Quality of life, care dependency and Paracetamol In advanced Dementia: is paracetamol the panacea to improve quality of life?
Dam, P.H. van

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Chapter 8

Summary
Worldwide, more than 55 million persons have dementia, the number increasing with nearly 10 million new cases each year. In the Netherlands, 250,000-290,000 persons have dementia, 32-38% of whom live in a long-term care facility (LTCF). As dementia is a progressive neurological disease for which there is still no cure, the primary goal of caring for persons with dementia is optimizing their quality of life (QoL).

Persons with dementia may not always be able to set their own goals and expectations. When persons with dementia are no longer able to assess their own QoL, family, friends and professional caregivers need to be their voice, as they are most familiar with their values, goals and needs.

There is evidence that the QoL of persons with dementia does not always decline as the disease progresses. However, there are symptoms and signs accompanying the progressing disease that have an impact on QoL, i.e., functional decline, and neuropsychiatric symptoms such as depression, aggression and psychosis. People surrounding persons with dementia face the challenge of optimizing these persons’ QoL, and every factor identified to facilitate this, such as finding undiagnosed pain and treating it, is an added benefit.

Pain is common in persons with dementia living in LTCF: 30 to 80% regularly experiences acute or chronic pain. The challenge is to identify those persons that are in pain and suffer from it. Ideal and the golden standard is that the persons self-report their pain. However, pain perception in persons with advanced dementia may be different and they are often no longer able to express pain adequately in terms of location, intensity and origin. Also, they are not always able to report the effect of pain treatment or side effects of the treatment. Underdiagnosed and therefore untreated pain may have a negative impact on neuropsychiatric symptoms like aggression, agitation and depression, but also on social interaction, daily functioning, appetite and sleep. It may therefore have a major negative impact on the QoL of persons with advanced dementia.

So far, paracetamol is step 1 of pharmacological pain treatment, also in older persons, as the side-effects remain limited in low dosage (≤ 4 g per day for acute use and ≤ 3 g per day for chronic use). The working mechanism of paracetamol still remains partly unclear. It is well known for its effects on pain and fever, but some people say they feel better when they take paracetamol. Is this because they had a fever, which is reduced by paracetamol and consequently they feel better? Or does paracetamol have other working mechanisms on well-being we do not yet know about? This is an interesting question, which to date remains unanswered.
Main findings in this thesis

In part I of this thesis we explored the characteristics and the QoL of persons using different types of pain medication. We also studied the association between the QoL, pain and use of pain medication (paracetamol, opioids, both paracetamol and opioids, or no pain medication) in persons with advanced dementia living in LTCF. The differences in characteristics and in QoL between persons with and without pain medication are described in Chapter 2. Cross-sectional data of the Communication, Systematic Assessment and Treatment of Pain, Medication Review, Occupational Therapy, and Safety (COSMOS) study in 67 Norwegian LTCF clusters showed that persons who used pain medication had 1) more advanced dementia, 2) pain scores more than twice as high, 3) significantly worse daily functioning, 4) more depressive symptoms, and 5) more neuropsychiatric symptoms, compared to persons who did not use any pain medication. The QoL measured by the QUALIDEM-6D was significantly lower in persons who used pain medication compared to persons who did not use any pain medication, except for the domain ‘social relationships’. The group of persons with advanced dementia living in LTCF with clinically relevant pain who did not use any pain medication daily had better overall QoL compared to persons who used paracetamol, opioids, or both paracetamol and opioids.

QUALIDEM-6D

The QUALIDEM is a validated questionnaire, specifically developed to measure QoL in persons with dementia living in LTCF. The instrument consists of 8 subscale domains (care relationship, positive affect, negative affect, restless tense behaviour, social relations, social isolation, feeling at home and occupation). For the studies in this thesis 19 of 37 items were deleted as recommended by the authors of the QUALIDEM manual for people with advanced dementia. Consequently, six domains were used (care relationship, positive affect, negative affect, restless tense behaviour, social relationships and social isolation; QUALIDEM-6D).

Chapter 3 describes the protocol of the Quality of life and Paracetamol In advanced Dementia (Q-PID) study. This study was a randomized double-blind placebo-controlled crossover trial in 95 persons with advanced dementia living in LTCF across the west of the Netherlands. All participating organizations were members of the University Network for the Care sector South Holland (UNC-ZH). Only persons with low QoL (QUALIDEM-6D ≤70) could participate in the study. Pain was not assessed prior to the study. The effects of regularly scheduled administration of paracetamol on QoL, discomfort, pain and neuropsychiatric symptoms, as found in the Q-PID study, are described in Chapter 4. The data of the Q-PID study showed that paracetamol, compared to placebo, did not have a positive effect on QoL, discomfort, pain or neuropsychiatric symptoms. However, there were participants who clearly derived benefit from paracetamol during and after the study, according to the assessments of their nurses/nursing assistants.
The Q-PID study

The Q-PID study was a 13-week double-blind, randomised, placebo-controlled crossover trial. In a crossover trial participants receive all treatments with a wash-out period in between. In this study, participants were randomly assigned to start with paracetamol or placebo for six weeks. After a wash-out period of one week, a second six-week administration period started with placebo (or paracetamol if the participant started with placebo). The placebo tablets resembled the paracetamol tablets in colour, size and composition, and contained quinine to give a bitter taste (placebo-controlled). Researchers, research nurses, professional caregivers and participants did not know which participant was assigned to which treatment arm (double-blind). Only the study pharmacy of the Leiden University Medical Center knew which participant was allocated to which treatment arm.

The Q-PID study included 95 residents with advanced dementia, being admitted to long-term care facilities affiliated with the University Network of the care sector Zuid-Holland (UNC-ZH). Inclusion criteria were 1) age ≥ 65 years, 2) advanced dementia (Reisberg Global Deterioration Scale (GDS) 5-7) and 3) QUALIDEM score ≤ 70. Exclusion criteria were the regular use of pain treatment, allergies to the study drugs (paracetamol or placebo), severe liver insufficiency or disease, use of > 4 units of alcohol/day, weight < 50 kg and/or concomitant use of flucloxacillin.

Flowchart of the Q-PID crossover trial

R= randomisation
Visit 1: Screening for inclusion and exclusion criteria
Visit 2: Baseline measurements
Visit 3 and 4: Follow-up measurements
Visit 5: Final and closing measurements
Part II describes the effect of regularly scheduled administration of paracetamol on care dependency and daily functioning, and how care-dependent persons with advanced dementia and low QoL living in LTCF are. After adjusting for period and order effects, and psychotropic medication use, no effect of scheduled administration of paracetamol, compared to placebo, was found on care dependency and daily functioning in a group of 95 persons with advanced dementia with low QoL living in LTCF. This was shown in the Q-PID study and is described in Chapter 5.

Cross-sectional data of the Q-PID study (baseline) were used to describe how care dependent the participants in the Q-PID study were and which factors were associated with care dependency and daily functioning (Chapter 6). Almost 80% of the total group were completely or to a great extent dependent on care provided by professional caregivers. Most care dependency was seen in learning ability (66.3%), eating and drinking (61.2%) and performing activities (59.3%). The items on which the population was least care dependent, i.e., to a great extent or completely independent, were communication (60.5%), maintaining body posture (58.1%) and mobility (48.8%).

The care dependency of persons with very severe dementia (GDS 7) was much higher compared to persons with moderate to severe dementia (GDS 5 and 6), and better social relationships according to the QUALIDEM-6D domain social relationships were associated with less care dependency (Chapter 6). Dementia severity (measured by the Global Deterioration Scale - GDS 7) and the QoL domain 'social relationships' were independently associated with daily functioning meaning worse daily functioning when having very severe dementia (GDS 7) compared to persons with moderate to severe dementia (GDS 5 and 6) and better social relationships were associated with better daily functioning.

Overall conclusion

QoL in persons with advanced dementia is influenced by many factors, such as environment, background and psychological factors such as depression and agitation. This thesis provides evidence that administration of paracetamol or placebo alone is not effective, i.e., no ‘panacea’, for improving QoL, discomfort, pain, neuropsychiatric symptoms, care dependency and daily functioning in persons with advanced dementia living in LTCF. Personalizing interventions, collaboration between different health care workers and family/friends, and combining pharmacological and non-pharmacological interventions are important to maintain the best QoL possible, and we recognize that this will be challenging, but not impossible.