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Harmon, Joanne; Summons, Peter & Higgins, Isabel. "Experiences of the older hospitalised person on nursing pain care: an ethnographic insight" Published in the *Journal of Clinical Nursing*, Vol. 28, Issue 23-24, p. 4447-4459, (2019).

Available from: https://doi.org/10.1111/jocn.15029

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Accessed from: http://hdl.handle.net/1959.13/1418242

DR. JOANNE RACHELE HARMON (Orcid ID: 0000-0002-7003-1334)

Article type : Original Article

- i. **Title**: Experiences of the older hospitalised person on nursing pain care: An ethnographic insight
- ii. Running head: older person pain care

iii. Author information:

Dr Joanne HARMON, RN B.Nursing (Hons) PhD B.App. Sci. (Cons tech)

Lecturer Nursing, Division of Health, School of Nursing and Midwifery.

University of South Australia. Australia

Dr Peter SUMMONS, B. Engineering (Computer) M. Computing PhD Grad Dip (Education)

Senior Lecturer, School of Design Communication and IT, Faculty of Science and Information Technology. University of Newcastle Australia Peter.Summons@uon.edu.au

Prof. Isabel HIGGINS, RN Grad Dip Health Science (Nursing) Ass Dip (Nurse Education) MN PhD

Faculty of Health and Medicine, School of Nursing and Midwifery. University of Newcastle Australia Isabel.Higgins@newcastle.edu.au

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/jocn.15029

iv. Corresponding author's contact email address and telephone number s,

Dr Joanne Harmon RN B.Nursing (Hons) PhD B.App. Sci. (Cons tech)

Lecturer Nursing, Division of Health, School of Nursing and Midwifery. University of South Australia. 101 Currie street Adelaide SA 5001 Australia Joanne.Harmon@unisa.edu.au @DrJoanneHarmon

Authorship declaration:

Study Design; Data Collection (JH) and Analysis (JH, IH); Manuscript Writing (JH, IH, PS).

Acknowledgements

The author wished to acknowledge the older persons and registered nurses who participated in this study. I wish to gratefully acknowledge the input and assistance by Dr Lindy King for her assistance and encouragement in relation to this paper. I would also like to acknowledge A/Prof Erica Southgate and Prof. Sian Maslin-Prothero for their support in supervising the thesis.

Conflict of Interest Statement

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors. No conflict of interest has been declared by the author(s).

Aims and objectives

This paper presents an ethnographic insight into the older hospitalised person (those aged over 65 years) perceptions and experiences of pain care provision by nurses in acute care.

Background

Pain care provision by nurses remains less than optimal for the older hospitalised person despite numerous evidence-based guidelines. There is a paucity of research providing input from the experiences of the older hospitalised person in relation to their perspectives of pain care provision by nurses in acute care. Pain care research needs more involvement from those older persons with documented diagnoses of dementia, delirium, or cognitive impairment, and intellectual disabilities and those in their end-stage of palliation.

Design

A focused ethnographic study. The consolidated criteria for reporting qualitative research (COREQ) was used to report the findings of this study.

Methods

A focused ethnographic study was conducted in 8 acute care units within 2 large tertiary referral hospitals on the East Coast of Australia. Consisting of semi-structured interviews (n= 12) of cognitively intact older persons (11 hours). Twenty-three (23) semi-structured interviews with nine (9) RN participants (12 hours and 38 minutes). Participant observation period totalled 1,041 hours.

Results

The older persons experiences of receiving pain care was based on a formulaic assessment process focusing on intensity of pain and pain management options provided often lacked their input. The older persons often did not perceive their pain care provision as being of benefit to themselves. The nurses lacked insight and understanding on the nature of pain for the older person.

Conclusion

Understanding was gained into how the older persons pain care was hampered due to the lack of appropriate, and meaningful pain care provision and provides insight into why the older hospitalised person continues to experience a less than optimal experience.

Relevance to clinical practice

Older hospitalised persons can gain continuity of pain care when nurses negotiate with them in order to repattern or restructure their nursing routines for pain care provision. Older people need inclusion into pain care decisions. All vulnerable older persons require nurses to use an evidence-based pain assessment tool.

Introduction

Pain care provision for the older hospitalised person in acute care units will ideally start with a comprehensive assessment. This process should include investigation of the person's pain, medical history and recognition of any sensory and/or cognitive impairments (Herr, 2011). Older people will often have pre-existing persistent pain before hospital admission involving multiple sites that often have developed by many pathways resulting in different types of pain (Makris, Abrams, Gurland, & Reid, 2014). This pain may be present in addition to any acute pain experience whilst hospitalised. When undertaking a pain assessment for the older person, it is important to gain a complete understanding of all locations of pain and the conditions that could be causing the pain. Given the subjective nature of pain, special guidance is required when addressing the pain needs of vulnerable older adults defined by the International Association for the Study of Pain [IASP] (2019) as frail older persons and people with intellectual disabilities, whom may also have limited communication abilities.

Nurses need to utilise their knowledge, and skills to complete a comprehensive assessment of this kind (Herr, 2011). Integral to this nursing activity, is recognition that the older person's self-report can offer the most accurate and reliable method for identifying and characterizing their pain (Herr, 2011). Yet, the Deng et al. (2018) study of the prevalence and characteristics of hospitalized older people found up to 20% were suffering from moderate to severe pain. Further, that older patients with pre-existing chronic pain had less reduction in their pain (Deng et al. 2018). Despite the evidence that this problem exists, there is a lack of knowledge as to why pain care provision for the older person in acute care continues to be less than optimal.

Background

The older hospitalized person with unrelieved pain will have a worsening of their cognitive status, increased depression, more comorbidities and a longer length of stay (Corsi et al., 2018). Fillingim (2017) has noted a gradual increase in the awareness of the effects of undertreatment of pain for the older person; this finding was considered to contribute to greater recognition of pain management in this population group. Additionally, Tavernier et al. (2018) identified the organizational context in which nurse-led pain care provision was provided would act as either a barrier or a facilitator in relation to pain care provision.

Other research studies have captured older adults' perceptions of dignity in acute care settings (Tadd et al., 2011) and highlighted the importance of listening to the older person and learning from their feedback (Dickson, Riddell, Gilmour, & McCormack, 2017). Poor communication and information provision, along with institutionalized nursing care routines, also emerged as major contributors to the disempowerment of the older person from participating in their care (Selman et al., 2017).

The Hwang et al. (2014) study of emergency department (ED) encounters also identified older people will be less likely to receive any analgesia when compared to analgesia provided to younger adults. A further study of ED encounters by Fry, Arendts, Chenoweth, and MacGregor (2015) also identified the older person with a cognitive impairment as likely to experience an even longer delay receiving analgesia than those older persons who were cognitively intact. An integrated review by Dillane and Doody (2019) on the older person with intellectual disability and advanced dementia identified often their pain is also unrecognised.

Due to the highly personal and subjective nature of pain, an older person's experience of pain may be kept private (Herr, Coyne, McCaffery, Manworren, & Merkel, 2011). Although selfreport is the gold standard, for those unable to communicate, a glimpse may be gained into their experiences by observations of their behaviour (Fillingim, 2017). A person's individual response to pain can be expressed non-verbally as a behaviour such as a change in facial expression or body movement and this will be influenced by social, cultural and psychological factors (Herr et al., 2011). Similarly, there will be multifactorial contributions to the older persons' pain experiences in relation to the context and environment of care (Fillingim, 2017). Older adults continue to receive suboptimal pain management in the acute care setting (Brown & McCormack, 2006; Harmon, Higgins, Summons, & Bellchambers, 2012; Hwang et al., 2014).

The provision of care by nurses that the patient considers safe, satisfying and of benefit is known as culturally congruent care (Leininger, 1988, 2002, 2006). Culturally congruent pain care provision involves undertaking a pain history, assessment and management of pain and provision of education to ensure safe, effective relief is gained by the older person (Leininger & McFarland, 2002). Nurses aim to provide the older person with an individualized and culturally relevant pain care plan (Rosa, 2018). However, there is a lack of research on how nurses provide culturally congruent pain care provision within the acute care setting for the older person.

The purpose of the study is to provide understanding on how pain care provision by nurses is perceived by the older person to inform and advance clinical nursing practice. The research questions posed are: What are the culturally mediated barriers and facilitators to nurses' clinical practices when assessing and managing pain for the older hospitalised person?

Methods

This study used Focused Ethnography (FE) to explore and gain insights into Registered Nurses' pain care provision in acute care settings for the older hospitalized person. The Consolidated Criteria for Reporting Qualitative Research (COREQ) was used to report the findings of this study (Supplementary file 1). FE has stemmed from ethnography which provides a description of social process, known as processual ethnographies, which explore how culture and social systems were interrelated during a limited period of time (Boyle, 1994, p. 170). A FE approach allowed exploration of focused research questions to develop insights and understanding into RNs' pain care provision for the older person in acute care settings. Instead of focusing on the entire culture of the hospital, the use of FE provided a topic-orientated focus of looking, listening and thinking (Muecke, 1994) about the application of pain care provision within a small group (McFeat 1974) while maintaining a holistic, contextual and reflective manner (Hammersley & Atkinson, 2007).

An adaptation of the culture care theory by Leininger (1988), a nurse anthropologist who recognised subcultures within nursing, has underpinned this study. This novel application of the sunrise model of culturally congruent care captured aspects of how nurses can use their knowledge from a holistic perspective to provide pain care for the older person (Leininger & McFarland, 2002). This theory, used in conjunction with FE, allowed identification and understanding of how nurses undertook care decisions and actions within clinical practice to preserve, or pre-pattern their pain care provision into knowledge that directly related to meeting the needs of the older person (Leininger & McFarland, 2002).

The study methods included interviews, observation and document review.

Setting

The research was located on the east coast of Australia in two (2) separate hospital sites and eight (8) acute care units. These units comprised of medical, surgical, oncology and sub-acute units. The first author set aside two (2) months to gain access and was immersed for six (6) months in the field.

Participants

The participants in this study were purposively sampled from an initial pool of eleven (11) RNs and 44 older person inpatients. Nurses who were not RNs and patients aged under 65 were excluded. Two (2) RNs employed in the settings dropped out at the beginning of the study due to a change of employment, and two (2) of the older person inpatients declined to take part stating they were 'too tired'. A total of nine (9) RNs and 42 older persons participated in the study.

The older persons' ages ranged from 65 to 94 years old. Some were cognitively intact, and others had documented diagnoses of dementia, delirium, or cognitive impairment. Some older participants had intellectual disabilities, and some were in the terminal end-stage of palliation.

The average age of the nine (9) RNs in this study was 45 years, and they all held a nursing qualification of a baccalaureate degree. Of these, eight (8) RN participants had more than five (5) years of full-time acute care nursing experience and seven (7) indicating they had undertaken further postgraduate studies. Eight (8) RNs self-identified as a 'senior nurse'. All nurses worked both day and night shifts.

Data collection

Participant observation by the first author was undertaken on the RNs and the consenting older persons; this period totalled 1,041 hours with 73 hours spent as focused participant observation. Semi-structured interviews (n= 12) of cognitively intact older persons totalled 11 hours. Twenty-three (23) semi-structured interviews with the nine (9) RN participants were undertaken during the fieldwork period and totalled 12 hours and 38 minutes. The location of the interviews was determined by the participant's preference, with options provided for a private room, nursing station and/or bedside. All interviews were conducted in English, audio recorded, and transcribed by the first author. The document and policy reviews were also undertaken within the participating units of the hospitals by the first author.

Critical reflection involved the use of journaling, this step was undertaken to reduce the impact of the researcher-as-instrument within the collection, analysis and interpretation of the data (Borbasi, Jackson, & Wilkes, 2005). The journaling for this study incorporated a calendar diary, a document review journal, a reflective journal and a separate field journal for notes taken in the field during observations.

Data analysis

The data analysis process required a sequential series of steps to counter analytical overload due to the multiple and extensive amounts of data collected. The software program Nvivo was used to assist in the management of data (Bazeley & Jackson, 2013). Data analysis was undertaken in two (2) stages, qualitative descriptive analysis (Spradley, 1980) then thematic analysis (Brewer, 2000; Morse, 1994). Feedback was gained by consultation and member checking with the study nurse participants and the older person participants.

The qualitative descriptive analysis guided by Spradley (1980) included cultural domain analysis. A skeletal framework based on the conceptual framework of Leininger's culture care theory (1988) broadened the process. This step was to avoid premature closure and to gain data saturation by provision of insight into the emic purposes, meaning and definition of the objects and events as well as activities observed, and terminology used (Spradley, 1980). Development of taxonomies and typologies showed the relationships within the groupings of the cultural domains. At this point the analysis remained at a descriptive stage (Spradley, 1980).

The second level of analysis began with development of explanations and theories by reading and constant re-reading of the data and by asking further questions (Brewer, 2000). A line by line analysis was undertaken with emergence of codes from the data checking, comparisons were undertaken between the nursing doctoral supervision team and the first author of this study (Morse, 1994). Categories were developed and compared back to the raw descriptive data. The thematic analysis was a process that allowed the emergence of three main themes by constant iterative questioning, movement back and forth from the categories. The three themes were titled: *'the nurses' experiences of providing pain care for the older person'*, *'the experiences of the older person when receiving pain care'* and *'pain care, tension and disjunction'*.

Ethical considerations

Ethical approval [HREC 12/09/19/4.02] was gained from both the Hospital Human Research Ethics Committee and the University Research Ethics Committee. This study followed the processes outlined by the Australian National Health & Medical Research Council. (2018) for ethical considerations for older people with a cognitive impairment, an intellectual disability

or a mental illness. All participants in this study were purposively sampled and provided written informed consent. Written informed proxy consent was also gained for those older persons with any form of cognitive impairment by a third-party process. Ongoing consent was obtained using an independent senior nurse to gain assent (McKeown, Clarke, Ingleton, & Repper, 2010; Monroe, Herr, Mion, & Cowan, 2013; Sowney & Barr, 2007).

Ethnographic research requires ongoing access, and this is a form of emotion work (Bergman-Blix & Wettergren, 2014; Burawoy, 2003; Dickson-Swift, James, Kippen, & Liamputtong, 2009). Protocols were put in place before entry into the field to ensure a focus was placed on both physical and emotional safety for all involved (Dickson-Swift, James, Kippen, & Liamputtong, 2007, 2008). The emotional labour undertaken during the study required the main researcher to undertake reflection for dealing with the effects of emotion work (Bergman-Blix & Wettergren, 2014).

The data gained was stored in a locked and secure filing cabinet, in a locked room, and any other data was secured on a password protected USB. The first author, who undertook the study as a nursing doctoral student, is a RN and whose clinical speciality was intensive care nursing. She did not provide any direct patient care during the study and was not employed at any of the hospital sites.

Pseudonyms have been used for all older persons and the nurse participants whom have been de-identified to ensure anonymity and confidentially.

Results

The older persons' perceptions of pain care provision from nurses that emerged as a thread woven within all three themes provided the focus of the results. These themes have been briefly discussed using observational data and verbatim extracts from interview data to illustrate the perspectives of the older person.

Nurses' experiences of providing pain care for the older person: Not understanding the nature of pain

The theme *Nurses' experiences of providing pain care for the older person* explored the experiences of the nurses in this study when providing pain care for the older person. Provided were insights that revealed not only their understanding of pain in older people but also the constraints within the acute care environment they experienced when delivering care for comfort and relief of pain for the older person. Unpacking the meanings underpinning the nurses' understanding of the nature of pain for the older person was captured by their use of pain terminology.

The nurses' language was suggestive of a lack of knowledge in relation to comprehensive pain assessment and management. Of concern were the nurses' graphic descriptions of an older person in pain, which came across at times as sounding overly dramatic and inferred the person was experiencing extreme pain or a pain crisis. When the nurses spoke about the nature of pain for the older person, they stated the older person was used to being in pain, and their pain could be *real* or *genuine*. Importantly when the nurses spoke of older people as having *different thresholds* for pain, the meaning they attributed was at odds with the accepted definition of a pain threshold provided by the IASP (Loeser et al., 2012), namely

'the minimum intensity of a stimulus that is perceived as painful'.

When invited to elaborate on pain thresholds, RN Georgina compared two older persons, Hilda (78) had abdominal pain and was described as being *like the boy crying wolf* compared with Fleur's pain (92) from her fractured pelvis as being *genuine*:

> How Hilda handles her pain [pause 5 seconds] she goes "Oh I've got pain" then she moans and groans, on and off, all night but, [pause 10 seconds] but you have to treat it like it is pain--- [be]cause sometimes it is and sometimes it isn't---it's really hard--- I don't know. Especially when the lady in the bed next to her [Fleur] has a fractured pubic rami and she (...) genuinely did have a lot of pain when she was moving around the bed (...) but that's two different people with two different pain thresholds.

> > [RN_Georgina_interview_3]

When asked to clarify the meaning for when she used the term pain threshold for the older

person RN Elise spoke of the subjective nature of pain:

Pain it's like subjective, you know you have people who will be in pain with a low pain threshold and they will be rolling around in pain and agony. And yes, they hurt---but their pain might be minimal.

[RN_Elise_interview_2]

Whereas when RN Danielle elaborated on low pain thresholds, she spoke of older people as

not being *used* to being in pain, so any new pain was *unbearable*:

She's [the patient] had a fall and fractured her [pubic] rami--- but you see for her, she's got like, a low threshold, it's like an unbearable pain and it's not something she is used to, and we are still not on top of her pain.

[RN_Danielle_interview_1]

The IASP definition of pain tolerance is '*the maximum intensity of a pain-producing stimulus that a subject is willing to accept in a given situation*', however, when the study nurses used this term, they inferred it to have a homogenous meaning of all older persons were accepting of having a lot of pain:

Well, I think in a majority of older people the pain is real. Most old people have a high pain tolerance, so if there is pain, something's got to be triggering it, because most of them walk around in pain anyway, so if they are yelling out in pain, nine times out of ten it's a genuine pain.

[RN_Fran_interview_3]

The assumptions and meanings held by the nurses in relation to their interpretations of pain tolerance and threshold provided a barrier for the provision of pain management which was meaningful for the older person.

Older persons' perceptions of their thresholds of pain and tolerance were at variance to that spoken of by the nurses. Their pain impacted on their priorities such as the amount of time they could otherwise have spent focusing on self-care, eating, or spending time with family. Simon (65) was a Pacific Islander elder and he shared the impact of the nature of his pain the previous night when family were visiting, as not being able to fulfil his cultural obligation of being available for them;

> I didn't have much time with my family (...) the pain started to come back, it was, well I started to [silence 10 seconds] I got stressed out [frowns] so...I went into the bathroom and I locked myself in there. I was crying. I'm thinking 'ohhh no, oh not again. I wanted to hide my head under the pillow (...) I didn't have much time with my family. My head wasn't in the right place with the stories and things they wanted to talk about. I have to apologise to them

> > [Simon_interview_1]

When the nurses pain management processes did not engage in any adaption or negotiation with the older person to provide an optimal outcome for their pain this led to delays in provision of pain relief for the older person as shown by Simons' experience in the observational exemplar below:

Simon is sitting out of bed in a chair and his breakfast is in front of him untouched. At 0700 he informed his nurse RN Ann, he had pain, it is now 0725 and he has not received any pain medication.

[RN Ann walks in and makes eye contact with Simon and touches his arm]

Alright Simon? Are you alright to have a bit of a rest now?

[Simon responds by moaning and groaning as he gets up and lies down on top of the bed]

I was going to ... I asked for some Endone ... its back ... bad ... my pain

[RN Ann helps him get comfortable and places a pillow under his legs]

I know alright...Lie back Simon, I want your head up a bit. I'll get you comfortable and then I'll look after your leg

A doctor then walks in and picks up Simon's bedside chart, he nods to Simon, who smiles back at him, and then he turns to the RN

I am just checking up on Simon before I finish tonight, so I can go home. [he is the overnight medical officer doing his last round] Why is he... he is in quite a lot of pain now?

[RN Ann responds]

He can only have Endone TDS, He's just plateaued out

[The Doctor then turns and talks to Simon]

You were pretty bad at midnight last night and again at 03.30 this morning, I will bump the Endone up to 5mg four hourly for you ok?

[He then turns to the RN, Look, you really need to give him something now, why can we not give him his Endone?] RN Ann then looks at Simon who is moaning and groaning loudly on the bed before saying

It's just so painful, I'll get him something now

[RN Ann turns and walks out of the room with the chart in her hand and gets Simon his medication]

[RN_Ann_observation_2]

Simon spoke of feeling reassured when his health care providers had both talked out aloud in

front of him:

I told the nurse (...) and that doctor [about my pain], which drops my stress and worries, and stops me from [doing]all that stressing out, [be]cause then I know it is gunna [going to] happen and something is gunna get done about it [my pain].

[Simon_interview_2]

The nature of their pain also made some older persons feel at times they were unsafe during mobilisation and at risk of embarrassment. Not being able to ambulate quickly left some older persons fearful:

With my pain, I just can't do anything quick. I can't walk anywhere in a hurry or a rush. Anyway [pause---big breath in], I usually get up [and walk] to go to the toilet, well this morning I asked if I could go over on the chair, the nurse (...) She goes to me "Oh you walk alright" --- huh---alright? Well. I said that if I could walk I would, but I can't go fast because it hurts too much and now, I am worried that I will [expletive deleted] my pants (...)

[Molly_interview_1]

And a sense of shame when experiencing undignified care:

The other day when I couldn't get to the toilet because my pain was so bad, I was sooo embarrassed to have her [the nurse] sitting me behind the curtain. She said it was 'alright and nurses didn't mind' (...) and you know that's fine that they don't mind, but I was the one sitting there feeling like a fool and crying.

[Molly_interview_1]

When nurses excluded the older person, their ability to undertake a comprehensive pain assessment was hampered and this hindered their attempts when engaging in negotiation. Due to their lack of understanding in relation to the nature of that pain their ability to make clinical decisions were fraught with bias, and this often led to an inability to provide a meaningful outcome for older person.

The older persons' experiences of nurses focusing on numerical values for pain intensity: Wanting to give the right answer her response was: a ten.

When assessing pain, the nurses often invariably asked the older person inpatients, *can you give me your pain score out of ten*. The nurses all presumed the older person knew what they were talking about when they asked them this line of questioning. The nurse's intention was to adapt the pain of the older person as part of an objective measurement for documentation. When RN Clare was asked what her influences were when asking for a numerical pain score her response was:

I think that the scale [numerical rating scale] is quite good for [assessing] pain, so long as they [the older person] can understand the scale.

[RN_Clare_interview_1]

The older person, when asked this line of questioning, described feeling anxious about how to respond. They appeared to often be unaware of how to use their responses as part of a negotiation with nurses to relate to outcomes or which they felt was congruent and safe in relation to the nature of their pain. When asked how she felt when asked to rate her pain, Suzanne (65) said she provided her *usual* response, which she *hoped* was a *right*, as opposed to a wrong answer;

I can't rate it [pain]. I know I usually say about a two or a three. I just give a number and hope that I am right.

[Suzanne_interview_1]

Sometimes the older person spoke of providing an unvarying response;

So, I usually tell them [the nurses] it's an eight or when it's really bad a ten.

[Rhonda_interview_1]

The alternative accommodating strategy used by some older people was when being questioned about their pain was to engage in a demonstration by listing what hurt, how, when, and where. During her interview Belinda (76), was asked an open-ended question

Belinda, can you share and tell me about your pain? [interviewer]

That hand is alright [holds up right hand], except for the one finger [feebly wiggles right index finger] and that one finger was a little bit sore for a while as well [indicates second right finger by wiggling freely]. And I can move that one alright now without any trouble [flaps left hand] but the shoulders and the neck I just couldn't move at all [attempts to shrug shoulders] and it's still persisted down that side [indicates by shrugging again, her left side has a noticeable droop] and in that hand [flaps left hand again] this morning is the first time that I have been able to stretch those fingers [demonstrates with left hand by spreading out fingers].

[Belinda_interview_1]

Some older persons spoke negatively of their interactions with nurses that were based on being asked to rate their pain, which they felt lacked meaning for them. An example of this was provided by Alison (85);

> When all my nurse says to me first up [waking me up in the morning] is "How would you rate the pain?" I think--- well! ---Golly---now you're asking me. I'm not a very good person to help you, so I'll say, "don't ask me!" [Silence 15 seconds] I've just got a pain and that's it.

> > [Allison_interview_1]

It was as though Allison felt being unable to rate her pain, meant she could not comply, and be *a good person*. This also meant her story of her experience of waking up in pain was lost.

The nurses in this study when undertaking rounds of vital signs and asking about pain, often did not engage in negotiation about pain with the older person. The lack of adaption by the nurses meant for the older person they felt the assessment of their pain lacked congruence or meaning. The older persons were able to adapt their answers to the nurses' line of questioning to rate their pain intensity by use of a numerical value. Often the outcomes for the older

person was not having continuity or their pain comprehensively assessed, and this placed them at risk of not having their pain managed from their pain stories been lost.

Not being heard: Lost pain stories

The older persons in this study initially believed their pain stories were known by the nurses, and when they realised this was not the case, they spoke of their annoyance of having to repeat themselves to nurses. A source for this was identified when the nurses were invited to speak about pain in the older person. A common response from the RNs was older people *denied* or *ignored* their pain and *they would not tell* nurses they had pain:

You know, some of these older people ignore pain, they deny it or whatever. They won't tell you.

[RN_Elise_interview_1]

When a pain story had been lost the older person invariably became frustrated, and isolated. Retelling their stories of pain on each new admission into a ward and for every nursing shift became exhausting. This meant tension was observed to be present when pain care provision decisions and outcomes were not viewed as being beneficial by the older person and this was due to a lack of repatterning or restructuring by the nurses to modify or provide person centred pain care. The following observational exemplar highlights this experience for Molly.

> After being on the public waiting list for more than 18 months Molly was due to have a total hip replacement, however, this was cancelled on receiving a pre-op check-up, as atrial fibrillation was identified, and she received a pacemaker. After being discharged home she was readmitted the next day due to a fall. Then she was transferred to another hospital and spoke of not knowing if or when she will receive her hip replacement.

> > [Reflective_journal_64]

RN Georgina is undertaking routine vital sign monitoring and Molly becomes increasingly abrupt. [RN Georgina to Molly while she is attaching the BP cuff] "Have you got any pain?" [Molly sighs and nods to her right hip, she sounds weary] "[Sighs], only in the usual spot" [RN Georgina then asks her] "Where?" [Molly runs her right hand down right side of her hip and points] "Here" [RN Georgina to Molly] "Oh, do you have sciatica?" [Molly rolls her eyes upwards, sighs and groans] "No! [Sighs] Ohh [Groans] ohhh I am waiting for a hip[replacement]" [RN Georgina flicks through the chart and is looking downwards] "Oh ok. What have you got for it?" [Molly answers sharply] "A patch!" [RN Georgina doesn't look up but points to the medication chart] "Oh I see a Fentanyl patch" [Molly's voice initially softens but then becomes abrupt] "Yeah--- and something else it starts with a C? I think" [RN Georgina is now looking back down at the chart] "You're not thinking of Panadol, are you?" [Molly rolls her eyes, puts her hands up to her face and groans] "Nope, harrumph" [RN Georgina flips over a page and exclaims] "Oh, Codeine phosphate" "Yes, that's it"

[RN_Georgina_observation_3]

Molly spoke of her frustration on having to repeat her pain story as it had not followed her journey while an inpatient.

I am sick of telling people [nurses] how sore my hip is. I don't think that people realise.

[Molly_interview_1]

Later RN Georgina was invited to discuss Molly and her pain:

She didn't say that pain was from her hip, she said it was from her sciatica, not from her hip.

[RN_Georgina_interview_3]

The exemplar above highlighted Molly's experiences of having a lost pain story and how, although the nurse was listening to her, Molly's complaint of pain was not understood. At times when the nurses failed to understand, this meant they were unable to modify, repattern or restructure their pain care provision for a more beneficial outcome for the older person.
Pain care disjunction

Cognitively intact older persons were able to communicate to nurses their lost pain stories. However, vulnerable older persons who were not cognitively intact, had advanced dementia or an intellectual disability with or without a diagnosis of advanced dementia struggled. For them, communication was hampered and often they did not have a family member or carer to act as their advocate. The following exemplars can only infer some insight into their experiences.

A source of disjunction was noted when the nurses were invited to speak about providing pain care for those vulnerable older persons: with a diagnosis of advanced dementia; in their terminal end-stage of palliation, and those with an intellectual or congenital disability with or without a diagnosis of dementia. Of concern were the responses by some nurses who inferred these older persons did not belong in their unit.

> We are not supposed to have demented patients here, we have just started to ask for MMSE [mini mental score exam] because there have been instances where they have begun to slip through. We had one patient [here] with an MMSE with 13/30, so we sent them back to the ward they came from, we refused to have them here.

> > [RN_Danielle_interview_4]

When asked to provide more detail, RN Danielle commented:

As long as they are not aggressive, if there is any aggression, we will not accept them, so if they are one of those little ones that are

[RN_Danielle_interview_4]

disability with or without a diagnosis of dementia were at times referred to by the nurses as belonging to a homogeneous group by using an acronym DD [developmentally delayed].

Some study nurses spoke of being unable to *interact with them*.

We get a lot of older DD patients here, from the community and from [facility name deleted]. This [hospital name deleted] is their hospital of choice, they regularly send them here. The ones from [facility name deleted] you cannot interact with them much, the ones with really bad cerebral palsy and that. It's more like (...) you assess them mentally on how they respond to you and that's gained mainly from experience, having to deal with these people and reading their notes.

Older inpatients who had communication impairments due to a developmental or intellectual

[RN_Ann_interview_1]

One nurse also inferred her unit had refused to provide care for these older persons:

At the moment we have a DD lady with us, she usually lives in a group home. We've had a couple from group homes we have refused to treat because as far as we are concerned there is no family, we couldn't get informed consent. So, we the nurses turned around [to the treating team] and said we are not doing it

[RN_Hermione_interview_1]

When asked about specific pain assessment tools they used for assessing pain in the older person with any form of cognitive impairment, one nurse stated using them was not part of common practice. Although another nurse indicated awareness of a recognised need for an appropriate pain assessment tool for the older person with severe dementia and spoke of attempting to implement change:

> We do have a tool and every time I put the tool out it disappears, it's the Abbey pain scale. I put it in the filling system, in the slots that are provided (...) but it just goes. So, whoever is tidying up, usually its night staff or it could be any one, it goes. I don't know where they go. So therefore, we don't use the tool.

> > [RN_Barbara_interview_2]

From the documentation audit, it was clear there were no pain assessment tools used for pain assessment for vulnerable older persons or those with a communication impairment. Some RNs spoke of gaining a person-centred approach for pain care provision by asking the carers about behaviours that may be triggered by pain.

I want to wait for him [the older persons' husband] because he will elaborate that "When she is at home and in pain I know when she is in pain because she will do this and this"

[RN_Elise_interview_3]

Other nurses spoke of knowing when a person with a diagnosis of advanced dementia was in

pain through level of aggression:

So, you know, all demented people, they still can tell you if they have pain or not, sometimes they are more aggressive because they have got pain.

[RN_Georgina_interview_1]

At times older persons with advanced dementia were also not heard and were at risk of

having their pain story lost. This absence was demonstrated in the following observational

exemplar when Astrid (79) indicated to her nurse she had pain.

It is late at night 22.30 and RN Georgina is doing a round of vital signs in a four-bed room of women and they all have their curtains drawn. She pulls back a curtain and goes in towards Astrid who is lying in bed.

[Reflective_journal_62]

[Astrid is frowning and lying slumped in the bed. On seeing RN Georgina move her bedside curtain back she goes]

I can't breathe, I can't sleep. I get dreadful pain every time here [when]*I breathe in*[points to right side of episternum region].

[RN Georgina reaches to the back of the bed to the oxygen nasal prongs and puts them on Astrid, and then she uses bed mechanics to sit Astrid up before repositioning by fluffing her pillows and tucking her in]

It's ok, here have some oxygen

[Astrid is still frowning]

That's a bit better I can breathe now

[RN Georgina then connects Astrid to the OBS machine] How's your pain? You got that needle tonight already, has it worked? [Astrid replies by sounding very vague] *I had a needle?*[RN Georgina presses the start button on the blood pressure machine] *Yes, the nurses gave it to you*[Astrid replies] *God bless you all, you are very kind*[RN Georgina then writes up her vital signs, ensures that the nurse call buzzer is within her reach] *I'll give you the buzzer, the lights will go off soon*[She disconnects Astrid from the OBS machine, gels her hands and walks

[She disconnects Astrid from the OBS machine, gels her hands and walks off to the next bay]

[RN_Georgina_observation_2]

The observations and comments made by the nurses suggested the lack of documentation and non-use of an evidence-based pain assessment tool for vulnerable older persons meant a substantive barrier was present for pain care continuity. The needs and nature of pain in this group of older persons required sensitive, and beneficial application of nursing knowledge and care.

Discussion

For some older persons in this study, their provision of pain care was hampered due to the lack of the provision of appropriate, and meaningful pain care provision. The findings of this study underpinned by Leininger and McFarland (2002) on the provision of culturally competent care have illustrated the older persons perceptions on how pain care provision was not being provided in a manner fitting in with their needs. The findings in this study have identified instances of nurses lacking flexibility, and negotiation within the acute care environment to provide clinical decisions and undertake actions to provide culturally congruent and person-centred pain care. Culturally competent nursing pain care that is beneficial can only occur when a nurse is using their knowledge of a health care system to adapt for care provision in an appropriate manner the older person finds safe (Leininger & McFarland, 2002).

The use of Leininger's culture care theory (1988) for exploration into culturally congruent pain care provision for the older person in acute care has been a novel application of this theory. Gaining understanding on how nurses provide pain care has allowed insight into the perspectives of the older person. The findings have highlighted nurses are often not engaging in negotiation during pain care provision that is inclusive of input from the older person. This resulted in the development of cultural conflict when the older person viewed pain care as being of no benefit, or inappropriate (Leininger, 2002).

The findings show in some instances how a cultural imposition can be projected onto the older person by an all prevailing nursing culture (Leininger, 1988), such as by espousing beliefs the older person will not tell a nurse they have pain and a reliance on gaining a numerical value to rate the intensity of pain. This has resulted in a gap developing between the experiences of the older person and the provision of pain care by the nurses and led towards a major barrier for the development of therapeutic culturally congruent pain care (Leininger & McFarland, 2002). Gaining the older persons' perceptions has provided insight into why nurses should use evidence-based comprehensive pain assessment for provision of optimal relief and to avoid loss of continuity of care.

Previous studies have explored the perceptions of nurses in relation to pain care provision for the older hospitalised person (Coker et al., 2010; Harmon, Summons, & Higgins, 2019; Manias, 2012). However, there is a paucity of research focusing on the perceptions of the older person on receiving pain care from nurses in acute care (Joelsson, Olsson, & Jakobsson, 2010). Nor has there been extensive exploration in the context of older hospitalised persons unable to self-report their pain experiences (Cowdell, 2010).

There are numerous guidelines available for older person pain care provision for use in acute care settings such as the assessment of pain in older people: National Guidelines by Closs et al. (2007), and the interdisciplinary expert consensus statement on assessment of pain in older

persons by Hadjistavropoulos et al. (2007). The guideline on acute pain management in older adults by Herr, Bjoro, Steffensmeier, and Rakel (2006) and Schofield, O'Mahony, Collett, and Potter (2008) both provide a very a comprehensive literature review for the assessment of pain in older adults.

There are also guidelines for the older person unable to self-report for assessing pain in dementia patients with comorbid delirium and/or depression by Hadjistavropoulos, Voyer, Sharpe, Verreault, and Aubin (2008). Along with the position statement with clinical practice recommendations for pain assessment in the patient unable to self-report by Herr et al. (2011) and a procedural pain management guideline by Czarnecki et al. (2011). Findlay, Williams, Baum, and Scior (2015) notes a person with an intellectual disability will often display their pain in ways which can be subtle, and their expressions of pain will be variable and often idiosyncratic (Doody & Bailey, 2019). The ISAP (2019b) recommends for the older person with an intellectual disability and/or diagnosis of advanced dementia then the use of an appropriate pain assessment tool in conjunction with previously recorded pain baseline observations will be required, and a multidimensional approach with continuous reassessment with inclusion of family/caregivers (Findlay et al., 2015).

These findings are comparable with Brown and McCormack (2006), Manias, Bucknall, and Botti (2005) and Joelsson et al. (2010). These authors also noted a lack of strategies used by acute care nurses to provide evidence-based interventions for cognitively intact older person experiencing uncontrolled or problematic pain. Previously not identified within the literature were the numerous social rules being used by nurses to govern their clinical strategies for pain care. This finding has provided further insight and understanding of why sub optimal pain care provision has continued.

Comparable to the findings of Bach, Forman, and Seibaek (2018), this study identified nurses will speak of placing a high value on relieving pain and undertaking a creative approach to problem solving pain. It was noted by Carspecken (1996) that insight can be gained into the values held by a person through exploration of what they say that they do, as opposed to what was actually done in a situation when the espoused values of the organisation were required to be in operation. The findings of Dihle, Bjalseth, and Helseth (2006), who identified a gap between what nurses say they did and what was actually done by them in relation to pain assessment and management can also be confirmed within the findings of this study. The emerging knowledge from the findings in this study was that although nurses placed a high value when speaking about being a problem solver for pain, observation showed they excluded the older person from participating in problem solving about their pain.

The findings of this study were consistent with the literature about the older persons' experience of being an inpatient in acute care in relation to having to wait for nursing care (Anderson, Burman, & Skar, 2011). Neville and Roan (2014) confirmed nurses were conservative in their willingness to expend extra energy or time to manage pain for the older person with intractable or problematic pain. Similar to the findings in this study, obstacles to maintaining respect were noted to be uncaring attitudes and a culture of inflexible nursing care (Koskenniemi, Leino-Kilpi, & Suhonen, 2013).

When the study nurses inferred the most vulnerable of older persons as not belonging in their unit and alluding to refusing to care for them is against the fundamental principles underpinning the International Council of Nurses. (2012) code of ethics for nurses. During the observation periods and clinical documentation audit undertaken no evidence-based pain assessment tool specific for pain assessment in the older person with a cognitive impairment was present. Similarly, none were observed to be in use within any of the study units. Absent was documented involvement of the carers or family members of these older vulnerable

persons in relation to pain behaviours. The lack of comprehensive assessment of pain for all older persons in this study meant potentially it can be inferred, their pain was at times undetected and therefore at an increased risk of being not managed. This finding was even more so for those most vulnerable older persons.

Limitations

The findings of this study should be considered within the context of the study setting and sample, the views of this cohort of RNs may not be typical of other hospital sites or unit types. The first author identified an excessive use of neologisms and/or slang used by the study nurses with a lack of uptake and/or use of appropriate medical terminology when they spoke in the interviews. Electronic patient records were not in place and all documentation was paper based. Due to the subjective nature of pain, the findings from this study can only infer the implications for the cognitively intact older persons in relation to their experiences. However, for the most vulnerable group of older persons with cognitive impairment, their perceptions can only be implied due to their lack of voice within the study.

A limitation of using focused ethnography on nursing practices meant there was a narrow focus which did not include the input from family members, medical or allied health providers.

Conclusion

The findings from this study provide insight and understanding into the older persons' perceptions and experiences of pain care provision by nurses in acute care units. Despite the numerous guidelines available on pain care provision for the older person they continue to experience a less than optimal experience. Culturally safe congruent pain care provision for

the older person requires understanding of their goals and expectations, comorbidities as well as their cognitive and functional status. The assumptions and attitudes held by nurses in relation to the nature of pain experienced by the older person was conveyed into action a lack of value placed on their experiences of pain. The lack of understanding by the nurses in relation to the nature of pain for the older person extended into an inability within the acute care context to accommodate, negotiate, repattern or restructure their routines for pain care provision. This was stemming from a nursing culture of ritualised care unable to preserve or maintain supportive care and meant the pain care provided was often at times culturally incongruent and this was a major barrier within this organisational context for culturally congruent pain care provision.

Clinical practice implications

More consideration is required for nurses to use a systematic, multifaceted approach for a comprehensive assessment of pain and this required a variety of sources inclusive of the older persons input to provide the most accurate judgement regarding the presence of pain (Herr, 2011). Being involved and informed about pain care provision was spoken of very highly by the older person and was a source of comfort for them when waiting in pain. When the older person was excluded from input, they perceived their pain care provision was unsafe and placed them at risk of experiencing social embarrassment and shame. Having to repeat their pain story due to a lack of comprehensive documentation and absence of continuity of pain care meant the older person became increasingly frustrated and annoyed.

Clinical nurses need to reflect and consider if they are using the correct pain assessment tool for the management of pain in the older person. When in pain the older will respond with meaningful input to open questions as opposed to the provision of a numerical value. Nurses in acute care must start revaluating on how they provide pain care provision and begin to negotiate with the older person for their needs. Then document in a manner that will provide continuity of pain care that is culturally congruent, and meaningful for the older person.

References

- Anderson, L., Burman, M., & Skar, L. (2011). Experiences of caretime during hospitalisation in a medical ward: older patients' perspective. Scandinavian Journal of Caring Sciences, 25(4).
- Bach, A. M., Forman, A., & Seibaek, L. (2018). Postoperative Pain Management: A Bedside Perspective. *Pain Management Nursing*, 19(6), 608-618. doi:https://doi.org/10.1016/j.pmn.2018.05.005
- Bazeley, P., & Jackson, K. (2013). *Qualitative data analysis with NVIVO* (2 ed.). USA: SAGE.
- Bergman-Blix, S., & Wettergren, Å. (2014). The emotional labour of gaining and maintaining access to the field. *Qualitative Research*.
- Borbasi, S., Jackson, D., & Wilkes, L. (2005). Fieldwork in nursing research: positionality, practicalities and predicaments. *Journal of Advanced Nursing*, *51*(5), 493-501. doi:10.1111/j.1365-2648.2005.03523.x
- Boyle, J. S. (1994). Chapter 9. Styles of Ethnography. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 159-185). London: SAGE.
- Brewer, J. D. (2000). Ethnography (1 ed.). USA: Open University Press.
- Brown, D., & McCormack, B. G. (2006). Determining factors that have an impact upon effective evidence-based pain management with older people, following colorectal surgery: an ethnographic study. *Journal of Clinical Nursing*, *15*(10), 1287-1298.
- Burawoy, M. (2003). Revisits: An outline of a theory of reflexive ethnography. *American Sociological Review*, 68(5), 645-679.
- Carspecken, P. F. (1996). Critical ethnography in educational research: A theoretical and practical guide. New York: Routledge.
- Closs, S. J., Collett, B., Gaffin, J., Gough, J., Harai, D., Jones, L., . . . Schofield, P. (2007). The assessment of pain in older people: National Guidelines No 8. In Royal College of Physicians., British Geriatrics Society., & British Pain Society. (Eds.), Concise guidance to good practice: A series of evidence-based guidelines for clinical management (pp. 15): Royal College of Physicians.
- Coker, E., Papaioannou, A., Kaasalainen, S., Dolovich, L., Turpie, I., & Taniguchi, A. (2010). Nurses' perceived barriers to optimal pain management in older adults on acute medical units. *Applied Nursing Research*, 23(3), 139-146.
- Corsi, N., Roberto, A., Cortesi, L., Nobili, A., Mannucci, P. M., Corli, O., & Investigators, R. (2018). Prevalence, characteristics and treatment of chronic pain in elderly patients hospitalized in internal medicine wards. *European Journal of Internal Medicine*, 55, 35-39. doi:10.1016/j.ejim.2018.05.031
- Cowdell, F. (2010). The care of older people with dementia in acute hospitals. *International Journal of Older People Nursing*, 5(2), 83-92. doi:10.1111/j.1748-3743.2010.00208.x
- Czarnecki, M. L., Turner, H. N., Collins, P. M., Doellman, D., Wrona, S., & Reynolds, J. (2011). Procedural Pain Management: A Position Statement with Clinical Practice

Recommendations. Pain Management Nursing, 12(2), 95-111.

- Deng, L. X., Patel, K., Miaskowski, C., Maravilla, I., Schear, S., Garrigues, S., ... Ritchie, C. S. (2018). Prevalence and Characteristics of Moderate to Severe Pain among Hospitalized Older Adults. *Journal of the American Geriatrics Society*, 66(9), 1744-1751. doi:10.1111/jgs.15459
- Dickson-Swift, V., James, E. L., Kippen, S., & Liamputtong, P. (2007). Doing sensitive research: what challenges do qualitative researchers face? *Qualitative Research*, 7(3), 327-353. doi:10.1177/1468794107078515
- Dickson-Swift, V., James, E. L., Kippen, S., & Liamputtong, P. (2008). Risk to Researchers in Qualitative Research on Sensitive Topics: Issues and Strategies. *Qualitative Health Research*, 18(1), 133-144. doi:10.1177/1049732307309007
- Dickson-Swift, V., James, E. L., Kippen, S., & Liamputtong, P. (2009). Researching sensitive topics: qualitative research as emotion work. *Qualitative Research*, 9(1), 61-79.
- Dickson, M., Riddell, H., Gilmour, F., & McCormack, B. (2017). Delivering dignified care: A realist synthesis of evidence that promotes effective listening to and learning from older people's feedback in acute care settings. *Journal of Clinical Nursing*, 26(23-24), 4028-4038. doi:10.1111/jocn.13856
- Dihle, A., Bjalseth, G., & Helseth, S. (2006). The gap between saying and doing in postoperative pain management. *Journal of Clinical Nursing*, 15(4), 469-479.
- Dillane, I., & Doody, O. (2019). Nursing people with intellectual disability and dementia experiencing pain: An integrative review. *Journal of Clinical Nursing*, 0(0). doi:10.1111/jocn.14834
- Doody, O., & Bailey, M. E. (2019). Understanding pain physiology and its application to person with intellectual disability. *Journal of Intellectual Disabilities*, 23(1), 5-18. doi:10.1177/1744629517708680
- Fillingim, R. B. (2017). Individual differences in pain: understanding the mosaic that makes pain personal. *PAIN*, *158*, S11-S18. doi:10.1097/j.pain.00000000000775
- Findlay, L., Williams, A. C. d. C., Baum, S., & Scior, K. (2015). Caregiver Experiences of Supporting Adults with Intellectual Disabilities in Pain. *Journal of Applied Research in Intellectual Disabilities*, 28(2), 111-120. doi:10.1111/jar.12109
- Fry, M., Arendts, G., Chenoweth, L., & MacGregor, C. (2015). Cognitive impairment is a risk factor for delayed analgesia in older people with long bone fracture: a multicenter exploratory study. *International Psychogeriatrics*, 27(02), 323-328. doi:10.1017/S1041610214001732
- Hadjistavropoulos, T., Herr, K., Turk, D. C., Fine, P. G., Dworkin, R. H., & Helme, R. (2007). An Interdisciplinary expert consensus statement on assessment of pain in older persons. *The Clinical Journal of Pain*, 23(s1-s43), 1-43.
- Hadjistavropoulos, T., Voyer, P., Sharpe, D., Verreault, R., & Aubin, M. (2008). Assessing Pain in Dementia Patients with Comorbid Delirium and/or Depression. *Pain Management Nursing*, 9(2), 48-54.
- Hammersley, M., & Atkinson, P. (2007). *Ethnography: Principles in practice* (3 ed.). London: Routledge.
- Harmon, J., Higgins, I., Summons, P., & Bellchambers, H. (2012). Efficacy of the use of evidence-based algorithmic guidelines in the acute care setting for pain assessment and management in older people: a critical review of the literature. *International Journal of Older People Nursing*, 7(2), 127-140. doi:10.1111/j.1748-3743.2010.00261.x
- Harmon, J., Summons, P., & Higgins, I. (2019). Nurses' culturally mediated practices influencing pain care provision for older people in acute care: Ethnographic study. *Applied Nursing Research*, 48, 22-29. doi:https://doi.org/10.1016/j.apnr.2019.05.010

- Herr, K. (2011). Pain assessment strategies in older patients. *The Journal of Pain, 12*(3), S1-s3-13.
- Herr, K., Bjoro, K., Steffensmeier, J., & Rakel, B. (2006). Acute Pain Management in Older Adults. In M. Titler (Ed.), *The University of Iowa College of Nursing GNIR Research Translation and Dissemination Core (RTDC): Evidence-based practice guideline*. (Revised ed., pp. 116). Iowa USA: The University of Iowa Gerontological Nursing Interventions Research Centre & RTDC.
- Herr, K., Coyne, P. J., McCaffery, M., Manworren, R., & Merkel, S. (2011). Pain Assessment in the Patient Unable to Self-Report: Position Statement with Clinical Practice Recommendations. *Pain Management Nursing*, 12(4), 230-250.
- Hwang, U., Belland, L. K., Handel, D. A., Yadav, K., Heard, K., Rivera-Reyes, L., . . . Morrison, S. R. (2014). Is all pain is treated equally? A multicenter evaluation of acute pain care by age. *PAIN*, *155*(12), 2568-2574.
- International Association for the Study of Pain. (2019a). Guidelines for the management of pain in vulnerable populations. 2019 Global year against pain in the most vulnerable. Retrieved from
 - https://www.apsoc.org.au/PDF/GYAP/2019_GYAP/Fact_Sheet_1_Guidelines_for_th e_Management_of_Pain_in_Vulnerable_Populations_edited.pdf
- International Association for the Study of Pain. (2019b). Pain in cognitive impairment, not dementia related: management. 2019 Global year against pain in the most vulnerable. Retrieved from
 - https://www.apsoc.org.au/PDF/GYAP/2019_GYAP/Fact_Sheet_10_Pain_in_Cognitive_Impairment_not_Dementia_Related_Management.pdf
- International Council of Nurses. (2012). *The ICN code of ethics for nurses*. Retrieved from Geneva, Switzerland.: https://www.icn.ch/sites/default/files/inline-files/2012_ICN_Codeofethicsfornurses_%20eng.pdf
- Joelsson, M., Olsson, L., & Jakobsson, E. (2010). Patients' experience of pain and pain relief following hip replacement surgery. *Journal of Clinical Nursing*, 19(19/20), 2832-2838. doi:10.1111/j.1365-2702.2010.03215.x
- Koskenniemi, J., Leino-Kilpi, H., & Suhonen, R. (2013). Respect in the care of older patients in acute hospitals. *Nursing Ethics*, 20(1), 5-17. doi:10.1177/0969733012454449
- Leininger, M. M. (1988). The phenomenon of caring: Importance, research questions and theoretical considerations. In M. M. Leininger (Ed.), *Caring: An essential human need. Proceedings of the three national caring conferences* (pp. 3-16). Detroit: Wayne State University Press.
- Leininger, M. M. (2002). Culture Care Theory: A Major Contribution to Advance Transcultural Nursing Knowledge and Practices. *Journal of Transcultural Nursing*, 13(3), 189-192. doi:10.1177/10459602013003005
- Leininger, M. M. (2006). Culture care diversity and universality theory and evolution of the ethnonursing method. In M. M. Leininger & M. R. McFarland (Eds.), *Culture care Diversity and Universality: A Worldwide Nursing Theory* (2 ed.). NY: Jones & Bartlett.
- Leininger, M. M., & McFarland, M. R. (2002). *Transcultural nursing: Concepts, theories, research and practice* (3 ed.). USA: McGraw-Hill.
- Loeser, J. D., Arendt-Nielsen, L., Baron, R., Basbaum, A., Bond, M., Breivik, H., . . . Woda, A. (2012). Descriptions of Chronic Pain Syndromes and Definitions of Pain Terms. Part III: pain terms: A current list with definitions and notes on usage. In H. Merskey & N. Bogduk (Eds.), *Classification of Chronic Pain* (2 (revised) ed., pp. 1-9). Online: IASP.
- Makris, U. E., Abrams, R. C., Gurland, B., & Reid, M. (2014). Management of persistent

pain in the older patient: A clinical review. JAMA, 312(8), 825-837. doi:10.1001/jama.2014.9405

- Manias, E. (2012). Complexities of pain assessment and management in hospitalised older people: A qualitative observation and interview study. *International Journal of Nursing Studies*, 49(10), 1243-1254. doi:10.1016/j.ijnurstu.2012.05.002
- Manias, E., Bucknall, T., & Botti, M. (2005). Nurses' strategies for managing pain in the postoperative setting. *Pain Management Nursing*, 6(1), 18-29.
- McKeown, J., Clarke, A., Ingleton, C., & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing*, 19(13-14), 1935-1943. doi:10.1111/j.1365-2702.2009.03136.x
- Monroe, T. B., Herr, K. A., Mion, L. C., & Cowan, R. L. (2013). Ethical and legal issues in pain research in cognitively impaired older adults. *International Journal of Nursing Studies*, 50(9), 1283-1287. doi:https://doi.org/10.1016/j.ijnurstu.2012.11.023
- Morse, J. M. (1994). Chapter 3 "Emerging from the data". The cognitive process of analysis in Qualitative inquiry. In J. M. Morse (Ed.), *Critical Issues in Qualitative Research Methods* (pp. 23-43). London: SAGE
- Muecke, M. A. (1994). Chapter 10. On the evaluation of ethnographies. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 187-209). London: SAGE.
- National Health & Medical Research Council. (2018). *Chapter 4.5: People with a cognitive impairment, an intellectual disability, or a mental illness*. Retrieved from Canberra: https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018#toc_1354
- Neville, K., & Roan, N. (2014). Challenges in Nursing Practice: Nurses' Perceptions in Caring for Hospitalized Medical-Surgical Patients With Substance Abuse/Dependence. *Journal of Nursing Administration*, 44(6), 339-346.
- Rosa, W. E. (2018). Transcultural Pain Management: Theory, Practice, and Nurse-Client Partnerships. *Pain Management Nursing*, *19*(1), 23-33. doi:https://doi.org/10.1016/j.pmn.2017.10.007
- Schofield, P., O'Mahony, S., Collett, B., & Potter, J. (2008). Guidance for the assessment of pain in older adults: a literature review. *British Journal of Nursing*, *17*(14), 914-920.
- Selman, L. E., Daveson, B. A., Smith, M., Johnston, B., Ryan, K., Morrison, R. S., . . . Higginson, I. J. (2017). How empowering is hospital care for older people with advanced disease? Barriers and facilitators from a cross-national ethnography in England, Ireland and the USA. Age and Ageing, 46(2), 300-309. doi:10.1093/ageing/afw193
- Sowney, M., & Barr, O. (2007). The challenges for nurses communicating with and gaining valid consent from adults with intellectual disabilities within the accident and emergency care service. *Journal of Clinical Nursing*, *16*(9), 1678-1686. doi:10.1111/j.1365-2702.2006.01642.x
- Spradley, J. P. (1980). Participant observation. USA: Wadsworth Cengage Learning.
- Tadd, W., Hillman, A., Calnan, S., Calnan, M., Bayer, T., & Read, S. (2011). Right place -wrong person: dignity in the acute care of older people. *Quality in Ageing & Older Adults*, 12(1), 33-43.
- Tavernier, S. S., Guo, J.-W., Eaton, J., Brant, J. M., Berry, P., & Beck, S. L. (2018). Context Matters for Nurses Leading Pain Improvement in U.S. Hospitals. *Pain Management Nursing*, 19(5), 474-486. doi:https://doi.org/10.1016/j.pmn.2018.05.003