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Quality of life in nursing-home patients with dementia
# Table of Contents

Acknowledgments ........................................................................................................................................1

Abstract ..........................................................................................................................................................2

Sammendrag ................................................................................................................................................ 10

List of papers ............................................................................................................................................... 19

Abbreviations .............................................................................................................................................. 20

1.0 Introduction ..................................................................................................................................... 23

2.1 Background ........................................................................................................................................... 25

2.2 Dementia ........................................................................................................................................... 25

2.3 Prevalence and incidence of dementia ............................................................................................... 27

2.4 How to measure cognitive impairment ............................................................................................. 28

2.5 Course and severity of dementia ........................................................................................................ 29

2.5.1 Subjective cognitive impairment ................................................................................................ 29

2.5.2 Mild cognitive impairment ......................................................................................................... 30

2.5.3 Mild dementia ............................................................................................................................. 31

2.5.4 Moderate dementia ..................................................................................................................... 31

2.5.5 Severe dementia .......................................................................................................................... 31

2.6 Symptoms in dementia ...................................................................................................................... 31

2.6.1 Cognitive symptoms in dementia ............................................................................................... 31

2.6.2 Activities of daily living ............................................................................................................. 32

2.6.3 Neuropsychiatric symptoms ....................................................................................................... 33

2.7 Different types of dementia disorders ............................................................................................... 37

2.7.1 Alzheimer’s disease .................................................................................................................... 37

2.7.2 Vascular dementia ...................................................................................................................... 37

2.7.3 Lewy body dementia ................................................................................................................ 38

2.7.4 Frontotemporal dementia .......................................................................................................... 38

2.7.5 Secondary dementias .................................................................................................................. 38

3.1 Dementia care in Norway: From diagnosis to nursing home ............................................................... 39

3.2 Diagnoses, dementia teams, and in-home care .................................................................................. 39

3.3 Long-term residential care in Norwegian nursing homes ................................................................. 40

3.3.1 The nursing-home units ............................................................................................................. 40

3.4 The nursing-home residents ............................................................................................................. 41
Paper 3: Variables associated with change in Quality of Life among Persons with Dementia in Nursing Homes: A 10 Month Follow-Up Study (225) ................................................................. 77

Paper 4: Living with dementia in a nursing home, as described by persons with dementia: A phenomenological hermeneutic study ................................................................. 78

7.1 Discussion ............................................................................................................................................. 79

7.2 Is the QUALID a health-related quality of life instrument or a general quality of life instrument? . 79

7.1.2. Would it be possible to incorporate persons with dementia’s self-report on QOL in QUALID? ............................................................................................................................................. 80

7.3 The QUALID scale – sadness, tension, and well-being – paper 1 .................................................... 81

7.3.1 Sadness ....................................................................................................................................... 82

7.3.2 Tension ....................................................................................................................................... 82

7.3.3 Well-being .................................................................................................................................. 84

7.4 How does the QUALID score vary with dementia severity? ......................................................... 86

7.5 What affects and changes QOL over time? Papers 2, 3, and 4......................................................... 88

7.5.1 By proxy – papers 2 and 3 ............................................................................................................ 88

7.5.2 Descriptions by the person with dementia – paper 4 - what affects and change QOL over time 89

7.6 Did the persons with dementia talk about the items rated by the QUALID?............................... 92

7.6.1 Sadness ....................................................................................................................................... 92

7.6.2 Tension ....................................................................................................................................... 92

7.6.3 Well-being .................................................................................................................................. 92

8.0 Conclusion............................................................................................................................................. 93

9.0 Methodological considerations........................................................................................................... 94

10.0 Clinical implications and proposals for future research.............................................................. 95

References ................................................................................................................................................... 97
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Abstract
This thesis explores quality of life in persons with dementia living in nursing homes. Quality of life is a frequent outcome measure in research on medical treatment or care. In clinical care, some nursing homes use quality of life measures to evaluate their residents. The term is a difficult one to define, and a single definition lacks agreement. Various definitions include mainly the person’s cognitive abilities, dependency in activities of daily living, and ability to participate in activities that are meaningful to him or her. For persons with dementia, it becomes difficult to meet the criteria used in such definitions as their condition progresses. They will experience increasing cognitive decline and greater difficulties taking care of themselves and will subsequently have trouble living an independent life and participating in meaningful activities and social relationships.

Due to their symptoms, it is difficult for persons with dementia to provide information about their quality of life. Theories on quality of life in this population suggest that we must trust our evaluation of observations of behavior in the person to know something about his or her quality of life. Research, however, shows that there is a gap between how a family member or a professional caregiver (a proxy) rates the quality of life for the person with dementia and how the person rates his or her quality of life. Proxies emphasize neuropsychiatric symptoms, particularly depression but also agitation, irritation, and apathy, and cognitive impairment and ability to conduct activities of daily living as important influencers for quality of life. By contrast, when evaluating his or her quality of life, the person with dementia emphasizes depression as a primary influencer on quality of life rather than the other symptoms.

Several qualitative studies have investigated how persons with dementia experience life in the nursing home by interviewing them. Most often, persons with dementia report that they receive the necessary help and care, but they also report feeling of loneliness, depression, and boredom.

Approximately 80 percent of the residents in Norwegian nursing homes have some form of dementia. To maintain good quality of life in this setting, we need in-depth knowledge and understanding about how quality of life evolves in persons with dementia in nursing homes. Caregivers need knowledge about the variables that influence quality of life in this population so that they can adjust care in the best possible way.
The Quality of Life in Late-Stage Dementia scale (QUALID) has been translated into Norwegian and is used in research in Norwegian nursing homes. This scale measures behavior and frequency of behavior (daily/weekly) in persons with moderate and severe dementia but can also be used in those with mild dementia. The scale is completed by interviewing a caregiver who knows the person with dementia well and asks about the prevalence and frequency of 11 types of behavior (items) associated with quality of life. For each item, a score between 1 and 5 is possible, meaning that the total score ranges from 11 and 55 points; a score of 11 indicates a high quality of life, while a score of 55 indicates a very poor quality of life.

To acquire greater knowledge about quality of life as measured by the QUALID scale, it was necessary to investigate whether any of the behaviors or symptoms measured formed clusters as well as which other variables are associated with quality of life and changes in quality of life.

Aim of the thesis

The overarching aim was to describe quality of life in persons with dementia in nursing homes (NH) in Norway. To do this, we conducted four studies.

First (as described in paper 1), we wanted to increase our knowledge about which dimensions of quality of life the QUALID scale measures when used in a nursing-home setting with persons with dementia. Additionally, we wanted to investigate how each symptom of the QUALID scale varied across the severity of dementia.

Second (as described in paper 2), we wanted to prove or reject each of the two hypotheses that 1) quality of life (QOL) in NH patients with dementia is associated with the patients’ neuropsychiatric symptoms, impairment related to activities of daily living, and the severity of cognitive impairment; and 2) QOL in NH patients with dementia is not associated with the patients’ gender, age, and/or type of ward (special care unit (SCU) vs regular unit (RU)).

Third (as described in paper 3), we wanted to investigate whether changes in quality of life as measured by the QUALID scale and its subscales over a 10-month period are associated with baseline QOL scores, neuropsychiatric symptoms, use of psychotropic drugs, degree of dementia, and/or impairment in activities in daily living but not with gender and/or age.
In addition to the QUALID, for the first three studies we used the following scales:

The Neuropsychiatric Inventory Questionnaire with 10 items (NPI-10-Q) was used to assess the severity of behavioral and neuropsychiatric symptoms common in dementia. This version evaluates 10 different types of neuropsychiatric symptoms. A factor analysis has shown that when used in Norwegian nursing homes, the questionnaire has three components, namely, agitation, psychosis, and affect. Apathy did not cluster with any of the three components.

The Clinical Dementia Rating Scale (CDR) was used to rate the stage of dementia. The scale evaluates six cognitive and/or self-maintenances domains: memory, orientation (time and place), problem solving, community affairs, home and hobbies, and personal care, each with five possible answers. The scale can be used as a categorical variable (0 = no dementia, 0.5 = mild cognitive impairment or possible dementia, 1 = mild dementia, 2 = moderate dementia, 3 = severe dementia) or as a continuous variable by using the sum of boxes, with scores ranging from 0 = no dementia to 18 = severe dementia.

The Physical Self-Maintenance Scale (PSMS) was used to evaluate patients’ abilities to perform basic activities of daily living. The scale evaluates six different areas: the ability to go to the toilet, to eat, to dress, to wash, to walk, and to bathe independently; a lower score indicates better functioning. The scale is a continuous variable with scores ranging from 6 (best) to 30 (worst).

Each patient’s general medical health was rated using a four-point global scale. Taking into account the number of general medical conditions, the severity of those conditions, and the use of medications for each patient, we used the following ratings: good health = 1, fair health = 2, poor health = 3, very poor health = 4.

Because we know from earlier research that there is a gap between proxy-reported and self-reported quality of life, we also wanted to investigate what persons with dementia report about life in the nursing home.

Thus, the fourth aim (paper 4) was to investigate the experience of living in a NH and what makes life better or worse from the perspective of the person with dementia. To accomplish this, we conducted observations and interviews with persons with dementia in nursing homes, in addition to completing the QUALID.
Study 1

In the first study (paper 1), we conducted a principal component analysis on QUALID and investigated how symptom load varies across dementia severity. We included 661 persons with dementia with a mean age of 85.3 (SD 8.6) years; 71.4% were women. The QUALID and the Clinical Dementia Rating Scale (CDR) were applied. A principal component analysis (PCA) was applied to test the factor structure. Non-parametric analyses were applied to examine differences of symptom load across CDR groups.

The results showed that mean QUALID score were 21.5 (SD 7.1); CDR 1, 22.5%; CDR 2, 33.6%; and CDR 3, 43.9%. Cronbach’s α of QUALID was 0.74. The PCA analysis resulted in three components accounting for 53% of the variance: “sadness” (appears sad, cries, facial expression of discomfort), Cronbach’s α 0.65; “tension” (facial expression of discomfort, appears physically uncomfortable, verbalization suggests discomfort, being irritable and aggressive, appears calm), Cronbach’s α 0.69; and “well-being” (smiles, enjoys eating, enjoys touching/being touched, enjoys social interaction), Cronbach’s α 0.62. We constructed three subscales by using the QUALID items that clustered to the three components and called them sadness, tension, and well-being. The “tension” and “well-being” mean scores increased significantly with the severity of dementia (CDR score), suggesting poorer quality of life in these two domains with increasing dementia. The score on the subscale for “sadness” did not change in relation to dementia severity.

Conclusion: Three components of QOL were identified. The two subscales, “tension” and “well-being,” changed for the worse with increasing dementia, while the “sadness” factor did not change with increasing dementia.

Study 2

The second study (paper 2) was a cross-sectional study with the objective of examining which variables are associated with the total QUALID score and the scores of the subscales for sadness, tension, and well-being.

We included 661 persons with dementia living in nursing homes. To measure quality of life, the Quality of Life in Late-Stage Dementia Scale was applied. We used the CDR to measure
dementia, the PSMS to measure activities of daily living, and the NPI-Q-10 to measure neuropsychiatric symptoms.

The patients’ mean age was 85.3 (SD 8.6), and 472 (71.4%) were women. In all, 22.5% had CDR 1; 33.6% had CDR 2; and 43.9% had CDR 3. The mean PSMS score was 18.2 (SD 5.0); 43.1% lived in special care units and 56.9% in regular units.

In a linear regression analysis, NPI affective score, ($\beta$=0.360, p-value <0.001); NPI agitation score ($\beta$=0.268, p-value <0.001); PSMS total score ($\beta$=0.181, p-value <0.001); NPI apathy score ($\beta$=0.144, p-value <0.001); NPI psychosis score ($\beta$=0.085, p-value 0.009); and CDR sum of boxes score ($\beta$=0.081, p-value 0.026) were significantly associated with QUALID total scores (explained variance of 44.5%). Table 1 shows which variables were associated with the QUALID subscales.

Table 1. Variables associated with the QUALID subscales

<table>
<thead>
<tr>
<th>QUALID</th>
<th>Unadjusted analyses</th>
<th>Adjusted analyses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Beta</td>
<td>P-value</td>
</tr>
<tr>
<td><strong>Sadness</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NPI apathy</td>
<td>.207</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>General medical health</td>
<td>.135</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>NPIQ agitation subscale</td>
<td>.220</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>NPIQ affective subscale</td>
<td>.556</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Adjusted R square</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Tension</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Antipsychotic drugs, 0 = no</td>
<td>.252</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Anxiolytic drugs</td>
<td>.210</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>PSMS total</td>
<td>.283</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>NPIQ psychosis subscale</td>
<td>.389</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>NPIQ agitation subscale</td>
<td>.596</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>NPIQ affective subscale</td>
<td>.420</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Adjusted R square</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Well-being</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NPIQ apathy</td>
<td>.307</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>CDR sum of boxes</td>
<td>.275</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>PSMS total score</td>
<td>.332</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Ward type, 0 = SCU</td>
<td>.061</td>
<td>0.119</td>
</tr>
<tr>
<td>Adjusted R square</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
In addition to the regression analysis, we conducted a path analysis to investigate which causal variables to include in the model, to find the causal order of these variables, and to identify which “paths” are not important in the model. In the path analysis, we used the total QUALID score as a dependent variable and the total scores on the NPI, CDR, and PSMS as independent variables. The results showed that the level of dementia is associated with the NPI but not particularly with the QUALID; the NPI affects the QUALID the most. The PSMS also affects the QUALID but not as strongly as the NPI does. These results align with the results from the linear regression analysis, but the CDR has a stronger association with the QUALID in the linear regression analysis compared to the path analysis, which provides a clearer picture of the association between the variables. One reason for this could be the use of total scores in the path analysis and the use of subscales in the linear regression analysis.

Conclusion: Neuropsychiatric symptoms, apathy, severity of dementia, and impairment in activities of daily living are associated with reduced quality of life in nursing home patients with dementia.

Study 3

For the third study (paper 3), we conducted a longitudinal study with the objective of investigating variables associated with change in quality of life over a 10-month period as measured by the QUALID scale and the three subscales of tension, sadness, and well-being.

We used data from a control group of persons with dementia in nursing homes that had been followed up for 10 months in a randomized controlled trial. At baseline, there were 198 persons with dementia; 156 of them (79%) were women and the mean age was 87 (SD 7.7) years. After 10 months, 143 persons could be evaluated; 9 had moved and 46 were deceased.

The following scales were applied: the QUALID and the three subscales (sadness, tension, and well-being), NPI-10-Q, CDR, PSMS, and the scale of general medical health. In addition, we included the use of psychotropic medication, gender, and age.

The mean baseline QUALID score for the 198 patients included was 20.6 (SD 7.0); the mean follow-up score at 10 months for the 143 patients was 22.9 (SD 7.4), whereas the mean change
score of the 143 patients was 2.8 (SD 7.4). Quality of life improved in 30.8%, was unchanged in 14.7%, and deteriorated in 54.6% of patients. A regression analysis revealed that a change in the QUALID score was significantly associated with the QUALID baseline score (beta -.381, p-value .000), a change in the NPI score (beta .421, p-value .000), and explained variance of 38.1%.

Table 2 shows which variables were associated with the QUALID subscales.

Table 2. Variables associated with the QUALID subscales

<table>
<thead>
<tr>
<th>Change in QUALID Sadness</th>
<th>Unadjusted analyses</th>
<th>Adjusted analyses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in NPI-Q-10 score</td>
<td>.469 .000</td>
<td>.404 .000</td>
</tr>
<tr>
<td>Sadness baseline score</td>
<td>-.379 .000</td>
<td>-.438 .000</td>
</tr>
<tr>
<td>Adjusted R square</td>
<td></td>
<td>38.8%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Change in QUALID Tension</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in CDR score</td>
</tr>
<tr>
<td>Change in NPI-Q-10 score</td>
</tr>
<tr>
<td>Tension baseline score</td>
</tr>
<tr>
<td>Anxiolytics at baseline</td>
</tr>
<tr>
<td>Change in PSMS score</td>
</tr>
<tr>
<td>Adjusted R square</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Change in QUALID Well-being</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in PSMS score</td>
</tr>
<tr>
<td>Well-being baseline score</td>
</tr>
<tr>
<td>Change in NPI-Q-10 score</td>
</tr>
<tr>
<td>Adjusted R square</td>
</tr>
</tbody>
</table>

Conclusion: The results imply that a lower baseline score (better quality of life) results in a larger change in quality of life (toward a worse quality of life). Change in quality of life is most strongly associated with change in neuropsychiatric symptoms. In almost 50% of patients, quality of life did not deteriorate.
Study 4

In the fourth study (paper 4), we used a qualitative design. We included 12 persons living in three different nursing homes, 10 women and 2 men, to investigate the experience of living with dementia in a nursing home and to learn what makes life better or worse from the perspective of the person with dementia over time. One person had mild dementia (CDR 1); nine (CDR 2) had moderate dementia; and two (CDR 3) had severe dementia. Six lived in special care units and six in regular units. They ranged in age from 71 to 94; one 82-year-old woman with severe dementia died before the follow-up interview, and a 90-year-old woman with moderate dementia became ill and could not participate in the second interview.

A phenomenological hermeneutic research design was applied, and unstructured, face-to-face interviews and field observations were conducted twice, three months apart. The first interview took place within 6 months of admittance to the nursing home and the second interview 9 to 10 months after admittance.

The analysis revealed four themes. The first theme, “Being in the nursing home is okay, but you must take things as they are,” deals with the residents’ acceptance of living in the nursing home. They preferred to be at home, but some understood that that was not possible. They appreciated the help they received in the nursing home but experienced having to adjust to routines and that they could not expect too much. The second theme, “Everything is gone,” addresses the losses they live with, from losing their home, work, and hobbies to losing themselves, as some talked about. The third theme, “Things that make it better and things that make it worse,” deals with the importance of having personal belongings present in their lives, being able to do what one likes, and having a private life. Violation of their private living space made life in the nursing home worse. The fourth theme, “Persons – for better or worse? Staff, family, and co-residents,” addresses the need to have good relationships, both with caregivers and family members. The residents like their caregivers and particularly the primary nurse, even if this person does not always treat them well. The residents missed their family members; some felt abandoned by them. Furthermore, the residents said that they did not have friends among the other residents.

Conclusions: Persons with moderate and severe dementia are able to communicate their feelings and thoughts about their lives in the nursing home and can name several factors that have impacts
on their quality of life. They are content with life in general, but everyday life is boring, and their sense of contentment is based on their acceptance of certain facts of reality and their ability to adjust their expectations.

Sammendrag
Denne studien handler om livskvalitet hos personer med demens som bor på sykehjem.

Mange studier bruker livskvalitetsmål for å vurdere om behandling eller pleie virker. Noen sykehjem bruker også livskvalitetsmål for å vurdere hvordan beboerne har det på sykehjemmet.

Livskvalitet er et begrep som er vanskelig å definere, og det finnes ingen definisjon som aller er enig i. De definisjonene som finnes tar i stor grad utgangspunkt i personens kognitive evner, evne til selvstendighet i dagliglivets aktiviteter og evne til deltagelse i aktiviteter som er meningsfulle for personen. For personer med demens blir det vanskelig å oppfylle mange av kravene i de ulike definisjonene. Personer med demens får i forløpet av sin demenssykdom vanligvis en økende kognitiv svikt, større og større problemer med å ta vare på seg selv og vil til slutt ha vansker med å leve et selvstendig liv og kunne delta i meningsfulle aktiviteter og sosialerelasjoner.

På grunn av demenssymptomene blir det vanskelig for personer med demens å uttale seg om egen livskvalitet, og teorier om livskvalitet hos personer med demens tilsier at man også må stole på observasjoner av atferd hos personer med demens for å få vite noe om deres livskvalitet.

Forskning viser imidlertid at det er sprik mellom hvordan et familiemedlem eller en pleier (en proxy) skårer livskvaliteten til personen med demens, og hvordan personen med demens skårer egen livskvalitet. Blant annet vektlegger en proxy nevropsykiatriske symptomer, særlig depresjon men også agitasjon, irritasjon og apati, kognitiv svikt og evne til å utføre aktiviteter i dagliglivet som viktige faktorer for livskvalitet hos personer med demens, mens personen med demens vektlegger depresjon, men ikke de øvrige symptomene når han eller hun uttaler bedømmer sin livskvalitet.

Noen kvalitative studier har undersøkt gjennom intervju hvordan personer med demens opplever livet på sykehjemmet. Personene forteller at de får nødvendig pleie, men de forteller også om ensomhet, depresjon og kjedsomhet.
Omtrent 80 prosent av beboerne på norske sykehjem har en eller annen form for demens. For å kunne opprettholde god livskvalitet på sykehjem, trenger vi kunnskap om hvordan livskvalitet utvikler seg hos personer med demens på sykehjemmet. Pleierne trenger kunnskap om faktorer som påvirker livskvalitet hos personer med demens slik at de kan tilrettelegge omsorgen på en best mulig måte.

Et livskvalitetsskjema som er oversatt til norsk og i bruk i forskning i norske sykehjem, er Livskvalitet hos personer med moderat og alvorlig demens skalaen - Quality of life in late stage dementia scale, som kalles QUALID. Dette skjemaet skårer atferd og hyppighet av atferd (daglig/ukentlig) hos personer med moderat og alvorlig demens, men kan også brukes hos personer med demens av mild grad. Skalaen fylles ut ved at man intervjuer en pleier som kjenner personen med demens godt og spør om forekomst og hyppighet av 11 ulike typer atferd (ledd) som man forbinder med livskvalitet. For hvert ledd i QUALID kan man gi en skåre på 1 til 5, det vil si at sumskåren kan variere mellom 11 og 55. En skåre på 11 angir god livskvalitet og en skåre på 55 angir svært dårlig livskvalitet.

For å få mer kunnskap om livskvalitet skåret med dette skjemaet, fant vi det nødvendig å undersøke om noen av symptomer som skåres henger sammen og måler noe av det samme, og også finne ut hvilke variabler som påvirker livskvalitet og endring av livskvalitet.

Målsetting for avhandlingen

Den overordnede målsetting var å beskrive livskvalitet hos personer med demens på sykehjem i Norge. For å gjøre dette utførte vi fire studier.

Først (studie 1) ønsket vi å få en forståelse av hvilke livskvalitetsdimensjoner QUALID harnår skalaen brukes til å måle livskvalitet hos personer med demens på sykehjem. I tillegg ville vi undersøke hvordan symptomene målt med QUALID varierer med grad av demens.

Det andre målet (studie 2), var å bevise eller avvise to hypoteser; 1) Livskvalitet hos personer med demens i sykehjem er assosiert med pasientenes nevropsykiatriske symptomer, svikt i dagliglivets aktiviteter og grad av kognitive svikt, og 2) Livskvalitet hos personer med demens i sykehjem er ikke assosiert med pasientens kjønn, alder eller type avdeling (skjermet vs somatisk avdeling).
Det tredje målet (studie 3) var å undersøke om endring i livskvalitet målt med QUALID og QUALIDs subskalaer i løpet av en 10 måneders periode er assosiert med baseline livskvalitetskåren, nevropsykiatriske symptomer, bruk av psykofarmaka, grad av kognitiv svikt og svikt i dagliglivets aktiviteter, kjønn og alder.

I de tre første studiene brukte vi i tillegg til QUALID følgendeskalær;

For å måle nivå av nevropsykiatriske symptomer brukte vi Nevropsykiatrisk skåringskjema (neuropsychiatric inventory questionnaire) (NPI-Q-10). Denne versjonen skårer 10 ulike typer nevropsykiatriske symptomer. En faktoranalyse har vist at NPI-Q-10 brukt på norske sykehjemspasienter med demens har 3 sub-komponenter eller subskalaer kalt agitasjon, psykose og affektiv. Apati klustret ikke til noen av de tre komponentene

For å måle grad av demens brukte vi Klinisk demensvurderingsskala (KDV). Denne skalaen skårer seks ulike kognitive evner og/eller selvhjelpsevner: hukommelse, orineteringssans (både tid og sted), problemløsningsevne, sosiale evner, evne til å ivareta hjem og hobby og evne til å ivareta personlig pleie. Hvert område har fem svaralternativer, fra 0 = ingen problem (helt frisk), til 3 = store problem. Man kan enten skåre kategorisk (0, ½, 1, 2 eller 3) eller summere skårene til en kontinuerlig skåre (0-18 poeng). Kategorisk skåre på 0 betyr ingen demens, ½ mulig demens, 1 mild grad av demens, 2 moderat grad av demens og 3 alvorlig grad av demens.


I tillegg vurderte vi grad av somatisk sykdom på en firepunkts kontinuerlig skala, hvor god helse=1, passe god helse =2, dårlig helse =3 og veldig dårlig helse =4. Ved bruk av denneskalalen tar man hensyn til pasientens diagnoser, alvorligheten av de ulike sykdommer og bruk av medisiner.
Med kunnskap om forskning om livskvalitet vet vi at det er forskjell mellom proxyrapportert og selvrapportert livskvalitet, og av den grunn ønsket vi å undersøke hva personer med demens selv sier om hvordan de har det på sykehjemmet.

Det fjerde målet (studie 4) ble derfor å undersøke opplevelsen av å bo på sykehjem og hva som gjør livet bedre eller verre sett fra perspektivet til personen med demens. Dette gjorde vi ved å gjennomføre observasjoner og intervjuer med sykehjemsbeboere med demens i tillegg til anvendelse av QUALID.

Studie 1

I den første studien (artikkel 1) gjorde vi en faktoranalyse, en prinsipal komponent analyse (faktoranalyse), av QUALID og undersøkte om livskvalitetsskåringen var forskjellig ved ulike grader av demens. Vi inkluderte 661 pasienter med demens med gjennomsnittlig alder 85,3 (SD 8,6) år, 71,4 prosent var kvinner. QUALID skalaen og klinisk demensvurdering skalaen (KDV) ble brukt til å skåre henholdsvis livskvalitet og grad av demens. En prinsipal komponent analyse ble brukt til å teste faktor-strukturen. Ikke-parametriske analyser ble brukt for å teste for hvordan livskvalitetssymptomene i QUALID varierte med grad av demens(KDV-grupper).

Gjennomsnittlig QUALID skåre var 21,5 (SD 7,1), KDV 1; 22,5%, KDV 2; 33,6%, KDV 3; 43,9%. Cronbach’s α for QUALID var 0,74. Faktoranalysen viste at QUALID består av tre faktorer som kan forklarer 53% av variansen. De tre faktorene er: “tristhet” (ser trist ut, gråter, har et ansiktsuttrykk som uttrykker ubehag Cronbach’s α 0,65), “uro” (ansiktsuttrykk som uttrykker ubehag, ser ut til å ha fysisk ubehag, verbalisering som er uttrykk for ubehag, er irritable og aggressiv, ser rolig ut, Cronbach’s α 0,69), “velbehag” (smiler, nyter å spise, liker berøring, liker sosial interaksjon, Cronbach’s α 0,62). Vi konstruerte tre sub skalaer ved å bruke de ledd fra QUALID som klustret til hver av de tre faktorene og kalte dem subskaler for tristhet, uro og velbehag. Gjennomsnitt skåre på subskalaene “uro” og “velbehag” økте signifikant med økende grad av demens (KDV skåre), tydende på dårligere livskvalitet på disse to områdene med økende grad av demens. Skåren på subskalaen «tristhet» endret seg ikke med grad av demens.
Konklusjon: Vi fant at QUALID består av tre faktorer og at de ledd i QUALID somkladet på faktorene «uro» og «velbehag» endret seg til det verre med økende grad av demens, mens ledd som klustret i faktoren «tristhet» ikke var forskjellig ved ulike grader av demens.

Studie 2

Den andre studien (artikkel 2) hadde et tverrsnittdesign hvor vi undersøkte hvilke faktorer som var assosiert med skåringene på QUALID totalsum og av sub skalaene tristhet, uro og velbehag.

Vi inkluderte 661 personer med demens som bodde på sykehjem. Til å måle livskvalitet brukte vi QUALID skalaen. Vi brukte KDV for å måle grad av demens, PSMS for å måle selvhjelpsevne, og NPI-Q for å måle nevropsykiatriske symptomer.

Pasientenes gjennomsnittsalder var 85,3 (SD 8,6) år, 472 (71,4%) var kvinner. Av alle hadde 22,5% mild demens (KDV 1), 33,6% moderat demens (KDV 2), og 43,9% alvorlig demens (KDV 3). Gjennomsnittlig PSMS skåre var 18,2 (SD 5,0), 43,1% bodde i skjermet enhet og 56,9% i vanlig somatisk enhet.

En linear regresjonsanalyse viste at NPI-affektiv skåre, (β=0,360, p-verdi <0,001), NPI-agitasjonsskåre (β=0,268, p-verdi <0,001), PSMS total skåre (β=0,181, p-verdi <0,001), NPI-apati (β=0,144, p-verdi <0,001), NPI psykose (β=0,085, p-verdi 0,009), og KDV totalsum (sumskåre) (β=0,081, p-verdi 0,026) var signifikant assosiert med QUALID totalskåren (forklart varias 44,5%).

Tabell 1 viser hvilke variabler som var assosiert med sub skalaene i QUALID.
Tabell 1. Variabler assosiert med subskalaene i QUALID

<table>
<thead>
<tr>
<th></th>
<th>Ujustert analyse</th>
<th>Justert analyse</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>QUALID tristhet</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NPI apati</td>
<td>2,07</td>
<td>0,106</td>
</tr>
<tr>
<td>Generell medisinsk helse</td>
<td>1,135</td>
<td>0,065</td>
</tr>
<tr>
<td>NPIQ agitasjon</td>
<td>2,220</td>
<td>0,085</td>
</tr>
<tr>
<td>NPIQ affektiv</td>
<td>5,556</td>
<td>0,511</td>
</tr>
<tr>
<td>Varians</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>QUALID uro</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Antipsykotika, 0=nei</td>
<td>2,252</td>
<td>0,123</td>
</tr>
<tr>
<td>Anxiolytika 0=nei</td>
<td>2,210</td>
<td>0,062</td>
</tr>
<tr>
<td>PSMS total</td>
<td>2,283</td>
<td>0,173</td>
</tr>
<tr>
<td>NPIQ psykose</td>
<td>3,89</td>
<td>0,126</td>
</tr>
<tr>
<td>NPIQ-Q agitasjon</td>
<td>5,963</td>
<td>0,427</td>
</tr>
<tr>
<td>NPIQ affektiv</td>
<td>4,20</td>
<td>0,240</td>
</tr>
<tr>
<td>Varians</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>QUALID velbehag</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NPIQ apati</td>
<td>3,07</td>
<td>0,270</td>
</tr>
<tr>
<td>KDV summert skåre</td>
<td>2,275</td>
<td>0,133</td>
</tr>
<tr>
<td>PSMS totalskåre</td>
<td>3,323</td>
<td>0,229</td>
</tr>
<tr>
<td>Type avdeling, 0=skjermet</td>
<td>0,061</td>
<td>0,089</td>
</tr>
<tr>
<td>Varians</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Konklusjon: Vi fant at nevropsykiatriske symptomer, apati, grad av demens og svikt idagliglivets aktiviteter er assosiert med redusert livskvalitet hos personer med demens på sykehjem.

Studie 3

I den tredje studien (artikkel 3) anvendte vi et longitudinelt design og undersøkte hvilke variabler som var assosiert med endring i livskvalitet, både endring i QUALID totalskåre og endring i de tre sub skalaene tristhet, uro og velbehag.

Vi anvendte data fra en kontrollgruppe personer med demens i sykehjem som var blitt fulgt opp i 10 måneder i en randomisert kontrollert intervensjonsstudie. Ved baseline bestod den av 198 personer med demens, av disse var 156 (79%) kvinner, gjennomsnittsalder var 87 (SD 7,7) år. Etter 10 måneder kunne 143 personer med demens evalueres. Frafallet skyldes at ni personer hadde flyttet og 46 personer hadde dødd.

Følgende skalaer ble brukt i analysene: QUALID totalskåre og de tre sub skalaene, KDV, PSMS, NPI og en skala til å måle generell somatisk helse. I tillegg brukte vi bruk av psykofarmaka, kjønn og alder.

Resultat: gjennomsnittlig baseline QUALID skåre av alle 198 var 20,6 (SD 7,0), oppfølgingsskåre av de 143 som ble fulgt opp etter 10 måneder var 22,9 (SD 7,4), mens gjennomsnittlig endring av de 143 var 2,8 (SD 7,4). Livskvalitetskåren ble bedre hos 30,8%, var uendret hos 14,7%, og ble verre hos 54,6% av pasientene. En regresjonsanalyse viste at endring i totalskåren på QUALID (avhengig variabel) var signifikant assosiert med: QUALID baseline skåre (beta ,381, p-verdi ,000), endring i NPI skåren (beta ,421, p-verdi ,000), forklart varians 38,1%.

Tabell 2 viser hvilke variabler som var assosiert med subskalaene i QUALID.
Tabell 2. Variabler assosiert med subskalaene i QUALID

<table>
<thead>
<tr>
<th>Endring i QUALID Tristhet</th>
<th>Ujusterte analyse</th>
<th>Justerte analyse</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Beta</td>
<td>p-verdi</td>
</tr>
<tr>
<td>Endring i NPI-Q-10 skåre</td>
<td>.469</td>
<td>.000</td>
</tr>
<tr>
<td>Tristhet baseline skåre</td>
<td>-.379</td>
<td>.000</td>
</tr>
<tr>
<td>Varians</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Endring i QUALID Uro</th>
<th>Beta</th>
<th>p-verdi</th>
<th>Beta</th>
<th>p-verdi</th>
</tr>
</thead>
<tbody>
<tr>
<td>Endring i CDR skåre</td>
<td>.239</td>
<td>.004</td>
<td>.214</td>
<td>.003</td>
</tr>
<tr>
<td>Endring i NPI-Q-10 skåre</td>
<td>.391</td>
<td>.000</td>
<td>.270</td>
<td>.000</td>
</tr>
<tr>
<td>Uro baseline skåre</td>
<td>-.358</td>
<td>.000</td>
<td>-.423</td>
<td>.000</td>
</tr>
<tr>
<td>Anxiolytika ved baseline</td>
<td>-.196</td>
<td>.019</td>
<td>-.026</td>
<td>.733</td>
</tr>
<tr>
<td>Endring i PSMS skåre</td>
<td>.173</td>
<td>.023</td>
<td>-.008</td>
<td>.924</td>
</tr>
<tr>
<td>Varians</td>
<td></td>
<td></td>
<td>34,6%</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Endring i QUALID Velbehag</th>
<th>Beta</th>
<th>p-verdi</th>
<th>Beta</th>
<th>p-verdi</th>
</tr>
</thead>
<tbody>
<tr>
<td>Endring i PSMS skåre</td>
<td>.232</td>
<td>.005</td>
<td>.185</td>
<td>.019</td>
</tr>
<tr>
<td>Velbehag baseline skåre</td>
<td>-.370</td>
<td>.000</td>
<td>-.370</td>
<td>.000</td>
</tr>
<tr>
<td>Endring i NPI-Q-10 skåre</td>
<td>.354</td>
<td>.000</td>
<td>.186</td>
<td>.017</td>
</tr>
<tr>
<td>Varians</td>
<td></td>
<td></td>
<td>25,3%</td>
<td></td>
</tr>
</tbody>
</table>

Konklusjon: Studien viser at de pasientene som hadde best livskvalitet ved baseline fikk mest forverring av sin livskvalitet etter 10 måneder. Endring i livskvalitet til det verre skyldes i første rekke forverring av nevropsykiatriske symptomer. Imidlertid gjaldt det kun for noe over halvparten av pasientene. For nesten 50 prosent av pasientene ble livskvaliteten ikke verre.

Studie 4

I den fjerde studien (artikkel 4) anvendte vi et kvalitativt design. Vi inkluderte 12 personer, 10 kvinner og to menn, som bodde på sykehjem for å undersøke hvordan de opplever å bo i sykehjemmet og for å lære om hva de synes gjør livet bedre eller verre på sykehjemmet over tid. En hadde mild demens (KDV 1), ni (KDV 2) hadde moderat demens og to (KDV 3) alvorlig demens. Personene ble inkludert fra tre forskjellige sykehjem, halvparten bodde i skjermet enhet, de andre på somatisk enhet. De var fra 71 til 94 år. En kvinne på 82 år med alvorlig demens døde.
for andre intervju, og en kvinne på 90 år med moderat demens ble syk og kunne ikke deltapå andre intervjuet.

Vi brukte fenomenologisk-hermeneutisk forskningsdesign, og gjennomførte ustrukturert intervjuer og observasjoner to ganger med tre måneders mellomrom. Det første intervjuet fant sted innen seks måneder etter innleggelse og det andre ni til ti måneder etter innleggelse.


Konklusjonen: Studien viser at personer med demens av moderat grad kan kommunisere følelser og tanker om livet på sykehjemmet, og kan fortelle om flere faktorer og hendelser som innvirker på deres opplevelse av å bo på sykehjemmet, og som indirekte påvirker deres livskvalitet. De er generelt fornøyd med livet på sykehjemmet, men de opplever at hverdagen er kjedelig. Å kunne være fornøyd er avhengig av at de aksepterer rutinene sykehjemmet og evner å tilpasse segdem.
List of papers


Abbreviations
AD Alzheimer’s disease
ADL activities of daily living
AN auxiliary nurse
ARD alcohol-related dementia
BARS Brief Agitation Rating scale
BPSD behavioral and psychological symptoms in dementia
CDR Clinical Dementia Rating Scale
CDT Clock-Drawing Test
CMAI Cohen-Mansfield Agitation Inventory
CSDD Cornell Scale for Depression in Dementia
DCM dementia care mapping
DEMQOL Quality of Life for People with Dementia Scale
DSM *Diagnostic and Statistical Manual of Mental Disorders*
DQOL Dementia Quality of Life Scale
FLD frontal lobe dementia
FTD frontotemporal dementia
GAI Geriatric Anxiety Inventory
GDS Geriatric Depression Scale
HRQOL health-related quality of life
IADL Instrumental Activities of Daily Living Scale
ICD *International Classification of Diseases and Related Health Problems*
IQCODE Informant Questionnaire for Cognitive Decline in the Elderly

IPA International Psychogeriatric Association

LBD Lewy body Dementia

MCI mild cognitive impairment

MMSE Mini-Mental State Examination

NCD neurocognitive disorders

NH nursing home

NHs nursing homes

NPI Neuropsychiatric Inventory

NPI-Q Neuropsychiatric Inventory Questionnaire

NPS neuropsychiatric symptoms

PADL personal activities of daily living

PCA principal component analysis

PCC person-centered care

PD Parkinson dementia

PSMS Personal Self-Maintenance Scale

PWD persons with dementia

QALY quality-adjusted life year

QOL quality of life

QOL-AD Quality of Life in Alzheimer’s Disease Scale

QUALID Quality of Life in Late-Stage Dementia Scale
1.0 Introduction

Quality of life is a frequently used outcome measure in both medical treatment and clinical trials in various patient groups. The focus of this thesis is quality of life (QOL) in persons with dementia (PWD) living in nursing homes (NHs) in Norway and on methods used to measure QOL in persons with dementia of mild to severe degrees in NH settings.

There is little agreement in the literature on what QOL is, which dimensions should be included (1), whether it is possible to define it, and how it should be measured, all because of its abstract content (2). Hence, measuring QOL is difficult. There is agreement, however, that QOL is subjective and that the gold standard should be the voice of the person we want to study (3-6). This means that, if we want to know something about QOL in PWD, we should talk to those with dementia and ask them about their quality of life.

Knowledge about the factors that enable and maintain a high QOL in PWD is needed in order to accommodate and adjust the care provided to this population. The Norwegian Ministry of Health and Care Services points out that the quality in health care services must be based on the perspectives and needs of the persons who are receiving the services (7). This makes it problematic to use data collected from a proxy (a nurse or family member), yet it is also difficult to collect data from PWD, especially those whose dementia has reached a moderate or severe degree. Persons in these stages of dementia have impaired memory and language abilities and often have reduced or poor insight into their own impairments that makes it difficult for them to talk about their QOL. Therefore, a proxy scale could be a good alternative. Using a proxy scale requires us to have knowledge about its properties and its capacity to effectively measure QOL.

A QOL scale in clinical use in Norwegian nursing homes is the Quality of Life in Late-Stage Dementia Scale (QUALID). It is easy to use and has proved reliable (8). With this scale, we wanted to investigate the QUALID’s factors when used in a NH setting with PWD. Additionally, we wanted to investigate how each symptom measured by the QUALID varied across the range of dementia severity.

Furthermore, in order to adjust care so the person can maintain a high QOL, it is important to know which symptoms are associated with QOL and which are associated with a change in QOL.
The literature on QOL in PWD points in different directions, depending on the source of the data collected for the various research studies.

Proxy-based information about QOL seems to be associated with impairments related to activities of daily living (ADL), depression, behavioral disturbances, and the degree of cognitive impairment. The use of self-reported information on QOL, however, seems to be associated with depression in the person (9, 10).

Hence, to be able to say anything accurate about QOL in this population and whether or not the QUALID measures QOL, it is necessary to collect information from the PWD living in a NH. Exploring a phenomenon such as QOL in a NH population is best done on site. Conducting face-to-face interviews with the persons we want to know something about and spending time with them in their everyday lives on the units with other residents and the health care staff have the potential to provide information on how QOL in NH is maintained.

The nursing services in a nursing home should safeguard all aspects of each resident’s life in a way that makes everyday life meaningful and maintains the person’s QOL. As approximately 80 percent of the residents in Norwegian NHs have dementia (11), it is vital to understand what QOL means in this population and how to maintain good QOL.

Thus, we decided to examine the QOL of PWD living in NHs using two different methods. In papers 1, 2, and 3 of the thesis, we used a quantitative design by applying the QUALID as reported by proxy, and in paper 4, we used a qualitative design by interviewing PWD.
2.1 Background

2.2 Dementia

Dementia is a collective term for a chronic, irreversible brain syndrome. There are several
different underlying disorders that can cause dementia, but in accordance with the diagnostic
criteria, the disorders leading to dementia should all cause cognitive impairment, an impaired
ability to function in everyday life, and changes in behavior such as impaired emotional control,
in social behavior, and in personality and motivation (12, 13). Consciousness is usually not
affected, according to the definition of dementia (14).

In the criteria of the Diagnostic and Statistical Manual of Mental Disorders (DSM) (13) and the
International Classification of Diseases and Related Health Problems (ICD) (12), dementia is
defined as a syndrome caused by diseases primarily affecting the brain. It is usually of chronic or
progressive character, with impairment or failure in higher cortical functions such as memory,
orientation, the ability to think and learn, and impairments in speech and awareness. Cognitive
impairment, particularly memory loss, leads to impaired function in everyday life and affects
social life (14). In order to use the term dementia, reduced memory must be present, and
impairment in ADL must be associated with impaired cognition. In addition, the condition must
have persisted for at least six months (14).

Tables 1 and 2 summarize the content of the diagnostic criteria in DSM 5 and ICD 10. The most-
recently revised edition of the DSM, DSM 5, was published in 2013. It introduced a new concept
whereby dementia, delirium, and amnestic and other cognitive disorders are classified as
neurocognitive disorders (NCD). These are divided into mild and major NCD subtypes.
Neurocognitive disorders are considered to be acquired, and they represent a decline from a
previous level of function, thus differentiating these disorders from developmental disorders (15,
16). One reason for the introduction of the two categories is the opportunity for the early
detection of cognitive impairment, which can encourage early interventions and effective
treatment plans (15). An early diagnosis provides an opportunity for the individual to plan for the
future before cognitive impairment interferes with judgment and reasoning. There are frequent
concerns, however, that subjective memory loss or normal forgetfulness will be misdiagnosed as
a mild NCD and that a large number of false diagnoses will result. In addition, as there is
currently no effective treatment for dementia, a label might create unnecessary anxiety or result in unnecessary treatment with ineffective prescription drugs (15).

Table 1. The dementia syndrome according to ICD-10 research criteria

<table>
<thead>
<tr>
<th>ICD 10</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>A decline in memory, especially for new information, objectively verified</td>
</tr>
<tr>
<td>2.</td>
<td>A decline in other cognitive abilities such as judgment, thinking, planning, organizing, and abstraction:</td>
</tr>
<tr>
<td></td>
<td>- Mild: the decline influences the activities of daily living</td>
</tr>
<tr>
<td></td>
<td>- Moderate: the decline makes it impossible to function without help</td>
</tr>
<tr>
<td></td>
<td>- Severe: the decline results in the need for continuous help</td>
</tr>
<tr>
<td>3.</td>
<td>Preserved awareness of the environment</td>
</tr>
<tr>
<td>4.</td>
<td>A decline in emotional control or motivation, or a change in social behavior:</td>
</tr>
<tr>
<td></td>
<td>- Emotional lability</td>
</tr>
<tr>
<td></td>
<td>- Irritability</td>
</tr>
<tr>
<td></td>
<td>- Apathy</td>
</tr>
<tr>
<td></td>
<td>- Coarsening of social behavior</td>
</tr>
<tr>
<td>5.</td>
<td>The condition should have been present for at least six months.</td>
</tr>
</tbody>
</table>
Table 2. Mild and major neurocognitive disorders according to DSM 5 criteria

<table>
<thead>
<tr>
<th>DSM 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>I.</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>II.</td>
</tr>
<tr>
<td>III.</td>
</tr>
<tr>
<td>IV.</td>
</tr>
</tbody>
</table>

2.3 Prevalence and incidence of dementia

Worldwide, close to 47 million people live with dementia today. This number is expected to double every 20 years, and in 2050, it is estimated that almost 132 million people will have dementia (17). A review conducted by Alzheimer’s Disease International showed that the incidence of dementia increases exponentially with advancing age, from 3.1/1000 persons at ages 60–64 to 175.0/1000 persons at age 95+ (17).

There are no current data on the number of persons with dementia in Norway, but it is estimated that approximately 78,000 persons live with dementia in Norway (17, 18), and that there are approximately 10,000 new dementia cases each year (19).
2.4 How to measure cognitive impairment

Several instruments are employed to measure cognitive impairment in persons with dementia, and a few of these are in clinical use; the most frequently used instruments in Norway are described below.

The *Mini-Mental State Examination* (MMSE) is a widely used 20-item cognitive screening instrument. The questions involve orientation, memory, attention, language, and the ability to follow written or verbal commands. The scores range from 0 to 30, where 30 is the best possible score, indicating no cognitive impairment (20). The Norwegian version has been found to be valid and reliable (21).

The *Clock-Drawing Test* (CDT) is a cognitive test for visuo-constructive and other cognitive abilities. There are different ways to conduct and score the test. Sometimes the patient is asked to draw a circle (a clock) first; other times, a circle indicating a clock face is predrawn. Using Shulman’s instructions and scoring system, which are used in the Norwegian version of the CDT, the patient is asked to draw a clock, fill in the numbers, and set the hands at a particular time, i.e., 11:10. The scoring ranges from 0 to 5, where 5 indicates the best possible score (22).

The *10-Word Test*, or the Word-List Learning Test, is an instrument used to evaluate the learning aspect in memory. The words are read aloud to the patient three times; the patient tries to repeat them after each reading. The more words the patient remembers, the better (23). After 5 to 10 minutes, the patient is asked to recall the 10 words, and thereafter, he or she is asked to recognize the 10 words among a list of 20 words, 10 of which were not presented earlier.

The *Verbal Fluency Test* assesses semantic verbal fluency. There are many versions of this test; the most frequently used is the FAS version, where the patient is asked to name as many words beginning with F, A, and S as possible in 60 seconds. Another version is the animal naming test, where patients attempt to name as many animals as possible in 60 seconds. The score is the number of different words or animals listed (23).

The *Trail Making Test* (TMT) is used to evaluate visual search, scanning, speed of processing, mental flexibility, and executive functions. There are two trail making tests, A and B. In the TMT A, the patient is asked to connect numbered circles by drawing a line from the lowest (1) to the highest (25) number in ordered sequence. In the TMT B, the numbers are from 1 to 13 and, in
addition, there are letters from A to L. The patient is asked to draw a line from 1 to A, to 2 to B, and so on (24).

The Informant Questionnaire for Cognitive Decline in the Elderly (IQCODE) is an instrument used to screen for dementia by proxy. An informant who knows the patient well rates his or her changes in function over the last 10 years according to 16 (the short version) or 26 items (the long version). The two versions of the instrument correlate highly. Each question is rated from 1 (much improved) to 5 (much worse) (25, 26). The average score is calculated, and a score higher than 3.44 (27) is indicative of cognitive impairment that could be caused by Alzheimer’s disease.

2.5 Course and severity of dementia

In the following subjective cognitive impairment and the course of dementia from mild cognitive impairment to severe dementia is described. But first, an instrument that is often used to rate severity of cognition and dementia, the clinical dementia rating scale is presented.

The Clinical Dementia Rating Scale (CDR) is frequently used to rate the stage of dementia. The scale has six questions about memory, orientation (time and place), problem solving, community affairs, home and hobbies, and personal care; each question has five possible answers (28). The scale can be used as a categorical variable (0 = no dementia, 0.5 = mild cognitive impairment or possible dementia, 1 = mild dementia, 2 = moderate dementia, 3 = severe dementia) or as a continuous variable by using the sum of boxes, with scores from 0 = no dementia to 18 = severe dementia. The two scoring systems correlate strongly (19, 29).

2.5.1 Subjective cognitive impairment

Subjective cognitive impairment (SCI) is a term used to describe a patient who is experiencing reduced cognitive abilities. The results of neuropsychological testing should be within normal for the person’s age range and level of education (30). SCI could be a very early symptom of dementia and has been found to be associated with mild cognitive impairment (MCI) nearly two decades later among older women (31). However, Yates and colleagues found a clear association between SCI and reduced mood. In a study by Yates et al., mood problems were more strongly related to the presence of SCI than MCI. This implies that SCI may be related to anxiety and depression rather than being related to MCI (32, 33).
The transition from SCI to dementia is not well understood. A 2014 meta-analysis by Mitchell and colleagues found that older persons with SCI were twice as likely to develop dementia as persons without SCI. They learned that approximately 2.3 percent progressed to dementia and 6.6 percent progressed to MCI per year (34).

2.5.2 Mild cognitive impairment
People with MCI comprise a heterogeneous group, and for some persons, this could be a preclinical stage of dementia, especially dementia due to Alzheimer’s disease. In contrast to dementia, the decline is not severe enough to interfere with independent functions of daily living (35).

MCI is often divided into amnestic MCI and non-amnestic MCI. In amnestic MCI, a person forgets important information that he or she previously recalled easily, such as appointments, conversations, or recent events. In non-amnestic MCI, a person’s ability to make sound decisions or to understand how to complete a complex task is impaired (36).

Peterson et al. at the Mayo Clinic were the first to suggest criteria for MCI. These stated that 1) people with MCI should demonstrate objective memory impairment for their age with neuropsychological test results adjusted for age and length of education; 2) general cognitive function should be preserved; 3) there should be no ADL impairment; and 4) their profile should not meet the criteria for dementia (37, 38). Transferring these criteria to clinical practice was difficult, and in 2004, another set of criteria was suggested, the Winblad criteria. The Winblad criteria stated that 1) the person is neither cognitively normal nor does he or she have dementia; 2) there is evidence of cognitive deterioration, either by an objectively measured decline over time and/or a subjective report of decline by the self or another person; and 3) activities of daily living are preserved, and complex instrumental functions are either intact or minimally impaired (36).

There is a risk of potential misdiagnosis and confusion regarding whether the patient has mild cognitive impairment or mild dementia. Persons with long-standing poor memory or poor cognitive function in areas other than memory can get a score of 0.5 with the CDR, and this contaminates the MCI diagnosis when poor memory function is normal and does not progress (37). Another issue concerns the heterogeneity of diagnosing either mild dementia or MCI using
the CDR score of 0.5. How to separate these two in order to know which persons actually do have dementia and which ones do not is difficult. Essentially, those with MCI often have memory impairment while other cognitive functions and activities of daily living are normal. Those with dementia are usually more impaired, also in activities of daily living (38).

2.5.3 Mild dementia
Using both the ICD-10 criteria and the CDR scale, dementia severity is classified as mild, moderate, or severe. In mild dementia, the degree of cognitive impairment affects everyday life and everyday activities. Somewhat dependent on the diagnosis of dementia, the person struggles with short-term memory loss, orientation problems, or aphasia but is usually still able to take care of himself or herself at his or her own home. He or she may sometimes require help for more complicated tasks (14).

2.5.4 Moderate dementia
In this stage of dementia, the person needs help to conduct many everyday activities, and living on his or her own becomes difficult. Many persons with dementia move to a nursing home during this stage. If the person still lives at home, in-home nursing care visits are usually needed and take place on a regular basis.

2.5.5 Severe dementia
In Norway, most persons with severe dementia live in a nursing home. In this stage, the person is no longer capable of taking care of himself or herself.

2.5 Symptoms in dementia
Several cognitive and neuropsychiatric symptoms of dementia are described below. Early symptoms of dementia diseases may differ, but as the diseases progress, the symptoms become more similar, and in the end stages, all persons with dementia will need help to conduct everyday activities (14).

2.5.1 Cognitive symptoms in dementia
Memory loss is the most recognized cognitive symptom in dementia. In the early stages, the person with dementia forgets recent events, messages, and names. As the disease progresses, it is difficult to remember more remote events, and at a severe stage, the person with dementia has
problems remembering anything at all, including recognizing family members, knowing himself or herself in the mirror, and his or her general life history.

One’s sense of orientation becomes impaired; problems with both time and place orientation are common. This results in the person with dementia getting lost in unfamiliar places at first and later in familiar places, and not knowing the time, for instance, confusing day and night and not knowing what season or year it is.

Executive problems are common, which means that the person with dementia has difficulties planning, organizing, and conducting activities and tasks. The ability to focus and pay attention is impaired, as well as reasoning and judgment.

Aphasia is the loss of the ability to speak. Both expressive (speaking the correct words) and impressive (understanding what is said) aphasia are common. Helping the person with dementia to communicate using both verbal and non-verbal communication is important.

Apraxia is motoric difficulties conducting planned tasks or movements, even though the person is physically able to perform them. Persons with dementia will typically have problems stretching out an arm to put a sweater on, for example, or be unable to sit down when they should sit in a chair.

Agnosia is the inability to process sensory information, for instance, problems understanding what an item is or what it is used for. Examples include the inability to remember what a toothbrush is or not understanding what a cup is used for.

The person with dementia will have motoric problems as well, for example, problems with balance, impaired coordination of movement, and impaired ability to calculate distances. Some people become incontinent, especially in an advanced stage of dementia (14).

2.5.2 Activities of daily living

Activities of daily living (ADL), both personal and instrumental activities, become difficult in dementia, and a decline in ADL is required for a dementia diagnosis. The impairment in ADL makes it difficult to function at home without help. In the early stages of dementia, the person can have problems using the phone or a computer, or handling money, paying bills, and doing grocery shopping (instrumental ADL). As the disease progresses, personal ADL becomes
increasingly difficult, and the person will have problems with self-care, such as getting dressed or taking a shower. In Norway, the two scales by Lawton and Brody are often used to rate ADL (39). One is used to measure instrumental ADL (IADL), and the other is used to measure personal ADL (PADL). The PADL scale is described in chapter 6.5.3. Measuring the level of function in the person with dementia is important in order to provide necessary help.

2.5.3 Neuropsychiatric symptoms
Neuropsychiatric symptoms (NPS) are common in dementia (11, 40), and nearly all nursing-home patients with dementia experience clinically significant NPS. Expressed in another way, approximately 70 to 95 percent of all persons with dementia will develop at least one symptom during the course of the disease (41, 42). These symptoms result in decreased quality of life and cause severe discomfort for the person with dementia, his or her family members, and the staff in long-term care institutions (43, 44). NPS are often the reason for admittance to nursing homes (45) and include a wide range of behavioral and psychological symptoms (BPSD). The term BPSD was initially presented at the International Psychogeriatric Association (IPA) consensus conference in 1996 and is defined as “signs and symptoms of disturb perception, thought content, mood or behavior that frequently occur in patients with dementia” (46). Today, the two terms, NPS and BPSD, are used to describe the same symptoms. The symptoms are also increasingly measured individually, such as apathy or depression in dementia. Neither the DSM 5 nor the ICD-10 provides good reliable definitions or diagnostic criteria for NPS/BPSD (47). However, principal component analysis of the Neuropsychiatric Inventory (NPI) measuring NPS have shown that some NPS form clusters (42, 48), and these clusters represent common sub-syndromes in dementia: delusions and hallucinations as a psychosis sub-syndrome; irritability, agitation, aberrant motor behavior, and disinhibition as an agitation sub-syndrome; and finally, an affective sub-syndrome that includes depression and anxiety (42, 48). Apathy was in a factor analysis not included in any cluster (48).

Several neuropsychiatric symptoms are found to be common and persistent in persons with dementia. A review by Selbæk, Engedal, and Bergh showed that the mean prevalence of having at least one NPS was 82 percent, with the highest prevalence rate for agitation and apathy (41). The review also showed that the persistence of individual neuropsychiatric symptoms varied substantially, but having at least one NPS was highly persistent across the studies (41). A recent
longitudinal study by Brodaty and colleagues found that overall levels of NPS increased over a three-year period. In particular, delusions, hallucinations, agitation, anxiety, apathy, disinhibition, irritability, and aberrant motor behavior increased (49). In this study, depression, euphoria, nighttime behavior, and appetite did not increase significantly (49). Other studies have found some of the same symptoms to be among the most prevalent, such as apathy, agitation, irritability, anxiety, and depression (11, 44).

The different dementia diseases can initially present with different types of neuropsychiatric symptoms. Early in Alzheimer’s disease, the NPS are often depressive symptoms and lack of initiative (14). In Lewy body dementia, hallucinations and appetite disturbances are often the first NPS observed (14, 49). Frontotemporal dementia will often present itself in an early phase with inhibition and loss of interest, apathy, anxiety, and restlessness(14).

Several instruments have been developed to measure NPS, such as the Cohen-Mansfield Agitation Inventory (CMAI) (50), which measures agitation in the person with dementia, and the shorter CMAI subscale, the Brief Agitation Rating Scale (BARS) (51). There are also symptom-specific assessment scales for depression, such as the Cornell Scale for Depression in Dementia (CSDD) (52) and the Geriatric Depression Scale (GDS) (53). The Rating Anxiety in Dementia Scale (RAID) (54, 55) rates anxiety in dementia; it has recently been translated into Norwegian but not yet published. The Geriatric Anxiety Inventory (GAI) could also be used(56).

An instrument frequently used to measure NPS is the Neuropsychiatric Inventory (NPI) (57), which includes items regarding presence, frequency, and intensity of 12 symptoms. The symptoms measured by the NPI are described below.

The most common psychotic symptoms in patients with dementia are delusions and hallucinations. In these patients, it can be difficult to differentiate between psychotic symptoms such as delusions and hallucinations and dementia symptoms such as disorientation in time and place and misidentification (41).

Delusions are false beliefs about an external reality. They are often of the paranoid type. An example is that the person with dementia thinks his or her spouse is unfaithful. Delusions are firmly sustained, and it is difficult, if not impossible, to make the delusional person understand that the delusion is not true. Delusions are more common than hallucinations in dementia(41).
Hallucinations are perceptions that appear to be real. These can affect all of the senses, but visual hallucinations are the most common, followed by auditory hallucinations. In Lewy body dementia, visual hallucinations are part of the symptom cluster of the disorder (14).

Affective symptoms include anxiety and depression. Anxiety is common in dementia, and in the later stages of the disease, persons with dementia will typically ask questions repeatedly and be anxious about being away from home and missing a parent, usually the mother. Anxiety can perhaps be linked to the reduced ability to understand what is happening to and around the person with dementia, and frequently it is accompanied by other symptoms such as depression and agitation.

Depression is highly prevalent in dementia (41, 58, 59). Common symptoms of depression include decreased positive affect and pleasure in social contact or usual activities, social isolation and withdrawal, loss of appetite, disruption of sleep, irritability, fatigue, feelings of worthlessness and hopelessness, and suicidal thoughts. These symptoms affect the functioning of everyday life and have a negative impact on quality of life (58). Several symptoms of dementia and depression overlap, making it difficult to diagnose depression in dementia.

Apathy is often associated with depression, but it is a distinct symptom of dementia (60). Apathy means that the person with dementia is passive or lacks initiative, and it is a prevalent neuropsychiatric symptom, with increasing prevalence as the disease process progresses (41, 61). Typically, a person with dementia and apathy will refuse or not initiate participation in activities (41, 62).

Disinhibition is another neuropsychiatric symptom of dementia. Disinhibition means the person with dementia exhibits inappropriate behaviors, such as conduct that crosses the line of acceptable normal behavior (14).

Sleep disturbances are seen in persons with dementia not only because of their increased need for sleep but also because of disturbed sleeping patterns. A sleep disturbance might be caused by boredom in the nursing home, resulting in the person sleeping during the day and staying awake at night (14), but it can also be related to poor lighting in the nursing home environment (63, 64).
Aberrant motor behavior, such as wandering, picking at clothing, or general restlessness are other symptoms that are disturbing for the person with dementia, for co-residents in the nursing home, and for the staff (14).

According to the review by Selbæk and colleagues (41), symptoms of agitation represent one of the most prevalent neuropsychiatric symptoms, with a prevalence rate up to 80 percent. Agitation can be described as aggressive behavior, physically non-aggressive behavior, and agitated verbal behavior (65). The cause of agitation in dementia is poorly understood, but environmental factors, genetic factors, unmet needs, pain, physical diseases, delirium, and changes in the brain due to the dementia disorder are probable factors of importance (66-68).

The treatment of NPS includes both pharmacological interventions, such as the use of analgesic or psychotropic drugs, and non-pharmacological interventions, such as taking a person-centered approach to patient care. Music therapy and physical exercise may also be effective (69-72). NPS sometimes result from pain the patient experiences, and use of pain medication has been found to reduce verbal aggression, pacing, and restlessness (73). Treating NPS with psychotropic medications has only modest benefits, and such drugs are known to cause severe side effects (74-77). Thus, non-pharmacological interventions should be the first line of treatment. A randomized controlled trial (RCT) by Rokstad and Rosvik (78) showed that two models for implementing person-centered care (PCC) in NH, the VIPS practice model (VPM) and dementia care mapping (DCM), reduced agitation, psychosis, and the general level of NPS as measured by the NPI. In addition, the VPM group showed a significantly reduced level of depression, and the DCM group showed significantly better QOL compared to the control group (78). Other studies have also demonstrated that psychosocial interventions may reduce NPS (79, 80), particularly aggression, apathy, and depression, addressing the question of whether the symptoms are sometimes expressions of unmet needs or the failure of the environment to meet the needs of the person with dementia in a person-centered way.
2.6 Different types of dementia disorders
Several common types of dementia and their risk factors are described below.

2.6.1 Alzheimer’s disease
The most common disease leading to dementia is Alzheimer’s disease (AD). Approximately 60 percent of all PWD have AD. The first symptoms are usually memory problems regarding recent events, difficulties in communication, apathy, executive function problems, and changes in behavior (14). We know about several risk factors for AD. The most important is aging; the older one gets, the higher the risk for developing AD. In addition, several modifiable lifestyle risk factors for AD have been identified, and prevention in midlife may reduce the risk for AD or at least postpone its onset (81). Such risk factors are obesity, diabetes, and hypertension as well as vascular disorders. The risk factors for AD are similar to those for heart and cardiovascular diseases. Other known risk factors are a low level of education, poor physical activity throughout life, and depression in midlife (81, 82). The genetic risk factors for AD are unclear, but the contribution of each gene is, in most cases, small; however, as many gene variations contribute, the genetic load in some persons could be high (83, 84).

2.6.2 Vascular dementia
Vascular dementia (VAD) affects approximately 20 percent of those with dementia. VAD has risk factors similar to those of vascular diseases and is caused by cerebrovascular diseases, mainly large-vessel strokes or small-vessel disease. VAD is also caused by chronic arteriosclerosis with hypoperfusion leading to subclinical brain injury and silent brain infarction (85). VAD can be static or progressive and often has a step-like development because of new vascular incidences.

Memory problems are also common in this type of dementia, but the first symptoms in VAD depend on the location of the vascular incident. Disturbance in gait, incontinence, changes in mood or personality, reduced psycho-motoric speed, and executive dysfunction are frequently present but not specific for VAD (86).

VAD and AD share several risk factors, e.g., hypertension, diabetes mellitus, and hypercholesterolemia. A synergistic effect probably exists between AD and cerebrovascular
disease, resulting in a mixed presentation of the two disorders, which is common in very old persons with dementia (85).

2.6.3 Lewy body dementia
Lewy body dementia (LBD) accounts for approximately 10 percent of dementia cases. Typical for LBD is fluctuation in consciousness often followed by visual hallucination, reduced ability to recall, and impaired executive capability. Risk factors for LBD are not well studied, but known risk factors are advanced age, male gender, and a family history of LBD (87, 88). LBD has risk factors similar to and overlapping with Parkinson disease (PD) and AD (87).

2.6.4 Frontotemporal dementia
Frontotemporal dementia (FTD) accounts for about 5 percent of dementia cases, and several genetic components have been identified as risk factors for FTD (89). Unlike other dementias where impaired memory is a common early symptom, the first symptom in FTD is often a change in behavior or personality. Other early cognitive symptoms are speech problems, problems recognizing people or things, orientation problems, neuropsychiatric symptoms such as depression and irritability, and motoric problems such as loss of balance (14).

2.6.5 Secondary dementias
There are several other diseases leading to dementia; most of them are rare. These include but are not limited to alcohol-related dementia (ARD), HIV-related dementia, and dementia in Huntington’s disease, Creutzfeldt-Jakob disease, and several other neurodegenerative diseases (14).
3.1 Dementia care in Norway: From diagnosis to nursing home

3.2 Diagnoses, dementia teams, and in-home care
Diagnosing dementia can be done by the family doctor, with or without help from a dementia team, or at the hospital, either at a memory clinic or other specialized geriatric, neurological, or psychiatric (geriatric psychiatry) unit. Those with typical symptoms of dementia are often diagnosed by their family doctor. The typical phenotype of such a person with dementia is an individual who is older than 65 years of age with memory problems and impairments in ADL and no complicating comorbidities. Younger patients and patients with unclear symptoms and comorbidities should, preferably, be referred to specialist care services (90).

Dementia teams in the municipalities are interdisciplinary teams. Most teams consist of a registered nurse (96%) along with an auxiliary nurse (40%), an occupational therapist (41%), a physiotherapist (8%), and a physician (53%) (91). The dementia team collects information from the patient and his or her relative(s) that is needed to enable the family doctor to establish a dementia diagnosis (91, 92).

The dementia team often cooperates with the in-home nursing service. Guidance and education of both the health care staff and the relatives of the person with dementia are important. The team can visit the person with dementia before he or she needs help and can assess the need for services and care.

After the diagnosis has been made, most dementia teams follow up the person with dementia and his or her family every six months or once a year and retest the patient annually (90).

The in-home nursing service offers medical nursing service and practical aid to those who cannot manage to take care of themselves any longer. There is a large variation in the number of hours of help per month provided to PWD, but on average, during the last month before admittance to a nursing home, a person with dementia receives only four hours of in-home nursing care (93).

Day care centers for persons with dementia may offer exercise, music groups, and other activities for PWD and also provide respite care. Approximately 20 percent of all persons with dementia living at home make use of a day care center, and each person stays at the center an average of two days a week (93).
3.3 Long-term residential care in Norwegian nursing homes

Organization

Over the last six decades, the municipalities have become responsible for nursing-care services and for providing care to adults who need nursing care in old-age homes. During the 1970s, the counties were still responsible for long-term nursing homes for persons with severe diseases and those most in need of care, but in 1988, the responsibility for nursing homes was transferred to the municipalities (94, 95).

In Norway, the municipalities offer and provide in-home nursing care and long-term care in institutions financially supported by the tax system. This means that, regardless of economic status, all Norwegians have access to health care, as the basic costs for medical services are covered by the tax system. However, persons in nursing homes have to pay for non-medical services, currently 75 percent of the person’s national insurance basic income, and 85 percent of income above this, with deductions for the support of a home-dwelling spouse or other dependents (96). During the last 30 years in particular, access to both in-home nursing care and long-term nursing care in institutions, including care for persons with dementia, has increased (94).

3.3.1 The nursing-home units

In 2014, Norwegian nursing homes had a total of 40,000 beds. This number has remained relatively stable during the past decade (97). Although the total number of beds has not increased, there has been an increase in single-bed rooms. During the last 15 to 20 years, many nursing homes have been rebuilt, and in 2014, the percentage of single-bed rooms was 97.5, and 83.3 percent of these also had a private bathroom (98). This increases the opportunity for a private life in the NH.

The nursing homes offer services in regular units (RU) for elderly persons with severe physical impairments (although many have a dementia disorder as well), special care units (SCU) for persons with dementia, and specially designed respite care units and rehabilitation units. The SCUs and the RUs are long-term units (95, 98).
The nursing homes encompass several areas:

- Long-term living arrangements for persons with severe physical illness;
- Long-term living arrangements for persons with severe psychiatric illness, particularly persons with dementia;
- Long-term living arrangements for disabled persons who need placement in institutions;
- Rehabilitation and relief for aged and sick patients;
- Acute units for temporary placement of home-dwelling persons; and
- Palliative care for elderly persons (95)

The sizes of the nursing homes and units vary depending on the size of each municipality. RUs, however, usually care for between 20 and 30 patients. By law, SCUs should not have more than 12 beds (99); however, they are often just as large as the RUs but divided into smaller units, with a mean number of 7.9 beds (100). In 2011, 24 percent of all nursing-home beds were in SCUs (100).

The staff

In 2013, 26 percent of the health care staff in the municipalities lacked formal qualifications; 40 percent had a high school education (mostly auxiliary nurses); and 34 percent of the staff had a college degree (mostly registered nurses) (101). On average, SCUs have a higher number of staff per patient, with an average of three patients per staff member on a weekday dayshift, compared to RUs (100).

3.3 The nursing-home residents

An estimate from the Norwegian Medical Association indicates that approximately 25 percent of all persons older than 80 years of age will need a nursing-home placement. About 80 percent of persons living in a long-term care unit in a NH have a possible dementia disorder, although many do not have a diagnosis of dementia (11, 19, 102). Most of the PWD also have other chronic disorders. Studies report that between 60 percent and 75 percent of residents in nursing homes are women (75, 78, 103); the mean age is approximately 86 years (75, 104).
3.3.1 Drug treatment of persons in nursing homes

Studies show that nursing-home residents use a mean number of 5.1 different drugs a day (105, 106). In Kirkevold’s 2005 study, the drugs used most often were psychotropic drugs (antipsychotics, hypnotics, anxiolytics) (54%), cardiovascular drugs (54%), alimentary tractand metabolic drugs (47%), vitamin and mineral supplements (45%), antithrombotic drugs (34%), analgesics (32%), and antidepressants (31%) (105).

Comparing numbers from 1997 to 2009, Ruths and colleagues found an increase in the prescribing of psychotropic drugs overall from 57.6 percent to 70.5 percent (75). Antidepressant medication was the most commonly prescribed drug in 2009. Women, patients younger than 80 years, and those residing in SCUs were, in general, most likely to be prescribed psychotropic drugs (75).

In a study from 2005, Kirkevold found that 17 percent of patients living in SCUs and 11 percent of patients in RUs received medication covertly. Psychotropic and cardiovascular drugs were most often concealed in food (105).

3.4 Basic care in nursing homes

Nursing homes are expected to provide both a homelike atmosphere (personal and social) and medical care, as described in Hauge’s thesis (107). Basic care can be described as necessary medical care, help with medication, sufficient and appropriate food, and help with dressing, bathing, eating, and other needs. In a study from 2006, Kirkevold and Engedal found that most patients in Norwegian nursing homes receive good basic care. However, participation in leisure activities was not prioritized (108). This is a major deficit that should be addressed. A review from 2014 concludes that there is sufficient evidence to support the value of personalized and pleasant activities both with and without social interaction for the treatment of agitation and reminiscence therapy to improve mood (109). Social relationships have been found to be important for persons with dementia living in nursing homes (110, 111).

Neuropsychiatric symptoms and impaired ADLs are factors found to be associated with reduced quality of care (108). According to Kirkevold’s study in 2004, these two factors were found to lead to the use of restraints in patients (103, 112). Although as many as 23 percent of patients in
RUs and 13 percent in SCUs were subjected to the use of mechanical restraints during one week, the use of restraints was frequently not documented. Common forms of restraint included securing the patient to a chair or holding his or her hands during washing. It was usually a registered nurse (44.2%), an auxiliary nurse (10.5%), or a caregiver without formal education (13.2%) who made the decision to use restraints. The nursing-home physician made the decision in only 23 percent of the cases (103).

3.5 Person-centered care
Person-centered care is based on the care philosophy of the English psychologist Tom Kitwood (113). Kitwood used the term personhood to describe a person’s value, and he defined personhood as “a standing or status that is bestowed upon one human being, by others, in the context of relationships and social being. It implies recognition, respect and trust” (113). He claimed that impairment in cognition due to dementia does not diminish the person to something less than a person. A person with dementia still has the same basic psychological needs as any other person—sometimes accentuated as a result of dementia.

Kitwood described how the development or progression of dementia seen in the patient is a result not only of neurological brain damage but also of several other factors, such as the person’s life history, personality, health condition, and the type of social environment in which the person with dementia lives. This means that if the person with dementia is constantly seen as someone who is not capable, who does not understand, who cannot do things, and who is judged in relation to his or her cognitive impairment, this might create feelings of depression and hopelessness and undermine the individual’s personhood. To unintentionally ignore, disempower, and objectify the person with dementia Kitwood called malignant social psychology (113). If the value of being human is diminished because of the dementia disorder and if the person is not met as a unique human being, this can affect his or her ability to cope with the disease and how the symptoms evolve (113, 114).

Providing PCC is a task that demands knowledge, skills, and will from both leaders and front-line staff in a nursing home (115, 116). PCC means that the care and interventions provided are tailored to fit the person to whom the care is given. The perspective of the person with dementia should be incorporated into the planning of care and should be a core feature of how the
intervention should be carried out. PCC highlights the importance of seeing behavior as communication (117). Providing care that aligns with what the person with dementia likes and doesn’t like and paying attention to his or her communication are important elements of providing PCC.

The use of PCC has been tested in randomized controlled trials (78-80) and been found to reduce agitation, depression, and the need for antipsychotic medications. A review of personalized activities concludes that it is suitable for improving mood and treating agitation (109).

The health care staff in nursing homes and in-home nursing staff need to understand how their actions, their ways of speaking to the PWD, and how they organize the care affect the patient.

4.0 Awareness in dementia

Cognitive impairment in dementia may lead to reduced insight and a lack of awareness of different domains, among others QOL, ADL, and social relationships (118-122). It is unknown how much insight or awareness of disease, self, relationships with others, and surroundings persons with dementia, particularly those with moderate and severe dementia.

Awareness can be defined as “knowledge that something exists, or understanding of a situation or subject at the present time based on information or experience” (123), or as a “reasonable or realistic appraisal of a given aspect of one’s own situation, functioning or performance” (124). Awareness of disease can be defined as “recognition of changes caused by the deficits related to the disease process” (125). According to Sousa and colleagues, awareness of disease encompasses three dimensions: the ability to recognize a specific deficit (anosognosia), the emotional response to the difficulties, and the ability to understand the impact of the impairment on activities of daily living (125). In relation to dementia, insight is seen as “recognition of memory deficits” or as a broad phenomenon including both awareness and plans for the future (119). Definitions of awareness and insight are overlapping. In this thesis, the term awareness will be used.

Awareness is influenced by an interaction between cognitive functioning, individual psychological responses, and the social context (126). Awareness may be expressed explicitly
through what is said or implicitly through behavior. A lack of awareness can, among others things, be seen as assuming one is still able to drive a car or do things at work one used to be able to do, or not understanding that it is necessary to take a shower. Behaviors such as these might lead to increased marginalization of the person with dementia, where the caregiver pays too much attention to practical tasks (“what practical tasks do I have to help you with?”) and too little attention to the psychological needs (“what is it that you need to be happy or content?”) of the person with dementia (113, 127, 128).

Awareness in mild dementia has been studied in regard to several domains, yet it remains difficult to conclude anything about the relationship between awareness and dementia (118), and lack of awareness of one domain does not necessarily mean that the person with dementia is unaware of another domain (118, 124, 125). Clare and colleagues found that, at least in the early stages of dementia, awareness is stable, and it should not be assumed that it will decrease. Although neuropsychological functioning may decline, self-ratings of depression, anxiety, and QOL may remain stable (129).

Woods and colleagues studied awareness and QOL in persons with mild dementia (130). They found that QOL was not related to the degree of cognitive impairment but was significantly associated with depressed mood, severity of irritability, self-concept, male gender, and the quality of the relationship with the caregiver (spouse, friend, or other family member). The awareness of memory function, functional abilities, and conscientiousness were associated with depressed mood and self-concept but not related to QOL (130). The discrepancy between self-reporting and proxy reporting on memory function and functional abilities was related to QOL, but this was mediated by depressed mood and self-concept, indicating that, at least in mild dementia, self-report measures of QOL are valid (130).

As in Woods’s study (130) including quality of relationships, Nelis and colleagues studied awareness of social and emotional functioning in the early stage of dementia. They found that lack of awareness was related to cognitive dysfunction and NPS but not to social relationships and quality of life (124).

Few studies have examined awareness in persons with moderate and severe dementia. In one study, Tappen and colleagues found persistence of awareness of the self in persons with moderate
and severe dementia (128). Clare and colleagues found that all the participants in their study showed awareness to varying degrees and could talk about their experiences in the residential care homes (127, 131, 132).

There is no clear understanding of how awareness changes over time in dementia. Some studies find that awareness declines as dementia progresses; other studies find that awareness remains stable throughout the course of dementia, while in some persons awareness improves (125, 129). It is likely that awareness remains stable, to some extent, in moderate and severe dementia, and that PWD have an understanding of their situation and how they are treated in the nursing home, as also described by Clare and colleagues (131, 132). This is in line with Kitwood’s theory on person-centered care, describing how care and social inclusion is of significance in how the symptoms of dementia evolve and how quality of life is maintained throughout the disease process (113, 133). The difference in perspectives between the person with dementia and the caregiver is affected by both the person’s lack of awareness of his or her own limitations and needs and the knowledge and attitudes of the caregiver (127, 128). It is the relationship between the person with dementia and the caregiver’s ability to focus on resources that remain available to the person with dementia that helps the patient to still feel like a person and have his or her personhood maintained (113, 114, 133).

Understanding how each person’s awareness is affected by dementia is important, as this will be of consequence regarding the quality of care when tailoring interactions that best suit each individual with dementia (127).

5.1 Quality of life
Quality of life (QOL) is a term used to describe a person’s feelings and thoughts about his or her own life. Overall QOL is influenced by personal values, preferences, expectations, social and psychological support, economic, biological, and physiological variables (3, 134-139) and is an elusive, multidimensional term encompassing both objective and subjective variable values (1, 137, 139-141). What a person has, does, and is surrounded by is of indirect importance for QOL because of the consequences of these for the experience of QOL (5). QOL is difficult to define, and various definitions are used in different studies.
The World Health Organization (WHO) describes QOL as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (137). The definition further states that QOL is affected by the person’s “physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment” (137). Whether or not this definition is suitable for use with PWD is uncertain, as it sets high requirements for a person’s cognition. QOL has also been defined as an “integration of cognitive functioning, activities of daily living, social interactions, and psychological well-being” (142).

Næss describes QOL as one of several variables that affect the person’s welfare; other variables are health (physical and mental), pain, and living conditions (neighborhood, housing, family, income). Næss writes that QOL is “to have a core of happiness” (own translation) and that the term must be tied to the individual, the individual’s experiences, and internal condition (4). Others describe QOL as subjective well-being (139, 143, 144). Subjective well-being is sometimes called atheoretical (143); other times subjective well-being is described by theories used in research (139, 143).

If QOL is a subjective experience of well-being (4, 5, 139, 145), then an evaluation of behavior might tell us something about the person’s QOL (3, 146). Behavior caused by negative emotions can be measured, as it crosses the line of normally accepted behavior and is seen as stress in the person (3). However, reduced cognition and impairment in ADL can also be signs of disease and not necessarily a sign of reduced QOL.

The term health-related quality of life (HRQOL) is often used to separate the more general QOL from variables affecting the person’s state of health. HRQOL measures are used to evaluate functional status or results of medical care (134, 141). However, the two terms are difficult to separate and are thus used interchangeably in the literature. It is difficult to imagine how a medical condition would affect only the diseased, injured, or unhealthy part of the body and not the rest of the person’s life.

Quality-adjusted living years (QALY) represent a method to evaluate the cost-effectiveness of a treatment, where the cost of the treatment is compared to its effect. QALY is sometimes used to rate HRQOL. In the literature, when evaluating HRQOL this way, a person’s adjustment by
coping and accepting the situation on some occasions becomes a problem because coping and adjustment render the measurement incorrect (147-149). A standardized measurement needs to be constant to be valid; it has to be able to measure the same variable over and over again. Coping or psychological adjustment to a situation can possibly disturb the measurement. Neither QALY nor QOL and HRQOL in relation to QALY will be discussed further in this thesis.

5.2 Quality of life and coping
As the definitions above show, quality of life depends on the person’s thoughts about his or her own life. Coping mechanisms influence this and refer to how a person deals with things that happen to him or her in life and the struggle to overcome and manage the stresses of living and adapting (150, 151). Folkman and Lazarus describe coping as the use of different strategies to alter or change a situation into something the person can handle and accept (problem-focused coping) and how a person regulates the emotional distress associated with the situation (emotion-focused coping) (151-153). Coping is associated with personality traits and is seen as both a situation specific and a flexible state (153, 154). A review of studies on coping among family caregivers of persons with dementia from 2012 found that persons who had dysfunctional coping strategies had higher levels of anxiety and depression, while persons who used emotional support and acceptance-based coping strategies had less anxiety and depression (155).

There are several theories about changes in coping related to age. One theory is that coping is developmental and changes in stages related to age, and that men and women have different stage changes during life (151). Another aging theory on coping says that coping is contextual and a result of what people have to deal with as they age, influenced by past experiences and present resources. A person will try to achieve the best possible outcome, with maximized gains and minimized losses, involving direction, goal, and a specification of the outcome (156-161). For a person with dementia living in a nursing home, this would mean, for instance, that to achieve the best possible quality of life, coping should result in an acceptance of not living at home, accepting spending time with other residents and caregivers there, and accepting receiving help.

Antonovsky describes how a feeling of confidence that things will work out as well as can be expected and that life is manageable and meaningful is important in coping. When confronted
with a difficult situation, the person should find it meaningful to deal with and believe that he or she has understood the situation and believes that the resources needed to deal with the situation are available (162, 163).

5.3 Quality of life in dementia

QOL measurements are often used as indicators of the health care received by PWD or as an outcome measure in clinical studies (164, 165). Often, a proxy rater is used to rate the QOL in PWD.

Lawton writes that QOL in dementia is the same as in people in general (3) and includes “competent cognitive functioning, the ability to perform activities of daily living and to engage in meaningful time use and social behavior, and a favorable balance between positive emotion and absence of negative emotion” (3, 6). Lawton describes QOL as a combination of external (objective) and internal (subjective) dimensions (see Figure 1). The two external dimensions are 1) behavioral competence, including activities of daily living, cognitive performance, and social behavior; and 2) external environmental factors such as private space in the nursing home, lighting in the living area, or a homelike atmosphere in the institution (3, 6). The two internal factors are 1) the person’s perceived quality of life and 2) his or her psychological well-being (3, 6). The subjective factors can be difficult for a proxy rater to evaluate, but perhaps subjective factors can be interpreted through behavior such as smiling or crying (3).
Figure 1. Lawton’s description of QOL in persons with dementia. QOL is seen as a combination of two external (1. behavioral competence and 2. external environmental factors) and two internal (1. perceived quality of life and 2. psychological well-being) dimensions.

Furthermore, Lawton writes, “for the patient with AD beyond the relatively early stage, measurement of the subjective half of QOL is usually foregone. More cognitively impaired patients do not introspect, or at least do not report reliably on interior phenomena… We must therefore rely on behavior, externally evaluated, as our window on QOL for the cognitively impaired person” (3).

Byrne-Davis and colleagues, another group that has researched QOL, draw on the coping theory of Lazarus and Folkman (151, 161) and find strong evidence that PWD can self-report on QOL (5). They describe how three cognitive processes influence the QOL ratings. The first process is the person’s coping strategies, where in a situation that feels dissatisfying or threatening, the
person will evaluate his or her resources and deal with the situation to resolve the dissatisfaction. The second process is social comparison, where, even if the condition or situation is seen objectively as poor, the person with dementia can evaluate the situation in a positive light and use social comparison to deem others with the same condition as worse of (5). Thirdly, Byrne-Davis and colleagues include self-rated happiness as part of the QOL of PWD, in that happiness may have an effect on all aspects of the QOL process and influence the person’s belief in his or her ability to cope (5).

5.2.2 Self-rated vs proxy-rated QOL
In several studies comparing QOL, information about QOL is reported by both persons with dementia and by proxy. Such studies show that there is a gap between what the caregiver finds important for QOL in the PWD and what the person with dementia finds important for her/his own QOL. The caregiver consequently report that QOL of the PWD is poorer compared to the PWD own rating of QOL, see table 3. However, the better the caregiver knows the PWD, the higher the correlation between the two evaluations of QOL in PWD, meaning better correspondence between the reported QOL (9, 10, 166-169). There can be several explanations for a poor association. One explanation could be that proxy rater’s evaluation of QOL in the person with dementia is influenced by the cognitive impairment, the ADL impairment and by depressive symptoms and other NPS in the person with dementia. However, studies using information from the person with dementia also report that depression influence on self-reported QOL (169-173). A proxy rater’s own QOL and the presence of depression in the caregiver can also affect the rating of the PWD’s QOL. In addition, the proxy’s expectations to life, gender, and age might as well influence the QOL rating in the PWD (167, 169).
Table 3. Differences between proxy and self-report on quality of life, based on two reviews (9, 10)

<table>
<thead>
<tr>
<th>Variables measured</th>
<th>Self-report</th>
<th>Proxy report</th>
</tr>
</thead>
<tbody>
<tr>
<td>Socio-demographic (age, gender, education)</td>
<td>No association (9, 10)</td>
<td>No association (9, 10)</td>
</tr>
<tr>
<td>Activities of daily living</td>
<td>No association (9)</td>
<td>Uncertain association (9)</td>
</tr>
<tr>
<td></td>
<td>Unclear or no association (10)</td>
<td>Negative associations (10)</td>
</tr>
<tr>
<td>Cognition</td>
<td>No association (9, 10)</td>
<td>Negative association (9, 10)</td>
</tr>
<tr>
<td>Behavioral disturbances, agitation</td>
<td>No associations (9, 10)</td>
<td>Negative associations (9, 10)</td>
</tr>
<tr>
<td>Depression</td>
<td>Negative association (9, 10)</td>
<td>Unclear association (9)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Negative association (10)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Unclear association (9)</td>
<td>Negative association (9)</td>
</tr>
<tr>
<td>Psychotropic drug use</td>
<td></td>
<td>Negative association (9)</td>
</tr>
</tbody>
</table>

Only a few qualitative studies have explored what it is like to live with dementia and how it influence on QOL from the perspective of the person with dementia (110, 111, 131, 165, 174-176), hence the experience of living with the chronic disease dementia is not well studied.

Some qualitative studies have investigated how PWD experience daily life in nursing homes with a specific focus on unmet needs (177, 178), awareness of self (132, 179), and activities (177, 180, 181). The articles describe how, by remembering their past, PWD maintain identity and cope with and accept life in the nursing home (131, 132, 165, 179). Further in these studies many PWD describe life in the NH as difficult (131, 175, 176), and they report feelings of
worthlessness and not being seen or heard as individuals (131, 176). Feelings of homesickness and not belonging in the NH (176), feeling captive, isolated (111, 131), and lonely (111, 175) are common. To counter these feelings, nursing home staff play an important role to help the person with dementia in his or her everyday life (165, 180). But practical help is not enough for a good life and good QOL. The person with dementia needs to experience a feeling of meaningfulness in life even when he or she is in need of care around the clock. To have a meaningful everyday life, the person with dementia needs to partake in activities that are meaningful for her or him (110, 177, 180, 181). What a meaningful activity is, depends on each person’s preferences (177). This can happen only if the staff know the likes and dislikes of the person with dementia well (113), and the interaction between the staff and the person with dementia has “a good quality” (177). This is not surprising, as all people prefer to interact and talk to people they know and like.

Nursing-home staff have been found to be busy and unavailable to residents (165). In addition, PWD report that fixed environmental structures and activity schedules may result in boring and monotonous days with limited opportunities to be active (165, 177, 180-182).

5.4 Scales to assess quality of life in persons with dementia
Several scales measuring QOL in PWD are used in research (164, 183). In clinical practice in Norwegian nursing homes, however, few are in regular use. Some scales are designed to collect information from proxies or the person with dementia only; others are designed to collect information from both the proxy and the PWD (184-186).

Two of the most frequently used QOL scales for use among PWD are the Dementia Quality of Life Scale (DQOL) (185) and the Quality of Life in Alzheimer's Disease scale (QOL-AD) (187). The DQOL is a self-rating scale for persons with mild and moderate dementia. It measures five QOL domains: self-esteem, positive affect, negative affect, feeling of belonging, and sense of aesthetics (185). The QOL-AD has both a proxy and a self-report version, and it measures domains of interpersonal relationships, financial difficulties, physical condition, memory, mood, and overall health (187). These two scales have recently been compared in a French study, where the QOL-AD was found to be suitable for quick evaluations during geriatric consultations, while the DQOL was better suited to a more in-depth evaluation (188). Another scale used in dementia
research is the Quality of Life for People with Dementia Scale (DEMQOL) (189), also consisting of one proxy and one self-report section.

Proxy-rated scales are particularly useful when collecting information about persons with moderate and severe dementia. The proxy-based observational scale QUALID, developed in the US by Prof. Myron Weiner and colleagues (190) is used to measure QOL in persons with moderate and severe dementia. The scale has been translated to Norwegian, Spanish, and Swedish (191, 192) and has been found to be a reliable instrument in use among nursing-home patients in Norway (193, 194). The scale is described in section 6.5.1.

5.5 Criticism of the term quality of life

It is a challenge to collect data about something if we do not really know what it is or how to quantify it (138, 195). The severity of dementia sometimes makes it difficult to collect information from the person with dementia, and, therefore, many QOL scales used in research and/or clinical practice collect observational data from professional or family caregivers. As proxy information often differs from information collected directly from a person with dementia, we cannot know whether proxy information is an accurate reflection of the quality of life of the person with dementia.

Another issue raised in the literature is the difficulty of comparing the QOL scales and the different dimensions of QOL because investigators deliberately or consequentially used different words or phrases to define and/or measure quality of life (2, 183). In addition, the settings in which the scales are most effectively used can differ (188). Hence, we end up measuring and comparing different and unclear dimensions of QOL. Most of the health-related quality of life scales in use have no theoretical or philosophical grounding but are created by “experts” in the medical field (195-197). This is also the case for the Quality of Life in Late-Stage Dementia Scale applied in the current study.
6.1 The present thesis

6.2 Aims
The overarching aim of this study was to describe the quality of life for persons with dementia in nursing homes in Norway. Four specific aims were addressed:

The first aim, described in paper 1, was to increase our knowledge about which dimensions of quality of life the QUALID Scale measures when used in a nursing-home setting with persons with dementia. Additionally, we wanted to investigate how each symptom of the QUALID varied across the severity of dementia.

The second aim, described in paper 2, was to prove or reject the following hypotheses: 1) QOL in NH patients with dementia is associated with patients’ neuropsychiatric symptoms, impairment in activities of daily living, and severity of cognitive impairment; and 2) patients’ QOL is not associated with their gender, age, or type of ward (SCU vs RU).

The third aim, described in paper 3, was to investigate whether changes in quality of life as measured by the QUALID Scale and its subscales over a 10-month period are associated with baseline QOL scores, neuropsychiatric symptoms, use of psychotropic drugs, degree of dementia, and impairment in activities in daily living, but not with gender or age.

The fourth aim, described in paper 4, was to examine the experience of living in a nursing home and to investigate what makes life better or worse from the perspective of the person with dementia.

6.3 Design
In papers 1 and 2, a quantitative cross-sectional design was used. Data were collected through standardized interviews with primary nurses. In paper 3, a quantitative longitudinal design was used. Data were collected at baseline and at a 10-month follow-up.

In paper 4, a qualitative design was used. Data were collected twice: the first time within six months following the admittance of the person with dementia to the nursing home and the second time three to four months later.
6.4 Participants
The data used in the first three studies (papers 1, 2, and 3) were collected in 2011 to be used in an RCT (78). The RCT aimed to evaluate the effects of two different methods of implementing PCC in Norwegian nursing homes (78). The inclusion criteria were as follows: participants should have status as permanent residents (until death) and should have been in the nursing home for at least four weeks; participants should have a diagnosis of dementia, a score on the Clinical Dementia Rating Scale (CDR) of 1 or above, and should not be terminally ill (78).

To recruit patients, all 51 nursing homes in Oslo, Norway, with more than 30 beds were invited to participate. Of these, 44 units in 16 nursing homes with a total of 899 patients agreed to participate. From this patient sample, 721 patients or their next of kin consented to participate, and following the assessment of dementia, 665 patients were included. Due to missing data in four cases, 661 patients were included in the analyses; see Figure 2. We have no information about the extent to which the nursing homes that agreed to participate differed from those that declined, but no selection criteria were applied.
Figure 2

Number of patients in the nursing-home wards who consented to participation: 899

Patients/next of kin who consented to participation: 721

Number of patients/next of kin who did not consent: 178

Number of patients without dementia and thus excluded: 56

Number of patients with dementia: 665

Number of patients excluded due to missing data: 4

Number of patients included in study: 661

Flow chart. Inclusion of patients for papers 1 and 2.
Papers 1 and 2

For the studies described in papers 1 and 2, we used baseline data that were collected before randomization. As two nursing homes dropped out of the PCC study, one before and one shortly after randomization, we included more patients than were randomized into the PCC trial. The participants included in this study did not differ from those included in the RCT with regard to age, gender distribution, and dementia severity as measured by CDR and QOL measured by QUALID. For various patient characteristics disaggregated by CDR groups, see Table 4.

The distribution of dementia diagnoses was as follows: Alzheimer's disease, n = 353 (53%); vascular dementia, n = 26 (4%); mixed dementia of AD + VAD, n = 12 (2%); Lewy body dementia, n = 22 (3%); frontal lobe dementia, n = 27 (4%); and unspecified dementia, n = 221 (34%).

Table 4. Patient characteristics by CDR groups described in papers 1 and 2

<table>
<thead>
<tr>
<th></th>
<th>ALL (N = 661)</th>
<th>CDR 1 (N = 149)</th>
<th>CDR 2 (N = 222)</th>
<th>CDR 3 (N = 290)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (SD)</td>
<td>85.34 (8.63)</td>
<td>85.84 (9.09)</td>
<td>85.05 (8.42)</td>
<td>85.31 (8.75)</td>
<td>.528a</td>
</tr>
<tr>
<td>Gender Female (%)</td>
<td>472 (71.4)</td>
<td>99 (66.4)</td>
<td>165 (74.3)</td>
<td>208 (71.7)</td>
<td>.254b</td>
</tr>
<tr>
<td>Type of unit SCU (%)</td>
<td>285 (43.1)</td>
<td>33 (22.1)</td>
<td>99 (44.6)</td>
<td>153 (52.8)</td>
<td>.000b</td>
</tr>
<tr>
<td>QUALID total score (SD)</td>
<td>21.52 (7.13)</td>
<td>18.92 (6.29)</td>
<td>21.09 (6.90)</td>
<td>23.25 (7.26)</td>
<td>.000a</td>
</tr>
<tr>
<td>Psychotropic medication yes (%)</td>
<td>63.7</td>
<td>67.8</td>
<td>66.7</td>
<td>59.3</td>
<td>.114b</td>
</tr>
</tbody>
</table>

a Kruskal–Wallis test; b chi-square test, SCU – special care unit; QUALID – Quality of Life in Late-Stage Dementia; CDR – Clinical Dementia Rating Scale
The participants included in the study described in paper 3 were those randomized into the control group of the PCC study, at baseline a total of 198 patients. Of this number, 118 resided in regular nursing home units (RU), and 80 resided in special care units (SCU) for PWD. See Table 5 for characteristics of the residents included in paper 3.

<table>
<thead>
<tr>
<th></th>
<th>Baseline N = 198</th>
<th>Follow-up N = 143</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (SD)</td>
<td>87 (7.7)</td>
<td>87.2 (7.9)</td>
</tr>
<tr>
<td>Gender female (%)</td>
<td>156 (77)</td>
<td>116 (81.7)</td>
</tr>
<tr>
<td>CDR 1 (%)</td>
<td>49 (24.7)</td>
<td>23 (16.1)</td>
</tr>
<tr>
<td>CDR 2 (%)</td>
<td>73 (37)</td>
<td>57 (39.9)</td>
</tr>
<tr>
<td>CDR 3 (%)</td>
<td>76 (38)</td>
<td>63 (44.1)</td>
</tr>
</tbody>
</table>

CDR – Clinical Dementia Rating Scale

Before the 10-month follow-up, nine persons had moved from the nursing home and 46 were deceased. The latter 46 patients differed from the baseline patient group as they were older (p-value 0.036), had more-severe dementia (p-value 0.002), had worse general medical health (p-value 0.001), were males (p-value 0.002), and were more impaired in ADL (p-value 0.010).

Of the patients residing in SCUs, a larger proportion had moderate or severe dementia (85%) compared to those in the RUs (68.7%) (chi-square test, p-value 0.022). There were no differences in gender or age in regard to ADL impairment or changed behavior between persons living in RUs and those living in SCUs.
Paper 4

For the qualitative study described in paper 4, 12 residents were included; 10 (83%) were women, two (17%) were men. The age range was 71 to 95 years, and they were recruited from three different nursing homes. Half of the residents lived in special care units for persons with dementia and the other half lived in regular units. The inclusion criteria were having dementia, having stayed in a NH for a maximum of six months, and having a life expectancy of more than three months. The degree of dementia was rated with the CDR, which was completed by the primary nurse for the resident. All patients except one had moderate or severe dementia. One person died before the follow-up interview; one did not want to be interviewed the first time but consented the second time; one did not want to be interviewed the second time; and one person became severely ill and could not participate in the second interview, for a total of 20 interviews. See Table 6 for the characteristics of the residents included in paper 4. All names in the table are pseudonyms.
Table 6. Characteristics of residents for paper 4

<table>
<thead>
<tr>
<th>Facility</th>
<th>Gender/ name</th>
<th>Age</th>
<th>Level of function at first encounter</th>
<th>CDR</th>
<th>Time in ward after admission to the nursing home</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1. Interview</td>
</tr>
<tr>
<td>No 1</td>
<td>Female, Lisa</td>
<td>94</td>
<td>Severe aphasia, used walker</td>
<td>2 (3)</td>
<td>2 months</td>
</tr>
<tr>
<td>SCU</td>
<td>Female, Marta</td>
<td>78</td>
<td>Moderate aphasia, walked without aid</td>
<td>2</td>
<td>2 months</td>
</tr>
<tr>
<td></td>
<td>Female, Mina</td>
<td>83</td>
<td>Moderate aphasia, walked without aid</td>
<td>2</td>
<td>2 months</td>
</tr>
<tr>
<td>No 2</td>
<td>Female, Ella</td>
<td>82</td>
<td>Moderate aphasia, used high walker</td>
<td>3</td>
<td>5 months</td>
</tr>
<tr>
<td>SCU</td>
<td>Female, Betty</td>
<td>81</td>
<td>Moderate aphasia, walked without aid</td>
<td>2</td>
<td>5 months</td>
</tr>
<tr>
<td></td>
<td>Female, Hanna</td>
<td>76</td>
<td>Severe aphasia, walked without aid</td>
<td>2</td>
<td>5 months</td>
</tr>
<tr>
<td>RU</td>
<td>Female, Vera</td>
<td>92</td>
<td>Mild aphasia, walked without aid</td>
<td>1</td>
<td>5 months</td>
</tr>
<tr>
<td></td>
<td>Female, Nelly</td>
<td>94</td>
<td>Severe aphasia, used high walker</td>
<td>2 (3)</td>
<td>5 months</td>
</tr>
<tr>
<td>No 3</td>
<td>Male, Bob</td>
<td>71</td>
<td>Severe aphasia, used walker</td>
<td>2</td>
<td>4 months</td>
</tr>
<tr>
<td>RU</td>
<td>Male, Peter</td>
<td>83</td>
<td>Moderate aphasia, walked without aid</td>
<td>2</td>
<td>5 months</td>
</tr>
<tr>
<td></td>
<td>Female, Mary</td>
<td>95</td>
<td>Moderate aphasia, used wheelchair</td>
<td>2</td>
<td>5 months</td>
</tr>
<tr>
<td></td>
<td>Female, Anna</td>
<td>90</td>
<td>Mild aphasia, used walker</td>
<td>2</td>
<td>3 months</td>
</tr>
</tbody>
</table>
6.5 Measurements used in papers 1, 2, and 3

6.5.1 The Quality of Life in Late-Stage Dementia Scale

The Quality of Life in Late-Stage Dementia Scale measures health-related quality of life in persons with dementia using proxy ratings. The scale was developed by Prof. Myron Weiner and colleagues (190). The scale was translated into Norwegian by three researchers following the procedures described by Acquadro et al. (198). The three translations were aggregated into a preliminary version, which was translated back into English by a person fluent in both English and Norwegian. This version was sent to Prof. Weiner for his comments on the translated version. The final version of the Norwegian QUALID was agreed upon after revisions based on Prof. Weiner’s comments and a discussion in the research group (8).

The scale consists of 11 items; each asks for an observable type of behavior in the PWD. Each item can be scored between 1 and 5 depending on the frequency and severity of the behavior and how the behavior is initiated. The minimum score is 11, indicating a high quality of life, and the maximum score is 55, indicating a poor quality of life. To score the items “smiling,” “enjoys eating,” “enjoys being touched,” “enjoys social interaction,” and “being calm/relaxed,” the scoring is reversed, so a higher score (closer to 5) means the behavior appears less frequently. To score the other items – “crying,” “appearing sad,” “facial expression of discomfort,” “appears physically uncomfortable,” “making sounds of discomfort,” and “being irritable/aggressive” – a lower score means the behavior appears less frequently.

The Norwegian version of the QUALID has good inter-rater reliability and an acceptable level of internal consistency. Cronbach’s $\alpha$ has been found to be 0.79 and intra-class correlation 0.83 (8). The psychometric properties of the Spanish and Swedish versions, as well as the original US English version, were examined and found to be acceptable (8, 190-192).
6.5.2 The Clinical Dementia Rating Scale
The Clinical Dementia Rating Scale (CDR) was used to rate the severity of dementia. The scale has six questions (items) on memory, orientation (time and place), problem solving, community affairs, home and hobbies, and personal care, each with five possible answers (28). The scale can be used as a categorical variable (0 = no dementia, 0.5 = possible dementia, 1 = mild dementia, 2 = moderate dementia, 3 = severe dementia) or as a continuous variable by using the sum of boxes, with scores from 0 = no dementia to 18 = severe dementia. The two scoring systems correlate strongly (29). In the present study, both sum of boxes and the categorical variable were used. The scale is found to be valid and reliable in a Norwegian nursing-home population (19).

6.5.3 The Physical Self-Maintenance Scale
The Physical Self-Maintenance Scale (PSMS) was used to evaluate patients’ abilities to perform basic activities of daily living. The scale evaluates six different areas (ability to go to the toilet, to eat, to dress, to wash, to walk and to bathe) where lower scores indicate better functioning. The scale is a continuous variable with scores ranging from 6 (best) to 30 (worst) (39). The scale has been used in several Norwegian studies and is in clinical use in nursing homes (78, 184, 199, 200).

6.5.4 The Neuropsychiatric Inventory Questionnaire
The Neuropsychiatric Inventory Questionnaire with 10 items (NPI-Q-10) was used to assess the severity of behavioral and neuropsychiatric symptoms. Each symptom is rated as “not present = 0” or “present = 1.” If the symptom is present, the rater will assess the severity of the symptoms as 1 = mild, 2 = moderate, or 3 = serious. The minimum score is 0 and the maximum score is 30 (57, 201).

The original version of the NPI includes 10 neuropsychiatric symptoms (57). Another version with 12 items was developed later and includes eating disorders and night-time behavior disorders (202). The nursing-home version used in this study was developed in 2000 and intended for use in routine clinical practice (201).

In the present study, we also used subscales of the NPI-Q-10 in the analyses, based on a previous large principal component analysis conducted with data from Norwegian nursing-home patients (48). The factors include agitation, consisting of the items agitation/aggression, irritability, and
disinhibition (minimum score 0, maximum 9); psychosis, consisting of the items hallucinations and delusions (minimum score 0, maximum 6); and affective, consisting of the items depression and anxiety (minimum score 0, maximum 6). The symptom apathy was analyzed on its own. These subscales have also been used in a previous Norwegian study (78).

6.5.5 General medical health
Each patient’s general medical health was rated with a four-point global scale, and we used the following ratings: good health = 1, fair health = 2, poor health = 3, and very poor health = 4, taking into account each patient’s number of general medical conditions, the severity of those conditions, and his or her use of medication. This instrument is reliable used as a continuous scale (203). In the present study, the ratings were coded the other way around.

Gender, age, use of medications, and length of stay in the ward were collected from the patients’ nursing-home records.

6.5.6 Diagnosis of dementia
In papers 1, 2 and 3, two experienced geriatric psychiatrists (GS and KE) independently used all information from the patients’ NH records and the collected data of the RCT to make dementia diagnoses according to ICD-10. In cases where they disagreed, the final diagnoses were made in consensus. Dementia due to Alzheimer’s disease, vascular dementia, mixed dementia of AD and VAD, dementia due to Parkinson’s disease, and unspecified dementia (UD) were diagnosed in accordance with the criteria for research of the ICD-10 (12). To diagnose frontal lobe dementia (FLD), the Manchester-Lund criteria (204) were used, and for Lewy body dementia (LBD), the revised consensus criteria were used (205).

6.6 Data collection – paper 4
Interviews and field observations were carried out twice. The first interview and observation took place within six months of the resident entering the nursing home; the second interview and observation took place three to four months after the first interview.
6.6.1 The interviews

Interviews have their basis in normal conversation, but they are professional conversations with a structure and an aim or aims. They are used to gain in-depth knowledge of a phenomenon or topic through nuanced descriptions given by key informants. In the present study, unstructured interviews were used; these have a loose structure, and the aim is to obtain in-depth experiential accounts. Open-ended questions can be rearranged and changed according to what the informant wants to talk about. The more detailed the descriptions of the situation or the phenomenon’s qualitative variations are, the better (206). During the interviews in the present study, the residents were asked to talk about their experiences of living in a NH and what makes it a good or not a good life. The questions were put in simple, everyday language. If the resident didn’t understand a question, it was rephrased.

The interview material in a hermeneutic phenomenological study should provide open, nuanced descriptions of different aspects of the resident’s experiences, feelings, and thoughts. However, when interviewing persons with moderate and severe dementia who are struggling with symptoms such as memory loss and aphasia, there is a risk of “thin” data, where “thin” means a lack of rich, detailed descriptions (206). Asking clarifying questions can be seen as controlling the interview, as all questions are potentially leading (206, 207). The challenge for the researcher is to get the informants to describe openly and clearly their experiences of the phenomenon without leading or influencing them to describe experiences that are not theirs. This involves negotiating a line between (too much) guidance and sufficient support for the informants to freely describe their experiences (206, 208).

In order to grasp the experiences of others, the researcher should be *consciously naïve*, open to new and unexpected phenomena, and not bound by preset categories and interpretative schemes (206, 208). To achieve this in the present study, it was important to observe the mood and level of engagement the residents showed during activities and to listen carefully to what they talked about during the interviews in order to recognize unexpected phenomena.

To find informants and get access to nursing-home units for a study such as this one, it is necessary to seek permission from the management in the nursing home and often the relatives of residents, if residents are not able to provide their consent. In the present study, the head nurse for the unit was given the inclusion criteria and found the residents who met them. In all three
nursing homes, the head nurse or each resident’s primary nurse asked the residents to consent to participation. In two of the nursing homes, if the resident was unable to provide consent, the head nurse or the resident’s primary nurse informed the resident’s next of kin about the study. This person was also informed that he or she could refuse to participate. In the third nursing home, the PWD’s next of kin was contacted by phone if the PWD did not have the capacity to give consent. These individuals were informed about the study and given the option of refusing to participate. All 12 residents who were asked to participate consented to participation. In addition, on the day of the interview/observation, the residents were given an explanation of the intention of the interview in simple, everyday language (209). Interviews were not conducted if there was any indication that the resident did not understand the implications of participating, and the interview was terminated if the resident no longer wanted to talk.

It is difficult to know how many informants are necessary for a qualitative study. The included informants must be able to verbalize/describe their experiences and/or thoughts and feelings regarding the situations/issues relevant to the study (208), and a number somewhere between 10 and 20 informants was assumed to be enough to gain sufficient variation in the experiences of the phenomenon in focus (the perspectives). After interviewing 12 persons with dementia, no new information appeared in the interviews. The informants all had difficulties with aphasia, which of course limited the richness of their responses. Still, many described the same situations, and the literature argues for ending the interviews when no new information emerges from the data (210).

The interviews, which lasted approximately 20 minutes, were conducted in the residents’ private living area and tape-recorded.

6.6.2 The field observations
Observational or participatory fieldwork is used to describe what is happening in a field (211). Fangen describes how observing persons within their context (in this study, the nursing-home unit where the resident lived) (212) can give the researcher a clearer understanding of the everyday life of the person with dementia. The observations thereby support the interview and the interpretation of the verbal interview material provided by the informant. Observing activities that the resident enjoys and finds meaningful can shed light on subjective feelings the resident would not be able to talk about because of the symptoms of dementia, as also described by Lawton (3).
How much time should be spent in the field observing depends on the topic studied. Lincoln and Guba argue that enough time should be spent in the field to truly get to know the phenomenon (213). How much time constitutes “enough” will, of course, vary depending on the field and the topic studied, and the researcher’s knowledge/familiarity of the field and topic.

The time spent focused and concentrating while collecting data material is limited, but Allen writes that the ability to collect data material starts to decline after four hours (211). In the present study, approximately four hours were spent with the residents at each meeting. These four hours always included at least one meal, usually breakfast or dinner and afternoon coffee. In addition, I usually observed an activity provided by the nursing home. The amount of time spent is, of course, also dependent upon available resources, including how much time the researcher has and the financial costs. In the present study, we wanted to observe a full day in the nursing home. It would be difficult to manage to visit each person with dementia for a full day twice due to the number of persons included and the project’s time limit. Therefore, we decided to split the day in two and visit each person during the morning, from approximately 8:30 until 13:00, and in the afternoon, from approximately 12:00 to 16:30.

The field observations were conducted the same day as the interview in order to spend time with the resident, to get to know each one, and also to observe interactions between the resident and the caregivers and other residents. The researcher interacted with the resident if the resident wanted to talk. Spontaneous conversations between the researcher and the resident were written down, but not tape-recorded. Key words and sometimes whole sentences were written down during the conversations. The notes were elaborated directly after the observations.

Participation in a field study raises methodological questions. As soon as a researcher enters the field, she or he influences or affects it in some way, as it is impossible not to make some sort of contribution to it. Even when the goal is strictly to observe, it is impossible to be invisible. Participation can also mean full participation, where the researcher tries to be a member of the field, in this case, one of the staff (214). In the present study, it was important not to be confused with a caregiver because I wanted the residents to talk about their experiences and relationships with the caregivers; hence, I did not undertake full participation. I did not wear a uniform or take part in daily activities in the unit such as conducting morning care or serving meals. However, I did interact with the residents in a participatory observation; I talked with them if they wanted to
talk to me and took part in activities such as word games, dice games, and music groups if they agreed to let me take part in these activities. The participatory observation is a form of social encounter, and it was important to think through how my conduct affected the field and to be aware of my choice of clothing and language used (211, 214).

All descriptions of the observations are filtered through the interpretation of the researcher and how the phenomenon of QOL in the nursing home is understood by the researcher, as well as how familiar or detached the researcher is to the field. Both detachment and familiarity have their weaknesses and strengths, as the researcher affects the field and the field affects the researcher (211). As I am familiar with the field “nursing home unit,” I had a partial insider position, understanding at least to some degree the actions of the caregivers and the way things worked in the nursing-home units. Knowing the medical jargon used by registered and auxiliary nurses and knowing the social structures in the nursing-home unit provided me with security when talking to the staff and the residents. This knowledge might have helped reassure the staff that I would not disrupt normal activities in the unit. There is also the chance that being familiar with the field would make me blind to important things that happened in the unit, potentially missing important aspects because I took them for granted or as normal occurrences in a nursing-home unit, while these may be things one should question. Having an outsider position, on the other hand, without an already established understanding of the field, might give a researcher a “clear mind,” but this could also result in misunderstandings (211) about what is happening in the field. Either way, the results are always colored by who and where we are and our relationship with the field.

Taking field notes during the observations and soon after, and later transcribing them, is necessary to preserve as much data as possible (described in section 6.7.2). A system of noting different sorts of verbatim exchanges in order to remember what kind of material each represents is important. During the observations, the level of engagement and mood in the residents and the interaction between the resident and caregivers and other residents were written down with codes for mood and type of activity, inspired by dementia care mapping the method (215). Mood and engagement were given a score between -5 and +5 in five-minutes intervals, and conversations and the setting were described. There should be rich descriptions of scenes and actions, dialogues, and experiences. After each observation, field notes were written and read in chronological order to get an overview of the day and were used as support and compared to the
interview material. Before the second observation and interview, the notes were reread to recall what the resident talked about and what happened in the unit the first time.

6.7 Analysis

6.7.1 Statistics papers: 1, 2, and 3
In papers 1, 2, and 3, statistical analysis was conducted using the SPSS (statistical program for social science) package, version 19. See also Table 7 for an overview of the statistical methods used.

Paper 1
In paper 1, categorical data were analyzed using a chi-square test. Because of the skewed distribution of continuous data, we used the Kruskal–Wallis test to assess differences between groups. Due to multiple testing, we considered a p-value <0.001 as statistically significant. A principal component analysis (PCA) with varimax rotation and Kaiser Normalization was applied to test the factor structure. The number of components was determined by evaluating the criterion of eigenvalues above 1 and examining the scree plot. Loadings greater than or equal to 0.4 were judged to be of significance. We repeated the PCA for two subgroups – those with a diagnosis of AD and those with dementia diagnoses other than AD.

Paper 2
In paper 2, distribution of each variable was examined by inspecting histograms, Q-Q and box plots. The continuous variables were fairly well normally distributed. Correlations were tested with Persons R and Spearman's rho. The Mann–Whitney U test or the Kruskal–Wallis test was used to test for differences between groups (demographics). For the linear regression analyses, we used CDR sum of boxes since this score can be treated as a continuous variable. We constructed three QUALID subscales based on the principal component analysis described in paper 1. Four linear regression analyses were carried out using the QUALID total score and each of the three QUALID subscale scores as the dependent variables. As independent variables, we used the items from the unadjusted analyses that were significantly associated with the four
dependent variables. Age and gender were included in all analyses. However, before we conducted these analyses, we checked for inter-correlations between the independent variables. As expected, the three NPI subscales correlated highly with the NPI total score (0.6 and above), and thus, the NPI total sum score was excluded from the analyses. Except for the scores on the PSMS and the CDR sum of boxes/CDR categorical score, which correlated highly (Spearman’s rho 0.60 and 0.51, respectively), no variables correlated higher than 0.5. We did the analyses using both the enter and the backward methods, and the results were almost identical.

In addition (not shown in paper 2), we conducted a path analysis and structural equation modeling using the total QUALID score and the total NPI score. A path analysis is a method employed to describe the contribution and strength of all the variables through the possible pathways (216).

Paper 3

In paper 3, distribution of each variable was examined by inspecting histograms, Q-Q plot, and box plots. The Mann–Whitney U test or the Kruskal–Wallis test was used to test for differences between groups (demographics). Paired sample t-test was used to compare the mean scores on the rating scales between baseline and follow-up. We checked for inter-correlations between the variables using Spearman’s rho. No variables except the QUALID total score and the QUALID subscale scores correlated above 0.5. After the preliminary analysis showing the distribution of the data and changes in the QUALID scores between baseline and follow-up (10-month follow-up – baseline), an unadjusted analysis of the associations between changes in the QUALID and various patient variables at baseline was performed. Thereafter, we constructed four linear regression analyses using the change in scores (the follow-up score subtracted from the baseline score) of the total QUALID score and each of the three QUALID subscale scores as the dependent variables. As independent variables, we used the items from the unadjusted analyses that were associated with the four dependent variables with a p-value < 0.2. Age, gender, and the baseline total QUALID and subscale scores were included in all analyses.

As a second step, we conducted another set of four regression analyses using the same dependent variables. As independent variables, we used the changes in the scores of the NPI-10-Q, the CDR, the PSMS, and use of psychotropic drugs. Age, gender, and the baseline total QUALID
and subscale scores were also included in these four analyses. We applied both the enter and backward method in the regression analyses. The results were almost identical, and we decided to report the results of the backward method.

Table 7. Overview of statistics used in papers 1, 2, and 3

<table>
<thead>
<tr>
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<th>Paper 1</th>
<th>Paper 2</th>
<th>Paper 3</th>
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</thead>
<tbody>
<tr>
<td>Histograms, Q-Q plots, and box plots</td>
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<td></td>
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<tr>
<td>Paired sample t-test</td>
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<td>X</td>
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<td>Chi-square test</td>
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<td>X</td>
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<td>Mann–Whitney U test or Kruskal–Wallis test</td>
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<td>with varimax rotation and Kaiser Normalization</td>
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<tr>
<td>Correlations (Pearson’s R and Spearman’s rho)</td>
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<td>X</td>
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<tr>
<td>Linear regression analyses</td>
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<td>X</td>
</tr>
<tr>
<td>Path analysis and structural equation modeling</td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

6.7.2 Transcription and analysis – paper 4

All but three interviews were transcribed by me (M. Mjørud). The last three interviews were transcribed by a consultant at the Norwegian National Advisory Unit for Ageing and Health. They were subsequently read while listening to the interviews in order to ensure that the transcriptions were correct. The analysis was done by the research group (Mjørud, Engedal, Røsvik and Kirkevold).

The transcription of field notes and interview material should be transparent, so other researchers can do their own analysis later.
Transcribing interviews

The interviews were audio-recorded and transcribed verbatim, meaning each word and sound was transcribed. As soon as the spoken words are written down on paper, it is no longer possible to hear the intervals between the words, the speed used when speaking or if a low or powerful voice was used (206, 211). In the transcription pauses in speaking were marked by dots on a line or using return-button to make space in the text. Long pauses were marked as (long pause). Crying was marked as (crying). During the interview situation, there is also the body language, which it is not possible to tape record.

Transcribing field notes

Transcription of the field notes was done as soon as possible after the observations, too prevent forgetting important details (211). The written material is what the researcher finds important and chooses to write down. Similar to the interviews, written field observation material differs from speech. Preferably there should be a system to distinguish between different sorts of observations, so that directly recorded verbatim exchanges can be distinguished from indirect quotation. In this study I tried to write down spoken words when they were said in order to get the correct wording. Physical descriptions of the rooms and lighting, interactions, activities and level of engagement in the residents were partly written down during the observations and with the codes (described in 6.6.2), and elaborated directly after the observations (211).

The analysis of interviews and field notes

The analysis of the interviews was based in text analysis as described by Ricoeur (217-219) with naïve interpretation, structured analysis and comprehensive understanding. The observations were not analyzed on their own but used as a support mechanism for the interpretation of the interviews because of the residents’ cognitive impairment and speech problems, as described by Klinke (220). First naïve interpretation was attained through reading the entire content of the interviews for an overall impression about life in the nursing home. Then, in the structured analysis, we conducted critical reading, which means that the text was broken down to meaningful units, and these units were compared to the observations. An example is the resident
sleeping through an activity (i.e. quiz) and, during the interview, saying that the activities in the NH are boring. By reading the interviews critically, a deeper understanding of the content is gained and similarities and differences across the interviews are discovered. An example is several residents talking positively about the primary nurse, and the observations confirming that the primary nurse is the one who most often talks to the resident during the observations. The meaning units are gathered into themes describing how the participants experienced living in the NH. After reflecting upon the themes, the interviews were reread to determine whether the emerged meaning units gave a new understanding of the material. The final themes were reflected upon in relation to the research question and the context of the study (comprehensive understanding) (218). The credibility of the final interpretation was secured through grounding of the meaningful units in the text through phrases from the respondents (213, 217) and by comparing the phrases with observations made in the unit. An example is the quote “the staff is annoying”, which was observed as staff moved wheelchairs without first telling the residents.

6.8 Ethical considerations
Both the quantitative and the qualitative study were approved by the Regional Committees for Medical and Health Research Ethics in South-East Norway, August 2011.

On one hand, many persons with moderate and severe dementia have reduced or no capacity to consent. Therefore, it is difficult to know if they want to participate in research, and research should be conducted only when the person included can consent to it (221). On the other hand, without research, persons with dementia will be offered fewer adjusted health care services and the care cannot be evidence-based. Not conducting studies can thus also be a questionable research practice (222, 223). In this study, the physician in the nursing home together with the head nurse decided whether or not the persons with dementia were able to give informed consent. If the person with dementia was able to consent, he or she was asked to give written informed consent or oral consent with witnesses present. The person’s relatives and the primary nurse were also informed. For those with dementia who were not competent to give informed consent, the closest relative was informed of the study and could refuse participation. Additionally, the persons with dementia were, before both the observation and the interview, informed of the aims of the observation and the interview and could at any time refuse participation. As described earlier, the interviews and/or observations were terminated if the person with dementia showed
any type of behavior indicating that he or she no longer wished to participate in the study, for instance, if the person told me to go away, seemed restless, or answered questions in an angry voice.

6.9 Abstracts of the four papers included

Paper 1: Principal component analysis of the Norwegian version of the Quality of Life in Late-Stage Dementia (QUALID) Scale (224)
Aims: To investigate which factors the QUALID scale measures when used among people with dementia in nursing-homes and to find how the symptom load varies across the different severity levels of dementia.

Methods: We included 661 PWD (Mean age +/- SD, 85.3 +/- 8.6 years; 71.4% women). The QUALID and the Clinical Dementia Rating Scale (CDR) were applied. A principal component analysis (PCA) with varimax rotation and Kaiser Normalization was applied to test the factor structure. Non-parametric analyses were applied to examine differences of symptom load across the three CDR groups.

Results: The mean QUALID score: 21.5 (+/- 7.1), and the CDR scores of the three groups were 1 in 22.5%, 2 in 33.6% and 3 in 43.9%. The results of the statistical measures employed were the following: Cronbach’s α of QUALID, 0.74; Bartlett’s test of sphericity, p <0.001; the Kaiser-Meyer-Olkin measure, 0.77. The PCA analysis resulted in three components accounting for 53% of the variance. The first component was “tension” (facial expression of discomfort, appears physically uncomfortable, verbalization suggests discomfort, being irritable and aggressive, appears calm, Cronbach’s α = 0.69), the second was “well-being” (smiles, enjoys eating, enjoys touching/being touched, enjoys social interaction, Cronbach’s α = 0.62) and the third was “sadness” (appears sad, cries, facial expression of discomfort, Cronbach’s α = 0.65). The mean score on the components “tension” and “well-being” increased significantly with increasing severity levels of dementia.
Conclusion: Three components of QOL were identified. QOL decreased with increasing severity of dementia.

Additional comments to paper 1:

Of the 11 items measured in the QUALID, 8 increased significantly with increasing CDR scores. The 3 that did not increase significantly were “appears sad,” “cries,” and “facial expression of discomfort.” The results of this study aligned with those of a Spanish study (similar results of the PCA) (191) and another Norwegian study (193), which found a comfort factor similar to the present well-being factor.

Paper 2: Variables associated to quality of life among nursing-home patients with dementia (104)

Objectives: To study which variables are associated with quality of life (QOL) in persons with dementia (PWD) living in nursing homes (NHs).

Method: A cross-sectional study included 661 PWD living in NH. To measure QOL, the Quality of Life in Late-Stage Dementia Scale (QUALID) was applied. Other scales were: the Clinical Dementia Rating Scale (CDR), the Physical Self-Maintenance Scale (PSMS), and the Neuropsychiatric Inventory Questionnaire (NPI-Q).

Results: The patients’ mean age was 86.9 (SD 7.7), 472 (71.4%) were women. Of all, 22.5% had CDR 1; 33.6% had CDR 2; and 43.9% had CDR 3. The mean PSMS score was 18.2 (SD 5.0), 43.1% lived in special care units, 56.9% in regular units. In a linear regression analysis, NPI-affective score (β=0.360, p value <0.001), NPI-agitation score (β=0.268, p-value <0.001), PSMS total score (β=0.181, p-value <0.001), NPI-apathy (β=0.144, p-value <0.001), NPI-psychosis (β=0.085, p-value 0.009), and CDR sum of boxes score (β=0.081, p-value 0.026) were significantly associated with the QUALID total score (explained variance 44.5%).

Conclusion: Neuropsychiatric symptoms, apathy, severity of dementia, and impairment in activities of daily living are associated with reduced QOL in nursing-home patients with dementia.
Additional results and comments for paper 2:

The results of the path analysis/structural equation modeling presented in Figure 3 show the strength of the variables through the possible pathways using the total QUALID score and the total NPI score. As can be seen, the CDR score has a direct effect on the NPS and the PSMS scores but does not have a direct effect on the QUALID total score. It is the NPS score that most strongly influences the QUALID score. This is in line with the results of the linear regression analysis, but we can see that the CDR score has a stronger influence on the QUALID score in the linear regression analysis compared to the path analysis, and that the path analysis gives a clear picture of the pathways. One reason for this slight difference between the path analysis and the regression analysis could be the use of the total scores in the path analysis and the use of the NPI subscales in the linear regression analysis.

Figure 3

Path analysis. The pathways between the CDR, PSMS, NPI, and the QUALID. The CDR score has an effect on the NPI score and the PADL score, but no direct effect on the QUALID total score. The NPS score influences the QUALID score.
Paper 3: Variables associated with change in Quality of Life among Persons with Dementia in Nursing Homes: A 10 Month Follow-Up Study (225)

Aim: To investigate variables associated with change in quality of life (QOL), measured by QUALID scale and three subscales; tension, sadness and well-being, among dementia patients in nursing homes.

Method: A 10 months follow-up study including 198 (female 156, 79%) nursing home patients, mean age 87 (s.d 7.7) years. Scales applied: quality of life in late stage dementia (QUALID) scale and three subscales (well-being, sadness and tension), neuropsychiatric inventory questionnaire 10 items (NPI-10-Q), clinical dementia rating (CDR) scale, physical self-maintenance (PSMS) scale and a scale of general medical health. Use of psychotropic medication, gender and age was collected from the patient’s records.

Results: Mean baseline QUALID score: 20.6 (s.d 7.0), follow-up score: 22.9 (s.d.7.4), mean change 2.8 (s.d. 7.4). QOL improved in 30.8%, were unchanged in 14.7%, deteriorated in 54.6% of patients. A regression analysis revealed that change in QUALID score was significantly associated with: QUALID baseline score (beta -.381, p-value .000), change in NPI score (beta .421, p-value .000), explained variance 38.1%. Change in score on wellbeing subscale associated with: change in PSMS score (beta .185, p-value .019), wellbeing baseline score (beta -.370, p-value .000), change in NPI score (beta .186, p-value .017), explained variance 25.3%. Change in score on tension subscale associated with: change in CDR sum-of-boxes (beta .214, p-value .003), change in NPI score (beta .270, p-value .000), tension baseline score (beta -.423, p-value .000), explained variance 34.6%. Change in score on sadness subscale associated with: change in NPI score (beta .404, p-value .000), sadness baseline score (beta -.438, p-value .000), explained variance 38.8%.

Conclusion: The results imply that a lower baseline score (better QOL) results in a larger change in QOL (towards worse QOL). Change in QOL is mostly associated with change in neuropsychiatric symptoms. In almost 50% of patients QOL did not deteriorate.
Paper 4: Living with dementia in a nursing home, as described by persons with dementia: A phenomenological hermeneutic study

Aim: To investigate the personal experience of living in a nursing home over time from the perspective of the person with dementia and to learn what makes life better or worse in the nursing home.

Background: Persons with dementia have described life in nursing homes as difficult and lonely. Persons with dementia often reside in nursing homes for several years; therefore, knowledge is needed about how their quality of life is affected in the nursing-home setting in order to be able to provide the best care possible.

Design: A hermeneutic phenomenological research design was applied.

Methods: Unstructured, face-to-face interviews and field observations were conducted with each participant twice, three months apart.

Results: The analysis revealed four themes: “Being in the nursing home is okay, but you must take things as they are”; “Everything is gone”; “Things that make it better and things that make it worse”; and “Persons – for better or worse? Staff, family, and co-residents.”

Conclusions: Persons with dementia are able to communicate their feelings and thoughts about their lives in the nursing home and can name several factors that have impacts on their quality of life. They differentiate between members of the staff, and they prefer their primary nurse. They are content with life in general, but everyday life is boring, and their sense of contentment is based on their acceptance of certain facts of reality and their ability to adjust their expectations.

Relevance to clinical practice: Health care leaders should provide guidance and education to staff that will enable them to gain insights into how their behaviors affect the everyday life and quality of life of persons with dementia living in nursing homes. Primary care nurses should be given the time necessary to plan and implement activities preferred by each person with dementia.
7.1 Discussion

The aim of this study was to explore the quality of life of persons with dementia living in nursing home through the use of two different methods: quantitatively with the QUALID scale and qualitatively with observations and interviews.

First, the QUALID scale was used to measure quality of life in persons with dementia by proxy. The results are described in paper 1-3. The first question that should be discussed is whether this scale measures health related quality of life or general quality of life in persons with dementia, and if it is possible to incorporate self ratings of QOL in quality of life measures like QUALID. Further, the discussion will focus on each item and the components found in the PCA (paper 1) and what affects and change QOL as measured by QUALID over time (paper 2 and 3), and how this compares to the results from the interviews (t) and to theories and definitions of QOL.

The second part of the discussion will focus on whether persons with dementias have the ability to report on QOL. This is of importance because information on quality of life and living in a nursing home was collected through observations and interviews with persons with dementia living in nursing homes as described in paper 4. The results will be compared to earlier studies, to theories and definitions of QOL and the theories on coping and aging.

7.2 Is the QUALID a health-related quality of life instrument or a general quality of life instrument?

It is difficult to determine whether the QUALID scale is a general quality of life scale or a health related quality of life scale. The type of QOL is rarely specified nor is the concept of QOL theoretically explained in research papers. The paper by Weiner and colleagues that presented the scale use the term quality of life consistently through the text, but the scale is also defined as “an instrument for use in the assessment of clinical management and treatment effects on QOL” (190), which would indicate it is a HRQOL scale.
Health-related quality of life scales focus on how medical or nursing treatments influence diseases or illnesses (134). This can be any sort of treatment, for instance, drug therapy, surgery, or nursing care provided to (nursing home) patients. One could argue that any QOL measure used for this population in NH would be a health-related QOL measure because persons with dementia living in NH are dependent on nursing care. The results from the measurement should be used to evaluate and improve the care provided. Living with a chronic disease such as dementia, however, affects all parts of life. The person with dementia is dependent on others for help; he or she loses the ability to communicate with others and loses his or her autonomy, becoming more or less helpless. These losses will, in turn, lead to a poorer social life and often to depression, anxiety, and a feeling of loneliness. Thus, it is difficult to understand how “only” the dementia disorder will influence QOL, as all aspects of life are affected by a dementia disorder. For this reason, it is probably necessary to measure general QOL, and thus the question arises of whether the use of the QUALID captures all aspects of (general) QOL or only health-related aspects of QOL. I suggest that we do not know the answer to this question.

7.1.2. Would it be possible to incorporate persons with dementia’s self-report on QOL in QUALID?

One could argue that since dementia is caused by a variety of incurable (at least presently), progressive diseases, the person with dementia will constantly experience new losses and impairments, and it will be difficult to master and learn to live with the disease. Self-reporting of QOL will increasingly be poorer and poorer and, eventually, will likely become invalid (3). On the other hand, most studies comparing proxy- and self-reported information on QOL find that the proxy informant almost always rates QOL in the person with dementia as poorer than the person’s own perception of his or her QOL (9, 10). Perhaps the person with dementia learns to live with the disease, constantly adjusting to the progression of impairments, as described in the literature on coping (5, 151), and thereby has a better life and QOL than the proxy assumes. Further, by evaluating the interviews in paper 4, one could argue that the interviewed persons with dementia used reminiscence as a coping strategy. Stories from their own lives, combined with pictures from events in their lives, were used to remember what their lives were like and to describe who they were and what they used to do. Approximately half of the informants with a dementia disorder knew why they were in the nursing home and they talked about dementia—
“it is something in my head.” Perhaps holding onto the past helped them to deal with their present situation in the nursing home. In that case, self-reported QOL would be important to incorporate in the measurement of QOL. But it could also be that a person with dementia has poor insight into his or her own impairments and, therefore, rates his or her own QOL as better compared to a proxy’s experience.

The QUALID scale focuses solely on behavior that can be observed and is dependent upon the rater’s perception and evaluation of observable behavior in the person with dementia. The QUALID scale does not focus on the person with dementia’s own perception or awareness of the situation. All items (or questions to the rater) are based on behavior that is possible to observe in the patient, regardless of the patient’s communicative abilities. This means that, even though the family caregiver has no competence regarding dementia or the professional caregiver has no competence regarding dementia or knowledge of the patient, it is possible to rate QOL according to QUALID. We will argue that it would be possible to add the person’s self reported QOL to the proxy observation. At least for the items of the well-being factor (from the PCA, paper 1), we could ask the person with dementia about the same behavior, for example if he/she usually enjoys the meals, if he/she likes to be touched, if he/she likes to spend time with fellow residents in the unit, if he/she often cry, and so one. Of course, not all persons with a severe degree of dementia would be able to give valid answers to all kind of behaviors, but as experienced in the interviews of paper 4 and what is found in other qualitative studies, many persons with dementia of a moderate and severe degree can give valid answers about what they feel (131, 132, 165, 176).

In the following, the QUALID items and components found in the principal component analysis, paper 1, will be discussed.

7.3 The QUALID scale – sadness, tension, and well-being – paper 1
The principal component analysis conducted in the first study, showed that the QUALID holds three components, called sadness, tension and wellbeing (224). This result was identical to an earlier PCA of the QUALID scale done by a Spanish research group (191) on the same type of persons with dementia. The “wellbeing” component was identical with an earlier Norwegian study by Barca and colleagues (193), which is a strong indication for this component’s stability.
Whether these three dimensions are truly dimensions of QOL is, however, uncertain. The original QUALID and the Norwegian version of the QUALID are added to the manuscript; see the appendix.

7.3.1 Sadness
The first component is called sadness. The items or symptoms measured in this component are crying, appearing sad, and having a facial expression that suggests discomfort. Sadness is a symptom of depression (226, 227) and one could argue that this component and these items are truly symptoms of depression. Both proxy-based and self-report-based QOL scales find that depression is associated with reduced QOL (169, 184, 228). Still, evaluating each item and the possible answers (see appendix) makes one wonder whether the caregiver ratings are correct. Two of the possible answers for the item “crying” are that a patient can be crying “for no apparent reason” (option 4 or 5). Is it normal to assume that a person with dementia cries for no (apparent) reason? Not knowing the reason why the person with dementia cries is not the same as there not being a reason to cry. And if the caregiver knows that the person with dementia is depressed and hence cries, how would they rate crying? Option 2 or 3 focuses on a response to something that happens in the environment, an external stimulus. This could be, for instance, falling and getting hurt, or because a fellow resident in the nursing home has assaulted her, or a family member leaving after a visit. In such a case, one can question whether option 2 or 3 of the QUALID is a measure of poor QOL. The same problems arise by rating the item “appears sad”, where the caregiver again is asked to score behavior that arises for no apparent reason.

We would argue that the sadness component is a dimension that, at least to some degree, affects QOL, as it measures symptoms of depression. Yet in some cases, it could also measure a sad event that anyone would react to with sad feelings, even crying.

7.3.2 Tension
The next component we called tension. It included the items “appears physically uncomfortable – squirms, writhes, frequently changes position”; “makes statements or sounds that suggest discontent, unhappiness, or discomfort (complains, groans, screams)”; “is irritable or aggressive (becomes angry, curses, pushes or attempts to hurt others)”; and finally, “appears emotionally calm and comfortable.” The principal component analysis also included the item facial expression of discomfort, described in the sadness component. See the appendix about possible
responses to the items. As for the sadness component, it is difficult to decide if it measures QOL only. The tension component contains symptoms that can be seen as NPS. Numerous proxy-based studies have found that neuropsychiatric symptoms are associated with QOL in PWD (78, 229, 230). This was also the result reported in papers 2 and 3 (104, 225) and the path analysis conducted for paper 2.

In most studies, the same proxy reports both NPS and QOL. Could it be that caregivers’ reports on QOL are influenced by the observation of NPS and the caregivers’ evaluations of the symptoms? This is likely because no association has been reported between proxy-reported NPS and self-reported (person with dementia) QOL (9, 10). An illustration of this is, for instance, two situations reported in paper 4 where 1) a nurse enters the room without knocking, and this irritates the person with dementia, and 2) a resident describes how the primary nurse’s “hands are so strong, I don’t have to scream, but . . . .” Such caregiver behavior is probably not intentional, but it may anger or frustrate the resident that the caregiver does not understand the cause of the resident’s feelings; hence, the caregiver might rate the person with dementia as angry or irritated without recognizing what led to such behavior, i.e., the caregiver’s own actions or words (response options 4 and 5). Kirkevold et al. found that neuropsychiatric symptoms and impaired ADL were factors associated with reduced quality of care (108). Regardless of the reason for anger or irritation, the PWD will have negative feelings and, thereby, poorer QOL. His or her QOL, however, would not be as poor if the care provided were better.

As discussed earlier, the wording in the response options is not clear and can be misunderstood. We will argue that most behavior in a person with dementia has a meaning. Accordingly, in the item concerning “statements or sounds that suggest discontent, unhappiness or discomfort,” the option for answers states that it is possible to complain and scream without cause (option 4 and 5). There are several reasons why the two items in particular, “having an agitated and irritated behavior” or “making sounds that suggest discomfort,” can be misinterpreted. One is related to the person’s cognitive impairment, such as impaired speech and vocabulary, aphasia, or cognitive impairment leading to impaired understanding and general misinterpretation of what is happening in the environment. Another reason is the under-diagnosis of pain in persons with dementia; since the person cannot articulate his or her pain, pain-related behavior may be misunderstood by the caregiver as meaningless behavior (73, 231). Further, it is quite common for older people to have
sensory problems such as auditory and vision impairments and for this reason, to become irritated when they are unable to hear or see what is going on. In addition, it is a normal, healthy reaction to protect oneself or react in some way when something we do not understand is happening to or around us, scares us or makes us angry. Hence, if a person with dementia doesn’t understand what is being said or what is happening, if he or she becomes scared, angry, or frustrated, his or her behavior is normal, even if the caregiver doesn’t understand the behavior or evaluates the behavior as meaningless. As Næss writes, QOL is a term tied to the person’s experiences and internal condition, and being in pain or being scared, angry, or frustrated repeatedly are negative feelings that, in turn, have a negative impact QOL, and this is measured with the QUALID scale.

In the care philosophy of person-centered care, it is a prerequisite that all behavior has meaning and a reason (113). Crying and looking sad, as well as irritation and agitation, are behaviors that mean something; they indicate that the patient is not at ease and may be feeling sad, depressed, or angry; as a result, he or she has poor QOL. Persons with dementia living in nursing homes experience many losses. The informants described in the interviews how they felt that everything was gone (paper 4). This experience is not “no apparent reason”; it is a very understandable and good reason for feeling sad. However, if the health care staff in the nursing home lacks knowledge about both the person with dementia and the dementia disorder, this might lead to misunderstanding when the PWD tries to communicate. In addition, most nursing homes do not have arenas for the discussion and planning of person-centered care; some have a task-centered care approach instead. Practicing PCC could help the staff to better understand the residents’ behaviors and thereby improve their QOL, in turn decreasing their depressive symptoms, which was shown in the RCT by Rokstad and Røsvik (78).

7.3.3 Well-being
We assume that the third component in QUALID, well-being, measures QOL. The items of this component rate smiles, social interaction, touching, and enjoyment during meals. These items can be difficult for nursing-home patients to initiate themselves, and thus caregivers will not observe such behavior often. For instance, the items “enjoys touching/being touched” and “enjoys interacting or being with others” could be difficult to measure accurately. Engaging in interaction, for instance, conversation, when you have problems speaking is difficult. Another issue is the ability to move. If you are confined to a wheelchair or have problems with
orientation, you might not be able to move around the way you would like to in order to find the people you prefer to be social with. Hauge et al. found that nursing-home patients who were able to fled the common areas as soon as they could (107). Even though the persons included in Hauge’s study did not have dementia (at least not moderate or severe dementia), the same issue arises as in the present study. Who decides where you should sit and who you should spend time with? As Byrne-Davis’s study (5) showed, persons with dementia are able to reflect upon social relationships, activities, and what makes them happy. Again, the care environment and social relationships seem important for rating QOL.

The focus on behavior that is dependent on cognitive abilities, such as initiation, reflects the cognitive aspects addressed in most QOL definitions (3, 137) and may explain why proxyratings of QOL show that level of cognition influences QOL.

The item “enjoys touching” is very much dependent upon the way this is done. A person with severe dementia will not necessarily understand what is happening if a familiar caregiver strokes her cheek and then runs off in a hurry. A caregiver sitting down next to the person with dementia, showing that he or she wants to spend time with the person, could be what the person with dementia needs, even if he or she has never met the caregiver before. Again, the wording in the rating options for these items depends on the caregiver reflecting upon the ability of the person with dementia to interact and move around as he or she pleases. But, as argued earlier, regardless of the cause, the feelings of the PWD are the same, and feelings are related to QOL.

Another item in the well-being component is the smile item. This item differentiates between “smiling spontaneously” (option 1) and smiling “only in response to external stimuli” (options 3 and 4). What the difference is between these two, if there is a difference, and whether the caregiver knows the difference are all uncertain. Does smiling “spontaneously” mean smiling because of happy thoughts? As described by Næss, QOL is to have a core of happiness (4), and spontaneous smiling is probably a sign of this. If it is, it is a sign of good QOL and some happy thoughts, but how often does one smile alone without “external stimuli”? Is it a sign of good QOL if you smile the few times a day the primary nurse says hello to you, but never smile during the rest of the day? If the caregiver rates the QOL as high because she sees you smiling when she is present and does not see that you are sad when she is away, is QOL good?
A third item in the well-being component is “enjoys eating.” Given the QUALID Scale’s focus on behavior, does “enjoy eating” mean that if you sit quietly and eat your food during the meal, that you enjoy eating? A problem with this item is the cultural understanding of enjoying a meal. Some will interpret this as enjoying the food, whereas others will interpret this as enjoying the social situation around a common meal with small talk.

In conclusion, supported by Lawton’s theory regarding observations and evaluations of behavior (3), we suggest that the QUALID is a measure of QOL because it measures behaviors, regardless of their cause. However, several of the possible rating alternatives can be misinterpreted by the proxy, especially the alternative “for no apparent reason.” A high score indicates that something is not right, and that the person with dementia is struggling with something. Even if the caregiver does not know or think that the behavior has a reason, she can still rate the behavior because it is something she can see, and the rating is not dependent on the person with dementia being able to talk. To rate QOL accurately and to avoid the pitfalls of using this scale, it is important for the rater to have knowledge about dementia and how communication problems in persons with dementia influence their behaviors. It is also important to know what is going on in the environment where the PWD lives. We suggest that a proxy using this scale should be trained in order to avoid misinterpretations. We further suggest that the QUALID could be used to measure changes in behavior.

7.3 How does the QUALID score vary with dementia severity?
The other result reported in paper 1 is the variety in QUALID scores across the different CDR stages, both on single items and on the three components. Both the tension and the well-being component scores increase (indicating poorer QOL) significantly with increasing severity of dementia (CDR 1 to CDR 3). The sadness component does not. Comparing this result to Table 2 in paper 3 (proportion of change in scores on the total QUALID score and the three components), we see the same result that the sadness score does not worsen over time. Both the tension and the wellbeing scores do. One reason why the sadness component does not vary is that this component probably also is a measure of depression. As seen in a study by Barca et al., the score of the mood component (sadness) of the Cornell Depression Scale did not differ between the various CDR scores, whereas all other symptoms (behaviors other than mood) of the Cornell Depression Scale
were associated with the severity of dementia, including the symptoms that measure behavior such as agitation and aggression (59). Another study by Selbæk et al. also showed that the affective component of the NPI scale did not change much over time as dementia progressed, whereas this was the case for agitation (40). We previously concluded that the component tension of the QUALID is closely related to challenging behavior such as agitation and aggression.

The fact that well-being decreased with increasing severity of dementia indicates that QOL will worsen by severity of dementia. But this is not the case for all persons with dementia who were included in our study. The second paper focused on variables that affect QOL in PWD, and the third paper focused on variables that affect a change in QOL over time (104, 225). The results in papers 2 and 3 aligned with other proxy-based QOL research. In approximately half of the persons with dementia, the total QUALID score increased over time, meaning that QOL worsened. However, studying the separate components (Table 2 in paper 3), we see that almost 22 percent of the persons with dementia get a lower (meaning better QOL) score on the well-being subscale and almost 34 percent have no change. So, the conclusion that we just made claiming that QOL will worsen by severity of dementia is in our study true for about half of the patients. Better QOL ratings at baseline and a change in severity of NPI scores resulted in a larger change in QOL over time (as reported in paper 3) (225). Learning to live in the nursing home, by getting necessary help to conduct ADLs and addressing medical needs, getting enough food and not being alone, are some probable reasons why well-being can increase.

We do not know how coping mechanisms in the PWD influence on increased or decreased QOL as we did not apply any coping measurement in our study. Neither did we include any measurements of awareness in our study, but Clare and colleagues found that at least in early stages of dementia, awareness is stable and it should not be assumed it will decrease. Even though the neuropsychological functioning declined, Clare and colleagues found that self-ratings of depression, anxiety and QOL remained stable (129).
7.4 What affects and changes QOL over time? Papers 2, 3, and 4

As there is a difference in results in studies using proxy- and self-reported information, and we do not really know what the phenomenon QOL means to each person or what affects and change it, we have to study the results we have and try to explain them by use of theories on QOL and coping, what affects nursing care, and how and why the proxies rate the way they rate.

7.4.1 By proxy – papers 2 and 3

Paper 2

The results in paper 2 showed that the QOL was worse among the youngest and the oldest patients. Further, severity of physical illness, dementia and impairment in ADLs and number of NPS all affected QOL in the PWD. According to Lawton, QOL is the same in persons with dementia as in persons without dementia and is dependent on “competent cognitive functioning, the ability to perform activities of daily living and to engage in meaningful time use and social behavior” (3). The results in paper 2 align with this definition; the more impairment in ADL and cognitive decline, the worse QOL a person will have. A problem with the definition is the focus on competent cognitive functioning. It stresses the importance of cognitive abilities that our society values highly. In contrast, Kitwood stresses the importance of being seen and treated as a person with feelings, and not base the value of a person on his or her cognitive abilities.

Age is usually not found to be associated with QOL (9, 10), but one study found that younger PWD had worse QOL (228). The association between age and QOL could perhaps be explained by the youngest persons becoming depressed because they have a serious disease at a young age, and the oldest persons have many comorbidities and greater impairments in ADL. Coping theories, however, can describe how persons can compensate for increasing impairment and focus on those things they are still able to do, and hence still be able to rate their QOL as good (157, 160, 161). This could be one reason for why QOL did not decrease in about half of the patients at 10 months follow-up. However, as we did not use any measure of coping we do not know if this is true.

The Well-being subscale is associated with the total score of PSMS (paper 2/table 3). Impairment in ADL is often found to be associated with QOL in proxy based studies, and ADL abilities are as well often incorporated into QOL definitions (3, 142). The interviews (paper 4) revealed some
awareness in the persons with dementia regarding receiving necessary help to conduct basic ADL. They appreciated the help they received, because many understood they could no longer live at home and they saw the help as necessary. The residents felt safe that someone looked after them, however a few also talked about the importance of being as independent as possible. This result shows that the care environment is very important. This could mean that if the care provided fits with the likes of the person with dementia, it does not necessarily mean receiving help to conduct ADL will lead to decrease in QOL.

Paper 3

In paper 3 we looked at how the QOL scores change over time and the percentage of patients having improved, unchanged or worsened score on the QUALID scale at follow-up (table 2). We also studied the variables associated with changes in the QOL scores. For the change in QUALID total and the change in the wellbeing component, only the baseline scores were significantly associated with changes. For change in the tension component, the tension baseline and change in CDR score were significantly associated with change. For change in the sadness component, only baseline sadness score and type of ward were significantly associated with change. The PWD living in SCU deteriorated more in QOL compared to those living in RU. For all the dependent variables, a lower baseline score gave a larger change, meaning worse QOL over time in the nursing home. This result could be explained by regression to the mean, and a floor and/or ceiling effect of the scale. However, we did control for other variables. As also discussed in the paper coping styles, awareness of disease and life expectations might as well influence on the QOL.

7.4.2 Descriptions by the person with dementia – paper 4 - what affects and change QOL over time

As described in paper 4, four themes emerged from the interviews. These were “Being in the nursing home is okay, but you must take things as they are”; “Everything is gone”; “Things that make it better and things that make it worse”; and “Persons – for better or worse? Staff, family, and co-residents.”

Most of the PWD were aware of their situation and were able to describe feelings and thoughts about their everyday lives in the nursing home. Even when it was difficult to understand the resident because of aphasia or very slow or soft speech, the transcripts showed that the replies
were coherent. Answers and themes were repeated during both interviews, and we found agreement among the answers between the two interviews. Hence, we conclude that at least some persons with dementia of a moderate and severe degree are able to give valid answers about their experiences of living in NHs. This has also been found in other studies (110, 111, 132).

The residents talked positively about the staff, particularly the primary nurse, and said they get the practical help they need. This makes them feel safe. But they also described the staff as absent and sometimes hard-handed and rude. As described in the paper, this was confirmed during observations, as staff was difficult to find, moved wheelchairs without asking the patient, and entered private rooms without knocking first.

The residents focused on their losses during the interviews. Coping strategies (150, 156) were visible in several of the interviews, as also described by Byrne-Davis (5). The residents compared themselves to other residents in the ward and said that at least they were not as bad off as other residents. The residents clearly had awareness in several domains regarding their situation in the nursing home, as also described in several other studies (127, 128, 132).

The awareness the residents showed highlights the need for an increased focus on how the care environment affects QOL. One particular situation from the observations illustrates how important caregivers’ behaviors are:

The resident had severe dementia and could not answer questions asked during the interview. However, when the primary nurse entered the room without knocking, the resident’s feelings were triggered and when the nurse left, she described her thoughts on the behavior of this nurse in a very reflected way (quote): “You know, I got so mad at her, but I thought I should behave so she doesn’t go around telling everyone I answered her.”

The residents said they were content, that the nursing home was as good a place as it could be, and that one could not expect more. However, they also said they had to accept how things were done. This is in line with the study by Nelis and colleagues, who found that unawareness was related to cognitive decline but not to social relationships (124). The acceptance of the situation in the nursing home is dependent upon the ability to balance positive and negative aspects of living there, as also described in aging theories where the person uses coping to achieve the best possible outcome (151, 157). The quote above is an example of a resident adjusting her behavior.
so the nurse will not think ill of her and not talk about her. The resident evaluates her own conduct to achieve something she sees as positive. This is in line with the quality of life definition from the WHO, which notes a person’s “perception of (their) position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (137). All the residents included in the study were well aware that they were not home, and some understood that it was necessary to be in a nursing home. They talked about expectations related to nursing homes and said that the nursing home was as good as could be expected.

All the interviewed persons expressed satisfaction with morning care, meals and medication. This is in line with earlier studies of how basic care is provided in Norwegian nursing homes (107, 108).

As also described in other studies (111, 175), the residents were lonely; they missed their families and their past lives and hobbies. The persons with dementia expressed boredom, not enjoying the activities provided in the nursing home and they were observed sleeping through the day. This is also in line with results from an earlier Norwegian study (108). These results are interesting compared to the results of paper 3, where apathy were the variable strongest associated with the wellbeing subscale (paper 3/table 5). Could some of the apathetic behavior be a result of boredom, loneliness and difficulties in initiation? As described by Lawton, quality of life is dependent upon “competent cognitive functioning, the ability to perform activities of daily living and to engage in meaningful time use and social behavior” (3). He also says that “more cognitively impaired patients do not introspect”. The residents all have dementia, they need help to perform ADL, they think the activities in the nursing home are boring and they need help to engage in meaningful time use and they do not care about the other residents. If they do not get tailored help to conduct the activities needed to maintain good QOL, this could possibly be one reason why many persons in NH are depressed. Even if the cognitive abilities to communicate feelings and thoughts are impaired due to dementia, the feelings of loneliness, loss and depression linger in the person. As Lawton says, we have to rely on observations. However, the person with dementia still feels that something is wrong and hence introspect. We suggest that at least some persons with dementia of moderate or severe degree have the possibility to be introspective, which disagrees with Lawton (3).
7.5 Did the persons with dementia talk about the items rated by the QUALID?
In the following section each QUALID item will be discussed within the component from the PCA (paper 1).

7.5.1 Sadness
The component “sadness” is difficult to rate due to the wording in the response options. The item “sadness” was talked about in the interviews, but the word “sad” was rarely used. The residents talked about being lonely and bored, and one said she “is nothing” (paper 4).

The item “cries” was apparent several times, as several of the residents cried during the interviews. One said she cried a lot. It is not known if crying occurred frequently or if it was the interview situation that was disturbing and the questions provoked emotions they preferred not to talk about.

The item “having a facial expression that suggests discomfort”: Discomfort was not a feeling the residents said anything about. However, they often slept or sat for long periods of time staring down at the floor during the observations.

7.5.2 Tension
The item “aggressive or irritated” was mentioned by the residents during the interview; they gave good reasons for feeling this way, and it was never without cause.

None of the other items in this component, “appears physically uncomfortable,” “makes statements or sounds that suggest discontent,” and “appears emotionally calm and comfortable,” illustrates themes the residents talked about. Of course, there were times when the person with dementia made sounds that suggested unhappiness, such as crying, or when he or she did not appear emotionally calm, also crying.

7.5.3 Well-being
The first item or behavior the QUALID asks for is smiling. The residents were not asked whether they smile, but instead if they thrived in the nursing home. They all replied that they were content in the nursing home and that they accepted certain realities (see paper 4).

The QUALID scale rates social contact and whether the resident initiates this as a sign of positive QOL. The interviews revealed that the residents feel neither friendship nor connected to the other
residents. The residents expressed that they like the caregivers, but the caregivers are often absent. Therefore, this QUALID item may give the wrong impression regarding QOL. Rating residents who are able to leave the common areas because they do not want social contact is not easy using QUALID. Also, the residents, who reported feelings of loneliness and missing family members, are difficult to rate using the QUALID. It is possible to feel lonely without being alone, and the QUALID does not ask explicitly about feelings of loneliness.

As described earlier, the item of enjoying and initiating touching is also difficult to rate accurately. Only one resident mentioned this during the interviews, when she said she enjoyed getting a hug from her husband: “then the day is saved” (quote from paper 4). None of the interviewed persons talked about the primary nurse or another nurse giving them a hug or a stroke on the cheek. However, it is possible that these happened but the person with dementia did not recall such occurrences during the interview. Another issue is that not all people are used to or enjoy touching/hugging; hence, rating this item accurately depends upon the caregiver knowing the patient well.

It would be nice to have an instrument that combines both proxy- and self-rated QOL. Rather than trusting proxy-based scales solely, it would probably be more useful to conduct several qualitative interviews with the persons we want to know something about and/or to conduct field studies, for instance, using dementia care mapping, to get a more or less objective view of what life in the nursing home is truly like.

8.0 Conclusion
The question asked in the beginning of the discussion, whether the QUALID captures all parts of (general) QOL or only health-related QOL, is still difficult to answer. With the QUALID Scale, the caregiver measures behaviors that tell us something about feelings in the person with dementia. However, there are several methodological pitfalls related to the use of QUALID, and to complete the scale accurately, the caregiver must know the person with dementia and have comprehensive knowledge about dementia.

The PCA reported in paper 1 resulted in three components or subscales of the QUALID, called sadness, tension, and well-being. The subscales likely provide knowledge about the different
dimensions of quality of life measured by the QUALID scale. Using the total score and the three subscales in further analyses (papers 2 and 3) provided knowledge about how different variables are associated to proxy-rated QOL. Particularly, neuropsychiatric symptoms such as agitation, apathy, and psychosis, but also impairments in activities of daily living and cognitive impairments are associated with baseline and changing scores on the QUALID. The QUALID total score and the score on the well-being and tension subscales increased with increasing CDR score, meaning that QOL decreased.

The interviews showed that persons with dementia are able to report on their feelings and thoughts about what life is like in the nursing home and that they can tell what makes life better or worse in the nursing home. They are content, but this is based on their acceptance of their situation. They are also lonely and miss their old lives.

9.0 Methodological considerations
The term quality of life is difficult to grasp; it includes several dimensions and is affected by many different variables. We believe that it is not possible to cover all dimensions using one scale, and maybe Lawton is right in his suggestion that the use of measurement of observable behavior that breaks with normally accepted behavior and demonstrates stress in the patient is enough to rate QOL. However, the interviews showed that the persons with moderate and even severe dementia could express feelings and concerns regarding life in the nursing home and the care they received. As the staff is often absent from the common areas, it must be difficult for them to know about all the factors that interfere with the residents’ lives in the NH and their QOL. We did not include level of education of the staff or size of units in the analysis. This could perhaps have provided some information about whether staff education is a factor that could influence a proxy’s ability to recognize and understand signs of QOL and symptoms of dementia in patients.

Another consideration is the amount of time spent in the nursing home with the residents. If more time had been spent in the nursing homes, perhaps during weekends and evenings, this might have provided a more-nuanced description of life in the nursing home.
Another limitation is the residents included in the interview study. Most could communicate fairly well, and 10 of the 12 were women of approximately the same age who had lived most of their adult lives in Oslo. This may have influenced how they perceived and coped with life in the nursing home.

The residents included in papers 1, 2, and 3 were invited to participate in the RCT on PCC by Røsvik and Rokstad, and for paper 3, we used those randomized into the control group. They are representable for nursing-home residents in Oslo (78).

10.0 Clinical implications and proposals for future research

The PWD included in paper 4 were, to a large extent, aware of their situations in the NHs. We suggest that many persons with moderate dementia as well as some with a severe degree are able to give valid answers about their experiences of living in NHs and about their QOL. Future research should focus on how to have both proxy information about QOL and self-rated information incorporated in one scale, as done in rating anxiety symptom in persons with dementia.

Future research should continue to study how quality of life in persons with dementia evolves or changes over time and should incorporate measures of coping to examine how coping strategies influence QOL as dementia progress. Further, studies should also examine how different methods of person-centered care could improve QOL. It would also be interesting to study how improvement in QOL might influence work satisfaction and task-prioritizing of caregivers and the workplace culture.

Measures should be taken to help patients with decreasing QOL to maintain an acceptable level of QOL. As apathy was the variable that most strongly affected the well-being subscale, it would be interesting to see how activities tailored specifically for the reduction of apathy would affect QOL and especially the well-being component of any QOL measurements. The clear statement from the PWD that life in the NH is boring calls for action by leaders in NHs and municipalities regarding the tasks that health care staff should conduct and whether more guidance and training in dementia care would be beneficial.
The staff needs knowledge of the important role they play regarding the everyday life and QOL of the PWD. Particularly, the role of the primary nurse should be strengthened through guidance and education, as a positive relationship between the resident and the primary nurse may enhance the possibility for a good life in the NH and reduce feelings of loneliness. If the primary nurse has knowledge of the resident’s likes and dislikes, and knows how to use this knowledge practically, it is easier to tailor activities to the interests and needs of the resident (232).

Another important issue that should be given increased attention in clinical practice and health care education is the person with dementia’s ability to perceive what is happening around him or her and the ability to verbally address this.
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APPENDIX

Original US version of QUALID
The QUALID is administered in interview format to an informant following the instructions below.

Informants may be either a family member or professional caregiver who by having regular contact is familiar with the subject’s general behavior. Informants must, in addition to being familiar with the subject, have spent a significant portion of at least 3 days out of the last 7 days with the subject, in order to accurately rate the items on the scale. The scale is scored by summing the responses. The possible scores range from 11 to 55, with 11 representing the highest quality of life.

The final items on the scale require that the interviewer make a judgement about the validity of the interview. Provide both a rating of the overall quality of the interview, which includes the informants ability to understand the items and responses and the effort the informant put forth in answering questions, and the familiarity of the informant with the subject. These items are not included in the score, but offer information about the validity and usefulness of the ratings for that subject.

Informants are handed a blank copy of the scale so that they may look at the items as they are read aloud, and the following instructions are given:

I want to ask you some questions about name’s quality of life. I want you to rate his/her behaviors using the responses under each question on this page. (point to the responses on the first question) There is no one right or wrong answer, I just want to know how you would rate his/her behavior from your observations.

Specifically, I want to know about his/her behavior over the past week only, not how he/she previously behaved. Remember that your answers should reflect his/her behavior over the past seven days. If you are not sure what the question means, you can ask me about it. If you have difficulty choosing a rating for an item, just make your best guess. Again, indicate your observation about his/her behavior over the past week.

Which response best describes _______ over the past week…

A. [S] smiles
   1. spontaneously once or more each day
   2. spontaneously less than once each day
   3. only in response to external stimuli; at least once each day
   4. only in response to external stimuli; less than once each day
   5. rarely, if at all

B. [S] appears sad
   1. rarely or never
   2. only in response to external stimuli; less than once each day
   3. only in response to external stimuli; at least once each day
   4. for no apparent reason less than once each day
   5. for no apparent reason once or more each day

C. [S] cries
   1. rarely or never
   2. only in response to external stimuli; less than once each day
   3. only in response to external stimuli; at least once each day
   4. for no apparent reason less than once each day
   5. for no apparent reason once each day or more
QUALITY OF LIFE IN LATE-STAGE DEMENTIA (QUALID) SCALE ©

D. [S] has a facial expression of discomfort - appears unhappy or in pain (looks worried, grimaces, furrowed or turned down brow)
   1. rarely or never
   2. less than once each day
   3. at least once each day
   4. nearly half of each day
   5. most of each day

E. [S] appears physically uncomfortable –he/she squirms, writhes, frequently changes position
   1. rarely or never
   2. less than once each day
   3. at least once each day
   4. nearly half of each day
   5. most of each day

F. [S] makes statements or sounds that suggest discontent, unhappiness or discomfort (complains, groans, screams)
   1. rarely or never
   2. only in response to external stimuli; less than once each
   3. only in response to external stimuli; at least once each day
   4. without cause less than once each day
   5. without cause once or more each day

G. [S] is irritable or aggressive (becomes angry, curses, pushes or attempts to hurt others)
   1. rarely or never
   2. only in response to external stimuli; less than once each day
   3. only in response to external stimuli; at least once each day
   4. without cause less than once each day
   5. without cause once or more each day

H. [S] enjoys eating
   1. at most meals and snacks
   2. twice a day
   3. at least once a day
   4. less than once each day
   5. rarely or never

I. [S] enjoys touching/being touched
   1. almost always; almost always initiates touching
   2. more than half the time; sometimes initiates touching
   3. half the time; never initiates touching, but doesn't resist touching
   4. less than half the time; often or frequently resists touching/being touched
   5. rarely or never; almost always resists touching/being touched
## QUALITY OF LIFE IN LATE-STAGE DEMENTIA (QUALID) SCALE ©

<table>
<thead>
<tr>
<th>Quality of Life in Late-Stage Dementia (QUALID) Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name (L, F, MI)</td>
</tr>
<tr>
<td>Date (M/D/Y)</td>
</tr>
</tbody>
</table>

**J.** [S] enjoys interacting or being with others
1. almost always; almost always initiates interaction with others
2. more than half the time; sometimes initiates interaction with others
3. half the time; never initiates interaction, but doesn't resist interaction with others
4. less than half the time; often or frequently resists interacting with others
5. rarely or never; almost always resists interacting with others

**K.** [S] appears emotionally calm and comfortable
1. most of each day
2. more than half of each day
3. half of each day
4. less than half of each day
5. rarely or never

__________ Total Score (sum of all items; scores range from 11 to 55 with lower scores representing higher quality of life)

**Quality of Interview**
(Administrator's judgement):
- 0 Interview appeared valid
- 1 Some questions about interview, but probably acceptable
- 2 Information from interview of doubtful validity

**Knowledge/familiarity**
of caregiver with subject:
- 0 Very familiar; provides daily care
- 1 Somewhat familiar; often provides some care
- 2 Not very familiar; only dispenses meds, minimal contact

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Norwegian version of QUALID
Livskvalitet ved langtkommen demens (QUALID) skala©

Norsk oversettelse: Knut Engedal, Irene Røen, Eivind Aakhus, Sverre Bergh, Susan Juell, Geir Selbæk.

Pasientens navn
Dato (dag/måned/år)
Informantens navn
Informantens forhold til pasienten
Utfylt av / stilling

QUALID gjennomføres som et intervju av en informant ved å følge instruksjonene som er beskrevet her.

Informanten kan enten være et familiemedlem eller et helsepersonale som ved regelmessig kontakt er kjent med pasientens vanlige atferd. Informanten må, i tillegg til å kjenne personen, ha tilbrakt en vesentlig del av minst 3 av de siste 7 dagene sammen med personen, for å kunne vurdere svaralternativene i skalaen korrekt. Totalskåren finner man ved å summere svarene. Skårene vil ligge mellom 11 og 55, med 11 som uttrykk for høyest livskvalitet.

I de siste punktene i skalaen vurderes intervjuets gyldighet. Vurder både intervjuets samlede kvalitet, som inkluderer informantens evne til å forstå spørsmålene og svarene, og innsatsen som informanten viser ved besvarelser av spørsmålene, samt hvor godt informanten kjenner personen. Disse punktene regnes ikke med i totalskåren, men gir informasjon om gyldighet og nytteverdi av vurderingen som er gjort av denne personen.

Informantene får utlevert en kopi av skalaen slik at de kan se svaralternativene mens de leses høyt, og følgende instruksjoner blir gitt:

Jeg vil stille deg noen spørsmål om (pas. navn) sin livskvalitet. Jeg vil at du skal vurdere hans/hennes atferd ved å velge det svaralternativet som passer best under hvert spørsmål på denne siden (pek på svaralternativene under det første spørsmålet). Det er ingen riktige eller feil svar, jeg vil bare vite hvordan du vil vurdere hans/hennes atferd ut fra dine observasjoner.

Hvilket svaralternativ beskriver __________ best den siste uken...
Hvilket svaralternativ beskriver best gjennom den siste uken...

A. Personen smiler
   1. ☐ spontant en eller flere ganger daglig
   2. ☐ spontant, men sjeldnere enn en gang daglig
   3. ☐ bare som respons på ytre stimuler, minst en gang daglig
   4. ☐ bare som respons på ytre stimuler, sjeldnere enn en gang daglig
   5. ☐ sjelden eller aldri

B. Personen virker trist
   1. ☐ sjelden eller aldri
   2. ☐ bare som respons på ytre stimuler, sjeldnere enn en gang daglig
   3. ☐ bare som respons på ytre stimuler, minst en gang daglig
   4. ☐ uten noen åpenbar grunn, sjeldnere enn en gang daglig
   5. ☐ uten noen åpenbar grunn, en eller flere ganger daglig

C. Personen gråter
   1. ☐ sjelden eller aldri
   2. ☐ bare som respons på ytre stimuler, sjeldnere enn en gang daglig
   3. ☐ bare som respons på ytre stimuler, minst en gang daglig
   4. ☐ uten noen åpenbar grunn, sjeldnere enn en gang daglig
   5. ☐ uten noen åpenbar grunn, en eller flere ganger daglig

D. Personen har et ansiktsuttrykk som uttrykker ubehag – virker ulykkelig eller smertepåvirket (ser bekymret ut, skjærer grimaser, rynker pannen eller slår ned blikket)
   1. ☐ sjelden eller aldri
   2. ☐ sjeldnere enn en gang daglig
   3. ☐ minst en gang daglig
   4. ☐ nesten halvparten av dagen
   5. ☐ mesteparten av dagen

E. Personen viser kroppslig ubehag – hun/han vrir på seg, virker utilpass, skifter stadig stilling
   1. ☐ sjelden eller aldri
   2. ☐ sjeldnere enn en gang daglig
   3. ☐ minst en gang daglig
   4. ☐ nesten halvparten av dagen
   5. ☐ mesteparten av dagen

F. Personen kommer med ytringer eller lager lyder som tyder på misnøye, tristhet eller ubehag (klager, stønner, roper/skriker)
   1. ☐ sjelden eller aldri
   2. ☐ bare som respons på ytre stimuler, sjeldnere enn en gang daglig
   3. ☐ bare som respons på ytre stimuler, minst en gang daglig
   4. ☐ uten åopenbar grunn, sjeldnere enn en gang daglig
   5. ☐ uten åpenbar grunn, en eller flere ganger daglig
Hvilket svaralternativ beskriver best gjennom den siste uken?

G. Personen er irritabel og aggressiv (blir sint, banner, dytter eller forsøker å skade andre)
   1. sjelden eller aldri
   2. bare som respons på ytre stimuli, sjeldnere enn en gang daglig
   3. bare som respons på ytre stimuli, minst en gang daglig
   4. uten åpenbar grunn, sjeldnere enn en gang daglig
   5. uten åpenbar grunn, en eller flere ganger daglig

H. Personen nyter å spise
   1. ved de fleste måltidene, og mellom måltider
   2. ved minst to måltider daglig
   3. ved minst ett måltid daglig
   4. sjeldnere enn daglig
   5. sjelden eller aldri

I. Personen liker berøring/kroppskontakt
   1. nesten alltid, tar nesten alltid initiativ til berøring
   2. mer enn halvparten av tiden, tar av og til initiativ til berøring
   3. halvparten av tiden, tar aldri initiativ til berøring, men motsetter seg ikke å bli berørt
   4. mindre enn halvparten av tiden, motsetter seg ofte å bli berørt/bli tatt på
   5. sjelden eller aldri, motsetter seg nesten alltid berøring/bli tatt på

J. Personen liker samvær med andre
   1. nesten alltid, tar nesten alltid initiativ til samvær med andre
   2. mer enn halvparten av tiden, tar av og til initiativ til samvær med andre
   3. halvparten av tida, tar aldri initiativ til samvær med andre, men motsetter seg ikke
   4. mindre enn halvparten av tiden, motsetter seg ofte samvær med andre
   5. sjelden eller aldri, motsetter seg nesten alltid samvær med andre

K. Personen virker følelsesmessig rolig og avslappet
   1. mesteparten av dagen
   2. mer enn halvparten av dagen
   3. halvparten av dagen
   4. mindre enn halvparten av dagen
   5. sjelden eller aldri

Totalskår (summen av skåringene på alle spørsmålene).
Skåringen varierer mellom 11 til 55 hvor laveste sum representerer høyest livskvalitet

Intervjuets kvalitet

Kunnskap/kjennskap

Intervjuets kvalitet

Kunnskap/kjennskap

Intervjuet virket gyldig
Noen betenkeligheter, men sannsynligvis akseptabelt
Informasjonen fra intervjuet har tvilsom gyldighet

God kjennskap, gir daglig omsorg
Noe kjennskap, gir ofte omsorg
Ikke særlig god kjennskap, gir bare medisiner, har lite kontakt
Errata

Paper 2

Abstract; result:

The patients’ mean age was 86.9 (SD 7.7) years;

- Replaced by:

Mean age: 85.3 (SD 8.6) years
Errata

Artikkel 3

“Variables Associated with Change in Quality of Life among Persons with Dementia in Nursing Homes: A 10 Months Follow-Up Study”.

I tabell 1 er alle =-tegn er blitt til fem-tall. Disse femtallene skulle vært likhetstegn =.