The main aim of this thesis was to study the relationship between mastication, cognition, and quality of life (QoL) in elderly persons with dementia. In a clinical setting, an experimental approach (randomized clinical trial; RCT) was used to examine the effect of increased masticatory activity on cognition and QoL. Supplemental research was done by reviewing the existing literature. In this general discussion, the outcomes of the RCT will be reflected upon, including how this relates to the literature, and what conclusions can be drawn for the future.

**RELATIONSHIP BETWEEN MASTICATION AND COGNITION**

In the literature, there is a body of evidence emerging that there is, in fact, a relationship between mastication and cognition. This literature is discussed in chapter 2. The results from the cross-sectional analysis from the baseline data of the RCT, as discussed in chapter 6, agree with these findings; correlations between global cognition and masticatory performance, and between verbal fluency and masticatory performance were found. Masticatory performance was assessed with an objective mixing ability test, which was developed for this purpose, and which is discussed in chapter 5. With this test, the correlation between mastication and cognition was objectively studied for the first time, in elderly persons with dementia, rather than through self-report, as was done by, e.g., Miura et al. ¹. Furthermore, cognition was extensively assessed, instead of only globally screened. The fact that only two cognitive functions showed a correlation means that other cognitive functions — *i.e.*, (working) memory and attention, visuospatial (working) memory and function, and verbal long-term memory — did not correlate. Others have also found that mastication influences some, but not all, cognitive functions. For example, chewing
a piece of gum might improve sustained attention but not memory, or chewing a piece of gum improved (working) memory but not attention. In healthy elderly persons, better masticatory function related positively to recall and recognition of sentences, recall of test session, and prospective memory, but not to face recognition, recall and recognition of actions, attention, and tests for executive function. Clearly, there is still more work to be done, to investigate how mastication might be related to exactly which cognitive functions.

**RELATIONSHIP BETWEEN QUALITY OF LIFE AND MASTICATION**

Besides cognition, mastication is also related to QoL. QoL is a patient-based, nonmedical appraisal of the burden presented to individuals suffering from dementia. An important part of QoL is being contented, having fulfilling encounters and maintenance of dignity. QoL can be influenced by masticatory function and oral health; for example being able to eat healthy foods without help or the need for mashing creates enjoyable mealtimes which improves QoL, whereas suffering from a dry mouth hinders denture use, and thus, speech and social interaction, which lowers a person's QoL. Pain of course can play an important role. Painful conditions such as pain in the skull, jaw, or neck (e.g., Temporomandibular Disorders) are known to lower a person's QoL. Assessment of the longitudinal data suggested that the implementation of the intervention might have negatively influenced QoL, as restless and tense behaviors increased in the intervention group. As discussed in chapter 7, however, the intervention was not implemented successfully, with oral care being performed more or less haphazardly, and this might have led to apprehension with the participants.

**PAIN**

One interesting finding of the RCT was that relatively little orofacial pain was reported. In the cross-sectional analysis, pain during mandibular excursions was rarely found, as almost 90% of the participants indicated to have ‘no pain’, and the maximal summed pain score was 4 out of a possible maximal score of 16. However, as mentioned in chapter 1, in elderly persons with (severe) dementia, self-report is most likely unreliable. Since there are no observation scales specifically aimed at assessing orofacial pain, as discussed in chapter 3, presence of pain during these mandibular excursions was not measured in another way, besides self-report. Given the voluntary nature of the excursions it was assumed that no major painful condition arose during the assessments.

However, since pain tends to be underdiagnosed and undertreated in elderly
persons suffering from dementia, it seems likely that there were, in fact, undiagnosed orofacial painful conditions that influenced the mandibular excursions and masticatory performance. Common oral conditions in elderly persons are, amongst others: dental caries, (advanced) gingivitis (i.e., inflammation of the gums; bleeding gums), periodontitis (i.e., inflammation of the supportive tissue around the teeth), xerostomia (dry mouth), and candidiasis, which can present as: pseudomembranous candidiasis [in Dutch, spruw]; denture stomatitis; and/or angular cheilitis (fissures at mouth corners). These conditions are uncomfortable, if not painful. For example, even if it is asymptomatic in most patients, denture stomatitis can be painful and/or can give a burning sensation in the mouth. Similarly, pseudomembranous candidiasis is often clinically not relevant, but in some patients, it can cause discomfort and changes in taste; angular cheilitis is most uncomfortable when one has to open the mouth, for example during mandibular excursions.

One case in particular was exemplary in how attention for oral health care and possible presence of pain can improve and impact quality of life (QoL).

One nursing home resident, (let’s call her Ms. Daisy), showed typical behavior. She was always in a bad mood, quickly agitated, would never smile or make pleasant conversation, and spent her time sitting alone in her wheelchair, leaning with her arm at the dining table, resting her chin in her hand, covering her mouth a bit. She would lament and wail, sometimes softly, sometimes she cried out loud. ‘Oh, Ms. Daisy, hush!’ That’s what the nursing staff called at her, if she was being too loud or disturbing other residents. On ‘good’ days, she would sit there, alone at the dinner table, quietly whimpering. On ‘bad’ days, she would be returned to her room, maybe given some tranquilizing medicine.

When the project started in her nursing home, the resident dental hygienist was allowed to take the time to visit and inspect every participant’s mouth. Ms. Daisy turned out the have a serious case of oral candidiasis, and most likely felt discomfort, pain, experienced altered taste. She was perhaps even aware of this, as her general behavior of avoiding contact and covering her mouth changed immensely when her candidiasis was treated; she smiled, laughed, even hugged members of the staff. She no longer felt inhibited to engage in social interactions, had a good mood, and was pleasant to be around. This reflected positively on the staff and other residents, who in turn became more pleasant and relaxed.

Clearly, the behavior indicated (orofacial) pain, as described in chapter 3, such as calling out (vocalization), the sloughed posture (body movements), her behavior (withdrawn; aggressive; sad), holding her face, and resisting oral care. Awareness of (oro-)facial pain would have improved her QoL, and that of those around her, a lot sooner.
Randomization, allocation concealment, and blinding

In chapter 4, the proposed method for data collection is described. There are a few critical comments that can be made. For example, the design was intended as a longitudinal matched cluster randomized single-blind multicenter design. In one participating center, due to crossover of nursing staff, the control group was contaminated, and the cluster match was lost. This happened early in the project, and therefore it was decided to include the control group in the intervention group. The nursing staff of the new intervention group was briefed and trained accordingly. Complete randomization and allocation concealment is preferred, to prevent selection bias. However, sometimes a certain ward was thought to be better suited for participation in the intervention group than others, for example due to presence of a stable team of nursing staff rather than one including many temporary workers. This might have created a selection bias. The study was designed to be single blind, and indeed, the trained examiners were blind for the intervention. It is possible that, due to the nature of the dementia, participants were also blind for, or perhaps unaware of, the intervention. However, some data were provided by proxies (such as the QoL ratings), and these proxies were members of the nursing staff, who regularly interacted with the participant; never for example a family member. These members of the nursing staff were sometimes the same persons that were also performing the intervention. Non-blinded examiners tend to rate more positively, thus creating ascertainment bias.²⁰ It is possible that inadvertently, bias was introduced; future studies should be aware of this limitation and make an effort to avoid this.

Missing values

An unexpected finding was the amount of missing values. It was estimated (chapter 3) that there would be about 10% dropout due participant’s relocation and mortality. However, the return rates that could reasonably be expected for the proxy questionnaires were not taken into consideration in these calculations.

The initial response rate of the current study is normal to high; in survey studies, return rates on questionnaires are commonly about 60%²¹ to 70%²² in community samples, and lower (e.g., 42%)²³ in proxy questionnaires. In the current RCT, proxy-assessed activity of daily living (ADL) baseline scores were obtained for 66.6% (chapter 6; n=76/114). Similarly, 64.4% of the proxies returned completed QoL questionnaires for baselines assessments (chapter 7; n=67/104). For the longitudinal repeated assessments, however, results were worse; after 24 weeks, for only 25% of the participants, complete case data on QoL were available (chapter 7; n=26/104).

If we view these results in the light of the design, with multiple assessments, we might understand the response rates better by considering the following. If for a
single survey, the response rate is 65%, then repeating the survey 4 times would lead
to an expected response rate of \((0.65)^4 = 0.18\), \(i.e.,\) a response rate of about 20%,
which is in line with the current findings of 25% response rates for complete cases.

Efforts to increase response rates were made from the beginning, as personal
contact was established and maintained, the questionnaires were hand-delivered,
and follow-up inquiries were made – actions that are known to improve response
rates \(^{21}\). The questionnaires were comprehensive, but as length of the questionnaires
is not of influence on response rates \(^{21,22}\), it is not likely that this was of influence on
the results. Generic looking questionnaires were used, which should have been no
problem, because adding a feel of authority to the presentation of the questionnaire
by printing logo’s and adding signatures does not improve response rates \(^{24}\). As an
alternative, internet-based surveys might seem appropriate, but they are found to
be less effective in generating a response than paper surveys \(^{25}\).

It is understandable, but nevertheless most unfortunate, that such low response
rates were obtained, and future studies should take these response rates into con-
sideration when performing power calculations. Besides missing values due to the
response rates on the questionnaires, low responses were obtained with the neu-
ropsychological tests and the assessment of the masticatory performance.

The response rates for the neuropsychological tests were slightly better compared
to the proxy response rates. Global cognition, for example, was successfully assessed
with the Mini Mental State Examination (MMSE, \(^{26}\)) in about 80% (chapter 6,
\(n=93/114\)). Repeated response rates for global cognition were relatively high, 54%
\((n=56/104)\). This is probably due to the external trained examiners, who always
aimed for 100% response, and only a participant’s (mental or physical) inability
to participate, rather than a rater’s unwillingness to participate, influenced these
response rates.

However, less than 50% of the participants were successfully examined with the
full test battery, which was applied to those participants who scored higher than
5 of the MMSE (see chapter 3). In fact, a score of MMSE \(<9\), indicating severe
dementia \(^9\), was obtained for more than half the sample. In Figure 8.1, a frequency
distribution of the MMSE scores is given for the sample from chapter 6, and in
Figure 8.2, the same data is presented in a pie chart, clearly illustrating the severity
of the dementia in the sample.

The advanced dementia level of the sample was one of the reasons that partici-
pants attending daycare, with generally less severe dementia, were actively recruited
in the later stages of the trial. In future trials, it would be worthwhile to actively
include, from the beginning, care organizations with residents with less severe de-
mentia, such as low-medium care wards (‘verzorgingshuis’) and daycare facilities.
A bottom cut-off score for global cognition at baseline for participation might be
considered, although global cognition did not appear to influence, for example, the
ability to participate in the mixing ability test, as described in chapter 6, and the
overall participation rates for the neuropsychological tests are not disappointing.
Figure 8.1: Distribution of global cognition of the participants in the cross-sectional study, assessed with the Mini Mental State Examination (MMSE). Participants are classified into a Severe/Moderate/Mild category (MMSE: 0–9; 10–19 and >20, respectively).¹⁹

![Bar chart showing distribution of MMSE scores across severity categories](image)

Figure 8.2: Pie chart of participants’ distribution according to Dementia Severity. Note that over half of the participants suffered from severe dementia according to Schiffczyk et al., (2010).¹⁹

![Pie chart showing distribution of dementia severity](image)
Masticatory performance was assessed with a combination of techniques (chapter 4). Mandibular excursion assessments were successfully performed in about 40% of the cases (i.e., chapter 6: 42.3% (n=44/104) and chapter 7: 41.2% (n=47/114)). Due to the severity of the dementia, participants often did not understand the verbal instructions at first explanation, however, using non-verbal communication, offering a demonstration and mimicking the desired motions, successful assessment was often still achieved. It was found that maximal mouth opening was easier modeled and assessed than protrusion and laterotrusions. Only complete assessments have been included in the analyses; it might be worthwhile to reconsider this in future papers, and only focus on maximal mouth opening, because limited maximal mouth opening alone is considered a clinical sign in studies on temporomandibular disorders.

The mixing ability test with two-color chewing gum, which was developed for this thesis, was found to be adequately responsive and reliable (chapter 5), although validity needs to be further established. The mixing ability test was used to assess the association between masticatory performance and cognition in a cross-sectional study of the clinical sample (chapter 6) and was taken as a measure of intervention success in chapter 7. The rationale behind this was that if the intervention increased oral health and thereby masticatory activity, masticatory performance would improve as well. Similar assumptions and assessments have been made, for example, when using a timed walk or a “Timed Up and Go” task to investigate the effect of a walking intervention.

A correlation between masticatory performance and cognitive measures was found, in a subsample of persons participating in the mixing ability test (chapter 6). About half of the participants did not perform the mixing ability test. There were several reasons for ‘nonperformance’. First of all, some participants were excluded based on predefined criteria, such as facial paralysis. Others were eligible to participate, but were withdrawn by an intervening proxy. For example, a member of the nursing staff would indicate that a participant should not perform the mixing ability test. This was done without a medical imperative, i.e., there was no physical or ethical reason that called for exclusion. Instead, the advice was given, for example, out of fear for agitation or exhaustion. Whether or not this fear was based on a thorough risk assessment was never debated; the trained examiners were instructed to respect the proxies’ instructions, and thus excluded the participant from the test. This may have led to a selection bias, which could be reflected in the higher dependency scores for ADL of the group of ‘nonperformers’. This group comprised both the participants that were excluded based on the predefined criteria, as well as those excluded by proxy request. Participants that were more dependent were perhaps considered too vulnerable, and therefore excluded by a proxy.
Adherence

During the process of implementing the intervention, there was a growing concern about the actual adherence to the intervention. This was the main reason that an ad hoc terminalis analysis was conducted, rather than the planned end-analysis. Several factors contributed to the concern with regard to intervention adherence.

Reports for intervention success varied greatly between nurses from the same ward, some mentioning all went ‘great’ whereas others indicated major problems. Attendance to the clinical lessons was low, and after a survey, it was found that, among daily nursing staff, the awareness of the project and the importance of oral health in general was also low. There were many changes in nursing staff, dentists, dieticians, and also in management, which did not facilitate embracing and embedding of the intervention.

At a few nursing homes, that had a local dental hygienist, plaque checks were performed, at baseline and at random intervals later on. These plaque checks indicated no improvement over time. The tick-off lists, if filled out, also indicated low frequency of oral care (data not shown). On the other hand, when we were presented with tick off lists showing 100% successful oral care moments, all filled out in the same handwriting and ink, it was felt that this was perhaps not reflecting the actual situation. Deception by those unwilling or unable to comply is common in clinical trials, but also impossible to predict, and hard to prevent or prove.

Obstacles for implementation success

The interviews with the daily nursing staff indicated difficulties such as a lack of time, and a lack of money, for example to buy oral care supplies or harder foods. A lack of commitment by the managers was also mentioned, leaving the nursing staff feeling unsupported. These are common, but serious obstacles for innovation.

This lack of managerial commitment was also felt in participating in the clinical lessons.

It was felt that managers did not facilitate or prioritize attendance, as staff was expected to attend the lessons in their own time, without financial compensation and with no regard for personal commitment such as caring for (young) family members. Only occasionally, adaptations in work schedules were made to facilitate attending clinical lessons. Managers rarely attended the lessons themselves, which was most unfortunate as management support and active leadership is related to intervention success. Sometimes, instead of the daily nursing staff, replacements attendees were sent, such as high-school students who were on an orienting internship. Temporary workforce staff was excluded from attending the clinical lessons.
Nurses’ ideas about the importance of oral health and their ability in providing oral care can improve after training, although a clinical effect of education on oral hygiene is not (yet) evident \(^{32,33}\). This conclusion was recently confirmed in a review study \(^{34}\). Continuous education and support of staff on providing oral health care is therefore recommended \(^{35}\), especially as nurses are typically only marginally trained in providing such care, if at all \(^{32,36}\).

In the present study, nursing staff did not always realize and appreciate the benefit of good oral health and mastication for general health and QoL. For example, it was thought that for elderly persons with dementia, having no teeth and eating or being fed pureed foods would be ‘easy and enjoyable’, which did not help in motivating staff to provide oral health care. Offering one clinical lesson was not enough to change this overall negative attitude towards oral care.

**Complexity of change**

Besides negative attitudes and (perceived) lack of managerial support, the lack of implementing success might be explained by looking at the complexity of the intervention \(^{37}\). According to Sterns, Miller and Allen \(^{37}\), complex changes are hard to implement. A change is complex when the outcome of the change is uncertain, and the level of agreement between parties is low. On the opposite, a change is not complex when the outcome is certain and agreement is high. A non-complex change is for example adding plants to the living room to increase a sense of home, or allowing a resident to choose his/her own bedtime, to increase autonomy. These changes do not involve an elaborate interaction or are the potential source of conflict, the outcome is quite certain, and can thus be implemented easily in nursing homes. A complex change, however, is typically only implemented by very committed teams and organizations. Providing oral health care is a complex change, as there is uncertainty of the effect – will oral health increase, will QoL increase, or perhaps cognition? Having the effort being evaluated scientifically might have increased this uncertainty. There is much disagreement between the parties; the resident and nursing staff are likely to have some (initial) conflict as they attempt to provide oral care, and despite clinical lessons and supervision of an dental hygienist, there were questions regarding (or even resistance towards) certain actions; for example, about storing dentures overnight, or about brushing teeth when the gums are bleeding. Having to adapt their approach to each resident individually increases the complexity for the nursing staff even more.

From a literature review on psychosocial intervention, it became clear that knowing the resident personally is an important factor for intervention success \(^{38}\). Interestingly, these authors noted that nursing staff seem to be preoccupied with the risk of physical harms (e.g., falling) or causing agitation, and are more focused on prevention of oppositional behavior such as outbursts, than they are on promoting autonomy and improving QoL \(^{38}\). This is in line with the current observations;
nursing staff were quite concerned with the physical wellbeing of participants, and with maintaining a level of serenity in the ward, and could therefore be reluctant to start providing oral health care, since it caused (initial) resistance behaviors.

CLINICAL RELEVANCE

The clinical relevance of these findings is profound. It was shown in this thesis, in both literature and the clinical sample, that there is an association between masticatory performance and cognition. This would suggest that maintenance or rehabilitation of oral function is important, especially for those persons most affected by cognitive loss and unable to communicate possible pain, such as elderly persons suffering from dementia.

At the same time, it was found that successfully implementing an oral health care intervention is quite challenging. Comparable results for oral care interventions have recently been reported. The implementation of the Dutch 'Oral health care Guideline for Older people in Long-term care Institutions' (OGOLI) ⁴⁹ has been studied in another longitudinal design in the Netherlands and Belgium ⁴⁰,⁴¹. Unfortunately, after six months, the only positive finding was that residents who were completely dependent had less denture plaque. However, all plaque levels were still higher than expected ⁴⁰. The results after five years were not much different, as the plaque levels were still high in both intervention group and control group ⁴¹. Intensive supervision of the implementation seems only marginally beneficial ⁴². Similarly, in a residential setting, training the daily nursing staff led to improvements of oral hygiene at 11 month follow up, mostly in denture hygiene, and with almost half of the residents still having poor oral health ⁴³. The need for dental treatment also remained high despite training in yet another study, even though the staff’s ability to assess oral health and the residents’ oral hygiene improved ³³.

Nevertheless, there are also inspiring reports: it was found that an intervention focused on providing oral health care (i.e., brushing after each meal and weekly cleaning by a dentist or dental hygienist) for nursing homes residents was able to differentiate the intervention group from the control group after six months and two months, based on MMSE scores ⁴⁴. It would be very interesting to further investigate the factors that determine the implementation success of an intervention.

The introduction of a designated Oral Health Coordinator (OHC) who received outside training and ongoing support from a trainer, had a positive effect on the oral health of institutionalized elderly after one year ⁴⁵. The level of authority and enthusiasm of the OHC was key in intervention success; more important than education ⁴⁵. A positive effect on oral hygiene was reported after 3 months and even after 6 years, of having designated supervising staff members, alongside picture-based instruction cards, providing materials and practical oral care instructions to nursing staff in a residential setting ⁴⁶. Assigning a designated oral care nurse each
day and equipping this person with a custom-made trolley was found to reduce plaque scores, gingivitis, and periodontal disease\textsuperscript{47}. Presence of a designated oral care professional also increases positive attitude towards oral care in nursing home staff\textsuperscript{48}.

Committing specific members of staff to performing the oral health care was found to be effective in improving the oral health of residents suffering from dementia\textsuperscript{49}. In this pilot study, dedicated mouth care aides were allowed spending 4 hours per day, for 5 days per week, to providing oral care to all the residents. They received daily training for two weeks, including providing oral care alongside the dentist, followed by expert support for a few hours per week. Training included theory and practical information on oral care and also instruction by a psychologist on dealing with behavioral issues they might encounter. There was a significant improvement in oral hygiene and thoroughness of care, e.g., flossing and tooth picking had become part of the routine\textsuperscript{49}.

The addition of counseling on how to deal with resistant behaviors is promising, indeed. Studies confirm that resistant\textsuperscript{50} and uncooperative\textsuperscript{51} behavior from dependent residents (both cognitively healthy and suffering from dementia) play a major role in oral health. An intervention executed by researchers combining tactics for reducing resistant behaviors and oral health care best practices proved very successful\textsuperscript{52}. In fact, loss of cognition does not have to influence oral health, as long as someone is independent for oral health care; however, as one becomes dependent, impaired cognition puts a person at great risk for impaired oral hygiene, most likely due to un-cooperation\textsuperscript{53}. Recommendations for reducing care-resistant behaviors in oral care are available\textsuperscript{54}, but they are not part of the Dutch guideline\textsuperscript{35} nor part of nurses training\textsuperscript{36}.

From all of the above, some suggestions for future research and policy makers can be made. First, it would still be interesting to investigate the effect of increased masticatory activity on cognition and QoL in elderly persons with dementia. A successful implementation of an oral health care intervention would be key to this.

Secondly, therefore, it would be worthwhile to further investigate how to implement oral care interventions for elderly persons with dementia. Factors for success will most likely include continuous education, including individual coaching and providing the ability to work alongside a dental professional (‘training on the job’), and designating a daily oral care provider, to increase accountability. Training should include both theory and practical instructions; both in providing oral care and in responding to resistant and uncooperative behaviors. In order to practically organize this, our final recommendation would be to commit dedicated professionals to this task, rather than designating a member of the daily nursing staff to provide oral care
and rotating this responsibility on a daily or weekly basis. This dedicated, designated oral care nurse, the so-called Denticure, will be trained in both providing oral health care for elderly persons and in handling uncooperative behavior. The Denticure provides all daily oral care, is the liaison between nursing staff and dental professionals, and since (s)he does not have other nursing tasks, there is no conflict of priorities, or lack of time or skill. Assigning the task of oral care to one or two specific persons rather than the group also creates transparency, direct accountability, and responsibility. The Denticure can establish good rapport with the residents, and will develop a tailored approach for each individual client.

Simply trying to add the task of oral care to the workload and responsibility of the – already overburdened – daily nursing staff under the premise of ‘it only takes two minutes’ is denying both the value and effort of offering oral health care. As it is of great importance to general health, and, since the nursing homes residents of the future are expected to offer challenging dental situations, we would strongly recommend the appointment of a Denticure in every nursing home. With an estimated possible workload of 4–6 clients per hour, one fulltime Denticure could provide excellent oral health care, once daily, for 40 residents. Specialized training for this job must commence as soon as possible, and adequate funding must be made available.
REFERENCES

15. Zuluaga D.J., Montoya J.A., Contreras C.I., Herrera R.R. – Association be-
tween oral health, cognitive impairment and oral health-related quality of life. *Gerodontology.* 29(2); e667–e673, 2012.


50. Willumsen T., Karlsen L., Naess R., Bjorntvedt S. – Are the barriers to good oral hygiene in nursing homes within the nurses or the patients? *Gerodontology*. 29(2); e748–e755, 2012.