/greatproject_KTAframework/en/
76. Wøien H, Bjørk IT. Intensive care pain treatment and sedation: Nurses' experiences of the conflict between clinical judgement and standardised care: An explorative study. *Intensive Crit Care Nurs.* 2013 Jun;29(3):128–36.

Tables and figures

Table 1: Participants' demographic information

Participants' demographics			n	%
N = 18 (100%)				
Gender				
	Male		3	16.7
	Female		15	83.3
Age				
		mean 30 years; SD 11.1		
	< 20		3	16.7
	21-30		9	50
	31-40		3	16.7
	41-50		2	11.1
	> 51		1	5.5
Work experience				
		mean 7.6 years; SD 9.9		
	< 5 years		12	66.7
	5-10		1	5.5
	10-20		3	16.7
	> 20		2	11.1
Level of education				
	Nursing student		3	16.7
	Vocational educated		11	61.1
	Bachelor educated		3	16.7
	Academic educated		1	5.5
Profession				
	Nursing student		3	16.7
	RN		14	77.8
	Physician		1	5.5

Figure 1: flowchart of attendance

