Nurses and caregivers experiences of recognising and managing pain in people with dementia in residential care in New Zealand

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Background

- Dementia is estimated to affect 47.5m world-wide and has substantial impact[1]
- People with dementia may suffer pain but have difficulty in communicating their pain[2]
- Nurses and carers need to recognise and manage pain when caring for people with dementia
- Limited research in New Zealand on this topic

World Health Organisation. 2016. Dementia. Fact sheet No.362. Available from: http://www.who.int/mediacentre/factsheets/fs362/en/

Zwakhalen SM et al. Eur J Pain 2000;13(1):89-93

Aims

To explore

- How nurses and caregivers in residential care in NZ recognise and manage pain in people with dementia
- Their suggestions for improving care

Setting

Five dementia and psychogeriatric units in Dunedin NZ

Methods

- Developed a semi-structured interview schedule
  - recognise and manage pain in dementia; improving care
- Ethics approval from University of Otago
- Posted information to 8 unit managers in Dunedin
  - advertise project using a poster with our contact details
- Student researcher (JW) interviewed participants at the University/the unit
- Interviews were recorded, transcribed, themes were identified

Results

- Managers at 5 units agreed to advertise the project
  - 3 dementia units and 2 psychogeriatric units
- Participants were 1 nurse and 1 caregiver from each unit
- Themes identified in interviews
  - Motivation for caring
  - How participants currently recognised and managed pain
  - How this could be improved

Results

Motivation for caring

To improve residents' quality of life

*I just believe in the fact that **one day it might be me**, and so that is the philosophy behind my care here. So making sure that under no circumstances are shortcuts taken with care. Whatever we can do to **enhance their quality of** life (nurse 4)*

*Just being able to **assist them in their journey,** you know? Bringing out the positive stuff in their life. Interacting with them and their families and just assisting them (nurse 2)*

*I can see that I'm **making life more c**omfortable for them (nurse 3)*

*It's quite rewarding **to see them smiling and cheerful**. There's a lady in there, oh she loves to dance, and I get her up all the time and have a dance with her (caregiver 5)*

Results

Recognising pain - caregivers

Recognised pain if a resident showed any unusual behaviour (e.g. rocking, grimacing, wriggling).

We know them personally because we have the same people everyday. We're with them all the time. Once you get to know them, you ***know what's normal*** *(caregiver 1)*

Grimacing*, you know, or they* ***go quiet*** *and they just don't interact like they normally do. Wriggling around a lot if they're chair or bedridden because they just can't get comfortable (caregiver 2)*

Oh yes, definitely ***facial expressions****, and* ***yelling*** *is another. They become quite vocal and angry, and you know, it's not usually the way they act. The biggest thing I've learned, that (there) is* ***no truth in it at all (the saying) "no brain, no pain"*** *(caregiver 4)*

Results

Recognising pain - nurses

Admission: Full assessment of a resident's needs, documented any potential for pain, and developed a care plan.

Day-to-day: Observation. No assessment tools used regularly; some had tried them in the past

*I rely on **observation**. I think I've been here long enough to do that. I will also ask them in many different ways. Are you sore? Where are you sore? (nurse 1)*

*The residents can **become withdrawn**. Often we find if people are **miserable**, and if its pain, they stay in their room. They don't eat their meal and stop participating in the activities (nurse 3)*

*We look at **facial expressions**, **noises** they are making, increased signs of restlessness, agitation, aggression or irritability (nurse 4)*

Results

Managing pain - caregivers

Non-pharmacological measures might be tried (heat pack, massage, bedrest). Resident's pain would be reported to the nurses

*I suppose, yes, **re-positioning them**. We've had **heat** things that…**packs**, yeah, that um, yep. Just will heat up in the microwave or something. I've put that on, yeah (caregiver 4)*

*Well some of them, because they might have knee trouble and stuff, so you would manage that to make them as **comfortable** as possible, so maybe that person can't stand for too long so you might **sit them** (down). Um, raised toilet chair if they have trouble getting onto a low chair. So those sort of things would do (caregiver 1)*

*Uh just **tell the RN** and usually they'll check, you know, for breaks and things like that, that have…or else ring the hospital and get them to X-ray (caregiver 2)*

Results

Managing pain - nurses

Check residents for physical signs of pain (e.g. injury, inflammation), response to initial measures, and, if needed, administered a previously-prescribed analgesic.

*First of all you would try and make the person **comfortable** and sort out some analgesia for them (nurse 1)*

*If people are distressed with pain, sometimes a **hot Milo** can be helpful. Some of the carers give a shoulder massage. Sometimes a walk can help. A rest on the bed. Perhaps they haven't put on enough clothes, and it's a cooler day (nurse 3)*

*We avoid rushing them during cares. I'm big on **careful handling**. You have to use transfer belts to avoid pulling patients from their arms to minimise the risk of bruising or shoulder dislocation and skin tears (nurse 4)*

Results

Managing pain - severe pain

I don't think Panadol's a wonder drug. If I was in a lot of pain, I'd want something ***a bit stronger than Panadol.*** *If someone's pain hasn't subsided, we have to wait 4 more hours until we can give them more Panadol (caregiver 1)*

But our young nurses find it hard to anticipate pain. And I think they struggle with the idea of administering morphine….. it takes ages for the medication to take effect. So it is, it's just a bit of a struggle trying to ***educate young nurses not to be afraid*** *(nurse 4)*

We'll put up a ***morphine pump*** *and give them a slow dose of morphine to keep them under control. That's actually made end of life issues for a lot of people very comfortable actually. And family are often accepting of (them) having some morphine (nurse 3)*

Results

Improving pain care - education

Participants thought that more frequent, regular sessions on dementia and pain would help improve care. Pharmacists had some involvement

*It (educational programme) definitely helped me directly in my work. I look at the residents differently. I can **understand a lot better** how they feel and how I can make them feel more at ease (caregiver 2)*

*I find it personally useful to keep learning. Our care manager organises education sessions. We cover many topics, not all at once, but throughout the year. We also get a medication session with the **people from the pharmacy a few times every month** or every couple of months (caregiver 5)*

*You come in and get trained on how to do the job. They'll say to you that part of your job is to notice any changes, but that's something you **have to learn yourself** (caregiver 1)*

Results

Improving pain care - education

*I think it (education) would be a very good thing to do. We haven't had any training sessions on pain for some time. I've been to them, and I've **found them very useful**. Some of our young nurses come from diverse areas (of nursing). To care for the elderly, it's a field which is entirely new to them (nurse 1)*

*We've had both the **pain clinic people**, and **pharmacists** come to talk about pain actually. I have found this very useful) in my work…All the caregivers have to do an aged care related education (programme), and pain is covered in that (nurse 3)*

*We have regular educational sessions here with the **pharmacist** and we've got the **pharmacist** available for any questions as well (nurse 5)*

Results

Improving pain care - team input

*I think it would be good to **review pain management as part of a team** because we're the ones there, and we're with them all the time so we know (caregiver 1)*

*We collaborate with the **GP and our carers**. We also have a **nurse practitioner** that visits us regularly, and they are specialists in older people's mental health (nurse 3)*

*We **work as a team**. We have the nurses and caregivers reporting, and it's got to be a team or collective assessment of a person. We have three monthly reviews of the resident. Physios are used on an as necessary basis, and once they're involved with somebody, they keep coming back to see them. The GP's also do three monthly reviews, and are here every week, so if we've got any problems, we can refer them onto him (nurse 5)*

Results

Improving pain care - other ideas

*(Pain) should be **reported and documented better**. If you go away after PRN medication is given, you might not know the effect later if it's not documented. So just better communication amongst us (staff) in terms of the effectiveness of what we're doing (nurse 2)*

*Doctors with their **writing, it is difficult to try and decipher** what is actually written, and you do end up making medication errors because we have a number of crossings in the same medication chart. We are looking forward to having computerised forms (nurse 4)*

*Although I think pain is managed really well here, but there have been **assessments that have been wrong** when people have come here. They've been assessed as having dementia, and really, they're in pain and they're dying. That actually happened to my father, it was sort of mind boggling and I just felt he was assessed wrong (caregiver 4)*

Conclusion/Discussion

Strengths

- Interviews - input from other nurses, piloted, modified
- One interviewer

Weaknesses

- Small study, one centre, one country, so not generalisable
- Last few interviews – views over-represented
- Self selection - managers who agreed to participate

Conclusion/Discussion

Nurses and caregivers

- recognised pain by closely observing behaviour
- managed pain with non-pharmacological and pharmacological methods

Nurses and caregivers

- wanted frequent, regular education sessions on pain in dementia in order to improve residents' care.
- valued multidisciplinary discussions on pain management

Pharmacists

- involvement varied, so
- there is scope for more pharmacist involvement in multidisciplinary discussions on pain management.

Thank You - Any questions?